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REVIEW

Supporting self-management in adults after stroke – synthesis of qualitative studies

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Abstract

Aim: The aim of the review was to identify, analyse and synthesise the results of qualitative studies focusing on patients' experiences of self-management after stroke. The research question according to the Participants, Phenomenon of Interest, Context format was as follows: What are patients' experiences of self-management after stroke? *Design:* A literature review aimed at synthesising the findings of qualitative studies was conducted in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement. *Methods:* Qualitative studies were searched in the EBSCO, PubMed and Web of Science databases in November 2023. Searching and sorting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline. The methodological quality of the included studies was assessed using the Critical Appraisal Skills Programme. According to these criteria, 1072 studies were retrieved. Eight studies were included in the review. *Results:* The analysis of the eight qualitative studies revealed four themes: understanding the meaning of self-management; individual capacity and readiness; needs; and resources and supports in this area. The fourth theme includes five subthemes: family, healthcare professionals, peers, environment, and technology. *Conclusion:* Findings can inform routine practice to develop self-management support after stroke. Self-management support can enable stroke survivors and their families to take control of their long-term condition, from diagnosis to living with the disease.

Keywords: lived experience, patient experience, qualitative, self-management, stroke.

Introduction

Stroke is considered a significant contributor to mortality and morbidity in both developing and non-developing countries (Zawawi et al., 2020). The consequences of stroke are a chronic health problem affecting patients' quality of life and their independence in daily living (Fryer et al., 2016). Programmes providing self-management (SM) support to patients and their families are gaining increasing attention and showing promising results in terms of reducing long-term unmet needs after stroke. However, insights into what good SM support looks like may vary depending on the views of professionals, the individual preferences, skills and experiences of patients and their families, and how care and rehabilitation is organised in a particular healthcare setting (Jones et al., 2016).

There is no universally accepted definition of SM, but most definitions take a comprehensive and holistic approach, which includes self-care that addresses all aspects of life affected by chronic disease (Pearce et al., 2015).

SM can provide stroke survivors with a pathway to support their recovery (Fryer et al., 2016). SM is defined as the challenges individuals have to overcome in order to live with one or more chronic conditions. These tasks include confidence in managing medical care, coping roles, and managing emotional states. Priorities change throughout the different phases of recovery from stroke (Pearce et al., 2015). SM programmes for stroke survivors may include education about stroke and its likely consequences, but the main focus is on training skills that lead to people taking an active role in their own treatment. Skills training may include problem solving, goal setting, decision making, and coping skills (Fryer et al., 2016). The European Stroke Action Plan for 2018–2030 (Norrving et al., 2018), international guidelines for the management of stroke, recommend that all patients should be offered programmes in SM of the disease, including active problem solving and individual goal setting (Fugazzaro et al., 2021). Stroke survivors who have completed SM programmes have reported an improvement in their ability to achieve life goals

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and to take responsibility for their lives, rather than being dependent on other people for their life satisfaction (Fryer et al., 2016). Most SM programmes are usually provided as an 'add-on' to existing standard care (Jones et al., 2016).

Adopting a person-centred perspective in the age-appropriate care of stroke patients could help to promote innovative approaches in practice for the benefit of younger age groups of adults (Holloway et al., 2022). An open dialogue and decision-making process involving both the stroke patient and the caregiver is strongly recommended to establish shared rehabilitation goals and to support ongoing recovery after discharge. An individualised approach to rehabilitation is needed that focuses on shared priorities and includes individual or collective support for the stroke patient and their caregiver (Pereira et al., 2021). Approaches to support SM require the same attention as guidance and expertise that patients and their families need, particularly in the early phases after stroke (Jones et al., 2016). Ongoing consultation with stroke survivors about their wishes regarding rehabilitation, priorities, and goals is important to tailor the specialist approach to the stage people are at after stroke (Pereira et al., 2021).

SM of patients after stroke has been the subject of several systematic reviews, which have focused on describing the implementation of interventions, programmes to manage the consequences of stroke (Ruksakulpiwat & Zhou, 2021), or evaluating their effectiveness on patients' quality of life after stroke (Fryer et al., 2016) and improving mobility-related outcomes (Sahely et al., 2023). Some of the more recently published reviews have evaluated the effectiveness of SM interventions after stroke in specific groups, such as patients with aphasia (Wray et al., 2018). In particular, a significant proportion of research syntheses have included randomised clinical trials (Fryer et al., 2016; Wray et al., 2018) with the aim of using high-quality evidence to support the effectiveness of SM-promoting interventions. Syntheses of qualitative studies in this area have not been published to date, with the available review studies reflecting healthcare professionals' experiences of implementing SM support interventions after stroke (Boger et al., 2015a; Sadler et al., 2014) rather than patient perspectives. Given that SM is a key component of effective care after stroke, it is vital to understand it in more depth. To understand the factors that influence SM, it is particularly important to examine it from the patients' perspective. For this reason, our review focused on analysing the experiences of patients with SM after stroke.

Aim

The aim of this review was to identify, analyse and synthesise the results of qualitative studies focusing on patients' experiences of SM after stroke. The primary research question according to the Participants, Phenomenon of Interest, Context (P-PI-Co) format was as follows: What are patients' experiences of self-management after stroke?

Methods

Design

A literature review aimed at synthesising the findings of qualitative studies was conducted in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement (Tong et al., 2012).

Eligibility criteria

We included a study in the review if: (a) the study was an empirical qualitative study; (b) it focused on the experiences of adult patients with SM after stroke; and (c) in the case of mixed research, it had a well-defined qualitative part. Study protocols, quantitative studies, mixed studies without a defined qualitative part, and review studies were excluded.

Inclusion criteria were defined according to the P-PI-Co format as follows:

- *Participants*: the target population was adult patients after stroke; search keywords *'stroke' OR 'cerebrovascular stroke' OR 'cerebrovascular accident' OR 'ischemic stroke' OR 'ischaemic stroke'*;
- *Concept*: the central topic was self-management; search keywords *'self-care' OR 'self-management' OR 'interventions' OR 'rehabilitation';*
- *Context:* studies related to the experiences of patients with SM were included; search keywords *'patient experience' OR 'healthcare experience' OR 'lived experience' OR 'patient journey' OR 'patient satisfaction'*.

Search strategy

In the initial phase of the review, the second author (E.G.) conducted a preliminary search of the PubMed database to find all reviews on the topic and also to identify the keywords that would be most relevant to the review question. In addition, a search was conducted for reviews in four relevant peer-reviewed journals (Disability and Rehabilitation; Journal of Health Psychology; International Journal of Qualitative Studies on Health and Well-Being; Topics in Stroke Rehabilitation) that most frequently publish qualitative studies related to stroke. In the second step, search terms and their combinations relevant to the experience with SM after stroke were identified. Qualitative studies were searched in the EBSCO, PubMed and Web of Science databases in November 2023. The following keywords and combinations of keywords were used in the databases using Boolean AND and OR operators: stroke, self-management, patient experience, lived experience, qualitative.

The search included peer-reviewed studies (regardless of study design) published in English and was not limited by time period. Grey literature (e.g., dissertations) was not included in the review. Using these criteria, 1072 studies were retrieved.

Study selection inc. PRISMA flow diagram

The search and sorting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline (Page et al., 2020), see Figure 1. Only qualitative studies were included. Qualitative studies focus on the experiences of patients with SM after stroke (e.g., their experiences of demands vs. SM, perceived needs and priorities, etc.). Quantitative studies tend to focus on evaluating the effectiveness of selected SM programmes and did not meet the inclusion criteria. Therefore, they were excluded from the review. Eight studies were included in the review, as shown in Table 1.

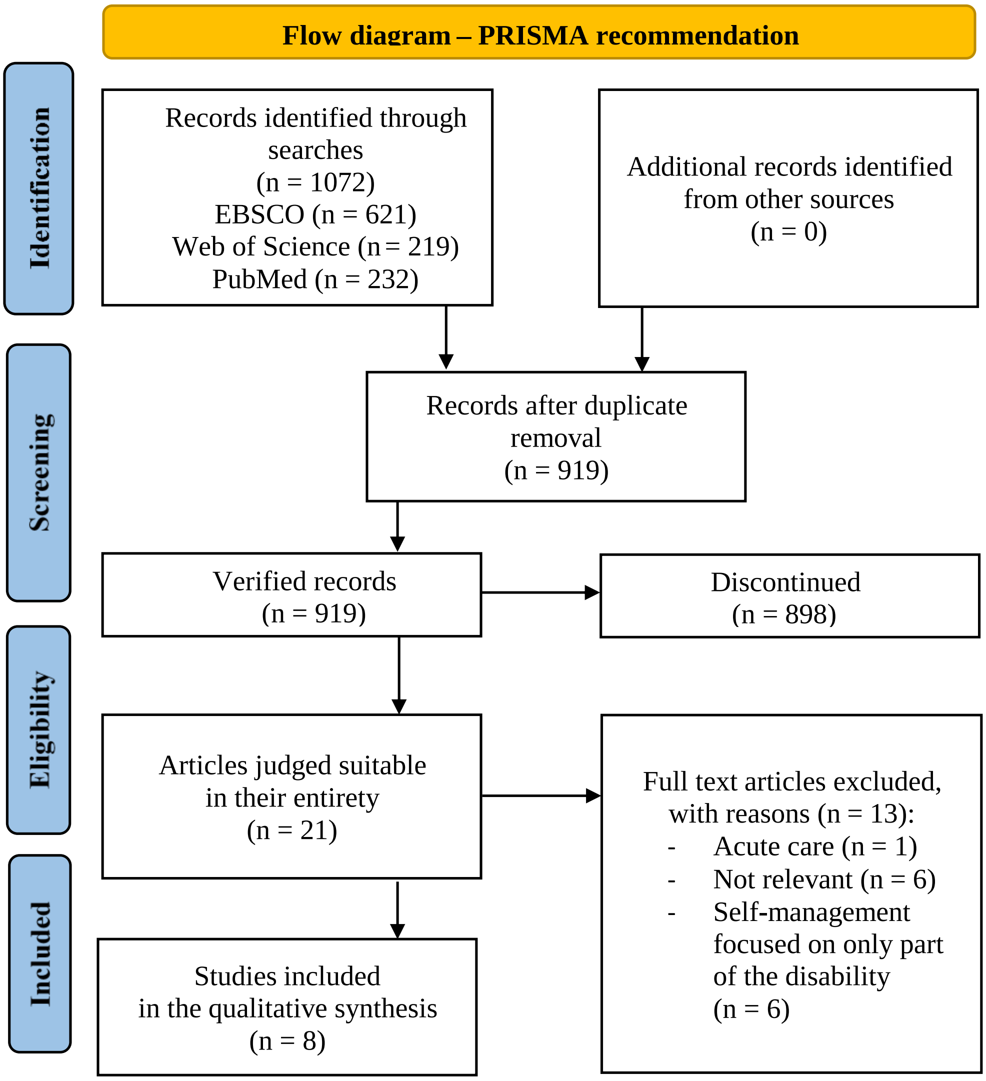

Figure 1 Flow diagram of the study selection process

Evaluation of quality of articles

The methodological quality of each included study was assessed using the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme [CASP], 2018).

Data extraction

The review used thematic synthesis (Thomas & Harden, 2008), which involves three stages: coding the results (line-by-line coding), developing descriptive themes, and generating analytical themes. In the first step, data were extracted from the primary studies (participant quotes). Each step of data extraction and synthesis was conducted by two independent authors (R.B., E.G.). Descriptive characteristics were created for each theme. The entire process was carried out with the study aim and research question in mind.

Results

Descriptive characteristics of the included qualitative studies

Eight research studies focusing on the experiences of patients with SM after stroke were included in the literature review. Purposive sampling was used for all eight studies. The numbers of participants ranged from 14 to 36 (Table 1).

We identified the following supporting themes that reflect the experiences of patients with SM after stroke: understanding the meaning of SM, individual capacity and readiness, and needs in SM. The fourth theme, resources and support in SM, includes five subthemes: family, healthcare professionals, peers, environment, and technology.

Understanding the meaning of self-management

Understanding the meaning of SM was addressed in four studies. The meaning of the word self-management was perceived similarly by participants in all four studies (Boger et al. 2015b; Klockar et al., 2023; Sadler et al., 2017; Satink et al., 2015). In a Dutch study, several post-stroke participants reported that they could not identify with the word and found it difficult to grasp. However, they did say that they understood what was meant by SM. They understood the term SM to mean ‘doing it yourself’, ‘organising your life’, being able to ask for help only when needed (Satink et al., 2015). SM was perceived as an unfamiliar concept in an English study (Boger et al., 2015b), where SM was presented as a way to maintain independence and autonomy, to ‘start and do it yourself’, to ‘do things for yourself’. Most perceived SM as a positive concept. Some participants viewed SM as a broad concept related to everyday life in the home environment (Klockar et al., 2023), while others understood SM primarily as managing one’s health (Sadler et al., 2017). Yet other participants described their SM as a complex, long-term, and personal learning process (Satink et al., 2015). The concept was explored not only from the patients’ perspective, but also from the perspective of healthcare professionals, particularly physiotherapists. SM was perceived differently in relation to their practice settings. Physiotherapists’ different understandings of the meaning of SM were shaped by the context in which they worked. Therapists in inpatient stroke units generally understood SM within an individualistic framework, whereas those in community settings developed a broader concept of SM based on partnership cooperation (Sadler et al., 2017).

Individual capacity and readiness

The importance of SM in coping with the demands of post-stroke care intensifies as part of the transition from hospital to home care. Study participants agreed that they were unprepared for independent care in the home environment and for managing activities of daily living immediately after discharge (Klockar et al., 2023; Satink et al., 2015). The transition to home was identified by participants as a time when they wished group SM programmes had been offered. Many felt a lack of support during this period (Clark et al., 2018). One issue was the vacuum they experienced between hospital discharge and their first follow-up at three months. The acute phase was described as an overwhelming experience by several participants, and the support and care from stroke unit staff was remembered as professional and friendly by most of them. There is an overlooked opportunity here to start the process of support in SM earlier in the course of stroke, when healthcare professionals and stroke patients could combine their skills, ideas, and expertise (Klockar et al., 2023). Young and middle-aged stroke survivors reported difficulties in accessing follow-up health services. This suggests that young and middle-aged stroke survivors are vulnerable because they are outside the follow-up system. Difficulties in accessing health services led to a range of unmet physical, psychological, and social needs, and problems after stroke (Martinsen et al., 2015). People after stroke expressed a need for information resources to support their SM, such as equipment, expert advice, experience, and therapies. They found the current range of resources to be inadequate and difficult to access. Attempts to find resources required considerable effort and led to feelings of uncertainty and frustration (Boger et al., 2015b).

Table 1 Study characteristics

Authors Years Country	**Aim**	**Design**	**Sample size**	**Age range**	**Time period after stroke**	**Data collection**	**Data analysis**	**Credibility**	**CASP**
Bally et al. (2023) Netherlands	To review post-stroke patients' attitudes towards the use of digital technologies in supporting SM in the post-acute phase of the disease.	exploratory qualitative approach	36	54–90	6–18 months	semi-structured interview	thematic analysis	triangulation of researchers	8
Boger et al. (2015b) England	To explore factors that facilitate or hinder SM after stroke from the patients' perspective.	exploratory sequential mixed methods approach	28	46–80	23–83 months	focal groups	thematic analysis	triangulation of methods	10
Clark et al. (2018) England	To analyse patients' views on the benefits of group programmes in SM; potential problems and timing of group programmes in SM.	iterative	14	47–78	4–174 months	semi-structured interview	thematic analysis	negative case analysis, saturation, triangulation of researchers	10
Klockar et al. (2023) Sweden	To explore how people after stroke practice SM in the post-acute phase.	descriptive qualitative study	18	44–87	29–48 days	semi-structured interview	content analysis	triangulation of member checking researchers	10
Martinsen et al. (2015) Norway	To explore the experiences of young and middle-aged stroke survivors with health services and identify aftercare needs.	interventional	16	21–67	2–10 years	in-depth interview	hermeneutical phenomenological approach	triangulation of researchers	10
Pereira et al. (2021) Portugal	To explore how people after stroke and their caregivers adapt to the situation over time and how health professionals support the transition to a home environment.	multi-perspective, longitudinal	8 stroke patients 10 caregivers 6 health professionals	43–79	within 6 months after discharge	in-depth semi-structured interview	thematic and narrative analysis	triangulation of researchers	10
Sadler et al. (2017) England	To explore the views of stroke survivors and physiotherapists on SM, focusing on what SM means and the factors they believe enable and hinder SM after stroke.	exploratory qualitative approach	13 stroke patients 13 physiotherapists	53–89	2–6 months	semi-structured interview	thematic analysis	saturation, triangulation of researchers, direct quotes	9
Satink et al. (2015) Netherlands	To explore the reflections (views) of stroke survivors about self-management, readiness and self-management support needs.	naturalistic design based on constructivist epistemology	16	53–84	from 3 months	focal groups	comparative analysis	triangulation of researchers	10

CASP – Critical Appraisal Skills Programme

Participants emphasised that the follow-up care system needed to be flexible and tailored to their overall life situation to enable them to fulfil other responsibilities in their family, study, and work lives. Stroke survivors' uncertainty and anxiety about their physical symptoms affected their psychological well-being. Poor physical function was a practical barrier to performing activities important to SM (Martinsen et al., 2015). But physical function was not the only determinant of successful SM. There was evidence that people with disabilities were able to perform SM effectively if they had the right support (from informal or formal sources), skills and qualities (such as confidence and determination) (Boger et al., 2015b). Common individual factors were psychological problems and cognitive deficits in stroke survivors, including lack of motivation, confidence and ability to take responsibility, as well as fatigue and cognitive impairment associated with stroke (Sadler et al., 2017). Reported residual symptoms included aphasia, motor impairment, motor weakness, fatigue, poor mood, and poor balance (Clark et al., 2018). Findings suggest that self-efficacy, as expressed by participants, is an important component influencing SM. However, findings also indicate that self-efficacy alone is not a sufficient mediator of SM after stroke, as other attributes such as decision making, communication skills, determination, and resource seeking were also valued and contributed to individual SM (Boger et al., 2015b). Participants sought new ways of performing activities after stroke. They felt it was important not to be passive, but rather to take responsibility, try to solve problems and come up with creative solutions to problems they encountered. In contrast, a small number of participants claimed that they were unable to act, became more passive, or avoided activities after stroke (Klockar et al., 2023). The ability to make decisions about one's own life seems to be crucial for returning to everyday life (Martinsen et al., 2015). The home environment was an important place for SM, providing motivation to carry out normal daily activities (Klockar et al., 2023).

Needs in self-management

The findings point to both the continuing importance of SM support and the changing priorities throughout the different stages of recovery from stroke (Boger et al., 2015b; Klockar et al., 2023; Satink et al., 2015), from practical needs and problems arising in the early stages to psychological and emotional needs in the later ones (Satink et al., 2015). Eight out of 14 participants in one study spoke of the need for an SM group programme to be individualised or tailored to the person. Stroke can cause a wide range of residual symptoms, and the symptoms themselves can be managed differently in different people (Clark et al., 2018).

Pereira et al. (2021) concluded that the approach of professionals during rehabilitation should be modified according to the changing needs and expectations of stroke patients and caregivers. Participants who received some follow-up care perceived that it was not tailored to their specific needs (Martinsen et al., 2015). The resources available to support people after stroke may be too general and do not take into account individual disability-related needs (Boger et al., 2015b). The findings of Bally et al. (2023) also highlighted the importance of tailoring information to patients' needs and concerns. Being an active decision maker, rather than a passive receiver, appears to be an important feature of a successful 'self-manager' after stroke (Boger et al., 2015b). Being able to establish a relationship with a 'helper' to express experiences and concerns about living with the effects of stroke was identified as essential (Martinsen et al., 2015). It was evident that the factors needed for good decision making, such as sufficient information and good communication skills, were often not ideal (Boger et al., 2015b). Communication skills were identified as an important factor influencing an individual's ability to engage in SM so that the person affected by stroke can seek support and obtain information (Boger et al., 2015b). The conceptualisation of SM varied between participants, with the majority associating SM with the ability to independently perform activities of daily living. This ability was expressed in terms of a desire to carry out the same activities that they may have done prior to stroke, such as activities associated with personal hygiene, cooking, grocery shopping, and other household activities (Klockar et al., 2023), but also to engage more fully in social roles, including managing the household and finances, and returning to work without relying on others for assistance (Sadler et al., 2017). Some study participants realised after their stroke that they should listen to their body and take care of themselves (Klockar et al., 2023) for example by eating properly, getting enough sleep, or avoiding risks when walking outside. They viewed SM as taking responsibility for maintaining their health, including taking care of their appearance, dressing well and maintaining personal hygiene (Sadler et al., 2017). Some participants described not being able to drive a car as challenging because it reduced their independence and their ability to manage daily activities independently (Klockar et al., 2023). From the perspective of study participants, stroke patients, caregivers, and healthcare professionals, support from the whole rehabilitation team was an important strategy for coping with difficulties and challenges during the adaptation and rehabilitation process. Adaptation was not an individual process and others were involved (Pereira et al., 2021). The findings highlight that recovery from stroke is lengthy and that there are gaps in the follow-up of young and middle-aged stroke survivors. Participants' experiences very clearly indicate a gap between needs and actual services provided (Martinsen et al., 2015).

Resources and support in self-management

Social groups can be an important source of support for stroke survivors. Building these social relationships can help to reduce the fears associated with the stigma of having suffered a stroke (Pearce et al., 2015).

Family support

Stroke survivors described their partners and children as important in the recovery process, as someone without whom they would not have been able to cope with the situation after their stroke (Satink et al., 2015). They talked about family support after discharge from hospital, with more than half describing dependence on family members for practical matters and emotional support. Such support could be a barrier to the acquisition of self-care practices in the context of striving for independence in daily life (Boger et al., 2015b; Sadler et al., 2017; Satink et al., 2015). On the other hand, they valued and needed the support of relatives to some extent (Satink et al., 2015). Physiotherapists felt that SM was influenced by the support provided by family caregivers, acknowledging that the quality and availability of this support varied, which may have enabled or hindered SM. For stroke survivors, support meant that family members did things for them. Therapists viewed them as helpers to foster self-sufficiency (Sadler et al., 2017). Caregivers can potentially facilitate SM (Boger et al., 2015b).

Coping and learning to live with the effects of stroke and maintaining optimism about the future, even if it is different from what was previously expected, was both a challenge and a goal for stroke survivors and their caregivers. Discussion within families helped to find new meaningful activities and strategies (Pereira et al., 2021). Although participants appreciated their relatives helping them with activities, they emphasised that even if the activities were difficult for them, if they felt some involvement in the decisions they made and the activities they participated in, it reduced the feeling that their lives were run by others (Satink et al., 2015). The so-called ripple effect illustrates the impact that stroke can have on family and friends, as well as the impact that family and friends can have on a person's SM. Participants described the need for caregivers and themselves to understand what was going on. A shared understanding was seen as important because caregivers of stroke individuals could then offer encouragement in the right direction. Therefore, being able to share SM group sessions with family and friends if they chose to do so was considered important for stroke survivors (Clark et al., 2018). The support and presence of family caregivers during the adaptation process and rehabilitation sessions were generally favoured by both stroke survivors and healthcare professionals, and were desired by caregivers. Situations in which caregivers were unable to attend rehabilitation sessions were perceived as more stressful for themselves and the stroke survivor (Pereira et al., 2021). When it came to activities of daily living, such as grocery shopping, laundry, or other demanding household tasks, stroke survivors received some form of support from family members or neighbours. Several participants had relatives who moved in with them for a period of time to help them, and a few participants were assisted by community services. Some participants described how relatives or friends provided emotional support or encouraged them to cope independently, for example by leaving home (Klockar et al., 2023). Partners and children provided support and encouraged their loved ones to be active and carry out daily activities after stroke. Sometimes, partners confronted the stroke survivor about taking responsibility and being active, which facilitated the development of SM (Satink et al., 2015). Informal caregivers often provided personal care, emotional support, and practical assistance that enabled the person to engage in important SM strategies; this often made them essential for SM after stroke. Caregivers often acted as advocates for the person affected by stroke (Boger et al., 2015b). Home care workers were also mentioned as possible key figures for SM support, as they got to know the individual after some time. Support in coping with a shrinking social circle was also needed and was even linked to support in SM (Satink et al., 2015). Informal caregivers are important for stroke survivors' SM. They can limit SM options by performing SM activities on behalf of the person affected by stroke (Boger et al., 2015b).

Support from healthcare professionals

There are differences in the understanding of SM between stroke survivors and healthcare professionals, which limits the successful implementation of SM strategies into practice (Sadler et al., 2017). The perspective of healthcare professionals tended to be biomedical, whereas the perspective of stroke survivors and caregivers included biomedical, social, and psychological needs. These differences have implications for goal setting and treatment expectations (Pereira et al., 2021). Physiotherapists commonly viewed SM as a process in which stroke survivors are expected to actively engage in their rehabilitation and manage their recovery and health. Stroke survivors identified factors related to care and support that they believed enabled their early recovery after stroke rather than SM per se, particularly the quality of interpersonal relationships with therapists and family support, whereas physiotherapists spoke of a range of factors that enabled and hindered SM after stroke (Sadler et al., 2017). A study conducted in Portugal by Pereira et al. (2021) showed that stroke survivors wanted more support from their relatives and healthcare professionals. Some healthcare professionals were concerned about high or unrealistic expectations from families, which appeared to be a potential source of tension or the creation of divergent agendas. Over time, the mismatch in professional approaches appeared to widen the gap between the efforts of professionals and the needs of both people with stroke and caregivers (Pereira et al., 2021). Participants needed to feel confident in professionals' skills and their ability to provide support or direct them to appropriate resources (Boger et al., 2015b). Confidence in professionals' work and their commitment to meeting families' needs was important in helping them become more proactive and motivated. It helped if the healthcare professional was patient and sensitive to their thoughts. For some, the healthcare professional was a person they could confide in (Pereira et al., 2021). They valued therapists as encouraging professionals with specific expertise (Sadler et al., 2017). Stroke survivors reported that healthcare professionals could enhance or hinder stroke survivors' engagement in SM strategies, for example, through the way information was provided or therapy goals were set. Support from professionals was essential for continued progress after stroke (Boger et al., 2015b). Some stroke survivors questioned the quality and competence of healthcare professionals caring for them. Health services paid attention to their physical condition, but not their psychological well-being, leading to despair and doubt about the willingness and ability of professionals to provide relevant support (Martinsen et al., 2015). Physiotherapists working in the community, but not in a stroke unit, considered the nature of the therapist-patient relationship a prerequisite for the success of supporting SM practices after stroke. They spoke of their role as being more of a 'guide', with the development of relationships and collaboration with stroke survivors at the heart of person-centred care to facilitate SM. This consisted of supporting shared decision making and providing tailored information and education (Sadler et al., 2017). At six months post-disability, the focus was less on recovery and more on regaining control over their lives. In this sense, advice from healthcare professionals was not always perceived as helpful or meaningful (Pereira et al., 2021).

Peer support

Study participants felt that other people who had experienced stroke could better understand what they were going through. Most participants considered mutual support positive because of the potential for shared problem solving, increased motivation, and reduced loneliness (Boger et al., 2015b; Clark et al., 2018). The importance of peers was emphasised by participants for their understanding and lack of shame (Satink et al., 2015). Trust and kinship between peers is important, especially when sharing personal information in a group of strangers (Clark et al., 2018). Others also highlighted the involvement of close friends or members of the local community. Although study participants emphasised the importance of caregivers being present, there was disagreement about the appropriate time to involve caregivers. It was not always perceived positively, leading to different perspectives and potential conflicts within the family (Pereira et al., 2021). Peer support is important for SM and can come from a variety of sources, including stroke clubs, work, friends, and interests. Stroke clubs improve SM by creating an environment that acknowledges the shared experience of stroke (Boger et al., 2015b). Fellow sufferers can also play the role of friends in a support network, as they have experienced stroke themselves and understand its consequences. Meeting peers could elicit recognition and give participants confidence (Satink et al., 2015).

Environment

A 'space for sharing support' addresses mutual support, the role of family and friends in SM, and factors that influence whether a stroke survivor feels included. The focus is on creating a space where they feel comfortable, an environment that supports

SM (Boger et al., 2015b; Clark et al., 2018). People who have experienced stroke wish to feel accepted and included in community life again. Negative reactions from the environment discourage stroke survivors from engaging in self-care activities, whereas positive reactions allow people to feel more confident. Returning to 'normal life' after stroke has been shown to be an important SM goal for many participants (Boger et al., 2015b). Study participants reported that the level of resources and services after stroke did not meet their SM needs. SM was hindered by a lack of resources and access to appropriate professional support (Boger et al., 2015b; Klockar et al., 2023; Satink et al., 2015). Stroke survivors had limited opportunities to actively participate in and influence the type of follow-up services they received (Martinsen et al., 2015). Evidence suggests that current healthcare support systems and structures may not meet the expectations of individuals in terms of providing them with real choice after stroke (Boger et al., 2015b). A number of benefits of mutual support have been highlighted, including collective problem solving. Shared education on best practice with caregivers has also been seen as a positive outcome (Clark et al., 2018).

The importance of technology

Stroke patients' views on how digital health technologies could support SM in health and well-being, as well as integrated care for stroke survivors, varies. Barriers to the use of digital technologies identified by patients are as follows: no need for health-related technology due to satisfaction with the care provided and preference for physical contact with a healthcare professional; the technology is too complex; application updates cause difficulties; further inflexibility where patients feel pressured and / or bothered by push notifications; and finally, reluctance to be dependent on the mobile phone as it can get lost (Bally et al., 2023). Study participants did not actively seek support through social networks such as patient peers or patient organisations (Klockar et al., 2023). As key features that should be included in future digital health technologies, stroke patients identified trusted health information, an online library of stroke health and care information, a personal health record, and online support for rehabilitation (Bally et al., 2023).

Based on the findings of the studies, we identified factors that facilitate or limit the level of SM in relation to stroke (Table 2).

Table 2 Factors influencing the level of self-management (Part 1)

Factors that increase the level of self-management	Factors that limit (reduce) the level of self-management
favourable home environment (Klockar et al., 2023)	inadequate support provided by family caregivers (Sadler et al., 2017)
support from family members (Boger et al., 2015b, Klockar et al., 2023; Pereira et al., 2021; Sadler et al., 2017; Satink et al., 2015)	dependence on family members (Boger et al., 2015b, Sadler et al., 2017; Satink et al., 2015)
individual and organisational factors (Sadler et al., 2017)	resources not taking into account individual needs related to disability after stroke (Boger et al., 2015b)
the quality and nature of the therapist-patient relationship (Sadler et al., 2017)	health professionals not offering relevant support (Boger et al., 2015b)
setting priorities (Satink et al., 2015)	negative environmental reactions (Boger et al., 2015b)
careful planning of one's activities (Satink et al., 2015)	lack of professional support after discharge (Clark et al., 2018)
participation in decision making (Satink et al., 2015)	problems with access to follow-up health services (Martinsen et al., 2015)
coming to terms with the impact of stroke on lifestyle (Satink et al., 2015)	insufficient and difficult to access information resources (Martinsen et al., 2015)
peer support (Satink et al., 2015)	inflexible follow-up care (Martinsen et al., 2015)
high self-efficacy (Boger et al., 2015b)	limited access to psychosocial support (Martinsen et al., 2015)
sufficient information (Boger et al., 2015b)	complex technologies (Bally et al., 2023)
communication skills (Boger et al., 2015b)	
support from professionals (Boger et al., 2015b)	
positive reactions from the environment (Boger et al., 2015b)	
mutual support (Boger et al., 2015b; Clark et al., 2018)	

Table 2 Factors influencing the level of self-management (Part 2)

Factors that increase the level of self-management	Factors that limit (reduce) the level of self-management
shared education on best practice with caregivers (Clark et al., 2018)	
trust in the work of professionals (Pereira et al., 2021)	
availability of information resources (equipment, expert advice, experience, and therapies) (Martinsen et al., 2015)	
the opportunity to establish a relationship with a 'peer' to express experiences and concerns about living with the effects of stroke (Martinsen et al., 2015)	
psychosocial interventions (Martinsen et al., 2015)	

Discussion

Knowing how stroke survivors understand and experience SM in different contexts is crucial for developing effective SM support. Five studies in the review focused specifically on stroke survivors' views of SM, while two examined the experiences of both stroke survivors and other people who may influence their SM, such as healthcare professionals and caregivers (Pereira et al., 2021; Sadler et al., 2017). Stroke survivors' attitudes towards the use of digital technologies to support SM in the post-acute phase were addressed in the remaining study included in the review (Bally et al., 2023). SM refers to an individual's ability to manage symptoms, treatments, lifestyle changes and the psychosocial, cultural and spiritual consequences of health problems in collaboration with family, community and healthcare professionals (Richard & Shea, 2011).

The review found significant differences in how the meaning of SM is understood and perceived in practice. In the relatively new and emerging field of SM after stroke, self-management is little known and rarely used (Parke et al., 2015). SM implies strict adherence to best medical recommendations. The perspective taken in this review is closer to that of healthcare providers, whereas for others it means adapting advice and modifying adherence to recommendations.

In our review, we conclude that returning home was initially experienced as a shock; discharge was perceived as a loss of the supportive environment in hospital. Home became a place where stroke survivors felt they could be themselves and where they began to trust their bodies again (Satink et al., 2013). In particular, participants emphasised the management of daily activities and social relationships as important for maintaining meaning in life (Audulv et al., 2021; Ruksakulpiwat & Zhou, 2021). These activities provide a sense of satisfaction and self-confidence. Current evidence suggests that SM programmes can be beneficial for stroke survivors living in the community. The benefits of these programmes include improved quality of life and self-confidence (Fryer et al., 2016). The results of our review suggest that the availability of such programmes is limited. Resources that are integral to optimal SM include individuals (e.g., family members, friends, healthcare providers) and community resources and services. Community resources help individuals cope with various aspects of their illness, including medical, psychosocial, spiritual, and financial aspects (Schulman-Green et al., 2012). Difficulties in accessing health services led to a range of unmet needs, particularly physical, psychosocial, and informational needs, as well as practical support from professional or environmental resources (Guo et al., 2021). Our review suggests that dysfunctional, inflexible follow-up care is frustrating and demotivating for patients after stroke (Parke et al., 2015). When these people had the right support (from informal or formal sources), they were more successful in SM.

Stroke survivors reported difficulties, fatigue, and cognitive impairment (Satink et al., 2013), and described a lack of psychological and social support to help them accept changes in their self-perception, identity (Pearce et al., 2015). There is evidence that self-efficacy is an important variable associated with a range of outcomes following stroke (Jones & Riazi, 2011). Self-efficacy, an individual's confidence in their ability to perform a task or behaviour, is commonly considered to mediate between the acquisition of SM skills and the implementation of SM behaviours (Parke et al., 2015).

The findings from this review highlight the importance and relevance of SM support at all stages of recovery from stroke. Patients' experiences of SM support highlight the recognition that the needs of stroke survivors change during recovery (Duncan Millar et al., 2023; Parke et al., 2015; Pearce et al., 2015). Our review highlights both the continuing importance of SM support and the changing priorities during recovery from stroke, ranging from practical needs and problems to psychological and emotional needs. Negative psychological problems are associated with threatening physical symptoms and perceived disability, which may lead to greater social isolation or a decline in communication or participation. Timely and sustained access to psychological care is crucial for patients (Guo et al., 2021), and our review concludes that psychological services for stroke survivors are limited.

Regarding information, the aforementioned challenges (e.g., information not provided, not given enough time, not timed appropriately, or not comprehensible) must be addressed (Duncan Millar et al., 2023; Guo et al., 2021; Zawawi et al., 2020). The timing and nature of information is important to patients after stroke for reasons of response and understanding, as outlined in the review. Our findings are consistent with those of Taule et al. (2015); the communication skills of professional caregivers and their ability to attend to individual needs, and the mutual trust expressed when meeting with healthcare professionals were important. It is essential to cooperate with healthcare professionals who offer guidance and information specific to the stage of recovery and enable patients to feel respected, valued and in control of decisions about their lives (Duncan Millar et al., 2023; Pearce et al., 2015). Involving family members in SM programmes can be beneficial for stroke survivors (Warner et al., 2015) or make the situation more difficult (Satink et al., 2013). The perspectives of patients or caregivers are somewhat at odds with those of professionals (Guo et al., 2021). Stroke survivors tend to prioritise psychosocial and participation goals in rehabilitation. However, they feel that these goals are not recognised by healthcare professionals. Instead, professionals focus more on functional improvements, such as resuming basic activities of daily living or preventing falls during recovery from stroke (Satink et al., 2013).

The existence of a social group with other stroke survivors and a group of people who are understanding and supportive is important (Duncan Millar et al., 2023; Pearce et al., 2015). One described element of SM support is the formation of a partnership between the patient and healthcare professional (Parke et al., 2015). While our review demonstrates the specific value of therapists in the context of stroke, it appears that effective implementation of SM requires a whole system approach.

Opinions on digital health technologies and online access vary among patients, with some fearing loss of their device and over-complexity of the technology, while others would appreciate online support. Statistically significant improvements in self-efficacy of exercise behaviour, cognitive symptom management, communication with physicians, function, psychological well-being, energy, health stress and self-rated health were found with online support that lasted for four months (Jaglal et al., 2013). A meta-analysis by Zeng et al. (2022), demonstrates that interventions via mobile apps and messaging are more effective than those based on phone calls, and the shorter the intervention interval, the better the patients' adherence to medication. Access to SM programs could be significantly improved with online support.

Despite the increasing incidence of stroke, there is no comprehensive model of post-acute care for stroke patients. Research on stroke has focused on acute care and early supported discharge, with less attention paid to long-term support in the community. Similarly, relatively little research has addressed long-term support for informal caregivers (Aziz et al., 2016). SM has a statistically significant effect on quality of life, self-sufficiency and mental health (Wray et al., 2018). The unmet subjective needs of community-dwelling, not institutionalised stroke survivors cover a wide range and many details remain to be explored (Guo et al., 2021). Inadequate post-stroke care can lead to unmet needs for stroke survivors and caregivers. This may compromise their optimal management of life after stroke. Facilitating a full life for stroke survivors and their caregivers requires service providers to think about their different needs (Zawawi et al., 2020).

Conclusion

SM is an interactive process that individuals with chronic illness take part in every day to manage their condition. The evidence suggests that the term SM may be misleading because it implies that it is what people do on their own to maintain their health and well-being. The results of the review show: the different support needs for SM during recovery; the need for psychological and emotional support during recovery; the considerable information needs of patients and caregivers, which also vary during recovery; and the importance of good communication between patients and healthcare professionals. Participants' accounts suggest that neither individual capacity nor support for SM is sufficient for effective SM; a supportive environment is also needed. Support for SM refers to the collective elements that seem to be prerequisites for successful SM, the need for social support. Collective elements include the support and presence of family caregivers during the adaptation process and rehabilitation sessions, healthcare professionals, involvement of family, close friends or members of the local community. SM support refers to the help provided to people with long-term conditions to manage their health on a day-to-day basis. Studies have shown the impact on confidence, skills and knowledge, as well as on psychosocial and physical health. Health technologies could support SM related to health and well-being as well as integrated care for patients after stroke. Providing information, goal setting, problem solving, promoting self-efficacy, which is an important component of individual SM capacity, and implementing digital information and assistance systems are effective interventions targeting SM in stroke survivors. The result is the provision of comprehensive coordinated support, consisting of a professional team of physicians, psychologists, physiotherapists, healthcare professionals trained in patient education, family members and community members. The processes of SM overlap and influence each other; each SM process must be considered in the context of the whole. The challenge now is to incorporate this knowledge into routine practice and to develop new interventions to effectively support SM.

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