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Factors that impact health-related quality of life in 168 myasthenia gravis in West China: Disease severity, social support, and coping style

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Abstract

Background: Myasthenia gravis (MG) is associated with reduced health-related quality of life (HRQOL). This study aimed to investigate factors that impact HRQOL in MG in a patient population in West China. *Methods:* A series of questionnaires were completed by 168 patients to assess the relationships between HRQOL and social support and coping style. We also evaluated the contributions of clinical characteristics to HRQOL. One-way analysis of variance (ANOVA), correlation and regression analysis were conducted to identify predictors that negatively impact HRQOL in MG. *Results:* There were significant differences in HRQOL scores among patients with different ratio of disease cost to income each month (F = 5.831, $P = 0.001$) and frequency of MG symptoms (F = 9.128, $P < 0.001$). Spearman's correlation analysis showed that reduced HRQOL had low correlation with Myasthenia Gravis Composite score (r = 0.461, $P < 0.001$), confrontation (r = 0.312, $P < 0.001$) and acceptance-resignation coping style (r = 0.433, $P < 0.001$). Stepwise regression analysis further revealed that acceptance-resignation coping style ($\beta = 0.380$, $P < 0.001$) and MGC score ($\beta = 0.322$, $P < 0.001$) were the main predictors of HRQOL.

Conclusions: Our study revealed the factors that impact HRQOL in MG patients and provided the first demonstration that acceptance-resignation is the main independent predictor of poor HRQOL in MG, other than disease severity.

Keywords: Myasthenia gravis, quality of life, disease severity, society support, coping style

INTRODUCTION

Myasthenia gravis (MG) is a rare, chronic autoimmune disease characterized by fluctuating muscle weakness and fatigability.[1] Despite advancing treatment and significant improved life expectancy[2], most MG patients could not reach complete stable remission.[3] They continue to suffer from persistent illness, multiple symptoms[4] and requiring prolonged pharmacological treatment. Previous studies[3,5-8] have shown that MG affected patients' health-related quality of life (HRQOL) both in physical and mental aspects. It has been reported that age, educational level, occupation, the status of thymus, the type of MG and generalized myasthenia gravis (GMG); and disease severity were factors influencing the HRQOL of MG patients.[2]

No new clinical predictors were detected even in a large population-based study including 858 MG patients by Boldingh *et al*..[9] Boldingh *et al*.[9] pointed out that the impact of non-clinical factors on MG should receive more attention. The prolonged course of illness living with the MG is often a highly stressful event for the patients. In 2013, a qualitative study of MG patients[10] implied that the illness-related coping strategies were key factors to lifes of patients with MG. For general population and chronic MG patients, it has been confirmed that coping style played an important part in health outcomes.[11-16] However, few quantity study has focused on the impact of coping style on the HRQOL in MG patients.[17]

Therefore, the aim of our study was to investigate the coping styles MG patients and to

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examine the relationship between coping style and HRQOL in a group of Chinese MG patients.

METHODS

MG patients were consecutively recruited from the Outpatient Department of Neurology, West China Hospital, Sichuan University from October 2015 to September 2016. Patient enrollment satisfied the following inclusion criteria: first, the diagnosis was made by a neurologist based on 2015 Chinese guidelines[18] for the diagnosis and treatment of MG patients. Second, patients had a disease duration over 1 month and were in a stable state. "Stable" was defined as the patients not having acute phase progression or an MG crisis during the preceding 4 weeks. Patients were excluded if they were unable to complete the questionnaires because of a lack of Chinese literacy or cognitive impairment determined by a team member. Patients with other severe diseases such as myocardial infarction or malignant tumor, which might confound the HRQOL measures were also excluded. Informed consent was obtained from all the patients. Our study has been approved by the West China Hospital Institutional Review Board and Ethics Committee.

All data were collected during the clinical visit. Gender, age, marital status, educational level, employee status, disease duration, ratio of disease cost to income each month and frequency of MG symptoms were documented by the physician. Osserman classification[19] and MG-Composite (MGC) scores[20] were evaluated by the same neurologist on the day of consultation. MGC scores consists of 10 questions with total scores ranging from 0 to 50, and higher MGC scores indicate worse clinical status.[20]

Health-related quality of life

The 15-item Myasthenia Gravis Quality Of Life questionnaire (MG-QOL15)[21] was developed by Burns *et al*. by simplifying the MG-QOL60.[5] The MG-QOL15 has 9 items on mobility, 3 items on symptoms, 2 items on emotional well-being, and 1 item on general contentment. Items on the MG-QOL15 are scored on a 5-point Likert scale ranging from 0 – 'not at all' to 4 – 'very much'. Higher MG-QOL15 scores indicate worse QOL. The Chinese version MG-QOL15 showed comparable construct, discriminant and concurrent validity, and internal consistency with the original version.[22]

Social support

Social Support Rating Scale (SSRS) complied by Xiao[23] in 1994 was used to assess the social support. It consists of 10 questions divided into three sections: subjective support, objective support, and utilization of support. The total score of the three sections is the score of SSRS which ranges from 12 to 66. Higher SSRS scores indicate better social support. SSRS has been widely used and has high reliability and validity.[24]

Coping style

The Medical Coping Modes Questionnaire (MCMQ) was used to evaluate coping style of the MG patients. It was developed by Feifel *et al.* in 1987 to assess illness-related coping strategies and widely globally.[25-27] It has 19 items dividing into 3 sections: confrontation, avoidance, and acceptance-resignation. The items are answered on a four-point continuum, ranging from 1 (never) to 4 (very often). The Chinese version of MCMQ includes 20 items as one item ("For the disease, you often feel that they can only accept their fate") was added to the acceptance resignation subscale during translation. The higher the scores, the more the coping style the patients used. For the Chinese version, the Cronbach's α coefficients in confrontation, avoidance, and acceptance–resignation subscales were 0.69, 0.60, and 0.76, respectively.[28]

Statistical analysis

SPSS for Windows version 20.0 software (SPSS Inc., Chicago, IL) was used for data analysis. Continuous data are reported as mean ± SD (Standard Deviation), and categorical variables as frequencies or percentages. The differences in MG-QOL15 scores among different groups of patients were tested using *t* test or one-way analysis of variance (ANOVA). Correlations between two variables were assessed using Pearson's correlation if the data fit bivariate normal distribution or Spearman's correlation if not. Multiple regression analysis (stepwise method) was conducted to identify predictors for the MG-QOL15. A correlation coefficient of 0.7 to 0.9 was defined as a high correlation, 0.5 to 0.7 as moderate, and 0.3 to 0.5 as low.[29] Statistical significance as defined as $P < 0.05$.

RESULTS

A total of 168 MG patients (98 women and 70 men; mean age 38.73 ± 14.86 years) were enrolled in this study. Table 1 showed other characteristics of the sample.

MGQOL-15, social support and coping style

The mean total score of MGQOL-15, social support was 17.67 and 39.27, respectively. The other variables were shown in Table 2.

Correlations between MG characteristics, social support, coping styles, and MGQOL-15

We did not observe significant differences in MGQOL-15 among the gender, age, marital status, educational level, employee status, Osserman Class, and disease duration subgroups. There were significant differences in MGQOL-15 scores among patients with different ratio of disease cost

Table 1: Patient characteristics (n = 168)

Characteristics	Patients	MGQOL-15	t/F/r	*P*
Gender				
Male	70 (41.7%)	17.31±12.97$^{\Delta}$	- 0.301	0.764
Female	98 (58.3%)	17.92±12.71$^{\Delta}$		
Age (years)	38.7 ± 14.9$^{\Delta}$	–	0.027$^{\#}$	0.732
Marital status			0.503	0.681
Unmarried	39 (23.2%)	16.72±12.57$^{\Delta}$		
Married	117 (69.6%)	17.85±13.04$^{\Delta}$		
Divorced	5 (3.0%)	14.20±9.20$^{\Delta}$		
Widowed	7 (4.2%)	22.29±12.79$^{\Delta}$		
Educational level			0.968	0.382
Elementary	22 (13.1%)	20.05±16.07$^{\Delta}$		
Secondary	118 (70.2%)	17.84±12.55$^{\Delta}$		
University	28 (16.7%)	15.07±10.76$^{\Delta}$		
Employment status			-1.314	0.191
Working	73 (43.5%)	16.19±11.33$^{\Delta}$		
Not working	95 (56.5%)	18.80±13.75$^{\Delta}$		
MGC score	3.00 (8.75)☆	–	0.461	**<0.001****
≦4	105 (62.5%)	13.40±10.06$^{\Delta}$		
5-11	44 (26.2%)	24.00±14.13$^{\Delta}$		
≧12	19 (11.3%)	26.58±12.91$^{\Delta}$		
Osserman class			2.631	0.052
I	60 (35.7%)	14.28±9.61$^{\Delta}$		
IIa	16 (9.5%)	17.00±14.45$^{\Delta}$		
IIb	76 (45.2%)	20.37±13.73$^{\Delta}$		
III	16 (9.5%)	18.19±14.88$^{\Delta}$		
Disease duration (years)	1.0 (4.0)☆		0.726	0.485
≦1	53 (31.5%)	19.06±12.71$^{\Delta}$		
1-3	55 (32.7%)	16.11±12.90$^{\Delta}$		
≧3	60 (35.7%)	17.87±12.80$^{\Delta}$		
Ratio of disease cost to income each month			5.831	**0.001****
<10%	67 (39.9%)	15.33±9.96$^{\Delta}$		
10%-40%	35 (20.8%)	13.63±10.60$^{\Delta}$		
40%-70%	31 (18.5%)	19.74±13.11$^{\Delta}$		
≧70%	35 (20.8%)	24.34±16.40$^{\Delta}$		
Frequency of MG symptoms (during the past month)			9.128	**<0.001****
0	60 (35.7%)	12.82±10.71$^{\Delta}$		
<4	32 (19.1%)	16.97±11.19$^{\Delta}$		
≧4	76 (45.2%)	21.79±13.63$^{\Delta}$		

Δ: mean ± SD (Standard Deviation), ☆: median (range), #: spearman correlation, **: $P < 0.01$

Table 2: Scores of MGQOL-15, social Support and coping style (n = 168)

Questionnaire	score
MGQOL-15	17.67±12.78$^{\Delta}$
Social Support	39.27±7.70$^{\Delta}$
Subjective support	4.00, 6.00-10.00$^{\square}$
Objective support	10.00, 19.00-29.00$^{\square}$
Utilization of support	3.00, 6.00-9.00$^{\square}$
Coping Style	
Confrontation	19.55±3.46$^{\Delta}$
Avoidance	3.00, 15.00-18.00$^{\square}$
Acceptance-resignation	5.00, 7.00-12.00$^{\square}$

Δ: mean ± SD (Standard Deviation), □: IQR(interquartile range), P25-P75

to income each month (F = 5.831, P = 0.001) and frequency of MG symptoms (F = 9.128, P < 0.001). Spearman's correlation analysis showed that HRQOL had low correlation with Myasthenia Gravis Composite score (r = 0.461, P < 0.001, shown in Table 1).

The total scores and three divisions of social support had no significant correlations with MGQOL-15.

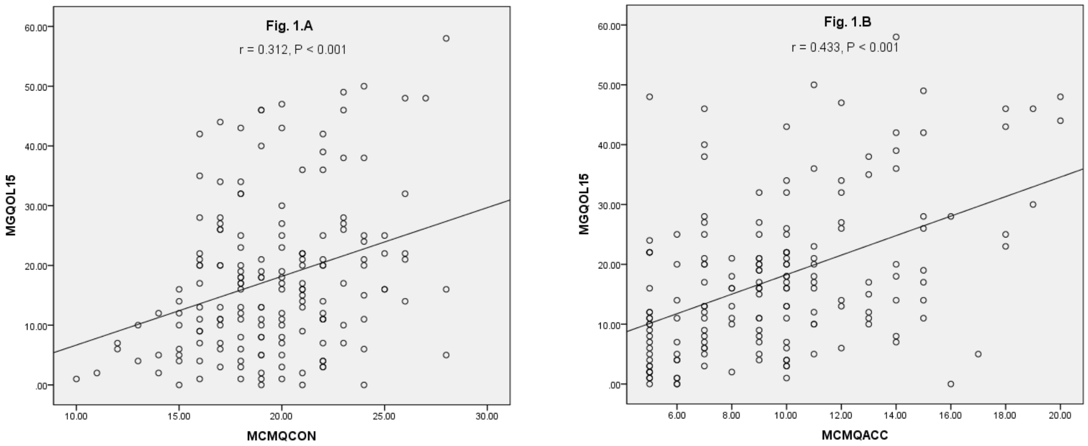
Spearman's correlation analysis showed that HRQOL had low correlation with confrontation (r = 0.312, P < 0.001) (Figure.1A) and acceptance-resignation (r = 0.433, P < 0.001) (Figure.1B). There was no significant correlation between avoidance division and MGQOL-15.

Factors of patients' quality of life

Stepwise regression analysis (Table 3) showed that acceptance-resignation (β = 0.380, P < 0.001) and MGC (β = 0.322, P < 0.001) were the main predictors of MGQOL-15, followed by ratio of disease cost to income each month (β = 0.167, P = 0.006), the frequency of MG symptoms (β = 0.153, P = 0.012) and confrontation (β = 0.150, P = 0.012).

DISCUSSION

This study revealed that acceptance-resignation and MGC score were two main predictors of HRQOL in MG. Ratio of disease cost to income each month, frequency of MG symptoms (during the past month) and confrontation were also significantly associated with HRQOL. However, social support did not have significant correlation with HRQOL.



MGQOL-15 scores were significantly positively correlated with confrontation division (Fig. 1.A) and acceptance-resignation (Fig. 1.B) scores. MGQOL15: The 15-item Myasthenia Gravis Quality Of Life questionnaire, MCMQCON: confrontation division of MCMQ (The Medical Coping Modes Questionnaire), MCMQACC: acceptance-resignation division of MCMQ

Figure 1. The correlations between HRQOL and divisions of MCMQ

Table 3: Factors related to patients' quality of life (n = 168)

Independent variable	**B**	**SB**	**t**	***P***
Constant	-17.995	-	-3.906	**<0.001****
Acceptance-resignation	1.325	0.380	6.446	**<0.001****
MGC	0.681	0.322	5.242	**<0.001****
Ratio of disease cost to income each month	1.819	0.167	2.805	**0.006****
Frequency of MG symptoms (during the past month)	2.182	0.153	2.526	**0.012***
Confrontation	0.555	0.150	2.527	**0.012***

R^2 = 0.466, Adjusted R^2 =0.449, ***P*** < 0.001

Previous studies[2,5,30] found disease severity played an important role in reduced HRQOL in MG patients. Our data also showed similar finding. MG patients with higher MGC score and frequency of MG symptoms (during the past month) had worse function which led to bad HRQOL. This implies that clinicians should pay more attention to the disease severity of MG patients. MGC score and other assessment tools could be used as clinical routine assessment of disease progression and treatment effect.

A study[31] that enrolled 1,660 MG patients in 2022 indicated that low income was associated with a poorer HRQOL. In our study, ratio of disease cost to income each month also negatively affected QOL of MG. At least two out of three MG patients suffered from changes in work and/or income.[32] It is not difficult to understand that long term treatment expenditure and decrease in income has a high impact on the perceived burden of disease. Public welfare, commercial insurance, and other favorable policy may mitigate these financial difficulties among MG patients.

Raggi *et al*.[33] found that tangible support was an independent predictor of mental health status in MG. However, we did not find significant correlation between social support and HRQOL in our MG patients. Some studies[34,35] on social support and HRQOL in other diseases also showed that social support overall did not play a significant role in HRQOL. This may be due to the assessment tool of HRQOL we used. The MG-QOL15 mainly evaluates the symptoms and consists of only 2 items concerning emotional well-being.

Coping can be understood as the strategy and actions patients use to manage the disease, the problems resulting from the disease, and to maintain the emotional well-being.[36] Previous studies in other diseases has shown that a more negative coping style (e.g., acceptance-resignation and avoidance) result in poorer HRQOL.[37,38] We also found in our study that acceptance-resignation coping style is the main predictor of poorer HRQOL in our MG patients. In addition, we found the more confrontation MG patients used, the lower HRQOL they had. This may be associated with a characteristics of MG. As unlike other chronic diseases such as diabetes and stroke, there was no evidence to show that changing lifestyles of the patients could help the MG patients to improve their disease prognosis.[39] As such, MG patients often attributed their disease to their own personality after failing to find the cause or the control/cure.[10] As they could not take more initiative except for taking medicine and facing the challenges of MG passively.[10] Our study indicated that clinicians should not only just prescribe medications, but also provide more explanations to their MG patients. This could help the patients to have a better perception of their illness and cope with their disease. The patients could be encouraged to adopt a healthy lifestyle with a balanced diet and a positive attitude to face their autoimmune disorder; and avoid a nihilistic attitude that 'nothing they can do for their illnesses'.

In conclusion, our study revealed the factors that impact HRQOL in MG patients and provided the first demonstration that other than the disease severity, acceptance-resignation is the main independent predictor of poor HRQOL in MG.

DISCLOSURE

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Conflicts of interest: None.

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