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# **RESEARCH ARTICLE**

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# Supporting someone after their stroke: family members' views and experiences of self-management

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# ABSTRACT

**Purpose:** Self-management has increased in recognition in stroke research and rehabilitation along with growing trends of shorter hospital stays and more patient-centred care. Family members are key persons in the self-management process, but their views and experiences of self-management have not been studied in detail. This study aimed to explore family members' understanding of self-management, the strategies they use and the challenges they face when providing support.

**Methods:** For this descriptive study, semi-structured interviews with family members (n=27) were conducted. Data were analysed using inductive content analysis.

**Results:** The analysis resulted in three main categories and eight subcategories. Most family members saw self-management as performing practical tasks, such as daily living activities and rehabilitation training. However, family members described a broad range of actions to support self-management, including emotional and motivational support. They found it challenging to give the right amount of support and expressed a need of more information after discharge.

**Conclusions:** Family members' conceptualisations of self-management differ from the strategies they use to provide support. A clearer understanding of self-management as a collective process can benefit the development and delivery of efficient self-management support.

- > IMPLICATIONS FOR REHABILITATION
- Family members are co-managers to people with stroke, as part of a collective approach to self-management.
- Health services should aim at enhancing family members' understanding of self-management and strengthen their role as co-managers.
- Self-management interventions can promote a holistic perspective by guiding family members and balancing their involvement.

# Introduction

Self-management support has become more established in stroke rehabilitation and research [1,2] and come into greater focus as stroke care aims more for increasingly early discharge from hospital and a greater role for rehabilitation at home [3,4]. Self-management is often referred to as an individual's ability to deal with practical, physical, psychological, and emotional challenges in life with a long-term condition [5,6] and can be seen as a long-term process [7]. Some descriptions of self-management strategies focus on the management of symptoms and behaviours directly related to a long-term condition, for example, taking medication, whereas others involve strategies for maintaining a good quality of life despite the presence of a diagnosis in a wider perspective [8,9]. Various frameworks have been developed to illuminate the complexity of self-management, which typically address individual skills and strategies [5,8,10,11]. Among these, the Taxonomy of Everyday Self-Management Strategies (TEDSS) provides a framework outlining seven key domains of self-management in everyday life. These domains comprise strategies such as problem-solving, seeking support, managing everyday activities, dealing with emotions and social relations, in addition to strategies for controlling the disease and maintaining a healthy lifestyle [8].

Numerous interventions and programmes to support self-management in individuals with stroke have been developed, with reporting positive changes in activities of daily living, quality of life, and psychosocial outcomes [12–17]. Self-management programmes can have theoretical foundations such as self-determination theory, the transtheoretical model of behaviour change or, most often, social cognitive theory (SCT) [18]. The application of SCT in self-management contexts has focused on the role of self-efficacy in individual human agency, emphasising an individual's belief in their ability to succeed in a prospective situation [18,19]. Consequently, most studies and interventions concerning self-management have focussed on individual skills and behaviour

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**KEYWORDS** Stroke; self-management; family; social support;

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[14,20,21]. However, considering self-management as an individual process provides a limited view of the reality of most people living with long-term conditions such as stroke. Both social and environmental factors impact the self-management process [1,22], and family members can be the main supporters at a stage when stroke survivors' confidence and knowledge to self-manage is evolving [23-25]. The social networks that influence self-management ability may also include healthcare professionals, friends, neighbours, colleagues, other acquaintances and even pets [22,24,26,27]. It has therefore been suggested that self-management should be seen more widely as a collective process that focuses on an individual's ability to manage a situation in conjunction with their support network [21,26,27]. This process is also aligned to Bandura's descriptions of collective agency, in which people's abilities and actions are coordinated to shape a common future [19]. Even so, this collective approach has received limited recognition in research, and studies on family members' involvement in the rehabilitation of stroke patients have focused mainly on their perceived burden and their own coping strategies [28-30].

Self-management strategies and support from social networks are increasingly important due to constraints on healthcare resources, the promotion of early discharge from the hospital, and a focus on patient-centred care [4,31–33]. It has repeatedly been reported that people with stroke and their family members feel unprepared at discharge and experience a lack of professional support after they return home [34–36]. For future healthcare sustainability, it is crucial to enhance self-management support to people with stroke which, in turn would involve members of their social networks [37]. Thus, self-management needs to be understood as a collective process, including family members perspectives. This study aimed to explore the experiences and perceptions of stroke survivors' family members, focusing on their understanding of self-management, their strategies and the challenges they face in supporting self-management.

# Methods

# Study design

A descriptive qualitative study using semi-structured interviews [38] and inductive content analysis [39] was conducted. Informed by a social-constructionist approach, we sought to gain a deep understanding of participants' perceptions and experiences of supporting self-management. The Consolidated Criteria for Reporting Qualitative Research checklist (COREQ) guided the reporting of the study [40].

#### Participants and recruitment

Participants were family members nominated by a person with stroke, who were taking part in a research project on the implementation of a self-management intervention in a Swedish setting, the self-management project SELMA [41]. The nominating person had suffered mild to moderate stroke, was admitted to a stroke ward in a hospital in southern Sweden and was subsequently discharged to home. One of the interviewers (the first author (LM) or a research assistant) contacted potential participants by phone to provide information about the study aim and procedures. Six persons could not be reached or declined to participate. Twenty-seven people agreed to participate and a time for an interview was scheduled. Written information about the study procedures was sent by mail to each participant prior to the interview. Ethical approval was granted from the Swedish Ethical Review Authority (DNR 2020-02116, 2021-03476, 2022-03099-02).

#### Data collection procedures

Semistructured interviews [38] were conducted by telephone by the first author and a research assistant between September 2021 and September 2023. The first author is a female PhD student and registered physiotherapist whose main work experience is in academia and qualitative research. The research assistant is a female registered nurse with experience of working in a hospital stroke ward. The interview guide was developed by the research team and tested in three pilot interviews with family members. Data from the pilot interviews were included in the analysis since no significant changes to the interview guide were needed. Before the interviews started, participants were once again informed about the study, and informed consent was audio recorded. A short general description of self-management derived from the literature [5,6,9] was given to introduce participants to the topic and provide a basis for them to elaborate on during the interview. The description was as follows: "Self-management is about having strategies to handle everyday life and manage activities of daily living. The strategies may be about finding ways to solve practical problems, making decisions and knowing how to achieve what you want and what you use to do so. Some people want to manage things on their own whereas others prefer to ask others for help." The main questions of the interview guide were "What do you think of when you hear the term self-management?," "What are you doing to support [your family member] in self-management?," and "What are the opportunities and challenges you face when supporting [your family member] in self-management?" In addition, follow-up questions were included. Most of the interviews lasted between 20 and 30 min (range 11-49 min) and all interviews were audio recorded and transcribed verbatim.

## Data analysis

The data analysis followed the phases of content analysis described by Elo and Kyngäs (2008), which was chosen because it is a low-inference method suitable for topics where previous research is limited [42]. Accordingly, the manifest content of the data were analysed [39]. In the first phase of the inductive analysis, the first author read and reread the transcripts to familiarise herself with the data and identified meaning units guided by the aim of the study. In the second phase, the meaning units were assigned descriptive codes that were subsequently organised into categories by collating codes that could be related (Table 1). This was performed using qualitative data analysis software (NVivo v.14) [43]. The coding process was reviewed by one of the other authors (ME). The researchers moved back and forth between the data and the categories to preserve the original meaning. Since the meaning units and codes were in Swedish, the Swedish researchers (LM, ME, MK, CG) were involved in the first step of categorisation. All the authors subsequently reviewed the categories and were involved in developing representative names. This iterative process continued until a consensus was reached. The collaborative approach and the careful categorisations of data ensured the accuracy of the findings and the trustworthiness of the study [38].

# Results

#### Participants

Twenty-seven people were interviewed, seventeen of whom identified themselves as females and ten who identified themselves as males. Their relationships with the people with stroke are presented in Table 2. Participants were between 26 and 86 years old (missing

Table 1. Examples of codes and meaning units allocated to the main category "being a pillar of practical support in everyday life."

Example of meaning unit	Example of code	Subcategory	Main category
"he has, except cardio training and that, he has special exercises for his face"	Specific rehabilitation exercises including walking training	Regaining and maintaining bodily functions through physical training	Being a pillar of practical support in everyday life
"so we introduced a pill-organiser so it would be easier for him to remember by himself"	Reminding of medication	Managing symptoms and medication	Being a pillar of practical support in everyday life

Table 2.	Participant	characteristics.

				Interview, N
		<u> </u>		months after
Participant	Relationship	Gender	Age	stroke
P01	Noncohabitating partner	F	68	2
P02	Spouse	М	86	2
P03	Spouse	F	57	6
P04	Spouse	F	64	1
P05	Cohabitating partner	М	82	1
P06	Daughter	F	26	4
P07	Spouse	М	65	7
P08	Spouse	М	60	4
P09	Spouse	F	74	2
P10	Daughter	F	43	2
P11	Ex-spouse	М	61	1
P12	Spouse	М	76	2
P13	Spouse	F	72	2
P14	Spouse	F	75	4
P15	Daughter	F	38	1
P16	Spouse	М	68	2
P17	Daughter	F	27	4
P18	Daughter	F	46	4
P19	Father	М	Missing	3
P20	Spouse	М	66	5
P21	Spouse	F	50	4
P22	Spouse	F	65	2
P23	Noncohabitating partner	М	67	2
P24	Spouse	F	67	1
P25	Cohabitating partner	F	38	1
P26	Daughter	F	59	3
P27	Spouse	F	76	3

N=1), and the interviews took place between one and seven months after their family member had been discharged from the hospital to home. Some of their family members had experienced several strokes, and some had experienced stroke for the first time.

#### **Findings**

The analysis resulted in three main categories of participants' understanding, views and experiences of self-management. Self-management was often conceptualised and supported in practical terms, summarised as "Being a pillar of support in everyday life." It was also highlighted as the management of psychosocial aspects, included in "Providing social and emotional support." Finally, views and experiences of the challenges of the supportive role were included in "Balancing the complexity of being the support" (Figure 1).

#### Being a pillar of practical support in everyday life

This category comprised participants' concepts of self-management and ways to provide support in terms of practical actions to manage everyday life or to manage issues directly related to the stroke.

#### Managing everyday life activities at home

Participants described self-management as managing "on your own" and "doing as well as you can" in everyday life, referring to, for example, ensuring personal hygiene, getting dressed, making coffee or food for oneself, and doing other house chores. Although they were asked about the meaning of self-management in general, most of the participants referred to the self-management of someone who had experienced a stroke. The examples of self-management they provided varied in complexity, from simply being able to eat or serve oneself food to choosing what to eat or cooking a whole meal. Additionally, being able to get out of bed, move freely around the house or perform chores such as washing and cleaning was referred to as self-management. One female participant (**P10**, daughter) gave several examples of what she thought self-management was:

It is like, to come back to normal life, before this happened, to have, to be able to go out, like they do, go up and down the stairs, to put spreads on your sandwich, to go shopping, get dressed, like...eh...that you need support in your everyday life so it doesn't deviate so much from how it used to be, that you manage to take care of yourself. That is what I am thinking.

Participants explained how they supported activities to enable the people with stroke to manage more independently. This could include providing minor manual assistance and verbal guidance when a person was getting dressed or moving around and ensuring safety when performing practical tasks. Transport issues were highlighted as a significant obstacle to stroke survivors' abilities to manage their life independently, and several participants regularly assisted in driving their family member with stroke to activities or to work.

# Regaining and maintaining bodily functions through physical training

Many participants mentioned performing rehabilitation exercises or general physical training as a significant part of self-management. Some described self-management as when a person with stroke follows prescribed rehabilitation exercise programs, with the help of healthcare staff or on their own. Others saw general physical training or training for well-being as part of self-management. Participants explained how they supported rehabilitation by providing manual support to enable training, making it possible for their family member to access rehabilitation services or reminding them about the training. One daughter (**P17**) gave an example of her practical support:

...with the rehabilitation in the beginning it was so to say, maybe when she would go, yeah it was an exercise where she needed some kind of sheet or long towel that she could use to pull her leg, sort of. So you could sort that and fold it and stuff like that. And there was some kind of mat that needed to be rolled up to be used in the rehabilitation that I helped with. So to prepare some equipment, she asked for help with as well, in the beginning.

#### Dealing with care contacts

To manage contact with healthcare and social insurance authorities was also acknowledged as part of stroke survivors' self-management. Some participants thought that they could assist in communication between their family member and healthcare professionals by clarifying things for both parties and helping to remember what had been said. This was described by one woman as follows (**P14**, wife):

To talk about it, and be there for different meetings... because you pick up different things, if you, like you, as a patient maybe you do not remember, you get stuck in the first thing and then, so that has been good, that you can be there and clarify what has been said. That is good. I think that is important.



Figure 1. Main categories and subcategories.

#### Managing symptoms and medications

Some of the participants mentioned that managing medications and stroke symptoms was part of self-management. They supported the people with stroke by reminding them to take their medicine, and one participant (**P1**) shared a strategy to enable her partner to manage his medication more independently:

He has quite many medications so we introduced a pill-organiser so it would be easier for him to remember by himself.

Another woman described how her husband had been advised about how to balance rest and activity and how to use sunglasses to manage his symptoms after stroke.

#### Providing social and emotional support

Although few participants initially acknowledged social and emotional management as self-management per se, most participants explained how they supported the stroke survivor in their emotional processing of the situation and encouraged them to work towards improvement. They regarded this as a very important part of their support. Two participants had experienced a stroke themselves and highlighted that this had helped them support their family members' self-management. This lived experience gave them a good understanding of their family members' situations and enabled them to provide a feeling of security.

#### Being there and enabling social connections

Several participants said that it was not always necessary to do things: just "being there" allowed the person with stroke to talk about their situation and emotional issues and helped them deal with their situation. Some participants believed that this type of support could prevent depression. Another support strategy was to initiate conversation, play games, or suggest activities that could serve as distractions from the current situation, including getting together with other family members or friends. One woman (**P24**, wife) stated:

And we have been talking about that as well, I said now you should not ponder so much, but do fun things, let's go out to see some friends. That has helped him a lot.

#### Being a motivating supporter

Having the determination and drive to return to activities and everyday life as it was before the stroke and to make positive progress was described by two participants as a prerequisite to self-management. This could be facilitated by being challenged by others to try things, as described by one daughter (**P26**):

Yeah, but that is what I am thinking, that they challenged her too. Because in the beginning it was also, I cannot do that, that will never work. Yeah, but pick up, pick up that butter knife and try, look, put on the spread and do that. Like, that was an example, of...empowerment or what one should say, to know where the limits are, now we can raise the bar and show mum, or NN, that you can really do this. And then NN does it and she can make it.

Participants also expressed that they facilitated motivation by giving verbal encouragement, showing interest in their family member's rehabilitation or being involved in the scheduling of training and goal setting. This was seen as the main way of providing support by some participants. One daughter (**P17**) stated:

Ehm, I think it is mainly about motivation and encouragement and that...maybe you cannot do so much physically, because that is sorting itself. But it is to keep the motivation up, especially when you are at home or speak on the phone and that, that you, you can ask how it is going with the rehabilitation, how much she is doing. Yeah, keep her responsible like, about what she is doing in her rehab and that. But she is very motivated; it is nothing I have felt has been a problem. But it is that you are encouraging them, to do their rehab and do the exercises at home, and I did that a lot more in the beginning than I am doing now.

# Balancing the complexity of being the support

The stories shared by the participants outlined a complex picture of the attitudes and practices of providing support for self-management. The complexity stemmed not only from the different experiences among individuals but also from the individuals' ambiguous perceptions of their role.

#### The duality of the commitment

Taking on the supportive role was described as meaningful and seen as a natural part of the relationship by most participants. Only one man said that he felt obliged to provide support, as he was helping his ex-wife, although they had been divorced for several years. However, the efforts and degree of involvement in self-management varied among the participants. There were participants who expressed that their role was not burdensome, although they had to support and take more responsibility than before. They described managing everyday life tasks together with the stroke survivor, for example, cleaning the house or going to the supermarket. A few participants did not find their support necessary since the family member with stroke managed well on their own. In contrast, some participants described the supportive role as tiring, time-consuming and limiting their own life. This particularly applied when the participants were children of a stroke survivor or when a stroke survivor had physical impairments. It was especially difficult if participants experienced that providing support limited their own everyday lives or meant that they frequently had to drive the person with stroke or travel to be able to provide support.

One woman (P1, noncohabitating partner) said:

It has been really tough; it is like you said, a full-time job to look after him now...and now, now I am at home, where I really live. For the first time I have actually slept here for two nights, and our son who lives out there keeps an eye on him. Reminds him. But he says himself, I have spoken to him on the phone, that he has managed to remember his medicine and insulin and that, so he has, but I feel you have to check on him anyway...

Participants experiencing a burden of their role in supporting self-management highlighted the need to take care of themselves to be able to carry on. They described the need for time to manage their own everyday lives and to regain energy.

Another duality involved balancing supportive actions and one's own control behaviours in relation to the stroke survivors' needs. Participants revealed that they wanted to give space to the people with stroke to manage on their own, avoid being overprotective and not provide help when it was not needed. At the same time, some participants felt that they were nagging their family members when they reminded them about rehabilitation training or were constantly checking them. One woman (**P21**) described her concerns about her husband:

I do not know if it was good or bad, but I do know that I was worried in the beginning when I was about to leave him. I was working truly long days and I was like, can you call if you go out and like that, I do not think it would have been so good if I was there like a mother.

#### Facing hindrances and challenges

In addition to the complexity of the role, participants' ability to support self-management was affected by hindrances and challenges. Although practical and physical support was only a part of what they provided, geographical distance was perceived as a significant hindrance to being supportive, and participants expressed that being available on the phone was not the same thing. Other work and family commitments were also highlighted as limiting participants from providing as much support as they wanted.

Not being involved in care or not receiving enough information about rehabilitation and impairments following stroke were other factors perceived by many participants as hindering their support of self-management. Participants felt that they were not informed about the plans for continued care and rehabilitation and what was expected of them as supporters in these processes. Some participants reported a particular lack of information and knowledge about symptoms and the normal course of recovery after stroke, which could have helped them in their supportive role. One woman stated (**P18**, daughter):

We felt that we were not informed that it actually demanded a lot from us./.../I felt like, we are novices in this. Of course, you could have figured out that like, dad does not have an arm, so maybe he cannot cook...but I mean, we were in shock. We would have needed a bit more information like, I had to take sick leave in the end!

Participants also described emotional challenges that emerged in everyday life when supporting self-management. One was to stay on top of things and be supportive without losing patience, described by one woman as follows (**P3**, wife):

Yeah, that you are one step ahead, like, all the time, always getting questions, again and again about the same thing, not getting annoyed and... yes, there is a lot of that kind of different circumstances or what I should say.

Other challenges were described in a positive manner since they facilitated the use of creativity and alternate solutions to solve problems. This could, for example, be to change the routine for getting dressed, not rushing the person with stroke and being prepared to rearrange activities.

# Discussion

This is the first study to explore the experiences and perceptions of self-management among family members supporting a person after stroke within a Swedish context. The emotional and practical burdens and challenges were highlighted, similar to other studies [28–30], but the novel findings were those of the participants' conceptualisations of and strategies to support self-management. The participants' focus on practical matters in their explanations of the term self-management contrasts with the range of actions depicted in their stories of providing support, that also included psychosocial aspects. The findings of this study expand the knowledge of family members' roles in self-management processes and indicate that their understanding of the concept of self-management can be broadened.

Participants primarily explained self-management as managing activities in daily life or performing rehabilitation and physical exercises to promote recovery. This is similar to findings among stroke survivors, that often describe self-management as doing things "on their own" or "looking after oneself" [23,44,45]. Some of our participants also thought of self-management as dealing with healthcare contacts or being able to control the intake of medicine. Only a few participants described the term self-management in more subtle ways, such as having a motivational drive towards improvement. This focus on practical management probably arises since practical things are tangible and that healthcare support often focuses on those aspects, which may influence how family members perceive self-management. However, participants' practical focus does not fully align with

definitions and conceptualizations of self-management in the literature, which also include emotional and social strategies [6,8,46]. Interestingly, participants described support strategies related to all domains in the TEDSS framework [8], with emphasis on support in social connections, dealing with emotions and encouraging motivation. These actions seemed to be enacted more implicitly and indicates discrepancies between how family members understand self-management and what they do to support it. Increasing family members' understanding of the multifaceted meaning of self-management, as described in the literature, can enhance their appreciation of different types of support and guide them in adopting and prioritising support strategies. Thus, it may enhance family members abilities to provide proficient support over time and achieve more balance in their lives. This may require education intertwined with self-management interventions or transition-to-home routines.

Participants experienced various difficulties and challenges in their role and particularly highlighted that insufficient information regarding care and rehabilitation was something that prevented them from providing support to the extent they wanted. Research has consistently shown that family members of stroke survivors experience a lack of professional support and information after discharge [29,34,47,48]. Information sharing and sustained contact with healthcare professionals seem essential when family members are included in the self-management process, and more research is warranted on how to meet these needs. Another challenge raised by participants in our study involved balancing the amount of support they provided for the stroke survivors; to be helpful but not overprotective. Studies have shown that family members may unintentionally hinder self-management by performing supportive actions that are too helpful or cautious although independence is an expected outcome of self-management for stroke survivors [2,7,22]. Therefore, family members may need more guidance in how to provide the right support at the right time and to the right extent. Mendes Pereira and colleagues [25] found that family members adjust, develop and learn to prioritise their support to stroke survivors during the first six months after discharge, which indicates this is a critical period in shaping the self-management process.

The stories shared by our participants revealed how deeply involved family members are in the day-to-day activities of stroke survivors, which is consistent with the findings of previous studies [23,24]. This study illustrates how family members are part of an environment where self-management is integrated and therefore can be seen as a process based on collective agency [19]. This approach to self-management as a common process, or comanagement process, has been promoted in other studies [24,36,46] but should be acknowledged more in research and practice. In practice, this could involve engaging family members early in the rehabilitation process with a "co-management" approach, highlighting their contributing role and the importance of support beyond practical support. It is also important to recognise the emotional and physical impact of a caring role, particularly for family members. At the same time, they need support to balance their involvement so they can stay healthy and maintain a good guality of life. In research, we would suggest that more needs to be done to involve family members in helping define and describe self-management and what it means to them and their family members. This approach could be used to generate and refine the content and programme theories for self-management programs. Furthermore, we should aim to develop more knowledge of support by the social network beyond immediate family members, and how it can be promoted in self-management interventions.

# Strengths and limitations

This is one of the first studies with an explicit focus on family members' perceptions of their role in supporting self-management in people with stroke. The study's trustworthiness was supported by a diverse set of participants, enhancing transferability [38], and an iterative analysis process that maintained closeness to the data, strengthening credibility. The first author's reflexive notes and team discussions contributed to confirmability [38]. Rigour was further supported by the experienced researchers and adherence to the COREQ checklist [40,49].

However, some limitations of this study need to be acknowledged. Two people conducted the interviews individually, which might have led to differences in how the interviews progressed; yet, the same semistructured interview guide was followed, and the interviewers discussed the guide and interview technique during the period of data collection. The interviews were conducted by telephone because of reorganisation of the SELMA project due to the COVID-19 pandemic. Interviews by telephone cannot provide full nonverbal communication which can affect how the conversation develops. At the same time, some people may feel more comfortable speaking with unfamiliar persons over the phone. Most of our participants gave rich stories and telephone interviews allowed us to interview many people. To minimise the likelihood of overanalysing the data, we only analysed manifest content, i.e., what was said with words [39].

We chose to provide a general explanation of the concept of self-management to participants before the interview started. The intention was to present an idea of the concept as opposed to self-care, both of which translate to the same word in Swedish ("egenvård"). The twofold meaning of the Swedish term and the explanation of self-management itself may have influenced the participants' descriptions. However, we experienced that participants elaborated freely on their thoughts and provided their own examples.

Participants were mostly partners or spouses of stroke survivors, and all adult children who participated were daughters. This could reflect who the primary supporters are for many people recovering from stroke; nevertheless, future studies should aim to include perspectives on the self-management of persons with all kinds of family and friendly relationships. The participants' family members had mild to moderate stroke, and the situation for these individuals may be different from that of persons with severe stroke. Our results are therefore representative of people with characteristics similar to those of our participants.

# Conclusion

This study highlighted the significant role of family members in the self-management process of stroke survivors at home. They provided practical, psychosocial and motivational support. Importantly, their support was more holistic in comparison to how they conceptualised self-management. These findings underscore the need for a more comprehensive understanding of self-management among lay supporters of people undergoing stroke rehabilitation. It also indicates the need for researchers and healthcare teams to work more closely with family members of people with stroke and their wider social networks to advance understandings of the self-management process and how and when support is provided. The acknowledgement of self-management as a collective process opens opportunities for developing more efficient self-management interventions.

# **Author contributions**

CRediT: Linnea McCarthy: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Validation, Visualization, Writing - original draft, Writing - review & editing; Maya Kylén: Conceptualization, Data curation, Formal analysis, Funding acquisition, Methodology, Resources, Validation, Visualization, Writing – original draft, Writing - review & editing; Catharina Gustavsson: Conceptualization, curation, Formal analysis, Methodology, Validation, Data Visualization, Writing - original draft, Writing - review & editing; Tracy Finch: Conceptualization, Formal analysis, Methodology, Validation, Visualization, Writing - original draft, Writing - review & editing; Fiona Jones: Conceptualization, Formal analysis, Methodology, Validation, Visualization, Writing - original draft, Writing - review & editing; Marie Elf: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing - original draft, Writing - review & editing.

# **Disclosure statement**

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# Data availability statement

The data that supports the findings of this study are available from the corresponding author, [LM], upon reasonable request.

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