Quality of life among persons suffering from multiple sclerosis

Kvaliteta života osoba oboljelih od multiple skleroze

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Summary

Objective: To examine the quality of life of people affected by multiple sclerosis and to determine whether there is a difference in the quality of life according to sex, age, education, employment status, marital status and overall duration of the disease.

Materials and methods: The study included 81 patients with MS (32 men and 49 women) over 18 years of age. The survey instrument used was a standardized MSQoL-54 specific questionnaire for measuring the quality of life of patients with multiple sclerosis.

Results: Men rated their health significantly better than women in dimensions of energy/vitality (p = 0.028) and dimensions of pain (p = 0,018), while women rated significantly better in the dimension health perceptions (p = 0.025). The dimensions of health that described physical health (p < 0.001), pain (p = 0.047), sexual functioning (p = 0.036), social functioning (p = 0.047) and overall quality of life (p = 0.012) were significantly worse rated by the oldest respondents. Ratings of physical health (p < 0.001) and overall quality of life scale (p = 0.017) were significantly the lowest in subjects older than 55 years. According to the level of education, significant differences were present only in dimensions to energy/vitality (p = 0.004) and health distress (p = 0.015). As regards to employment status, dimensions that described physical health (p = 0.001), health perception (p = 0.001), social function (p = 0.002), health distress (p = 0.010), overall quality of life (p = 0.001), social function (p = 0.002), health distress (p = 0.010), overall quality of life (p = 0.003) were the significantly worse rated respondents. According to disease duration the lowest rating to quality of physical health was given by respondents suffering from MS for 21 years and longer (p = 0.007).

Conclusion: Research shows that multiple sclerosis impairs the quality of life of patients. The use of instruments designed to measure multiple sclerosis patients' quality of life, based on subjective perceptions of quality of life, facilitates the implementation of targeted interventions and measures that improve the quality of life.

Key words: multiple sclerosis, quality of life, MSQoL-54

Sažetak

Cilj: Ispitati kvalitetu života osoba oboljelih od multiple skleroze, te utvrditi postoji li razlika u kvaliteti života prema spolu, dobi, stručnoj spremi, radnom statusu, bračnom stanju i ukupnom trajanju bolesti.

Materijali i metode: Istraživanjem je bio obuhvaćen 81 punoljetni ispitanik obolio od MS (32 muškarca i 49 žena). Kao instrument istraživanja uporabljen je standardizirani specifični anketni upitnik za mjerenje kvalitete života oboljelih od multiple skleroze MSQoL-54.

Rezultati: Muškarci ocjenjuju svoje zdravlje značajno boljim od žena u dimenziji energija/vitalnost (p = 0,028), a žene značajno boljim u dimenziji opće percepcije zdravlja (p = 0,025). Dimenzije zdravlja koje opisuju tjelesnu aktivnost (p < 0,001), tjelesnu bol (p = 0,047), seksualno djelovanje (p = 0,036), socijalno djelovanje (p = 0,047) i ukupnu kvalitetu života (p = 0,012) značajno lošije ocjenjuju najstariji ispitanici. Ocjena čestice tjelesnoga zdravlja (p < 0,001) i ukupna skala kvalitete života (p = 0,017) značajno je najniža u ispitanika starijih od 55 godina. Prema razini obrazovanja, značajne su razlike prisutne samo u dimenzijama

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energija/vitalnost (p = 0,004), te uznemirenost zbog zdravstvenih poteškoća (p = 0,015). Kada je riječ o radnom statusu, dimenzije koje opisuju tjelesnu aktivnost (p = 0,001), opću percepciju zdravlja (p = 0,001), socijalno djelovanje (p = 0,002), uznemirenost zbog zdravstvenih poteškoća (p = 0,010), ukupnu kvalitetu života (p = 0,009), tjelesno zdravlje (p = 0.001), mentalno zdravlje (p = 0,007) i ukupnu skalu kvalitete života (p = 0,003), značajno lošije ocjenjuju umirovljeni ispitanici. Prema trajanju bolesti, najnižu ocjenu tjelesnoj aktivnosti daju ispitanici koji boluju 21 i više godina (p = 0,007).

Zaključak: Istraživanje pokazuje da multipla skleroza narušava kvalitetu života oboljelih. Upotrebom instrumenta za mjerenje kvalitete života oboljelih od multiple skleroze, na temelju subjektivnog doživljaja kvalitete života, omogućava se poduzimanje ciljnih intervencija i mjera koje poboljšavaju kvalitetu života.

Ključne riječi: multipla skleroza, kvaliteta života, MSQoL-54

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Introduction

According to the definition by the World Health Organisation (WHO), the quality of life is defined as individuals' perception of their position in life in the special context of culture and the environment.¹ A more comprehensive definition of the quality of life has been put forward by Felce and Perry who have defined the quality of life as an overall well-being which comprises objective descriptors and subjective evaluations of physical, material, social and emotional well-being, with the extent of personal development and purposeful activity all weighted by a personal set of values.¹

The quality of life is primarily a psychological category stemming from an individual's integral psychological structure in interaction with one's physical and social environment.² Therefore, an individual's quality of life does not primarily depend on the advantages afforded to or defects encumbering him or her, but on one's own ability to compensate for the defects and utilise the existing advantages.²

A chronic illness may be a limiting factor in various activities, significantly diminishing the quality of life.³ Multiple sclerosis (MS) has a multi-facetted impact on the quality of life. MS primarily limits physical activities. Furthermore, there are indirect factors such as incapacity to perform work, social isolation, and increased dependence on others that can lead to psychological changes.

In the first study on the quality of life of MS patients, published in 1992, it was determined that MS patients enjoy a significantly lower quality of life in comparison with patients suffering from rheumatoid arthritis and inflammatory bowel disease.⁴ Global studies have also demonstrated that MS patients enjoy a lower quality of life than the healthy population and patients suffering from some other chronic illnesses.⁵

Most studies concerning the quality of life of MS patients demonstrated a negative relationship between depression and fatigue on one hand and subjective quality of life on the other.^{6,7,8,9} Fatigue is

among the most frequent symptom of MS. It may be defined as uncontrollable apathy, lack of energy or sense of exhaustion without any association with depression or muscle weakness. The fatigue syndrome may not be objectively assessed and, therefore, approximately 30 fatigue assessment scales exist.

Research studies frequently cite a correlation of physical pain and reduced quality of life.^{6,10,11} Pain is also a frequent MS symptom observed in approximately 50% of patients.¹² Many researchers have determined that exercise and physical activity are correlated with improved quality of life of MS patients and that the implementation of rehabilitation programmes may significantly improve their quality of life.^{13,14,15}

Experience concerning the quality of life and problems faced by MS patients significantly vary across Europe. There is the European Register for Multiple Sclerosis that collects the basic information on demographics, course of the illness, disability, medication, hospitalisation and test results. By providing the Register, based on comparable and reliable information, the EUReMS shall allow scientific research, adoption of healthcare policies, and organisation of patients and caregivers ultimately improving the quality of life of MS patients.¹⁶ In her research, Titlic (2007) determined that MS patients are largely content with the elements they incorporated into their personalities as young people, but dissatisfied with their capacity to achieve economic and social objectives, and that patient quality of life is significantly lower than that of a healthy population.¹⁷

It is the objective of our research to examine the quality of life of multiple sclerosis patients and determine if there are differences in the quality of life by gender, age, professional qualifications, employment status, marital status and overall duration of the illness.

Materials and methods

Respondents comprise MS patients undergoing regular outpatient examinations at Požega General

County Hospital, patients undergoing rehabilitation at Lipik Special Medical Rehabilitation Hospital, patients registered with MS patients' associations in Osijek-Baranja County, Brod-Posavina County, Vukovar-Srijem County and the City of Pozega.

The criteria applied to inclusion in the research were MS diagnosed in accordance with the McDonald Criteria, age of 18, and a written consent given by individual respondents.

This study was approved by the ethical commissions of all the institutions where the research was conducted. The research was conducted according to the Declaration of Helsinki.

The research encompassed 81 respondents and it was conducted from 1 November 2014 to 1 February 2015. A survey questionnaire was used as the instrument of the research – containing demographic information (age, gender, professional qualification, marital status, employment status), clinical information (duration of the illness) and the standardised MSQoL-54 (The Multiple Sclerosis Quality of Life – 54) questionnaire.¹⁸ Consent to use the survey questionnaire was obtained from its author, Barbara G. Vickrey.

The MSQoL-54 questionnaire consists of a general questionnaire designed to measure the quality of life – the Short form health survey (SF-36) – and further 18 questions designed for MS patients. That questionnaire contains 54 questions grouped in 14 aspects: physical activity, limitations due to physical health, limitations due to emotional problems, physical pain, emotional function, energy and vitality, general health perception, social function, cognitive function, health distress, sexual function, and overall quality of life. The MSQoL-54 is the first specialised instrument designed to measure the quality of life of MS patients.¹⁹

The results of the MSQoL-54 questionnaire are scored according to the Likert scale. After the calculation of individual aspects of the questionnaire, Physical Health Composite (PHC) Score and Mental Health Composite (MHC) Score –correlated to the quality of life – are calculated. All the individual aspects and both of the composite scores may range from 0 to 100 points where 0 represents the worst possible and 100 represents the best possible quality of life related to mental and physical health.

The Kolmogorov-Smirnov test was used to test the normality of distribution. Average values of continuous variables are expressed by median and interquartile range, while nominal indicators are given as absolute and relative numbers. Differences between category variables were tested using the χ^2

test and the Fisher's exact test. The Mann-Whitney test was used to determine differences between two independent groups, while the Kruskal-Wallis test was applied to sets of three or more independent groups. Originally written database software was used as well as the SPSS for Windows statistical package (version 15.0, Carry, NY, USA), with the significance level of p = 0.05.

Results

The research involved 81 respondents including 32 (39.5%) men and 49 (60.5%) women suffering from MS. The respondents' average age is 50 (interquartile range of 38–57 years), and the average duration of the illness is 10 years (interquartile range of 5–20 years), with no significant variation by gender. There are 25 respondents (30.9%) aged 46 to 55, while 12 (14.8%) of the respondents are younger than 30, and 22 (27.2%) of them are older than 55.

In respect of their level of education, the majority of the respondents had completed high-school education -53 (66.3%) of them, 6 (7.5%) respondents had a master's degree and 6 (7.5%) had a bachelor's degree, while 15 (18.8%) respondents had no qualifications or vocational education.

19 (25%) respondents are employed, 12 (14.8%) were unemployed and 50 (61.7%) respondent were retirees.

12 (14.8%) respondents are single, among whom there are significantly more men than women – eight of them (25%). At the same time, there were significantly more women than men among 10 (12.3%) who were divorcees – eight of them (16.3%) (χ^2 test, p = 0.023). 53 (65.4%) are married, while six (7.4%) were widowed.

The illness was present for up to 10 years in cases of 45 (55.6%) respondents, 11 to 20 years in 17 (21%) respondents, while 19 (23.5%) of them had been ill for more than 20 years.

The respondents were the least satisfied with limitations of activity due to physical health, with physical activity and limitations due to emotional problems. The average score of the general health perceptions is 40 (interquartile range of 26–50) and it is significantly lower for the men for whom it stands at 33 (interquartile range of 21–44) (Mann-Whitney test, p = 0.025). The energy/vitality aspect received the average score of 44 (interquartile range of 32–56) and it is significantly lower for the women for whom it stands at 36 (interquartile range of 28–52) (Mann-Whitney test, p = 0.028). The average score for physical pain is 47 (interquartile range of 27–61) and it is significantly lower for the women for whom it

stands at 38 (interquartile range of 22–53) (Mann-Whitney test, p = 0.018). In terms of other aspects, there are no statistically significant differences by gender (Table 1).

As regards to physical activity, the lowest score was given by the most elderly respondents and it amounts to 15 (interquartile range of 1–50) (Kruskal-Wallis test, p < 0.001).

Physical pain presents a significantly greater problem to elderly respondents who gave it an average score of 34 (interquartile range of 15–53) unlike respondents aged 35 or younger who gave it an average score of 54 (interquartile range of 28–75) (Kruskal-Wallis test, p = 0.047).

Sexual function received the lowest score -21 (interquartile range of 0-48) (Kruskal-Wallis test, p = 0.036) – from the most elderly respondents, as well as social function which received an average score of 38 (interquartile range of 23–58) (Kruskal-Wallis test, p = 0.047).

The overall quality of life is significantly the worst in the most elderly respondents (Kruskal-Wallis test,

Table 1. Average MSQoL-54 score by gender
Tablica 1. Srednja ocjena MSQoL-54 prema spolu

p = 0.012). The physical health score is significantly the lowest in the most elderly respondents (Kruskal-Wallis test, p < 0.001). The overall quality of life scale is also the lowest in the respondents aged 55 or older (Kruskal-Wallis test, p = 0.017) (Table 2).

The overall energy and vitality score is 44 (interquartile range of 32–56) and, by the level of education, significantly lower scores are observed in cases of unskilled workers and workers possessing vocational qualifications (Kruskal-Wallis test, p = 0.004). Distress due to health problems received a score of 55 (interquartile range of 35–75) while master's degree respondents exhibited significantly lower distress levels (Kruskal-Wallis test, p = 0.015). The lowest level of distress due to health problems is exhibited by the respondents who have attained a university-degree (Kruskal-Wallis test, p = 0.015). Physical health also received the highest score from the respondents who have attained a master's degree (Kruskal-Wallis test, p = 0.015).

Median (interquartile range) by gender								
Srednji interkvartilni raspon prema spolu								
Scale	Men	Women	Total	p* - value				
Skala	Muškarci	Žene	Sveukupno	p* vrijednost				
PH	28 (15-45)	33 (10-65)	30 (11-50)	0.357				
HP	33 (21-44)	45 (30-50)	40 (26-50)	0.025				
Energy / Energija	52 (37- 56)	36 (28-52)	44 (32-56)	0.028				
RLP	0 (0-0)	0 (0-50)	0 (0-25)	0.082				
Pain / Bol	53 (33-70)	38 (22-53)	47 (27-61)	0.018				
SeF	58 (13-100)	58 (17-83)	58 (17-92)	0.453				
SocF	50 (35-61)	50 (33-67)	50 (33-63)	0.950				
HD	60 (45-73)	55 (30-79)	55 (35-75)	0.971				
OQoL	50 (41-68)	50 (40-59)	50 (40-62)	0.577				
EWB	56 (44-72)	52 (36-76)	56 (40-76)	0.757				
RLE	0 (0-92)	0 (0-83)	0 (0-83)	0.950				
CF	50 (36-79)	50 (28-70)	50 (30-75)	0.775				
РНС	39 (33-47)	37 (28-51)	39 (29-48)	0.985				
МНС	44 (32-72)	44 (25-58)	44 (34-63)	0.809				
MSQoL-54	42 (35-53)	39 (31-58)	40 (32-56)	0.714				

MSQoL-54 The Multiple Sclerosis Quality of Life – 54, PH physical health, HP health perception, RLP physical role limitation, SeF sexual function, SocF social function, HD health distress, OQoL overall quality of life, EWB emotional wellbeing, RLE emotional role limitations, CF cognitive functioning, PHC physical health composite, MHC mental health composite / MSQoL-54 kvaliteta života bolesnika s multiplom sklerozom – 54, PH fizičko zdravlje, HP percepcija zdravlja, RLP ograničavanje fizičke uloge, SeF seksualna funkcija, SocF društvena funkcija, HD zdravstvene nevolje, OQoL sveukupna kvaliteta života, EWB emocionalno blagostanje, RLE ograničenja emocionalne uloge, CF kognitivno funkcioniranje, PHC sastav fizičkog zdravlja, MHC sastav mentalnog zdravlja

* Kruskal-Wallis test

Median (interquartile range) by age								
	Srednji interkvartilni raspon prema godinama starosti							
Scale	< 35	36–45	46–55	> 55	p* - value			
Skala					p*vrijednost			
PH	68 (38-83)	45 (23-65)	25 (8-45)	15 (5-33)	< 0.001			
HP	45 (35-66)	45 (29-50)	35 (25-48)	37 (18-46)	0.110			
Energy / Energija	52 (32-66)	52 (28-56)	44 (36-52)	38 (23-53)	0.332			
RLP	0 (0-44)	0 (0-25)	0 (0-25)	0 (0-19)	0.944			
Pain / Bol	54 (28-75)	54 (37-65)	38 (28-47)	34 (15-53)	0.047			
SeF	67 (42-88)	67 (40-94)	58 (6-92)	21 (0-48)	0.036			
SocF	58 (44-67)	58 (33-67)	50 (40-58)	38 (23-58)	0.047			
HD	48 (29-85)	60 (45-80)	60 (50-75)	50 (26-68)	0.308			
OQoL	55 (50-73)	55 (49-70)	50 (38-59)	43 (33-50)	0.012			
EWB	64 (49-85)	60 (39-80)	52 (36-76)	48 (39-63)	0.322			
RLE	0 (0-58)	33 (0-100)	33 (0-34)	0 (0-100)	0.631			
CF	38 (20-69)	58 (40-85)	50 (21-73)	53 (30-75)	0.272			
РНС	50 (38-55)	45 (37-53)	36 (29-43)	27 (20-37)	< 0.001			
МНС	49 (37-65)	49 (37-73)	44 (37-56)	36 (28-52)	0.177			
MSQoL-54	50 (37-60)	48 (37-62)	39 (33-52)	31 (24-47)	0.017			

Table 2 Average MSQoL-54 score by age *Tablica 2. Srednja ocjena MSQoL-54 prema dobi*

MSQoL-54 The Multiple Sclerosis Quality of Life – 54, PH physical health, HP health perception, RLP physical role limitation, SeF sexual function, SocF social function, HD health distress, OQoL overall quality of life, EWB emotional wellbeing, RLE emotional role limitations, CF cognitive functioning, PHC physical health composite, MHC mental health composite

MSQoL-54 kvaliteta života bolesnika s multiplom sklerozom – 54, PH fizičko zdravlje, HP percepcija zdravlja, RLP ograničavanje fizičke uloge, SeF seksualna funkcija, SocF društvena funkcija, HD zdravstvene nevolje, OQoL sveukupna kvaliteta života, EWB emocionalno blagostanje, RLE ograničenja emocionalne uloge, CF kognitivno funkcioniranje, PHC sastav fizičkog zdravlja, MHC sastav mentalnog zdravlja

* Kruskal-Wallis test

Table 3 Average MSQoL-54 score by education levels *Tablica 3. Srednja ocjena MSQoL-54 prema razini obrazovanja*

	Median (interquartile range) by education levels							
	Srednji interkvartilni raspon prema razini obrazovanja							
Scale Skala	master's degree <i>magisterij</i>	bachelor's degree visoka sprema	high-scholl education srednja sprema	no qualifications or vocational education nema kvalifikacija ili strukovna sprema	p* - value p*vrijednost			
PH	28 (5-71)	30 (4-100)	33 (15-55)	30 (10-45)	0.906			
HP	53 (26-76)	55 (37-71)	35 (28-50)	40 (25-50)	0.097			
Energy / Energija	62 (54-81)	58 (36-70)	44 (28-52)	36 (28-52)	0.004			
RLP	25 (13-100)	0 (0-25)	0 (0-0)	0 (0-31)	0.052			
Pain / Bol	49 (23-76)	38 (20-54)	47 (27-63)	47 (27-53)	0.718			
SeF	58 (50-96)	83 (0-94)	67 (25-92)	33 (8-58)	0.139			
SocF	60 (42-73)	50 (27-88)	50 (33-63)	42 (33-58)	0.427			
HD	80 (73-93)	60 (49-89)	55 (29-66)	60 (43-80)	0.015			
OQoL	64 (40-78)	47 (35-80)	53 (43-66)	45 (40-50)	0.303			

EWB	84 (54-91)	68 (47-88)	55 (36-72)	52 (40-76)	0.052
RLE	50 (0-100)	0 (0-50)	0 (0-100)	0 (0-34)	0.534
CF	70 (35-93)	68 (40-93)	50 (23-70)	50 (29-64)	0.277
PHC	52 (42-66)	41 (28-71)	37 (28-48)	37 (29-48)	0.047
MHC	63 (45-91)	46 (31-72)	46 (31-67)	40 (36-49)	0.205
MSQoL-54	59 (45-72)	44 (30-72)	41 (31-57)	37 (32-47)	0.094

MSQoL-54 The Multiple Sclerosis Quality of Life – 54, PH physical health, HP health perception, RLP physical role limitation, SeF sexual function, SocF social function, HD health distress, OQoL overall quality of life, EWB emotional wellbeing, RLE emotional role limitations, CF cognitive functioning, PHC PHC physical health composite, MHC mental health composite

MSQoL-54 kvaliteta života bolesnika s multiplom sklerozom – 54, PH fizičko zdravlje, HP percepcija zdravlja, RLP ograničavanje fizičke uloge, SeF seksualna funkcija, SocF društvena funkcija, HD zdravstvene nevolje, OQoL sveukupna kvaliteta života, EWB emocionalno blagostanje, RLE ograničenja emocionalne uloge, CF kognitivno funkcioniranje, PHC sastav fizičkog zdravlja, MHC sastav mentalnog zdravlja

* Kruskal-Wallis test

As regards to employment status, dimensions that describe physical health (Mann-Whitney test, p = 0.001), health perception (Mann-Whitney test, p = 0.001), social function (Mann-Whitney test, p = 0.002), health distress (Mann-Whitney test, p = 0.010), overall quality of life

(Mann-Whitney test, p = 0.009), physical health composite (Mann-Whitney test, p = 0.001), mental health composite (Mann-Whitney test, p = 0.007) and overall quality scale of quality of life (Mann-Whitney test, p = 0.003) were significantly worse rated respondents (Table 4).

Table 4 MSQoL-54 average score by employment status *Tablica 4. Srednja ocjena MSQoL-54 prema radnom statusu*

Median (interquartile range) by employment status								
Srednji interkvartilni raspon prema stanju zaposlenja								
Scale	Employed	Unemployed	Retired	p*- value				
Skala	Zaposlen	Nezaposlen	Umirovljen	p*vrijednost				
PH	30 (15–67)	53 (50-83)	25 (5-42)	0.001				
HP	50 (45–55)	38 (30–49)	34 (20-45)	0.001				
Energy / Energija	44 (32–56)	46 (28–66)	44 (32–52)	0.840				
RLP	0 (0–50)	0 (0–50)	0 (0–75)	0.289				
Pain / Bol	47 (23–63)	51 (30–77)	46 (27–56)	0.699				
SeF	67 (25–92)	67 (33–92)	42 (4–92)	0.551				
SocF	58 (50-67)	63 (38–73)	42 (25–58)	0.002				
HD	78 (50–86)	75 (40–80)	55 (30-60)	0.010				
OQoL	55 (50–73)	58 (45–73)	50 (39–55)	0.009				
EWB	68 (48-80)	64 (30–86)	52 (40–69)	0.142				
RLE	51 (0-100)	0 (0–58)	0 (0–33)	0.060				
CF	75 (40–90)	40 (20–78)	50 (28-60)	0.077				
PHC	46 (37–59)	49 (35–58)	36 (25–42)	0.001				
MHC	58 (48–72)	48 (35–61)	39 (31–50)	0.007				
MSQoL-54	58 (40-63)	49 (33–59)	37 (30–47)	0.003				

MSQoL-54 The Multiple Sclerosis Quality of Life – 54, PH physical health, HP health perception, RLP physical role limitation, SeF sexual function, SocF social function, HD health distress, OQoL overall quality of life, EWB emotional wellbeing, RLE emotional role limitations, CF cognitive functioning, PHC physical health composite, MHC mental health composite

MSQoL-54 kvaliteta života bolesnika s multiplom sklerozom – 54, PH fizičko zdravlje, HP percepcija zdravlja, RLP ograničavanje fizičke uloge, SeF seksualna funkcija, SocF društvena funkcija, HD zdravstvene nevolje, OQoL sveukupna kvaliteta života, EWB emocionalno blagostanje, RLE ograničenja emocionalne uloge, CF kognitivno funkcioniranje, PHC sastav fizičkog zdravlja, MHC sastav mentalnog zdravlja

* Mann Whitney test

There are no statistically significant differences concerning the physical and mental health scores by marital status even though widowers/widows gave the lowest scores to the aspects of physical activity, energy/vitality, sensation of pain, sexual function, social function, overall quality of life and emotional function. Mental health, as well as overall quality of life, is at a somewhat lower level in cases of widowers/widows – but without any statistically significant difference by group (Table 5).

By duration of the illness, the lowest score for the physical activity was given by respondents who had been ill for 21 years or more (Kruskal-Wallis test, p = 0.007). There are no significant differences concerning physical and mental health or in the overall scale (Table 6).

Table 5 Average MSQoL-54 score by marital status
Tablica 5. Srednja ocjena MSQoL-54 prema bračnom statusu

Median (interquartile range) by marital status								
Srednji interkvartilni raspon prema bračnom stanju								
Scale	Married	Single	Divorced	Widowed	p* - value			
Skala	Oženjen/a	Neoženjen/a	Rastavljen/a	Udovac/ica	p*vrijednost			
PH	40 (15-63)	23 (6-49)	23 (4-45)	20 (8–60)	0.523			
HP	40 (28–50)	38 (27–54)	30 (19–58)	40 (34–53)	0.902			
Energy / Energija	44 (34–56)	46 (23–59)	48 (31–61)	38 (16-46)	0.720			
RLP	0 (0–25)	0 (0–0)	0 (0–100)	0 (0–100	0.082			
Pain / Bol	47 (31–62)	50 (20-55)	39 (15–74)	34 (15–47)	0.018			
SeF	67 (25–92)	58 (0-92)	42 (0-67)	33 (0-63)	0.351			
SocF	50 (35–67)	46 (34–66)	46 (25–59)	25 (13–48)	0.197			
HD	60 (45–75)	43 (25–76)	58 (23-81)	50 (23–68)	0.533			
OQoL	53 (40–68)	50 (46-65)	50 (38–60)	34 (20–48)	0.171			
EWB	52 (38–74)	58 (42–79)	60 (46–88)	44 (3–61)	0.236			
RLE	33 (0–50)	0 (0–50)	17 (0–100)	0 (0–25)	0.550			
CF	55 (28–75)	40 (15–55)	50 (37–79)	50 (30–74)	0.617			
PHC	48 (35–67)	39 (28–63)	47 (39–63)	37 (28–43)	0.310			
MHC	39 (23–49)	37 (23–47)	36 (26–51)	28 (21–47)	0.809			
MSQoL-54	43 (35–57)	34 (29–57)	42 (34–54)	31 (26–45)	0.328			

MSQoL-54 The Multiple Sclerosis Quality of Life – 54, PH physical health, HP health perception, RLP physical role limitation, SeF sexual function, SocF social function, HD health distress, OQoL overall quality of life, EWB emotional wellbeing, RLE emotional role limitations, CF cognitive functioning, PHC physical health composite, MHC mental health composite

MSQoL-54 kvaliteta života bolesnika s multiplom sklerozom – 54, PH fizičko zdravlje, HP percepcija zdravlja, RLP ograničavanje fizičke uloge, SeF seksualna funkcija, SocF društvena funkcija, HD zdravstvene nevolje, OQoL sveukupna kvaliteta života, EWB emocionalno blagostanje, RLE ograničenja emocionalne uloge, CF kognitivno funkcioniranje, PHC sastav fizičkog zdravlja, MHC sastav mentalnog zdravlja

* Kruskal-Wallis test

Table 6. MSQoL-54 average score by duration of the illness *Tablica 6 Srednja ocjena MSQoL-54 prema trajanju bolesti*

Median (interquartile range) by duration of the illness Srednji interkvartilni raspon prema trajanaju bolesti						
Scale	Up to 10 years	11-20	21 or more years	p*- value		
Skala	Do 10 godina	11-20	21 ili više godina	<i>p</i> *vrijednost		
PH	45 (19–65)	25 (15-45)	8 (0–31)	0.007		
HP	40 (30–50)	35 (28–50)	33 (25–50)	0.698		
Energy	40 (28–54)	52 (40–58)	40 (32–56)	0.275		
Energija						
RLP	0 (0–25)	0 (0–0)	0 (0–75)	0.403		

Pain	47 (28–63)	47 (34–55)	32 (15–55)	0.342
Bol				
SeF	67 (6–92)	58 (33–92)	25 (0-58)	0.050
SocF	50 (38–67)	50 (33–60)	42 (25–58)	0.104
HD	55 (35–75)	60 (51–78)	85 (29–75)	0.473
OQoL	55 (45–68)	50 (45-55)	45 (28–63)	0.112
EWB	52 (36–78)	60 (46–74)	48 (74–68)	0.609
RLE	0 (0–75)	0 (0–58)	0 (0-100)	0.879
CF	48 (20–69)	55 (40–75)	55 (30-80)	0.272
PHC	39 (32–52)	39 (34–46)	33 (20–43)	0.077
MHC	47 (35–63)	44 (36–67)	43 (32–70)	0.886
MSQoL-54	44 (32–58)	40 (36–55)	39 (26–51)	0.515

MSQoL-54 The Multiple Sclerosis Quality of Life – 54, PH physical health, HP health perception, RLP physical role limitation, SeF sexual function, SocF social function, HD health distress, OQoL overall quality of life, EWB emotional wellbeing, RLE emotional role limitations, CF cognitive functioning, PHC physical health composite, MHC mental health composite

MSQoL-54 kvaliteta života bolesnika s multiplom sklerozom – 54, PH fizičko zdravlje, HP percepcija zdravlja, RLP ograničavanje fizičke uloge, SeF seksualna funkcija, SocF društvena funkcija, HD zdravstvene nevolje, OQoL sveukupna kvaliteta života, EWB emocionalno blagostanje, RLE ograničenja emocionalne uloge, CF kognitivno funkcioniranje, PHC sastav fizičkog zdravlja, MHC sastav mentalnog zdravlja

*Kruskal-Wallis test

Discussion

The influence of MS on the patients' quality of life has been determined on the basis of the performed research. The average score of overall physical health is 39, the overall mental health score is 44, and the MSQoL-54 scale score is 40. The mental health level exceeds the physical health level, which means that physical health has a smaller impact on the reduction of quality of life. It may be said that the quality of life of the respondents suffering from MS is low. The research has determined that most of the people assess their personal quality of life at the level of 60 to 80 out of 100.²⁰ According to published data, 60 is the threshold of unsatisfactory quality of life.

In this research, the respondents gave the lowest scores to the aspects describing limitations to activities due to physical health, limitations due to emotional problems and physical activity, while the highest recorded scores were given for sexual function, distress due to health problems and emotional function. In a research performed in 2009, Tepavcevic, Pekmezovic and Drulovic determined a higher score concerning physical health.²¹ In their research, the highest scores of the individual aspects of the quality of life concern physical pain and cognitive functions, while the lowest ones pertain to limitations due to physical health and general perception of health. In this research, the physical and mental health scores are largely in agreement with the results obtained in other studies.9,17,21

Differences in the quality of life have been observed in relation to demographic variables such as gender, age, level of education, marital status etc. The research has determined that there are differences in the quality of life of MS patients by their age. Health aspects describing physical activity, physical pain, sexual function, social function and overall quality of life are given significantly lower scores by the most elderly respondents. The physical health score and the overall quality of life scale is the lowest, by a significant margin, in respondents older than 55. In the research performed in 2011, Tadic, Dajic, Prtina and Popovic determined that age is the most important factor affecting physical aspects of quality of life in addition to depression and employment.²² In a research performed in 2011, Szilasiova and others did not determine any relationship between age and quality of life.9

It is clear from the results that men assessed their health as significantly better compared to the assessment by women – in the aspect of energy/vitality and in the aspect of physical pain. Women assessed their health as significantly better in the aspect of general perception of health. The score given by men for the overall quality of life scale is higher than the one given by the women. A research performed by Heiskanen, Vickrey and Pietila in 2011, demonstrated that there are differences in the overall quality of life MSQoL-54 scale by gender – namely, women gave lower scores concerning physical and mental health.²³ In this research, significant differences were derived by education levels concerning the aspects of energy/vitality, health distress and physical conditions. Persons who have obtained a master's degree are characterised by higher scores on the overall scale of quality of life. Other research studies also exhibit similar results.^{10,24}

As regards to the aspect of marital status, this research has not determined significant differences in the scores given for physical and mental health by the groups. In their research, Kisic Tepavcic and her collaborators confirmed a statistically significant relationship among the aspects of quality of life measured on the MSQoL-54 scale and the marital status, i.e. married respondents enjoyed a statistically significantly better quality of life.²¹ The research studies indicate that married people and people in common-law marriages enjoy greater personal quality of life than singles.¹⁷

The results of this research indicate significant differences in accordance with the employment status in dimensions describing physical activity, general health perception, social function, heath distress, overall quality of life, physical health composite, mental health composite and overall scale of quality of life. Retired respondents achieve significantly poorer scores than employed or unemployed respondents. The results obtained by other research studies indicate that unemployed people achieve lower scores for physical and mental health.^{21,23,25} MS most frequently occurs at the prime of one's life, when the affected person has numerous economic and social responsibilities. Research and analyses performed throughout Europe point to favourable psychological and physical effects of continued employment because they contribute to slowing down the progress of the illness. However, many are compelled to abandon their employment due to insufficient support. In their research, Kikuchi and others proved that support in terms of professional placement, increase of income or retention of the existing income as well as readily accessible information on the illness contribute to an improvement of the quality of life.²⁵ In their research performed in 2013, Tadic and Dajic point to a correlation of physical health, duration of illness, level of education and employment.²⁵

This research provided results indicating that there are differences in the quality of life depending on the overall duration of the illness. The score pertaining to physical activity is significantly lower in respondents who have been ill for 21 years or longer. Many other research studies proved a negative relationship of the quality of life and duration of the illness.^{7,21} Vuger-Kovacic's research in 2011 proved that the duration

of the illness was positively correlated with the quality of life.²⁰ There is a possible explanation arguing that patients find new occupations over the years of coping with the illness and that they increasingly reorient themselves to remaining opportunities.

The quality of life topic is important and current. Even though this research has not examined the impact of social support on the quality of life, it is known that its influence is significant. A research performed by Yamout and others in 2013 determined that MS patients' quality of life is not exclusively related to physical incapacitation, but also to social support levels, area of living, depression, education levels, employment, fatigue and religiousness.¹⁰ Accordingly, the evaluation of those factors for each MS patient is proposed in order to adjust targeted interventions. The results of a research performed in Finland determined that the need for psychological and social support was significantly related to the quality of life in the early stage of MS.²³ Respondents reported that their psychological and social wellbeing outweighs their physical function in respect of the quality of life. Nursing science research indicates that nurses and family members are an important source of psychological and social support to MS patients in the early stage of the illness.²²

This research provides an overview of MS patients' health and needs. The study's limitation is why the study includes patients from one region, so the results may not be representative of the whole MS population in Croatia. To prevent such sample fluctuations, a large multicentre study is needed.

Conclusion

Research shows that multiple sclerosis impairs the quality of life of patients. The obtained research results might be helpful in determining the guidelines for the education of patients as well as multiple sclerosis patients' families and they point to the need for inclusion of other professionals in the team. The treatment is interdisciplinary (medical, psychological, psychotherapeutic, involving physical rehabilitation and social-occupational aspects). The use of the instruments designed to measure multiple sclerosis patients' quality of life, based on subjective perceptions of quality of life, facilitates implementation of the targeted interventions and measures that improve the quality of life.

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