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A Review of the Social Participation of Stroke Survivors

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ABSTRACT

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Stroke is a global disease, significantly affecting patients' physical health and quality of life. One of the most prominent impacts is the social participation barrier. Social participation levels are considered a crucial factor influencing patients' quality of life. The social participation of stroke patients is affected by many factors, and the level is not ideal. Currently, there is no unified definition of social participation. A commonly accepted concept is the desire of stroke patients to participate in activities within the social environment, taking on certain social roles to meet personal needs and achieve individual value. There is a diversity of assessment tools available. Among them, the most widely used is the Stroke Impact Scale, followed by the French Activities Index and the Impact on Participation and Autonomy. Social participation plays an important role in influencing patients' physical and mental health and quality of life. At present, the relevant research on social participation is not in-depth and should be paid more attention to. The purpose of this study is to conduct a review of the concept, assessment tools, current status of social participation, and influencing factors of social participation. This review aims to provide a reference for conducting further research on social participation among stroke patients.

Keywords: Assessment Tools; Influencing Factor; Research Progress; Social Participation; Stroke

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Background

Stroke is a serious cerebrovascular accident characterised by high morbidity, disability, and mortality, which seriously impacts the health and quality of life and brings a heavy economic burden to families and countries (Yi *et al*., 2020). Because of concerns about stroke in recent years, the global stroke mortality rate has decreased. However, many survivors still suffer severe physical damage from stroke, which affects families and society as a whole. A study showed (Alaszewski *et al*., 2007) that 40 percent of stroke survivors are left with moderate disabilities and 15 to 30 percent are left with severe disabilities such as motor dysfunction, dysphagia, and affective disorders. One of the most prominent effects is barriers to social participation (Bergström *et al*., 2017). Social participation ability is considered to be an important indicator of stroke rehabilitation. Stroke rehabilitation has undergone a paradigm shift in recent years, with social engagement becoming the central focus and primary outcome measure. Studies have confirmed that stroke survivors have varying degrees of challenges in social participation, with more than half of stroke survivors having social participation restrictions 1 year after the onset of stroke (Nowotny *et al*., 2004), and even mild cases without limb dysfunction can encounter obstacles due to physical and psychological factors. To improve the rehabilitation of stroke patients has always been a common goal of rehabilitation clinicians (Hashidate *et al*., 2021).

Social participation in stroke has received attention from scholars around the world, but the research on social participation in stroke is not deep enough; for example, the concept of social participation is not clear, which leads to the inconsistency of the assessment tools for social participation, and there is no targeted measurement tool at present. There are many influencing factors of social participation, and the mechanism of interaction between the influencing factors is complex and unclear. This study makes a review of the above problems.

The purpose of this review is to understand the relevance of social participation in stroke. The topics included: The concept and current situation of social participation in stroke; Influencing factors of social participation in stroke; Measures of social participation in stroke.

Literature Review

In the 1940s, foreign scholars put forward the concept of ‘participation’, and at that time, scholars mainly researched social participation from the perspective of psychology. In the 1950s, the scope of research on social participation began to expand, covering the fields of sociology, medicine, public health, gerontology, and so on, and has been deepened in the above-mentioned fields. In the 1990s, the concept of social participation was widely used in the field of rehabilitation, and there was an ideological shift in the treatment of people with disabilities as a social creation rather than an individual attribute (Levasseur *et al*., 2022). The World Health Organisation (WHO) updated the International Classification of Functioning, Disability, and Health (ICF), and social participation was formally recognised as an important evaluation indicator of an individual's rehabilitation outcome (Morone & Pichiorri, 2023). The ICF stresses the importance of evaluating the effectiveness of a person's rehabilitation at the physiological, psychological, and social levels rather than focusing on the individual's physiological functioning or psychological state alone, defining participation as "a person's ability to participate in life situations" (Ueda & Okawa, 2003). In subsequent research, some scholars have questioned the concept of participating in ICF, arguing that it is vaguely defined and does not specify what it means to participate in a certain life situation (Whiteneck & Dijkers, 2009). In addition, the ICF concept of participation ignores an important factor, namely the subjective experience of individuals in the process of participation (Ueda & Okawa, 2003). Therefore, scholars from various countries have carried out further research and exploration of the concept of "participation." American scholars such as Hammel *et al*., using qualitative research and rhizomatic theory, have argued that participation includes not only integration into life situations but also personal meaning and subjective satisfaction of integration into life situations (Hammel *et al*., 2008). According to the American Occupational Therapy Association, social engagement is an activity that takes place between patients and their relatives, friends, community, and peers and occurs naturally when patients actively participate and engage in activities of daily living that they find meaningful. Using meta-ethnographic research methods and integrative qualitative research in the context of British culture, British scholars Woodman *et al*., argue that social participation is a complex and dynamic process in which patients continually assess and screen the activities they participate in, identify barriers, build confidence, and ultimately realise their self-worth by overcoming barriers through participation in meaningful activities (Woodman *et al*., 2014). Zhou Xuan *et al*. constructed a model of independence, influence, and interaction of social participation in stroke hemiplegic patients through qualitative interviews with 12 stroke hemiplegic patients, and the study pointed out the attributes of social participation from the patient's perspective: autonomy and sense of self-worth (Zhou X & Zhou L S, 2019). He Yannan *et al*., defined participation as the behavioural process of an individual's integration into the life situation and the subjective experience of this behavioural process, which is the result of the interaction between an individual and the environment. They emphasised that social participation is integration into the environment, and attention is paid to the subjective feelings of the participants. Häggström, A. & Lund, M. (2008). Explored the experiences and descriptions of social participation in people with acquired brain injury through content analysis and found that social participation implies four dimensions of satisfaction: completing tasks, making decisions and exercising influence, engaging in worthwhile activities, helping others, and sense of belonging (Häggström & Lund, 2008). Another study explored the implications of social participation from the perspective of persons with disabilities and found that actively participating and being part of it, exercising choice and control, seizing or giving up opportunities, assuming personal and social responsibility, influencing or supporting others, connecting with the community, and feeling a sense of belonging were the main connotations (Hammel *et al*., 2008).

Methods

A systematic literature review was conducted to meet the study's objectives. All included studies were original articles. This review focuses on the social participation of stroke survivors. Therefore, all the included studies were studies that explored the idea of social involvement in stroke. Inclusion criteria: The subjects were stroke patients, or the subjects contained relevant information about stroke patients and could be extracted separately; The main contents of the literature include the concept, measurement tools, and influencing factors of social participation in stroke; Research types include cross-sectional study, longitudinal study, cohort study, case-control study, mixed study, etc. Exclusion criteria: The type of study was interventional; Review and conference abstracts; repeated publications; Full text and incomplete information cannot be obtained.

Results & Discussion

Status of Social Participation in Stroke

Current research suggests that the status of social participation during the rehabilitation process is not encouraging (De Graaf *et al*., 2022). Many studies have shown that the majority of stroke patients have low levels of social participation after discharge from the hospital and that even in the absence of physical and psychological barriers, the level of social participation may be reduced to varying degrees (Hagger *et al*., 2017). Researchers have described the process of social engagement and transformation in stroke patients centred on the "hard return" and have shown that the outcomes of social engagement in stroke patients are not satisfactory (Zhou *et al*., 2020). A study showed that stroke patients had different levels of social participation at different time intervals. The social participation at 6 months and 12 months was medium-high, and at 18 months it was medium-low, and middle-aged and young stroke patients had low social participation. Community-based stroke patients have poor levels of social participation, with only 11 percent of patients fully satisfied with their level of social participation. A study showed that stroke patients had difficulties reintegrating into society and had decreased social participation (Chau *et al*. 2009). It has been shown that the level of social participation in stroke patients does not return to pre-stroke levels, and most patients are chronically inactive (Mountain *et al*., 2020). Lower levels of social participation are associated with the influence of a variety of factors, such as level of functioning and depressive and motor deficits (Xiao *et al*., 2021). It has been noted that the ability to participate is related to the patient's age, family income, education, environment, and other factors (Faria-Fortini *et al*., 2018).

Factors Influencing Social Participation in Stroke

The ICF provides a standardised framework for describing a patient's health status and its associated influencing factors. In ICF, influencing factors of social participation are divided into two parts (Fernández-López *et al*., 2009); one is body structure and function, activity and participation, and the other is environmental and personal factors. Participation is considered to be the result of the combined action of the above two parts. Individual factors include socio-demographic factors, intrinsic abilities and behaviours, and psychosocial aspects. Environmental factors are related to the physical, social, and attitudinal environment in which people live. Based on the literature review, the prerequisites for social participation in stroke patients are summarised below.

Demographic Factors

Demographic factors include age, gender, economic status, education level, etc. The younger of patients, the better the economic conditions, the higher the education level, and the higher the level of social participation (Tse *et al*., 2017). The more educated the patient is, the more likely he or she is to actively seek social support, enhance the management of his or her disease, and improve functional impairment, thereby improving social participation and integrating into society as soon as possible. Some studies have found that patient's marital status, type of carer, mode of payment for healthcare, ability to perform activities of daily life, neurological deficits, and the presence or absence of comorbid chronic conditions are influential factors in patients’ social participation.

Physiological Factors

Stroke patients are left with a certain degree of neurological impairment, and these sequelae and complications have a certain impact on their level of social participation (Faria-Fortini *et al*., 2018). Some studies found that factors affecting the social participation of stroke patients are not only related to the individual and the community but also related to the patient's physical disability and mental disability, and different levels of functional impairment all seriously affect patients' willingness to participate in society. The lower limb impairment and neurological deficits in stroke survivors, the less impact on patients' mobility and functional independence, and the higher their level of social participation (Ezekiel *et al*., 2019). Therefore, to improve the level of social participation of patients, we should pay attention to the change in functional independence of patients and reduce the degree of dysfunction as early as possible through active rehabilitation exercises.

Psychological Factors

Post-stroke physical and speech disorders cause patients‘self-image to change, and a positive psychological state can improve the quality and frequency of patients’ social interactions, thus effectively avoiding self-isolation and social alienation (Della Vecchia *et al*., 2021). Hinojosa *et al*., showed that up to 33% of stroke patients experience negative emotions such as anxiety and depression after the onset of the disease, leading to reduced confidence and enthusiasm for social participation (Hinojosa *et al*., 2011). A good mood can improve patient’s quality of life and willingness to participate in society, so we should pay attention to patients’ negative emotions, provide timely comfort, assist patients in reducing the adverse effects of negative emotions on physical and mental health, and encourage patients to go out and have contact with the community to divert their attention and increase their willingness and ability to participate in society. The lives of the patients after stroke have been turned upside down; if they can take effective and positive ways to cope with negative emotions such as anxiety, fear, and depression, they can overcome them very well.

Environmental Factors

The environment refers to the sum of physical, social and attitudinal environments perceived by patients at different stages of their lives when they return to their communities (including their families, workplaces, leisure and places of worship, etc.) after receiving treatment in medical institutions, and can be divided into tangible physical environments and intangible humanistic environments. The physical environment includes air temperature and humidity, light, road conditions, provision of barrier-free facilities, access to information and technology, etc., such as employment security services, government budgets, and insurance for rehabilitation treatment, etc. Matching these facilities with the needs of the patients will facilitate their outings and thus promote participation. The human environment includes people's communication environment and people's overall values and attitudes towards the participation of stroke patients in various activities, such as the presence of discrimination, positive communication in the family support system, and the avoidance of overprotection, which can indirectly affect patients' participation in social activities (Hinojosa *et al*., 2011). A quiet and friendly environment can provide physical and emotional support and create opportunities to facilitate the participation of stroke patients in social activities. Most studies have shown that environmental factors have a significant impact on functional recovery and social participation of stroke patients at home, and the impact of environmental factors on stroke survivors varies slightly by country and region (urban, rural).

Assessment Tools for Social Participation of Stroke Patients

Social participation as the ultimate indicator of stroke rehabilitation outcomes has received attention from scholars in various countries (Woodman *et al*., 2014). Therefore, it is important to select appropriate and accurate tools to assess the level of social participation of stroke survivors. At present, the study about social participation has gradually received attention from the rehabilitation medicine community at home and abroad. In recent years, scholars have paid attention to the compilation and development of scales that can be used to clinically assess patients' ability to participate, among which the Stroke Impact Scale (SIS), the Involvement and Autonomy Inventory (IPA), the London Handicap Scale (LHS), and the Life Habits Evaluation Scale (LHES) have been used more frequently.

The Stroke Impact Scale (SIS) includes 59 items across eight dimensions: strength, hand function, ADL (activities of daily living), mobility, communication, emotion, memory and cognition, participation, and a stroke recovery rating (Wang *et al*., 2022). The Impact on Participation and Autonomy (IPA) scale, created by Cardol *et al*. (1999), assesses autonomy in daily life through 25 items across four dimensions: indoor activities, family roles, outdoor activities, and social life. It uses a 5-point Likert scale (0-4), with higher scores reflecting more restricted participation. The French Activity Index (FAI) is a self-reported questionnaire that evaluates four aspects of daily activities—household chores, leisure, work, and outdoor activities—across 15 items rated on a 1-4 scale; higher scores indicate greater activity levels. The London Barrier Scale, developed within the ICF framework, consists of six items rated on a 1-6 scale, where higher scores suggest fewer barriers to participation (Kossi *et al*., 2020). The Life Habits Assessment (Life-H), a more comprehensive tool, includes 77 items within 12 categories to cover diverse aspects of life participation (Lee *et al*., 2023). The Rating of Perceived Participation (ROPP) consists of 22 items across nine dimensions, each scored from 0 to 4, where higher scores reflect greater limitations in social participation (Sandström & Lundin-Olsson, 2007). Lastly, the Community Participation Index (CPI) evaluates participation based on the ICF's concept of "autonomy," considering both engagement and empowerment in activities (Kersey *et al*., 2022).

Conclusion

In summary, scholars from different cultural backgrounds have used different methods to explain and improve the concept of social participation. Researchers generally believe that social participation is a kind of social behaviour that interacts with others in the society or community, including the meaning of personal life integrated into the life situation, subjective satisfaction and subjective feelings of patients. At present, the level of social participation of stroke patients has been reduced to varying degrees, and the level of social participation of stroke survivors is different at different time intervals after the onset of stroke, and the level of social participation of patients with different onset ages is different. There are many factors affecting social participation, including population sociology, physiological factors, psychological factors, and environmental factors. There is currently no uniform measurement of social engagement. Among all measurement tools, SIS is the most widely used, followed by FAI and IPA.

Declarations

Ethics Approval and Consent to Participate: Not applicable

Conflicts of Interest: There is no conflict of interest in the author's byline.

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