Self-management from the perspective of people with stroke – An interview study

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ABSTRACT

Objective: Self-management support can improve quality of life, mood, self-efficacy, and physical function following a stroke. Knowledge of how people with stroke understand and experience self-management in different contexts is crucial to developing effective self-management support. This study explored how people with stroke understand and practice self-management during the post-acute phase.
Method: A descriptive study using qualitative content analysis to explore data from semistructured interviews
Results: Eighteen participants were interviewed. Most participants interpreted self-management as 'taking care of their business' and 'being independent". However, they encountered difficulties performing daily activities, for which they felt unprepared. Although interest in implementing self-management support increases, participants did not report receiving specific advice from healthcare professionals.
Conclusion: People continue to feel unprepared to manage everyday activities after hospital discharge and must largely work things out for themselves. There is an overlooked opportunity to start the process of self-management support earlier in the stroke pathway, with healthcare professionals and people with stroke combining their skills, ideas and expertise. This would enable confidence to self-management to flourish rather than decrease during the transition from hospital to home.
Practical implications: Individual tailored self-management support could help people with stroke more successfully manage their daily lives post-stroke.

1. Background

Despite reductions in mortality due to advances in acute care, many stroke survivors live with long-lasting consequences following acute care [1], including physical, cognitive and psychosocial limitations [2]. Stroke guidelines recommend early supported discharge (ESD) from the hospital and rehabilitation programs that increasingly take place at home [3,4]. ESD is often viewed as positive by people with stroke, but also as demanding and challenging for them and their families, as it requires considerable time and effort [5]. People with stroke also feel ill-equipped to manage the transition from the acute care setting to home [6]. Accordingly, self-management support (SMS) has been

highlighted as critical part of stroke rehabilitation [7]. SMS is tailored to individual needs, providing people with the support needed to develop the skills, knowledge and confidence to manage their daily lives and live to the fullest extent possible [8,9]. A prominent approach to SMS is based on social cognitive theory and the construct of self-efficacy, featuring strategies to support goal mastery, reflection and problem-solving [10].

The available evidence suggests that a person's self-management ability can impact their quality of life, mood, self-efficacy, and physical function following a stroke [8,11,12]. Healthcare professionals (HCPs), who support people in developing self-management skills, should provide support in a tailored way, considering a person's

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capabilities, hopes, goals and preferences. It is also crucial that HCPs understand how people with stroke perceive self-management support to engage with these individuals to help them develop confidence, skills and knowledge during rehabilitation and beyond.

Although evidence increasingly suggests that SMS has positive effects [8–10], the content and theoretical underpinnings of interventions can vary [13,14]. Self-management overlaps with related concepts such as coping strategies and person-centred care, which may lead to confusion regarding what constitutes a self-management intervention.

Studies have explored what the term self-management means for people with stroke. Satink et al. [7] reported that this concept was perceived as a complex and personal learning process in which striving to be independent in daily activities is crucial. In addition, discrepancies have been found in the understanding self-management among people with stroke and HCPs [2]. For example, research has shown that people with stroke may not perceive SMS as part of their care and rehabilitation, while HCPs tend to perceive it as a process in which they expect people with stroke to play an active role [2]. Boger et al. [15] found that self-management is important for both HCPs and decision makers, but the understanding of this concept is not always clear. Interestingly, the study also found that many people with stroke understood the concept despite a lack of communication regarding self-management in their interactions with HCPs. Several studies have also used the term self-care to refer to self-management, which makes navigating this terminology even more challenging [16]. However, a unifying framework, The Taxonomy of Everyday Self-management Strategies, has been proposed to clarify this conceptual confusion [17]. This framework may be useful for researchers and healthcare services seeking a better understanding of self-management strategies in the daily life of people with neurological conditions. One study that used this taxonomy to describe the strategies used by people with neurological conditions found a wide range of strategies interacting with and complementing each other, thus suggesting that SMS should be tailored to the needs of each individual [18].

In summary, the demand for self-management support (SMS) for individuals with stroke and their families has increased as more focus is placed on recovery and rehabilitation at home rather than in acute care hospitals. However, it is necessary to improve our understanding of how self-management is perceived and practised by people with stroke, as there may be discrepancies between their understanding of the concept and that of healthcare services. Additionally, little is known regarding how people with stroke perceive and experience self-management shortly after being discharged, as research on self-management perceptions in this context and population is limited. This study addresses these gaps by exploring how people with stroke perceive and experience self-management in the post-acute phase following discharge.

2. Method

A descriptive study using qualitative content analysis to explore data from semistructured interviews was conducted between May and December 2021. The study was approved by the Swedish Ethical Review Authority (ID: 2020–02116). An audit trail containing a transparent description of the research process was developed. The COREQ (COnsolidated criteria for REporting Qualitative research) checklist was followed [19] (Supplement A).

2.1. Participants

We used a purposeful sampling technique to recruit patients from an acute ward for people with neurological disorders at a regional hospital in central Sweden. To capture different views, we sought to ensure variation in terms of sex, age, and degree of impairment among participants. Participants were eligible if they were > 18 years old, fulfilled the criteria for a clinical stroke diagnosis, and could comprehend and speak Swedish.

2.2. Procedures

Eligible participants were identified by the research team through their contacts with the ward and were provided with written and oral information regarding the study. An interviewer contacted people who agreed to participate approximately one month following discharge to arrange an interview. Individual phone interviews were conducted by the first author (a physiotherapist) and an occupational therapist. Both interviewers had previous experience working with people with stroke and were trained in interview techniques before the data collection process. Verbal consent was obtained from participants before the interviews.

An interview guide with open-ended questions was designed to encourage participants to talk and reflect freely on their experience of self-management post-discharge. The questions covered what self-management meant to the people with stroke and their self-management experiences (Supplement B). The interview guide was pilot tested on four persons who represented the target group (not included in the sample), which resulted in a few minor revisions to the interview guide. All interviews were recorded, lasted approximately 20 min and were transcribed by the first author.

2.3. Data analysis

Data were analysed using qualitative content analysis featuring an inductive approach [20]. Transcripts and audio files were uploaded to NVivo v.12 software for qualitative analysis [21]. The analysis was iterative, and all the authors were involved at different stages of the process. First, four researchers (EK, MK, CG, ME) read the transcripts in their entirety to obtain an overall understanding of the content. Subsequently, meaning units were identified, i.e., single words or a few sentences that were significant to the study's aim. During this initial preliminary analysis, discussions were simultaneously held by the research group to determine information redundancy. The codes were then grouped into categories according to the similarities among them. The following step involved comparing similarities and differences in the analysis to reach a consensus regarding the final identified categories. These categories were refined, discussed, and negotiated among the research team until a complete list of categories was finalized. All authors discussed the categorization until a consensus was reached. Table 1 provides an example of the categorization process.

2.4. Rigour

To enhance credibility, analyst triangulation was applied in the research group, meaning that the codes and categories were discussed on several occasions throughout the whole analysis process and during a research seminar with external reviewers. During these meetings, alternative interpretations were considered, and the analysis continued until consensus was reached. To reduce potential researcher biases and ensure that the analysed material stayed close to the original data, rich and varied quotes from the participants were used. A professional translator translated the quotations from Swedish to English. All participants had the opportunity to read and comment on the material after the analysis phase. One participant accepted and confirmed that the analysis resonated with her experiences.

Table 1
Example of the analysis by subcategories and examples of codes and meaning units in the category "Taking care of yourself".

Category	Subcategory	Example of codes	Example of meaning units
Taking care of yourself	Managing daily activities independently	Independence in daily activities	Self-management is really taking care of your own business.

3. Results

3.1. Participants

Eighteen people with stroke were interviewed, including five men and thirteen women. Participants' ages varied between 44 and 87, and their number of days since stroke varied between 29 and 48. Additional characteristics of the participants can be found in Supplement C.

3.2. Interpretation of interview content

The generated categories and sub-categories exposed different strategies, activities or support that the participants used to create their game plans for self-management. The three main categories were: 1) taking care of yourself, 2) taking action – self-management in practice, and 3) personal strategies to deal with the day. Each category comprised multiple subcategories (Fig. 1). Taking care of yourself and the related subcategories referred to components of the self-management strategies that the participants used to create a supporting atmosphere. Taking action – self-management in practice, included actions that showed how self-management was operationalized by the participants. Personal strategies to deal with the day referred to the participants' attitudes towards self-management—positive or negative—and what kind of self-management support the participants needed.

3.3. Taking care of yourself

3.3.1. Managing daily activities independently

Conceptualizations of self-management varied among the participants, with the majority of participants associating self-management with being able to manage daily activities independently. This ability was expressed in terms of the desire to perform the same activities that they could perform before their stroke, such as activities related to personal hygiene, cooking, grocery shopping, and other household tasks. Participants repeatedly noted that they did not want to burden anyone with their problems and wanted to maintain their independence. As one participant stated,

> Well… it's really that you're taking care of yourself. Caring for yourself. Dealing with your own troubles and, yes… self-management, it's really that you are taking care of your own business. *(Male, 85)*

In contrast, while most participants considered self-management as a broad concept connected to daily life, others understood self-management as primarily pertaining to managing their health, such as by taking pills when they felt unwell. This conception was often related to their stroke but also included other conditions, such as having a headache. Some participants also claimed that self-management was closely related to their ability to engage in physical exercise.

Some participants lived in rural areas and had to travel long distances to reach the nearest grocery store. Since all participants' driver's licences had been temporarily revoked, those who lived in rural areas were forced to seek help from others. Some of these participants described their inability to drive as challenging as it reduced their independence and their ability to manage daily activities independently.

3.4. Being kind to and taking care of yourself

Some participants claimed that self-management meant, in part, being kind to and taking care of yourself. They expressed a desire to prioritize their own time following their stroke. Some participants described how they had pushed themselves throughout their lives but noted that following their stroke, they realized that they should listen to their body and take trivial chores such as cleaning windows less seriously. Participants who wanted to prioritize their own time and activities expressed a desire to be more selective regarding the tasks into which they invested effort.

> Yes, I want to feel well, so I must try to work towards this. To strive towards things that make me feel well. *(Female, 79)*

3.5. Dealing with things on your own to build confidence

Most participants noted that self-management was important for their independence and that they wanted to deal with everyday activities on their own. They explained that being able to manage everyday activities gave them a sense of satisfaction and helped them build confidence. They stated that it was important for their desire to be independent to be respected and that relatives or health services did not automatically provide help that they did not request or need. As one participant noted,

> All the time, I've been told: 'But mom, I'll do it for you, I'll fix that!' And that ends up with me telling my daughter or whoever else: I can do it by myself, I want to, I want to, I will find a solution! *(Female, 63)*

Although the majority of statements made by participants pertained to the need for independence and their attempts to do things for themselves, one participant expressed feelings of hopelessness regarding being able to manage things in the future.

3.6. Take action – Self-management in practice

3.6.1. Finding new ways to perform activities post-stroke

Many participants discussed their self-management by describing how they now performed activities differently due to their impairments, which quickly became normal everyday life. They view it as essential not
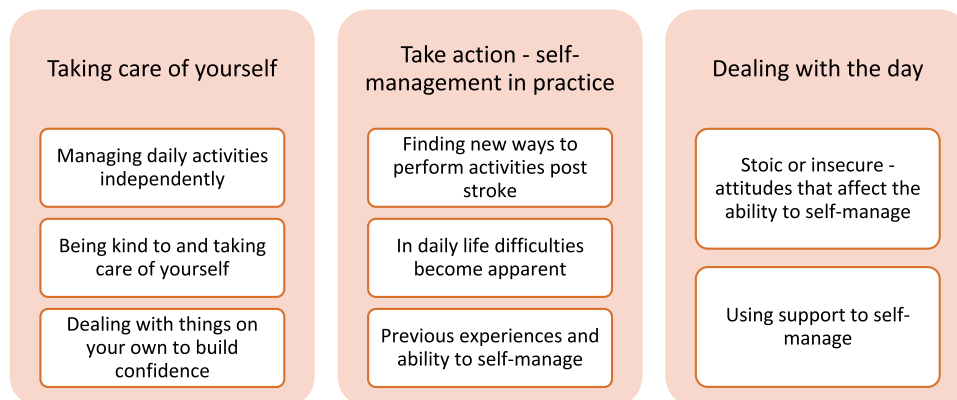

Fig. 1. Overarching theme with main categories and subcategories.

to become passive but rather to take responsibility and do their best to solve problems. Most participants emphasized that not doing the activities they had done before their stroke was not an option. This goal often required them to develop creative solutions to problems they encountered. For example, one participant cut her hair to make it easier to wash, and another built a device for his tractor that enabled him to control it with his weaker hand. These solutions were not suggested by HCPs but were rather based on participants' own initiative. In contrast, a small number of participants claimed that they were unable to take action, i.e., that they had become more passive following their stroke or avoided activities.

> No, I don't do things. I just don't. I don't have the energy… and I don't want to risk falling again. *(Female, 65)*.

3.7. In daily life, difficulties become apparent

Several participants described encountering real situations after being discharged and finding it difficult to perform daily activities. They had not been aware of the extent of their functional limitations until they arrived home. One participant made the following statement:

> Well, I felt more normal in the hospital – but I didn't have to do anything there! *(Female, 79)*

Arriving home and encountering functional limitations that hindered their ability to manage their daily lives was an experience for which they were unprepared. On the other hand, awareness of these limitations forced participants to deal with the situation at hand. Many participants noted that they could not have imagined that things would be so different after arriving home. As one woman said,

> It is a shock to come home and… yes, you knew what had happened, but you didn't understand how much it would affect you in your everyday life, really. *(Female, 44)*

Most participants felt pleased about their return to their home environment despite encountering activities that they did not know whether they could manage, such as using stairs or taking a shower. The home environment was an important arena for self-management, as it challenged them to try to perform regular daily activities. No participants were forced to move or make significant adjustments to their homes to manage their daily lives following their stroke.

3.8. Previous experience and the ability to self-manage

Some participants discussed the ways in which they used their previous experiences in life to handle their new situations following their stroke. Some participants described previous experiences that required them to trust their own abilities, such as being a business leader or a single parent. Others described using self-management strategies based on previous experiences of illness or disability, which they transferred to their new situation following their stroke. For example, one participant who suffered from severe tremors related examples of strategies developed during an earlier episode of tremors that could also be used now, such as using both hands to carry things. Strategies used to overcome functional limitations that had been successful in the past increased participants' sense of control and security. A few participants expressed the view that their situation following their stroke was unique and could not be compared to their previous experiences; they employed expressions such as "No, I cannot use anything from the past" or "No, this cannot be compared."

3.9. Personal strategies to deal with the day

3.9.1. Stoic or insecure – Attitudes that affect the ability to self-manage

Many participants described their inner drive to manage their situation, claiming that this drive was something they had possessed their entire lives. They described how this drive gave them the positive

energy, determination, and courage necessary to try to perform activities that seemed difficult. They explained that they trusted their ability to manage things even in their new, post-stroke situation. However, not all participants had this inner drive, and some participants expressed uncertainty regarding their physical ability and the medical restrictions they encountered. These limitations prevented them from engaging in daily activities such as gardening or shopping.

> You feel like: what am I allowed to do? What can I do? How far can I walk? How much can I push myself? I was unsure of what I dared to do. *(Female, 65)*

3.9.2. Using support to self-manage

All participants noted that they were unable to manage everything on their own once they arrived home. They received some types of support from family members or neighbours with regard to managing their daily activities, for example, grocery shopping, laundry, or other difficult household activities. A few participants had relatives who moved in with them for some time to help, and several participants received support from community services. Some participants described how relatives or friends provided emotional support or encouraged them to self-manage, for example, to leave the house for a cup of coffee.

Several participants described the acute phase as an overwhelming experience, and most participants recalled the support and care they received from the staff in the stroke department as professional and friendly. One problem was the vacuum that they experienced between being discharged from the hospital and their three-month follow-up visit. During this time, many thoughts and questions arose concerning how to manage their health condition and daily activities, and many participants found that they were unprepared for their new situation. Participants' short hospital stays left them with a feeling of being abandoned and of having unanswered questions. One participant made the following statement:

> …you really don't get that you've been sick, that comes after, these thoughts and how things will be, and yes… you don't have anything to ask at the time (when you are still in the hospital). *(Female, 74)*

At the time of the interviews, some participants had not yet received the standardized three-month post-discharge follow-up call from the stroke ward regarding medical issues. All but one participant had received a call from a home rehabilitation team to check on their perceived need for rehabilitation. Some participants had accepted a period of home rehabilitation.

4. Discussion and conclusion

4.1. Discussion

This study explored experiences of self-management among people returning home after an acute stroke. The participants reported that they had to create their own strategies and plans for managing their daily lives, including prioritizing tasks and seeking support from family and friends, due to a lack of guidance from healthcare professionals regarding self-management strategies. Analysis of the data collected from the participants emphasized the overall theme of "creating a game plan for self-management." This theme highlights the importance of providing additional support and guidance regarding self-management to individuals with stroke as they transition from hospital to home to improve their ability to manage their daily lives and their overall quality of life.

This study was conducted in Sweden, a high-income country featuring highly specialized stroke care and policies that encourage person-centred stroke care and home rehabilitation [3,22]. Nevertheless, it is noteworthy that none of the participants in the study reported receiving encouragement or support from HCPs in their efforts to self-manage after returning home. This lack suggests that there may be a

gap in HCPs' knowledge concerning how to provide counselling and education with respect to self-management strategies beyond merely managing medical symptoms and controlling the disease. Simultaneously, the study found that many participants lacked knowledge regarding medical issues such as the need to follow prescriptions, thus highlighting need for improved information provision and follow-up after discharge. This finding is consistent with previous research that has identified a lack of self-management support prior to discharge and challenges with the transition from inpatient rehabilitation to home [23]. It should be noted that this study was conducted in a Swedish context; a similar study performed in another context or geographical area might have gained other experiences. For example, Pereira's [24] study, conducted in Portugal, showed that persons with stroke wanted more support from their relatives and HCPs, which was not revealed in the current study. Persons with stroke in rural Indonesia prioritized maintaining religious duties and contributing to the family post-stroke [25]. More research is needed to explore cultural differences in self-management support and experiences among persons with stroke. While most studies have been conducted in high-income countries, stroke is rapidly increasing in low- and middle-income countries [25]. By better understanding cultural differences, we can improve self-management support worldwide.

Despite the lack of support for self-management offered by HCPs, most participants noted that to them, this concept meant taking care of yourself and indicated that they had a strong desire to be independent and self-reliant. They took actions and created their own strategies and game plans to manage their daily lives and seemed to have an inner drive to solve problems. Previous research has indicated that the successful management of activities can increase self-efficacy, which is a component of self-management skills [26]. This claim supports our findings that the significant number of activities that the participants in this study performed may have helped them develop self-management skills on their own. These results are in line with the taxonomy of self-management developed by Audulv and colleagues [17], which includes strategies such as prioritizing activities and engaging in healthy behaviours that align with the subcategory of "taking care of yourself" in this study.

In addition, this study found that the participants did not actively seek support from social networks such as peer patients or patient organizations. Previous research has shown that peer support and social networks play a crucial role in self-management [18,27,28]. In the present study, it is possible that the participants did not prioritize making connections to social groups at the time of the interviews, as they may still have been processing their stroke and trying to manage day-to-day tasks and activities, consistent with previous research that showed how focus change over time post stroke[24]. It is also unclear whether the participants were aware of the availability of such social support groups. Additionally, the COVID-19 pandemic, which was ongoing at the time of the interviews, may have limited the feasibility of social meetings and events. Most participants in this study were able to perform and accomplish daily activities successfully, which may have had a positive impact on their self-efficacy and ability to self-manage despite the lack of social support from peers and patient organizations. Previous research has shown that people with stroke were able to flexibly and creatively adapt to the restrictions associated with the COVID-19 pandemic [29].

Although many participants seemed to be autonomous and self-reliant, they nevertheless expressed a desire for more contact with healthcare after being discharged in addition to the support they received from their home rehabilitation team, which focused primarily on improving their functional ability. Even participants with minimal impairment felt a need for more contact with the healthcare system after being discharged because they felt dazed and shocked following their stroke, feelings which they perceived that the healthcare system had not considered. These findings may indicate discrepancies between how HCPs and people with stroke interpret a stroke event and the support

that is needed thereafter, a point which has been noted in previous research, e.g., by Pindus et al. [30]. In the present study, most participants also reported difficulties performing daily activities after returning home despite having undergone exams in acute stroke care. This finding suggests that such exams may not take individual needs into account to a sufficient degree but may focus instead on standardized basic daily activities. The discrepancies between how disability is experienced by people with stroke and how it is assessed and managed by HCPs have been described previously by Tistad et al. [31] and continue to be an issue in healthcare.

This study faces certain limitations that should be taken into consideration when interpreting the findings. First, the participants were a relatively active group with mild or moderate stroke diagnoses and without aphasia. Accordingly, the results of this study may not be generalizable to individuals with different levels of stroke severity, aphasia, or severe cognitive deficits. Second, the sample was quite homogeneous in terms of ethnicity and gender, with a majority (n = 13) of participants being female. This issue should be addressed in future studies using more diverse samples. Despite these limitations, the participants did exhibit various background characteristics, such as age, living conditions, and degree of impairment. In addition, the interviews were short (with an average duration of 20 min) but nevertheless provided rich content and met the aims of the study. The interviews were conducted by telephone due to the COVID-19 pandemic, which may have affected the results, as telephone interviews tend to be shorter [32] and may be more fatiguing for individuals with stroke due to the lack of visual cues and the necessary reliance on verbal communication. As fatigue is a common problem following stroke [33], this form of data collection method might be more difficult for people with stroke. However, due to COVID-19, telephone interviews were necessary as an alternative to face-to-face interviews to protect the health and safety of participants and researchers. Telephone interviews have been described as a viable option when conducting interviews [34].

4.2. Conclusion

This study found that people continue to feel unprepared to manage everyday activities after being discharged from acute stroke settings and must often figure things out on their own. Thus, there is an overlooked opportunity to start the process of self-management support earlier in the stroke pathway, with HCP and patients working together to combine their skills, ideas and expertise. This approach would allow patients' confidence in self-management to continue to grow rather than decrease during the transition from hospital to home.

4.3. Practical implications

It is important for HCPs to assess the needs and skills of individuals with stroke in light of the challenges they may face upon returning home and to provide tailored SMS as soon as possible. This support should take into account the motivation and problem-solving skills of the individual in question, and additional support should be provided to those who may be lacking in these areas. It is also important for healthcare professionals to maintain a high level of motivation in individuals who already have strong motivation and to develop self-management support methods based on the knowledge and experiences of individuals recovering from a stroke.

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CRediT authorship contribution statement

Erika Klockar: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Writing – original draft, Visualization, Project administration. **Maya Kylén**: Conceptualization, Methodology, Validation, Formal analysis, Writing – original draft, Visualization. **Catharina Gustavsson**: Conceptualization, Methodology, Validation, Formal analysis, Writing – original draft, Visualization. **Tracy Finch**: Conceptualization, Validation, Formal analysis, Writing – review & editing. **Fiona Jones:** Conceptualization, Validation, Formal analysis, Writing – review & editing. **Marie Elf:** Conceptualization, Methodology, Validation, Formal analysis, Writing – original draft, Visualization, Supervision, Project administration, Funding acquisition.

Declaration of Competing Interest

None.

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