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LIFE AFTER STROKE AND THE KEY ROLE OF COORDINATED REHABILITATION FROM THE PERSPECTIVE OF THE STROKE SURVIVOR FAMILIES

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Summary

Introduction. Stroke significantly affects the lives of survivors, requiring adaptation to lost capabilities while impacting physical, mental, and emotional well-being. Stroke is a leading cause of acquired disability in adults and a significant contributor to mortality, particularly among older individuals and in low-income countries. A stroke is described as a neurological deficit caused by acute damage to the central nervous system.
Aim. The study's main aim was to explore the use of coordinated stroke rehabilitation before, during, and after hospital discharge. It examined components of coordinated rehabilitation, focusing on the needs of the client's family. This study was conducted as part of the GAJU 066/2022/S project and approved by the ethics committee under 6/2022.
Materials and methods. This study used a qualitative research approach and semi-structured interviews with family members caring for stroke patients. The data collected was then analyzed using various coding strategies with the assistance of ATLAS.ti software. This rigorous methodology ensured the reliability and validity of the study's findings.
Results. The effects of strokes are profound, not only on patients but also on their families and caregivers. Adapting to life after a stroke necessitates significant changes in family dynamics, values, and norms. The importance of effective communication and support from healthcare staff during patient hospitalization cannot be overstated. Respondents highlighted the role of quality care and communication in ensuring a positive hospital stay. However, they also pointed out certain deficiencies, such as delayed stroke diagnosis and inadequate information about post-discharge care and rehabilitation. The study underscored the importance of at-home rehabilitation in familiar environments for functional improvement.
Conclusions. Life after a stroke presents a substantial challenge for patients and their families, requiring physical, psychosocial, and emotional adaptation. Coordinated rehabilitation facilitates post-stroke adjustments for patients and families and increases overall quality of life. Improved coordination and communication among healthcare providers, development of multidisciplinary rehabilitation teams, and effective post-discharge monitoring and support systems are essential for comprehensive care tailored to the needs of the patients and their families. Stroke patient family members advocate for enhanced support and services for better rehabilitation and for coping with post-stroke challenges.

Keywords: **stroke, coordinated rehabilitation, family, healthcare, communication**

INTRODUCTION

Stroke is a severe medical condition that can profoundly affect the physical, mental, and emotional well-being. A stroke is a neurological deficit caused by acute damage to the central nervous system [1]. It is the leading cause of acquired physical disability in adults and a significant cause of death, with a high incidence,

especially in the elderly and in low-income countries [2]. Post-stroke prognoses are uncertain, with a high risk of death within one year [3].

The incidence of stroke is increasing, placing a significant economic burden on healthcare systems, with a global cost estimated to be US$ 721 billion [4]. The increase in the incidence and burden of stroke translated into an increased need for effective rehabilitation and the promotion of equal opportunities for people with disabilities.

Stroke rehabilitation is multidisciplinary and involves the coordinated collaboration of various professionals and community resources [5; 6]. Treatment success depends on effective communication and coordination among rehabilitation team members [7].

AIM

This study investigated how coordinated care and rehabilitation can be implemented before, during, and after a stroke patient is discharged from the hospital. The components of coordinated rehabilitation were explored, i.e., the patient/client, their family, and treatment specialists. This article focuses primarily on the needs of the client's family. This study was conducted as part of the GAJU 066/2022/S project, approved by the ethics committee under 6/2022.

MATERIALS AND METHODS

Research Strategy. This study employed a qualitative research approach, focusing on the experiences of family members caring for patients after a cerebrovascular accident (CVA)/stroke. The principal data-gathering method was semi-structured interviews with family caregivers.

Participants. A total of 32 family members of stroke patients were initially approached to participate in this study; however, only 12 agreed to participate. All participants were thoroughly briefed on the research objectives before participating. To ensure the confidentiality and anonymity of the respondents, all interviews were coded.

Data Collection. The semi-structured interviews were designed to gather two types of information: (a) details about the caregiver (e.g., their relationship to the patient, their caregiving role), and (b) their experiences and perceptions garnered from utilizing coordinated rehabilitation services.

The interview framework used guided conversations while allowing flexibility for participants to share their experiences and perspectives freely.

Data Analysis. Data obtained from the interviews were analyzed using ATLAS.ti software. This analysis employed various coding strategies, including open, axial, and selective coding, depending on the depth and richness of the data provided by the participants. This meticulous process aimed to comprehensively explore the themes and patterns emerging from the caregivers' narratives.

Research Risks. Acknowledging the limits associated with this qualitative research is essential. Given its qualitative nature, the study does not allow for the generalization of findings. Moreover, since the research focuses on the caregiver experiences of family members, combining results from multiple interviews introduces a degree of subjectivity to data coding. To mitigate this issue, the coding process was discussed with other experts in the field to reduce the influence of individual biases.

RESULTS

The results of our study show that stroke has far-reaching consequences not only for the person directly affected but also for family members and caregivers. Adaptation to life after a stroke requires considerable family adaptability, often transforming family roles, values, and typical daily patterns. Most participants in this study emphasized the importance of effective communication and support from healthcare professionals during hospitalization, supporting other authors' views [8, 9, 10].

The respondents identified several key factors contributing to improving the hospital stay, such as improved quality of care and increased communication with hospital staff. However, respondents also pointed to shortcomings linked to hospital care, such as delayed stroke diagnosis and inadequate information regarding follow-up care and rehabilitation [11; 10]. Home-based rehabilitation was found to provide familiar surroundings that encouraged rehabilitation activities related to practical needs (daily hygiene) and improved functional abilities (exercise, food preparation, home care) [6; 12].

Our findings also highlight the need for better access to information and rehabilitation care coordination. Many respondents described gaps in post-hospital discharge rehabilitation care [13, 14, 15]. Additionally, contact and support from GPs were reported as variable, with some respondents noting difficulties with GP accessibility and less-than-desirable quality of communication [10].

Home visits from specialists are essential for families and are crucial in reducing rehabilitation care burdens on families and caregivers and improving coping strategies for new challenges [16; 12]. Home visits provide practical and emotional support and help families and caregivers better manage rehabilitation and health care for the affected family member.

Stress, anxiety, and depression are significant factors affecting the well-being of partners and caregivers of stroke patients. Our study showed that caregivers needed better support and more information to effectively manage rehabilitation care for loved ones [17].

Participants shared their experiences obtaining needed information and stressed the need for better access to quality care, improved coordination, and increased access to expert information. These findings suggest that strengthening communication between clinicians, patients, and their families is critical to improving outcomes in stroke care [18; 19].

Our study also revealed the extent of the disruption to the lives of stroke survivors and their families. Further, it showed the importance of comprehensive and coordinated post-stroke care, including medical treatment, rehabilitation, and long-term support strategies. We found that effective communication and the availability of stroke care information are essential to improving the quality of life of stroke patients, their families, and caregivers.

DISCUSSION

Post-hospital discharge care for stroke survivors and support for a quick return to everyday life is a multifaceted challenge. Practical strategies for improving cooperation and communication between rehabilitation professionals and increasing access to coordinated rehabilitation services for stroke patients are essential. Only this approach ensures that all patients receive the high-quality and comprehensive rehabilitation care crucial for a triumphant return to everyday life.

In their research, Gonçalves-Bradley et al. [20] emphasized the importance of discharge planning and the creation of personalized care plans that (1) take into consideration the needs of the patient and their families, (2) facilitate the transition from hospital to home, followed by (3) coordinated rehabilitation, thus, optimizing the care provided.

In our research, family caregivers identified good communication during the stay on the hospital ward as very important, in part because it showed concern for the patient. Other vital items from the family caregiver's perspective included specialist interventions, treatment and rehabilitation, family support, and prompt discharge home.

However, family caregivers also highlighted several factors during the ward stay that affected them negatively. Creasy et al. [21] pointed out that acute care facilities should assess, prepare, educate, and provide support for family caregivers prior to the inevitable discharge of the patient; these obligations facilitate the transition from acute care to home care. A smooth transition is in the patient's and family's best interest. During our research, it became apparent that, from the perspective of the families, these transition-smoothing elements were lacking. Elements such as information/education on how to transition the patient to home care, easy access to health care and treatment specialists, psychological, financial, and emotional support, and preparation of the home environment so that it was conducive for rehabilitation as well as daily patient care were all found to be lacking.

If we focus on discharge elements, we must consider obstacles and auxiliary factors associated with the patient's stay on the ward. In answering this research question, all participant responses were evaluated to understand better the barriers to smooth discharge and effective patient follow-up. Experts recommended supplementary elements such as more options for accessing quality inpatient and outpatient care, utilizing various long-term rehabilitation options, and the use of compensatory aids. Yan et al. [22] reported that rehabilitation care and therapy are increasingly crucial for post-stroke patient care. This statement is supported by experts who encourage early rehabilitation as an essential factor for early discharge. Research participants emphasized the importance of interprofessional teams. MacKenzie et al. [23] noted that interprofessional teams are recognized as the standard of care for stroke survivors.

The most cited barriers to a smooth discharge include environmental factors, time constraints, staffing constraints (lack of staff, staff turnover), lack of space and equipment, and organizational constraints (i.e., lack of collaboration or complete absence of interprofessional care teams). Hadely et al. [24] described work environment factors as significant barriers to implementing recommended practices for stroke clinical practice. Specifically, work environment factors included a lack of (1) time, (2) treatment resources, and (3) standardized assessments [24]. Munce et al. [25] reported that environmental factors (i.e., time and resources) were rarely cited as facilitators for implementing recommended treatments and interventions; team factors can be used to overcome environmental factor deficits in the absence of multiple organizational resources (i.e., time, collaboration, and information transfer). Hadely et al. [24] concluded that effective teamwork could significantly improve the implementation of clinical recommendations but also impact post-stroke functional gains [26] and length of hospital stay [27].

Based on findings noting the need for improved discharge monitoring, hospitals should develop discharge monitoring programs. Based on barriers identified by practitioners, family members, and patients, consideration should be given to expanding post-discharge transportation options and expanding partnerships with skilled nursing facilities and practitioners to aid with discharge coordination (e.g., providing aids, monitoring, and adherence to long-term rehabilitation plans). Additionally, clinicians can take steps to improve patient discharge and home monitoring relative to identified and modifiable barriers.

As part of daily interprofessional collaboration, a standardized approach to post-discharge referrals and barrier monitoring would allow all stakeholders to

explore and proactively address discharge barriers for each patient. With the increased involvement of professional teams, it becomes easier to determine which patients are medically ready for discharge and assess their post-discharge needs, thereby increasing patient autonomy. Furthermore, interprofessional teams also provide support for GPs, patients/clients, and their families in overcoming transition to home care barriers, which would also support quality improvement initiatives. Meo et al. [28] noted that although barriers to discharge can often be identified on admission, they are still challenging to overcome.

Ultimately, a seamless discharge to the home environment requires significant policy and administrative changes, e.g., the introduction of discharge guidelines, structured long-term rehabilitation plans, and methods for assessing rehabilitation plan adherence.

Another central concern faced by family caregivers is the psychological complexity, emotional stress, and physical difficulty associated with their new role. While factors like family support, familiar home surroundings, and hobbies can help significantly reduce the burden on caregivers, they often still lack sufficient help and awareness of post-discharge services and rehabilitation programs available to stroke survivors and their families. The lack of coordinated discharge leads to inadequate support for patients and their caregivers and highlights the need for more and better information on available services. Communication with GPs after discharge was often found to be insufficient, underscoring the need to strengthen this aspect of post-discharge stroke care.

One challenge in coordinated rehabilitation is ensuring that patients have adequate resources and services after discharge from the hospital. The lack of rehabilitation services, especially in-home services, and the lack of rehabilitation care coordination are significant barriers that must be overcome. Additionally, support for patient families and family caregivers is essential since the patient's family is crucial for motivating the patient to engage in rehabilitation activities. Educating families and providing information on available support services are indispensable for ensuring continuity of care and a positive home environment.

Lack of information about care and support options after hospital discharge can lead to isolation and frustration for patients and their caregivers. Therefore, developing and implementing information and education programs that provide patients and families with essential information and facilitate healthcare system navigation is crucial.

Interprofessional collaboration and coordination between different healthcare providers must be strengthened to ensure comprehensive and continuous monitoring and care of patients after stroke. Improving communication and cooperation within the health system can contribute significantly to the efficiency of the rehabilitation process and ensure better patient outcomes. Coordinated rehabilitation after a stroke is a multifaceted process that not only involves physical recovery but also deals with psychosocial and emotional challenges.

The importance of coordinated rehabilitation is obvious. Nonetheless, full implementation still poses challenges. Chief among them is the lack of comprehensive rehabilitation services, particularly in the home setting, followed by the lack of awareness among patients and their caregivers of available resources and programs. This situation highlights the urgent need to (1) improve rehabilitation care systems, (2) provide more and better information and support to patient families, and (3) ensure continuity of care after discharge from the hospital.

CONCLUSIONS

From the stroke family's perspective, life after a stroke presents significant challenges that require not only physical but also psychosocial and emotional adaptation. Coordinated rehabilitation plays a crucial role in this process, helping stroke survivors and their families cope better with the consequences of the condition and facilitating a rapid return to the highest possible quality of life.

Research has highlighted several key factors essential for patients' families after stroke. One of these is the availability and coordination of rehabilitation services necessary for effective recovery and reintegration of patients into everyday life. Although family support and a familiar home environment are valuable resources, families often face a lack of awareness of rehabilitation and support options after hospital discharge. This lack of coordinated care leads to isolation and frustration for patients and their caregivers.

Improving coordination and communication between healthcare providers, developing multidisciplinary rehabilitation teams, and establishing effective systems to monitor and support patients after hospital discharge are crucial to ensuring comprehensive care that meets the needs of patients and their families. It is essential that the healthcare community recognizes the importance and needs of families caring for patients after stroke and provides them with the necessary information and support.

From the family's perspective, coordinated rehabilitation is not only the basis for physical recovery but also for emotional and social adaptation after a stroke. The development and implementation of comprehensive rehabilitation programs that are accessible, flexible, and adaptable to the individual needs of patients and their families are, therefore, essential to ensure optimal treatment outcomes and maximally improved quality of life after stroke. Families of stroke patients call for more support and enhanced services to enable effective rehabilitation and help them cope with the challenges of life after stroke.

Perspectives of further studies. Our research showed the impact of stroke on both patients and their families. It highlighted the importance of coordinated care and rehabilitation throughout the treatment process – from hospitalization to return home. Respondents identified (1) effective communication and support from healthcare professionals, (2) access to information, and (3) care coordination as areas that need improvement. Home visits by professionals proved to be a valuable resource for families, helping to reduce their burden and facilitate adaptation to the role of caregiver or a family member of a stroke survivor. Our study opens the door for further research and development of strategies to improve the quality of life of people affected by stroke and their families, especially in the context of better care coordination and access to information and services.

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COMPLIANCE WITH ETHICAL REQUIREMENTS

All personal information gathered during this study was processed in compliance with the European Parliament and Council's Regulation EU 2016/679 of 27 April 2016 on the protection of natural persons concerning the processing of personal data and on the free movement of such data (General Data Protection Regulation, GDPR). The research was conducted as part of the GAJU 066/2022/S project, approved by the Ethics Committee No. 6/2022. The study used the basic bioethical norms of the Helsinki Declaration of the World Medical Association on Ethical Principles (amended in 2008), the General Declaration on Bioethics Convention on the Rights of Man, and Biomedicine (1997).

AUTHOR'S CONTRIBUTION TO THE ARTICLE

Lesia Shuranova – conceptualization, investigation, methodology, writing – review & editing, visualization;

Jitka Vacková – supervision, writing – review & editing;

Kvetoslava Rimárová – supervision; writing – review & editing;

Marcela Míková – supervision;

Lenka Motlová– supervision;

Renata Švestková– supervision;

Ingrid Baloun– supervision;

Barbora Faltová– supervision.

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Резюме

ЖИТТЯ ПІСЛЯ ІНСУЛЬТУ ТА КЛЮЧОВА РОЛЬ КООРДИНОВАНОЇ РЕАБІЛІТАЦІЇ З ТОЧКИ ЗОРУ СІМЕЙ, ЯКІ ПЕРЕЖИЛИ ІНСУЛЬТ

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Вступ. Інсульт суттєво впливає на життя людей, які його пережили, вимагаючи адаптації до втрачених можливостей і впливаючи на фізичне, психічне та емоційне благополуччя. Інсульт є основною причиною набутої інвалідності у дорослих і значним фактором смертності, особливо серед людей похилого віку та в країнах з низьким рівнем доходу. Інсульт описується як неврологічний дефіцит, спричинений гострим пошкодженням центральної нервової системи.

Мета. Основна мета дослідження полягала у вивченні застосування координованої реабілітації після інсульту до, під час та після виписки з лікарні. Було вивчено компоненти координованої реабілітації з акцентом на потребах сім'ї клієнта. Це дослідження було проведено в рамках проєкту GAJU 066/2022/S і схвалено етичним комітетом 6/2022.

Матеріали та методи. У цьому дослідженні використовувався якісний дослідницький підхід та напівструктуровані інтерв'ю з членами сімей, які доглядають за пацієнтами з інсультом. Зібрані дані були проаналізовані з використанням різних стратегій кодування за допомогою програмного забезпечення ATLAS.ti. Ця сувора методологія забезпечила надійність і достовірність результатів дослідження.

Результати. Наслідки інсульту є глибокими не лише для пацієнтів, але й для їхніх родин та осіб, які за ними доглядають. Адаптація до життя після інсульту вимагає значних змін у сімейній динаміці, цінностях і нормах. Важливість ефективної комунікації та підтримки з боку медичного персоналу під час госпіталізації пацієнта важко переоцінити. Інтерв'юйовані підкреслили роль якісного догляду та комунікації у забезпеченні позитивного перебування в лікарні. Однак вони також вказали на певні недоліки, такі як запізніла діагностика інсульту та недостатня інформація про догляд та реабілітацію після виписки. Дослідження підкреслило важливість реабілітації вдома у звичному середовищі для функціонального покращення.

Висновки. Життя після інсульту є значним викликом для пацієнтів та їхніх родин, що вимагає фізичної, психосоціальної та емоційної адаптації. Скоординована реабілітація полегшує постінсультну адаптацію пацієнтів та їхніх родин і підвищує загальну якість життя. Покращена координація та комунікація між медичними працівниками, створення мультидисциплінарних реабілітаційних команд, а також ефективні системи моніторингу та підтримки після виписки є важливими для надання комплексної допомоги, адаптованої до потреб пацієнтів та їхніх родин. Члени сімей пацієнтів, які перенесли інсульт, виступають за посилення підтримки та послуг для кращої реабілітації та подолання постінсультних викликів.

Ключові слова: **інсульт, координована реабілітація, сім'я, охорона здоров'я, комунікація**