Quality of Life is Impaired in Myelin Oligodendrocyte Glycoprotein Antibody Associated Disease

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Background

Myelin Oligodendrocyte Glycoprotein Antibody Associated Disease (MOGAD) is a rare neuro-inflammatory disease that affects the central nervous system.[1] Given its rarity and relatively recent recognition as a distinct disease entity, there is a paucity of studies examining quality of life (QoL) in people with MOGAD.

Objectives

To assess different QoL domains including anxiety, depression, and stigma in people with MOGAD, and to understand the impact of the disease on their cognitive function and social roles.

Methods

In this cross-sectional study, a self-administered survey, developed in collaboration with "The MOG Project", was distributed through the organization's online platforms. Demographic and clinical characteristics were collected and QoL was assessed using the QoL in Neurological Disorders (Neuro-QoL) short questionnaires in pediatric and adult patients, with scores compared to reference populations, yielding standardized T-scores .[2]

Results

A total of 259 participants completed the survey. Of the respondents, 58.1% reported varying levels of anxiety, 30.7% displayed evidence of depression, 29.8% showed degrees of stigma, 58.5 % indicated cognitive dysfunction and 57.7% noted an impairment of their ability to participate in social functions. **T-scores were significantly worse than the reference population in several domains**, including anxiety ($p < 0.001$), stigma ($p = 0.005$), cognitive dysfunction ($p < 0.001$) and social interactions ($p < 0.001$). There was no clear association between demographic factors, type of disease-modifying therapy, and type of clinical presentation with QoL domains. A relapsing vs monophasic disease course was associated with worse anxiety, stigma, cognition, and social interactions ($p < 0.05$). Relapse within 6 months prior to completing the survey was associated with worse ability to participate in social interactions ($p = 0.02$). The presence of comorbidities was also associated with worse scores in stigma, cognition, and social interactions ($p < 0.05$).

Table 1: Patient demographics and clinical characteristics

Characteristic, n (%)	**N = 259**
Respondent	
Caregiver	50 (19)
Patient	209 (81)
Sex assigned at birth, female	191 (74)
Age	
0-17 years old	39 (15)
18-34 years old	69 (27)
35-54 years old	94 (36)
55+ years old	57 (22)
Race, White or Caucasian	218 (84)
Current primary residence	
Africa	2 (0.8)
Asia	7 (2.7)
Europe	44 (17)
North America	185 (71)
Oceania	16 (6.2)
South America	5 (1.9)
Time between symptom onset and diagnosis, less than 6 months	167 (64)
Experienced more than one attack	155 (60)
Last attack, within the last 6 months	102 (39)
Type of attacks	
Acute Disseminated Encephalomyelitis and/or Encephalitis	59 (23)
Brainstem lesions	55 (21)
Optic Neuritis	178 (69)
Other/Not sure	49 (19)
Transverse Myelitis	85 (33)
More than one type of attack	59 (23)
Current treatment	
None	52 (20)
Biological agents[a]	31 (12)
Combination of treatments	68 (26)
Corticosteroids	31 (12)
Immunoglobulins	45 (17)
Oral Immunosuppressants[b]	23 (8.9)
Other/Not sure	9 (3.5)
Comorbidities[c]	104 (40)
Psychiatric disorder[d]	113 (44)

[a] *Biological agents include Tocilizumab and Rituximab.*
[b] *Oral immunosuppressants include Azathioprine and Mycophenolate mofetil.*
[c] *Comorbidities include diabetes, cancer any other autoimmune disease, and others.*
[d] *Psychiatric disorders include clinically diagnosed Depression, Post Traumatic Stress Disorder, Generalized Anxiety Disorder, Bipolar Disorder and others.*

Figure 1: Neuro-QoL T-Scores by domain for children and adult participants

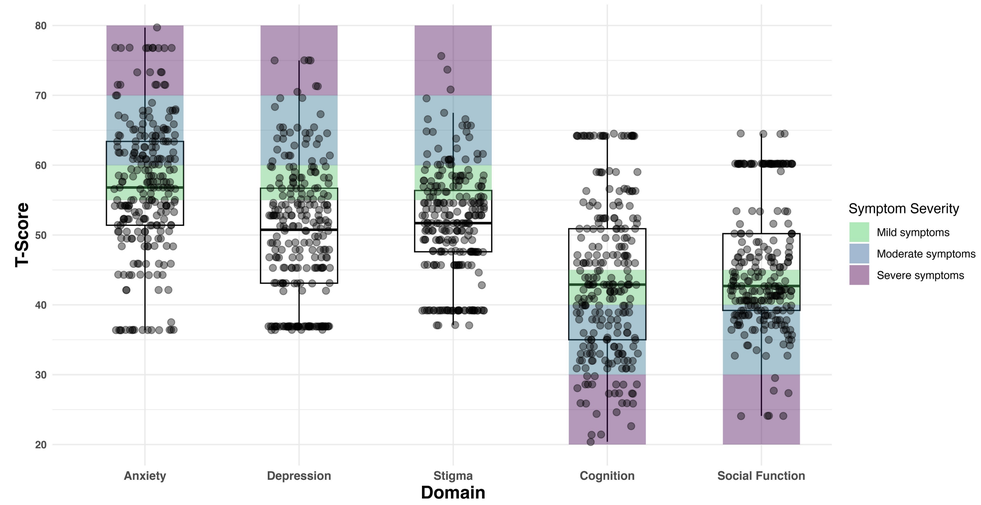

Table 2: Frequency of anxiety, depression, stigma, cognitive function, and social relations difficulty symptom levels in children and adults

	Levels			
	Within normal limits	**Mild symptoms[1]**	**Moderate symptoms[2]**	**Severe symptoms[3]**
Anxiety				
Children *(N= 28)*	9 (32%)	8 (29%)	10 (36%)	1 (4%)
Adults *(N= 220)*	95 (43%)	38 (17%)	65 (30%)	22 (10%)
Total *(N= 248)*	104 (42%)	46 (19%)	75 (30%)	23 (9%)
Depression				
Children *(N= 28)*	19 (68%)	6 (21%)	2 (7%)	1 (4%)
Adults *(N= 220)*	153 (70%)	35 (16%)	26 (12%)	6 (2%)
Total *(N= 248)*	172 (69%)	41 (17%)	28 (11%)	7 (3%)
Stigma				
Children *(N= 28)*	20 (71%)	7 (25%)	1 (4%)	0 (0%)
Adults *(N= 220)*	154 (70%)	35 (16%)	28 (13%)	3 (1%)
Total *(N= 248)*	174 (70%)	42 (17%)	29 (12%)	3 (1%)
Cognitive function				
Children *(N= 28)*	16 (58%)	4 (14%)	4 (14%)	4 (14%)
Adults *(N= 220)*	87 (40%)	40 (18%)	72 (32%)	21 (10%)
Total *(N= 248)*	103 (41%)	44 (18%)	76 (31%)	25 (10%)
Social relations				
Children *(N= 28)*	15 (54%)	5 (18%)	7 (25%)	1 (4%)
Adults *(N= 220)*	90 (41%)	67 (30%)	57 (26%)	6 (2%)
Total *(N= 248)*	105 (42%)	72 (29%)	64 (26%)	7 (3%)

[1] *Mild symptoms were attributed to those with scores 0.5 – 1.0 SD higher/worse than the mean for Anxiety, Depression and Stigma, and 0.5 – 1.0 SD lower/worse than the mean for Cognitive function, and Social relations.*

[2] *Moderate symptoms were attributed to those with scores 1.0 – 2.0 SD higher/worse than the mean for Anxiety, Depression and Stigma, and 1.0 – 2.0 SD lower/worse than the mean for Cognitive function, and Social relations.*

[3] *Severe symptoms were attributed to those with scores ≥ 2.0 SD higher/worse than the mean for Anxiety, Depression and Stigma, and ≤ 2.0 SD lower/worse than the mean for Cognitive function, and Social relations.*

Conclusion

We found a high prevalence of impaired QoL in people with MOGAD, as compared to the reference Neuro-QoL population, with significant impairments observed in the domains of anxiety, stigma, cognitive dysfunction and social interactions

Even though a portion of participants displaying symptoms of depression or anxiety were officially diagnosed and/or used psychiatric medication, this was not in the majority of participants with impairments in relevant QoL domains. This raises the possibility that these conditions may be underdiagnosed, and suggests that screening for such symptoms in clinical practice may be useful.

References

1. Banwell B, Bennett JL, Marignier R, et al. Diagnosis of myelin oligodendrocyte glycoprotein antibody-associated disease: International MOGAD Panel proposed criteria. *Lancet Neurol* 2023; 22: 268–282.
2. Neuro-QOL | RehabMeasures Database, https://www.sralab.org/rehabilitation-measures/neuro-qol (accessed 31 July 2023).

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