

Health-related Quality of Life of People with Multiple Sclerosis in Oman

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ABSTRACT

Objectives: Multiple sclerosis (MS) is a disabling neurological disorder with significant adverse effects on patients' quality of life (QoL). Despite the increased prevalence of MS in Arabian Gulf countries in recent years, no study has assessed the impact of MS on the health-related QoL (HRQoL) of Omani patients. Therefore, the objective of this study was to determine the impact of MS on HRQoL of Omani patients using the validated disease-specific self-administered MS International QoL (MusiQoL) instrument. **Methods:** We conducted a descriptive cross-sectional survey between April and December 2019 on 177 Omani patients with MS attending Sultan Qaboos University Hospital and Khoula Hospital in Oman using the MusiQoL instrument. **Results:** The majority (51.4%) of patients had poor HRQoL, and 48.6% had moderate HRQoL. We found that being > 30 years, female, married, separated, widowed, or divorced, and having visual and sleep problems resulted in poorer HRQoL scores. Among the different HRQoL components, relationships with the healthcare system and relationships with family and friends were the most affected by the disease process. Our results also showed that psychological wellbeing and coping domains of MusiQoL questionnaires are significantly reduced in females compared to males. **Conclusions:** Understanding the HRQoL of Omanis with MS provides valuable knowledge that could help optimize the management of this disease.

Approximately three million people worldwide are affected by multiple sclerosis (MS), with Caucasians having a higher incidence than sub-Saharan Africans.¹ The estimated crude prevalence of MS in Oman rose to 15.9/100 000 by 2019, suggesting that Oman should be placed in the medium-risk zone for MS.² MS is a chronic, inflammatory, and disabling disorder that causes demyelination in the nervous systems of young and middle-aged adults.³ This inflammatory disease is characterized by phases of exacerbation in which the symptoms are heightened and phases of symptom subsidence, where the symptoms are minimal.⁴ These symptoms may include sensation changes, vision problems, dysarthria, muscle weakness, imbalance, mood changes, depression, pain, fatigue, and heat intolerance.⁵ In addition to these symptoms, MS

can influence many characteristics of a patient's personal life and has considerable repercussions on their quality of life (QoL).⁶ Patients with MS need long-term treatment. One of the major goals in treating MS is to decrease the negative effects of this chronic disease on patients' QoL.⁷ Health-related QoL (HRQoL) is a complicated concept in which a patient's health is evaluated through physical, emotional, mental, and social components.⁸ An assessment of HRQoL is necessary to enable a better and holistic course of treatment to improve the overall QoL of the patient.⁵

Since objective indicators do not accurately reflect the effect of MS on a patient's personal life, many instruments to effectively measure QoL from the patient's perspective have been developed.⁸ Many HRQoL surveys for MS are available and have been extensively used. However, most of

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these surveys are generic instruments and not specific to MS.⁵ In 1992, the MS International QoL (MusiQoL) questionnaire was developed and validated in 15 countries.⁹ This instrument is short, self-administered, and multidimensional, and it specifically studies patients' points of view regarding the effect of MS on their QoL.^{10,11} The MusiQoL has been translated into many languages, including Arabic, and has been psychometrically assessed and validated based on a standardized methodology. Previous studies from around the world have used MusiQoL to evaluate patients' points of view on the impact of MS on their daily lives.^{12–15} However, to the best of our knowledge, no studies have focused on the effect of MS on HRQoL in Omani patients. Each country has unique factors, practices, beliefs, traditions, and healthcare systems, which could lead to differences in patients' QoL.¹⁶ Therefore, there is a need for research into the HRQoL of Omani patients with MS because presently, there is no researched information about the subject.

According to the Atlas of MS 2013 map, Oman, which is part of the Arabian Gulf, is a low-risk region for MS.¹⁷ The prevalence of MS in this zone started to increase during the first decade of this century, except in Oman, which reported a low prevalence rate of 4/100 000 in 2005.¹⁸ One could therefore hypothesize that Omanis may have different genetic factors than their Arab neighbors.¹⁹ Thus, this study aims to assess the impact of MS on the HRQoL of Omani patients using the validated disease-specific self-administered MusiQoL instrument.

METHODS

This cross-sectional descriptive study was carried out between April and December 2019 on 177 MS patients who attended the neurology outpatient departments of two major hospitals (Sultan Qaboos University Hospital and Khoula Hospital in Muscat, Oman). The study was approved by the Research and Ethics Committees of the College of Nursing, Sultan Qaboos University Hospital, and the Ministry of Health (REC/2017-2018/09). Participants in the study were patients who had been diagnosed with MS by the senior neurologist of these two tertiary care hospitals based on the McDonald criteria. Both male and female MS patients > 18 years who were willing to participate were included in the study. Patients perceived to have physical or mental

challenges in answering the questions were excluded from the study. According to a recent hospital-based study, 15.9% is the prevalence rate of MS in Oman, and all patients are treated in tertiary care hospitals in Muscat. The study sample size was calculated using the following formula: $N = Z^2 P (1-P)/d^2$ where N is the number of samples, Z is the level of confidence (95% = 1.96), P is the prevalence (15.9%), and d is the effect size (5%).

$N = (1.96)^2 \times 0.159 (1-0.159)/0.05^2 = 205$, was the final sample size. We collected the patient list from the hospital registry, and a consecutive sampling method was used to approach the patients during this data collection period. The response rate was 86%.

The research instrument used was a self-reported questionnaire in Arabic consisting of three sections. Section one includes questions related to sociodemographic variables (age, gender, occupation, place of living, education level, marital status, and occupation). Section two included clinical profile (disease course – relapsing-remitting, primary progressive, or secondary progressive), disease duration, type of MS-specific therapies, visual functions, and sleep patterns. Section three is the MusiQoL part to assess HRQoL. The MusiQoL questionnaire, which comprises 31 items that describe nine dimensions. Each dimension is named according to its constitutive items, as follows: activities of daily living (eight items); psychological wellbeing (four items); symptoms (three items); relationships with friends (four items); relationships with family (three items); relationship with the healthcare system (three items); sentimental and sexual life (two items); coping (two items); and rejection (two items).⁹ Each item was responded to using a six-point Likert scale, where 1 = never/not at all, 2 = rarely/a little, 3 = sometimes/somewhat, 4 = often/a lot, 5 = always/very much, and 6 = not applicable. The negatively worded item scores were reversed. All dimension scores were linearly converted to a 0–100 scale, and the higher scores indicated poor HRQoL. A score of up to 20 was considered good HRQoL, a score of 20.1–60 was considered moderate HRQoL, and a score > 60 was considered poor HRQoL. Results from the validation of MusiQoL suggest that the instrument is a disease-specific instrument that is sensitive to changes in the clinical status of patients.^{9,20} The researchers also reported that the instrument demonstrated good internal validity and

consistency, external validity, and reproducibility with a Cronbach's alpha of 0.92.

Data was collected by research assistants who are senior registered neurology nurses and were specifically trained to collect data from MS patients. Information about patients diagnosed with MS was collected from the hospital registry. Three subtypes of MS were identified from the patient file and were defined as: 'relapsing-remitting', 'secondary progressive', and 'primary progressive'. The selected participants were then approached in the neurology outpatient departments of the two hospitals when they came for their routine follow-up visits. After a thorough explanation of the study purpose and assurance of anonymity, as well as their confidentiality and right to withdraw at any time from the study, written informed consent was obtained from every subject involved in the study. The subjects were then interviewed in a private room by the research assistant. Participants were given the self-reported questionnaire, and the research assistant helped those who required assistance. All personal identifications of patients remained anonymous to ensure that there was no violation of privacy. Data confidentiality was maintained, and all physical data files were kept in locked cabinets in the researcher's office. All the signed informed consent forms with the respondent's details were stored and locked separately from the data. Confidentiality was also maintained by assigning code numbers instead of names to the data files.

SPSS Statistics (IBM Corp. Released 2015. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp.) was used for data entry, data cleaning, and data analysis. The data was audited for accuracy by two investigators. Normality of data was checked with the Shapiro-Wilk test before proceeding with data analysis. A *p*-value of < 0.050 was considered statistically significant for all tests. Descriptive summaries of sociodemographic and clinical characteristics (means, standard deviations, frequencies, and percentages) were used to describe the sample. Comparison of HRQoL scores with demographic and clinical variables was done with an independent *t*-test and analysis of variance (ANOVA).

RESULTS

A total of 177 Omani patients diagnosed with MS, with a mean age of 34.71±8.69 years,

Table 1: Demographic and clinical profile of participants (N = 177).

Variables	n (%)
Age, years	
< 30	57 (32.2)
31–50	108 (61.0)
> 50	12 (6.8)
Gender	
Male	47 (26.6)
Female	130 (73.4)
Place of living	
Muscat	95 (53.7)
Outside Muscat	82 (46.3)
Educational level	
Up to elementary school	17 (9.6)
High school and higher secondary	65 (36.7)
University education	95 (53.7)
Marital status	
Single	56 (31.6)
Married	109 (61.6)
Separated/divorced/widowed	12 (6.8)
Occupation	
Employed	97 (54.8)
Unemployed	80 (45.2)
Disease course	
Relapsing-remitting	163 (92.1)
Primary progressive	5 (2.8)
Secondary progressive	9 (5.1)
Type of MS-specific therapies	
Disease-modifying medicines	150 (84.7)
Disease-modifying medicines and physiotherapy	27 (15.3)
Visual functions	
Normal	103 (58.2)
Visual impairments	74 (41.8)
Sleep patterns	
Normal	118 (66.7)
Sleep disturbances	59 (33.3)

MS: multiple sclerosis.

participated in the study. Descriptive statistics showed that 73.4% of the patients were female. Almost half (53.7%) of the participants lived in Muscat, the capital city of Oman, and 53.7% had a university education. In addition, 61.6% were married, and 54.8% were employed. The majority (92.1%) of patients were classified as having relapsing-remitting MS, while 2.8% had primary progressive MS and 5.1% secondary progressive MS. Visual impairments were reported by 41.8% of the respondents, while 33.3% experienced sleep

Table 2: Mean and standard deviation (SD) of total and component scores of health-related quality of life (HRQoL) of multiple sclerosis patients.

Components of HRQoL	Mean ± SD
Activities of daily living	57.4 ± 22.2
Psychological wellbeing	60.3 ± 22.8
Symptoms	56.6 ± 20.3
Relationship with friends	63.1 ± 15.0
Relationship with family	75.7 ± 24.2
Sentimental and sexual life	52.3 ± 39.6
Coping	49.8 ± 25.8
Rejection	42.2 ± 25.3
Relationship with the healthcare system	81.7 ± 18.9
Total HRQoL	60.6 ± 11.4

disturbances. Table 1 presents the demographic profile of the respondents.

The mean duration of the disease was 6.6±4.57 years. Over half (51.4%) of the respondents had poor HRQoL (60.1–100 scores), while 48.6% of them had moderate HRQoL (20.1–60 scores). Surprisingly, no patient had a good HRQoL (0–20 scores) (Figure 1).

The total mean score of the HRQoL of the respondents was 60.6±11.4 [Table 2]. The relationship with the healthcare system and relationship with family was the most affected components, with mean scores of 81.7±18.9 and 75.7±24.2, respectively. The least affected subscale was rejection, with a mean score of 42.2±25.3.

Table 3 illustrates the comparison of means of HRQoL and gender. Females reported a poor HRQoL in total and the components of HRQoL. Statistically significant differences were seen with psychological wellbeing ($t = -2.353$, $df = 175$, $p = 0.020$), coping ($t = 2.630$, $df = 175$, $p = 0.009$), and total HRQoL ($t = -2.145$, $df = 175$, $p = 0.033$), with males having better HRQoL. The relationship between HRQoL components and other demographic variables did not show any statistically significant differences.

The results of the ANOVA of the demographic and clinical variables with the total mean scores of HRQoL of MS patients are presented in Table 4. Only significant results are presented in the table. The results suggest a significant difference between total HRQoL scores and age groups ($F(2,174) = 5.107$, $p = 0.007$), marital status ($F(3,173) = 4.155$, $p = 0.007$), sleep pattern ($F(1,175) = 12.620$,

Table 3: Comparison of HRQoL scores of MS patients based on gender.

Component scale of HRQoL	n	Mean ± SD	t-test	p-value
Activities of daily living				
Male	47	55.6 ± 23.2	-0.660	0.510
Female	130	58.1 ± 21.8		
Psychological wellbeing				
Male	47	53.7 ± 22.2	-2.353	0.020
Female	130	62.7 ± 22.6		
Symptoms				
Male	47	53.4 ± 17.9	-1.266	0.207
Female	130	57.8 ± 21.0		
Relationship with friends				
Male	47	61.1 ± 14.3	-1.040	0.300
Female	130	63.8 ± 15.3		
Relationship with family				
Male	47	73.2 ± 25.7	-0.844	0.400
Female	130	76.7 ± 23.6		
Sentimental and sexual life				
Male	47	53.2 ± 40.8	0.188	0.851
Female	130	51.9 ± 39.3		
Coping				
Male	47	41.5 ± 22.5	-2.630	0.009
Female	130	52.9 ± 26.3		
Rejection				
Male	47	42.6 ± 26.2	0.128	0.898
Female	130	42.0 ± 25.0		
Relationship with the healthcare system				
Male	47	77.6 ± 22.6	-1.731	0.085
Female	130	83.1 ± 17.2		
Total HRQoL				
Male	47	57.5 ± 11.8	-2.145	0.033
Female	130	61.6 ± 11.1		

HRQoL: health-related quality of life; MS: multiple sclerosis; SD: standard deviation.

$p < 0.001$), and visual functions ($F(1,175) = 6.236$, $p = 0.013$). Post-hoc analysis revealed age group > 31 years old, being separated, divorced, or widowed, group perceived poor HRQoL than others. Being female, and having sleep and visual disturbances are associated with poor HRQoL scores.

DISCUSSION

The MusiQoL questionnaire was used to assess the respondents' MS-specific HRQoL. To our best knowledge, this study is the first to investigate the HRQoL of Omani patients with MS using this

Table 4: Association of total HRQoL of MS patients with their demographic and clinical characteristics.

Demographic and clinical profile	n	Mean ± SD	df	F	p-value
Age, years					
< 30	57	56.7 ± 11.1	2,174	5.107	0.007
31–50	108	62.5 ± 10.8			
> 50	12	61.7 ± 14.4			
Marital status					
Single	56	56.7 ± 10.7	3,173	4.155	0.007
Married	109	61.8 ± 11.0			
Separated/ divorced/ widowed	12	66.9 ± 12.0			
Visual functions					
Normal	103	58.8 ± 11.5	1,175	6.236	0.013
Impairments	74	63.0 ± 10.9			
Sleep patterns					
Normal	118	58.5 ± 11.3	1,175	12.620	<0.001
Disturbances	59	64.7 ± 10.5			

HRQoL: health-related quality of life; MS: multiple sclerosis; SD: standard deviation; df: degree of freedom.

valid and reliable questionnaire. We found that being > 30 years, female, married, separated, widowed, or divorced, and having visual and sleep problems were significantly associated with poorer HRQoL. Among the different HRQoL components, relationship with the healthcare system and relationship with family and friends were the most negatively affected as a result of the disease process. Our results also showed that psychological wellbeing and coping domains of MusiQoL questionnaires are significantly reduced in females compared to males.

The MusiQoL instrument is the best to use in our setting because it has been validated in 14 languages, including Arabic, and the differential item functioning was found to be satisfactory in more than 15 countries around the world.⁹ The use of this questionnaire is suitable for international settings, and such use can be beneficial for comparing different populations. The MusiQoL instrument has the advantage of being shorter than other instruments and more suitable for clinical practice.¹³ It is well known that HRQoL is affected by the population’s different cultural backgrounds and healthcare systems.

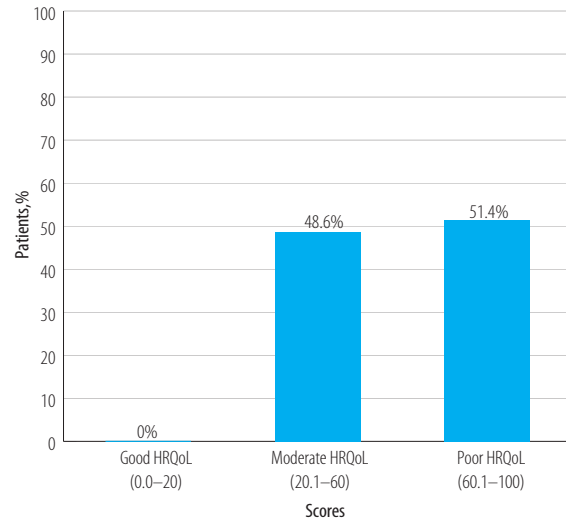


Figure 1: Percentage of patients with multiple sclerosis based on their health-related quality of life scores (HRQoL).

All patients had a high MusiQoL score that fell in the moderate to low HRQoL category. This result can be explained by the fact that over 90% of the studied population suffers from the relapse-remitting MS subtype. Studies have shown that the worst level of HRQoL is observed in patients with relapse-remitting MS.¹² Similarly, other studies have revealed that the more progressive the disease course, the poorer the HRQoL for the MS patient.²¹ However, in our study, the low percentage (> 8%) of patients with progressive disease did not allow us to compare the HRQoL between the three different disease courses.

The study found that patients with MS showed a low level of HRQoL in the components of the relationship with the healthcare system, family, and friends. This, therefore, implies that having MS affects interpersonal relationships with family and friends. In addition, studies have shown that social support is an important component that can help improve HRQoL in MS patients. Interestingly, while all support is important, psychological support to the MS patient appears to be more required than material support in all dimensions of HRQoL.²² Hence, understanding which components greatly affect patients with MS will allow us to develop strategies to mitigate their effect and positively affect HRQoL.

Comparison of means among the categories of sociodemographic characteristics showed that older

adults, females, those who are separated, divorced, or widowed, and patients with visual and sleep problems have poorer HRQoL. This result supports the findings of many other studies that also showed that younger age (< 30 years) and being a male were significantly linked to a better HRQoL in similar studies conducted using MusiQoL instrument.^{13,23,24}

We also found that the patient's marital status played a significant role in affecting their total HRQoL. Being single was associated with higher HRQoL levels. Being married was associated with a lower HRQoL while being divorced, separated, or widowed had the lowest scores. This result appears to contradict the findings of previous studies, which showed that being married was associated with higher HRQoL levels.^{10,25} For instance, a study of 1992 patients from 15 countries reported that patients with MS who have partners had significantly higher HRQoL than single patients.¹³ In trying to better understand the possible explanation for this difference, we noted that all these previous studies asked respondents whether they were 'single' or 'not single'. It is possible that a separated, divorced, or widowed person would answer as single; therefore, the differentiation between single and separated, widowed, or divorced may not have been as clear to their respondents. This could have influenced the results and increased the score for the 'single' component. In our study, we can argue that a single patient who has never been married has the highest HRQoL. A married patient probably has more responsibilities and, therefore, has a lower HRQoL, while a separated, divorced, or widowed patient lacks the family support they once had, and this easily shows as having the lowest HRQoL. Omani patients with MS showed a low HRQoL dimension of relationship with family, which could also explain the aforementioned association.

The present study showed poor HRQoL perception among MS patients with sleep and vision disturbances. Other researchers support this finding.^{26,27} Increased levels of inflammatory cytokines or lesions in the brain may disrupt pathways involved with sleep which may contribute to sleep disruption in MS patients.²⁸ Visual disturbances in MS patients need to be considered in the light of falls, which are commonly reported among them.²⁹ These findings highlight the importance of carefully screening all patients with MS for the presence of sleep and visual problems so that a variety of strategies to

reduce the effects of these problems on the HRQoL are implemented promptly. Future research on sleep quality in MS should consider exploring sleep disturbance, particularly its relationship with disease activity. Vision rehabilitation may be required for patients experiencing visual difficulties in the course of the disease progression. Therefore, it is important to use a holistic interdisciplinary approach to address the person's needs with MS.

In the present study, educational level, employment status, disease course, and MS-specific therapy did not show any difference in perception of HRQoL. Unlike other study populations,¹⁰ Omani MS patients who have a higher level of education do not have a better HRQoL. This could be because only slightly < 10% of the studied sample did not have a high school or university education. In addition, our results do not show a higher HRQoL among employed MS patients when compared to the unemployed patients, contrary to other studies.³⁰ This observation could be unique to the Omani population and may be associated with the society and particular characteristics of Omani MS patients.

When examining demographic variables, we found that only gender exhibits differences in some MusiQoL dimensions. Other sociodemographic variables did not affect the different component scales of the MusiQoL questionnaire. We found that the HRQoL of males is somewhat higher than that of females but only for two MusiQoL domains. Both psychological wellbeing and coping scores were higher for women than men, which means better functions for the latter. As a mediator between MS and psychological wellbeing, coping is an important domain to be assessed. As MS advances, coping becomes of paramount importance to the patient's psychological wellbeing.²⁴ Studies have shown that emotional and psychological functions are lower in women with MS than in men.^{13,30} The finding that coping and psychological wellbeing appear to negatively impact females more than males must be further explored to understand the reasons for these differences among the genders. One possible reason in our setting is that Oman is a patriarchal society whose culture places high expectations on men, who should show physical and mental ability, power, efficiency, and productivity. These findings are very important in developing coping strategies targeting Omani men and women with MS who could benefit

from a psychological rehabilitation program. Studies suggest that patients should change their lifestyles, ambitions, and expectations from their physical performances and adapt themselves to live with the disability to better cope with MS.³¹

Eye examinations in the early stages to prevent diminishing visual acuity, sleep clinics to empower them with strategies to overcome their sleep disturbances, and psychological counseling with family support can play an important role in improving the HRQoL of these patients living with MS.

Several limitations of our study should be examined. First, the size of the studied population is relatively small, and additional research with a larger sample of Omani patients is necessary to confirm our results. Second, our study did not assess fatigue, depression, anxiety, and other major symptoms like pain, bladder/bowel symptoms, and disability, which have been shown to affect HRQoL.^{6,32} It is recommended that future research on the observation of all the major symptoms experienced by these patients could be assessed. Another limitation is the cross-sectional study design, which does not allow us to interpret the associations as causal relationships. Only a longitudinal study can better understand the course of MS and the coping mechanisms in Omani patients.

Understanding the HRQoL of MS patients will help healthcare providers to assess their patients and treat them better. This research will help patients with MS who have not been coping well with their disease be better identified, treated, and referred to counselors when deemed necessary. The results of this study will contribute to the limited body of literature on Omani patients with MS and allow us to develop strategies for improving their HRQoL. Such information will aid stakeholders, including the Ministry of Health of Oman, to plan strategies to improve their HRQoL to ease the burgeoning load of this disease to the Omani society.

CONCLUSION

Poor HRQoL has been reported by Omani patients with MS in our study. We found that being > 30 years, female, married, separated, widowed, or divorced, and having visual and sleep problems resulted in poorer HRQoL scores. Moreover, relationships with the health care system and family and friends most

negatively affect patients' HRQoL. Understanding these results is of paramount importance to the Omani health care system to design a more comprehensive approach to more effectively care for Omani patients with MS. Understanding factors influencing HRQoL among people with MS is helpful for the health care workers to design early intervention programs.

Disclosure

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