Perception of self-care ability among patients with stroke post-discharge: A qualitative descriptive study in Iran

Original Research

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ABSTRACT

Background: Patients with stroke, once at home, experience different perceptions of their ability for self-care. The purpose of this qualitative descriptive study was to elucidate patients' perception of their self-care ability. Methods: Semi-structured interviews were held with 10 patients with stroke, within one month following discharge from hospital. Sampling was purposeful and continued until data saturation was reached. All recorded interviews were transcribed and imported to MAXQDA software. The transcripts were content analyzed, following the five-step method by Granheim and Lundman. Results: Three main categories and ten subcategories were revealed: immersion in distress (feeling of sorrow and sadness, lack of control of life, feeling of anxiety and worry), perceived difficulty (dependency on others, disabling nature of the disease, multiple underlying diseases and mental health problems) and compatible adaptive reaction (acceptance of disability, improving health literacy, enhancement of spiritual health). Conclusions: Patients with stroke reported limited ability for self-care post-discharge, which had a considerable effect on their engagement in self-care behaviors and application of recommended treatment methods at home. The findings have implications for designing nurse-led interventions to promote self-care in this vulnerable patient population.

KEYWORDS

Ability, Perception, Post-discharge, Qualitative Descriptive Study, Self-Care, Stroke

BACKGROUND

Investigating and understanding self-care ability is extremely important for evaluating the capacity of patients with stroke to participate in the activities to manage their recovery in the period following discharge and through their transition from acute conditions (Sidani & Doran, 2014). Stroke is a chronic condition induced by cerebrovascular incidents, which can cause some permanent damage in cognition, perception, movement, and/or emotional deficiencies. This damage is often associated with

limitations in physical, psychological and social functions. Accordingly, patients with stroke require full support to be able to function and take care of themselves (Brown et al., 2013; Hoyle et al., 2012; Silva Júnior et al., 2020).

Every year, almost 16 million people around the world have a stroke; of these, five million persons experience functional limitations. Two-thirds of stroke patients experience another stroke within five

years of the first stroke (Tornbom et al., 2017). The sudden experience of a stroke and associated functional limitations is overwhelming and influences patient's perceived self-care ability. This in turn increases complexity of the patient's situation, in particular in the presence of concurrent health problems and of mental, emotional and social consequences. The consequences can further negatively impact patient's self-care ability (Kristensen et al., 2017). Perception and cognition are other personal factors influencing perceived self-care ability in patients with stroke (Casey et al., 2008; Jones & Riazi, 2011).

The World Health Organization has identified social, political, and cultural changes at the global, national, and regional levels as affecting the health of the population (Riegel et al., 2017). Challenges such as the global financial crisis, epidemiological transition from communicable to non-communicable diseases, increased inequality and cost of healthcare among countries threaten the health of a large proportion of the population in Asia (World Health Organization, 2009). Support for self-care following a stroke can result in improvement of daily activities performance and reduces the risk of dependency and death in patients suffering from stroke (Riegel et al., 2017).

Nurses need to understand the various social, political, economic, and individual factors so that they can identify those that affect a patient's self-care ability (Brucker, 2018; Wilkinson & Whitehead, 2009). Understanding how the factors contribute to self-care can provide an essential foundation for designing more effective rehabilitation intervention programs and self-management interventions for patients with stroke. Considering the limited information available regarding perceived self-care ability in patients with stroke following hospital discharge in Iran (Jafari-Golestan et al., 2019), this qualitative descriptive research was designed to elucidate patients' perceptions of their self-care.

METHOD

This qualitative descriptive study involved semistructured interviews with stroke patients in Iran, held in 2019.

Inclusion Criteria of Participants

The interviews elicited patients' views of their self-care ability, experience and behaviors. Patients with stroke were eligible for this study if they 1) were within the one-month period following discharge from acute care hospitals; 2) were living independently at home; 3) were able to express themselves clearly; and 4) had good cognition (indicated by a score > 21 on the Mini Mental State Exam) and physical function (indicated by a score > 22 on the FIM form) (Penta et al., 2001), implying that patients had no one-sided hemiplegia and hemiparesis, no need for walking aides (e.g. walker or a cane), going to the toilet independently, and living in the house independently.

Sampling

The target population included patients with stroke receiving rehabilitation. Healthcare providers at the rehabilitation center in the city of Tehran assisted in identifying and referring potentially eligible patients to the study, and those meeting all eligibility criteria were selected. Purposive sampling was used to represent patients with different sociodemographic and health characteristics. Diversity was considered in terms of age, gender, education, job, marital status, and frequency of stroke attacks. Sampling was stopped when information saturation was reached. In total, 13 eligible patients provided informed consent, and the concurrent analysis of their responses reached saturation. Most patients were interviewed in a private, quiet location at the rehabilitation center, at their convenience.

Data Collection

The interview questions were: Describe your experience on a day in your life at home after you were discharged from the hospital; describe your selfcare ability. What actions do you take at home to take care of yourself? Additional exploration questions were asked to probe for clarification and/or a more in-depth description of participants' experiences. Can you tell me more about it? Can you give me an example? Have you ever faced such a situation before?

The duration of the interview varied between 20 to 30 minutes per participant. The interviews were conducted and audio-recorded with participants'

consent. Sampling continued until data saturation, that is, no new information was forthcoming (Speziale et al., 2011). The saturation was achieved at the 10th interview; however, three additional patients were interviewed to confirm saturation. The transcripts of the interviews were verified for accuracy and consistency by listening to the recordings. The first author analyzed the transcripts line by line, which were read repeatedly and thematically analyzed for their contents. Co-authors of the study verified the emerging themes.

Data Analysis

Data analysis was performed based on the Graneheim and Lundman (2004) five-step process. The method involved: (1) the interviews were transcribed verbatim and imported to MAXQDA software, (2) each transcription was considered as a unit of analysis and was read several times by the researcher to achieve a general understanding of its content, (3) the sentences or entire paragraphs of text were determined as meaning units to extract primary codes (4) comparison of primary codes and those reflecting similar ideas were combined to form the categories, and (5) determining the latent content of data and extracting the underlying concepts.

Conformability, credibility, and reliability criteria suggested by Guba and Lincoln (1994) were maintained during the analysis. To achieve this, the researcher established a trusting connection with the participants. After determining the primary codes, the participants' opinions were compared to the codes and interpretations, and the data were modified in case of any contradictions. Also, controlling techniques were performed on selected codes and categories by two Research team members' who were expert in qualitative descriptive research.

Ethical Approval

This study was approved by the Ethics Committee of the University of Social Welfare and Rehabilitation Sciences under Approval Code No. IR.USWR.REC1396.208. All participants were informed clearly and entirely about the aim of the study and about the reason for using a tape-recorded during the interviews. They were also ensured about the anonymity and confidentiality of their

information and recorded sound files. They were also informed about their right to withdraw from participation during any stages of the study, prior to signing the consent form.

RESULTS

The characteristics of participants are comprised 13 patients (three men and ten women) aged 48 to 87, with an average age of 63.7 years.

The data analysis revealed three main categories and ten subcategories characterizing the participants' perceptions of their self-care ability post-discharge.

Immersion in Distress

This category included subcategories: feeling of sorrow and sadness, lack of control over life, and feeling of anxiety and worry.

Feeling of sorrow and sadness

According to participants, emotions such as unpleasant deep sadness due to disability, disappointment, and feeling of loss of roles, feeling of imbalance, uncomfortable sense of dependence on others, tendency for social isolation, feeling of imposing heavy burden for caring on relatives, and the feeling of imminent death are the effects of distress associated with illness.

"This illness is terrible. I was so irritated after being discharged from the hospital; I went home and felt miserable." (Female, married, 50 years old)

Lack of control over life

In this category, the participants reported feelings of always awaiting something horrible to happen, being unable to perform house chores and dealing with the children, having a problem in self-care, lack of family support, unfavorable home atmosphere, and feeling of helplessness.

"At first, disability was complicated because I always managed and performed all the house chores by myself. So, at first, I really couldn't take it; then I was forced to go to the hospital and other places; now I feel like a bomb has dropped on my head; this illness destroyed my family, and now I don't know what my

husband and son are up to." (Female, married, 49 years old)

Feeling of anxiety and worry

The participants expressed feelings of worry about inability to take on their responsibilities, losing family cohesion (the children's education and upbringing, house chores, their conjugal life), worry about frequency of the stroke, worry about exacerbation of their disability, worry about permanent dependency, feeling envy of their life before the disease, restrictions due to the disease, and previous capabilities.

"I had a second stroke. What will happen if I have another stroke when I'm sleeping? ... I'm so worried about my vague and dark future." (Male, married, 60 years old)

Perceived Difficulty

This category consisted of four subcategories: dependency on others, disabling nature of the disease, multiple underlying diseases, and mental health problems.

Dependency on others

Feelings such as lack of power, being unable to perform daily activities, needing to be taken care of by the children, inability to stand up and walk, insufficient energy, inability toward self-care, inability to cope with disability, being unable to help oneself, being unable to pick up objects by hand, moving hands, lack of independency toward others, being unable to return to work, incapability in maintaining personal hygiene, eating, and taking medicine on time are aspects of dependency.

"When I returned home after stroke, I felt empty. I felt I was imprisoned in my own home. I completely turned into a dependent person. I was entangled in grief, sadness, and distress and did not know what future would hold for me. I felt like a real loser." (Female, married 73 years old).

Disabling nature of the disease

Participants described 'disabling' experiences resulting from stroke such as having problems with

body balance when walking, feeling of numbness in the hands and feet, urinary incontinence, chronic fatigue, intolerance of activity, having problems in recalling events, becoming unconscious, feeling weak and lethargic, emotional vacuum, sleep disorder, excess sleep, needing full support of family and the medical team at home at the same time, and feeling of weakness in the upper and lower limbs.

"I get bummed when I can't do anything with this hand. Every night I have to pick up this hand with my other hand and put it on my stomach. My hand sticks to my body; I can't move it ... I just call God and the Imams to be my savior. But nobody comes to the rescue." (Female, divorced, 72 years old)

Multiple underlying diseases

Participants reported having hypertension, diabetes, back pain, cardiovascular problems, joint diseases, breathing problems, and anorexia.

"My blood sugar level and its fluctuations ... diabetes... that's my main problem...I think all of my problems are because of diabetes... anyway, all the problems came to me in turn... I've even experienced diabetic coma... and my blood sugar level dropped... my blood sugar fluctuations influence my ability for self-care." (Male, married, 63 years old)

Mental health problem

Participants described experiences such as fear, nervous irritability, sense of loss, having no good feelings, limited social relationships due to fear of disability, fear of injuring the caregivers, fear of falling, fear of permanent disability, fear of extra trauma during rehabilitation, and being afraid of staying alone at home.

"I am very irritable and nervous after having a stroke and I cannot stand the slightest sound in my surroundings. At parties, I quickly get frustrated by the hustle and bustle of those around me and try to leave as soon as possible, although I know this will exacerbate my loneliness and social isolation."

(Male, married, 60 years old)

Compatible Adaptive Response

This category included the following three subcategories: acceptance of disability, improving health literacy, and enhancement of spiritual health.

Acceptance of disability

Participants described getting used to disability, coping with disability, collaboration in self-care, applying strategies to overcome pain, inherent interest in performing activities, interest in repeating, practicing and being interested in learning, talking to disabled organ, and talking to oneself about the disabling problems.

"I have experienced left hemiplegia due to stroke. After hospital discharge and several days of rest at home, I decide to start doing my activities as before. I use a walker. I accepts my conditions and understands my limitations, but I irregularly performs rehabilitation exercises. ". (Female, married, 70 years old)

Improving health literacy

Participants showed some knowledge about the disease and its outcomes. They were informed about the nature of the disease, recognition of warning symptoms and signs of the disease, follow-up treatment, willingness to continue rehabilitation at home, ability to understand the reasons behind the disease, and perception of disability as significant effects related to this category.

"If I experience the same situation, I can now understand my situation. Now I have a hang of it and learned about it." (Female, married, 55 years old)

Enhancement of spiritual health

Participants explained the contribution of their faith in dealing with their condition; they had trust in and prayed to God, which strengthened their spirituality, that is, feeling peace after praying, connecting to the holy power, and self-connection.

"Praying makes me feel good ... I pray to God to give me health. I tell God if you bring me a box full of jewelry, I don't want it; I just want to be healthy again." (Female, divorced, 72 years old)

DISCUSSION

The results of this study demonstrated that the perception of self-care ability in patients with stroke post-discharge is different from the acute stage and the adverse consequences of the disabling nature of the disease are seen in all aspects of their existence.

In the acute phase of a stroke, early detection, reduction of the severity of the disease, and prevention of adverse events are far more important than having self-care skills. While in the chronic stage of the disease, the ability to take care of oneself and have a proper understanding of this ability is seen more vividly (Dalvandi et al., 2014).

A critical perspective obtained from this study was immersion in distress, which makes patients experience sorrow and sadness, lack of control over their life, anxiety and worry. Patients with stroke are faced with disorders that appear suddenly and unexpectedly and inhibit or limit their ability to carry out simple daily activities, which previously constituted their daily routine (Casey et al., 2008; Hoyle et al., 2012; Welmer et al., 2007). This contributes to consequent dependency on others, which creates feelings of loss such as loss of identity and connection with others (Casey et al., 2008), loss of independence accompanied by grief about the unfolding events. Results of previous studies have also established that lower levels of sorrow and sadness in patients with stroke are associated with higher levels of self-care (Bahrampouri et al., 2013; Brucker, 2018; O'Connor et al., 2021; Welmer et al., 2007). Many patients believe that they have lost their roles and responsibilities in life and themselves and are unable to deal with the existing issues of their lives (Jang & Shin, 2019). The repeatable nature of stroke incidents and the possibility of exacerbated disability is another cause of concern and anxiety among patients with stroke regarding self-care. The results our study are consistent with those of others.

Various factors influence the perception of patients with stroke about their self-care ability. The most salient factor relevant to the perception of their self-care ability is the **perceived difficulty** in carrying out usual activities due to the functional limitations associated with the nature of stroke (Ekstrand et al., 2016). Patients with stroke realize that their abilities are threatened due to the chronic and disabling nature of the disease and that they are unable to take care of themselves like before the disease. Some



researchers believe that perceived difficulty is the same as perceived ability, and it is possible to define it as the level of dependency on others (Grimby et al., 1998). This perspective consists of some experiences and perceptions including dependency on others, the disabling nature of the disease, a variety of physical problems, and mental health problems. It should be considered that disability is not a personal characteristic, but it is a result of interaction between the health conditions of a person, personal factors related to them, and the surrounding environment (Hoyle et al., 2012).

Another critical perspective revealed in this study was **compatible adaptive responses** which constitute three subcategories including acceptance of disability, improving health literacy, and enhancement of spiritual health.

The results of a study by Hammar et al. (2009) showed that patients could adapt themselves to their weakness and problems. A study performed on the perception of life experiences revealed that patients with stroke could accept the fact that they unable to return to the pre-stroke life conditions, and thus, they tend to cope with the new reality. However, to help themselves, they try to adjust their personal goals to carry out some activities based on their life before the stroke (Sadler et al., 2017).

Researchers found that patients with chronic diseases tend to pass three adaptation stages. The first stage is facing the fact that they perceive or have experienced a disorder or defect. In the second stage, they recognize that the disease impacts their future; and finally, they accept their disease (Casey et al., 2008). Also, other studies demonstrated that from the perspective of survivors, recovery means the ability to return to their life before the stroke; commencing such activities creates in them a sense of control and identity (Hoyle et al., 2012). If patients view themselves as unable to adapt to their self-care needs at home, then they have difficulty making arrangement and integrating services in their daily life at home, which may consequently reduce the quality of provisioned care and could result in the improper and inefficient allocation of resources (Hammar et al., 2009; Tornbom et al., 2017). Findings of our qualitative descriptive study suggested that patients should be educated regarding the adapting strategies related to disabilities to motivate them and promote their self-care ability within the functional limitations associated with stroke. Educating patients about performing tasks, practicing and doing exercises is useful in this regard. Furthermore, applying strategies in terms of mental and spiritual practices increases the sense of hope among these patients (McKevitt et al., 2004). Recognition and perception are essential to perceived self-care ability. Perceived self-care ability requires patients to possess a certain level of knowledge and skills that could assist them in managing their disease in the chronic phase and at home (Sun et al., 2017). The strategies related to selfcare are affected by various mental-social, economic, cultural, and environmental factors. Also, most behaviors related to health care are influenced by peoples' beliefs about the etiology of diseases (World Health Organization, 2009).

One limitation of the present study is the fact that the patients' residence would be a better location for conducting the interviews in the context of people's daily life. However, with regard to some cultural problems in Iran, participants were reluctant to be interviewed by the researcher at their home. So, we recommend future studies to address this issue in more detail. Also, the study was conducted in a large city. Therefore, it is suggested to conduct similar studies in other cities with diverse cultures and ethnicities. Also, it is recommended to carry out the study in the chronic phases of other diseases and disabling diseases. Because in most chronic diseases, having the ability to take care of oneself is important to promote patients' physical function and mental health, as well as to reduce burden on family caregivers. The development of such individual skills prevents the establishment of permanent disabilities.

CONCLUSION

Self-care ability arisen from the perception, experiences, and real assumptions of patients with stroke in the chronic phase (patients were 1-month post-acute phase) are of great importance. Patients have identified limited knowledge about self-care and reliance on family caregivers for engagement in daily activities. Patients and family caregivers' knowledge and needs should be considered when designing, implementing, and evaluating nursing interventions and rehabilitation programs.



The results of this study show that patients with stroke face many problems, one of which is the inability to take care of themselves. Discharge of these patients from the hospital to the home requires continued care. Nurses should assess patients' self-care ability, instruct them of strategies to promote self-care and of resources to support patients' engagement in self-care at home, with the ultimate goal to avoid complications requiring rehospitalization.

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