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Original Research

Understanding Social Participation in Post-stroke Patients: A Phenomenological Study

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ABSTRACT

Background: *Stroke is a leading cause of long-term disability worldwide. Post-stroke patients experience various physical and mental problems. This has a significant impact on the patient's life, affecting their ability to perform daily activities and participate in community social activities. As many as 50% of post-stroke patients still experience problems with social participation. The purpose of this study was to investigate the social participation of patients after experiencing a stroke.*

Methods: *This research is qualitative research with a phenomenological approach conducted at RSUD by Dr. Soedono Madiun. Data collection was carried out through interviews and documentation of 6 patients who had a stroke for at least 4 months which were included in the purposive sampling criteria.*

Results: *From the thematic analysis that has been carried out, there are three themes regarding the social participation of post-stroke patients: (1) social participation of post-stroke patients, consisting of continuity in social activities, decreased activity, and socialization limitation; (2) social participation barriers, consisting of internal factors and external factors; and (3) coping strategies, consisting of physical recovery, staying connected, and social support.*

Conclusion: *Post-stroke patients experience changes in social participation; they find it difficult to get involved in various social activities due to various barriers within themselves and their environment. Recommendations for future research are to consider variables that exist as a consideration of research results, such as environmental conditions, stroke severity, gender, and so on.*

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INTRODUCTION

Acute, focal neurological impairment caused by vascular injury (infarction hemorrhage) of the central nervous system is known as a stroke. Globally, stroke ranks as the second most common cause of death and disability. Numerous risk factors, disease processes, and mechanisms can contribute to stroke, which is not a single

disease. Although its impact varies depending on the subtype, hypertension is the most significant modifiable risk factor for stroke (Murphy & Werring, 2020).

Stroke is a health problem for both industrialized and developing countries, including Indonesia (Prasetyaningsih & Kurniawan, 2021). According to findings from Basic Health Research, the prevalence of stroke in Indonesia has reached 10.9% percentile, compared to the stroke incidence rate of 7.0% percentile in 2013, while the number of stroke patients in East Java Province reached 21.120 people or around 12.4% of the total population. The province ranks 8th in Indonesia in terms of the number of stroke cases (Kementrian Kesehatan Republik Indonesia, 2018).

Post-stroke, many patients experience several functional impairments that will require a period of rehabilitation. Stroke survivors frequently have poor quality of life (QoL), emotional suffering in the form of depressive symptoms and perceived stress, and functional disability in various domains (Fong et al., 2022). These disorders will hinder their ability to perform daily activities and social participation in the community (van der Veen et al., 2022).

Post-stroke patients often have to relearn how to interact with their surroundings and cope with various kinds of impairments resulting from the stroke itself (van der Veen et al., 2022). As many as 50% of post-stroke patients still experience participation problems after 4 months out of inpatient recovery. The level of social activity is reported to decrease in patients after 1 year of having a stroke, the level that is considered stable is above 3 years after having a stroke. Among stroke survivors, changes in life satisfaction throughout time have been documented.

One year after their stroke, 54% of stroke survivors reported feeling unsatisfied with their lives overall (Abualait et al., 2021). Based on the phenomena that occur in the background above, researchers are interested in exploring the social participation of post-stroke patents at RSUD Dr. Soedono Madiun. The purpose of this study is to find out more about how the social participation of patients after experiencing a stroke.

MATERIALS AND METHOD

This research uses qualitative research with a phenomenological approach or strategy. This research uses primary data sources, namely post-stroke patients at RSUD Dr. Soedono Madiun, data collection was carried out in August-September 2023. Informants were selected using a purposive sampling technique. In this study, the informants taken by researchers were six people with the following inclusion criteria: (1) patients suffered a stroke for at least 4 months; (2) able to speak and communicate in two directions; (3) do not have severe cognitive impairment expressed by MMSE and; (4) at least 20 years old.

This study used data collection techniques through semi-structured interviews and documentation with a voice recorder and notebook. The interviews in this study were conducted by a female researcher with an educational background in Occupational Therapy. Before the interview process, to test the validity and reliability of the interview guidelines, an initial interview trial was conducted with one informant who had characteristics according to the sample criteria which aimed to evaluate the clarity of the questions, the relevance to the research focus, and to ensure that interview guidelines were able to extract information by the research objectives.

The results of this pilot test served as the basis for adjusting and refining the interview guidelines before they were fully utilized. Next, the interviews were conducted using a semi-structured approach, which allowed for additional questions to

be developed during the process, depending on the informant's responses. The interview guide contained 16 questions on social participation. Interviews were conducted face-to-face in the medical rehabilitation room of RSUD Dr. Soedono and lasted between 30 to 40 minutes.

The interview was conducted after the informant had completed an occupational therapy session. The choice of time and place aimed to create a comfortable atmosphere for participants, while ensuring that their physical condition allowed them to participate in the interview optimally. Data saturation was reached when no new information or significant data variations were found from the interviews.

Credibility in this study used source triangulation through Focus Group Discussion (FGD) together with family members of informants as well as technical triangulation, namely in-depth interviews and documentation. The results of the research data were analyzed using thematic analysis with stages including open coding, axial coding, and selective coding which will produce themes and sub-themes. The steps of thematic analysis are as follows: (1) Managing and preparing data for analysis; (2) Reading the data thoroughly, the researcher must read all the data collected so that it can be known what data has been obtained if the researcher already understands all the data, then the selection/reduction of which data is important and related to the research question is carried out; (3) Making coding, researchers give a sign to the data that been classified, researchers give the same code to similar data, from this code results in categorization or new themes; (4) Using coding for material to make descriptions, after coding and producing themes, then researchers make descriptions briefly and arranged so that the themes they get become clearer, (5) Connecting themes; (6) Describing and interpreting themes and; (7) Compiling a narrative report. The translation process is carried out with a forward translation approach, after which back-translation is carried out.

Data validity includes: (1) Objectivity, researchers maintain emotional distance from the data, to maintain objectivity is to quote data directly as evidence of analysis; (2) Dependability, which is to make notes on each research process and be neatly maintained; (3) Credibility, researchers also interviewed family members of post-stroke patients regarding how the patient’s social participation and; (4) Tranferability, by making an in-depth description of the setting. The research was conducted after obtaining ethical clearance with number 1.420/VII/HERC/2023 from The Health Research Ethics Commitee Dr Moewardi Hospital.

RESULTS

The study was conducted at RSUD dr. Soedono Madiun, East Java Province. The informant data can be seen in table 1 as follows:

Table 1. Research Informant Data

Informant	Age	Occupation	Status	Last Education
Mr. E	69 years old	Lecturer	Married	Doctoral
Mr. R	75 years old	Retired Nurses	Married	Diploma 1
Mr. S	58 years old	Security Guard	Married	High School
Mr. K	47 years old	Vegetable Trader	Married	Elementary School
Mr. D	56 years old	Civil Servant	Married	High School
Mrs. A	43 years old	Housewife	Married	Junior High School

Based on the results of the thematic data analysis that has been carried out, three themes were obtained related to the exploration of social participation of post-stroke patients at RSUD Dr. Soedono Madiun. The data regarding the themes can be seen in Table 2 as follows:

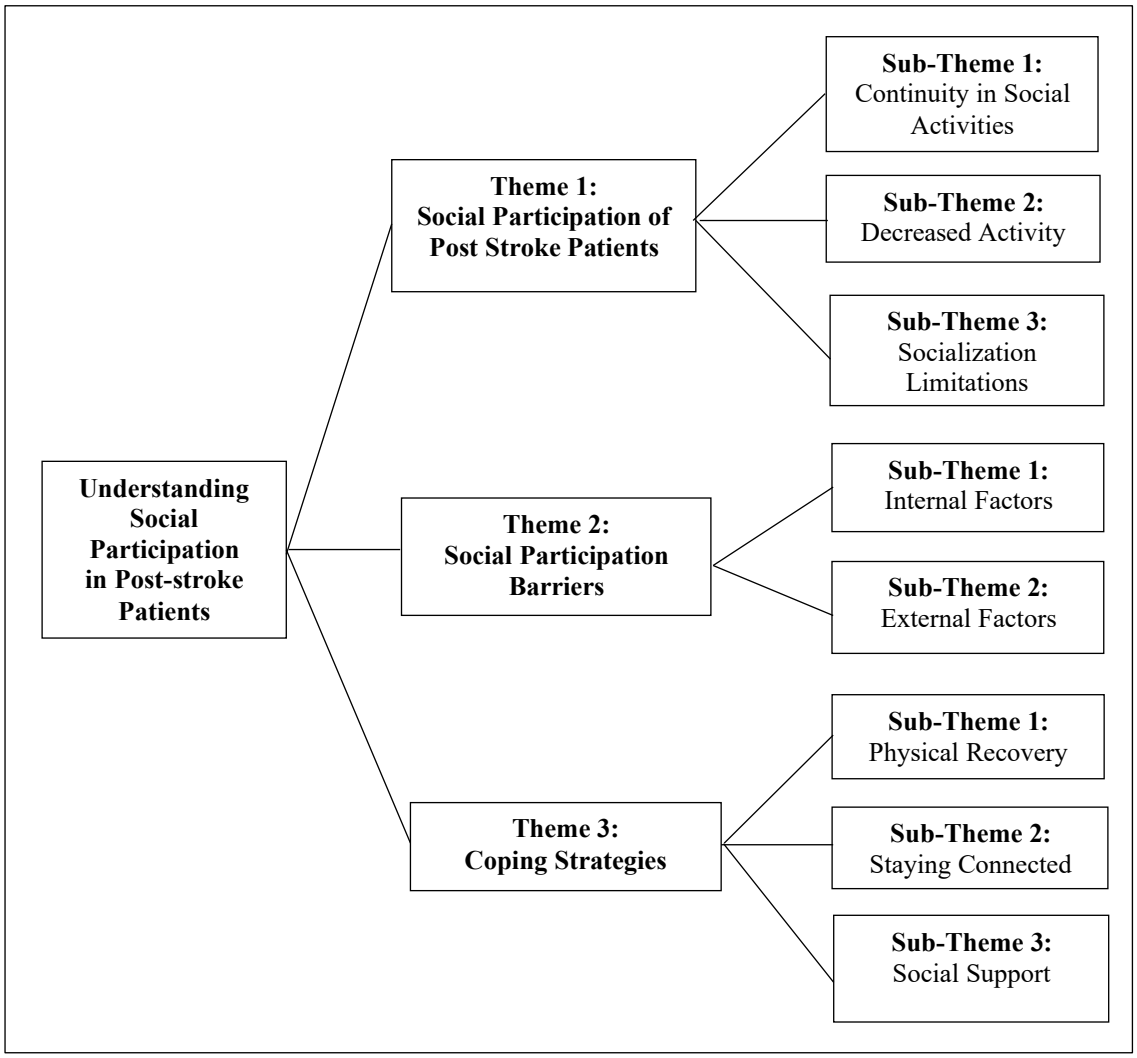

Figure 1. Theme and Sub-Theme

Theme 1. Social Participation of Post-Stroke Patients

The first theme, social participation of post-stroke patients, resulted in three sub-themes, namely continuity in social activities, decreased activity, and socialization limitations. On sub-theme one, continuity in social activities, after a stroke, patients experience limitations in daily activities and social activities. However, from the findings, it is not entirely true that patients limit themselves or carry out social isolation. This statement is reinforced by the expression of two informants as follows:

> *"...yes teaching, still teaching, making power points...yesterday dangdut 17an (Indonesia's Independence Day festivities) I also came, I also attended yesterday's neighborhood recitation (a Qur'an reading gathering) ..." (I1)*
> *"...yeah, we still come to the RT arisan (a rotating savings group) even now..." (I5)*

On sub-themes two, decreased activity. Post-stroke patients have difficulty working and enjoying their usual hobbies in their spare time, due to changes in their physical condition that make them easily experience fatigue. This statement is supported by the informant's expression as follows:

"Now I can't work, I can't sew because of the condition of my hand and legs..." (I6)
"...that's why I can't go fishing; I used to love fishing. Now I don't, I used to do it often, every day..." (I3)

On sub-themes three, socialization limitations. Stroke patients experience changes in friendship relationships. This statement is in line with the expressions of several informants as follows:

"...if there is an event on Sunday, we usually cook together, but I'm sick and can't get together..." (I6),
*"...*communication *using cellphones sometimes WhatsApp, video call, if chat can but less..." (I4)*

Theme 2. Social Participation Barriers

The second theme, social participation barriers, resulted in two sub-themes, namely internal factors and external factors. The first sub-themes are internal factors. After experiencing a stroke, informants said that their physical abilities became different, namely decreased endurance, slurred speech, weakness in the feet and hands, poor balance and posture. As expressed by the informants as follows:

"...what inhibits this is because of physical, physical limitations, not like usual, like hands, legs..., speech too, legs too... if I walk, I can go here and there, my hands can't hold these..." (I3)
"...my legs, thank God, are fine, but sometimes they're a bit heavy. It's only the hand that's heavy, but it's starting to be able to be moved but still 5%..." (I6)

In addition to physical canges, after experiencing a stroke some informants experienced emotional and behavioral changes that caused their social participation to be hampered. As expressed by the informants as follows:

"...very sensitive back, can be an obstacle in social participation..." (I3)
"...I'm embarrassed that I can't shake hands if I use my left hand, I'm embarrassed..." (I6)

The second sub-themes are external factors. Environmental conditions are the main external factors that hinder informants in carrying out social participation. They said that uneven road conditions, inaccessibility, and long distances made it difficult for informants to mobilize to carry out social participation in the community. This statement is supported by the expressions of several informants as follows:

"...the distance between my house and the activity is far, I can't attend because I'm tired...if I walk far, I don't have the energy, if it's close, I'll come." (I5)
"...if it's hot, in the past, when I was healthy, I could do it, but now it's difficult...I'm afraid at night, I'm afraid I'll fall." (I6)

Economic issues are included in external factors. Some informants have different economic backgrounds. Economic problems are also an obstacle when they want to participate in social activities that require them to spend funds, as expressed by the informants as follows:

"...because they are married, the obstacle is economic." (I4)
"...if there is a group event, you can contribute to the funding problem, because the economy is not good... if a neighbor is sick, there is a joint visit, I used to be able to give but now I can't." (I6)

Theme 3. Coping Strategies

The third theme, coping strategies, resulted in three sub-themes, namely physical recovery, staying connected, and social support. One sub-themes one, coping strategies. Maintaining a healthy body is also a strategy to re-engage in social participation. In addition to receiving rehabilitation interventions, patients continue to practice to improve their condition independently, for example through physical activity in daily activities at home. This statement is reinforced by the expression of two informants as follows:

"Waking up... morning exercise itself is straightened...exercise like that. Then the exercise is watering the plants, walking around in the yard." (I2)
"...my initiative. That's...what is the hoist-like exercise that I do myself... after returning from the hospital, I exercise, the exercise is a walk of about 500 meters." (I5)

Staying connected is a part of coping strategies. This strategy that patients use to increase social participation is to try to connect or maintain social interaction, which is often done by visiting friends' or neighbors' homes that are close or easy to reach, as well as communicating via messages and telephone using a mobile phone. As expressed by several informants as follows:

"...I'm still trying to deal with it, I'm still communicating. Use mobile phone, call, WA (whatsapp)... still good." (I3)
"...via cellphone, I can still use my left hand...it's for friends who are far away." (I5)

Next, what is included in the coping strategies is obtaining social support from family and friends. Having limitations after experiencing a stroke makes informants feel lonely, or hopeless. Informants use the support of family, and friends to get the spirit back involved in social participation. This statement was expressed by several informants as follows:

"...my friends are very supportive, so they make fun of me, so I'm encouraged." (I1),
"...family support is sometimes there are those who visit, relatives too... who take the family, my wife also actually doesn't have a need, so she takes me to therapy." (I2)
"...family support... keep your spirits up, get well soon." (I4)

DISCUSSION

Social Participation of Post-Stroke Patients

One sub-themes one, continuity in social activities, after a stroke. Some stroke patients successfully re-engage in social and leisure activities, individual differences can

be partly explained by several factors such as age, previous participation, perception of recovery, mobility, and social networks (Norlander et al., 2022). Such continuity is also achieved by increasing independence and ability, as well as the relationship with others (Darmadi et al., 2023).

The theory is in line with the researcher's findings that some post-stroke patients experience continuity with decline, where their overall activity level decreases, but they still participate in their usual social activities. On sub-themes two, decreased activity. The effects of stroke are loss of independence in social activities and experiencing barriers to participating in leisure such as making crafts and doing hobbies.

Lower energy levels are reported to be a barrier for stroke survivors, particularly for those of a younger age, impacting activity participation (Harrison et al., 2022). On sub-themes three, socialization limitations. One of the reasons patients only interact with friends in the neighborhood is the loss of social activities they used to participate in. Angeleri in Tiwari et al. (2021) says that a reduction in social activity is common after a stroke.

Social Participation Barriers

The first sub-themes are internal factors. These results are in line with research conducted by Trevorrow et al. (2024) if post-stroke patients experience physical barriers to participation, in particular, patients often report the impact of decreased function in the hands and feet, as well as increased fatigue, which significantly affects their ability to engage in the patient's social activities. Behavioral changes are shown by the embarrassment that makes them withdraw from social activities.

Many patients are uncomfortable with their disability and feel embarrassed or do not want to burden friends, or family with their post-stroke condition (Chleboun et al., 2021). These emotional changes can make it difficult for post-stroke patients to engage in social participation. The second sub-themes are external factors. Research conducted by Mohotlhoane and Nemakanga (2023) that cobblestone streets, slopes, and uneven roads near the house prevents post-stroke patients from going out and enjoying outside activities.

Nighttime is also an obstacle for patients, inadequate lighting is a risk factor for falls which ultimately makes patients not go out to participate socially and choose to stay at home (Thölking et al., 2020). Losing the ability to work after a stroke has an impact on the economic condition of the patient's family. This is in line with research that financial costs for participation activities are another issue that limits most stroke patients (Mohotlhoane & Nemakanga, 2023).

Coping Strategies

One sub-themes one, coping strategies. In addition to physical activity, patients also do their exercises or sports at home to be able to improve mobility, balance, fatigue, and endurance after a stroke, which aims to regain independence (van Dongen et al., 2021). Staying connected is a part of coping strategies. This is in line with the results of research by Gustavsson et al. (2018), that many post-stroke patients spend their time at home because they are unable to work and the disability makes it difficult for patients to meet people outside the home.

Mobile phones and computers replace face-to-face interactions and create the possibility for patients to stay connected with others. Social support from family and friends. Emotional support in the form of affection, attention, feeling valued, and self-

confidence helps patients regain the spirit to be healthy and continue their lives. Patients receive emotional support in the form of words of encouragement, advice, and motivation from family and friends (Zaini, 2022).

From the discussion above, it can be concluded that there are changes in the social participation of post-stroke patients, patients experience barriers to social participation but they have coping strategies to overcome problems. The implications of this study can be used as a consideration for occupational therapists in developing interventions to involve the social participation of stroke patients. This study has limitations; variables may affect the results of the study but are not used in data processing, these variables include environmental conditions where informants live, gender, stroke severity, and socio-economic background. Methodologically, time constraints during interviews impacted the quality of interviews, and a recommendation is expected to consider the times of conducting interviews.

CONCLUSION

Post-stroke patients experience continuity and a decline in engagement in social participation. The decline occurs due to internal and external barriers to social participation. To overcome these obstacles, post-stroke patients have coping strategies, namely by restoring physical conditions through medical rehabilitation interventions, maintaining social interactions through cell phones, and getting social support from other stroke patients, friends, and family. Suggestions for future research are to consider variables that exist as a consideration of research results, such as environmental conditions, stroke severity, gender, and so on.

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