

The influence of self-care agency on quality of life in patients with multiple sclerosis

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ABSTRACT

Objectives: This study aimed to determine the self-care agency's (SCA) influence on the quality of life (QoL) in patients with multiple sclerosis.

Materials and methods: The descriptive corellational study was conducted with 120 patients (84 females, 36 males; mean age: 40.1±11.6 years; range, 19 to 73 years) with multiple sclerosis between September 2017 and May 2018. The data were collected from the SCA scale and the Multiple Sclerosis Quality of Life-54 (MSQoL-54) scale. Multivariate variance analysis was performed to evaluate the relationship between the MSQoL-54 scale and the SCA scale and the influence of SCA on QoL.

Results: The mean score of the SCA scale was 93.37±25.47. In the evaluation of the MSQoL-54 scores, the patients received 53.92±10.78 points from the compound physical health subscale and 62.52±17.93 points from the compound mental health subscale. It was determined that SCA could explain the QoL related to physical health by 92% and mental health by 95%.

Conclusion: Since SCA affects components of QoL, SCA is key in ensuring or increasing the QoL and well-being. Furthermore, disability status comes to the foreground as another variable that influences all the fields of QoL. Therefore, care interventions should be undertaken to adapt the patients to treatment and functional capacity to prevent labor loss and decrease dependency.

Keywords: Multiple sclerosis, quality of life, self-care.

Multiple sclerosis (MS) is an inflammatory, autoimmune, chronic disease that causes damage to the myelin sheath and axons in the central nervous system, functional clearances, disability, and deterioration in quality of life (QoL).^[1] It is observed at a rate of 1/3,000 individuals worldwide and 1/300 in countries with a high prevalence, and about 2.8 million individuals are estimated to have been diagnosed with MS worldwide.^[2] Its incidence is reported to be 2.1/100,000 annually, and 50,000 individuals are reported to have been diagnosed with MS in Türkiye.^[2,3] The mortality risk (hazard ratio) is reported to be 10.2 in patients below 18 years of age and 4.2 in ages between

18 and 40.^[4] The appearance of the disease in young adulthood and its chronic nature, leading to morbidity and impairing the QoL, makes it important.^[5]

Sensory issues such as paresthesia or hypoesthesia, fatigue, visual problems such as diplopia, cognitive disorders, including memory and concentration, sexual dysfunction, urinary incontinence, and spasticity may be observed in patients.^[2] Furthermore, the disease may lead to economic burden due to loss of work or loss of status, social problems such as alterations in family processes, and loss of a spouse in case of divorce, all of which may impair the QoL as

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frequently as physical problems.^[6-8] Preserving and maintaining health and relieving the symptoms gain importance, and consequently, the concept of “self-care” has come to the foreground.^[9]

Self-care is the contribution and effort of the individual for their self-health and wellness through preserving and improving health.^[9] Self-care agency (SCA) is the initiation or application capacity of self-care behaviors.^[10] Disruption of SCA can lead to a decrease in QoL.^[11]

Self-care agency was shown to positively affect the QoL. Self-care behaviors represent a critical aspect of a healthy lifestyle. Individuals with high self-care power have high self-esteem and increase their QoL with healthy living behaviors.^[12] Since MS is a disease that requires regular and continuous follow-up similar to other chronic diseases, it requires a biopsychosocial approach.^[13] A contribution should be made to cope with the problems encountered due to the disease, and interventions should be made to increase the QoL. Hence, determining the SCA of patients with MS and its effect on the QoL is essential for nursing care. The nurse is responsible for determining the self-care power, supporting it if it is sufficient, and applying and following the interventions to improve it if it is insufficient. At this point, it does this by introducing supportive/educational and remedial nursing systems. From this point of view, this research aimed to determine individuals' self-care power and reveal its effects on QoL.

MATERIALS AND METHODS

The descriptive correlational study included 120 patients (84 females, 36 males; mean age: 40.1±11.6 years; range, 19 to 73 years) with MS who presented to the Neurology Outpatient Clinic of Ondokuz Mayıs University, Health Application and Research Center between September 2017 and May 2018. The inclusion criteria were as follows: ability to read and write Turkish, being 18 years of age or above, being diagnosed for at least six months, and not having another functional disorder that may influence the SCA and lead to disability.

Data were collected by the researcher in the outpatient clinic setting using an introductory information form, the SCA scale, and the Multiple Sclerosis Quality of Life-54 (MSQoL-54) scale. The Expanded Disability Status Scale (EDSS) score was obtained from the physician's examination.

The introductory information form consisted of 10 questions. These questions included sociodemographic data, such as age and sex, and disease-related data, such as attack frequency, MS duration, and MS type.^[14,15]

Kearney and Fleischer^[16] developed the SCA scale in 1979. The Turkish validity and reliability study was conducted by Nahcivan^[15] in 1994. It is a 5-point Likert scale with 35 items, with each item scored between 0 and 4. The minimum total score is 0, and the maximum is 140, with higher scores indicating better SCA. The scale has no cutoff score. The reliability coefficient of the scale was found to be 0.80.^[16] In the Turkish validity and reliability study of the scale, the reliability coefficient was reported as 0.92.^[15] In this study, the Cronbach's alpha coefficient was 0.952.

The MSQoL-54 instrument was developed by Vickrey et al.,^[17] and the Turkish reliability and validity studies were carried out by İdiman et al.^[18] and Tülek.^[19] The scale was developed by adding new items to the SF-36 (36-item Short Form Health Survey). The MSQoL-54 scale is composed of two main subscales, including the compound physical health (CPH) and the compound mental health (CMH). Higher scores indicate higher QoL. The scale has no cutoff score. The reliability coefficient of the scale was found to be 0.96 for CPH and 0.94 for CMH subscales.^[17] In the Turkish validity and reliability study of the scale, the reliability coefficient was reported as 0.94 for CPH and as 0.89 for CMH.^[18] In this study, the Cronbach's alpha coefficient was 0.857 for CPH and 0.704 for CMH.

While the MSQoL-54 scores constituted the dependent variable of the study, the total score of SCA scale, introductory information (age, sex, education level, and marital status), and characteristics of the disease (type of disease, disability score, duration of disease, and number of attacks) constituted the independent variables.

Statistical analysis

The G*Power version 3.1 software (Heinrich-Heine-Universität Düsseldorf, Düsseldorf, Germany) was used to determine the sample size (95% confidence interval, 0.95 power).^[20,21] The data were analyzed using the IBM SPSS version 21.0 software (IBM Corp., Armonk, NY, USA). In descriptive analyses, the mean ± standard deviation (SD) was provided for parametric tests, and the median, minimum, and maximum were given for nonparametric tests. The independent sample t-test

and one-way analysis of variance were used for the normally distributed data, and the Kruskal-Wallis H test was used for the nonnormally distributed data. The multivariate variance analysis was applied for the analysis of the relationship between MSQoL-54 and SCA scale and the influence of SCA on the QoL. A p-value <0.05 was considered statistically significant.

TABLE 1
Distribution of sociodemographic and disease-related data (n=120)

	n	%
Descriptive characteristics		
Age (year)		
18-29	27	22.5
30-39	34	28.3
40-49	34	28.3
50-59	18	15.0
≥60	7	5.9
Sex		
Female	84	70
Male	36	30
Education status		
Literate	5	4.2
Primary School	45	37.5
High School	46	38.3
University	24	20.0
Marital status		
Married	88	73.3
Single	32	26.7
Employment status		
Not working due to disease	35	29.2
Not working	62	51.7
Working	23	19.1
Disease-related data		
MS type		
RRMS	87	72.5
PPMS	9	7.5
SPMS	6	5.0
CIS	18	15.0
EDSS		
0-1.5	65	54.2
2-3.5	18	15.0
4-6	37	30.8
Number of attacks		
0-5	80	66.7
6-11	32	26.7
12 and above	8	6.6
Disease duration		
6 months-1 year	11	9.2
2-3 years	19	15.8
4-5 years	23	19.2
6-7 years	12	10.0
8 years and above	55	45.8

MS: Multiple sclerosis; RRMS: Relapsing-remitting MS; PPMS: Primer progresif MS; SPMS: Sekonder progresif MS; CIS: Clinically Isolated Syndrome.

RESULTS

The descriptive data and disease characteristics of the participants are presented in Table 1. Of the patients, 28.3% were in the 40 to 49 age group, 38.3% were graduates of intermediate/high school, 73.3% were married, and 51.7% were unemployed. Of them, 72.5% had relapsing-remitting MS, 54.2% had EDSS scores of 0 to 1.5, 66.7% had experienced 0 to 5 attacks, and 45.8% were diagnosed with MS for eight years or longer (Table 1).

The mean SCA scale score was determined to be 93.37±25.47. The mean score of the MSQoL-54 CPH subscale was 53.92±20.78, and the mean score of the CMH subscale was 62.52±17.93 (Table 2). Table 3 represents the distribution of the mean scores of the SCA scale and the MSQoL-54 scale. No statistically significant difference was found in the distribution of the SCA scale score according to the descriptive data and disease characteristics; however, sex was found to affect the mean scores of SCA scale (p<0.05, Table 3).

The mean SCA scale scores of patients who were university graduates were found to be statistically significantly higher than those of the other groups

TABLE 2
Mean scores of the MSQoL-54 subscales and SCA scale

Scale	Mean±SD	
Self-care agency scale	93.37±25.47	
CPH sub-dimensions	Physical health	44.79±32.17
	Physical problems-related role limitation	58.54±40.93
	Pain	61.79±28.50
	Energy-Fatigue	39.46±16.99
	Social functioning	66.52±25.40
	Health perception	46.04±23.85
	Health distress	59.25±23.67
	Sexual functioning	67.81±35.59
	Compound Physical Health (CPH)	53.92±20.78
	CMH sub-dimensions	Emotional problems-related role limitation
Emotional wellness		55.10±15.38
Health distress		59.25±23.67
Cognitive functions		64.37±25.27
Overall quality of life		54.40±20.54
Compound Mental Health (CMH)		62.52±17.93
Alteration in health	48.95±26.60	
Satisfaction from sexual functioning	57.10±33.44	

MSQoL-54: Multiple Sclerosis Quality of Life-54; SCA: Self-care agency; SD: Standard deviation.

TABLE 3
Distribution of the MSQoL-54 subscales and SCA scale according to the descriptive characteristics of the patients

Descriptive characteristics	MSQoL-54 Scale						Compound Physical Health (CPH) (n=120)						Compound Mental Health (CMH) (n=120)						SCA scale					
	Mean±SD	Median	Min-Max	χ ²	t	F	p	Mean±SD	Median	Min-Max	χ ²	t	F	p	Mean±SD	χ ²	t	F	p					
Sex																								
Female	57.6±20.2				3.104		0.002*	65.1±17.0				2.489		0.014*	97.7±24.9	2.941			0.004*					
Male	45.2±19.8						56.4±18.9								83.3±24.3									
Educational status																								
Literate	56.7±18.8							65.3	39.4-82.4						75.8±18.4 ^a									
Primary School	50.7±21.2				0.974	0.408		66.1	10.9-91.2	3.673				0.299	92.3±23.5 ^b				4.942					
High School	53.8±19.5							67.2	17.9-84.6						88.1±26.4 ^a				0.003*					
University	59.6±22.7							70	27.6-89.2						109.0±22.1 ^b									
Employment status																								
Not working due to disease	38.7±16.3 ^a				16.781	0.001**		55.5 ^a	10.9-89.7	16.439				0.001**	83.9±23.5 ^b				0.031*					
Not working	59.7±18.8 ^b							69.9 ^b	17.9-91.2						96.9±25.0 ^b									
Working	61.5±20.6 ^b							73.4 ^b	27.6-84.6						98.3±26.9 ^{ab}									
MS type																								
RRMS		53.8 ^a	9.4-89.5					66.1 ^a	10.9-91.2						92.1±26.7									
PPMS		29.7 ^a	19.6-79.9	15.460		0.001**		64.7 ^{ab}	31.8-89.7	10.669				0.014*	91.6±26.0			0.721	0.541					
SPMS		39.9 ^a	36.0-55.8					53.6 ^{ab}	52.7-77.5						90.5±24.3									
CIS		73.5 ^b	34.5-84.8					75.6 ^b	63.5-84.4						101.5±19.2									
EDSS																								
0-1.5	62.6±18.4 ^a							66.2±17.9 ^a							96.2±26.8									
2-3.5	50.9±19.4 ^b				18.228	0.001**		60.7±19.1 ^{ab}						0.039*	91.8±23.2			0.927	0.399					
4-6	40.1±17.5 ^b							57.0±16.2 ^b							89.2±24.0									
Number of attacks																								
0-5	58.5±20.2 ^a							66.0±17.4 ^a							95.5±26.0									
6-11	47.0±19.1 ^b				7.357	0.001**		57.8±16.9 ^{ab}						0.003*	89.7±23.9			0.905	0.408					
12 and above	36.0±18.1 ^b							46.7±16.6 ^b							86.5±26.6									
Disease duration																								
6 months-1 year	60.3±24.7 ^{ab}							74.2 ^{ab}	10.9-89.2						90.9±27.7									
2-3 years	55.7±20.0 ^{ab}							65.3 ^{ab}	17.9-79.9						89.2±27.2									
4-5 years	68.7±17.8 ^a				5.753	0.001**		76.1 ^a	26.8-91.2	14.358				0.006*	102.5±26.1			0.975	0.424					
6-7 years	50.8±20.8 ^{ab}							68.9 ^{ab}	40.2-89.7						93.7±25.0									
8 years and above	46.6±18.2 ^b							63.1 ^b	21.5-82.4						91.4±24.3									

MSQoL-54: Multiple Sclerosis Quality of Life-54; SCA: Self-care agency; SD: Standard deviation; MS: Multiple sclerosis; RRMS: Relapsing-remitting MS; PPMS: Primary progressive MS; SPMS: secondary progressive MS; CIS: Clinically isolated syndrome; χ²: Kruskal Wallis test statistics; t: Independent-samples t test statistics; F: ANOVA test statistics; p: Significance level; * p<0.05; ** p<0.001; a-b: No difference between the groups with the same letter.

TABLE 4
Multivariate analysis between the SCA scale and the MSQoL-54 scale

MSQoL-54 Scale	B	SD	t	p	r	R ²	
Compound physical health (CPH)	0.566	0.534-0.599	0.016	34.568	0.000*	0.614	0.921
Compound mental health (CMH)	0.666	0.638-0.694	0.014	46.773	0.000*	0.656	0.955

SCA: Self-care agency; MSQoL-54: Multiple Sclerosis Quality of Life-54; B: Beta coefficient; SD: Standard deviation. t: t value; p: Significance level; r: Correlation coefficient; R²: corrected specificity coefficient; * p<0.001.

($p < 0.05$, Table 3). The mean SCA scale scores of the employed patients were higher than unemployed patients ($p < 0.05$). The scores of the patients with clinically isolated syndrome (CIS) were higher than those in the other MS types, but the difference was not statistically significant ($p > 0.05$, Table 3). The EDSS score, the number of attacks, and disease duration were determined not to significantly affect the SCA scale scores ($p > 0.05$, Table 3).

The CPH and the CMH subscale scores were found to be influenced by sex, and females were determined to receive higher scores from all of the subscales of the QoL ($p < 0.05$, Table 3). While the subscales of the MSQoL-54 scale were not affected by educational status, they were influenced by employment status. The mean scores of the employed patients were found to be higher ($p < 0.05$, Table 3).

The mean scores of the patients followed up due to CIS were found to be higher ($p < 0.05$) (Table 3). The mean scores of the MSQoL-54 scale were found to increase as the EDSS score and the number of attacks decreased, and the difference was statistically significant ($p < 0.05$, Table 3). The patients with a disease duration of four to five years had statistically significantly higher MSQoL-54 scale scores ($p < 0.05$, Table 3).

When the effect of SCA on the QoL was evaluated, a highly positive relationship was found between the CPH and the CMH subscales ($p < 0.05$, Table 4). Self-care agency could explain CPH-related QoL at a rate of 92% and CMH-related QoL at a rate of 95% (Table 4).

DISCUSSION

The mean SCA scale score was 93.37 ± 25.47 in this study, compared to the 82.82 ± 22.82 found in the study of Kaşıkçı and Dayapoğlu^[22] and 88.42 ± 1.34 in the study of Bayram and Yurttaş.^[23] The results of this study are consistent with the literature. Given that the maximum score

of SCA scale is 140, SCA was determined to be satisfactory. According to the results of the studies, it can be said that the self-care power of patients with MS is moderate. Considering the sociodemographic variables of patients with MS in the literature and in this study, self-care power differs according to variables such as education level and sex. It is thought that MS type, EDSS score, disease duration, and increase in the number of attacks, which are variables related to MS, decrease the self-care power of individuals. Therefore, the variables mentioned above may reduce the self-care power of individuals with MS by affecting the adaptation process to the disease.

It was observed that the SCA was higher in female patients, which was statistically significant. Yang et al.^[24] reported that SCA was better in females. This was considered to result from women being more familiar with roles concerning care and caregiving, which could positively affect the behaviors of self-care.

Similar to another study, this study observed that SCA was significantly better in university graduates.^[25] The study of Kaşıkçı and Dayapoğlu^[22] revealed that SCA was better among those who were graduates of faculties. This was considered to be related to the fact that increasing education levels facilitates access to knowledge and increases the level of awareness.

Self-care agency was determined to be better in employed patients, which was statistically significant. Self-care agency was worse in patients who were unemployed due to their disease. Self-care agency was reported to affect the working status, and the risk of being unemployed due to MS was reported to increase by 8%.^[26] Given that the patients who cannot work due to their disease are the ones who are retired due to disability and who have a disability and functional restrictions due to symptoms, worse SCA may be expected in these patients.

Self-care agency was determined to improve in patients with CIS compared to the other MS types,

and SCA was determined to improve as the number of attacks decreased. Clinically isolated syndrome was reported to be an intermediate form in which disability has not yet developed.^[27] The small number of attacks suggests that disability is limited or not developed. Hence, this result was associated with the functional capacities not having reached a restrictive level.

Subscales of CPH and CMH were determined to be better among female patients, with statistical significance. Our results are consistent with the literature.^[20] Huh et al.^[28] reported a higher physical health-related QoL score and a lower mental health-related QoL score in female patients. Studies reported that women have better physical and mental health-related QoL.^[20,21] The prognosis of MS was reported to be better in female patients.^[29] It was thought that the higher QoL exhibited by women was related to this situation.

The MSQoL-54 scale was found to be affected by the working status, with statistical significance. Quality of life was found to be better in working patients. Physical and mental health-related scores were reported to be higher among employed patients compared to unemployed patients.^[30] While Abdullah and Badr^[30] reported that the working status affected the physical and mental health, Baumstarck et al.^[31] reported that the working status did not affect the physical and mental health. Given that MS may emerge at a young age, the inability of young people to work may impair the QoL components. Given that all these factors are determinants of health, it is possible that the QoL may be influenced by the working status.

The subscale scores of MSQoL-54 were higher in patients with CIS and were found to increase as the EDSS score and the attack number decreased, with statistical significance. It was observed that the physical and mental health scores of those with an EDSS score of 4 to 6 points decreased significantly compared to those with 0 to 1.5 points. Likewise, those with 0 to five attacks appeared to have lower physical and mental health than patients with 12 or more attacks. Physical health and, thereby, the QoL were reported to be impaired as the disability increased.^[21] Increased function loss directly affects the QoL. Usually, a new attack may lead to disability or short/long-term function loss. Hence, a better QoL may be expected in patients with CIS with lower EDSS and fewer attacks.

When the MSQoL-54 scale was evaluated according to the disease duration, CPH and CMH scores were higher in patients with a four- to five-year disease duration, with a statistically significant difference. The disease duration was observed to affect the compound's physical and mental health and result in an alteration in the health scores. Rezapour et al.^[21] reported that the physical and mental health scores decreased when the disease duration was longer than five years. Studies reported that the QoL is impaired as the disease duration prolongs and that the disease duration does not affect physical and mental health.^[30,31] Increased disability, duration of illness, and chronic illness could affect QoL.

A positive and significant relationship was found between SCA and QoL, where SCA affected physical and mental health-related QoL with a rate of 92%. On the other hand SCA explained mental health-related QoL by 95%. In studies conducted with patients with chronic diseases, the SCA was reported to significantly affect the QoL.^[13,25,32] Self-care agency brings physical well-being as it provides self-control.^[32] It is thought that patients' self-control skills improve their coping skills and thus increase their QoL by nurturing their mental health. The result was found to be affected in this direction.

It was observed that self-care could contribute to the health profiles of patients with MS and that self-care could be considered a dimension of QoL.^[33] Self-care agency supports performing activities of daily living. Balance and independence in activities of daily living can improve QoL.^[34] Therefore, it may be possible to increase self-care power and QoL by supporting activities of daily living.^[35] It was suggested that effective coping strategies with self-care power as a mutual effect could increase the QoL with the ability to perform daily living activities and well-being.

In addition, with self-care, the individual activates the positive coping mechanism and reveals their self-efficacy.^[13] Individuals with good SCA can develop self-confidence in managing MS, which can create future anxiety with the thought that they will overcome certain difficulties. All these factors can support SCA and QoL. On the other hand, considering that the QoL consists of many factors such as sociological, psychological, and personal coping and self-efficacy, it can be thought that self-care is one of the critical determinants of QoL.

This study was limited by its geography and social differences. Therefore, the results cannot be generalized to other groups. Causality and effect relationships are limited due to the descriptive design.

In conclusion, the patients in this study had good SCA. Self-care agency was influenced by sex, education level, and working status. The CPH and the CMH subscales were also affected by sex, working status, MS type, EDSS, disease duration, and the number of attacks. A significant positive relationship was determined between SCA and QoL, and SCA could explain the CMH-related QoL. The results indicated that the long duration of MS decreased the SCA of the patients. Therefore, supporting the patient and the family is important in MS, as in other chronic diseases. To improve SCA, nurses should support the patient and the family, create an instructive environment, provide guidance, and utilize a trainer role. Furthermore, the patients should be enabled to reach knowledge sources depending on their educational level under the guidance of the nurses, education programs should be arranged, and feedback should be obtained. Communication between the patients and the local authorities may be established to evaluate the working capacities to improve SCA and QoL. Quality of life is increased by improving the SCA. Hence, studies using methods and models for developing self-care are recommended.

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Patient Consent for Publication: A written informed consent was obtained from each patient.

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REFERENCES

1. Multiple Sclerosis International Federation, MSIF [Internet]. What is MS? [2021 Oct 25] Available at: <https://www.msif.org/about-ms/what-is-ms/> [Accessed: 03.01.2024]
2. Multiple Sclerosis International Federation, MSIF [Internet]. Atlas of MS 3rd Edition. [2020] Available at: <https://www.atlasofms.org/map/global/epidemiology/number-of-people-with-ms> [Accessed: 03.01.2024]
3. Türk Nöroloji Derneği [Internet]. World MS Day. [2022 May 28] Available at: <https://www.noroloji.org.tr/haber/1257/dunya-ms-gunu> [Accessed: 03.01.2024]
4. Burkill S, Montgomery S, Hajiebrahimi M, Hillert J, Olsson T, Bahmanyar S. Mortality trends for multiple sclerosis patients in Sweden from 1968 to 2012. *Neurology* 2017;89:555-62. doi: 10.1212/WNL.0000000000004216.
5. Alhazzani AA, Alqahtani MS, Alahmari MS, Asiri MA, Alamri NM, Sarhan LA, et al. Quality of life assessment among multiple sclerosis patients in Saudi Arabia. *Neurosciences (Riyadh)* 2018;23:140-7. doi: 10.17712/nsj.2018.2.20170335.
6. Landfeldt E, Castelo-Branco A, Svedbom A, Löfroth E, Kavaliunas A, Hillert J. The long-term impact of multiple sclerosis on the risk of divorce. *Mult Scler Relat Disord* 2018;24:145-50. doi: 10.1016/j.msard.2018.07.002.
7. García-Domínguez JM, Maurino J, Martínez-Ginés ML, Carmona O, Caminero AB, Medrano N, et al. Economic burden of multiple sclerosis in a population with low physical disability. *BMC Public Health* 2019;19:609. doi: 10.1186/s12889-019-6907-x.
8. Maurino J, Martínez-Ginés ML, García-Domínguez JM, Solar MD, Carcelén-Gadea M, Ares-Luque A, et al. Workplace difficulties, health-related quality of life, and perception of stigma from the perspective of patients with Multiple Sclerosis. *Mult Scler Relat Disord* 2020;41:102046. doi: 10.1016/j.msard.2020.102046.
9. World Health Organization [Internet]. WHO guideline on self-care interventions for health and well-being, 2022 revision. [2022 June 27]. Available at: <https://www.who.int/publications-detail-redirect/9789240052192> [Accessed: 03.01.2024]
10. Abotalebidiariasari G, Memarian R, Vanaki Z, Kazemnejad A, Naderi N. Self-care motivation among patients with heart failure: A qualitative study based on Orem's theory. *Res Theory Nurs Pract* 2016;30:320-32. doi: 10.1891/1541-6577.30.4.320.
11. Seifi K, Moghaddam HE. The effectiveness of self-care program on the life quality of patients with multiple sclerosis in 2015. *J Natl Med Assoc* 2018;110:65-72. doi: 10.1016/j.jnma.2017.01.010.
12. Momenabadi V, Kaveh MH, Nakhaee N, Karimzadeh Shirazi K, Sedighi B, Tabatabaei SHR. Health promoting self-care behaviors in patients with multiple sclerosis in the Southeast of Iran: Developing a model for practice. *Basic Clin Neurosci* 2020;11:687-99. doi: 10.32598/bcn.11.5.1670.1.

13. Strober LB. Quality of life and psychological well-being in the early stages of multiple sclerosis (MS): Importance of adopting a biopsychosocial model. *Disabil Health J* 2018;11:555-61. doi: 10.1016/j.dhjo.2018.05.003.
14. Özmen S. Determination of care burden of caregivers of multiple sclerosis patients and affecting factors [Master's thesis]. Erzurum (TR): Atatürk University; 2015. [2021 May 2]. Available at: <https://tez.yok.gov.tr/> [Accessed: 03.01.2024]
15. Nahcivan NÖ. Validity and reliability study: Adaptation of self-care ability scale to Turkish. *Hemşirelikbülteni* 1994;33:109-19.
16. Kearney BY, Fleischer BJ. Development of an instrument to measure exercise of self-care agency. *Res Nurs Health* 1979;2:25-34. doi: 10.1002/nur.4770020105.
17. Vickrey BG, Hays RD, Harooni R, Myers LW, Ellison GW. A health-related quality of life measure for multiple sclerosis. *Qual Life Res* 1995;4:187-206. doi: 10.1007/BF02260859.
18. Idiman E, Uzunel F, Ozakbas S, Yozbatiran N, Oguz M, Callioglu B, et al. Cross-cultural adaptation and validation of multiple sclerosis quality of life questionnaire (MSQOL-54) in a Turkish multiple sclerosis sample. *J Neurol Sci* 2006;240:77-80. doi: 10.1016/j.jns.2005.09.009.
19. Tülek Z. Determination of quality of life in multiple sclerosis patients who have been followed regularly. [Doctoral thesis]. İstanbul (TR): İstanbul University; 2006. [2021 April]. Available at: <https://tez.yok.gov.tr/> [Accessed: 03.01.2024]
20. Direk M. Examination of gait disturbance and quality of life in multiple sclerosis patients [Master's thesis]. Sivas (TR): Cumhuriyet University; 2017. [2021 April]. Available at: <https://tez.yok.gov.tr/> [Accessed: 03.01.2024]
21. Rezapour A, Almasian Kia A, Goodarzi S, Hasoumi M, Nouraei Motlagh S, Vahedi S. The impact of disease characteristics on multiple sclerosis patients' quality of life. *Epidemiol Health* 2017;39:e2017008. doi: 10.4178/epih.e2017008.
22. Kaşıkçı E, Dayapoğlu N. (2020). Examination of the level of disability, loneliness and self care ability of patients with Multiple Sclerosis. *Int J Caring Sci*. 2020;13(3):1668-77.
23. Bayram A, Yurttaş A. The relationship between adaptation to disease and self-care agency levels in patients with multiple sclerosis. *J Neurosci Nurs* 2022;54:102-6. doi: 10.1097/JNN.0000000000000630.
24. Yang H, Xie X, Song Y, Nie A, Chen H. Self-care agency in systemic lupus erythematosus and its associated factors: A cross-sectional study. *Patient Prefer Adherence* 2018;12:607-13. doi: 10.2147/PPA.S162648.
25. Habibi H, Sedighi B, Jahani Y, Hasani M, Iranpour A. Self-care practices and related factors in patients with multiple sclerosis (MS) based on the health belief model. *J Caring Sci* 2021;10:77-83. doi: 10.34172/jcs.2021.015.
26. Raggi A, Covelli V, Schiavolin S, Scaratti C, Leonardi M, Willems M. Work-related problems in multiple sclerosis: A literature review on its associates and determinants. *Disabil Rehabil* 2016;38:936-44. doi: 10.3109/09638288.2015.1070295.
27. MS Society [Internet]. Clinically isolated syndrome (CIS) [2022 June 22]. Available at: <https://www.mssociety.org.uk/about-ms/types-ms/clinically-isolated-syndrome-cis> [Accessed: 03.01.2024]
28. Huh SY, Joo J, Kim SH, Joung AR, Park K, Kim W, et al. Validity of Korean versions of the multiple sclerosis impact scale and the multiple sclerosis international quality of life questionnaire. *J Clin Neurol* 2014;10:148-56. doi: 10.3988/jcn.2014.10.2.148.
29. Coyle PK. What can we learn from sex differences in MS? *J Pers Med* 2021;11:1006. doi: 10.3390/jpm11101006.
30. Abdullah EJ, Badr HE. Assessing the quality of life in patients with multiple sclerosis in Kuwait: A cross sectional study. *Psychol Health Med* 2018;23:391-9. doi: 10.1080/13548506.2017.1366660.
31. Baumstarck K, Pelletier J, Boucekine M, Auquier P; MusiQoL study group. Predictors of quality of life in patients with relapsing-remitting multiple sclerosis: A 2-year longitudinal study. *Rev Neurol (Paris)* 2015;171:173-80. doi: 10.1016/j.neurol.2014.09.005.
32. Akpınar NB, Ceran MA. Chronic Diseases and rehabilitation nursing. *AMUSBFD* 2019;3:140-52.
33. Ponzio M, Tacchino A, Vaccaro C, Traversa S, Brichetto G, Battaglia MA, et al. Unmet needs influence health-related quality of life in people with multiple sclerosis. *Mult Scler Relat Disord* 2020;38:101877. doi: 10.1016/j.msard.2019.101877.
34. Noori M, Hosseini SA, Shiri V, Akbarfahimi N. The relationship between balance and activities of daily living with the quality of life of patients with relapsing-remitting multiple sclerosis. *JREHAB* 2019;19:292-301.
35. Cerea S, Ghisi M, Pitteri M, Guandalini M, Strober LB, Scozzari S, et al. Coping strategies and their impact on quality of life and physical disability of people with multiple sclerosis. *J Clin Med* 2021;10:5607. doi: 10.3390/jcm10235607.