



A survey measuring participation and autonomy of Iranian stroke patients referring a university hospital, 2017

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Abstract

Background: The participation of patients in their private and social affairs plays a crucial role in decreasing disability and improving quality of life. The present study was conducted to determine the rate of stroke patient Participation and Autonomy in their private and social life in Rafsanjan in 2017 .

Materials and Methods: This descriptive study included all Iranian stroke patients referring Ali Ibn Abi Talib Hospital in Rafsanjan in 2017, the total number of whom surmounted up to 100 subjects. A Persian version of Impact on Participation and Autonomy scale was used. Finally, collected data was analyzed using independent t-test and one way ANOVA.

Results: The results of the present research showed 37 subjects (38.1%) in the dimension of social life turned out to be at the optimum level. The dimensions of participation with people with poor income, except for autonomy in out-of-home duties and lower educational level, were statistically more than the role played by social life, duration of illness and severity of illness ($P < 0.05$).

Conclusion: The present research showed that more than half of patients suffering from stroke turned out to be quite functioning in private and social affairs, a point which turned out to be quite directly related to income and education level. While investigating the important factors affecting the participation of patients, it is highly recommended for researchers to determine the factors affecting the participation of the patients in order to improve the quality of life through providing necessary training, better health care and rehabilitation.

Keywords: Participation, Autonomy, Stroke, Iran.

Introduction

Brain stroke is a severe and serious neuropathic injury occurring mainly due to abnormal blood flow to the part of the brain tissue which is, in turn, is caused by cerebrovascular obstruction by a blood clot or rupture of one of the vascular vessels feeding that part of the brain (1).

Cerebrovascular diseases are the second most common cause of death in the world; additionally, these diseases are considered the sixth cause of total rate of illnesses worldwide, expected to reach the fourth rank by 2020 (2); each year, more than 5.5 million people globally and thousands in Iran die due to stroke, a rate which accounts for two-thirds of the deaths in developing countries. (1,3)

In industrialized countries, the prevalence of stroke is 5 per 1,000 population (4); this rate is about 5-10 people per 1,000 in developing countries (5).

Despite several epidemiological studies, population-based and demographic information is still low in developing countries (6).

This disorder is also the second cause of disability, leading to major changes in the lifestyle of patients (7). Stroke is a very important event that ultimately affects the quality of life and general lifestyle of patients (8), and leads to physical, functional, and psychological changes in their lives (9). This disease has unforeseen and destructive effects on the lives of patients that lead to changes in their lifestyle and ultimately affect psychological, physical, social, economic, family life and sexuality. In fact, it is a devastating incident for the patient and his family; the patient and his family undergo changes after a stroke which are quite new and shocking, and subsequent results of the disease depend on the individual and variables such as the severity of the lesion, the role of the family, financial resources, and finally facilitators and barriers faced with which the individual must struggle. (10)

Measuring the participation and collaboration of patient has been introduced as one of the primary goals of treatment in recent years; it is possible to evaluate this specific issue through assessing the patient's response to the disease, assessing the health status of the patients, measuring the improvement in life, the negative impact of the disease or the effects of treatment (11). Several factors affect the lives of patients, including age, severity of the lesion and the rate of disability, lack of social support, cognitive impairment and other health problems (12).

The present study was conducted to determine the effect of disease on the private and social life of patients with stroke. The present research investigates the quality of life of patients with post-stroke mental and physical disabilities, and other demographic factors, such as age, gender, level of education, and clinical factors. Despite the fact that several studies have reported low quality of life for such patients in Iran, no research has so far been conducted on patients struggling with stroke in Rafsanjan. Therefore, considering the effect of cultural and climatic factors on life, it seemed necessary to examine patients with stroke in Rafsanjan city.

The present research was conducted to examine the factors influencing the impact of stroke on the quality of life of patients through the provision of a questionnaire and assessing various factors, such as age, gender, level of dependence on daily life, disability, depression and social support in order to provide a clear picture of the impact of brain stroke

on the life of patients, their occupations, and the health system.

Materials and Methods

The statistical population included all stroke patients who were or are undergoing treatment in urban health centers in Rafsanjan city. All subjects were included in the study, 97 of whom were willing to participate in this research (97%). Two questionnaires were used to collect data, a demographic one which assessed factors like age, occupation, level of education, marital status, location, economic status, type of treatment, duration of illness, severity of illness, duration of diagnosis, symptomatology, length of treatment period, duration of disease control period, participation rate in life, and the site affected by the stroke; the second questionnaire was the Persian version of Impact on Participation and Autonomy (IPA-p) scale. The questionnaire was answered according to The Likert scale, expressing the aspects in five categories of strongly agree, agree, no idea, disagree, and strongly disagree. The questionnaire contains the following sections; the first part is about mobility and self-autonomy at home which consists of 9 questions. The second part is about being the ill person in the family, using and taking care of your money and having fun which consists of 11 questions. The third part consists of 6 questions about mobility and autonomy in out-of-home affairs. The fourth part is about playing a role in social life and communicating with relatives and enjoying their help and support, and it consists of 9 questions. The fifth part is about autonomy in obtaining academic qualifications which includes 3 questions. The sixth part is about autonomy in the acquisition and preservation of a job and consists of seven questions; finally, there were 5 questions related to being active in religious affairs, which were added to the English version of IPA (IPA-e), based on the results obtained from a previous work on (13). The validity and reliability of the questionnaire was obtained in a similar study, where about 50% of public respondents reported their perception of their participation to be "good" or "very good," and 60 percent of the experts reported the ability of the IPA-p scale to be desirable and excellent. Total Spearman's correlation coefficient was more than 0.8. For each of the Cronbach's alpha-IPA-P domains, IPA-p mean scores in two separate cases ranged from 0.885. The highest and lowest internal consistency belonged to the domain of social relations and learning and acquisition. The test retest ICCs were between 0.789 and 0.919 for 9 domains, all of which were significant $p < 0.001$ (14). First, all patients over 18 years of age were

examined at Ali ibn Abi Talib Hospital in Rafsanjan. Subjects were enrolled in the study if they had a current or a history of stroke. Being over 18 years old was the only inclusion criterion; exclusion criteria included uncontrolled diabetes mellitus, cancers, vasculitis, kidney failure, cardiac surgery and COPD, TIA, and disabling physical and mental disorder including multiple sclerosis, depression, or Schizophrenia. At the beginning of this study, the patients were given a description of the goals of the study and the implementation process. Then, written informed consent was obtained. Anonymous questionnaire was used to collect and record information in the present study. The participants were told that they could leave the study or remain unaware of the results of their questionnaires if they wished. Subsequently, the demographic questionnaire was completed by a trained and experienced expert in an interview with, either, the patient, or his relatives in a relaxed environment. A part of the demographic questionnaire, which included specialized stroke cases, was completed according to the records of patients in hospital or hospital archives. The cooperation questionnaire was then completed by interviewing the patient or his relatives. It should be noted that the presence of stroke, the severity of the disease, and the degree of disease control were confirmed by a neurologist and surgical specialist. Required data for the questionnaire was collected through interviewing the patient or relatives by an expert trained in a hospital and in a relaxed environment and referring to their medical records. Data was collected by computer and analyzed using SPSS 18. Descriptive statistics were used to determine absolute and relative abnormalities and they were, subsequently, represented in Tables. Also, independent t-test and one-way ANOVA were used to make necessary comparisons between the groups. P values less than 0.05 were considered significant.

Results

A total number of 97 patients were examined. The lowest age in the subjects under study was 41 and the highest was 99 years, with a mean of 68.86 ± 12.44 years. Also, the mean time from the onset of the disease was 22.88 ± 35.20 months, the time passed since the first diagnosis was 25.2 ± 37.15 months, the time passed since the onset of the symptoms was 23.44 ± 33.96 months, and the time since the start of medication was 18.67 ± 27.66 months. 47 (48.5%) subjects were housewives and retired, 48 (49.5%) were illiterate, 88 (90.7%) were married, 65 (67.01%) were residents of the city and 48 (49.5%) had an average income. In terms of participation status, 40 (41.2%) subjects in the domain of autonomy at home, 44 (45.4%) in the domain of role play in the family, 60 (61.9%) subjects in the domain of out-of-home affairs, 47 (48.5%) subjects in the domain of fulfilling religious functions, 35 (36.5%) in the domain of autonomy in education, 47 (48.5%) in autonomy in acquisition and preservation of the job, and finally 37 (38.1%) subjects in the domain of the role played in social life turned out to be at the optimum level. Participation with people with poor income, except for autonomy in out-of-home affairs and lower educational level, were significantly more than the role played by social life, duration of illness and severity of illness ($P > 0.05$). (Table 1). Frontal area lesions were the most affected sites, 27 cases (27.8%), and the thalamus was the least affected one with only 1 case (0.1%). With a frequency of 48 (49.5%), the majority of subjects were in the age group of 56-70 years. Subsequently, subjects over 70 years old with a frequency of 38 cases (39.2%) and subjects aged between 41-55 years old with 11 cases (11.3%) were in the second and third positions in terms of frequency.

Table 1: Frequency distribution of patients with stroke under study according to the status of participation (n=97)

Dimensions of participation	Desirable cooperation		Undesirable cooperation	
	Frequency	Percent	Frequency	Percent
Mobility and autonomy at home	40	41.2	57	58.8
Role of the ill person in the family, using and taking care of money and having fun	44	45.4	53	54.6
Mobility and autonomy in out-of-home affairs	60	61.9	37	38.1
Role in Religious Affairs	47	48.5	50	51.5
Autonomy in education and obtaining academic degrees	35	36.5	61	63.5
Autonomy in the acquisition and preservation of a job	47	48.5	50	51.5
The role played in social life and communication with relatives and their help and support	37	38.1	60	61.9

The results of independent T-test showed that the mean scores of participation dimensions of patients with stroke in urban and rural areas did not differ significantly ($p < 0.05$). The results of ANOVA test

showed that the mean score of all aspects of the participation of patients who were poor in terms of monthly income was higher than those with higher earnings. (Table 2)

Table 2: The mean and standard deviation of the status of participation of patients with stroke in terms of monthly income

Dimensions of participation	Maximum score	Low	Moderate	High	P-value
Mobility and autonomy at home	44	29.75±11.54	27.2±9.59	22.86±7.08	0.027
Role of the ill person in the family, using and taking care of money and having fun	55	40.17±9.26	34.10±10.21	30.11±8.61	0.006
Mobility and autonomy in out-of-home affairs	30	20.42±5.81	19.71±5.64	17.51±5.25	0.126
Role in Religious Affairs	25	14.67±4.42	14.31±5.21	11.65±5.10	0.04
Autonomy in education and obtaining academic degrees	15	11.67±2.35	10.39±2.56	9.83±1.64	0.051
Autonomy in the acquisition and preservation of a job	35	25.42±5.66	23.62±5.60	21.32±4.22	0.029
The role played in social life and communication with relatives and their help and support	45	30.50±8.66	26.12±8.45	21.36±6.22	0.001

The mean score of role play in the social life of widowed patients with stroke (32.57 ± 6.45) was significantly higher than the mean score of married subjects (24.18 ± 8.40) and single ones (24.2 ± 11.31) ($p=0.041$). The results of analysis of variance

showed that the mean score of participation in all aspects of participation in illiterate patients was higher than literate subjects or those who had higher education. (Table 3).

Table 3: Mean and standard deviation of participation rates of patients with stroke in terms of educational level

Dimensions of participation	Maximum score	Illiterate	Primary education	Secondary education	P-value
Mobility and autonomy at home	44	39.83±8.88	22.37±7.54	21.34±9.05	<0.001
Role of the ill person in the family, using and taking care of money and having fun	55	36.5±10.15	31.2±8.38	27.78±9.56	0.004
Mobility and autonomy in out-of-home affairs	30	21.08±5.36	17.6±4.37	15.07±6.32	<0.001
Role in Religious Affairs	25	14.96±5.5	11.6±4.17	12.14±5.08	0.008
Autonomy in education and obtaining academic degrees	15	10.94±2.34	10.14±1.78	8.86±2.54	0.008
Autonomy in the acquisition and preservation of a job	35	24.73±5.51	21.83±4.46	19.78±4.1	0.002
The role played in social life and communication with relatives and their help and support	45	27.39±8.74	22.51±7.36	21.5±8.21	0.009

The mean participation dimensions scores of patients suffering from stroke did not differ significantly among employee, housewife, retired, self-employed, worker and farmer ($p < 0.05$). The mean score of all aspects of the participation of patients struggling with stroke for more than 5 years old from the onset of the disease was higher than those with a starting age of less than 5 years ($p < 0.05$) (Table 4).

The mean score of all aspects of participation of

patients struggling with less advanced stages of the disease was significantly higher than other groups ($p < 0.001$). The mean score of all aspects of participation of patients with stroke was significant in terms of age, so that the mean score of all dimensions was higher in subjects over 71 years old compared to other age groups ($p < 0.05$). The mean scores of all aspects of participation of patients with stroke under study were significant according to the lesion site ($p < 0.05$).

Table 4: Mean and standard deviation of participation rates of patients with stroke in terms of the time passed since the onset of the disease

Dimensions of participation	Maximum score	1 year	1-5 years	More than 5 years	P-value
Mobility and autonomy at home	44	22.73±8.13	30.40±8.88	37.43±4.61	<0.001
Role of the ill person in the family, using and taking care of money and having fun	55	29.97±8.78	38.08±9.05	44.28±6.47	<0.001
Mobility and autonomy in out-of-home affairs	30	17.46±5.64	21.48±4.92	23.71±4.15	<0.001
Role in Religious Affairs	25	12.13±4.88	15.08±5.41	17.86±4.26	0.003
Autonomy in education and obtaining academic degrees	15	9.89±2.24	10.92±2.31	11.86±1.68	0.027
Autonomy in the acquisition and preservation of a job	35	21.36±4.87	25.84±5.1	26.57±2.76	<0.001
The role played in social life and communication with relatives and their help and support	45	22.09±7.97	28.92±7.79	34.0±3.91	<0.001

Discussion

Changing lifestyles, spreading unhealthy diets and reducing mobility in daily life have caused the spread of chronic and non-communicable diseases that have become the most important cause of mortality and disability in developed and developing countries. The impact of medical and health interventions in recent decades have brought about prolonged life expectancy in people with chronic illnesses, such as patients with stroke. These patients now have a longer lifespan made possible through advanced care; thus, they can live longer with their illnesses. The important point is trying to reduce the suffering of patients by changing their lifestyles towards healthy living.

The results of the present research showed that more than half of the patients with stroke continued to fulfill their role in the family, performed out-of-home affairs, continued their education, and performed acquisition and preservation of a job despite being in an unfavorable situation. Also, the status of participation of more than 30% of patients was undesirable in terms of autonomy at home, playing a role in religious affairs and social life. The findings of this study showed that stroke affected the participation of the subject in individual and social life severely. As these patients struggle with relatively long years of illness and receive different care, it is important to improve the participation of these people (15). The present study did not compare the status of participation of patients with healthy subjects. The results of the present research showed that patients with stroke did not participate in their daily life activities in a desirable manner. Various researchers, both domestic and international, have confirmed that the quality of life of patients with stroke is not optimal. However, quality of life and participation are measured in different ways and with different tools, but they are closely related in terms of concept and nature;

therefore, the results of researchers who showed that the quality of life of patients with stroke is at the optimal level is not evidently consistent with this study (16-19). The present research did not investigate the status of participation and autonomy of patients in different aspects of their life.

According to the results of the present study, the most undesirable and negative participation domain score was related to autonomy in gaining academic degrees and autonomy in social affairs. Considering that 48 (49.5%) of subjects were illiterate and without university education, such a finding should not seem so surprising on a second look. Also, the mean age of the patients (67.63 ± 12.26 years) could also justify their low participation in the domain of education. Fatahi also showed that the quality of life of patients suffering from stroke is closely associated with, and dependent on, age, education, and the time elapsed from the occurrence of stroke (16).

37 (38.1%) patients turned out to have undesirable out-of-home affairs. This issue seems to be influenced by various factors, such as physical disabilities (20), forms of verbal communication (21), forms of self-care (22), and difficulties in driving (23). The lesions and complications are common after a stroke. 51.5% of subjects obtained negative score in the domain of participating in religious affairs. Patients with stroke seem to be inclined to adhere to their religious beliefs in all circumstances. However, the results of the present study showed that these patients did not have a good participation in this regard due to their condition. The results of studies by Chang (2008) and Lager (2006) also confirmed this issue. (24-25) According to the findings of the present research, 48 patients (49.5%) had average monthly income. Given the economic conditions of the year (2016), these subjects were in an undesirable economic situation. If we add this number to 12 people

(12.4%) with a monthly income of 500 thousand USD, one will reach the number of 60 (61.9%), indicating the frequency of patients with low economic situation. Peron also achieved similar results in his study (26). Non-communicable chronic illnesses seem to have affected not just the well-off, but the entire community (27). Changing lifestyle toward less physical activity (28), psychological stress (29, 30), and a change in people's taste toward cheaper and lower quality food (31) might be some causes of stroke in the entire community.

The results of the present study showed that the mean participation score in the domains of autonomy at home, role play in the family, out-of-home affairs, obtaining educational qualifications, obtaining and retaining employment and social life was higher in people with lower income levels in comparison with those with higher income; thus, lower financial advances and subsidies might be a reason for the greater involvement of patients with a weaker economic situation. These subjects should, in every case, be struggling to save their living. This, in turn, leads to higher participation in various aspects of personal, social and occupational life. According to the findings of the present study, the mean participation rates in people with lower education was higher. If one considers participation as a necessary factor for higher quality of life, this point turns out to be inconsistent with the results of some researchers (16-19). Of course, it should be noted that 48 (49.5%) of subjects were illiterate and 35 (36.1%) had graduate education. Therefore, this contradiction seems to be due to the lack of education or lower education levels in the study.

The results of the present paper showed that the mean participation score did not differ significantly among patients residing in urban and rural areas. Noori et al. (2017) also found that there was no significant difference in the quality of life of people with hypertension living in urban and rural areas. Mohammadpour et al. (2013) also showed that there was no significant difference in the quality of life among the residents of the city and the rural area (32). However, Mollhoseyni et al. (2009) indicated that there was a significant relationship between the quality of life of patients and the place of residence and physical, psychological and social dimensions (33).

The results of the present study showed that people with lower monthly income had better performance in all dimensions of participation, a point which was also confirmed by the results of Amid-Pour study (34), although Ja'fari and Dalouni achieved contradictory results in this regard (25). Less financial support and lower economic status seem to encourage a person to engage further in

activities, a point which will ultimately lead to an increase in the quality of life, leading to greater participation in various aspects of daily activities on the part of the patients.

Also, according to the results of the present study, the mean score of role in social life of widowed patients was significantly higher than the mean score of married and single subjects. Mahani and Jafari indicated a relationship between marital status and quality of life (17-19). In this context, the United States Centers for Disease Control (ICDC) has stated that married individuals have more social protection than widows or divorced, and that emotional, instrumental and information support plays a crucial role in coping with physical and psychological stresses caused by stroke (35). The present author argues that because of lower social and financial support for widows, these people do their best to maintain their presence in the community in order to stabilize their physical and mental status, a point which might account for higher participations of widows in social events and activities. Also, the cultural and economic issues of the society under study should also be considered while analyzing this topic.

The results of the present research indicated that the occupation of people was not related to their participation in post-stroke activities, a point which was also confirmed by the results of Amid-Pour study (34), although Hassanpour and Yaqhoobi achieved inconsistent results (36-37). In most sources, jobs and income levels are considered together, but social status seems to be more related to jobs than income. A farmer or a freelancer may have an income of more than one employee. For this reason, the relationship between the job and the level of participation of people in maintaining health or autonomy in the promotion of health seems far-fetched.

According to the findings of the present study, the mean score of all aspects of participation of patients with 5 years elapsed from the onset of the disease was higher than those with a diagnosis that was less than 5 years. Also, home autonomy, role playing in the family, and role play in the religious affairs of patients who with more than 5 years elapsed from the onset of the disease was more than the other groups. In other words, the rate of participation of patients with longer elapsed time since the onset of the disease was higher. This finding was in line with the results of Hassanpour (36) and Fatahi (16) in regard with the quality of life of stroke patients, and inconsistent with the findings of Khaiatzade Mahani's study (19). The reason for higher participation of patients with a longer history of illness might be compliance with the disease, signs and disabilities associated with it. The fact that

some symptoms of illness are diminished or disappear over time is not beyond the reach of the mind. Therefore, compliance with existing status or discontinuation of symptoms might be the main reasons for the participation and autonomy of patients who have struggled with the disease for longer periods.

The mean participation score in the dimensions of autonomy at home, playing a role in the family, autonomy in out-of-home duties, playing a role in religious affairs, and playing a role in the social life of patients with more than 5 years elapsed since the onset of the symptoms of the disease or more than 5 years passed since the onset of medication was significantly higher than those with a history of symptoms less than 5 years. Of course, this problem depends completely on the diagnosis of the disease for a long time. Starting from the very beginning of symptoms or diagnosis, drug therapy is an obvious and logical matter and is exactly in line with the principles of diagnostic and therapeutic medicine. Therefore, this issue can be justified by the fact that the majority of aspects of participation of patients are increased with the passage of time since the diagnosis of the disease, getting more adopted or reduction of symptoms and improvement of physical function (38). The results of this study showed that the mean score of all aspects of participation of patients with high disease severity (stage) was significantly lower than other groups. Parsley showed that the severity of brain damage was associated with lower quality of life (17). Also, Tre kard showed that the quality of life of patients with congestive heart failure was related to the severity of the disease (39), a fact which is, also, confirmed by the results of the present study. There were subjects in the present study who had been sick for more than 15 years. According to the stated cases, the likelihood of the effect of pharmacological and non-pharmacological treatments on the patient's condition is very high and it cannot be exactly stated that higher severity of illness will decrease the rate of participation on the part of patients. The relationship between the severity of the disease and participation of patients might be justified through medical and physical explanations. However, if the patient is viewed from a psychological and humanistic lens, we can conclude that the amount of will and motivation of individuals to perform activities without considering the amount of ability or disability seems an unreasonable act. The fact that psychosocial perspectives and motivation can affect the quality of life of patients greatly and reduce their disability has been documented in numerous studies (40-43). According to the findings of the study, patients who receive adequate mental and psychosocial support

from the family and the environment are quicker to recover and more tolerant in dealing with treatment. Sufficient mental support will make it easier for an individual to get along with his or her illness. The physical complications of the disease can be tolerated and regulated by the family better; this, also, helps the patient accept it and try to overcome possible difficulties. Providing adequate support on the part of family will help the patient accept his illness; this even results in certain abilities in the individual (44). Not considering psychological status of the participants in the study and disregarding disabilities of the organs were the main limitations of the present research. Supportive resources such as insurance, living with children or receiving financial assistance from difficult organizations were not reviewed. It is recommended to consider support sources and important factors influencing the rate of participation of patients with stroke. The results of the present study indicate that more than half of the patients were inactive in personal and social affairs. According to the findings of the present study, it is recommended to use various educational, support and therapeutic and rehabilitation resources in cooperation with all healthcare system staff in order to improve the participation rate, increase the quality of life, and prevent further disability in these patients.

Conclusion

The results of the present study showed that more than half of the patients suffering from stroke were relatively passive in personal and social life and had undesirable rate of welfare affiliated with the level of income and education. While investigating important factors affecting the participation of patients, it is necessary for the researchers to determine the factors affecting the participation of the patients in order to improve the quality of life through providing necessary training, better health care and rehabilitation.

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