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The role of family-centered care in enhancing stroke rehabilitation outcomes: an integrative literature review

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ABSTRACT

Family-centered care (FCC), which emphasizes the involvement of family members as active participants in the care process, represents a significant paradigm within the realm of stroke rehabilitation. This study aimed to locate and synthesize the most recent evidence concerning the advantages, methodologies, and obstacles associated with the integration of FCC in stroke rehabilitation. The approach taken involves conducting an integrative literature review following the guidelines set forth by Whittemore and Knafl. A thorough exploration of four databases including PubMed, CINAHL, Scopus, and PsycINFO, was carried out, focusing on both quantitative and qualitative studies published between January 2012 and December 2022. Inclusion criteria comprised studies involving adult stroke patients undergoing rehabilitation, detailing family-centered interventions, and presenting outcomes for either the patients or their families. Upon the screening process, 25 studies met the inclusion criteria and were included in the analysis. Various strategies have been identified to effectively involve families in the rehabilitation process, such as educational initiatives, collaborative planning for home-based care, and provision of support for caregivers. However, the implementation of FCC faces challenges stemming from factors at the system level, provider level, and patient/family level, in conclusion, the integration of FCC in stroke rehabilitation yields substantial benefits for both patients and caregivers. It is imperative for nurses to engage families as collaborative partners, tailor interventions according to specific requirements, offer assistance to caregivers, and instigate changes at the systemic level.

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1. INTRODUCTION

Stroke is a leading cause of disability worldwide, necessitating effective rehabilitation strategies to optimize recovery outcomes [1]–[3]. The process of post-stroke rehabilitation is intricate, encompassing a diverse array of interventions aimed at reinstating functionality, enhancing survival rates, and optimizing the overall quality of life [4]. While rehabilitation customarily concentrates on the distinct requirements of stroke patients, there is an escalating recognition of the significance of integrating the family into the caregiving process [5]. Despite advancements in medical interventions, achieving optimal rehabilitation results remains a significant challenge. Family-centered care (FCC) has emerged as a promising approach to enhance stroke rehabilitation by actively involving family members in the care process [6].

Previous research underscores the critical role of family support in the rehabilitation of stroke survivors. Several previous studies highlight that active family involvement can lead to better functional recovery and increased patient satisfaction [7]–[9]. A previous study found that patients who received FCC exhibited significant improvements in mobility and daily living activities compared to those who received standard care [10], [11]. Another previous study also demonstrated that FCC reduced psychological distress in both patients and their caregivers, fostering a more supportive recovery environment [11].

FCC epitomizes a philosophical and pragmatic approach that acknowledges the pivotal role of the family in the lives of patients, involving them as equitable collaborators in the formulation, dispensation, and assessment of care [12]. Within the realm of stroke rehabilitation, FCC endeavors to empower patients and their families, cater to their needs and preferences, and foster cooperation between families and rehabilitation teams [13]. The theoretical underpinning of FCC encompasses the dissemination of information, respect for disparities, partnership and collaboration, negotiation, and care within familial and communal settings [14].

However, several unresolved issues persist. For instance, there is a lack of standardized FCC protocols, and the variability in family dynamics poses challenges to the universal application of FCC principles [15]. Additionally, limited training for healthcare providers on how to effectively implement FCC further complicates its integration into clinical practice [16]. Addressing these gaps is crucial for maximizing the benefits of FCC in stroke rehabilitation.

Previous studies have demonstrated that interventions incorporating families can ameliorate the functional, psychosocial, and quality of life outcomes of stroke patients [17]–[19]. Furthermore, FCC has been linked to heightened contentment with care, enhanced communication, and diminished caregiver strain [13], [20]. Nevertheless, the translation of FCC principles into clinical practice remains demanding, encountering obstacles at the systemic, provider, and patient/family levels [21]–[23].

This review seeks to address these gaps by synthesizing existing evidence on FCC and identifying best practices for its implementation. Unlike previous studies that have focused on specific aspects of FCC, this integrative review provides a comprehensive overview, examining various dimensions of FCC and their impact on stroke rehabilitation outcomes. We will also propose a framework for standardized FCC protocols that can be adapted to diverse family structures and healthcare settings. The sections that follow will systematically demonstrate the significance of FCC in stroke rehabilitation, review the current state of FCC implementation, identify key challenges and opportunities, and propose actionable recommendations for enhancing FCC practices. Through this integrative review, we aim to contribute to the body of knowledge on stroke rehabilitation and offer practical insights for healthcare providers to improve patient outcomes through effective FCC.

2. METHOD

2.1. Study design

This integrative literature review adheres to the methodology delineated by Whittemore and Knafl [24]. Integrative review represents a comprehensive method that permits the incorporation of diverse study methodologies to gain a deep comprehension of the concept of attention. This strategy is particularly appropriate for evaluating data regarding FCC in stroke rehabilitation, encompassing a broad spectrum of interventions, demographics, and settings.

2.2. Search strategy

A thorough search of the existing literature was carried out across several electronic databases, namely PubMed, CINAHL, Scopus, and PsycINFO. The search strategy involved utilizing a variety of keywords such as “stroke”, “rehabilitation”, “family-centered care”, “family involvement”, “family intervention”, “patient and family outcomes”, “implementation”, as well as “barriers and facilitators”. The search scope was limited to publications written in the English language, released between January 2012 and December 2022, and accessible in their entirety.

2.3. Eligibility criteria

Studies meeting the criteria for inclusion in the review encompass those involving adult stroke patients (aged ≥18 years) engaged in rehabilitation, interventions or approaches emphasizing family participation, reporting at least one patient or family outcome, and utilizing quantitative, qualitative, or mixed method designs. The included studies must be published in peer-reviewed journals and be available in full text format. Studies had to describe specific family-centered interventions or approaches in stroke rehabilitation settings. Conversely, studies failing to meet the inclusion criteria are those lacking a rehabilitation component, focusing solely on the pediatric population, or being opinion articles, editorials, or case studies with samples sizes less than 5. Additionally, studies were excluded if they were not published in English or if they focused solely on pharmacological interventions without any family involvement component.

2.4. Data extraction

Data were obtained from eligible research through the utilization of a predetermined data extraction template, encompassing details regarding the research's attributes (such as methodology, environment, participants), specifics of the intervention (like structure, strength, duration), assessed results, and main discoveries. The process of data collection was conducted autonomously by two reviewers, with discrepancies being addressed through dialogue and mutual agreement. A third reviewer was consulted when consensus could not be reached between the initial two reviewers. The data extraction template was piloted on five randomly selected studies to ensure its comprehensiveness and utility before full implementation. Regular meetings were held among reviewers to discuss any challenges in the extraction process and maintain consistency in data collection methods.

2.5. Data analysis

The data analysis employs a methodology of content analysis as proposed by Hsieh and Shannon [25]. The outcomes derived from the research endeavors were categorized into nascent classifications and themes, concentrating on the discernment of patterns, correlations, and fundamental principles linked to the inquiries of the study. A narrative synthesis technique was applied to encapsulate and exhibit the findings, placing particular importance on the explication and implementation of the results in the context of stroke rehabilitation practice.

2.6. Quality of study assessment

The methodological quality of the included studies is evaluated utilizing appropriate critical tools specific to each study design. The Jadad *et al.* [26] was employed for randomized controlled trials (RCTs). In the case of non-RCT quantitative studies, the Newcastle-Ottawa Cohort study checklist [27] was utilized. Regarding qualitative studies, the critical qualitative research evaluation checklist (CASP) [28] was employed. The assessment of each study's quality was conducted independently by two researchers, with any discrepancies being addressed through discussion until a consensus was reached.

3. RESULTS AND DISCUSSION

3.1. Result

3.1.1. Description of included studies

An initial search identified 945 publications, which were reduced to 753 after removing duplicates. Title and abstract screening led to the evaluation of 124 articles for eligibility. Ultimately, 25 studies met the inclusion criteria and were included in the analysis as shown in Figure 1.

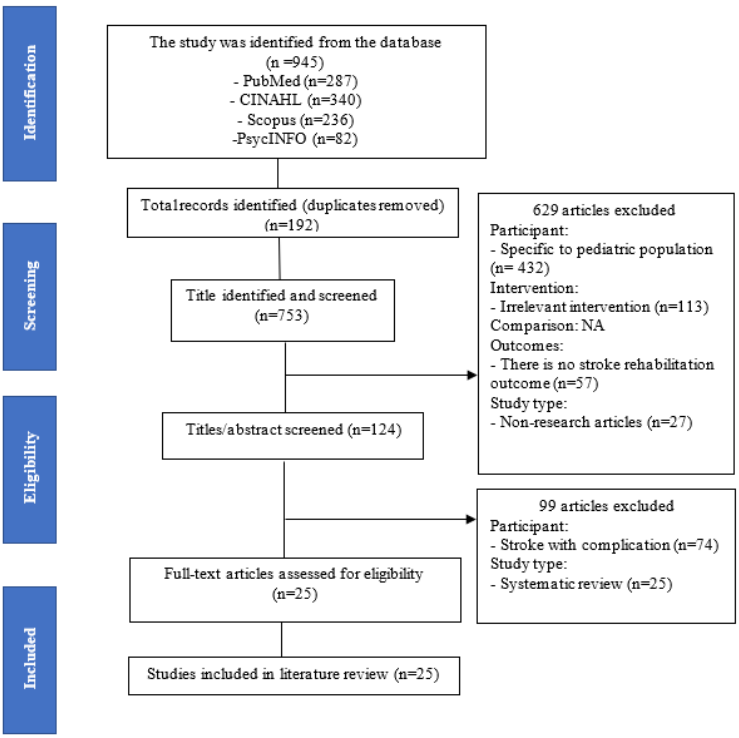

Figure 1. Flow diagram of studies identification

a. Theme 1: advantages of family engagement in stroke rehabilitation

– Subtheme 1.1: enhancement of functional and physical results

Several studies indicate that involving families in interventions notably enhances the functional and physical outcomes of stroke patients, such as autonomy in activities of daily living (ADL), movement, and stability. Family-mediated exercise interventions (FAMEs) have been found to optimize patient recovery and increase family participation after acute stroke, while considering available resources. Additionally, interventions facilitated by caregivers have been reported to improve the recovery of physical functions among stroke patients [29]–[32].

– Subtheme 1.2: enhancement of psychological well-being and quality of life

The engagement of families in stroke rehabilitation is linked to an enhancement in the psychological well-being and quality of life of patients and caregivers. These studies demonstrated that family involvement in stroke rehabilitation significantly contributed to enhancing the psychological well-being of patients, leading to reduced feelings of isolation and increased motivation during the recovery process. Furthermore, family engagement in rehabilitation programs was linked to improved quality of life for both stroke survivors and their caregivers, fostering a sense of support and understanding within the family unit [33], [34].

– Subtheme 1.3: improved compliance with treatment plans

Various studies demonstrate that family involvement enhances stroke patients' adherence to treatment plans and regimens. These findings underscore the significance of family involvement in promoting treatment adherence among stroke patients. By incorporating family members into the rehabilitation process, healthcare providers can create a supportive environment that encourages patients to adhere to their treatment plans, ultimately leading to better outcomes in stroke recovery [35], [36].

b. Theme 2: approaches for engaging families in stroke rehabilitation

– Subtheme 2.1: interventions and educational initiatives

A range of interventions and educational initiatives were identified in the analysis to involve families in stroke rehabilitation, encompassing skills training sessions. Studies indicated that practical skills training sessions empower caregivers to actively engage in patient care and enhance their readiness for the transition to home. These training sessions equip caregivers with the necessary skills and knowledge to support stroke patients effectively, leading to improved rehabilitation outcomes and a smoother transition to home care. By involving families in these educational initiatives and skills training sessions, healthcare providers can enhance the overall quality of care and support for stroke survivors during their recovery process [37], [38].

– Subtheme 2.2: collaborative planning for return to home

Multiple studies underscore the significance of collaborative planning for returning home involving patients, families, and interdisciplinary rehabilitation teams. These studies have highlighted the significance of involving multiple stakeholders in the planning process to ensure a comprehensive and coordinated approach to post-stroke care. The involvement of patients, families, and rehabilitation teams in the planning process is essential for addressing the diverse needs of stroke survivors and ensuring a patient-centered approach to care. This collaborative model of care not only enhances the quality of rehabilitation but also promotes continuity of care and improves patient outcomes post-stroke [39], [40].

– Subtheme 2.3: assistance and resources for caregivers

Research underscores the necessity for tailored assistance and resources for caregivers of stroke survivors, including respite programs, support groups, and educational materials. By tailoring assistance and resources to the specific needs of caregivers, healthcare providers can better support the well-being of both caregivers and stroke survivors. These interventions not only benefit the caregivers directly but also contribute to improved outcomes for the patients by ensuring a supportive and knowledgeable caregiving environment [41], [42].

c. Theme 3: obstacles and enablers for FCC

– Subtheme 3.1: factors at the system level

The analysis identified various system-level obstacles and enablers to FCC in stroke rehabilitation. Healthcare system policies, resource allocation, and organizational culture were found to significantly impact the implementation of FCC. Institutional barriers such as rigid scheduling systems and limited staffing resources often hindered the effective delivery of family-centered care. Moreover, addressing system-level barriers, promoting a FCC model, facilitating collaborative planning, and offering tailored support for caregivers are critical strategies to improve the quality of stroke rehabilitation and support the overall well-being of patients and their families [43]–[45]. The successful implementation of FCC requires systemic changes at both policy and operational levels to create an environment conducive to family engagement.

- Subtheme 3.2: factors related to healthcare providers

Studies underscore the significance of healthcare providers' attitudes, beliefs, and communication abilities in facilitating FCC. These studies have highlighted the significance of healthcare providers' approach in fostering partnerships with patients and families to ensure collaborative decision-making and care delivery. FCC involves a partnership approach between healthcare providers and families in health care decision-making, emphasizing mutual respect and shared decision-making. However, challenges such as assumptions about family needs and provider-centered care practices can hinder the implementation of FCC. Moreover, cultural competence among healthcare providers is essential in delivering FCC, as understanding cultural beliefs and customs can enhance care provision and prevent misunderstandings [46]–[50].

- Subtheme 3.3: factors at the patient/family level

The analysis identified patient and family attributes that might impact their participation in stroke rehabilitation. Family support and participation have been identified as crucial factors that can influence long-term rehabilitation outcomes for stroke survivors. Close-knit family relationships and active involvement in the rehabilitation process have been associated with improved function in stroke survivors. Furthermore, the presence of family members and the patient's moderate dependence in daily activities have been positively linked to increased physical activity levels in stroke patients, emphasizing the role of family support in promoting patient engagement in rehabilitation [51]–[53].

3.2. Discussion

This integrative literature review integrates recent research findings regarding the advantages, techniques, and obstacles associated with the implementation of FCC in stroke rehabilitation. The results indicate that the engagement of families in the rehabilitation process has the potential to enhance functional outcomes, emotional well-being, quality of life, and adherence to treatment regimens among stroke patients. These conclusions are consistent with prior studies that underscore the significance of familial support in the recuperation of stroke survivors [13], [20] and contribute to the body of evidence by elucidating the specific mechanisms that underlie these advantages.

While the positive impact of FCC is well-documented, several critical gaps and challenges remain. The review highlights that the lack of standardized FCC protocols and the variability in family dynamics present significant barriers to the universal application of FCC principles. Studies emphasize the necessity of tailored interventions that address these variances, yet practical guidelines remain sparse [16], [54]. Furthermore, the review identifies several systemic, provider-related, and patient/family-related barriers to FCC implementation. Systemic barriers, including rigid institutional regulations and insufficient medication education, impede the seamless transition from hospital to home, thereby affecting continuity of care [55]. Additionally, patient and family dynamics, including lack of support and inadequate knowledge about stroke rehabilitation, further complicate FCC implementation [56].

The involvement of families in the rehabilitation process has the potential to enhance functional outcomes, emotional well-being, quality of life, and adherence to treatment regimens among stroke patients. Family involvement in functional rehabilitation has been shown to improve self-rated health (SRH) and have strong psychological effects on therapy through physical and emotional support [57]. Additionally, additional family support after stroke has been reported to increase social activities and improve the quality of life for caregivers [58].

Moreover, engagement in long-term rehabilitation has been associated with favorable effects on physical performance and psychosocial functioning of stroke survivors, while its absence has been linked to functional deterioration, rehospitalization, and reduced quality of life [59]. Patient engagement in rehabilitation and physical activity has also been connected to improvements in functional outcomes during inpatient rehabilitation [45]. Furthermore, cognitive impairment predicts engagement in inpatient stroke rehabilitation, suggesting that interventions to increase engagement can lead to improved functional outcomes [60].

Moreover, the review delineates various approaches for involving families in stroke rehabilitation, encompassing educational programs, cooperative home planning, and specialized caregiver assistance. The significance of a cooperative strategy involving patients, families, and healthcare professionals is underscored, aligning with the fundamental tenets of FCC [14]. Nevertheless, this review extends existing scholarship by emphasizing the necessity for interventions tailored to the distinctive requirements and preferences of families, as well as the criticality of sustained resources and support services.

Early supported discharge and home rehabilitation services for patients who have suffered a stroke offer an approach to managing rising demand for hospital beds and seem to achieve comparable clinical outcomes to inpatient rehabilitation. Shorter lengths of stay, however, can mean less access to therapists, potentially less recovery, and more burden to the caregiver and family; therefore, novel, more efficient approaches to augment practice with less costs are needed [61]. A review on family-centered approach towards post-stroke rehabilitation recommended keeping the caregivers informed, involving them in setting

rehabilitation goals, teaching coping skills, and improving self-efficacy [62]. Intervention programs that span time and include core skills of providing stroke-related information, caregiver skill training, stress-coping strategies, and problem-solving seem valuable [63].

Despite the numerous potential benefits associated with FCC, the review also enumerates several barriers to its implementation, including systemic, provider-related, and patient/family-related factors. These barriers, such as rigid institutional regulations, uncooperative provider dispositions, and pre-existing familial dynamics, mirror the challenges documented in prior literature [21], [22], [64]. Nonetheless, this review offers additional insights by highlighting potential enablers, such as innovative service delivery models, empathetic provider communication, and family participation in collaborative decision-making.

Previous study indicates systemic barriers include rigid institutional regulations, premature discharge due to bed availability, inconsistent procedures for discharge planning, insufficient medication education, manpower shortages, administrative demands, lack of transparency in medical records, and portability of records [65]. These factors can impede the seamless transition of stroke patients from hospital to home and affect the continuity of care. Provider-related barriers encompass uncooperative provider dispositions and a lack of provider buy-in for FCC approaches [13].

Furthermore, provider attitudes, beliefs, and communication abilities play a significant role in facilitating FCC, and resistance or lack of understanding among providers can hinder the successful implementation of this care model. Patient and family-related factors, such as pre-existing familial dynamics, can also pose challenges to FCC in stroke rehabilitation. Issues like lack of family support, negative experiences with healthcare providers, and inadequate knowledge about stroke and rehabilitation can impact the engagement of families in the rehabilitation process [64]. Additionally, family dynamics and readiness to participate as therapy facilitators can influence the effectiveness of family-assisted rehabilitation interventions [59].

Addressing these barriers requires a multifaceted approach that includes developing standardized FCC protocols, enhancing provider training, and supporting families throughout the rehabilitation process. The review underscores the importance of a cooperative strategy involving patients, families, and healthcare professionals, aligning with the fundamental tenets of FCC. Future research should focus on creating adaptable FCC frameworks that cater to diverse family structures and healthcare settings.

3.2.1. Implications for clinical practice

Healthcare providers should actively engage families as care partners, recognizing their crucial role in patient recovery. This includes involving them in therapy sessions, encouraging their presence during inpatient care, and regularly updating them on patient progress. Tailored interventions should consider the unique needs and preferences of both patients and families, addressing dynamics, values, and cultural factors. Shared decision-making enhances engagement and satisfaction, while sustainable support, education, and access to resources reduce caregiver stress. System-level changes, like policies supporting family involvement and interprofessional collaboration, are vital for embedding FCC into healthcare systems, ensuring consistently high-quality, person-centered care.

3.2.2. Study limitations

This review has limitations worth noting. Despite a thorough literature search, relevant studies in languages other than English may have been missed. Heterogeneity in study designs and populations limits quantitative analysis, and findings are primarily narrative. Most studies were conducted in high-income countries, potentially limiting generalizability to low-resource settings. However, the review offers a robust synthesis of recent evidence on FCC in stroke rehabilitation, highlighting areas for future research and practice improvement. Addressing these gaps can enhance care quality and outcomes for stroke patients and families.

4. CONCLUSION

The objective of this review was to locate and synthesize the most recent evidence concerning the advantages, methodologies, and obstacles associated with the integration of FCC in stroke rehabilitation. Finding of this study revealed that FCC in stroke rehabilitation is linked with a broad spectrum of advantages for both patients and caregivers. In spite of obstacles to execution, there is evidence that favors the adoption of a family-centered approach within the healthcare system. Practical implications encompass actively involving families as collaborators, customizing interventions according to specific requirements, offering continuous support to caregivers, and integrating changes at the system level. Subsequent studies ought to explore the enduring effects, varied experiences among different populations, and efficient strategies for implementation. This review highlights the benefits of FCC in stroke rehabilitation but identifies gaps and

future research directions. Longitudinal studies are needed to assess long-term impacts, particularly on patient and caregiver outcomes. Further research should explore the experiences of culturally diverse populations and assess the adoption and sustainability of FCC in different settings. Involving patients and families as active research partners can enhance relevance and impact, driving meaningful changes in care and policy.

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