

## Engaging patients in stroke rehabilitation unit: an approach in patient centered care

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### ABSTRACT

**Background:** Engagement and collaboration between healthcare providers and patients are pivotal in driving patient-centered care, particularly stroke care. A comprehensive and holistic approach to treating stroke patients necessitates the active involvement of caregivers and patients in the decision-making process.

**Objectives:** This study set out to conduct a comprehensive literature review focusing on patient engagement and participatory approaches within the Stroke unit

**Methods:** A scoping review was conducted by compiling scholarly articles from ScienceDirect, PubMed, and ProQuest from 2020 to 2024. Specific keywords, including Patient Engagement, Early Mobilization, and Stroke, were utilized. Adhering to the PRISMA method and pre-established inclusion and exclusion criteria, initially, 540 research articles were retrieved, ultimately undergoing analysis of 15 articles

**Results:** The findings underscore the importance of holistic and participatory approaches, the engagement of patients and practitioners, the development and integration of therapy and rehabilitation programs, self-management, early mobilization, and efficient communication. Engagement between patients and healthcare professionals is of paramount importance. Practitioners' active participation significantly enhances patient involvement. Trust is particularly crucial for individuals who have experienced a stroke, as it profoundly influences their decision-making processes. Emphasizing health literacy and promoting shared decision-making can improve communication and patient involvement, even when facing time constraints.

**Conclusions:** In conclusion, the active involvement of patients and participative action of practitioners across various facets of therapy and rehabilitation augments program effectiveness and positively influences the quality of life for post-stroke patients. Enhancing stroke survivors' outcomes through self-management and early movement initiatives is particularly beneficial for individuals experiencing communication difficulties. This approach necessitates a coordinated team effort and ongoing support throughout the rehabilitation process.

**KEYWORD:** engagement; participatory approaches; patient centered care; rehabilitation; stroke

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## INTRODUCTION

The prevalence of stroke, referred to as a cerebrovascular accident (CVA), is increasing, with projections indicating an incidence rate of approximately 89.32 per 100,000 individuals by the year 2030(1), even as stroke mortality rates are declining. Patients facing the uncertain prospects of recovery and mortality from stroke seek to cope with these challenges with the support of healthcare professionals. Active involvement in their medical decisions and obtaining information about stroke are vital components of patient-centred care and advanced care planning(2).

Shared decision-making is essential, involving collaboration between patients and healthcare professionals in clinical examinations, treatment options, and their respective benefits and drawbacks(3). A comprehensive and fiscally responsible approach to healthcare is imperative to facilitate optimal recovery. However, comprehensive multi-dimensional healthcare programs catering to stroke and brain injury patients currently need to be expanded. Thus, a holistic approach to stroke care, as recommended by the Institute of Medicine in 2010, is crucial(1). Holistic and multidisciplinary rehabilitation, aligned with a patient-centred approach, underscores the significance of personal factors such as

attitudes, values, preferences, and coping styles for stroke patients(35). This approach, thereby, centralizes healthcare services around patient needs and expectations. This approach is tied to enhanced patient compliance, increased accountability for personal health, and improved health outcomes(5).

In their publication, Muscat et al. explore the intersection of technology and patient-centred care in the context of health literacy and shared decision-making. Technology is identified as a valuable catalyst in enhancing health literacy and simplifying decision-making processes for patients through the provision of easily understandable tools, video-based content, verbal narratives, and visual aids for health communication. Additionally, technology supports acquiring health literacy skills necessary for effective shared decision-making, bolstering patient engagement in their healthcare journey(6).

These approaches highlight patient engagement and collaboration between practitioners and patients in delivering patient-centred care. Incorporating new technologies and tools enhances patient engagement and outcomes while fostering close partnerships between patients, stroke survivors, and healthcare professionals to

ensure care decisions are grounded in patient needs and preferences. The authors' review examined available literature on holistic and participatory approaches to patient-centred stroke care.

## MATERIALS AND METHODS

The search strategy involved conducting a systematic review of articles on patient engagement and enhancing early mobilization in stroke units. Articles were sourced from Science Direct, PubMed, and ProQuest, using a combination of keywords and Boolean operators, such as "patient engagement," "early mobilization," and "stroke," to align with the research objectives. The essence of this article can be encapsulated in the following PICOT question: (1) P

(Population): Stroke patients; (2) I (Intervention): Patient centred care ; (3) Comparison: not patient centered care; (4) O (Outcome): Patient Engagement ; and (5) T (Time): During stroke rehabilitation. The selection criteria for our online article searches were stringent and meticulously defined. These parameters were established to ensure relevance and quality in the gathered literature: (1) Only research published within the last decade, specifically from 2020 to 2024, was deemed acceptable. This temporal restriction enables the inclusion of the most recent findings within the field. (2) The primary focus was directed towards studies examining stroke patients' involvement in early mobilization practices, thereby underscoring the significance of

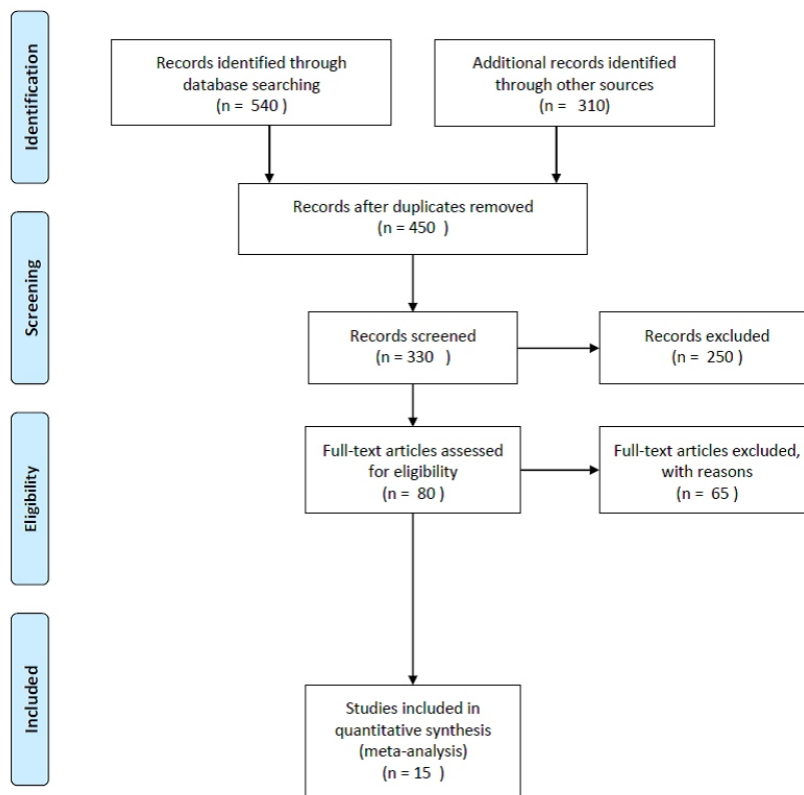


Figure 1. PRISMA Flowchart

timely physical activity in the recovery process. (3) We prioritized articles available in open-access format, encompassing scientific reviews and original research, to guarantee that the information remains accessible for further investigation and validation. (4) Lastly, all articles selected for inclusion must be authored in English to ensure consistency and comprehensibility throughout our comprehensive review process. Exclusion criteria encompassed articles that did not address the involvement of stroke patients in early mobilization. The data extraction process was conducted with strict adherence to the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) methodology. This involved retrieving 540 research articles from various databases. After eliminating duplicates, 443 articles were reviewed for completeness. Ultimately, 15 articles meeting the established criteria were selected from the identified databases. The PRISMA flowchart, representing the research process, is depicted in **Figure 1**. In the course of

conducting the article search, a set of keywords was employed. This endeavour yielded 540 relevant articles from three distinct databases - Science Direct (42), PubMed (384), and ProQuest (114) - utilizing the keywords Patient Engagement, Early Mobilization, and Stroke. Subsequently, 33 articles were found to be eligible for selection. A comprehensive review of the full text was undertaken to evaluate their eligibility. Ultimately, twelve articles aligned with the inclusion criteria and were deemed suitable for evaluation by the Joanna Briggs Institute (JBI) guidelines. The prisma flow diagram for literature identification is depicted in Figure 1. Table 1 serve as a concise summary of the research findings incorporated within this article.

## RESULTS AND DISCUSSION

### RESULTS

In **Table 1**, a succinct overview of the key research findings was integrated into this article, summarizing the critical insights derived from our analysis. Additionally,

**Table 1. Article Mapping**

<b>Author, Year</b>	<b>Findings</b>
Skolarus et al. (2022)	<p>Advanced care planning (ACP) ensures medical care aligns with individual values, which is crucial for stroke patients.</p> <p>Participation in ACP is low among stroke survivors, particularly in minority groups.</p> <p>The study compares the PREPARE program (with an easy-to-read advance directive) to using an advance directive alone.</p> <p>The PREPARE program includes state-specific advance directives and educational resources.</p> <p>A trial showed that combining PREPARE with the advance directive increased ACP participation among stroke survivors.</p> <p>Of 986 participants, 91 were stroke survivors; those in the PREPARE group completed more ACP tasks and found it more helpful.</p>

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Mc Shan et al. (2022)	Regular patient feedback improved the relevance and effectiveness of the Diabetes Prevention Program Group Lifestyle Balance (DPP-GLB) for individuals with acquired brain injury (ABI).
Kernan et al. (2021)	Primary care teams provide post-stroke care focused on patient-centred support. Care begins by involving caregivers and screening for issues like depression. Some patients may require referrals for specialized care. Ongoing management emphasizes risk control and promoting healthier lifestyles.
Kayes et al. (2022)	Engagement is essential and encompasses various forms of connection. The therapeutic relationship between stroke survivors and their clinicians is foundational for other relationships. The connection is facilitated through five collaborative processes: Knowing, Trusting, Adapting, Investing, and Reciprocity.
Williams et al. (2021)	Therapy engagement is crucial for successful rehabilitation outcomes. Engagement influences outcomes independently of various factors (education, health issues, emotional distress, apathy, initial ability). Neuropsychological assessments can identify traits impacting therapy engagement.
Prick et al. (2022)	About half of acute stroke survivors prefer to participate in decision-making processes. Most of them believe they are capable of contributing. However, their actual involvement levels are limited. Active participation of acute stroke survivors in decision-making processes is favoured by approximately half of the individuals, with the majority considering themselves capable of contributing. However, their actual involvement levels remain limited.
Blaquera et al. (2024)	The interdisciplinary team focuses on policy and funding for home visits and telehealth, ensuring culturally responsive environments. Collaborative planning with evidence-based treatment protocols, emphasizing patient and family engagement, coordinated by nursing professionals. Nursing Roles: Nurses administer therapies as delegated by rehabilitation specialists. Goals target patient and family well-being, enhancing daily activities and overall quality of life.
Rethnam et al. (2021)	Early mobilization clinical practice guidelines (CPGs) have various influencing factors that influence their use as decision-support tools. While the benefits and harms of early mobilization are mentioned, CPGs often lack specific details on interventions, populations, and outcomes. This lack of detail creates uncertainty for clinicians treating stroke patients. Strict CPGs may limit their practical application and lead to underutilizing early mobilization strategies.
Christiansen et al. (2022)	The ART system, particularly the TheraMem extension, is feasible for upper limb mobility rehabilitation post-stroke.
Amorim et al. (2023)	Serious Games (SGs) are tailored for stroke survivors, addressing their unique needs. Players prefer games that mirror real-life activities and feature relatable avatars. Positive feedback and personalized methods enhance player motivation and effectiveness. Chronic survivors value social interaction through gaming.
Blatchford et al. (2022)	The modified Life After Stroke program had positive outcomes for some participants, but others found it unsuitable. Offering self-management programs promptly after stroke and providing diverse delivery options beyond face-to-face, group-based learning may enhance participation in post-stroke programs.

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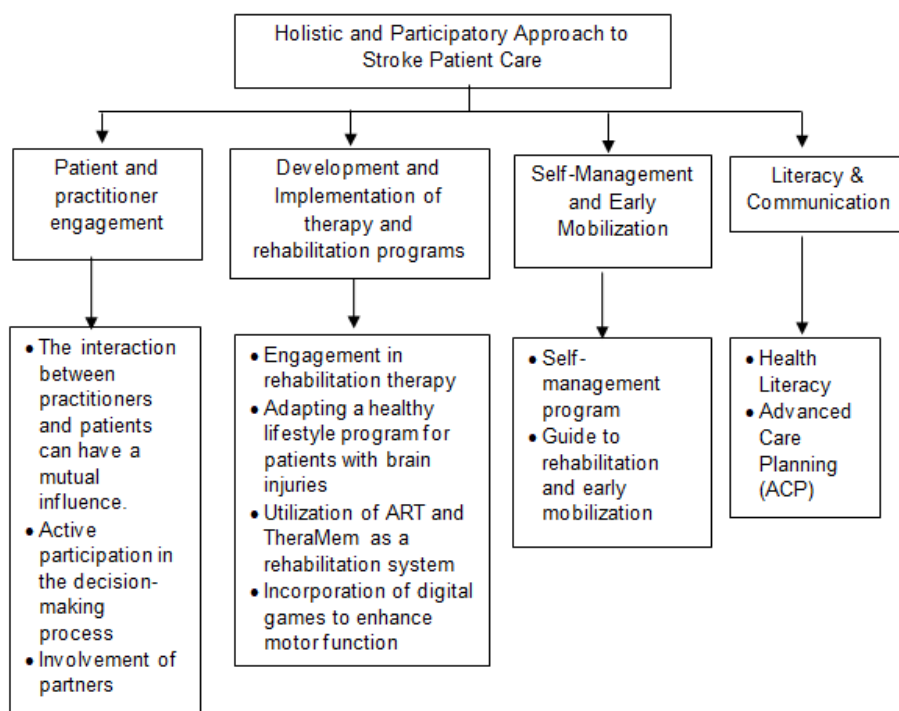
Kwok et al. (2022) Involving post-stroke partners, even those with aphasia, in the research process from start to finish had a positive impact. Their contribution enriched the research by offering practical guidance and lived experience knowledge despite facing unique cognitive, communication, and mobility challenges.

Cook & Pompon (2023) Health literacy is crucial for post-stroke rehabilitation outcomes. Low health literacy can impact well-being and community health outcomes, especially for stroke survivors with aphasia. To enhance health literacy, focus on accessing, understanding, appraising, and applying health information. Efforts to improve health literacy should consider language accessibility, readability levels, and information validity.

(Kagan et al., 2024) Collaboration between a Stroke Team and a community-based Aphasia Team was crucial. The project utilized the iKT model and gathered information over several years. Outcomes included the provision of accessible information about aphasia to patients and the development of new products. The implementation process highlighted the need for further work on the sustainability of communicative access interventions for stroke patients with aphasia.

Alaparthi et al. (2020) Early mobilization improves patient outcomes, regardless of ventilation status. ICU-specific scoring systems help track patient status over time.

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**Figure 2. A Conceptual Framework for Patient Engagement in Early Mobilization of Stroke Patients**

**Figure 2** depicts a conceptual framework aimed at promoting the active engagement of patients in the early mobilization efforts for stroke survivors, emphasizing the importance of their involvement in the rehabilitation process. This study elucidates a framework designed to enhance patient engagement in the early mobilization of stroke survivors. A holistic approach to patient care encompasses the comprehensive evaluation of a patient's physical, emotional, social, economic, and spiritual needs. This methodology incorporates services that address the entirety of the human experience. Nursing educators must integrate holistic care into nursing curricula to enhance the quality of care provided to patients and nursing professionals. Furthermore, this approach can facilitate the design of participatory healthcare systems.

The Holistic and Participatory Approach to Stroke Patient Care encompasses four fundamental concepts: Patient and Practitioner Engagement, Development and Implementation of Therapy and Rehabilitation Programs, Self-Management and Early Mobilization, and Literacy and Communication. Patient and Practitioner Engagement is characterized by the reciprocal influence between practitioners and patients. It emphasizes the importance of active participation in the decision-making process and the involvement of caregivers and partners. The Development and Implementation of Therapy and Rehabilitation Programs involve creating an Occupational Therapy

Scale, adopting healthy lifestyle programs tailored for patients with brain injuries, utilizing ART (Adaptive Rehabilitation Technology) and TheraMem as integrated rehabilitation systems, and incorporating digital games aimed at enhancing motor function. Additionally, self-management and early mobilization consist of structured self-management programs and comprehensive guides to rehabilitation and early mobilization practices. Literacy and Communication focus on improving health literacy and facilitating Advanced Care Planning (ACP), ensuring that patients are well-informed and actively involved in their care decisions.

The documented research underscores the vital significance of active engagement from both patients and healthcare professionals in therapy and rehabilitation. It emphasizes the need for self-management and open communication when managing stroke. This participatory approach is crucial for enhancing the effectiveness of programs and subsequently elevating the quality of life for post-stroke patients.

## **DISCUSSION**

Holistic and multidisciplinary rehabilitation is essential for stroke patients, as it emphasizes a patient-centred approach considering various personal factors. These factors include individual attitudes, deeply held values, personal preferences, and unique coping styles significantly influencing recovery. By prioritizing each patient's specific needs and expectations, this method

transforms the delivery of healthcare services, making them more responsive and tailored to individual circumstances. This focus on personalization fosters greater patient compliance with treatment plans and promotes a heightened sense of accountability for one's health. Ultimately, this approach leads to improved health outcomes, enhancing the quality of care and patient recovery experience(4).

The involvement of patients and healthcare professionals mutually influences each other. **Table 1** elaborates on the concept of article mapping, emphasizing the significance of patient engagement for stroke survivors. This discussion is further expanded within a framework in **Figure 2** that embraces a holistic approach to patient care, which involves a thorough assessment of a patient's diverse needs-physical, emotional, social, economic, and spiritual. Practitioners' active participation fosters patient engagement, while passive involvement from healthcare providers diminishes patient engagement. This collaboration is shaped by self-assurance, positive influence, and emotional responses during interactions. Primary care teams play a vital role in delivering comprehensive post-stroke care that prioritizes patients' needs and preferences. This compassionate approach begins with caregivers' active involvement in the recovery process and the execution of thorough screenings to identify potential issues, such as depression, that can significantly impact the patient's rehabilitation journey(7).

In certain instances, patients may require referrals to specialized healthcare providers to address specific challenges or complications that may arise following a stroke. The emphasis of ongoing management is on controlling risk factors and promoting the adoption of healthier lifestyles. This holistic approach seeks to minimize the likelihood of future strokes and enhance patients' overall well-being and quality of life as they navigate their recovery(7). Numerous studies have demonstrated that patient engagement is enhanced when patients develop stronger relationships with their healthcare providers. These relationships play a significant role in influencing patient participation in decision-making processes (8,9). Patient engagement encompasses various forms of connection. The dynamic between stroke survivors and healthcare practitioners is essential. This relationship entails the components of Knowing, Trusting, Adapting, Investing, and Reciprocity. Trust is essential in the therapeutic relationship. Patients must have confidence in their practitioners, while practitioners depend on patients' self-knowledge. This mutual trust fosters open communication about rehabilitation goals. Practitioners must adapt to individual patients' needs and align them with their emotional and physical states. Emotional investment from both parties enhances motivation and commitment. The reciprocal nature of this engagement means that trust and investment reinforce each other, while a lack of enthusiasm can hinder



progress and create negative feelings (10). The growing emphasis on improved health literacy, effective communication, and shared decision-making underscores the necessity for patient-centred communication. Enhanced relationships contribute to increased empathy, superior communication quality, and greater patient involvement in their own care processes.

Chronic diseases represent a significant cause of mortality and morbidity on a global scale. Healthcare systems are evolving to provide enhanced support for individuals with chronic conditions or those at elevated risk (11). A primary objective of these reforms is to empower patients through self-management and decision-making support, facilitating greater involvement in their healthcare processes. Shared decision-making (SDM) entails a collaborative approach wherein healthcare professionals and patients jointly engage in decision-making, discussing care preferences and formulating a mutually agreed-upon care plan. This approach is positioned between a paternalistic model, characterized by healthcare providers taking unilateral control, and a scenario in which patients make decisions exclusively based on the information provided (12).

The advocacy for SDM is founded on its capacity to enhance informed decision-making, promote treatment adherence, and improve overall patient outcomes, thereby establishing it as a crucial component of patient-centred care. Despite the increasing

interest in SDM, its application is constrained by several barriers, including time limitations and the diverse circumstances of patients. Nonetheless, favourable factors such as the motivation of healthcare professionals and the documented positive impacts of SDM on care processes and patient outcomes contribute to its potential effectiveness. Implementing theory-based strategies may significantly enhance the application of SDM in managing chronic disease, resulting in improved adherence to treatment decisions (12,13). Shared decision-making, a process that has been shown to have a positive impact on patients, empowers them, leading to greater treatment compliance and reduced risk of pathology-related complications (3). Understanding patient preferences and developing a shared understanding of their situation are pivotal in the decision-making process (12).

Approximately fifty per cent of acute stroke survivors express a preference for participating in decision-making processes. The majority of these individuals believe they possess the capability to contribute meaningfully to such discussions. Nevertheless, their actual levels of involvement remain limited, indicating a discrepancy between their desire to participate and the reality of their engagement in decision-making activities (14). Furthermore, the engagement of patient partners - those with lived experiences of health issues - in research contributes significantly to various research stages, despite encountering challenges in cognition,

communication, and mobility(15).

Active participation in therapy is crucial for attaining favourable rehabilitation outcomes. The extent of engagement holds significant importance in its own right. It profoundly influences results, irrespective of other contributing factors, including an individual's educational background, pre-existing health conditions, emotional distress, a lack of motivation, or initial capabilities. Furthermore, neuropsychological assessments serve as valuable instruments for identifying specific traits and characteristics that may affect an individual's willingness and capacity to engage comprehensively in the therapeutic process(16).

Involving patient stakeholders in modifying and implementing healthy lifestyle programs enhances their relevance and effectiveness, as seen in programs such as Diabetes Prevention Program Group Lifestyle Balance (DPP-GLB). The Diabetes Prevention Program Group Lifestyle Balance (DPP-GLB) is a 12-month intervention to promote healthy lifestyle choices. Initially, this program was not specifically tailored for individuals who have experienced traumatic brain injury (TBI) or stroke. Through community-based participatory research, the program has been developed in collaboration with various stakeholders, including members of stroke support groups, to adapt it for individuals with acquired brain injury (ABI) (17).

Engaging patient stakeholders has significantly enhanced our understanding of

their needs, creating a more accessible program for TBI and stroke survivors despite our team's limited personal experience with these conditions. Moreover, using Serious Games (SGs) has shown promising results in improving upper extremity motor function in stroke patients. Incorporating positive feedback mechanisms and personalized approaches significantly boosts players' motivation levels and effectiveness in rehabilitation. Moreover, stroke survivors who face chronic challenges often place great importance on the social aspect of gaming, as it fosters connections and interactions with others, making their recovery journey more enjoyable and less isolating(18,19).

Rehabilitation for stroke requires several essential components. The interdisciplinary team is committed to advocating for the development of policies and securing funding that facilitates effective home visits and telehealth services. This approach ensures that healthcare environments are not only accessible but also culturally responsive, thereby addressing the diverse needs of the populations served. The team engages in comprehensive, collaborative planning, incorporating evidence-based treatment protocols. This highlights the importance of active participation from both patients and their families in the care process. These efforts are coordinated primarily by skilled nursing professionals, who ensure that each stage of care is aligned with best practices and tailored to individual patient needs. Within this framework, nurses play a crucial

role by administering therapies prescribed by rehabilitation specialists. They apply their clinical expertise to deliver care that is not only effective but also compassionate, thereby supporting patients in their recovery journeys. The team's overarching goals focus on enhancing the well-being of patients and their families. By improving daily activities and addressing the holistic aspects of health, the team aims to significantly elevate the overall quality of life for those they serve(20).

Stroke is a chronic condition affecting an individual's physical, psychological, and social well-being. Self-management interventions equip patients with the skills necessary for more effective illness and health management. The concept of self-efficacy, defined as the belief in one's capacity to attain specific outcomes, significantly influences behaviour and is associated with enhanced quality of life and decreased depression among stroke patients (21). Self-management and rehabilitation programs are pivotal after a stroke. Providing self-management programs soon after a stroke and offering diverse delivery options beyond face-to-face group-based learning can improve participation in these programs (22). Additionally, it's crucial to understand that early mobilization and appropriate rehabilitation play a significant role in successful recovery post-stroke (23,24). This knowledge is essential for all healthcare professionals and researchers in the field of stroke therapy and rehabilitation.

Early mobilization refers to facilitating

patient movement out of bed during the acute phase of a stroke, which has been shown to enhance functional capacity while minimizing potential complications. This intervention should commence no earlier than 24 hours post-stroke, emphasizing patient safety. The mobilization exercises are typically conducted for 15 to 45 minutes daily, divided into one to three sessions, and primarily concentrate on activities such as sitting, standing, and walking (25). A study assessing the effectiveness of an early mobility protocol for stroke patients within the intensive care unit evaluated a cohort of 60 patients admitted to a specialized stroke unit. The findings indicated significant improvements in muscle strength, pulmonary function, and overall quality of life following the intervention. This research supports the conclusion that early mobility is safe and effective for stroke patients and advocates its implementation as a standard practice in neurogenic intensive care units (26).

Health literacy plays a crucial role in the recovery process following a stroke. Insufficient health literacy can negatively impact both individual well-being and community health, particularly among stroke survivors affected by aphasia. To enhance health literacy, it is essential to emphasize the ability to access, comprehend, evaluate, and apply health-related information. Initiatives aimed at improvement should focus on ensuring language accessibility, enhancing readability, and verifying the validity of the information supplied (27). The experiences of

patients with aphasia and their families within acute care settings are frequently characterized by adverse outcomes stemming from communication challenges. These difficulties can result in adverse events and enduring physical and emotional consequences. While prior research has demonstrated the effectiveness of training for healthcare providers in stroke care, there is a paucity of evidence regarding strategies that facilitate sustainable change. Establishing community-based Stroke and Aphasia Teams employing Supported Conversation for Adults with Aphasia (SCA™) is a valuable resource for patients and their families. This initiative underscores the necessity for continued efforts to ensure adequate communication access for stroke patients with aphasia and their families(28).

Stroke remains a significant cause of mortality, with over 30% of older patients succumbing within a year following discharge from the hospital. The primary causes of death for these individuals include recurrent stroke and heart disease. Consequently, most stroke survivors must participate in advance care planning (ACP) to ensure that their end-of-life care reflects their values and preferences. Engaging in ACP not only enhances the quality of care but also improves the overall well-being of caregivers (29,30). Advanced care planning (ACP) is a vital process that ensures that medical treatment and interventions are in harmony with individuals' personal values and preferences, particularly for those who have

experienced a stroke. This alignment is essential as it can significantly affect the quality of care and patients' overall experience during recovery.

Despite the importance of ACP, participation levels among stroke survivors remain notably low, with even lower rates observed among minority groups. This gap highlights the need for targeted interventions to promote greater involvement in the ACP process within these populations. A recent study aimed to address this issue by comparing the effectiveness of the PREPARE program - which incorporates an easy-to-read advance directive - to using an advance directive on its own. The PREPARE program is designed to be user-friendly and includes state-specific advance directives and various educational resources that guide patients through the planning process.

The findings from the trial were encouraging. It showed that when the PREPARE program was combined with the advance directive, there was a marked increase in ACP participation among stroke survivors. Out of a total of 986 participants in the study, 91 were identified as stroke survivors. Notably, those who were part of the PREPARE group completed more ACP tasks and reported finding the program significantly more helpful in navigating their advance care planning needs. This highlights the potential of structured programs like PREPARE in enhancing the engagement of stroke survivors in their healthcare decisions (30). However, it's important to remember that

these conversations are a crucial part of patient care and should be prioritized to ensure comprehensive support for post-stroke patients.

Empowering stroke survivors through self-management and early mobilization is essential for improved outcomes, especially for those with communication challenges like aphasia. Ongoing ACP discussions align healthcare with patient values, enriching care quality for stroke survivors and their families. The framework promotes a patient-centred approach, emphasizing collaboration and support throughout rehabilitation.

## CONCLUSION AND RECOMMENDATION

In conclusion, the active involvement of both patients and practitioners across all facets of therapy and rehabilitation is paramount. This engagement enhances program effectiveness and significantly improves the quality of life for post-stroke patients research.

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