

Supplementary Material:

Patient perceptions of needs and expectations regarding the current management of myasthenia gravis: a biopsychosocial study

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Table S1. A comparison of different aspects with respect to age.

	< 50 years N = 59 ¹	≥ 50 years N = 149 ¹	p-value ²
EQ-VAS	65.2 (21.6)	66.4 (20.3)	0.359
To what extent does MG affect your daily life and allow you to lead a ‘normal’ life?			0.701
Not at all	6 (10.5%)	26 (17.8%)	
Slightly	15 (26.3%)	34 (23.3%)	
Moderately	18 (31.6%)	49 (33.6%)	
Quite a bit	12 (21.1%)	24 (16.4%)	
Completely	6 (10.5%)	13 (8.9%)	
Do you believe that your quality of life has improved as a result of the healthcare you have received?			0.003
Not at all	2 (3.5%)	6 (4.3%)	
Slightly	7 (12.3%)	2 (1.4%)	
Moderately	18 (31.6%)	29 (20.6%)	
Quite a bit	13 (22.8%)	59 (41.8%)	
Completely	17 (29.8%)	45 (31.9%)	
Do you think that the family members and informal caregivers of MG patients have access to information and resources where they are prepared and trained for their roles?			0.180
Not at all	32 (57.1%)	53 (37.6%)	
Slightly	12 (21.4%)	44 (31.2%)	
Moderately	8 (14.3%)	30 (21.3%)	
Quite a bit	2 (3.6%)	9 (6.4%)	
Completely	2 (3.6%)	5 (3.5%)	

	< 50 years N = 59 ¹	≥ 50 years N = 149 ¹	p-value ²
Has the onset of the disease affected your relationship with your partner?			0.011
Not at all	14 (25.0%)	58 (41.1%)	
Slightly	6 (10.7%)	21 (14.9%)	
Moderately	10 (17.9%)	25 (17.7%)	
Quite a bit	23 (41.1%)	24 (17.0%)	
Completely	3 (5.4%)	13 (9.2%)	
How does MG affect your relationships, free time, and family leisure activities?			0.079
Not at all	4 (7.1%)	24 (17.0%)	
Slightly	9 (16.1%)	35 (24.8%)	
Moderately	15 (26.8%)	39 (27.7%)	
Quite a bit	19 (33.9%)	29 (20.6%)	
Completely	9 (16.1%)	14 (9.9%)	
Has your employment situation changed as a result of your MG symptoms?			0.013
No	19 (35.8%)	78 (59.5%)	
Yes, I have decided to adapt my position or responsibilities	9 (17.0%)	11 (8.4%)	
Yes, I have reduced my working hours or dedication	3 (5.7%)	10 (7.6%)	
Yes, I have stopped working	22 (41.5%)	32 (24.4%)	
Do you believe that medical appointments or the treatment you receive for MG (pharmacological, rehabilitative...) affect your work life?			0.003
Not at all	12 (21.4%)	64 (45.7%)	
Slightly	7 (12.5%)	25 (17.9%)	
Moderately	12 (21.4%)	21 (15.0%)	
Quite a bit	11 (19.6%)	11 (7.9%)	
Completely	14 (25.0%)	19 (13.6%)	

	< 50 years N = 59 ¹	≥ 50 years N = 149 ¹	p-value ²
Have you experienced financial difficulties as a result of the onset of the disease?			0.012
Not at all	23 (41.1%)	76 (55.1%)	
Slightly	8 (14.3%)	28 (20.3%)	
Moderately	9 (16.1%)	16 (11.6%)	
Quite a bit	4 (7.1%)	11 (8.0%)	
Completely	12 (21.4%)	7 (5.1%)	
Do you believe that legislative and political bodies promote the reduction of inequalities associated with MG?	5 (8.9%)	20 (14.5%)	0.295

¹ Mean (SD); n (%)

² t-Student p value; Pearson's Chi-squared test

Table S2. A comparison of different aspects with respect to sex.

	Women N = 92 ¹	Men N = 116 ¹	p-value²
EQ-VAS	62.9 (22.1)	68.6 (19.1)	0.025
To what extent does MG affect your daily life and allow you to lead a ‘normal’ life?			0.045
Not at all	9 (10.0%)	23 (20.4%)	
Slightly	19 (21.1%)	30 (26.5%)	
Moderately	31 (34.4%)	36 (31.9%)	
Quite a bit	23 (25.6%)	13 (11.5%)	
Completely	8 (8.9%)	11 (9.7%)	
Do you believe that your quality of life has improved as a result of the healthcare you have received?			0.004
Not at all	5 (5.7%)	3 (2.7%)	
Slightly	7 (8.0%)	2 (1.8%)	
Moderately	28 (32.2%)	19 (17.1%)	
Quite a bit	28 (32.2%)	44 (39.6%)	
Completely	19 (21.8%)	43 (38.7%)	
Do you think that the family members and informal caregivers of MG patients have access to information and resources where they are prepared and trained for their roles?			0.001
Not at all	50 (58.1%)	35 (31.5%)	
Slightly	22 (25.6%)	34 (30.6%)	
Moderately	9 (10.5%)	29 (26.1%)	
Quite a bit	4 (4.7%)	7 (6.3%)	
Completely	1 (1.2%)	6 (5.4%)	

	Women N = 92 ¹	Men N = 116 ¹	p-value ²
Has the onset of the disease affected your relationship with your partner?			0.071
Not at all	24 (27.9%)	48 (43.2%)	
Slightly	11 (12.8%)	16 (14.4%)	
Moderately	17 (19.8%)	18 (16.2%)	
Quite a bit	28 (32.6%)	19 (17.1%)	
Completely	6 (7.0%)	10 (9.0%)	
How does MG affect your relationships, free time, and family leisure activities?			<0.001
Not at all	4 (4.7%)	24 (21.6%)	
Slightly	15 (17.4%)	29 (26.1%)	
Moderately	25 (29.1%)	29 (26.1%)	
Quite a bit	29 (33.7%)	19 (17.1%)	
Completely	13 (15.1%)	10 (9.0%)	
Has your employment situation changed as a result of your MG symptoms?			<0.001
No	25 (31.6%)	72 (68.6%)	
Yes, I have decided to adapt my position or responsibilities	16 (20.3%)	4 (3.8%)	
Yes, I have reduced my working hours or dedication	4 (5.1%)	9 (8.6%)	
Yes, I have stopped working	34 (43.0%)	20 (19.0%)	
Do you believe that medical appointments or the treatment you receive for MG (pharmacological, rehabilitative...) affect your work life?			<0.001
Not at all	18 (20.9%)	58 (52.7%)	
Slightly	15 (17.4%)	17 (15.5%)	
Moderately	19 (22.1%)	14 (12.7%)	
Quite a bit	16 (18.6%)	6 (5.5%)	
Completely	18 (20.9%)	15 (13.6%)	

	Women N = 92 ¹	Men N = 116 ¹	p-value²
Have you experienced financial difficulties as a result of the onset of the disease?			0.003
Not at all	34 (40.0%)	65 (59.6%)	
Slightly	14 (16.5%)	22 (20.2%)	
Moderately	13 (15.3%)	12 (11.0%)	
Quite a bit	9 (10.6%)	6 (5.5%)	
Completely	15 (17.6%)	4 (3.7%)	
Do you believe that legislative and political bodies promote the reduction of inequalities associated with MG?	14 (16.5%)	11 (10.1%)	0.188

¹Mean (SD); n (%)

² t-Student p value; Pearson's Chi-squared test

Table S3. A comparison of the different aspects of MG severity.

	OCULAR MG N = 53¹	GENERALIZED MG N = 103¹	p-value²
EQ-VAS	74.3 (15.7)	59.2 (21.7)	<0.001
To what extent does MG affect your daily life and allow you to lead a ‘normal’ life?			0.007
Not at all	16 (30.2%)	9 (8.8%)	
Slightly	10 (18.9%)	23 (22.5%)	
Moderately	17 (32.1%)	36 (35.3%)	
Quite a bit	5 (9.4%)	25 (24.5%)	
Completely	5 (9.4%)	9 (8.8%)	
Do you believe that your quality of life has improved as a result of the healthcare you have received?			0.300
Not at all	4 (7.5%)	3 (3.0%)	
Slightly	1 (1.9%)	7 (7.0%)	
Moderately	9 (17.0%)	26 (26.0%)	
Quite a bit	23 (43.4%)	36 (36.0%)	
Completely	16 (30.2%)	28 (28.0%)	
Do you think that the family members and informal caregivers of MG patients have access to information and resources where they are prepared and trained for their roles?			0.001
Not at all	13 (24.5%)	57 (57.6%)	
Slightly	18 (34.0%)	23 (23.2%)	
Moderately	15 (28.3%)	13 (13.1%)	
Quite a bit	5 (9.4%)	3 (3.0%)	
Completely	2 (3.8%)	3 (3.0%)	

	OCULAR MG N = 53 ¹	GENERALIZED MG N = 103 ¹	p-value ²
Has the onset of the disease affected your relationship with your partner?			<0.001
Not at all	29 (54.7%)	32 (32.3%)	
Slightly	8 (15.1%)	10 (10.1%)	
Moderately	11 (20.8%)	14 (14.1%)	
Quite a bit	4 (7.5%)	28 (28.3%)	
Completely	1 (1.9%)	15 (15.2%)	
How does MG affect your relationships, free time, and family leisure activities?			<0.001
Not at all	16 (30.2%)	8 (8.1%)	
Slightly	15 (28.3%)	14 (14.1%)	
Moderately	15 (28.3%)	26 (26.3%)	
Quite a bit	7 (13.2%)	31 (31.3%)	
Completely	0 (0.0%)	20 (20.2%)	
Has your employment situation changed as a result of your MG symptoms?			<0.001
No	41 (78.8%)	31 (33.3%)	
Yes, I have decided to adapt my position or responsibilities	6 (11.5%)	13 (14.0%)	
Yes, I have reduced my working hours or dedication	0 (0.0%)	7 (7.5%)	
Yes, I have stopped working	5 (9.6%)	42 (45.2%)	
Do you believe that medical appointments or the treatment you receive for MG (pharmacological, rehabilitative...) affect your work life?			<0.001
Not at all	31 (59.6%)	25 (25.3%)	
Slightly	11 (21.2%)	15 (15.2%)	
Moderately	5 (9.6%)	20 (20.2%)	
Quite a bit	2 (3.8%)	14 (14.1%)	
Completely	3 (5.8%)	25 (25.3%)	

	OCULAR MG N = 53 ¹	GENERALIZED MG N = 103 ¹	p-value ²
Have you experienced financial difficulties as a result of the onset of the disease?			<0.001
Not at all	39 (76.5%)	38 (38.4%)	
Slightly	6 (11.8%)	19 (19.2%)	
Moderately	5 (9.8%)	15 (15.2%)	
Quite a bit	1 (2.0%)	10 (10.1%)	
Completely	0 (0.0%)	17 (17.2%)	
Do you believe that legislative and political bodies promote the reduction of inequalities associated with MG?	6 (11.8%)	13 (13.1%)	0.812

¹Mean (SD); n (%)

² t-Student p value; Pearson's Chi-squared test