



Employment and its Associations in an International Cohort of Myelin Oligodendrocyte Glycoprotein Antibody Disease

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INTRODUCTION

Myelin oligodendrocyte glycoprotein associated antibody disease (MOGAD) can lead to significant disability by attacking the optic nerve, spinal cord, and brain. Since MOGAD typically presents in adolescence or young adulthood, the frequent medical visits required for symptoms can also disrupt one's ability to work and earn a meaningful income. The socioeconomic consequences of MOGAD, especially in adults, remain underreported.

The study addresses two main questions:

- What is the prevalence of unemployment and underemployment in MOGAD?
- What demographic, clinical, and country income-level factors are associated with lost employment and work hours in MOGAD?

METHODS

Ethics: Approved by the Massachusetts General Brigham Institutional Review Board. Additional approvals occurred by local ethics board, as needed.

Study Sites: Participants were recruited from clinical sites in 13 countries between April 2022 and August 2023. Recruitment was conducted through neurologist referrals. Participating countries included Australia, Italy, Singapore, United Kingdom, U.S.A. (high-income), Argentina, Brazil, China, Colombia, Dominican Republic, Malaysia, Turkey (upper middle-income), and India (lower middle-income).

Data Collection: Adults aged 18-70 with neurologist-diagnosed MOGAD completed a one-time survey. Data collected included demographic variables, clinical history including symptoms and treatment, and employment-related information.

Data Analysis: Generalized linear models assessed associations between MOGAD diagnosis and employment status, and reduced work hours. Key variables included participant age, gender, education, country income level, myelitis presence, visual loss, fatigue, depressed mood, pain, and disease duration. Certain clinical variables were binarized into presence/absence categories for clearer statistical comparisons. Data analyses were conducted using R (version 4.3.1).

RESULTS

Demographic Variables:

The study analyzed 117 participants with MOGAD (66.7% female, 33.3% male), with an average age of 39.7 years (Table 1). Participants were from 5 high-income, 7 upper-middle-income, and 1 lower-middle-income countries. Most participants (69.2%) were from China, India, and the U.S.A. The average years of schooling was 13.6, with 3.4% completing primary education, 18.8% high school, 47.0% college, and 17.9% professional schools.

Clinical Features:

The average age at first disease attack was 32.7 years, and the average duration of MOGAD was 5.2 years. At the time of the survey, 31.6% had unilateral visual loss, 23.9% bilateral visual loss, and 31.6% had myelitis. Comorbidities included obesity (12.0%), hypertension (8.5%), and asthma (6.8%). Moderate to high levels of fatigue were reported by 35.9%, and significant pain by 35.0%. Depressed mood interfered with job-related duties for 37.6%. Most participants (81.2%) received immunosuppressive treatments (Table 2).

Employment and Work:

Pre-MOGAD diagnosis, 63.2% of participants were employed, which decreased to 48.7% post-diagnosis. Average weekly work hours dropped from 31.6 to 19.5 post-diagnosis. Employment rates were 66.7% for women and 57.9% for men pre-diagnosis and 43.6% for women and 59.0% for men post-diagnosis.

There was a statistically significant positive association between high-income country residence (odds ratio (OR)=4.47, p=0.03) and employment, while depressed mood had a statistically significant negative association (OR=0.36, p=0.045). Myelitis (OR = 4.03, p=0.046), residence in a high-income country (OR=12.02, p=0.0038), and pain (OR=4.81, p=0.03) were positively associated with reduced work hours.

Table 1. Demographic and clinical characteristics

	Total group (n = 117)
Age (years)	
Mean ± SD	39.7 ± 12.7
Range	18 – 70
Gender, n (%)	
Male	39 (33.3)
Female	78 (66.7)
Level of education, n (%)	
Primary school	4 (3.4)
Secondary school	11 (9.4)
High school	22 (18.8)
Trade school	4 (3.4)
College	55 (47.0)
Professional school	21 (17.9)
Country income level, n (%)	
Lower middle-income	32 (27.4)
Upper middle-income	43 (36.8)
High income	42 (35.9)
Disease duration (years)	
Mean ± SD	5.2 ± 5.2
Range	0 – 31
Visual loss, n (%)	
Unilateral	37 (31.6)
Bilateral	28 (23.9)
Myelitis, n (%)	37 (31.6)
Freq. of fatigue, n (%)	
Never	31 (26.5)
Rarely	16 (13.7)
Sometimes	26 (22.2)
Often	24 (20.5)
Almost always	18 (15.4)
No answer	2 (1.7)
Pain level, from 0 - 10 (mean ± SD)	2.9 ± 3.1
Freq. of depressed mood, n (%)	
Not at all	43 (36.8)
Several days	27 (23.1)
More than half the days	22 (18.8)
Nearly every day	22 (18.8)
No answer	3 (2.6)

Table 2. Therapies used by MOGAD patients

One therapy	Two therapies	Three therapies
Azathioprine	Azathioprine and steroids	Mycophenolate mofetil, rituximab, steroids
Intravenous immunoglobulin (IVIg)	Mycophenolate mofetil and IVIg	Rituximab, IVIg, and steroids
Mycophenolate mofetil	Mycophenolate mofetil and steroids	
Ocrelizumab	Rituximab and IVIg	
Rituximab	Rituximab and steroids	
Rozanolixizumab	Toilizumab and IVIg	
Subcutaneous immunoglobulin (SCIg)	Steroids and plasma exchange	
Steroids		
Toilizumab		
Unknown		
No therapies		

Table 3. Variables associated with employment and work hours

Regression variables	Employment (multivariable analysis)			Work hours (multivariable analysis)		
	Odds Ratio	95% CI	p	Odds Ratio	95% CI	p
Age	0.97	0.94 - 1.01	0.16	1.03	0.98 - 1.08	0.33
Gender						
Male	Reference category			Reference category		
Female	0.67	0.26 - 1.67	0.39	1.76	0.51 - 6.24	0.37
Country income level						
Lower middle-income	Reference category			Reference category		
Upper middle-income	2.89	0.73 - 13.73	0.15	4.76	0.78 - 34.29	0.1
High income	4.47	1.19 - 20.10	0.035	12.02	2.45 - 73.67	0.0038
Myelitis	1.69	0.66 - 4.59	0.28	4.03	1.08 - 17.57	0.046
Optic neuritis	2.15	0.88 - 5.52	0.099	0.86	0.23 - 2.96	0.81
Fatigue	0.35	0.10 - 1.08	0.08	3.33	0.73 - 17.54	0.13
Pain	0.79	0.28 - 2.21	0.64	4.81	1.18 - 23.05	0.03
Depressed mood	0.36	0.13 - 0.98	0.045	1.55	0.34 - 6.9	0.56
Disease duration	0.99	0.90 - 1.09	0.84	0.89	0.77 - 1.03	0.12

DISCUSSION & CONCLUSION

Although our study cannot identify all aspects of the environmental components of work and employment, we are able to identify individual-level, self-reported aspects of the mostly treated history of MOGAD and its reported symptoms in the context of employment. There is a significant socioeconomic impact of MOGAD on adult employment. Post-diagnosis, employment rates dropped from 63.2% to 48.7%, with average work hours reduced from 31.6 to 19.5 hours per week. More than a third (37%) report losing employment due to MOGAD.

Our study had several notable limitations. Notably, our sampling was by convenience. People who had a clinically monophasic disease may not have presented for longitudinal neurological follow up to clinics and may therefore have been overlooked, underestimating the number of people who are employed. By contrast, people with severe disease such as bilateral visual loss may have been less willing to participate due to barriers to participation in a lengthy survey, overestimating our employment prevalence estimate. Similarly, patients with concerns about employment may have been more motivated to participate in a survey on employment. Importantly, there are no control participants in this study. Therefore, it is difficult to disaggregate which factors are related exclusively to MOGAD, the country setting, or to some relationship between the two.

The findings emphasize the often "invisible symptoms" of MOGAD, like depressed mood and pain, which are significant yet potentially modifiable factors that influence employment status. Targeted interventions for mood and pain management could improve employment outcomes for individuals with MOGAD.

Other resources on employment, such as job counseling and professional retraining opportunities can also be valuable for adults with MOGAD, given the relatively young age of diagnosis in this adult cohort.

DISCLOSURES

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