





## ORIGINAL ARTICLE

# How is the environment integrated into post-stroke rehabilitation? A qualitative study among community-dwelling persons with stroke who receive home rehabilitation in Sweden

Maya Kylén PhD<sup>1,2</sup>  | Charlotte Ytterberg PhD<sup>3,4</sup>  | Lena von Koch PhD<sup>3,4</sup>  | Marie Elf PhD<sup>1</sup> 

<sup>1</sup>School of Health and Welfare, Dalarna University, Falun, Sweden

<sup>2</sup>Department of Health Sciences, Lund University, Lund, Sweden

<sup>3</sup>Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden

<sup>4</sup>Karolinska University Hospital, Stockholm, Sweden

## Correspondence

Maya Kylén, Department of Health Sciences, Lund University, HSC Margaretavägen 1 B, 22240 Lund, Sweden.  
Email: maya.kylen@med.lu.se

## Funding information

This work was supported by Formas, grant number 2015/389, the Swedish Stroke Association and Dalarna University.

## Abstract

Studies have shown a need to consider environmental factors to best support the rehabilitation and recovery process after a stroke. In addition, despite intentions to increase individuals' participation in care and rehabilitation, patients and family members report weak participation. The aim of this study was to explore how the environment was integrated into rehabilitation at home from the perspective of patients after a stroke. We conducted a qualitative study with 17 patients rehabilitated at home. Data on the participants' experiences of the rehabilitation process and their perceptions of how the environment was considered in the process were collected via interviews and analysed using qualitative content analysis. The main category that was constructed from the data was "Partial integration of person- environment dynamics in the rehabilitation", which was informed by three subcategories: (a) I recover in my home: Challenges and opportunities in the environment, (b) Following a generic approach to therapy: Limited integration of the environment, and (c) Informed more than involved. Our study showed that the environment was integrated in a limited manner. The participants were more informed about than involved in their planning of the rehabilitation. The results are important for informing the ongoing development of rehabilitation at home and person-centred care strategies.

## KEYWORDS

health and the environment, home care, housing and community care, rehabilitation, stroke rehabilitation

## 1 | INTRODUCTION

The home as a place of care and rehabilitation for people with complex health conditions, such as stroke, has become an important

aspect of healthcare in Sweden as well as internationally (Fisher et al., 2020; Nergårdh et al., 2018; World Health Organization, 2016). This shift draws attention to the vital role home environments play in improving people's health (Marcheschi et al., 2018). According to

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2021 The Authors. *Health and Social Care in the Community* published by John Wiley & Sons Ltd.

McCormack and McCance (2006) the physical environment is an essential part of realising person-centred care. Studies have shown associations between the physical environment and health outcomes (Ulrich, 2008), but few studies have examined the interplay between environmental factors and rehabilitation in the home (Marcheschi et al., 2018). Research on rehabilitation and the environment is mainly conducted in hospitals, such as in stroke units (Rosbergen et al., 2017; Shannon et al., 2019), and not in the home.

A stroke can lead to physical, emotional and cognitive challenges (Arntzen et al., 2015; Pedersen et al., 2019; Pereira et al., 2020), with a risk of reduced participation in social activities (Hodson et al., 2016; Zingmark et al., 2019). Rehabilitation at home has been shown to be effective (Fisher et al., 2020), but patients and relatives have reported that they lack continuity, information and participation in decisions on continued care and rehabilitation (Nordin et al., 2015). They report experiences of care services that do not meet their needs or are not person-centred (Lindblom et al., 2020), which in turn may limit their possibilities to return to life as it was prior to the stroke.

Guidelines for stroke (Bernhardt et al., 2017; Norrving et al., 2018) and the World Health Organization (2001) have argued for the use of a holistic biopsychosocial model in which the environment is considered and the person's activity and participation in society is the goal of rehabilitation. The environment can be defined to include several dimensions, that is, physical, social, and attitudinal contexts, for example, home and neighbourhood (Kielhofner, 2002) that interact with and affect a person's functional level (González et al., 2020; Hale et al., 2019; Hammel et al., 2006; Rosso et al., 2011). A discrepancy between the individual's functional level and the requirements in the environment can affect the person's ability to perform daily activities and participate in everyday life (Brunborg & Ytrehus, 2014; Singam et al., 2015), which can lead to reduced health and quality of life (Wottrich et al., 2012). Due to functional limitations, people living with long-term conditions are more vulnerable to demands in their home (e.g., stairs, uneven sidewalks) and community environments (Lawton & Nahemow, 1973). To support recovery and enable a person to live an active and meaningful life, it is therefore important that healthcare professionals (HCPs) are aware of the opportunities that the environment offers as well as the environmental requirements and limitations.

Stroke early supported discharge (ESD) is a multidisciplinary team intervention aimed at facilitating discharge from hospital and providing stroke specialist rehabilitation at home. In general, ESD services are provided by a team consisting of physiotherapists and occupational therapists and to a varying extent also other professions such as speech and language therapists, physicians and nurses (SBU, 2015). ESD services are recommended to be coordinated together with the patient and their relatives at the hospital, including a home visit prior discharge (SBU, 2015). However, home visits pre-discharge are not always implemented in practise. Based on evidence, stroke care guidelines worldwide recommend ESD as part of an evidence-based stroke care pathway. However, ESD in Sweden is far from being implemented in practice. ESD has shown positive

### What is known about this topic?

- Care and rehabilitation increasingly take place in patients' homes.
- After a stroke, many patients feel abandoned and not supported enough, and coming home is a stressful event.
- Individuals with functional limitations are vulnerable to demands in their home and community environments.

### What this paper adds?

- The rehabilitation and the use of the environment was governed by a health expert perspective.
- The rehabilitation was generic rather than person-centred, and the environment was integrated to a limited extent.
- Participants expressed views about being informed more than involved.

results for people with mild to moderate stroke (Fisher et al., 2020; SBU, 2015). It facilitates the patient's participation in the rehabilitation process (e.g., shared decision-making) and enables a positive relationship between the person and caregiver. There are also studies that shows that the model support HCPs to include the home environment as a support in the rehabilitation process (von Koch et al., 2000). While these results are promising, there is a lack of knowledge of how the environment and complex daily activities, such as out of home mobility, are integrated in regular clinical ESD rehabilitation in the home environment after stroke (SBU, 2015). Adding to this, in some countries the voluntary sector is considered a part of available resources for rehabilitation or support after a stroke. This is not the case in Sweden. Thus, to further develop evidence-based healthcare services at home, it is important to know how environmental factors interact with everyday life and how such factors can be considered and used to support the recovery process after a stroke. Therefore, the aim of this study was to explore how the environment was integrated in rehabilitation at home from the perspective of people post-stroke, living in Sweden.

## 2 | METHODS

### 2.1 | Design

We used a qualitative design with an inductive analysis approach. Content analysis is a systematic iterative research method for analysing text. It involves a constant moving back and forward between analytical phases and the data. The method can develop an understanding and provide new insights and knowledge in different contexts. Inductive content analysis is an appropriate method if

the existing knowledge base is poor or if the information studied is fragmented (Elo & Kyngäs, 2008).

This study is part of a larger project called Rehabilitation and Architecture (REARCH) aiming to increase the knowledge of how the environment can facilitate and/or hinder person-centred rehabilitation at home (Kylén et al., 2019). In REARCH we are working in partnership with persons with stroke, their organisations and several stroke units. Working in partnership with those who are likely to benefit from the research results has the potential to increase the likelihood that results lead to policy and practice change.

## 2.2 | Participants and setting

We used purposeful sampling (Kyngäs, 2020) to recruit participants from three stroke units in three different municipalities in southern Sweden. Participants were eligible if they had recently had a mild to moderate stroke according to the Barthel Index cut-off of >15 (Govan et al., 2009), were receiving ESD, were discharged to their homes directly from the stroke unit and were able to communicate and formulate answers to questions in an interview. HCPs (i.e., the multidisciplinary ESD team) working at the stroke units identified and provided oral and written information about the study to eligible patients. Those who expressed interest to participate were contacted over the phone by a researcher (MK). The participants were informed about the study and had the opportunity to ask questions. Individuals willing to participate provided oral consent, and an interview was scheduled. For the present study, we selected 17 of the 34 participants in the larger REARCH study. We estimated the sample size based on our experiences and the aim of the study. We knew the participants well and selected them based on characteristics such as

gender, age, type of housing and neighbourhood. The participants we chose were expected to give rich data based on their varied experiences. However, we were open to include more participants from the main study, if additional new information was needed to continue coding, which was not the case. The final selection of 17 participants is presented in Table 2, for the purpose of this manuscript participant were given a pseudonym.

## 2.3 | Data collection

Data were collected in semi-structured face-to-face interviews approximately 3 months post-stroke, following a developed interview guide, based on existing research and the expert knowledge of the research team. The guide covered three themes exploring the integration of the environment in the rehabilitation post-stroke (see Table 1) and was tested, refined and optimised based on two pilot interviews (not included in the study sample). Open-ended questions were asked to encourage the participants to reflect freely about their experiences of how the environment was considered and used in their rehabilitation. They were further encouraged to reflect on the environment at home, how they had discussed the environment with the HCPs and how the environment had been used as part of the rehabilitation. During the interviews, probing questions, such as *Can you explain more?*, were used to achieve more detailed descriptions. Demographical data were also collected. After each interview the interviewer summarised reflections. These were used as a support during the analyses.

The interviews were conducted during home visits between August 2019 and January 2020, approximately 3 months after stroke onset. Before the interview, the participants were orally informed about the study aim, and they provided written informed consent.

**TABLE 1** Examples of questions (translated from Swedish) in the semi-structured interview guide, covering three themes exploring the integration of the environment in the rehabilitation post-stroke

Theme 1: Physical environment	Theme 2: Social environment	Theme 3: Rehabilitation and participation
<i>If you think about how it works for you in everyday life here at home, is there something that is good/less good? Why?</i>	<i>Have you met any others, friends or family that you do not live with after you came home from the hospital? How often (occasionally, regularly)?</i>	<i>Can you tell me about how you experienced the first few weeks after coming home from the hospital? Did anyone come to see you? What did you do when you met?</i>
<i>How do you experience doing (the activity) in this room? What you are describing now, is it before or after your stroke?</i>	<i>Do they come to your home, or do you usually go away? What do you usually do together? What you are describing now, is it before or after your stroke?</i>	<i>Did you and the person you met with agreed on any activity or training you should do? Can you tell me about what it is like to "train" in your home, how has it been? Where in the home have you trained?</i>
<i>If you had the opportunity to do exactly what you wanted with your home, what would you absolutely want to keep? Or change so that you can live as you want?</i>	<i>In what way do the environment support or hinder (e.g., proximity to friends, transportation, accessibility) your social life?</i>	<i>Did you feel that you were listened to and that your opinions were considered?</i>

TABLE 2 Characteristics of participants,  $N = 17$ 

Pseudonym	Gender	Age	Civil status	Pensioner	Type of residential area	Dependence on mobility devices <sup>a</sup>
Emma	F	80	Single living	Yes	City center	No
Sara	F	77	Single living	Yes	Suburb	No
Ann	F	72	Single living	Yes	Countryside	No
Doris	F	65	Single living	Yes	Suburb	Yes
Lena	F	89	Single living	Yes	City	Yes
Sven	M	79	Single living	Yes	Suburb	Yes
Rolf	M	71	Cohabiting	Yes	Suburb	No
Maria	F	34	Cohabiting	No, on sick leave	City	No
Jan	M	46	Cohabiting	No, on sick leave	City	Yes
Alice	F	73	Single living	Yes	City	Yes
Bengt	M	63	Single living	No, working	City	No
Marga	F	90	Single living	Yes	City center	Yes
Åke	M	61	Cohabiting	No, working	Suburb	No
Kurt	M	77	Cohabiting	Yes	Suburb	Yes
Mats	M	81	Cohabiting	Yes	City center	Yes
Lars	M	68	Cohabiting	Yes	City	Yes
Simon	M	65	Cohabiting	Yes	Suburb	No

<sup>a</sup>None of the participants were reliant on a wheelchair.

The interviews lasted from 20 to 30 min and were conducted by a female student and a researcher (MK; PhD), both had previous experience from conducting in-depth interviews for research purposes. The interviews were audio recorded and transcribed verbatim.

## 2.4 | Data analysis

The data were analysed using inductive qualitative content analysis (Kyngäs, 2020). The initial coding procedure was performed independently by two researchers (MK and ME) with input from the research team (LVK, CY) iteratively. First, the summarised reflections were read, and an open coding of the data material was performed. The researchers independently read the interviews several times to become familiar with the data and its content. Notes and headings were written in the margins using the participants' words. Following the open coding, meaning units that shared the same central meaning were extracted and grouped together. Codes with similar content were combined and formed into sub-categories according to similarities and differences. This was an iterative process. Finally, a higher-level, that is, a main category was constructed from the sub-categories combined meaning. In the analysis we are referring to all HCPs collectively because patients find it hard to distinguish.

## 2.5 | Rigour

To enhance trustworthiness, the codes, sub-categories and the main category that were constructed were discussed and verified on several

occasions within the research team and also at a research seminar (Denzin & Lincoln, 2000). During these meetings, alternative interpretations were considered, and the analysis proceeded until consensus among the research team was reached. The software tool NVivo (version 12) was used to manage data (Edlund & McDougall, 2019). The study is reported in accordance with the Consolidated criteria for reporting qualitative research (COREQ) guidelines for qualitative studies (Booth et al., 2014).

## 2.6 | Ethical considerations

The study was approved by a regional ethical review board for research (nr: 2015/389). Informed and written consent was obtained from all participants in the study, and the principles of the Declaration of Helsinki were followed (World Medical Association, 2001).

## 3 | FINDINGS

### 3.1 | Participants

The 17 participants (8 women, 9 men) were aged 34–90 years (median 72 years). All of them lived in ordinary housing in the community (i.e., not including needs assessed housing such as nursing homes), and approximately half were dependent on a mobility device, that is, cane, crutch/es or rollator ( $n = 9$ ). Nine lived in the city or city centre, seven in the suburbs and one in the countryside. Thirteen of the participants were retired, two were on sick leave and two were working full or part-time at the time of the interview (see Table 2).

### 3.2 | Results of analysis

The main category that was constructed from the data was *Partial integration of person- environment dynamics in the rehabilitation*. This main category was informed by three subcategories: (a) I recover in my home: Challenges and opportunities in the environment, (b) Following a generic approach to therapy: Limited integration of the environment, and (c) Informed more than involved (Figure 1).

### 3.3 | I recover in my home: Opportunities and challenges in the environment

The participants expressed many opportunities and challenges in their environment post-stroke. First, many thought it was pleasant to be at home, felt confident and secure, and found encouragement in being in their own supportive environment. Being at home was described as important and supported them in adapting to life after stroke. Many of the participants described using their own resources in the environment at home, which contributed to their recovery and rehabilitation. One participant was interested in fishing, so to practise his fine motor skills, he tied flies for fishing. Another participant was interested in playing the piano and played every day to accelerate his recovery. A third participant stated:

Before, I collected firewood in a basket and stored it. There was no need to carry in firewood often. And it was heavy. I am quite strong. But now, I go out and pick up just a couple of sticks; I do that all day, all evenings because I know it is good for me to move. (Ann, age 72)

The participants described performing housework, gardening and taking walks, all with the goal of improving functioning and returning to the life they longed for:

I long for everything to be as usual, and I feel more and more like that. (Simon, age 65)

Most participants thought that walking was good for recovery, so they did that every day. They walked primarily in the immediate surrounding areas, and many also pointed out that walking in these areas felt safe because they could easily orient themselves there. Some described having longer excursions by taking a bus or taxi one way and

walking back. The participants described that being able to perform tasks by themselves was a strength and that it encouraged them to do something every day to increase their competence:

Yes, the important thing for me was to train this and that. So to do things as quickly as possible, huh. I didn't want help with anything if I didn't need it. And it turned out that ... technical as I am, I could find solutions ... yes, dress myself and wash and make the bed and such. (Sven, age 79)

However, they also described barriers in the environment, such as stairs, heavy doors and small spaces, that limited their mobility and the possibility of using their living spaces. While some of the participants had such barriers removed by themselves or by the HCPs, others tried hard to secure housing adaptations but had not yet succeeded. For example, one woman had a heavy entrance door that she could not open without the neighbours' help. She wanted an automatic door opener installed, but it was not approved by the housing adaptation authority. Another challenge was related to handling assistive devices in the environment. As one woman expressed:

Yes, I'm afraid to board (the bus). First, I am going to get the bus card up, and then I'm going to lift the walker. Then I need to blip the card and get myself in. I take the x or x (bus route numbers), there are so many young moms with strollers, old people with walkers and stuff, so it is not easy to get around. I am wobbly in my legs and have poor balance. (Lena, age 89)

Some participants reported having heavy front doors that were difficult to open or garbage facilities in multi-family housing that were difficult to use and indicated that these types of barriers were not considered in the rehabilitation, which limited the participants' abilities to return to life as it was prior to the stroke.

For some of the participants, it was difficult to predict the challenges of coming home from the hospital. When they had been asked about possible barriers in their home environments, they had responded that everything probably would work out just fine. However, when they returned home, it was not as easy as they thought, and many of them experienced problems.

Yes, they (the HCPs at the hospital) asked, and I said, "I feel so good at home; I can do it all". And then when I got home, it was not like that. When you lie in your bed and just turn your head right and left, then you feel quite healthy, but when you get up, it was not so easy. (Sara, age 77)

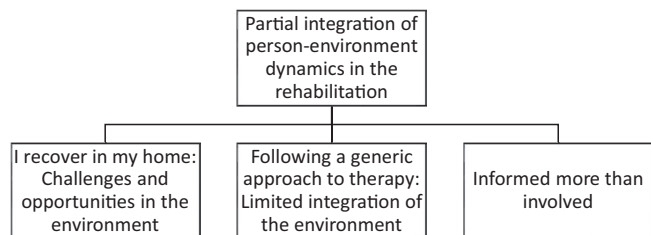


FIGURE 1 Main category and sub-categories

### 3.4 | Following a generic approach to therapy: Limited integration of the environment

The findings revealed that many of the participants had a rehabilitation plan that seemed to be generic, focusing mainly on their

impaired hand function or limited walking ability, which led to interventions specifically targeting the training of motor skills with limited usage of the home environment. As one participant revealed,

Yes, they had a program with certain themes, they regularly added new exercises. And then they asked, do you think it's okay to do this. Yes, sure. I'm going to do everything. Yes, today we're going to play cards, well okay. It was so clumsy, but yes, it went well. (Lars, age 68)

It was common for the participants to walk in the neighbourhood together with the HCPs, climb stairs and perform daily activities such as preparing coffee and meals. The participants did not always know why they performed certain tasks; instead, they described that the HCPs observed them in their environments, which they assumed was part of the rehabilitation programme, as two of the participants noted:

It has not been so much focus on specific training either, I think. It has been more like doing daily tasks as training. (Emma, age 80)

The participants also described how the HCPs asked them about how they managed basic daily activities such as taking a shower, and based on that information, the HCPs advised them on how to train by performing daily activities at home. The HCPs also provided them with information regarding what to think about when moving around at home; for example, they were told to be careful when walking around to avoid falls.

When asked if someone had inquired about their home environment at the hospital before discharge, many participants said that the HCPs had asked about potential barriers, such as if the home had stairs and/or elevators or if it was possible to enter the home without problems. They were also asked if they needed any assistive devices to manage everyday life but not about the accessibility in environments that were important for them to visit.

Yes, we talked about whether I might have needed someone, a shower stool, and things like that. Then I never needed it because I had a stool at home that worked. And we talked about ... they wondered if I needed help getting in and out of bed and stuff like that. Yes, it was a bit like that, I do not know who asked it. (Maria, age 34)

Beyond these regular questions about barriers in the home, the participants revealed that their home environments and close surroundings were hardly integrated in the rehabilitation. For example, some of the participants enjoyed gardening and wanted to perform activities outside the home; however, such activities were hindered by barriers in the environment, and they had to pause such activities. Additionally, some of the participants described that the rehabilitation

offered by the HCPs did not correspond to their needs. As an example, some of the participants received technical aids that they did not need.

In contrast, some of the participants also revealed that the barriers in the environment in their homes were discussed with the HCP and that these barriers were used as a point of departure in the rehabilitation. For example, participants who experienced difficulties in orienting themselves in the environment were offered support:

They (HCP) have been out and walked with me in the area. So, I have, bit by bit learned again how to find the way. (Kurt, age 77)

### 3.5 | Informed more than involved

In general, the participants had experiences of being informed rather than involved in the planning of their continuous rehabilitation at home and integration of the environment. The communication about the environment seemed to be characterised by the HCPs asking questions and the participants answering. This was most obvious at the hospital.

Many participants stated that they did not remember or that they did not understand the planning of their recovery period. The few participants who had experiences of participating in the planning often reported that they had mainly received brief information about their stroke and medications related to their discharge. At the hospital, they were informed that rehabilitation at home would be provided, but the information was very brief. Although many stated that their participation in the rehabilitation planning increased when they met the HCPs in the home, it was still more focused on information rather than shared decisions, as one participant said:

...we had no planning, I was advised ... and received information from the start; I knew what was going on ... Well, I cannot set any goals because I don't know what is needed. Because I cannot sit there and think, "Now I will do this and that to get well". I don't know; I just want to be as healthy as possible. (Simon, age 65)

In addition, at home, the participants said that they listened to what the HCPs told them to do and tried to act according to their guidance. Some described not knowing anything about rehabilitation and trusting the HCPs' expertise and counselling.

However, there were also descriptions of participation in the data. For example, when a participant had a strong wish to regain their strength, the rehabilitation was focused on training motor skills such as holding a pen and writing. In these examples, the participants provided rich narratives of the way in which the training had been planned and developed throughout the recovery period.

No, but then X [the occupational therapist] used to ask me what I wanted ... what I felt was a problem

or what I wanted to practise. And then we practised what I felt I needed to be practised as well. (Rolf, age 71)

Some of the participants also expressed that they did not want to discuss the physical environment and the rehabilitation with the HCPs, as they wanted to manage their own rehabilitation. They did not want to involve others in their goals or discuss their goals with others, and they reported that the HCPs respected this desire.

Few of the participants described interventions that were based on their own goals and desires to be part of society. For example, one woman who wished to perform a hobby with her friends was advised by an HCP to practice at home to improve her fine motor skills, but no training on how to travel to visit her friends by bus was offered. For her, transportation was the greatest challenge.

The low involvement in the rehabilitation planning could also have led them to be advised to practise activities that they did not usually perform or desire to perform in the future. For example, one person was offered bus training with an HCP even though she had never used bus transportation before nor was she planning to do so in the future.

No, I'm not using bus, but she who ... the physiotherapist, says I have to test. We only tested taking a bus from here and to the centre once. (Jan, age 46)

## 4 | DISCUSSION

In this article, we explored how the environment was integrated in rehabilitation at home from the perspective of participant's post-stroke. The main contribution of our study is the insight into how person-environment dynamics are integrated into the rehabilitation programme at home after a stroke.

Overall, the participants were satisfied with the support they received from the HCPs. However, the environment was only partly integrated into the rehabilitation programme and that challenges and opportunities in the environment were not always seen. The HCPs seemed to follow a generic programme in which the participants experienced being informed rather than involved; thus, the rehabilitation did not always correspond to their needs. Rehabilitation activities primarily focused on the participants' self-care and indoor mobility, such as household duties and walking and not on activities outside the home and possibilities to participate in society.

Standardised healthcare programmes based on scientific evidence are important to achieve good and safe care for patients (Rethnam et al., 2021). However, these programmes can also hinder person-centred rehabilitation because they are often based on generic goals and may not be meaningful to the individual patient's situation (Wade, 2020). For example, studies have reported that patients are sometimes routinely prescribed assistive devices, which make them more passive (Kubina et al., 2013). There is a risk that the healthcare will continue to reduce a person to a body and

focus on problems rather than involving the person and viewing the entire context and living space as resources in the rehabilitation (Pluut, 2016).

Our study showed that goals were set based on a professional perspective rather than from the person living in a specific context. This is a challenge because, in person-centred care, practitioners must work based on individual needs and collaborate with people who need support. This working method may be incompatible with how the system and HCPs currently operate within a biomedical model (Pluut, 2016). With regard to the different professions involved, theories applied in occupational therapy focus on the environment (e.g., Kielhofner, 2002), while in practice it is only applied to a limited extent due to policy, staffing and resourcing constraints. We mean that to provide person-centred care do not necessarily need to take more time or resources, it is rather a question about collaboration between care providers and an increased support to patients who can take more control over their situation.

The participants found it supportive for their recovery to be in their home environment and to be able to move around in their well-known neighbourhood. This finding has also been reported elsewhere (Randström et al., 2012). In our study, the participants described how they took the initiative to perform activities or recovery strategies such as walking every day, as well as more challenging activities such as shopping or gardening. They reflected upon their own performance and the barriers they needed to overcome which increased their motivation for further training. Previous research has shown the importance of an individual's own motivation and commitment as a main contributor to positive rehabilitation outcomes (Langhorne et al., 2011). Thus, there seems to be great advantages in supporting a person's own internal resources and motivation in the rehabilitation process. While it is encouraging that the participants performed activities by themselves and used their own resources in their environment, however, they did not describe this as rehabilitation activities based on discussions and planning with the HCTPs. In addition, the participants reported several psychological, physical and environmental barriers restricting their activity. Common personal barriers included feelings of weakness, fatigue or frustration, which has also been reported by (Singam et al., 2015). These barriers did not seem to be considered in the rehabilitation.

The environment seemed to be observed in a standardised manner rather than integrated into the rehabilitation based on a person's needs. This is in accordance with the results from a study on home-based rehabilitation and reablement conducted by Zingmark et al. (2019). They showed that therapists mainly focused on mobility indoors and physical functions rather than on activities to support individuals' social contact and communication skills. This finding is not surprising. Traditionally, rehabilitation has been focused on people's bodily functions, aiming to improve gait and recover balance and movement (Northcott et al., 2016; Zingmark et al., 2019, 2020) rather than to support the person in carrying out hobbies and participating in society. Previous studies have confirmed the need for a responsive, holistic strategy for rehabilitation and the importance of

social, cognitive and psychological dimensions in people's recovery and quality of life (Lawrence & Kinn, 2012).

The results showed that the participants experienced the planning and goal setting as vague. Many expressed that they did not remember if there had been any discussions regarding the planned rehabilitation. Some participants described that they had been informed and given guidance about useful rehabilitative activities to perform, but they were hardly involved in the planning of these activities. The results, along with those of several other studies, raise concerns that patients are often informed about the goals of care and rehabilitation but are rarely involved in the decision-making based on their own situations (Connolly & Mahoney, 2018; Lou et al., 2017; SBU, 2017; Wallström et al., 2017). Our study also shows that the participants view the HCPs as the experts, and they trusted their advice. Research has repeatedly shown that care remains unindividualised and controlled by HCPs, regardless of policy declarations regarding the introduction of patient-centred care (Abrahamson & Wilson, 2019; Luker et al., 2015; Vårdanalys, 2017). Furthermore, it has been reported that in the home, the relationship between the patient and HCPs and the balance of power can be levelled more easily (Hodson et al., 2016). However, the experiences of the participants in the present study indicated that involvement in and influence over one's own rehabilitation process cannot be taken for granted just because rehabilitation is taking place in the home. More efforts should be made to maximise individualised rehabilitation, with the environment being a natural part of such efforts. Without a proper planning dialogue in which the HCP ensures that the patient understands the intention of continued rehabilitation, the goal may remain unknown to the patient.

In this study, it was clear that the HCPs gave advice about plausible obstacles and risks in the environment. Although such advice is important, the results of this study demonstrate that focusing only on obstacles provides a very limited perspective and that many resources may go unnoticed. While our study provides a first view of how people with stroke experience rehabilitation at home from this perspective, further in-depth knowledge on how to best integrate the dynamic interplay between the environment and the person in interventions is needed. In particular, there is a need to review core documents guiding the rehabilitation protocol after a stroke to ensure that the environment is integrated in a more advanced manner. Furthermore, a home is closely related to a person's identity (Meijering et al., 2016; Nanninga et al., 2015), which makes it challenging for an HCP to make changes in the environment, even if the HCP considers such changes necessary from a safety perspective. Thus, it is important to recognise both obstacles and opportunities in the environment and include the patients in the decision-making process.

#### 4.1 | Implication for practice and policy

The relationship between a person and the environment is known to be complex (Lawton & Nahemow, 1973), and the dynamic interplay is associated with many health outcomes (Haak et al., 2015; Ulrich et al., 2008). According to the WHO, the environment is an

important determinant of health (WHO, 2018). Increasingly, care and rehabilitation are conducted in settings outside the hospital, and this healthcare reform will have implications for societal planning and healthcare organisation. For this reason, the environment must be on the agenda for healthcare service in both clinical practice and policy. To learn how to integrate the environment as a resource in the rehabilitation process, a first and important step is to listen to those people who have experiences to share, as we have done in this study. Second, interventions and guidelines that capture person-environment dynamics are needed and should be prioritised.

#### 4.2 | Limitations

The interview was one part of a larger data collection, and the length of the interviews were kept short, and the sample was small, yet the data were rich and reflected the participants' experiences. The sample varied with respect to gender, age (34–90), type of dwelling and setting in the community. In alignment with Malterud's (2016) recommendation for qualitative research, we consider our sample to be large enough to show varied experiences and small enough to allow for thorough analysis of all aspects of the data.

The data were collected approximately 3 months after stroke onset as the first 6 months are described as the critical period. Some participants had difficulties to retrospectively report all their experiences. Participants with stroke receiving ESD services were included, that is, all participants had mild/moderate stroke with no communication issues, so the findings may not be transferable to persons with severe stroke. Another limitation could be that the data were collected in one region, and contextual aspects and local policies may reduce the transferability of our findings to other contexts. However, the dominance of the HCP perspectives in rehabilitation has been reported in other contexts, for other healthcare contacts and we argue that room for improvement is likely to be present in many rehabilitation contexts.

### 5 | CONCLUSIONS

Our study showed that rehabilitation was dominated by the HCP's perspective and that there were more options to integrate the environment. The patient did not participate in the planning process. The results are important for informing the ongoing development of rehabilitation in home and person-centred care strategies. The results can support the development of rehabilitation in practice and be translated into interventions and training initiatives. However, further research is needed to explore how HCPs use the environment in rehabilitation to support and promote a comprehensive, more holistically driven form of rehabilitation.

#### ACKNOWLEDGEMENTS

The authors thank the people with stroke who participated in the study and the professionals who supported the practical procedure.



We also thank Charlotte Roos, former student in the project, for her contribution as a data collector.

## CONFLICT OF INTEREST

The authors declare no conflicts of interest.

## AUTHOR CONTRIBUTIONS

M.E. and L.V.K. conceptualised the study, M.E., L.V.K. and M.K. designed the methodology, with input from C.Y. M.E. and M.K. wrote the ethical application. M.K. collected the data together with a research assistant. The initial coding procedure was performed by MK and ME with continuous input from the research team LVK and CY. All authors revised and provided feedback on the draft and approved the manuscript for submission.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ORCID

Maya Kylén  <https://orcid.org/0000-0003-2887-3674>

Charlotte Ytterberg  <https://orcid.org/0000-0003-3704-8887>

Lena von Koch  <https://orcid.org/0000-0002-8560-3016>

Marie Elf  <https://orcid.org/0000-0001-7044-8896>

## REFERENCES

- Abrahamson, V., & Wilson, P. (2019). Positioning the six-month review in the recovery process post-stroke: The ideology of personal responsibility. *Health & Social Care in the Community*, 27(1), 249–259. <https://doi.org/10.1111/hsc.12677>
- Arntzen, C., Borg, T., & Hamran, T. (2015). Long-term recovery trajectory after stroke: An ongoing negotiation between body, participation and self. *Disability and Rehabilitation*, 37(18), 1626–1634. <https://doi.org/10.3109/09638288.2014.972590>
- Bernhardt, J., Hayward, K. S., Kwakkel, G., Ward, N. S., Wolf, S. L., Borschmann, K., Krakauer, J. W., Boyd, L. A., Carmichael, S. T., Corbett, D., & Cramer, S. C. (2017). Agreed definitions and a shared vision for new standards in stroke recovery research: The stroke recovery and rehabilitation roundtable taskforce. *International Journal of Stroke*, 12(5), 444–450. <https://doi.org/10.1177/1747493017711816>
- Booth, A., Hannes, K., Harden, A., Noyes, J., Harris, J., & Tong, A. (2014). COREQ (consolidated criteria for reporting qualitative studies). In D. Moher, D. G. Altman, K. F. Schulz, I. Simera, & E. Wager (Eds.), *Guidelines for reporting health research: A user's manual* (pp. 214–226). Wiley.
- Brunborg, B., & Yttrhus, S. (2014). Sense of well-being 10 years after stroke. *Journal of Clinical Nursing*, 23(7–8), 1055–1063. <https://doi.org/10.1111/jocn.12324>
- Connolly, T., & Mahoney, E. (2018). Stroke survivors' experiences transitioning from hospital to home. *Journal of Clinical Nursing*, 27(21–22), 3979–3987. <https://doi.org/10.1111/jocn.14563>
- Denzin, K. N., & Lincoln, S. Y. (2000). *Handbook of qualitative research* (2nd ed.). Sage.
- Edhlund, B., & McDougall, A. (2019). *NVivo 12 essentials*. Lulu.com.
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of advanced nursing*, 62(1), 107–115.
- Fisher, R. J., Byrne, A., Chouliara, N., Lewis, S., Paley, L., Hoffman, A., Rudd, A., Robinson, T., Langhorne, P., & Walker, M. F. (2020). Effectiveness of stroke early supported discharge: Analysis from a national stroke registry. *Circulation: Cardiovascular Quality and Outcomes*, 13(8), e006395. <https://doi.org/10.1161/CIRCOUTCOMES.119.006395>
- González, E., Requena, C., & Álvarez-Merino, P. (2020). Single time-point study of the home environment and functionality of older adults in Spain. *International Journal of Environmental Research and Public Health*, 17(22), 8317. <https://doi.org/10.3390/ijerph17228317>
- Govan, L., Langhorne, P., & Weir, C. J. (2009). Categorizing stroke prognosis using different stroke scales. *Stroke; A Journal of Cerebral Circulation*, 40(10), 3396–3399. <https://doi.org/10.1161/STROKEAHA.109.557645>
- Haak, M., Kylén, M., Ekström, H., Schmidt, S. M., Horstmann, V., Elmståhl, S., & Iwarsson, S. (2015). Relationships between perceived aspects of home and symptoms in a cohort aged 67–70. *Archives of Gerontology and Geriatrics*, 61(3), 529–534. <https://doi.org/10.1016/j.archger.2015.06.013>
- Hale, K., Østbye, T., Perera, B., Bradley, R., & Maselko, J. (2019). A novel adaptation of the HOME Inventory for elders: The importance of the home environment across the life course. *International Journal of Environmental Research and Public Health*, 16(16), 2826. <https://doi.org/10.3390/ijerph16162826>
- Hammel, J., Jones, R., Gossett, A., & Morgan, E. (2006). Examining barriers and supports to community living and participation after a stroke from a participatory action research approach. *Topics in Stroke Rehabilitation*, 13(3), 43–58. <https://doi.org/10.1310/5X2G-V1Y1-TBK7-Q27E>
- Hodson, T., Aplin, T., & Gustafsson, L. (2016). Understanding the dimensions of home for people returning home post stroke rehabilitation. *British Journal of Occupational Therapy*, 79(7), 427–433. <https://doi.org/10.1177/0308022615619420>
- Kielhofner, G. (2002). *A model of human occupation: Theory and application*. Lippincott Williams & Wilkins.
- Kubina, L.-A., Dubouloz, C.-J., Davis, C. G., Kessler, D., & Egan, M. Y. (2013). The process of re-engagement in personally valued activities during the two years following stroke. *Disability and Rehabilitation*, 35(3), 236–243. <https://doi.org/10.3109/09638288.2012.691936>
- Kylén, M., von Koch, L., Pessah-Rasmussen, H., Marcheschi, E., Ytterberg, C., Heylighen, A., & Elf, M. (2019). The importance of the built environment in person-centred rehabilitation at home: Study protocol. *International Journal of Environmental Research and Public Health*, 16(13), 2409. <https://doi.org/10.3390/ijerph16132409>
- Kyngäs, H. (2020). Qualitative research and content analysis. In H. Kyngäs, K. Mikkonen, & M. Kääriäinen (Eds.), *The application of content analysis in nursing science research* (pp. 3–11). Springer.
- Langhorne, P., Bernhardt, J., & Kwakkel, G. (2011). Stroke rehabilitation. *The Lancet*, 377(9778), 1693–1702. [https://doi.org/10.1016/S0140-6736\(11\)60325-5](https://doi.org/10.1016/S0140-6736(11)60325-5)
- Lawrence, M., & Kinn, S. (2012). Defining and measuring patient-centred care: An example from a mixed-methods systematic review of the stroke literature. *Health Expectations*, 15(3), 295–326. <https://doi.org/10.1111/j.1369-7625.2011.00683.x>
- Lawton, M. P., & Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer & M. P. Lawton (Eds.), *The psychology of adult development and aging* (pp. 619–674). American Psychological Association.
- Lindblom, S., Flink, M., Sjöstrand, C., Laska, A.-C., von Koch, L., & Ytterberg, C. (2020). Perceived quality of care transitions between hospital and the home in people with stroke. *Journal of the American Medical Directors Association*. <https://doi.org/10.1016/j.jamda.2020.06.042>
- Lou, S., Carstensen, K., Møldrup, M., Shahla, S., Zakharia, E., & Nielsen, C. P. (2017). Early supported discharge following mild stroke: A qualitative study of patients' and their partners' experiences of rehabilitation at home. *Scandinavian Journal of Caring Sciences*, 31(2), 302–311. <https://doi.org/10.1111/scs.12347>

- Luker, J., Lynch, E., Bernhardtsson, S., Bennett, L., & Bernhardt, J. (2015). Stroke survivors' experiences of physical rehabilitation: A systematic review of qualitative studies. *Archives of Physical Medicine and Rehabilitation*, 96(9), 1698–1708. <https://doi.org/10.1016/j.apmr.2015.03.017>
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- Marcheschi, E., von Koch, L., Pessah-Rasmussen, H., & Elf, M. (2018). Home setting after stroke, facilitators and barriers: A systematic literature review. *Health & Social Care in the Community*, 26(4), e451–e459. <https://doi.org/10.1111/hsc.12518>
- McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *Journal of Advanced Nursing*, 56(5), 472–479. <https://doi.org/10.1111/j.1365-2648.2006.04042.x>
- Meijering, L., Nanninga, C. S., & Lettinga, A. T. (2016). Home-making after stroke. A qualitative study among Dutch stroke survivors. *Health & Place*, 37, 35–42. <https://doi.org/10.1016/j.healthplace.2015.11.006>
- Nanninga, C. S., Meijering, L., Schönherr, M. C., Postema, K., & Lettinga, A. (2015). Place attachment in stroke rehabilitation: A transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine. *Disability and Rehabilitation*, 37(3), 1125–1134. <https://doi.org/10.3109/09638288.2014.955136>
- Nergårdh, A., Andersson, L., Eriksson, J., Lundberg, M., Nordström, K., & Lindevall, M. (2018). *God och nära vård-En primärvårdsreform*. <https://www.regeringen.se/rattsliga-dokument/statens-offentliga-utredningar/2018/06/sou-201839/>
- Nordin, Å., Sunnerhagen, K. S., & Axelsson, Å. B. (2015). Patients' expectations of coming home with very early supported discharge and home rehabilitation after stroke-an interview study. *BMC Neurology*, 15(1). <https://doi.org/10.1186/s12883-015-0492-0>
- Norrvig, B. O., Barrick, J., Davalos, A., Dichgans, M., Cordonnier, C., Guekht, A., Kutluk, K., Mikulik, R., Wardlaw, J., Richard, E., Nabavi, D., Molina, C., Bath, P. M., Stibrant Sunnerhagen, K., Rudd, A., Drummond, A., Planas, A., & Caso, V. (2018). Action plan for stroke in Europe 2018–2030. *European Stroke Journal*, 3(4), 309–336. <https://doi.org/10.1177/2396987318808719>
- Northcott, S., Moss, B., Harrison, K., & Hilari, K. (2016). A systematic review of the impact of stroke on social support and social networks: Associated factors and patterns of change. *Clinical Rehabilitation*, 30(8), 811–831. <https://doi.org/10.1177/0269215515602136>
- Pedersen, S. G., Anke, A., Aadal, L., Pallesen, H., Moe, S., & Arntzen, C. (2019). Experiences of quality of life the first year after stroke in Denmark and Norway. A qualitative analysis. *International Journal of Qualitative Studies on Health and Well-Being*, 14(1), 1659540. <https://doi.org/10.1080/17482631.2019.1659540>
- Pereira, C. M., Greenwood, N., & Jones, F. (2020). From recovery to regaining control of life—the perspectives of people with stroke, their carers and health professionals. *Disability and Rehabilitation*, 1–12. <https://doi.org/10.1080/09638288.2020.1722263>
- Pluut, B. (2016). Differences that matter: Developing critical insights into discourses of patient-centeredness. *Medicine, Health Care and Philosophy*, 19(4), 501–515. <https://doi.org/10.1007/s11019-016-9712-7>
- Randström, K. B., Asplund, K., & Svedlund, M. (2012). Impact of environmental factors in home rehabilitation – A qualitative study from the perspective of older persons using the International Classification of Functioning, Disability and Health to describe facilitators and barriers. *Disability and Rehabilitation*, 34(9), 779–787. <https://doi.org/10.3109/09638288.2011.619621>
- Rethnam, V., Hayward, K. S., Bernhardt, J., & Churilov, L. (2021). Early mobilization after stroke: Do clinical practice guidelines support clinicians' decision-making? *Frontiers in Neurology*, 12, 33. <https://doi.org/10.3389/fneur.2021.606525>
- Rosbergen, I. C. M., Grimley, R. S., Hayward, K. S., Walker, K. C., Rowley, D., Campbell, A. M., McGufficke, S., Robertson, S. T., Trinder, J., Janssen, H., & Brauer, S. G. (2017). Embedding an enriched environment in an acute stroke unit increases activity in people with stroke: A controlled before–after pilot study. *Clinical Rehabilitation*, 31(11), 1516–1528. <https://doi.org/10.1177/0269215517705181>
- Rosso, A. L., Auchincloss, A. H., & Michael, Y. L. (2011). The urban built environment and mobility in older adults: A comprehensive review. *Journal of Aging Research*, 2011, 1–10. <https://doi.org/10.4061/2011/816106>
- SBU. (2015). *Rehabilitation at home after early supported discharge (ESD) for elderly patients after stroke* (report no. 234). <https://www.sbu.se/234e>
- SBU. (2017). *Patientdelaktighet i Hälso-Och-sjukvården. En Sammanställning av Vetenskapliga Utvärderingar av Metoder som kan Påverka Patientens Förutsättningar för Delaktighet* (report no. 260). <https://www.sbu.se/260>
- Shannon, M. M., Elf, M., Churilov, L., Olver, J., Pert, A., & Bernhardt, J. (2019). Can the physical environment itself influence neurological patient activity? *Disability and Rehabilitation*, 41(10), 1177–1189. <https://doi.org/10.1080/09638288.2017.1423520>
- Singam, A., Ytterberg, C., Tham, K., & von Koch, L. (2015). Participation in complex and social everyday activities six years after stroke: Predictors for return to pre-stroke level. *PLoS One*, 10(12), e0144344. <https://doi.org/10.1371/journal.pone.0144344>
- Ulrich, R. S., Zimring, C., Zhu, X., DuBose, J., Seo, H.-B., Choi, Y.-S., Quan, X., & Joseph, A. (2008). A review of the research literature on evidence-based healthcare design. *HERD: Health Environments Research & Design Journal*, 1(3), 61–125. <https://doi.org/10.1177/193758670800100306>
- Vårdanalys. (2017). *Act without impact. Assessment of the Swedish Patient. Summary. Act 2014–2017*.
- von Koch, L., Holmqvist, L. W., Wottrich, A. W., Tham, K., & de Pedro-Cuesta, J. (2000). Rehabilitation at home after stroke: A descriptive study of an individualized intervention. *Clinical Rehabilitation*, 14(6), 574–583. <https://doi.org/10.1191/0269215500cr364oa>
- Wade, D. T. (2020). What is rehabilitation? An empirical investigation leading to an evidence-based description. *Clinical Rehabilitation*, 34(5), 571–583. <https://doi.org/10.1177/0269215520905112>
- Wallström, S., Ekman, I., & Taft, C. (2017). Svenskarnas syn på personcentrering i vården. In U. Andersson, J. Ohlsson, H. Oscarsson, & M. Oskarson (Red), *Larmar och gör sig till* (pp. 197–211). Göteborgs universitet: SOM-institutet. [www.som.gu.se/publicerat/bocker/70larmar](http://www.som.gu.se/publicerat/bocker/70larmar)
- World Health Organization. (2001). *International classification of functioning, disability and health*. WHO.
- World Health Organization. (2016). *Framework on integrated, people-centred health services*. <https://www.who.int/servicedeliverysafet/y/areas/people-centred-care/en/>
- World Medical Association. (2001). World Medical Association declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bulletin of the World Health Organization*, 79(4), 373.
- World Health Organization. (2018). WHO housing and health guidelines: executive summary. World Health Organization. <https://apps.who.int/iris/handle/10665/277465>. License: CC BY-NC-SA 3.0 IGO.
- Wottrich, A. W., Åström, K., & Löfgren, M. (2012). On parallel tracks: Newly home from hospital-people with stroke describe their expectations. *Disability & Rehabilitation*, 34(14), 1218–1224. <https://doi.org/10.3109/09638288.2011.640381>

- Zingmark, M., Evertsson, B., & Haak, M. (2019). The content of reablement: Exploring occupational and physiotherapy interventions. *British Journal of Occupational Therapy*, 82(2), 122–126. <https://doi.org/10.1177/0308022618792188>
- Zingmark, M., Evertsson, B., & Haak, M. (2020). Characteristics of occupational therapy and physiotherapy within the context of reablement in Swedish municipalities: A national survey. *Health & Social Care in the Community*, 28(3), 1010–1019. <https://doi.org/10.1111/hsc.12934>

**How to cite this article:** Kylén, M., Ytterberg, C., von Koch, L., & Elf, M. (2021). How is the environment integrated into post-stroke rehabilitation? A qualitative study among community-dwelling persons with stroke who receive home rehabilitation in Sweden. *Health & Social Care in the Community*, 00, 1–11. <https://doi.org/10.1111/hsc.13572>