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RESEARCH ARTICLE

How Saudi patients with multiple sclerosis evaluate their Health-Related Quality of Life using Euro-Questionnaire- 5 Dimensions (EQ-5D)

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Abstract

Background and aims: Multiple sclerosis is a chronic disease that might cause life- long disability and affect the patient's quality of life (QoL). There is an acknowledged lack of information about health-related quality of life (HRQoL) in Saudi patients with MS. this study aimed to assess how MS Saudi patients rate their QoL and the factors that affect the patient's perception of HRQoL.

Methods: A cross sectional study including 422 Saudi patients with MS was conducted. An EQ-5D questionnaire was used. Basic demographic and descriptive MS data were collected. SPSS package was used for statistical analysis of the resulting dataset.

Results: MS patients are either respondents with low or high health states. The characteristics of high health states were: better health profiles especially with mobility and self-care, younger females with higher health indices, shorter disease durations and relapsing-remitting type. Conversely, the respondents with low health states were: poorer health profiles, older male patients, longer disease duration and progressive type.

Conclusion: Our findings can be used to enhance the QoL of people with MS in KSA, facilitating physician-patient communication, promote shared decision making and appreciating patient priorities.

INTRODUCTION

Multiple sclerosis (MS) is an immune mediated neurological disease characterized by areas of demyelination of the central nervous system. The age of onset is primarily (20 – 45) years with a wide spectrum of clinical presentations linked with a broad spectrum of physical and social impairments [1, 2].

The epidemiology of MS is rapidly changing in different parts of the world. Recent studies in the Arabian Gulf suggest relatively high prevalence in recent years. However, it is now clear that MS in Saudi Arabia is fairly prevalent, in increase and under-diagnosed. The symptomatology of MS and site of lesions in Saudi patients are similar to that seen in European patients [3].

Patients with MS may suffer from fatigue, visual symptoms, cognitive difficulties, pain, psychic troubles, urinary and sexual dysfunction that could be associated with social and physical impairment [4]. The course of the diseases is typically characterized by episodic acute periods of worsening condition, gradual progressive deterioration, or both [5]. Nowadays, the impact of the physical disability of the disease on patient's quality of life (QoL) is well recognized [6].

WHO defined QoL as the individual perceptions of his position in life in the context of culture and value system in which he live, and in relation to his goals, expectations and concerns [7]. Euro-Qol Group developed the EQ-5D to provide a simple tool for use in clinical studies [8, 9]. Many studies recommended QoL assessment to evaluate MS progression and care management provided to patients [10, 11].

Although MS is a chronic disease that might cause lifelong disability; the information about quality of life (QoL) in Saudi patients with multiple sclerosis (MS) are lacked. So, the purpose of this study was to investigate the health related QoL in Saudi patients with MS. The response of the studied group to EQ-5D helped to assess how they could rate their quality of life. This is up to date the first known study that uses the EQ-5D responses of the MS Saudi patients comparing those with high self-rated health states with others with low self-rated health states.

Methods:

Ethical Considerations: A total of 422 subjects were asked to participate in this study after taking written consent from the patient. The study protocol was approved by the ethical committee of Faculty of Medicine, Taif University Confidentiality was maintained throughout the data collection process.

Participants and materials: Saudi MS patients were recruited from outpatient's clinic of King Abdul-Aziz Specialized Hospital, Taif; KSA and from King Abdul Aziz Medical City, Jeddah, KSA.

Using the EQ-5D, QoL and health status were self-evaluated using five dimensions (mobility, self-care, usual activities, pain/ discomfort and anxiety/depression) with only three possible response options ; no problem=1, moderate problem = 2 , severe problem =3.

Alongside the EQ-5D, a health status thermometer (VAS scale) records patient's subjective opinion of their health status [12]. Descriptive statistics was planned to assess the distribution of measures of EQ-5D and EQ-VAS [13, 14]. Additionally, health index can be generated from the EQ-5D data with a score range of 0 to 1, where (1) means best health condition [14].

Data collection and analysis: A face-to-face interview was conducted. Respondents were given a copy of the questionnaire which was simultaneously read out to them by the interviewer, who then completed the questionnaire for the respondents.

Outcome measures: for each respondent, the following were collected: background information about name, age, gender, and disease information about duration and type of disease.

EQ-5D descriptive system: respondents were asked to describe their own health state using the EQ-5D descriptive system, resulting in a five-digit number, called health profile. For example, profile 21132 indicates level 2 (some problems) on mobility, level 1 (no problems) for self-care and usual activities, level 3 for extreme pain or discomfort, and level 2 for moderate anxiety or depression. Calculation of the health indices was done using the Time Trade off (TTO) method [9, 15].

Respondents were asked to indicate their own current health state, on a 20 cm vertical (EQ VAS: visual analogue scale) calibrated from zero to 100 where zero was the worst imaginable health state and 100 was the best imaginable health state.

Statistical analysis: Data were presented as Mean ± SD. Statistical differences between groups were assessed by one-way Analysis of Variance (ANOVA) followed by Post Hoc multiple comparison tests (least significant different test; LSD) from the SPSS statistical package version 17.

Descriptive statistics were used to describe the demographic details, the background information and the health profile and status of the respondents. Comparison among quantitative parameters (EQ-5D index, VAS) was made using the two-sample *t*-test. Correlations between the time since diagnosis of MS and health index and status of respondents were done by Pearson correlation analysis and the correlation coefficients (r) were tested. $P < 0.05$ was considered statistically significant.

Results

Description of Respondents: The study enrolled eligible 422 MS patients out of 500 patients that were asked to participate. 68% of which were female and 32% were male. The respondents were classified according to their age into 3 groups. Group (a): included 146 patients range from 15-24 years, Group (b): include 160 patients range from 25-44 years, Group (c): include 116 patients > 45 years (table: 1).

Description of Health profile: Health profiles were examined to assess the proportions of people with MS at each level on the five dimensions, and the percentages of people reporting at least some problems can be seen in table 1, figure 1. 78% of patients aged (15-24) years showed positive self-reported severe or some limitations to anxiety/depression and 93% of them same group faced some or sever problems regarding pain/discomfort. The least impaired dimensions were mobility and self-care; (93.5%) reporting absence of limitation and (83.5%) lacking problems with self -care (Table 1 and figure: 1).

The condition became worse with aging as regarding mobility, self- care and daily activity. In group (b) (25-44 years): at the level of the previously mentioned 3 domains, most of the patients (in both sexes) recorded some to sever problems with them. Meanwhile, 58% and 60% of patients recorded a negative response of no problem concerning pain/discomfort and anxiety respectively, (table1, figure: 1).

Regarding patients of group (c) (>45 years), all females (n=71) showed a strong positive response (sever problem) to self- care, daily activity while males recorded the same response to daily activity, mobility and self-care. On the other hand, most of male and females were facing no problems with pain and anxiety at rates respectively of 58%% and 60%, (table1, and figure 1).

Considering the self-reported evaluation of health states using the EQ-VAS, there was significant difference in the mean values ±SD of EQ-VAS among the age groups. Higher record was observed in young age group (15-24, VAS= 80.9±12.07) and lower record of mean ±SD of VAS was observed in old age >45 years (VAS= 50.12±11.89) (table 2).

- *Health states (EQ-VAS) and health index:* The young age group that recorded high EQ-VAS was associated with high percentage of no problem with mobility and self-care (62.5% and 56% respectively). However, the old age group that recorded low EQ-VAS was associated with high percentage of sever problem with mobility, self- care and daily activity. We observed that 93%, 92% and 89% of old age patients recorded sever or some problems with mobility, self- care and daily activity respectively (table 1, 2).

The mean values ± SD of health index of MS Saudi patients that respond to this study (0.570±0.106) and that of health states was (65.4±18.02). Also, significant difference was detected in health indices and health states between male and female MS patients. It was higher in female than male patients with mean values ± SD of health index of male patients was 0.523±0.107 while that of female patients was 0.618± 0.085 (*p*=0.041). Also, higher health states were detected in female patients than male patients (mean values ± SD were 74.73±13.47&56.07±17.62 respectively (table 3).

However, there was significant difference ($p< 0.05$) between health indices and health states regarding types of MS. Higher mean values ± SD of both health indices and states was detected in relapsing remitting MS. Lower mean± SD values of health index and states were detected in secondary progressive type respectively (table: 4).

Scatter plots of health indices and health states against time detected since diagnosis of MS (figure: 2) revealed High significant negative linear correlation in male patients (P = 0.000 and r value = -0.867and -0.946). Also, significant negative linear correlation was observed in both health index and states of female patients in this study (P<0.05 and r value= -0.806 and -0.785). The health index and states were significantly decreased with increase in time since diagnosis of MS in both male and female patients.

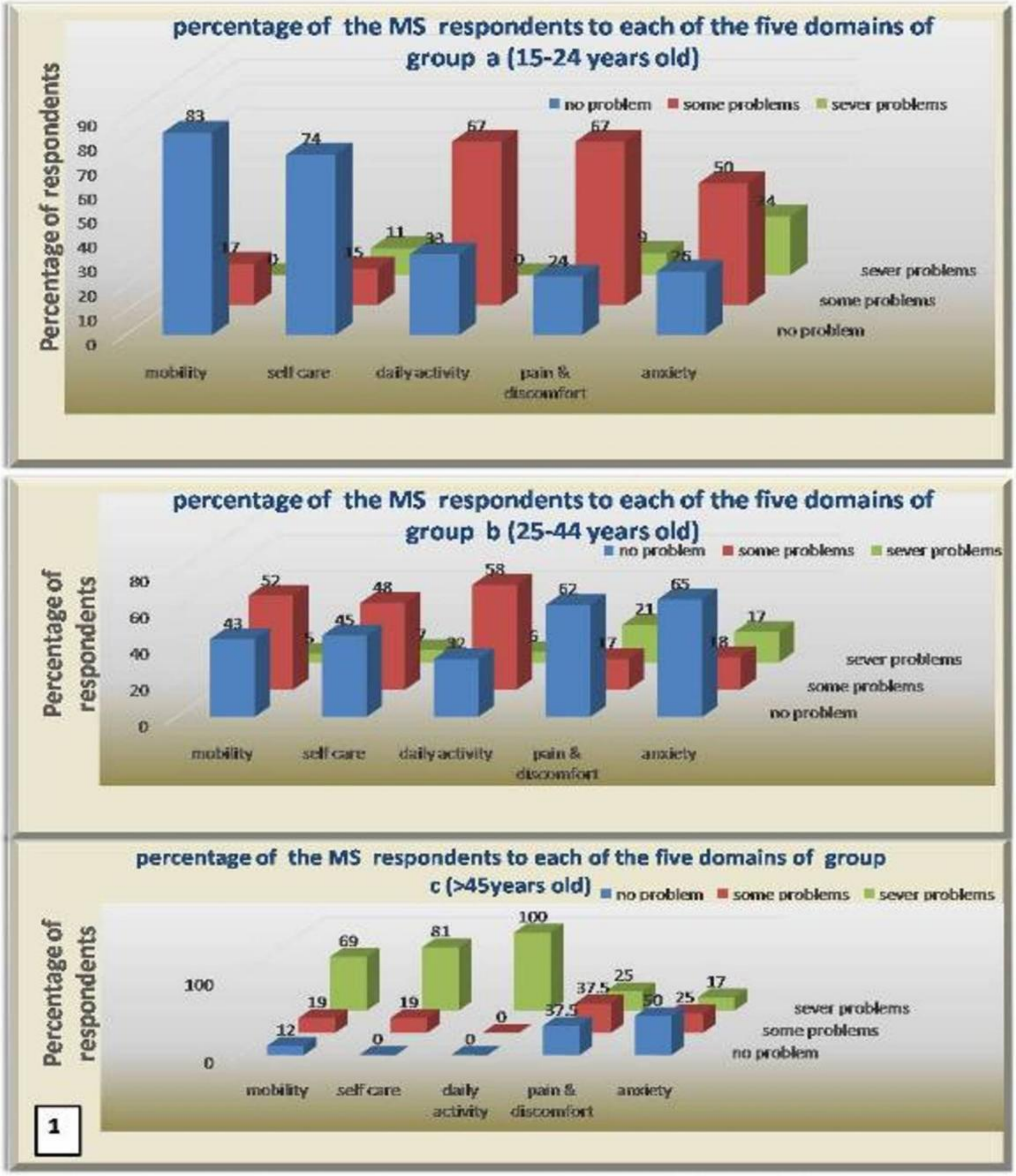
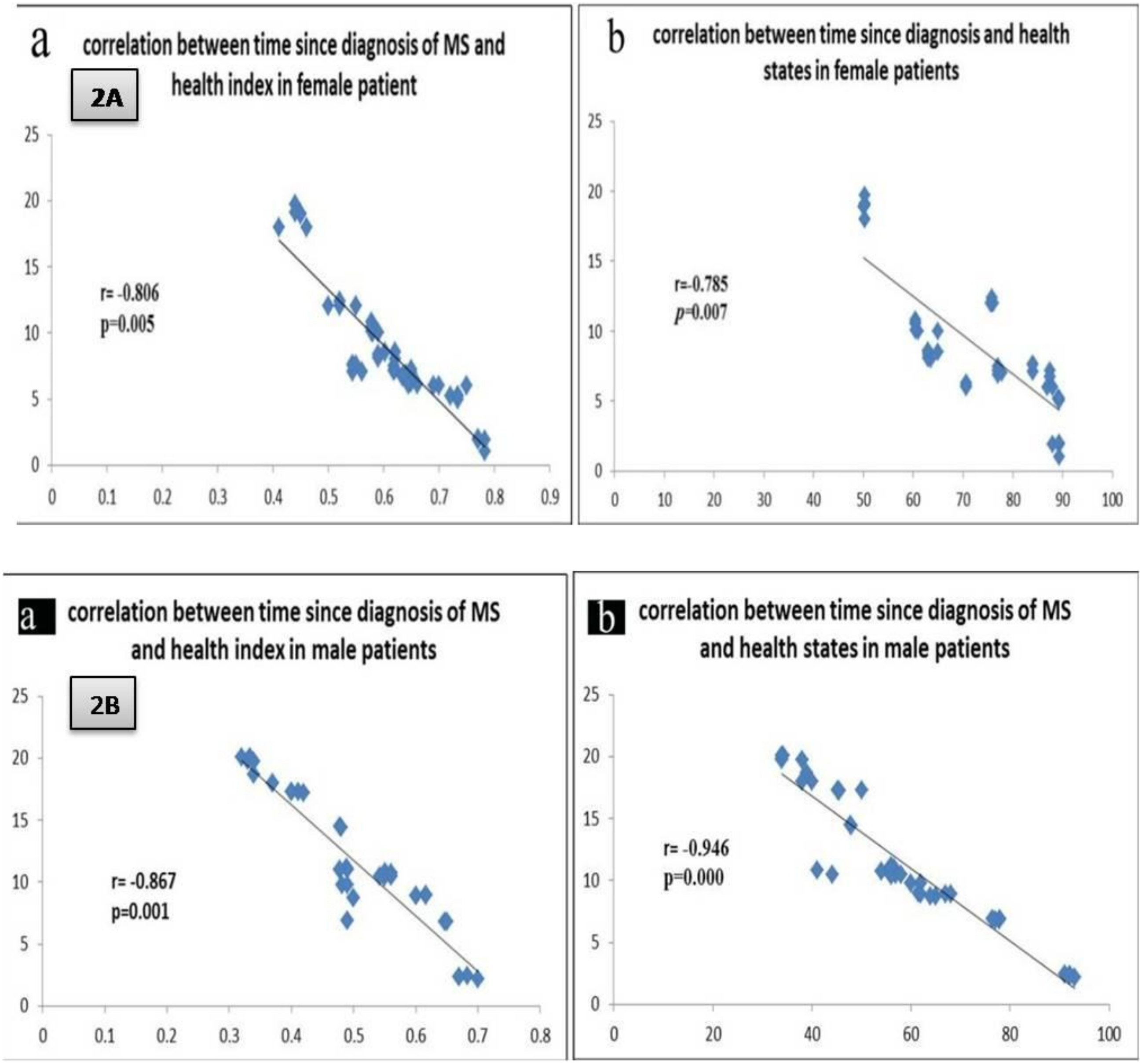


Figure (1): Health profiles of MS patients according to age groups (a, b, c) and the percentage of respondents reporting either no problems, some problems and severe problems on each of the 5 domains of EQ-5D.



<u>Figure (2):</u> correlation between time since diagnosis of MS and heath indices (a) and states (b) in female (2A) and male (2B) patients.

	Mobility			Self-care			Daily activity			Pain & discomfort			Anxiety		
	1	2	3	1	2	3	1	2	3	1	2	3	1	2	3
Group (a) (15-24 years age) N=146 (38%)															
Male N=66 (%)	41 62.5	25 37.5	0	37 56	16 25	13 19	41 62.5	25 37.5	0	8 12.5	58 87.5	0	0	46 69	20 31
Female N=80	74 93.5	6 7.5	0	66 83.5	8 10	6 7.5	13 16	67 84	0	24 30	45 57	11 13	32 40	32 40	16 20
Total N=146 %	115 78%	31 22%	0	103 70.5	24 16.5	19 13%	54 37%	92 63	0	11 7%	103 71	32 22	32 22	78 53	36 25%
Group (b) (25-44 years age) N= 160 (49%)															
Male N=67	23 35%	40 59%	4 6%	8 12%	59 88%	0	15 23	43 64	9 13	27 41%	0	40 59	27 41	0	40 59%
Female N=93	43 46%	43 45%	7 8%	49 53%	31 33%	13 14 %	33 35%	52 56 %	8 9 %	65 70%	21 23 %	7 7 %	69 74 %	20 22 %	4 4%
Total N=160 Percentag	66 41%	83 52%	11 7%	57 36%	90 56%	13 8	48 30%	95 59	17 11	92 58%	21 13	47 29	96 60	20 13	44 27%
Group (c) > 45 years age N= 116 (13%)															
Male N=45	10 22%	5 11%	30 67%	0	20 45%	25 55%	0	0	45 100%	15 33%	0	30 67%	0	15 33%	30 67%
Female N=71	0	21 30%	50 70%	0	0	71 100%	0	0	71 100%	28 40%	43 60%	0	57 80%	14 20%	0
Total N =116	10 9%	26 22%	80 69%	0	20 17%	96 83%	0	0	116 100%	43 37 %	43 37%	30 25%	57 49%	29 25%	30 26%

Table (1): Health profiles of MS patients within the three age groups represented as frequencies and percentages of the male and female respondents in the five domains of EQ-5D.

Table (2): mean ± SD values of Health states (EQ-VAS) of respondents in the three age groups

	Group (a) (15-24 years) N=146	Group (b) (25-44 years) N= 160	Group (c) > 45 years N= 116	*p*
Health states	80.9±12.07	70.03±20.36	50.12±11.98	0.00*

Table (3): Mean ± SD values of health indices and Health states in male and female MS patients that respond to the study.

	Health index	Health states
Male (N=178)	0.523±0.107	56.07±17.62
Female (N= 244)	0.618±0.085	74.73±13.47
P value	0.041*	0.016*

Table (4): Mean ± SD of Health states and health indices of the respondents according to type of MS.

Disease type	**Health index**	**Health states**
PPMS (N= 122)	0.432±0.19	60.13±21.9
RRMS (N= 200)	0.58±0.19	80.01±18.36
SPMS (N= 90)	0.356±0.178	45.91±14.90
DKMS (N= 10)	0.492±0.19	50.81±16.7
P value	0.000*	0.000*

PPRM: primary progressive MS, RRMD: relapsing remitting MS, SPMS: secondary progressive MS, DKMS: doesn't know, *P < 0.05 (significant)

Discussion

MS is a chronic disease with little effect on life expectancy, but a broad spectrum of variable physical and psychological impacts. In recent years, HRQoL questionnaires that measure the impact of illness have been developed and validated in populations with chronic diseases [16, 17].

This cross sectional study has used 122 Saudi responses to the EQ- 5D. The resulted data were used to assess health indices, the health profiles, and health status of the respondents. This is the first known study up to date that uses the EQ-5D for Saudi people with MS. It has shown the high percentage of problems recorded in all of the five dimensions of the health profile, and different factors that could affect.

Most of the respondents were of middle age group (25-44 years : 49%) and young age (15-24 years :38%) and most of them were female (%68).The characteristics of our respondents were with epidemiologic characters of the disease. Most people are diagnosed with MS between ages 20 and 50 years. The disease typically affects women especially in their peak years of family life and career development [18].

Analysis of the health profiles of the respondents (table: 1) revealed a low percentage of sever problems recorded in most of the 5 domains in females patients of young (15-24 years) and middle age (25-44 years) groups. However, in old age group, the prevalence of problems was high in most of the domains in both male and female patients. Also, health states of the patients were decreased with age. In Our study, lower life satisfaction was reported in old patients with MS than young patients. The increase in the frequencies of problems with age in Saudi patients was similar to that observed in United Kingdom (UK) [19].

Buchanan et al., [20] explained the association between young adults with MS and better dimensions of HRQoL by that MS-focused care results in a positive change in physical adaptation from baseline that causes patients to view their physical QOL in more positive terms.

We observed in this study that, the sense of problems with anxiety decreased with age in MS Saudi patients. This was in coincidence with the result of other study working on UK patients [21] where the problems related scores for anxiety was decreased with age.

The mean health states for Saudi MS patients reported in this work was 65.4 (SD=18.02) compared to health states of UK patients was 59.73 (SD 22.4) [19]. The health states of MS Saudi patients were notably higher than those of the MS patients in UK. High EQ-VAS was recorded in young age group and was associated with high percentage of no problem with mobility and self-care. Also, high health states and indices were observed in females with short duration of disease. However, the old age group that recorded low EQ-VAS was associated with high percentage of sever problem with self- care, mobility and daily activity. Also, low health indices and states were observed in males with longer duration of the disease.

Considering that the health profile scores are converted into health indices. So, health indices were moderately positively correlated with health states. Health states are not based directly on clinical symptoms of the disease and based on overall feeling of the respondent’s about their QoL. Other study working on chronic disease like asthma found that the clinical status of the patients does not always predict their self-rated health state [22], as patients with chronic disease develop new strategies to rearrange their experience and expectations. So, they may record higher rate of QoL than might be expected from their clinical status [23, 24].

Our results showed that the least predictive dimensions that affect patient's health states were anxiety/depression and Pain/discomfort. Most of patients especially in old age group reported no problems with these dimensions although they recorded low health (VAS). This could be explained by proper management of these problems by therapy and medication [19]. In contrast, patients that facing difficulties with self- care, Mobility and Usual Activities were associated with Low health states (VAS) in old age group. These types of patients may be suffered from difficulties in inclusion in general activities and loss of social life.

Also, the present study recorded differences in the prevalence of problems between different types of MS. A greater proportion of patients with a relapsing remitting type of MS (RRMS) were recorded. Patients with secondary progressive (SPMS) type were experiencing more problems and less health index and states. This was coinciding with the results observed in the MS patients of UK [9, 19]. The mean health state scores were correlated with sustained disability progression and relapse number [25].

Importantly, we found significant negative association between time since diagnosis of MS and health index and health status of the respondents. Increase in the duration of the disease was associated with low health indices and status. MS has several features that may contribute to low QoL with age. Firstly, MS affects neurological and neuropsychiatric function. Secondly, diagnosis of the disease in young adults is maximally influencing personal development and productivity. Thirdly, there is an unpredictable course of MS in which future disability and relapses are difficult for sufferers to anticipate. Finally, there is limited evidence of possible disease cure and high risk of side effects induced by used drugs [2]. So, the value of using HRQoL instruments in care of MS patients are increased, where they may help clinicians facilitate physician-patient communication, and appreciate patient priorities [2].

Conclusion and Recommendations

The present work emphasized that female Saudi patients with younger age and shorter duration of RRMS type were associated with better health profiles and higher health indices and states. Conversely, male Saudi patients of older age, longer durations and PMS type were facing poorer health profiles, lower health indices and states. The findings can be used to inform clinicians to evaluate QoL with MS in Saudi Arabia and should be included in future clinical trials. Educational attainment, treatment history and other life style factors could be considered on a larger scale of Saudi patients in future research work.

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No conflict of interest to declare.

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