

Relationship Between Perceived Social Support and Autonomy and Participation among Patients with Spinal Cord Injuries

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Abstract: Assessing participation level off individual in their personal and social life is off the most recent methods for measuring the level of health among them. The aim of this study is survey of the Relationship between perceived social support and autonomy and participation among patients with spinal cord injuries. In this descriptive-correlative investigation, 100 members of the association of spinal cord injuries in Tehran were selected by simple random sampling method. Their social support and autonomy and participation were studied in different aspects using cardol questionnaire of impact on participation and autonomy index for spinal cord injury and standard questionnaire of nortouse social support scale. Analysis of the data was performed with the help of SPSS 19 Software utilizing descriptive and analytic statistical tests this study showed that the perceived social support mean was $146/58 \pm 11/50$ and autonomy and participation mean is $63/79 \pm 17/79$. pearson's correlation test showed that there is a significant, positive relationship between social support and autonomy and participation ($p < 0/001$, $r = 0/37$). In this research, it is shown a meaningful and inverse relationship between autonomy and participation and social support of people suffering from spinal cord injuries. Also, the influences of traumatic events such as spinal cord injuries show that social support of these people can cause interpretation of the disorder with positive impacts, increases autonomy and participation people suffering from spinal cord injuries. Respecting the long duration of the disease among patients, improving the participation of patients very important.

Key words: Autonomy and participation, perceived, social support, spinal cord injuries, Iran

INTRODUCTION

With the advancement of science and technology, unprecedented changes have occurred in today human life. Life expectancy has increased significantly and indices of health and well being of societies have improved however, industrialization of human main activities, have led to injuries of the machine life incidents. Accidents, work accidents, natural disasters and social conflicts such as war including factors which can cause transient or permanent disabilities that spinal cord injury have consist an important and significant part of these incidents. Spinal cords injuries are among the human societies problems that created serious physical and mental problems for the disabled person and his family (Sekhon and Fehlings, 2001).

The prevalence of spinal cord injuries in the world, are between 40-80 people per million. This means that

each year 250-500 thousand people worldwide are suffering from spinal cord injuries (Lee *et al.*, 2014). It is anticipated that in our country there are more than 70 thousand disabled people to spinal cord injury that due to the high accident rate, this figure is rising, therefore attention and planning of health services and rehabilitation is more important in spinal cord injury (Kachuei *et al.*, 2012). The first step to promote health, is measuring the available health level, including the best known methods in the measurement of health, is assessment of life quality. This concept is often associated with concepts such as disability and impairment proposed as a good indicator to assess the health situation, especially in people who suffer from chronic diseases (Vazirinejad *et al.*, 2012). One of the weaknesses of quality of life index is that it is subjectively assessed and this greatly reduces the accuracy of the results. The subjectivity of results can cause that what is

measured as the level of quality of life influenced by inner feelings of an individual and in diverse situation to offer the same status of various sizes. Therefore it seems to be looking for another index and concept which not only don't have negatively charged concepts such as "mutilation" but less subjective and more tangible and objective way to assess the health status of individuals. In this way during the recent decade the autonomy and participation index was raised (Cardol *et al.*, 1999).

The concept of autonomy for appropriate participation is important and is a prerequisite for participation and ultimately to achieve the desired level of rehabilitation goals. Participation means engaging people in different situations of life. The concept of participation also encompasses various aspects of a person's life, and proportionate to the health of people, different aspects can be affected. For example, restrictions on the individual ability to move can physically affect different aspects such as autonomy and individual participation in matters such as the way of his recreation or type of his occupation (Skevington *et al.*, 1997). The more or less participation of people in some aspects of the life depends on the health status of an individual. In other words, different diseases and injuries can affect individual's participation in various aspects of life that recognition and measurement of this participation represents aspects of life that needs intervention and improvement (Vazirinejad *et al.*, 2012). In patients with spinal cord injury like other chronic illnesses, participation in individual and social life is very serious issue that must be considered and evaluated (Larsson *et al.*, 2005). As with any other debilitating and chronic disease, patients with spinal cord injury has face problems that affect all aspects of his daily life and an individual must acquire the ability to confront and adapt it that numerous social and psychological factors are involved in the field that social support is one of the cases (Ebrahimi *et al.*, 2002).

Social support is a social psychology factor known to facilitate health behavior. Tilden and his colleagues have raised social support as a subjective sense of belonging, acceptance, recognition and taking assistance in a case of need. According to the scientific literature, positive social support accompanied hospitalization reduction, better therapeutic compliance and reduces the risk of death in chronic diseases (Sayers *et al.*, 2008).

Some scholars have considered the source of support related to the perception of an individual and they express that one's belief is important that to be supported by the others not the social support itself. A person may have a lot of contact with friends and relatives in a day but what he understands of this

communication is hatred. So the effect that remains is the feeling of hatred and isolation but if a man feels supported although his communication is low, he will have feeling of peace and self-esteem (Dakhte, 1988).

Social support is an important and applied issue in nursing and nursing research. According to the nurse's support, they can identify vulnerable groups in terms of receiving social support to prevent isolation of this group of patients and to take steps in providing adequate supportive interventions to improve their quality of life (Toljamo and Hentinen, 2001; Borhani *et al.*, 2014) Due to multiple stressful factors in the lives of these patients, long-term physical problems and massive changes created in their lives that may reduce autonomy and participation in the life more and more. With regard to the need to support these patients in coping with the stresses and the effect of social environment on patients confrontation, this study aimed to determine the correlation between perceived social support with autonomy and participation of spinal cord injury patients admitted to the spinal cord injury association in Tehran.

MATERIALS AND METHODS

Procedure: This study was a cross-sectional study to determine the relationship between perceived social support with autonomy and participation in patients with spinal cord injuries that has been designed in 2016. Given that we didn't have the similar study, pilot study was used to determine the quantity of the sample. The sample of 100 patients who had paraplegia, were enrolled in the study with simple randomization.

The instrument used in this study included demographic questionnaire, Nortouse questionnaire of perceived social support (Nortouse), Cardol questionnaire of autonomy and participation and co-workers (Impact on Participation and Autonomy). The demographic questionnaire, personal information including information on age, sex, educational level, occupation, lesion specifications (cause and time of appearance of the lesion), living conditions, access to care and access to rehabilitation services were discussed. Perceived social support questionnaire has 40 questions that measure patients perceived social support from spouse, family members, friends, doctors and nurses and the score of each question based on Likert scale ranging from strongly agree with 5 points to strongly disagree with 1 point. Expressions numbers 5, 11, 13, 19, 21, 27, 29, 35 and 37 totally agree Rating 1 and getting the opposite score of 5. The maximum score of people in this questionnaire is 200 and the lowest score is 40. Nortous Social Support Questionnaire for the first time in Iran in 1384 was used by Heydari *et al.* (2006). In their study, to determine the reliability of Nortous social support instruments, the inter-rater method was used and by using

Cronbach's alphacoefficient the reliability of 0.92 has obtained (14). In this study, Cronbach's alpha reliability coefficient of 0.82 verified.

Autonomy and participation questionnaires for the first time were designed by cardol in dutch language and it is one of the most important instruments that the validity and reliability of them has repeatedly been approved by researchers (Cardol *et al.*, 1999; Cristian, 2004). In Iran it was used by Fallahpour in 2011 on stroke patients. In their study, to determine the reliability of instrument the inter-rater reliability was used and by using Cronbach's alpha reliability coefficient, the coefficient of 92/0 has been achieved (Fallahpour *et al.*, 2011). The questionnaire consisted of five areas (that are autonomy within the home, family role, autonomy outside the home, life and social relations, work and study). Each of these areas is measured to find best responds to questions in the domains of (four questions about the status of Mobility, five questions about their care towards themselves, six questions about activities in and around the home, one questions about the care and use of money, one questions about recreation, seven questions about life and social relations, five question about formal jobs or voluntarily jobs, one questions about education, one questions about the help and support of others, one general question to assess the overall situation of one's participation in individual and social life); that pays to investigation of the autonomy and participation of individuals. Each of these 32 cases is a scale of five options with scores ranging from zero to four score that includes:

- Very Good
- Good
- Medium
- Poor
- And very poor

That the range of total score domains of autonomy and participation of 9 area, from 0-128 with higher scores indicating more is the participation and autonomy. In this study, Cronbach's alpha reliability coefficient of 87/0 verified for this questionnaire. Inclusion criteria for this study is age over 18 years, spinal cord injury paraplegia and passed with at least 6 months of diagnosis. After approval of the plan in Ethics Committee of the of Nursing and Midwifery college and receive a code of ethics IR.SBMU.PHNM.2015.197, patients were encoded and randomly selected. After calling to selected individuals, the purpose of this study was explained patients and informed consent was obtained from them. To fill out the questionnaire, to visit individuals at home and interviews were completed face to face. Also on the need for proper responding (honest speech) its importance explained to them.

To analyze the data, SPSS (statistical Package for social sciences) software version 19, and the Pearson correlation coefficient, independent t-test, one-way ANOVA was used. P<0.05 was considered as statistically significant.

RESULTS AND DISCUSSION

Most participants in this study were male (61%). All were married and majority of the participants within 40-50 age range. The majority of the participants in this study (36%) 3-10 years had passed from the time of their injury. Most people are diploma and under diploma (57%) and retired (39%). All persons with paraplegia and 69% of their injury cause is a blow. Total 62% of people in the area of access to care had not received any support and in access to rehabilitation services 71% of patients had not received any rehabilitation services (Table 1).

The results showed that the average of perceived social support is 146.58±11.5and the average amount of autonomy and participation is 63.79±17.79. It can be concluded that spinal cord injury patients had good social support. Pearson's correlation coefficient showed that perceived social support has direct and significant

Table 1: Distribution of demographic characteristics of patients

Variable	No	Percentage
Gender		
Male	69	69
Female	31	31
Education		
Diploma and under diploma	57	57
Higher diploma	43	43
Employment situation		
Clerk	24	24
Housekeeper	23	23
Retired	39	39
Unemployed	14	14
Age		
Under 30	12	12
30-40	25	25
40-50	40	40
Above 50	23	23
The emergence of spinal cord injury		
Under 3 years	32	32
3-10	36	36
Above 10 Years	32	32
Rehabilitation services		
Receiving services	29	29
Not receiving services	71	71
Care services		
Receiving support	38	38
Not receiving support	62	62
Cause of spinal cord injury		
Blow	69	69
No blow	31	31

Table 2: Comparison of social support and autonomy and participation in terms of demographic characteristics of patients

Variables	Autonomy and participation			Perceived social support		
	p-value	Test statistics	Average (SD)	p-value	Test statistics	Average (SD)
Gender						
Male	<0.001*	20.53	70.07±18.13	0.045*	1.23	148.05±11.71
Female				51.54±8.39		143.29±8.68
Education	0.024*	53.20	60.70±15.57	0.067*	1.42	144.82±9.86
Diploma and underdiploma	0.024*	53.20	60.70±15.57	0.067	1.42	144.82±9.86
Above diploma			69.13±19.81			148.90±12.17
Employment situation						
Clerk	0.001+	10.72	63.54±15.35	0.063+	2.51	146.33±8.61
Housekeeper			52.30±9.30			142.34±8.48
Retired			74.41±19.00			149.87±13.48
Unemployed			57.35±14.59			144.78±8.80
Age (years)						
Under 30	0.007+	4.51	56.00±8.52	0.006+	4.38	142.00±9.61
30-40			57.52±13.62			148.08±10.25
40-50			66.27±14.45			143.62±9.63
Above 50			72.69±25.80			152.47±12.56
Time of SCI Emergence						
Under 3 years	<0.001+	49.09	57.21±12.19	0.155+	1.89	143.783±8.57
3-10			54.33±10.59			146.83±9.98
Above 10			82.68±15.30			149/09±13/74
Rehab services						
Receive services	<0.001*	0.693	83.51±15.85	0.131*	8.55	149.68±14.04
Not receive services			56.49±11.79			145.30±9.38
Care services						
Receive services	<0.001*	53.20	76.83±8.26	0.122*	3.11	148.76±12.93
Not receive services			57.92±18.13			145.24±9.58
Cause of CSI						
Below	<0.001*	0.025	55.37±11.59	0.071*	3.85	145.07±9.72
Not below			84.25±12.67			149.93±13.10

*t-test; +ANOVA

relationship with the amount of autonomy and participation of persons ($r = 0.37, p < 0.001$). So, whatever social support is more, the more is the autonomy and participation. Among the different aspects of perceived social support from family members with an average of 30.60 ± 2.16 and physicians with an average of 27.85 ± 3.29 the highest and lowest level of support received respectively. Average of perceived social support in terms of demographic characteristics (along with statistical tests results) is shown in Table 2. A significant correlation was found between perceived social support and gender ($p = 0.045$) and males had higher perceived social support than females. Significant correlation was found between total score of perceived social support with the age of the participants ($p = 0.006$) but none of the dimensions of perceived social support was significant with age. Between perceived social support with the duration of SCI, level of education, the reason of spinal cord injury, employment, access to care and rehabilitation services, there was found no significant relationship ($p > 0.05$).

Among the different aspects of autonomy and participation, social relations with an average of 16.90 ± 3.20 and work and study with an average of 8.24 ± 4.07 had the highest and lowest levels of autonomy and participation, respectively. Average of autonomy and participation by demographic characteristics of the

patients (along with statistical tests results) are shown in Table 2. There was a significant correlation ($p < 0.05$) between autonomy and participation with gender, age, duration of SCI, level of education, reason of spinal cord injury, employment, access to care and rehabilitation services.

The main result of this study is that social support is effective on autonomy and participation in spinal cord injury patients. So that if the social support is more, the greater the autonomy and participation would be. Due to medical and hygienic interventions in human societies over recent decades, we clearly observe an extension of life expectancy with chronic diseases, especially those with spinal cord injuries (Hosseini *et al.*, 2015). In other words, patients continue to live with the disease for a long time and while this is no longer like before the disease that he don't have the freedom and the possibility of carrying out any activity. Schaffer (2004) in this regard suggests that stressful events do not affect individuals in the same amount and these effects depend on the personality characters and the individual's assessment of stressful factors. Factors such as developmental stages, age, previous mental function of patients in social adjustment with difficulties, cultural and religious attitudes, social support, personality and confidence of the patients affects patient's cognitive response to the

disease. People who are benefitted more facilitating factors such as social and family support will adapt much faster to the disease itself (Shell and Kirs, 2001). So, that Larsson *et al.* (2005) concluded in their study that the access to social support has the greatest impact on adaptation and individual's participation rates compared to other personal factors related to health. So it can be said that social support is effective on the individual's autonomy and participation.

In this study, the highest level of support are from family members and spouses and because spinal cord injury as well as other chronic diseases in addition to physical symptoms have created psychological and social problems for patients and their families which stems from the nature and course of the disease, after the diagnosis, families trying to adapt it and to help patient to cope with his disease. Relying on the religious philosophy, the family believes that the existence of a problem is a way to gain more success and faith and this belief is a positive force for compatibility (Chan *et al.*, 2004; Patterson, 1995). This attitude of patient's family to help them give more power to patients to cope with their disease and families will be the comfort and safe place for patients. Family ties and bonds among Iranians deep roots that have been continued from the past to the present, this is not even covered in the eyes of foreign researchers. For example, in this field Pollack writes Iranians do not understand how to spend away from their family or remain unaware of their fate. Iranians are rooted in the family to some extent that they do anything that could do for them and proudly be the partner in each family member's problems, just like it happened to himself (Kafi, 2004).

In this study the lowest level of support are from doctors and nurses that various studies considering the professional caregivers as the main source of information support and rarely presented as a source of emotional and financial support. In the study of Chan *et al.* (2004) in China and Heidari (2010), all patients emphasizing the importance of supportive activities of physicians and nurses and many expect to get emotional support from their professional caregivers but most patients are not satisfied with the support received from them. While patients assess their supportive attitudes more than their professional abilities.

It was found that the men had higher perceived social support than women, this finding is consistent with studies of Vazquez *et al.* (2005). Geckova *et al.* (2003) quoted by Wilson and colleagues have suggested although women receive more social support than men but it is possible, because the more psychosocial problems, have fewer perception of social support.

All patients with spinal cord injuries participating in the study have shown some degree of autonomy and participation. The highest percentage scores obtained in the domain of "life and social relations" are consistent with stroke patients of Fallahpour *et al.* (2011) research, this shows that attention and contact with others increased in case of problems including disease in Iranian society and family members and relatives feel more close to the patient and try to express their sympathy (Heidarzadeh *et al.*, 2009; Borhani *et al.*, 2016). In other words it can be said patients with stressful and chronic disease, achieve different changes in their new world and these changes have been to the positive direction and increase their understanding of the changes that have occurred due to the new life and this increased their communication with others. In the present study the amount of autonomy and participation in men are significantly more than women. Given that men undertaking family responsibilities and are forced to work and taking roles in the society therefore they have greater autonomy and participation. However, the study of Fallahpour *et al.* (2011) and Sturm *et al.* (2004) in autonomy and participation, significant differences were not observed between men and women.

In this study, the relationship between education and participation and autonomy was significant so that the autonomy and participation in people over diploma degree are more than those diploma and under diploma. These people according to their physical condition and their presence in the university along with other people that are physically healthy increase the confidence of the people and mentally to achieve one of their goals that is to increase education can increase their satisfaction and increase the autonomy and participation of these people. In this study, those who received more rehabilitation and care services have greater autonomy and participation that are consistent with the study of fallahpour *et al.* In this context, Silver *et al.* (2012) acknowledge that a constant and early rehabilitation program taking an important role in improving the level of performance, prevention of complications of spinal cord injury and The faster return to the community and enhance the autonomy and participation of the people (Silver *et al.*, 2012). In this study, it was found that the impact of autonomy and participation in the group without a blow is more than a group with blow. The findings from the research of Mousavi in Iran and Andresen *et al.* (1999) in Europe is indicated that mental and emotional performance of spinal cord injuries are caused by the war are more than other people suffering from spinal cord injuries and this increased participation and positive changes than the other people suffering from spinal cord injuries. The reason of this can be the religious confrontation and

nationalistic feeling in dealing with the consequences of such disorder (Andresen *et al.*, 1999). Based on the findings of the present study it was found that the more time passed from damage and also the greater the age the more autonomy and participation would be. Time passage is one of the factors assumed that can cause growth and to change dysfunctional schemes. In fact, after some time has passed since the disaster, individual entered a new phase of life with the new schemes during which tries to address various aspects of the incident and to find the meaning for them (Tedeschi and Calhoun, 2004). This is the first study on autonomy and participation in spinal cord injury patients in Iran. A number of effective variables on autonomy and participation were examined. Given that the sampling was conducted in a single center and all samples is paraplegia, its generalization power will be low and so it is recommended that this to be considered in future studies. Fatigue caused by the large number of questions which still might affect the results, are from the limitations of this study.

CONCLUSION

The results of the present study indicate the correlation between perceived social support with participation and autonomy of patients with spinal cord injuries. So that, in this study the main source of family and spouse are from the key supportive resources of the patients. Therefore, to enhance health and improve autonomy and participation of patients, this should be of particular interest to social welfare institutions and the health of the wife and family of the patient in providing supportive and mental health care to be considered. Since the perception of social support for patients of doctors and nurses were at a lower level, it is necessary for nurses and doctors to check the needs of patients in terms of quality and quantity and with the mobilization of supportive available sources in the community and with participation of the families to take steps to improve the quality of life for patients.

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