

**Supplementary Material**  
**Experience of Daily Life with Generalized Myasthenia**  
**Gravis: A Qualitative Investigation and Assessment of**  
**Instrument and Content Validity**

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**Table S1** Components of the three COAs

	<b>MG-ADL</b>	<b>QMG</b>	<b>MGC</b>
Recall period	7 days	N/A	7 days for PRO
		Physical exam	N/A for physical exam
Response options	0 – Normal	0 – None	Differs per item
	1	1 – Mild	
	2	2 – Moderate	
	3 – Severe	3 – Severe	
Score range <sup>a</sup>	0–24	0–39	0–50
Number of items	8	13	10
Domains	Oropharyngeal	Ocular	Oropharyngeal
	Respiratory	Bulbar	Respiratory
	Extremities	Respiratory	Ocular
	Ocular	Limb/gross motor	Limb/gross motor

COA clinical outcomes assessment *MG-ADL* Myasthenia Gravis – Activities of Daily Living

*MGC* Myasthenia Gravis Composite *N/A* not available *PRO* patient-reported outcome

*QMG* Quantitative Myasthenia Gravis

<sup>a</sup>Higher scores indicate more severe impairment

**Table S2** Literature review strategy

Search strings	Search terms used in PubMed
1	"myasthenia gravis" [All Fields]
2	qualitative[Title/Abstract] OR (interview*[Title/Abstract]) OR (narratives[Title/Abstract]) OR (narration[Title/Abstract]) OR ("focus group*[Title/Abstract]) OR ("patient experience"[Title/Abstract]) OR ("experience of patient*[Title/Abstract]) OR (grounded[Title/Abstract]) OR (phenomenological[Title/Abstract]) OR (endpoint model*[Title/Abstract]) OR (concept*[Title/Abstract]) OR ("patient report*[Title/Abstract]) OR ("patientreport*[Title/Abstract]) OR ("self-report*[Title/Abstract]) OR ("self report*[Title/Abstract])
1 AND 2	("myasthenia gravis"[All Fields]) AND ((((((((((((((qualitative[Title/Abstract]) OR (interview*[Title/Abstract]) OR (narratives[Title/Abstract]) OR (narration[Title/Abstract]) OR ("focus group*[Title/Abstract]) OR ("patient experience"[Title/Abstract]) OR ("experience of patient*[Title/Abstract]) OR (grounded[Title/Abstract]) OR (phenomenological[Title/Abstract]) OR (endpoint model*[Title/Abstract]) OR (concept*[Title/Abstract]) OR ("patient report*[Title/Abstract]) OR ("patient-report*[Title/Abstract]) OR ("self report*[Title/Abstract]) OR ("self report*[Title/Abstract])
Filters	Abstract, English, Humans

The inclusion and exclusion criteria applied to the electronic database searches included:

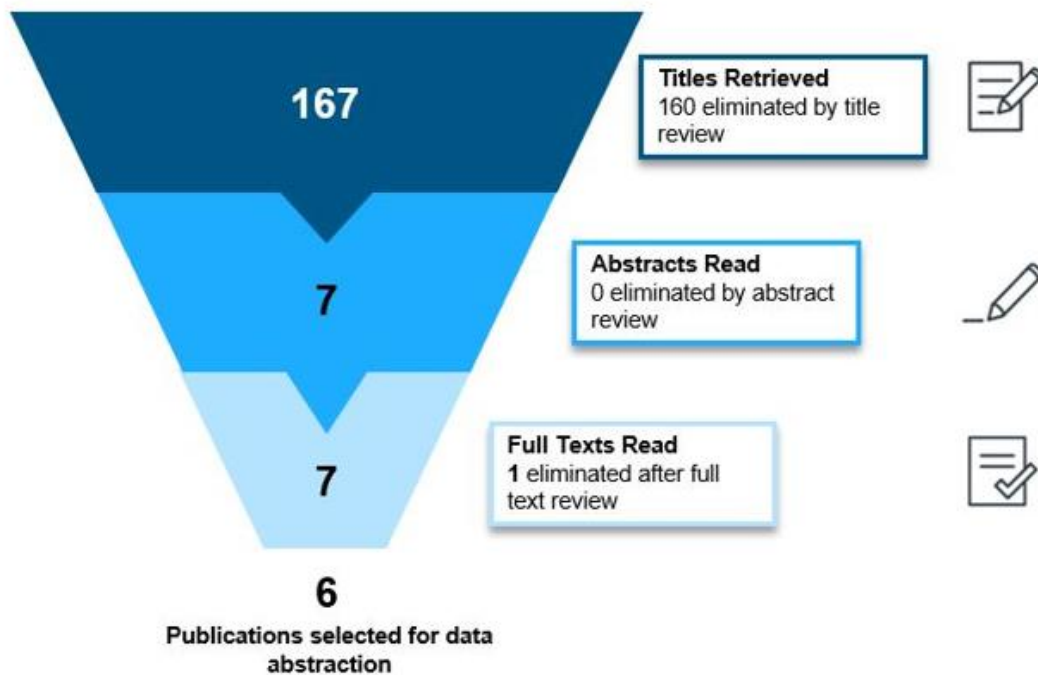
- **Inclusion criteria**

- Qualitative studies (interviews with patients including interviews during instrument development)
- Adult population with myasthenia gravis (MG)
- MG should be the primary topic of the article
- Patients' reports of any point of view regarding MG (impact of the disease on the patients, signs, and symptoms)

- **Exclusion criteria**

- Primarily focus on the pathogenesis, genetics, or molecular biology of MG
- Primarily focus on treatments of MG or treatment efficacy
- Non-peer reviewed research

**Fig. S1** Selection process for the targeted literature review



Of the 167 initial results, 160 articles with titles that were not related to “myasthenia gravis” were excluded. None of the remaining abstracts were found to include non-peer reviewed research, therefore, no further articles were excluded at this stage. Full texts were reviewed for the remaining seven articles; one was excluded, as it was not a qualitative study and did not contain any patient quotes. One additional paper, published after the original database searches were performed, was later included due to its direct relevance to the study parameters [1]. Therefore, a total of seven articles were included in the final literature review.

**Table S3** Qualitative studies selected for in-depth review and data extraction

Understanding existing qualitative research is paramount as a first step to understanding the patient voice. Accordingly, the seven articles reviewed all included patient interview studies in which patients were either directly asked about their experiences with MG, including symptoms and impacts [1-6] or were asked to provide input (i.e., cognitive debrief) regarding items for an MG instrument designed by researchers [1, 7]. Given the paucity of the qualitative studies uncovered in this review, all seven articles in **Table S2** were reviewed in-depth, and data about the signs, symptoms, and impacts described therein were extracted.

	Cleanthous 2021 [1]	Chen 2013 [2]	Kabasawa 2013 [3]	Barnett 2014[4]	Richards 2014 [5]	Raggi 2014 [6]	Barnett 2016 [7]
<b>Interview type</b>	In-depth patient interviews, cognitive debriefing interviews, clinical trial exit interviews	In-depth patient interviews	In-depth patient interviews	Semi-structured interviews	Online questionnaire with open-ended questions	Selection of concepts by patients from a list developed from literature search (Delphi-similar)	Cognitive debriefing interviews
<b>Study objective</b>	Develop the MG symptom PRO to assess key aspects of MG severity from the patient perspective	Explore the illness experience of patients with MG, their experiences of illness, its challenges, and their coping and support strategies	Investigate the prevalence and clinical characteristics of taste disorders in patients with MG	Explore the MG patient experience and related impairments	Investigate the psychosocial impact of ptosis as a symptom of MG	Develop a preliminary version of a disease-specific, patient-reported disability assessment instrument for MG based on the ICF	Cognitive interview of the MGII
<b>Number of patients</b>	103	9	371	20	166	13	13
<b>Study type</b>	Qualitative and mixed methods psychometrics	Qualitative study	Epidemiological study	Qualitative study	Qualitative study	“Delphi-type” study	Questionnaire development
<b>Population</b>	Patients with MG from US, UK, Canada, and Europe, mean age for wave 1 = 64.2 years, wave 2 = 66.9 years, and exit interviews = 51.9 years	Six patients with generalized MG, and three with ocular	Japanese patients with MG, 127 men and 244 women; mean age, 56.6 ± 16.9 years	MG patients representing the spectrum of the disease, median age = 62.5 years (range: 29–78); 11 (55%) patients were female	MG patients, mean age = 29.3 years with an age range of 18–63 years	MG patients, age = 29–68 years (mean 45.0, SD 11.4)	MG patients

ICF International Classification of Functioning, Disability and Health MG myasthenia gravis PRO patient-reported outcome SD standard deviation

**Table S4** Demographics and practice setting of clinicians participating in round-1 and round-2 interviews

<b>Round-1 interviews (n = 5)</b>					
	<b>Clinician 1</b>	<b>Clinician 2</b>	<b>Clinician 3</b>	<b>Clinician 4</b>	<b>Clinician 5</b>
Specialty	Neurologist	Neuromuscular specialist	Neurologist	Neurologist	Neurologist
Years treating MG patients	23	23	33	6	30
Practice setting	Private practice	Private practice	Private practice	Private practice	Community hospital
Number of gMG patients seen per month	8–10	8–10	20	12	8–9
<b>Round-2 interviews (n = 4)</b>					
	<b>Clinician 66</b>	<b>Clinician 77</b>	<b>Clinician 88</b>	<b>Clinician 99</b>	
Specialty	Physical therapist specializing in neurological conditions	Neurologist	Neurologist	Neurologist	Neurologist
Years treating MG patients	15	27	12	22	
Practice setting	Private practice	Private practice	Academic institution	Academic institution	
Number of gMG patients seen per month	6	6	3	6	

*gMG* generalized myasthenia gravis

**Table S5** gMG symptoms mentioned by patients and corresponding bothersome ratings from round-1 interviews

Symptom	Spontaneous vs aided mentions (n = 12)		Total (N = 12)	Bothersome rating, average (min:max) [n]
	Spontaneous	Aided		
<b>Respiratory muscle weakness</b>				
Shortness of breath	3	9	12	7.6 (5:10) [11]
<b>Fatigue</b>				
General fatigue	10	1	11	7.4 (4:10) [10]
<b>Muscle fatigability</b>				
Fatigability upon exertion	7	0	7	N/A
Fatigability progression throughout the day	6	0	6	N/A
<b>Limb and axial weakness</b>				
Muscle weakness of legs	8	3	11	6.9 (3:10) [10]
Muscle weakness of arms	4	6	10	6.3 (4:10) [8]
Muscle weakness of neck	4	4	8	6.8 (5:10) [7]
Muscle weakness of face	3	5	8	4.1 (1:10) [6]
Stiffness	1	1	2	9.5 (9:10) [2]
<b>Bulbar muscle weakness</b>				
Difficulty swallowing (dysphagia)	4	7	11	4.6 (0:10) [10]
Difficulty chewing	2	8	10	4.7 (0:10) [7]
Poor voice quality/losing voice (dysphonia)	5	4	9	5.3 (1:10) [7]
Speech impairment (dysarthria)	4	4	8	6.0 (2:10) [8]
Trouble swallowing liquids	3	3	6	5.0 [1]
Choking	3	3	6	7.0 (3:10) [2]
Trouble aspirating saliva	2	1	3	N/A
<b>Ocular muscle weakness</b>				
Drooping upper eyelid (ptosis)	4	7	11	3.4 (0:8) [9]
Double vision (diplopia)	4	4	8	4.4 (1:8) [7]
Blurry vision	1	0	1	10.0 (5:8) [1]
<b>Sleep-related issues</b>				
Sleep disturbance (poor sleep, excessive daytime sleepiness)	2	1	3	7.0 [1]
Sleep apnea	1	1	2	N/A

Symptom	Spontaneous vs aided mentions (n = 12)		Total (N = 12)	Bothersome rating, average (min:max) [n]
	Spontaneous	Aided		
<b>Motor function</b>				
Balance	3	1	4	6.5 (6:7) [2]
<b>Cognitive functioning</b>				
Brain fog/mental fatigue	3	0	3	7.7 (5:10) [3]
Cognitive impairment	1	0	1	N/A
<b>Pain-related</b>				
Aches/pain (jaw, back)	2	1	3	6.0 [1]
<b>Other</b>				
Heat sensitivity	6	0	6	9.5 (9:10) [2]
Loss of taste	1	2	3	5.0 (0:10) [3]
Gastrointestinal issues due to digestive issues	2	0	2	10.0 [1]
Incontinence due to muscle weakness	1	0	1	10.0 [1]

Concepts in blue are newly elicited in the concept elicitation patient interviews (i.e., not identified from the previously conducted literature review)

Bothersome ratings are based on the number of patients who provided a rating, which was not always the same number as those who endorsed the symptom

Symptoms were elicited spontaneously or after probing (aided). Not available (N/A) is indicated where bothersome ratings could not be obtained



**Table S6** Saturation of signs and symptoms during patient interviews

	Group 1	Group 2	Group 3
<b>Number of patients</b>	4	4	4
<b>Count of new concepts</b>	25	3	0
<b>Concepts first appearing in group, %</b>	89	11	0
<b>Symptoms</b>	<b>First mentioned during interviews</b>		
<b>Respiratory muscle weakness</b>			
Shortness of breath	12 (S = 3; P = 9)		
<b>Fatigue</b>			
General fatigue	11 (S = 10; P = 1)		
<b>Muscle fatigability</b>			
Fatigability upon exertion	7 (S = 7; P = 0)		
Fatigability progression throughout the day	6 (S = 6; P = 0)		
<b>Limb and axial weakness</b>			
Muscle weakness of legs	11 (S = 8; P = 3)		
Muscle weakness of arms	10 (S = 4; P = 6)		
Muscle weakness of neck	8 (S = 4; P = 4)		
Muscle weakness of face	8 (S = 3; P = 5)		
Stiffness		2 (S = 1; P = 1)	
<b>Bulbar muscle weakness</b>			
Difficulty swallowing	11 (S = 4; P = 7)		
Difficulty chewing	10 (S = 2; P = 8)		
Poor voice quality/loosing voice	9 (S = 5; P = 4)		
Speech impairment	8 (S = 4; P = 4)		
Trouble swallowing liquids	6 (S = 3; P = 3)		
Choking	6 (S = 3; P = 3)		
Trouble aspirating saliva	3 (S = 2; P = 1)		
<b>Ocular muscle weakness</b>			
Drooping upper eyelid	11 (S = 4; P = 7)		
Double vision	8 (S = 4; P = 4)		
Blurry vision	1 (S = 1; P = 0)		
<b>Sleep-related issues</b>			
Sleep disturbance (poor sleep, excessive daytime sleepiness)	3 (S = 2; P = 1)		
Sleep apnea	2 (S = 1; P = 1)		
<b>Cognitive functioning</b>			
Brain fog/mental fatigue	3 (S = 3; P = 0)		
Cognitive impairment	1 (S = 1; P = 0)		
<b>Motor function</b>			
Balance	4 (S = 3; P = 1)		

	Group 1	Group 2	Group 3
<b>Pain-related</b>			
Aches/pain (jaw, back)	3 (S = 2; P = 1)		
<b>Other</b>			
Heat sensitivity		6 (S = 6; P = 0)	
Loss of taste		3 (S = 1; P = 2)	
Gastrointestinal issues due to digestive issues	2 (S = 2; P = 0)		
Incontinence due to muscle weakness	1 (S = 1; P = 0)		

S spontaneous P probed

Concepts in blue are newly elicited in the concept elicitation patient interviews (i.e., not identified from the previously conducted literature review)

**Table S7** Impacts mentioned by patients and corresponding disturbance ratings during round-1 interviews

Impact	Spontaneous vs aided mentions (n = 12)		Total (N = 12)	Disturbance rating, average (min:max) [n]
	Spontaneous	Aided		
<b>Emotional</b>				
Depression	3	2	5	6.6
Upset about disease	3	0	3	N/A
Fear/anxiety	2	0	2	8.0
Irritation	2	0	2	N/A
Anger	1	1	2	9.5
Frustration	1	0	1	N/A
<b>Psychosocial</b>				
Stress	1	0	1	N/A
Loss of identity	1	0	1	10.0 [1]
Self-esteem	1	0	1	3.0 [1]
Loss of independence	1	0	1	7.0 [1]
Feeling alone/ misunderstood	0	1	1	10.0 [1]
<b>Daily activities</b>				
Eating	4	4	8	7.0 (7:7) [2]
Grocery shopping	3	0	3	6.0 (5:7) [2]
Housework	2	0	2	7.0 (5:9) [2]
Getting out of bed	2	0	2	N/A
Keeping up with children	2	0	2	N/A
Getting into car	1	0	1	N/A
Completing crafts	1	0	1	3.0 [1]
Cooking	1	0	1	6.0 [1]
Opening mail	1	0	1	N/A
Watching TV	0	1	1	N/A
Driving	0	1	1	N/A
Difficulty with computer	0	1	1	N/A
Reading	0	1	1	N/A
<b>Physical function</b>				
Difficulty walking	5	1	6	8.0 [2]
Exercising	3	0	3	8.0 [1]
Physical yard labor	2	0	2	N/A
Standing	1	0	1	10.0 [1]
Carrying items	1	0	1	3.0 [1]

Impact	Spontaneous vs aided mentions (n = 12)		Total (N = 12)	Disturbance rating, average (min:max) [n]
	Spontaneous	Aided		
Stepping up stairs	1	0	1	N/A
Weak grip/dropping item	1	0	1	N/A
Getting out of chair	2	0	2	N/A
<b>Self-care</b>				
Brushing hair	3	3	6	6.0 (1:10) [6]
Showering	3	3	6	5.5 (3:8) [2]
Brushing teeth	4	1	5	6.5 (3:10) [2]
Washing hair	3	1	4	2.0 [1]
Hot baths	2	0	2	N/A
Putting on makeup	1	0	1	N/A
Getting dressed	1	0	1	N/A
Washing face	0	1	1	N/A
<b>Professional</b>				
Work life	7	2	9	9.4 (7:10) [8]
<b>Social</b>				
Personal relationships	3	5	8	6.6 (4:9) [5]
Family life	2	4	6	8.0 (5:10) [3]
Participating in social activities	4	1	5	10.0 [1]
Cut out intolerant friends	2	1	3	N/A
Unable to commit to plans	2	1	3	9.0 [3]
Stays to themselves	2	0	2	10.0 [1]
Perceived by others as being intoxicated	1	0	1	N/A
<b>Burden</b>				
Financial burden	3	0	3	9.5 (9:10) [2]
Travel and time for medical appointments	1	0	1	4.0 [1]

Concepts in blue are newly elicited in the concept elicitation patient interviews (i.e., not identified from the previously conducted literature review)

Average disturbance ratings are based on the number of patients who provided a rating, which was not always the same number as those who endorsed the symptom

Symptoms were elicited spontaneously or after probing (aided). Not available (N/A) is indicated where disturbance ratings could not be obtained

## References

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