

## Original Article

## Examination of the Level of Disability, Loneliness and Self Care Ability of Patients with Multiple Sclerosis

**Esengul Kasikci**

Department of Medical Nursing, Faculty of Nursing, Ataturk University, Erzurum, Turkey

**Nuray Dayapoglu, PhD**

Assoc. Prof. Department of Medical Nursing, Faculty of Nursing, Ataturk University, Erzurum, Turkey

**Correspondence:** Nuray Dayapoglu, Assoc. Prof. Department of Medical Nursing, Faculty of Nursing, Ataturk University, Erzurum, Turkey E-mail: nuraydayapoglu@hotmail.com

### Abstract

This study was conducted to determine disability, loneliness, and self-care ability levels of patients with multiple sclerosis (MS), and to identify prognostic factors. This descriptive study was carried out with 92 MS patients who applied to the neurology polyclinic of a university hospital in the eastern part of Turkey between January and June 2015. The study data were collected using the BDQ, UCLA and SCAS. The Patient Identity form also served to collect data. The collected data were analyzed using the SPSS 18.00 statistical package software. The disability point average of participating patients was  $7.62 \pm 5.67$ , the self-care ability point average of was determined as  $82.82 \pm 22.82$ . The loneliness point average of participating patients was found to be  $50.14 \pm 13.47$ . The study found that of patients; 32.6% have no disability, 22.8% have minimal disability, 26.1% have moderate disability and 18.5% have severe disability. The study found a negative correlation between self-care ability and disability or loneliness:  $r = -0.243$  ( $p < 0.05$ ),  $r = -0.662$  ( $p < 0.001$ ), while there was a positive correlation between disability and loneliness:  $r = 0.408$  ( $p < 0.001$ ). It was determined that MS patients have moderate disability, they experience high levels of loneliness and their self-care ability is at a medium level. The study also found that as patient disability and loneliness levels increase their self-care ability decreases, and when their disability levels increase their loneliness levels also increase.

**Keywords:** Multiple sclerosis, self-care ability, disability, loneliness

### Introduction

Multiple sclerosis (MS) is a disease which negatively affects the health of productive adults and causes serious problems to their work force. Rated as the third most common disease cause of disability, MS is most often diagnosed between the ages of 20 and 40; with females being 2–2.5 times more likely to get MS than males (Comi, 2000; Akdemir, 2005).

It has been estimated that MS affects more than two million people worldwide, with a prevalence of about 15–145 per 1,000 in industrialized populations (Woodward & Mestecky, 2013). The frequency of MS occurrence in Turkey is not known exactly; however, it is estimated to be approaching 30-40 patients in 100,000, with a

total of 35,000 patients in general (Akdemir, 2005).

A major consequence of chronic neurological diseases such as MS is that they prevent people with that disease from performing their normal activities of daily living due to significant limitations and disability (Crawford et al., 2009; Kalb, 2007). Of all the neurological diseases, it is MS that mostly affects young adults and causes poor quality of life by creating disability in its early periods. Disability is defined as, 'a loss of physical, psychological, or anatomical structure and functions; which is viewed by the society as an aberration from normal' (Lieberman, Kopelowicz & Smith, 2000; Druss, Marcus, Rosenheck, 2000). In the progressive form of the

MS disease, irreversible disability is experienced over time.

Studies conducted on patients diagnosed with MS have revealed that patients have different levels of disabilities (Kaya, Akpınar & Çilli, 2003; Karlein, Ridder & Bensing, 2009; Motl & McAuley, 2009; Pittion-Vouyovitch et al., 2006). A semi-cross-sectional study of such, reveals that 44% of MS patients have severe disability (Dahl, et al., 2004). It has also been reported that MS causes disability over time (Kantarca & Wingerchuk, 2006). Another study found that 65% of patients have minimal or moderate disability while only 35% experience severe disability (Pugliatti, 2001). A study by Er and Mollaoglu (2011) discovers that 72.1% of MS patients need other people to assist them with the activities of daily living.

People with a chronic disease and disability often experience loneliness. The physical and psychological problems experienced by MS patients can cause them to suffer from social problems and to isolate themselves, thereby affecting their social support systems, their family lives and communications in general. A study on this reveals that 50% of MS patients feel that they are alone; with issues such as, functional constraints and lack of social support culminating in their loneliness (Beal & Sutiifbergen, 2007). Stuiifbergen, (2007) carried out a study to research sources of support for persons with multiple sclerosis, and most of those who were interviewed stated that other people do not understand them.

Neurological diseases affect the lives of their sufferers negatively, causing them to be unable to perform the activities of daily living, as well as leading to functional weaknesses such as: medical problems, disruption of general physical well-being, difficulty in patient treatment compliance, and weakened self-care ability. Decrease in self-care ability is an important factor that causes MS patients to be unable to manage their disease (Mollaoglu, Fertelli & Tuncay, 2006). The negative effect on patient treatment compliance can lead to complications and serious health problems (Heiderzadeh, Atashpeikar & Alilazar, 2010) The limited number of studies conducted reveals that the self-care ability levels of MS patients were moderate and the self-care abilities of healthy persons in the control group were higher than those of MS

patients (Mollaoglu, Fertelli & Tuncay, 2006; O'Hara, Sauza & Ide, 2000).

Patients with MS need significant support from nurses to cope with the disease symptoms in their own environments, and to survive the negativity and uncertainty which are bound to crop up as their illness advances, and to develop their self-care abilities (Mollaoglu, Fertelli & Tuncay, 2006). In the care of patients with chronic disease, one of the important roles of nurses is to enable patients satisfy their needs by encouraging them to participate in their self-care (Akdemir, 2005).

Nurses need to know to what extent patients' disability, loneliness and self-care ability are affected and they need to put in place some related factors which could help them to plan appropriate patients' care and take further steps in the right direction. However, a limited number of studies have been carried out in this area (Er and Mollaoglu, 2011; Beal & Sutiifbergen, 2007; Mollaoglu, Fertelli & Tuncay, 2006; ). In this context, the purpose of this study is to determine the factor by which the disability, loneliness, and self-care levels of MS patients are affected.

#### Study Questions:

1. What is the degree of disability, loneliness, and self-care ability of the MS patient?
2. What factors affect the degree of disability, loneliness and self-care levels of the MS patient?
3. What is the correlation between disability, loneliness and self-care ability of MS patient?

#### Methods

**Design and Sample:** This descriptive study was carried out to examine the disability, loneliness, and self-care ability of MS patients. The study population comprise of patients who registered in the neurology polyclinic of a university hospital in the eastern part of Turkey, and who had received a diagnosis of MS for at least, six-months according to McDonald's criteria. The researcher made an attempt to reach all patients who matched the study criteria and who had applied to the neurology polyclinic of the hospital between January and June 2015; at the end of the search, 92 patients were signed up to the sample group. Power analysis was performed

to determine whether the sample was sufficient, whether it gained confidence at intervals, whether it had a significant level, whether it effected size, and whether it was powered up to be 95%, 0.05, 0.45 and 99%, respectively for the one-way variance analysis done with 4 groups. This number indicated that the sample was sufficient ( O'Brien & Muller,1993).

**The Study Inclusion Criteria Were:** - Having an Expanded Disability Status Scale (EDSS) point average < 5 (EDSS was evaluated by a neurologist),

- Being 18 years of age or older,
- Being able to establish verbal communication,
- Not receiving a psychiatric diagnosis,
- Having the cognitive ability to respond,
- Voluntarily agreeing to participate in the study.

**Instruments:** For data collection, Patient Identity Form developed by a researcher was used as follows: Brief Disability Questionnaire (BDQ), to determine disability level, Loneliness Scale (UCLA), to determine loneliness level, and Self-Care Ability Scale (SCAS), to assess patients' status in engaging in self-care.

**Patient's Identity Form:** This is a questionnaire which was prepared by the researcher, and which contained a total of twenty-one questions in all. Eleven questions were about patients' demographic characteristics and ten questions were about patients' characteristics as related to disease.

**Brief Disability Questionnaire (BDQ):** The study also assessed the disability levels of patients using BDQ. This survey was developed by Stewart et al. (1988) to assess physical and social disability, based on the questions in the short form of the General Health Survey about disability. There were eleven questions on assessing disability in SDS which evaluates the previous one-month period. Possible scores on the scale ranged from 0 to 22 points. The levels of disability assigned to ranges of disability points were: 0–4, no disability; 5–7, minimal disability; 8–12 moderate disability;  $\geq 13$ , severe disability. The validity and reliability analyses of scale in Turkey were performed by Kaplan (1995) and the Cronbach alpha value was found to be 0.92. The Cronbach alpha coefficient of this study was 0.94.

**Loneliness Scale (UCLA):** Loneliness levels of patients were evaluated using the UCLA Loneliness Scale developed by Russel et al. (1980), and adapted to Turkish by Demir (1989). The UCLA Loneliness Scale contains 20 items, out of which 10 were reverse-coded and 10 were

plain coded. Patients were asked to remark on how often they experience situations listed in the items on four-point Likert-type scale. Possible scores covering the entire scale, ranged from 20 to 80 points. Higher scores indicate greater levels of loneliness. Score ranges of 50–64, 35–49, 20–34 received from the scale showed high-level, moderate-level and low-levels of loneliness, respectively. A study carried out to assess the reliability of the scale, found Cronbach's alpha coefficient to be 0.96 and the correlation coefficient obtained using a test-retest method to be 0.94. The Cronbach's alpha value of this study was 0.93.

**The Self-Care Ability Scale (SCAS):** This scale which was designed to assess patient's ability for self-care activities was developed by Kearney and Fleischer (1979), and in Turkey, its validity and reliability were confirmed and adapted to Turkish by Nahcivan (1999). This is a 35-item scale; possible values assigned to each statement ranged from 0 to 4 and are assessed based on a 5-point Likert-type scale. Eight questions in the tool (3, 6, 9, 13, 19, 22, 26, and 31) are negatively assessed and their score is reversed. The highest possible total score is 140; self-care ability increases proportionally with total score. The cronbach's alpha value of this study was 0.90.

**Data Collection:** Being a visiting day of the associated hospital, the researcher made Monday appointments with the MS patients who had applied to the neurological polyclinic to either come before or after the patient's medical examinations. Patients with MS were assessed in order to determine whether they matched the inclusion criteria for the study. Data collection forms were applied to MS patients who matched the criteria in face-to-face interview. Literate patients read and filled out their forms by themselves, while illiterate patients filled out their forms with the help of the researcher who read the forms to them. Completion of data collection forms for each patient took about 15–30 minutes.

**Statistical Analysis:** The study used numbers, percentages, min-max values and examination of means, t-test, one-way variance analysis, and Spearman correlation analysis. Fishers Least Significant Difference (LSD) was used in situations where variances were homogeneous and Dunnet C was used when they were not homogeneous to determine the significance of situations in one-way variance analysis, resulting

from each group with a significance level of  $p < 0.05$ . The collected data was analyzed using the SPSS 18 package program.

**Ethical Considerations:** Prior to this study, consent of the ethics committee from Ataturk University's Faculty of Health Sciences were sought for, also, institutional permission from Ataturk University Research Hospital, and verbal informed consent from participants were obtained.

### Results

The mean age of the patients is  $35.49 \pm 11.07$  (18–66) and 70.7% of them are female. Of the patients, 66.3% are married, 58.7% live in the city centre, and 47.8% received education at primary level, 48.9% of patients are housewives. The study revealed that the average disease duration for patients is  $66.59 \pm 69.6$  months, for 35.9% of patients the duration of disease is between 6 months and 2 years, 64.1% have relapsing-remitting MS, 55.4% have experienced attacks three or more times, 70.7% do not suffer any other chronic disease.

Analysis of the disability levels of 92 participating patients reveal that 32.6% of them have no disability, while 18.5% have severe disability.

As can be seen in Table 1, the patients' disability scale, loneliness scale, and self-care ability scale

point averages were found to be  $7.62 \pm 5.67$ ,  $50.14 \pm 13.47$ , and  $82.82 \pm 22.82$ , respectively.

According to Table 2, there is a significant difference in disability, loneliness, and self-care ability point averages by age group of patients ( $p < 0.05$ ). The results of the LSD advanced analysis test which was applied, revealed the source of difference between disability, loneliness, and self-care point averages; it also reveals that patients aged 48 and older have significantly higher disability points than other age groups; moreover, patients aged between 38 and 47 have higher loneliness points than patients aged between 18 and 27; patients aged 48 and older have significantly lower self-care ability points than other age groups.

The educational background of patients significantly affects disability, loneliness, and self-care points ( $p < 0.05$ ). The advanced analysis reveals that illiterate patients have a higher disability point average (Dunnet C); patients holding a bachelor's degree have a lower loneliness point average (LSD), and they have higher self-care ability point average (LSD) than patients at other education levels, with the exception of high school graduates (Table 2).

The correlation with loneliness, disability, and self-care ability point averages is statistically insignificant for patients' gender, marital status, and place of residence ( $p > 0.05$ ) (Table 2).

**Table 1.** Disability, loneliness and self-care ability scores of patients with MS

Scale	Min.	Max.	X	SD
Brief Disability Questionnaire (BDQ)	0	22	7.62	5.67
Loneliness Scale (UCLA)	20.00	80.00	50.14	13.47
Self-Care Ability Scale (SCAS)	33.00	132.00	82.82	22.82

**Table 2.** Comparison of disability, loneliness and self-care ability scores related to characteristics of patients with MS (n=92)

Characteristics		Disability		Loneliness		Self-care ability	
	n	X ± SD		X ± SD		X ± SD	
<b>Age (18/66)</b>							
18-27	25	4.08	4.32	44.68	12.69	88.80	20.15
28-37	30	6.57	4.46	48.40	14.28	83.63	17.65
38-47	25	9.04	4.14	52.44	11.44	87.96	23.41
48 age and above	12	14.67	6.71	61.08	10.44	57.58	23.86
		F=15.083 <b>p=0.000</b>		F=4.998 <b>p=0.003</b>		F=7.081 <b>p=0.000</b>	
<b>Gender</b>							
Female	65	7.88	5.41	49.51	14.60	82.05	22.49
Male	27	7.00	6.31	51.67	10.37	79.85	23.77
		t=0.674 p=0.502		t=-0.801 p=0.426		t=0.801 p=0.425	
<b>Education</b>							
Illiterate	10	14.90	5.11	57.20	11.38	59.80	23.11
Primary school	44	8.25	5.16	53.07	13.62	81.31	21.51
High school	20	6.40	5.40	49.90	11.62	84.70	20.52
University	18	3.39	5.28	39.33	10.40	97.17	18.03
		F=13.034 <b>p=0.000</b>		F=6.452 <b>p=0.001</b>		F=7.040 <b>p=0.000</b>	
<b>Marital Status</b>							
Married	61	8.34	5.22	50.52	13.03	83.26	21.81
Unmarried	31	6.19	6.30	49.39	14.51	81.94	25.04
		t=1.739 p=0.085		t=0.381 p=0.704		t=0.262 p=0.794	
<b>Income level</b>							
Low	59	9.15	5.53	54.08	12.95	70.05	22.30
Moderate	32	4.85	4.89	43.09	11.50	91.33	21.52
		t=3.703 <b>p=0.000</b>		t=4.060 <b>p=0.000</b>		t=-2.774 <b>p=0.007</b>	
<b>MS Type</b>							
Primary progressive	17	6.06	4.37	52.06	13.67	78.47	20.66
Relapsing-remitting	59	8.00	5.81	49.80	13.56	82.25	23.71
Secondary-progressive	12	9.00	6.45	50.67	13.57	86.92	24.25
Benign	4	5.45	4.50	45.50	15.20	97.25	6.02
		F=1.166 p=0.327		F=0.285 p=0.836		F=0.876 p=0.457	
<b>Duration of MS</b>							
6 month - 2 year	33	5.73	5.05	46.67	13.60	89.90	17.54
3- 7 year	32	6.84	5.35	52.31	13.02	75.31	21.66
8-12 year	18	8.39	3.71	49.22	14.34	88.39	22.23
13 year and above	9	15.8	5.47	57.00	10.39	73.11	35.07
		F=10.068 <b>p=0.000</b>		F=1.865 p=0.141		F=3.283 <b>p=0.025</b>	
<b>Comorbid Disease</b>							
Yes	27	11.6	5.75	56.48	13.99	73.74	28.12
No	65	5.82	4.58	47.51	12.44	86.58	19.24
		t=5.427 <b>p=0.000</b>		t=3.037 <b>p=0.003</b>		t=-2,171 <b>p=0.036</b>	

Statistically significant results are shown in bold

**Table 3.** Correlation between disability, loneliness and social self-care ability

Scale	Disability	Loneliness	Self-care ability
Disability	-	r= 0.408**	r= - 0.243*
Loneliness	r= 0.408**	-	
Self-care ability	r= - 0.243*	r= - 0.662**	-

\*p<0.05, \*\*p<0.001

The analysis of the relationship between patients' income level and disability, loneliness, or self-care ability, reveals that disability and loneliness point averages are higher for patients whose income levels are lower than their expenses, while their self-care ability point average is lower ( $p < 0.05$ ) (Table 2).

Table 2 shows the distribution of disability, loneliness, and self-care ability point averages relative to patients' disease characteristics. Analysis of the table demonstrated that some types of MS do not affect disability, loneliness, or self-care ability point averages ( $p > 0.05$ ). While the relationship between patients and the duration of disease and disability or self-care ability point averages were found to be statistically significant ( $p < 0.05$ ), duration of disease did not significantly affect loneliness point averages ( $p > 0.05$ ). The advanced analysis (LSD), which was performed to determine which groups were associated with differences in disability level, reveals that patients diagnosed for 13 or more years have significantly higher disability level points than any other groups. The advanced analysis (Dunnett C) performed for self-care ability reveals that patients diagnosed for between three and seven years have a lower self-care ability point average than those diagnosed for between 6 months and 2 years. The analysis of the study's findings showed a significant correlation between the presence of additional diseases and both self-care ability and disability point averages ( $p < 0.05$ ). Patients with additional diseases had higher disability and self-care ability point averages than patients with no additional diseases.

Table 3 shows the correlations between patient point averages received via disability, loneliness, and self-care scales. The study found a negative correlation between self-care ability and disability or loneliness:  $r = -0.243$  ( $p < 0.05$ ),  $r =$

$-0.662$  ( $p < 0.001$ ), respectively; while there was a positive correlation between disability and loneliness:  $r = 0.408$  ( $p < 0.001$ ). It was discovered that as disability and loneliness levels increase, self-care decreases, and as self-care level increases, loneliness level also increases.

### Discussion

The data collected from this study which was carried out to examine the disability, loneliness, and self-care ability of MS patients is discussed in the context of related literature.

This study finds the point average of the self-care ability scale to be  $82.82 \pm 22.82$ . It also observed that the self-care ability point average of patients is at a moderate level (where 0 represents the lowest ability and 140 the highest). There are a limited number of studies in this area. Mollaoglu et al. (2006) conducted a study with MS patients where he discovers the self-care ability point average to be  $76.60 \pm 9.47$ . The study results of O'Hara et al. (2000), and this study's results are consistent with each other, where self-care ability point averages of MS patients were found to be moderate. It is reported in the literature that one of the most important problems seen in MS patients is a deficit in self-care ability, and self-care is a critical factor for effectively coping with the disease (McLaughlin & Zeeberg, 1993).

The loneliness point average of MS patients who were included in the study was found to be  $50.14 \pm 13.47$ . The loneliness point average of participants were at a high level (possible scores on the scale ranged from 20–80). A study discovered that 50% of MS patients feel that they are alone, and they also experience some functional constraints which affects their social support, and culminates into loneliness (Beal & Sutiifbergen, 2007). Stuiifbergen, (1992) carried out a study to investigate support sources for

persons with MS, most of them stated that others do not understand them. Physical and psychological problems experienced in MS can cause a person to suffer social problems and to become isolated, and these have been found to negatively affect their independence, family relations and communications in general (Flynn, 2002).

This study reveals the disability point average of MS patients to be  $7.62 \pm 5.67$ , a moderate level of disability (8-12 points represent moderate disability). Moreover, it was determined that 32.6% of patients have no disability, 22.8% have minimal disability, 26.1% have moderate disability and 18.5% have severe disability. Er and Mollaoglu (2011) discovered that 37.7% of patients have no disability while 14.4% of them experienced severe disability. A semi-cross-sectional study conducted by Dahl et al. (2004) reveals that 44% of MS patients have severe disability. Pugliatti et al. (2001) reveals that 65% of MS patients have minimal or moderate disability and 35% have serious or severe disability, on the other hand Granieri et al., (1996) reported that 38% of patients have serious disability and 62% experience minimal or moderate disability.

It was discovered in this study that the group of participating patients who are of age 48 years and above experienced a significantly higher degree of disability than all other age groups and their self-care abilities are low. The study also found out that patients aged between 38 and 47 suffer more loneliness than patients aged between 18 and 27. Functional regression with increasing age can be considered as an important factor relating to self-care ability for MS patients. According to study results, disability and loneliness point averages have increased with increasing age. Cook et al. (2003), D'Alisa et al. (2005) and Mollaoglu et al. (2011) conducted studies on MS patients which reveals that as age increases, disability in physical and social areas also increases. The results of this and prior studies are consistent. In the case of progressive disease, irreversible disability is suffered over time. Approximately five years after the onset of MS, the majority of patients' experience dysfunction and half of them are substantially limited in performing their activities (Mollaoglu, Fertelli & Tuncay, 2006). Furthermore, physical, social, and economic changes occur with increasing age, causing people to feel more alone (Bilgili, Kitiş & Ayaz,

2012).

In this study, the analysis of patients' educational backgrounds reveals that illiterate patients experienced significantly greater disability. It was found that patients holding a bachelor's degree experienced significantly less loneliness and had greater self-care ability. Er and Mollaoglu (2011) and Lerdal et al., (2003) conducted studies with MS patients and gave results which are consistent with the results of this study. As the level of patients' educational background increases, their point averages for disability and the activities of daily living improve. Another study assessing disability in neurological diseases reported that degree of disability in physical and social areas increases with a decrease in patients' education. As education level of patients decrease their disability levels increase. A reason for this could be that people in the low-education level group have less opportunity to access information, and thus, benefit less from social support networks. However, a study previously conducted with MS patients did not find a significant relationship between educational background and self-care point averages (Mollaoglu, Fertelli & Tuncay, 2006). A reason for the decrease in loneliness point average and increase in self-care point average of patients as educational level increased might be explained to be due to an improvement in conscious coping mechanisms and in having better financial potentials and social conditions.

The study reveals that the degree of disability and loneliness of participating patients whose income level is lower than their expenses is significantly higher, while their self-care ability was found to be lower. Er and Mollaoglu (2011), carried out studies with MS patients and discovered an important difference between disability and daily living activities according to income levels of patients. It was revealed that as income levels of patients decrease they become more dependent on others to continue performing their daily living activities; and their disability point average also increases. These results are consistent with our study results. High-income patients probably have more resources made available to them, including accessory equipment and manpower to maintain their daily living activities and maintain their self-care more easily, which could be said to correlate with this result. As a follow up with the findings of our study, it was concluded that the self-care ability point average of low-income MS patients are

also low, which is compatible with results of study conducted with chronic disease patients (Bakoglu & Yetkin, 2000). The analysis of the effect of patients' income levels on loneliness reveals that patients, whose income levels are lower than their expenses, feel significantly more loneliness. In a literature review, Kaya et al. (2003) stated that social and economic parameters will be effective in creating emotional disorders and gaining continuity with them. It is also thought that because patients cannot allocate enough money to their social lives, they experience more loneliness.

While the difference between patient's disease durations and disability, self-care point averages was found to be statistically important, the difference between patient's disease durations and loneliness point averages was found to be statistically insignificant. The study reveals that patients who have been diagnosed for 13 or more years' experience significantly greater disability than all other groups. A relevant study did not find a significant relationship between duration of disease and disability; however, the comparison of patient's daily living activity points found an important difference between 0–3 year of disease duration and 7 or more years of disease duration. MS is a disease that causes progressive disability over time. As the disease progresses, disability level increases and the person needs help to perform their daily living activities (Woodward & Mestecky, 2013). This study reveals that patients who have been diagnosed for 3-7 years have lower self-care ability point average than those diagnosed for 6 months and 2 years. It was stated in one study that MS patients' ability to cope with disease decreases, as disease duration is increasing (Wollin, Spencer, McDonald, et al., 2013). Barak and Achiron (2006) concluded that perceptions of cognitive exhaustion in MS patients increased over time; and additionally they need help to meet their self-care needs. It has been observed that duration of disease does not affect loneliness point averages. The studies previously conducted on the mental dimension of MS, found similar results which correlates with the results of this study (Gottberg, et al., 2007; Soyuer, Unalan & Mirza, 2010).

While there is a negative correlation between self-care ability in MS patients and disability or loneliness, a positive correlation between disability and loneliness was seen. It was found that as disability and loneliness levels increase,

self-care decreases and as self-care ability increases, loneliness increases. Mansson and Lexell (2004) conducted a study to examine performances of MS patients on daily living activities, and they reported that there is a correlation between some parts of self-care ability scale and dependent states of patients. Wollin et al. (2013) stated that as severity of disease increases, patients' self-efficiency and ability to cope with disease increases correspondingly. According to our study results, as the disability level of MS patient's increase, their loneliness level also increases. A study conducted with MS patients found a significant relationship between functional constraints and perceived health status and loneliness, which is compatible with our own study results. Patients with minimal disability are usually able to maintain their business lives, perform their daily living activities and see hope for the future due to slow course of disease progression.

**Limitations:** This study is only generalizable to MS patients who applied to the neurology polyclinic of university hospital in the eastern part of Turkey for their weekly control between the dates specified.

**Conclusions:** This study found that MS patients have moderate disability, they experience high levels of loneliness, and their self-care ability is at a medium level. Moreover, as disability and loneliness levels of patients increase their self-care ability decreases. Consequently, when disability is experienced in MS patients, self-care ability and loneliness levels should be monitored to guide planning of nursing care; they should be assessed at periodically and factors affecting these parameters should be taken into consideration. Furthermore, in order to improve patient self-care abilities, nurses who are responsible for MS patients must not ignore the problems of disability and loneliness and should plan care with this in mind.

## References

- Akdemir, N. (2005) Common neurological diseases and nursing care. Akdemir N, Birol L, eds. Internal medicine and nursing care. Ankara, System Ofset Publishing, 2. Edition, 827- 858.
- Bakoglu, E., Yetkin, A. (2000) The evaluation of self-care agency of with hypertension patients. C.U. School of Nursing Journal 4 (1):41-49.
- Barak, Y., Achiron, A. (2006) Cognitive fatigue in multiple sclerosis: findings from a two-wave screening project. Journal of the Neurological Sciences 245(12):73–76.



- Beal CC, Sutiifbergen A. (2007) Loneliness in women with multiple sclerosis. *Rehabilitation Nursing* 32(4):165-171.
- Bilgili, N., Kitiş, Y., Ayaz, S. (2012) Assessment of loneliness, quality of sleep and affecting factors in elders. *Turkish Journal of Geriatrics* 15: 82-90.
- Comi, G. (2000) Why treat early multiple sclerosis patients? *Curr Opin Neurol* 13:235-240.
- Cook, AS., Potlo, A., Stewart, A. (2003) Environmental components of mobility disability in community living older person. *Journal of the American Geriatrics Society* 51: 393-398.
- Crawford, DK., Mangiardi M, Xia X, et al. (2009) Functional recovery of callosal axons following demyelination: a critical window. *Rehabil Psychology Journal* 52: 463-69.
- D'Alisa, S., Baudo, S., Mauro, A., et al. (2005) How does stroke restrict participation in long term post-stroke survivors? *Actual Neurol Scand* 112:157-162.
- Dahl, OP., Aarseth, JH., Myhr, KM., Nyland, H., Midgard, R. (2004) Multiple sclerosis in Nord-Trondelag County Norway: a prevalence and incidence study. *Acta Neurol Scan* 109:378-384.
- Demir, A. (1989) Validity and reliability of the UCLA loneliness scale. *Psychology Journal* 7(23):14-18.
- Druss, BG., Marcus, SC., Rosenheck, RA. (2000) Understanding disability in mental and general health conditions. *Am Journal Psychiatry* 157: 1485-1491.
- Er, F., Mollaoglu, M. (2011) Disability and activities of daily living in the patients with multiple sclerosis. *Journal of Neurological Sciences (Turkish)* 28(2):190-203.
- Flynn, S. (2002) Multiple sclerosis. The treetops model of residential care. *British Journal of Nursing* 11(9): 635-642.
- Gottberg, K., Einarsson, U., Fredrikson, S., Vonkoch, LA. (2007) Population-based study of depressive symptoms in multiple sclerosis in Stockholm county: Association with functioning and sense of coherence. *Journal Neurol,Neurosurg Psychiatry* 78:60-65.
- Granieri, E., Casetta, I., Tola, MR. (1996) Epidemiology of multiple sclerosis. *Neurol Clin* 14:291-308.
- Kalb, R (2007) The emotional and psychological impact of multiple sclerosis relapses. *Journal Neurol Science* 256: 29-33.
- Kantaracia, O., Wingerchuk, D. (2006) Epidemiology and natural history of multiple sclerosis;new insights. *Current Opinion in Neurology* 19:248-254.
- Kaplan, İ. (1995) Mental disorders and disability in a primary health care clinic in semi-rural area. *Turkish Journal of Psychiatry* 6: 169-179.
- Karlein, MG., Ridder, DT., Bensing, JM. (2009) Fatigue in multiple sclerosis reciprocal relationship with physical disability depression. *Journal Psychosomic Res* 53: 775-781.
- Kaya, N., Akpınar, Z., Çilli, A. (2003) Relation of quality of life to depression and anxiety in multiple sclerosis. *Anatolian Journal of Psychiatry* 4: 220-225.
- Kearney, BY., Fleisher, BJ. (1979) Development of an instrument to measure exercise of self-careagency. *Research in Nursing & Health* 22: 25-34.
- Lerdal, A., Celius, EG., Moum, T. (2003) Fatigue and its association with socio demographic variables among multiple sclerosis patients. *Mult Scler* 9:509-514.
- Lieberman, RP., Kopelowicz, A., Smith, TE. (2000) *Psychiatric rehabilitation*. Ed: Sadock BJ and Sadock VA. *Comprehensive Textbook of Psychiatry* Lippincott. Education Williams and Williams. Philadelphia 32: 19-20.
- Mansson, E., Lexell, J. (2004) Performance of activities of daily living in multiple sclerosis. *Disability and rehabilitation* 26 (10): 576-585.
- McLaughlin, J., Zeeberg, IB. (1993) Selfcare and multiple sclerosis: A view from two cultures. *Social Science and Medicine* 37 (3):315-329.
- Mollaoglu, M., Fertelli, T., Tuncay, F. (2006) Assessment of Self-Care Agency in Patients with Multiple Sclerosis. *Journal of Ataturk University School of Nursing* 9 (3): 2-3.
- Mollaoglu, M., Fertelli, TK., Tuncay, FO. (2011) Disability in elderly patients with chronicneurological illness: Stroke, multiple sclerosis and epilepsy. *Archives of Gerontology and Geriatrics* 53:227-223.
- Motl, RW., McAuley, E. (2009) Pathways between physical activity and quality of life in adults with multiple sclerosis. *Journal of Health Psychology* 2: 682-689.
- Nahcivan, NO., Tuncel, N. (1999) The exercise of self-care agency and effects of family environment in healthy young people. *Nursing Bulletin* 12 (45): 49-60.
- O'Brien, RG., Muller, KE. (1993) *applied analysis of variance in behavioral science* marcel dekker. New York, Chapter 8: 297-344.
- O'Hara, L., Sauza, L., Ide, L. (2000) A Delphi study of self-care in a community population of people with multiple sclerosis. *Clinic Rehabilitation* 14(1):62-72.
- Pittion-Vouyovitch, S., Debouverie, M., Guillemin F, et al. (2006) Fatigue in multiple sclerosis is related to disability, depression and quality of life. *Journal Neurol Science* 243: 39-45.
- Pugliatti, M., Sotgiu, S., Solinas, G., et al. (2001) Multiple sclerosis epidemiology in Sardinia: evidence for a true increasing risk. *Acta Neurol Scan* 103i 20-26.
- Russell, D., Peplau, LA., Cutrona, CE. (1980) The revised ucla loneliness scale: concurrent and discriminant validity evidence. *Journal of Personality and Social Psychology* 39:472- 480.
- Soyuer, F., Unalan, D., Mirza, M. (2010) Depressive

- symptoms in multiple sclerosis and the association with sociodemographic factors and functional status. *Turkish Journal of Neurology* 16 (1):31-35.
- Stewart, AL., Hays, RD., Ware, JEJ. (1988) The MOS Short-form general health survey. Reliability and validity in patient population. *Med Care* 26(7):724-735.
- Stuifbergen, A. (1992) Meeting the demands of illness: Types and sources of support for individuals with multiple sclerosis and their partners. *Rehabilitation Nursing Research* 14-23.
- Wollin, JA., Spencer, N., McDonald, E., et al. (2013) Longitudinal changes in quality of life and related psychosocial variables in Australians with multiple sclerosis. *Int Journal MS Care* 15: 90-97.
- Woodward, S., Mestecky, AM. (2013) In: *Neurological Sciences Nursing*, Durna Z, Karadakovan A., Topcuoglu MA, (Translation editors). *Neuroscience Nursing Evidence-Based Practice*, Embrey N, Matthews V. 1. Edition, Istanbul, Nobel Medicine Bookstores, 472-484.