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Quality of Life, Coping, and Social Support in Patients with Multiple Sclerosis: A Pilot Study

Multipl Skleroz Hastalarında Yaşam Kalitesi, Baş Etme ve Sosyal Destek: Pilot Çalışma

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Abstract

Objective: The aim of this study was to obtain information concerning the relationship between the sociodemographic attributes, social support systems, coping strategies, and quality of life of patients with multiple sclerosis (MS).

Materials and Methods: This study was designed as a cross-sectional study. The research was conducted with 214 patients from the MS Society of Turkey.

Results: Sociodemographic variables have an impact on the coping styles of patients with MS. When the relationship between coping and quality of life is examined, there is a positive correlation between the use of problem-focused coping strategies and quality of life, whereas there is a negative correlation between the use of emotion-focused coping strategies and quality of life. The scores of active coping, planning, use of emotional support, and use of instrumental support of patients who received social support were higher, whereas their denial scores were lower.

Conclusions: According to the findings of our study, the sociodemographic attributes and social support mechanisms of patients have an impact on their quality of life, as well as the way they cope with MS.

Keywords: Multiple sclerosis, quality of life, coping, social support

Öz

Amaç: Bu araştırmanın amacı multipl skleroz (MS) hastalarının sosyo-demografik özellikleri, sosyal destek sistemleri, kullandıkları baş etme stratejileri ve yaşam kaliteleri arasındaki ilişki hakkında bilgi edinmektir.

Gereç ve Yöntem: Bu çalışma bir kesit alma araştırması şeklinde tasarlanmıştır. Çalışma, Türkiye MS Derneği'ne kayıtlı 214 MS hastasıyla gerçekleştirilmiştir.

Bulgular: Cinsiyet, medeni durum ve eğitim düzeyi gibi sosyo-demografik değişkenler MS hastalarının baş etme stilleri üzerinde etkilidir. Baş etme ve yaşam kalitesi ilişkisi incelendiğinde sorun odaklı baş etme stratejilerinin kullanımı yaşam kalitesiyle pozitif yönlü bir ilişkiye sahipken duygu odaklı baş etme stratejilerinin kullanımı ise yaşam kalitesiyle negatif yönlü bir ilişkiye sahiptir. Sosyal destek alan hastaların aktif baş etme, planlama, duygusal destek kullanımı, maddi destek kullanımı puanları daha yüksekken inkar puanı daha düşüktür.

Sonuç: Çalışmamız sonuçlarına göre hastaların sosyo-demografik özellikleri ve sosyal destek mekanizmaları MS ile baş etmeleri ve yaşam kaliteleri üzerinde etkilidir.

Anahtar Kelimeler: Multipl skleroz, yaşam kalitesi, baş etme, sosyal destek

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Introduction

Multiple sclerosis (MS) is a disease that has a serious impact on people's lives after it is diagnosed, as well as in the period following the diagnosis. When the psychosocial and physical symptoms caused by MS are taken into consideration, social support plays a crucial role in every phase of the disease. Numerous studies have shown that there is a direct relationship between an increase in the quality of life of patients with MS and social support. The latter produces a protective effect in the lives of patients (1,2,3,4,5,6,7).

Quality of life is the outcome of the satisfaction individuals receive from all their sources minus all the worries they experience (8). It is this outcome that enables us to evaluate individuals within their environment. When associated with health, it demonstrates a multi-dimensional structure that has physical, psychological, social, and environmental aspects. Disease-related physical variables, namely the degree of physical disability and course of the disease, and frequency and number of exacerbations can be addressed as other elements that influence quality of life in MS (8). Studies have shown that patients with chronic MS have lower levels of quality of life and they encounter different problems (9,10).

For patients with MS, coping strategies play an important role in adapting to the psychosocial problems that affect them. Lazarus (11) defined coping as the cognitive and behavioral efforts made to control environmental and internal demands or the conflicts among them and these efforts may either expand or consume one's sources. According to Lazarus (12), there are two kinds of coping: i) problem-focused coping where the stressor is diverted and changed, and ii) emotion-focused coping where emotional reactions are regulated. Among the two coping strategies, problem-focused coping is often more functional in terms of easing the physical and psychologic issues, whereas emotion-focused coping is considered in relation to maladaptation and psychological problems (13). Therefore, coping plays an essential role in the psychosocial well-being and quality of life of patients with MS.

The existing literature suggests that there are problems concerning social support, quality of life and coping, specific to the case of patients with MS. Thus, the aim of this research can be summarized as discovering the relationship between the social support systems, preferred coping strategies, and quality of life of patients with MS.

Materials and Methods

Participants

This research was conducted with 214 patients with MS who were registered to Istanbul, Ankara, and Izmir branches of the Multiple Sclerosis Society of Turkey. The majority of the participants were female (59.2%), in the 36-46 years' age group (37.5%), married (52.8%), had a bachelor's degree (31.3%), and were in the 1001-2000 Turkish liras (TL) (43.2%) income group (see Table 1).

Data Gathering Process

The study was planned to be a cross-sectional research based on quantitative methodology. Prior to the study, ethics approval was obtained from an Ethics Commission of Hacettepe University Senate meeting held on 23.06.2015 (reference number: 4297). Following ethics approval, the Istanbul, Ankara, and Izmir branches of the Multiple Sclerosis Society of Turkey were contacted and their permission was received for conducting the research. The data were collected within the six-month interval between August 2015 and February 2016, from patients who volunteered to participate in the research. Written informed consent was obtained from each patient. Besides that, inclusion criteria were determined as being diagnosed as having MS for at least six months, being older than 18 years of age. Patients with any chronic disease other than MS were excluded. For collecting data, sociodemographic questions, as well as questions about social support were developed and used by the researchers. The brief COPE Scale and the World Health Organization (WHO) Quality of Life (WHOQOL-BREF-TR) were used as scales.

Instruments

Brief COPE Scale

The COPE inventory was developed by Carver et al. (14) in 1989 as a scale to assess coping strategies. Brief COPE, shortened and revised by Carver (15), was used in this research. The scale consists of 28 questions that describe problem- and emotion-focused coping strategies, and 14 subscales comprising active coping, use of emotional support, use of instrumental support, positive reframing, planning, acceptance, religion, self-distraction, denial, substance use, behavioral disengagement, venting, humor and self-blame. The psychometric assessment of the scale, which

Table 1. Sociodemographic information

		n	%
Sex	Female	126	59.2
	Male	87	40.8
Age (years)	24 years and younger	12	6.3
	25-35 years	61	31.8
	36-46 years	72	37.5
	47 years and older	47	24.5
Educational status	Not graduate of any school	9	2.8
	Primary school graduate	31	14.5
	Secondary school graduate	26	12.1
	High school graduate	64	29.9
	Bachelor's degree	67	31.3
	Postgraduate	20	9.3
Marital status	Single	63	29.4
	Married	113	52.8
	Spouse passed away/divorced	38	17.8
Average monthly income	1000 TL and below	44	25.0
	1001-2000 TL	76	43.2
	2001-3000 TL	26	14.8
	3001 TL and above	30	17.0

TL: Turkish lira

included a study of the validity and reliability for Turkish society, was made by Tuna (16).

World Health Organization Quality of Life

The WHO Quality of Life Scale (WHOQOL-BREF) is a five-point Likert-type scale that consists of 26 questions. It can be applied to individuals living under different living conditions and in different cultures. WHOQOL-BREF-TR, whose validity and reliability studies were performed by Eser et al. (17), and to which an extra question was added for the purpose of adapting it to Turkish culture, hence consisting of 27 questions, has four domains: physical, psychological, social relationships, and environmental domain. The questions prioritize the subjectivity of the person. It measures how patients perceive the definite physical symptoms caused by the disease, how they experience these symptoms, and how the disease interacts with physical activity, social relationships, and their environment.

Statistical Analysis

Non-parametric test techniques Spearman's correlation, the Mann-Whitney U and Kruskal-Wallis tests, as well as parametric test techniques, the t-test and ANOVA were used in the statistical analyses.

Spearman's correlation test was used to analyze relationships between the scale scores. Variations according to demographic variables were analyzed using the t-test and ANOVA because the physical domain, which is a sub-scale of the WHOQOL-BREF-TR quality of life scale, had normal distribution. The variation of the other scales according to demographic variables was analyzed using the Mann-Whitney U and Kruskal-Wallis tests because these scales did not have normal distribution. SPSS 23 was used for data analysis and $p<0.05$ was considered statistically significant.

Results

The findings obtained in the research were based on the relationship between sociodemographic variables and coping and quality of life, receiving social support and from whom it was received, as well as the relationship between social support and coping and quality of life. When the relationship between sociodemographic variables and coping and quality of life was examined (see Table 2), it was found that females used religion as a coping style more than males ($p=0.003$). In terms of age groups, the social relationships of patients with MS in the 25-35 years' age group were in a better place than those in the other age groups ($p=0.022$).

Among the marital status groups, married patients with MS had a mean rank score of 113.81, singles had 111.01, and divorced patients had a mean rank score of 82.82 in terms of social relationships domain scores. According to this, the social relationships domain score of the married patients was the highest, whereas that of divorced patients was the lowest ($p=0.024$). When the relationship between marital status and coping styles was examined, it was seen that married patients used active coping ($p=0.030$) and religion-based coping ($p<0.001$) more intensively compared with single and divorced patients. Substance use was more intensive in divorced patients compared with other patients ($p=0.005$).

When the relationship between educational status and quality of life was examined, the level of education of patients with MS increased their scores from the sub-scales of the physical health domain ($p<0.001$), social relationships domain ($p=0.003$), environmental domain ($p<0.001$), and psychological domain ($p=0.023$). In other words, an increase in the level of education of the patients led to an increase in every domain of quality of life. When the relationship between educational status and coping styles was examined, patients with MS who received postgraduate education constituted the group with the highest score in terms of active coping ($p=0.033$). In addition, as the level of education increased, religion-based coping decreased ($p<0.001$).

The physical health ($p<0.001$) and social relationships domain ($p=0.003$) scores of the highest income group, whose income was 3001 TL and above, were the highest, whereas patients in the 2001-3000 TL income group had the highest scores in the environmental ($p<0.001$) and psychological domains ($p=0.006$). The 2001-3000 TL income group used religion-based coping styles in a more intensive manner compared with the other groups ($p=0.007$).

As can be seen in Table 3, the use of coping strategies such as active coping, planning, positive reframing, and acceptance, which are considered as problem-focused coping strategies, was positively correlated with quality of life, whereas the use of coping strategies such as denial, substance use, and self-distraction, which are seen as emotion-focused coping strategies, was negatively correlated with quality of life.

A significant number of participants (81.8%) stated that they received social support during treatment. When we examined from whom they received this support, it was found that 78.5% received social support from their family, 38.8% from friends, 26.6% from other patients, 17.8% from relatives, and 9.8% received social support from their neighbors (see Table 4).

When the relationship between social support and quality of life was examined, the social relationships domain score ($p<0.001$) of patients with MS who received social support was discovered to be higher. In addition, the coping styles of the patients were examined with regards to whether they received social support; active coping ($p=0.008$), planning ($p=0.018$), use of emotional support ($p=0.029$), and use of instrumental support ($p=0.001$) of those who received social support were found higher, whereas their denial scores ($p=0.003$) were lower (see Table 5).

The social relationships domain score ($p=0.017$) of patients with MS who reported their family as their source of social support was discovered to be higher compared with that of the other patients. When these patients were examined in terms of their coping styles, the substance use score ($p=0.010$) of patients who failed to receive social support from their family was found higher compared with the scores of the other patients.

Psychological ($p=0.004$), social relationships ($p=0.002$), and environmental ($p=0.008$) domain scores of patients with MS who reported their friends as their source of social support were higher compared with those of the other patients, whereas they used the coping styles of active coping ($p=0.017$), planning ($p=0.020$), positive reframing ($p=0.001$), use of emotional support ($p=0.015$), and use of instrumental support ($p=0.012$) in a more intensive manner compared with the other patients. Use of instrumental support scores ($p=0.030$) of patients who received social support from other patients in the treatment process were found to be higher.

Table 2. The relationship between sociodemographic variables and coping and quality of life

	Sex	**n**	**Mean rank**	**U**	**p**
Religion	Female	126	117.21	4194.5	0.003**
	Male	87	92.21		
	Marital status	**n**	**Mean rank**	**χ^2**	**p**
Social relationships domain	Single	63	111.01	7.451	0.024*
	Married	113	113.81		
	Widowed	38	82.92		
Active coping	Single	63	97.29	6.986	0.030*
	Married	113	117.81		
	Widowed	38	93.75		
Religion	Single	63	85.03	15.869	<0.001**
	Married	113	122.22		
	Widowed	38	100.97		
Substance use	Single	63	113.03	10.482	0.005**
	Married	113	97.53		
	Widowed	38	127.97		
	Age	**n**	**Mean rank**	**χ^2**	**p**
Social relationships domain	24 years and younger	12	90.29	9.619	0.022*
	25-35 years	61	108.63		
	36-46 years	72	100.33		
	47 years and older	47	76.47		
	Education	**n**	**Mean**	**F**	**p**
Physical health domain	Primary school and less	37	19.68	5.404	<0.001**
	Secondary school	26	19.77		
	High school	64	20.02		
	Bachelor's degree	67	22.36		
	Postgraduate	20	25.90		
	Education	**n**	**Mean rank**	**χ^2**	**p**
Psychological domain	Primary school and less	37	86.26	11.391	0.023*
	Secondary school	26	96.23		
	High school	64	106.42		
	Bachelor's degree	67	115.37		
	Postgraduate	20	138.53		
Environmental domain	Primary school and less	37	80.92	27.080	<0.001**
	Secondary school	26	94.08		
	High school	64	94.96		
	Bachelor's degree	67	126.10		
	Postgraduate	20	151.93		
Social relationships domain	Primary school and less	37	79.64	16.305	0.003**
	Secondary school	26	95.94		
	High school	64	110.73		
	Bachelor's degree	67	113.40		
	Postgraduate	20	143.95		

Table 2. Continued

	Sex	n	Mean rank	U	p
Active coping	Primary school and less	37	101.15	10.509	0.033*
	Secondary school	26	100.77		
	High school	64	92.81		
	Bachelor's degree	67	120.87		
	Postgraduate	20	130.20		
Religion	Primary school and less	37	139.62	20.082	<0.001**
	Secondary school	26	125.25		
	High school	64	101.41		
	Bachelor's degree	67	97.66		
	Postgraduate	20	77.45		
	Income		**Mean**	**F**	**p**
Physical health domain	1000 TL and below	44	18.64	6.666	<0.001**
	1001-2000 TL	76	20.28		
	2001-3000 TL	26	23.58		
	3001 TL and above	30	23.63		
	Income	**n**	**Mean rank**	**χ^2**	**p**
Psychological domain	1000 TL and below	44	68.36	12.580	0.006**
	1001-2000 TL	76	88.45		
	2001-3000 TL	26	107.65		
	3001 TL and above	30	101.57		
Environmental domain	1000 TL and below	44	60.22	32.319	<0.001**
	1001-2000 TL	76	84.24		
	2001-3000 TL	26	124.60		
	3001 TL and above	30	109.48		
Social relationships domain	1000 TL and below	44	66.70	13.792	0.003**
	1001-2000 TL	76	89.35		
	2001-3000 TL	26	102.83		
	3001 TL and above	30	105.90		
Religion	1000 TL and below	44	88.35	12.252	0.007**
	1001-2000 TL	76	93.04		
	2001-3000 TL	26	105.96		
	3001 TL and above	30	62.08		

TL: Turkish lira

Discussion

In this research, we found that female patients with MS used religion as a coping style more intensively compared with their male counterparts. Similarly, according to a meta-analysis conducted by Tamres et al. (18) females were observed to use religion as a coping strategy more than males. In addition, level of social relationships of married patients was higher compared with that of the other groups, and it was observed that married patients used active coping and religion-based coping more intensively. Also in research conducted by Gulick (2), it was discovered that social support functions such as affect, affirmation, aid, and informational support were closely associated with the marital statuses of patients. Thus, it can be deduced that the marital status of individuals is closely associated with the process of their adaptation to social life.

The increase in the educational levels of patients with MS goes hand in hand with an increase in their physical health, social relationships, environmental, and psychological domains of quality of life. The coping scores of the educated group was observed to be the highest. In light of our findings, we think that as a person's knowledge ability increases, their level of life perception increases and this causes a direct and significant difference in their quality of life and ability to cope. Therefore, it is indisputable that high levels of education, which benefit the individual in so many ways, also have a seriously positive impact on disease processes.

When the findings were viewed in terms of income, the quality of life domain scores of patients with high income were found to be higher than those of patients in the lower income group. When the relationship between marital status, educational status, and income level were examined, the findings obtained strongly supported the findings of Benedict et al. (19) who suggested that sociodemographic variables had an impact on the quality of life of patients with MS.

When the relationship between coping and quality of life was analyzed, the use of problem-focused coping strategies was positively correlated with quality of life, whereas the use of emotion-focused coping strategies was negatively correlated with quality of life. Similarly, Aikens et al. (20) who worked with patients with MS, identified a positive correlation between the patients' use of problem-focused coping strategies and their quality of life. Goretti et al. (21) discovered that the use of problem-focused strategies affected the quality of life of MS patients positively. McCabe and McKern (10) suggested that all coping strategies constituted an important indication of the quality of life of patients with MS, and 'wishful thinking' was the strongest determinant of low quality of life.

The relationship between coping and qualty of life (r values)

	Physical health domain	Psychological domain	Environmental domain	Social relationships domain
Active coping	0.329**	0.437**	0.329**	0.287**
Planning	0.213**	0.240**	0.254**	0.187**
Religion	0.089	0.202**	0.079	0.062
Positive reframing	0.230**	0.396**	0.323**	0.259**
Acceptance	0.204**	0.293**	0.314**	0.324**
Humor	0.056	0.179**	0.111	0.140*
Use of emotional support	0.058	0.186**	0.240**	0.166*
Use of instrumental support	-0.056	-0.024	0.018	-0.060
Self-distraction	0.239**	0.331**	0.250**	0.219**
Denial	-0.303**	-0.301**	-0.348**	-0.216**
Venting	-0.096	-0.113	-0.116	-0.116
Substance use	-0.166*	-0.170*	-0.212**	-0.171*
Behavioral disengagement	-0.077	-0.118	-0.136*	0.010
Self-blame	-0.085	-0.290**	-0.114	-0.107

**p<0.01, *p<0.05

Table 4. Receiving social support and from whom it is received

		n	%
Receive social support	Yes	175	81.8
	No	39	18.2
Receive social support from family	Yes	168	78.5
	No	46	21.5
Receive social support from friend	Yes	83	38.8
	No	131	61.2
Receive social support from relative	Yes	38	17.8
	No	176	82.2
Receive social support from neighbors	Yes	21	9.8
	No	193	90.2
Receive social support from other patients	Yes	57	26.6
	No	157	73.4

Table 5. The relationship between social support and coping and quality of life

	Receive social support	n	Mean rank	U	p
Social relationships domain	Yes	175	114.44	2197.5	<0.001**
	No	39	76.35		
Active coping	Yes	175	112.70	2502.5	0.008**
	No	39	84.17		
Planning	Yes	175	112.15	2598.5	0.018*
	No	39	86.63		
Use of emotional support	Yes	175	111.79	2661.0	0.029*
	No	39	88.23		
Use of instrumental support	Yes	175	114.04	2268.0	0.001**
	No	39	78.15		
Denial	Yes	175	101.77	2409.5	0.003**
	No	39	133.22		

**p<0.01, *p<0.05

Our study shows that majority of patients MS received social support over the course of their treatment, this support was mainly provided by family and friends, and those who received social support had high scores in social relationships domain, active coping, planning, and use of emotional and instrumental support in quality of life, and their denial scores were lower compared with those of patients who received no social support. Movaghar et al. (6) asserted that patients with MS with high quality of life participated more in social life. In view of these results, we suggest that the capacity to defy and resist symptoms that emerge during disease process of patients with MS increases if a social support system is available, and patients who do not receive social support experience more difficulty in the process, and the resulting difference is by no means negligible. Therefore, we believe that support from family and friends is crucial in the treatment process of MS, as well as in the period following the process, and patients ought to be supported by their families and friends when needed in the process. It is important to provide families with disease-related information and sources because this would empower the families, and subsequently empower the patients. Accordingly, in the process of minimizing the effects of the disease, all healthcare professionals who actively work in the process, and use of all the elements of the individual's environmental structure would increase the treatment's likelihood of creating a positive impact in psychosocial terms.

Conclusion

In conclusion, it can be suggested that sociodemographic attributes of patients with MS, their communication with their social circle, and the availability of social support mechanisms have a considerable impact on the patients' ability to cope with MS, as well as on their quality of life.

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Ethics

Ethics Committee Approval: The study were approved by the Hacettepe University of Local Ethics Committee (Protocol number: 76000869/431-2065).

Informed Consent: Consent form was filled out by all participants.

Peer-review: Externally and internally peer-reviewed.

Authorship Contributions

Concept: E.E., Design: E.E., Data Collection or Processing: E.E., O.Z., B.Y., Analysis or Interpretation: O.Z., Literature Search: O.Z., B.Y., Ö.A., Writing: O.Z., B.Y., Ö.A.

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