Disability and Rehabilitation

ISSN: 0963-8288 (Print) 1464-5165 (Online) Journal homepage: www.tandfonline.com/journals/idre20

Challenges and rehabilitation needs among adults with myasthenia gravis – a Danish cross-sectional questionnaire study

Lene Klem Olesen, Charlotte Handberg, Malene Missel, Liselotte Schierakow & Ulla Werlauff

To cite this article: Lene Klem Olesen, Charlotte Handberg, Malene Missel, Liselotte Schierakow & Ulla Werlauff (29 May 2025): Challenges and rehabilitation needs among adults with myasthenia gravis – a Danish cross-sectional questionnaire study, Disability and Rehabilitation, DOI: 10.1080/09638288.2025.2512408

To link to this article: https://doi.org/10.1080/09638288.2025.2512408

© 2025 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

View supplementary material

Published online: 29 May 2025.

Submit your article to this journal

Article views: 69

View related articles

View Crossmark data

Full Terms & Conditions of access and use can be found at
https://www.tandfonline.com/action/journalInformation?journalCode=idre20

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2025.2512408

Taylor & Francis
Taylor & Francis Group

RESEARCH ARTICLE

OPEN ACCESS
Check for updates

Challenges and rehabilitation needs among adults with myasthenia gravis – a Danish cross-sectional questionnaire study

Lene Klem Olesen[a], Charlotte Handberg[a,b], Malene Missel[c], Liselotte Schierakow[c] and Ulla Werlauff[a]

[a]National Rehabilitation Center for Neuromuscular Diseases, Aarhus C, Denmark; [b]Department of Public Health, Faculty of Health, University of Aarhus, Aarhus C, Denmark; [c]Person with MG, Aarhus C, Denmark

ABSTRACT

Purpose: The aim was to examine disease-related challenges and rehabilitation needs among adults with Myasthenia Gravis (MG) to target future support initiatives.

Materials and methods: The study involved a cross-sectional questionnaire based on patient-reported outcomes within 11 domains/95 items, covering potential challenges and needs in living with MG. Data were compared against the subgroups gender, age, and years with MG.

Results: In total, 197 participants responded. The median number of challenges across all domains was 15 out of 95 with a higher prevalence in women than men and with no differences in relation to age or years with MG. The most prominent challenges were muscle strength, physical tiredness, and mental fatigue. The median number of total rehabilitation needs was three out of 95 with a higher prevalence in women than men, but with no differences between age and years with MG. The most prominent rehabilitation needs were physical tiredness, mental fatigue, and knowledge on existing interventions. Many participants reported unmet psychological needs, especially women, participants from 40 years of age, and participants who had lived with MG for more than five years.

Conclusions: MG significantly impacts on everyday functioning and activities. Disease-related challenges and rehabilitations needs manifested differently across genders. A profound difference was found between the number of challenges and rehabilitation needs reported.

ARTICLE HISTORY
Received 25 November 2024
Revised 22 May 2025
Accepted 23 May 2025

KEYWORDS
Myasthenia gravis; rehabilitation; needs; disease-burden; disease-impact; everyday challenges

IMPLICATIONS FOR REHABILITATION

- By investigating, understanding, and addressing the unique challenges and rehabilitation needs experienced across gender, lifespan, and years with myasthenia gravis, healthcare professionals can target more equitable and supportive initiatives.
- Healthcare professionals should apply a patient reported outcome assessment to generate data that can be used in the clinic consultation to target individual rehabilitation interventions.
- Healthcare professionals should access and support the psychological needs for rehabilitation from point of diagnosis and throughout the illness trajectory via psychological counseling.
- Empowering adults with myasthenia gravis to navigate and cope with their illness-related challenges and rehabilitation needs with resilience and dignity, will enhance their well-being and quality of life.

Introduction

Myasthenia gravis (MG) is a rare chronic autoimmune disease characterized by muscle weakness and fatigability that leads to functional impairment [1–3]. In Denmark, the incidence of MG is 9.2 per million person-year [1] and the prevalence is around 1500 people [4]. Muscle weakness is caused by dysfunction at the level of the neuromuscular junction [5]. Symptoms can manifest in ocular muscles (drooping eyelids and/or doble vision) and/or fatigable weakness in the striated muscles with the intensity and impairment fluctuating and changing from limbs to head drop, dysphagia and/or difficulty in talking [3]. Muscle weakness is exacerbated by repetitive muscle movement but normalizes with rest [6]. Fatigue is a common symptom of MG [3,6].

For women, the age at disease onset is typically between 20 and 39 years [7] and for men between 50 and 70 years [8]. Women have a bimodal onset curve with an early- and a late-onset peak compared to men who have a late-onset peak [9]. There is no curative treatment for MG, and people with MG often need ongoing treatment [10–12]. Traditional treatments for MG such as acetylcholinesterase inhibitors, corticosteroids, and immunosuppressants have shown efficacy but often cause significant long-term side effects [13]. Promising alternative molecular therapies for MG have advanced during recent years [13]. Around half of the people with MG achieve remission at some point, but even if the disease is well treated this does not necessarily equal a satisfying quality of life [14,15], and many people with MG struggle with symptoms that influence on their everyday lives [10–12]. They find it challenging to plan their day which again has negative consequences for their quality of life and rehabilitation [15–17]. Mahic et al. (2022) found that the mean number of symptoms per person was the same (five) after treatment as it was at diagnosis [10].

CONTACT Lene Klem Olesen leol@rcfm.dk National Rehabilitation Center for Neuromuscular Diseases, Denmark. Kongsvang Allé 23, 8000 Aarhus C, Denmark

Supplemental data for this article can be accessed online at https://doi.org/10.1080/09638288.2025.2512408.

© 2025 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

A Danish study showed that people with MG had an almost six times higher risk of exiting the labor market and an almost nine times higher risk of long-term sick leave from work two years after the time of diagnosis [11]. Another study found that 1/3 of the study population with MG were not satisfied with their treatment response compared to those who were satisfied with their actual disease symptoms [16]. MG has a profound impact on people's quality of life, functional capacity, and everyday life [11,12,16]. Hospitals often focus on medical treatment with the risk of overseeing other aspects of functioning [12], and adults with MG may experience that the support from the healthcare professionals is inadequate or fragmented [18].

According to the International Classification of Functioning (ICF), functioning is defined as body function, body structure, activity and participation [19]. Investigating, understanding, and supporting functioning will enable healthcare professionals to fully grasp the many aspects (body, activity, participation, personal and contextual factors) that influence on a person's functioning [19]. Rehabilitation is an important person-centered approach that seeks to help people become as independent as possible in all aspects of life, including everyday activities, and enable participation in work, education and meaningful life roles, etc. [20–22]. Consensus-based guidelines and national guidelines recommend rehabilitation to people with MG, however, focus is typically on medical management rather than other aspects of rehabilitation [23,24]. A systematic review on evidence-based practice in rehabilitation in MG based on two randomized controlled trials, one prospective case-control study and eight cohort studies show that the rehabilitation initiatives solely focused on physical, respiratory, and balance training [25]. Investigating rehabilitation in a broader perspective, as previously defined, as well as exploring MG-related challenges and rehabilitation needs among adults with MG is missing [26,27]. Rehabilitation guided by ICF may help professionals investigate and support the complex and fluctuating symptoms and needs of people with MG [21,28,29]. In Denmark, rehabilitation services are performed by two separate sectors: 1) the regions through hospitals and outpatient specialized rehabilitation, and 2) the local communities who are responsible for the generalized rehabilitation [30]. Healthcare professionals providing rehabilitation within both sectors are mostly physiotherapists, occupational therapists, nurses, and social and health assistants. This study aims to investigate self-reported MG-related challenges and rehabilitation needs among adults with MG in Denmark to help target future MG rehabilitation initiatives.

Materials and methods

Design and setting

This study involved a Danish cross-sectional questionnaire based on patient reported outcomes from adults with MG. The study was designed in close collaboration with adults with MG, interdisciplinary healthcare professionals at the Danish Rehabilitation Center for Neuromuscular Diseases (RCFM), and a consultant from the Danish patient organization for neuromuscular diseases. Together with the research team, the adults with MG participated in every part of the study, including interpretation of results and commenting on the manuscript. This study was affiliated with RCFM, a publicly funded highly specialized outpatient hospital [31].

Ethical consideration

According to the Central Denmark Region Committees on Health Research Ethics, this study was not liable to notification [File no. 1-10-72-6-23]. This study was conducted in accordance with the declaration of Helsinki (1964) [32] and conforms to the requirements of ICMJE [33]. The participants were informed through the invitation letter, that once they completed the survey, they automatically provided their informed written consent to participate in the study. This study adheres to the SAGER guidelines [34].

Participants

Participants were recruited from RCFM's patient database, and an invitation was sent to their personal digital mailbox (Borger.dk). Participants were eligible if they were diagnosed with MG, 18 years and older, referred to RCFM before August 1st, 2023, and able to read and understand Danish. Adults with MG who had stated in their medical records that they were not interested in research, were excluded ($n = 26$).

Data collection

The invitation included study information and a generic link to SurveyXact, a digital platform for customizing questionnaires [35]. An online questionnaire was developed, inspired by the need assessment questionnaire developed by the Central Denmark Region for people with cancer [36]. The adjusted questionnaire, containing 95 items within 11 domains, was pilot tested by six adults with MG and adjusted in relation to their feedback. Based on the pilot test, the estimated time to answer the questionnaire was 10–15 min, as the participants were asked to read through 95 listed items and mark their actual challenges/rehabilitation needs, or type others in if not listed. Data was collected from August 24th to September 11th, 2023. On September 8th, a reminder was sent through Borger.dk to all invited participants. Participants provided their email address in the questionnaire, so the research group could detect if any participants replied twice.

Need assessment questionnaire

The questionnaire contained questions on demographics and diagnosis and consisted of 11 domains: practical/home (five items), transportation (four items), social (four items), work/school/education (11 items), family (two items), physical (25 items), emotional (17 items), treatment (six items), assistive technology (six items), collaboration with professionals (six items) and KRAM-factors (nine items). It contained a total of 95 items to identify and state possible challenges and rehabilitation needs (Appendix). Rehabilitation needs are defined in the survey as issues that the participants need help and support to manage. Within each domain, the participants were asked to mark (a) whether they experienced one or more of the items as a MG-related challenge, (b) whether they experienced "other challenges," or (c) whether they experienced "no challenges." In case one or more (including "other") challenges were experienced, a follow-up-question was presented concerning their need for support (rehabilitation need) in relation to the challenge. The follow-up-question contained two response options; (I) I need support to manage the specific challenge, or (II) I can manage by myself/already receiving the necessary support. In case "no challenges" were experienced within a domain, the program would skip the follow-up question on need for support and forward the participant to the next domain. Ticking off the boxes "challenge" and "need for support" was registered as one identified challenge/need, meaning that each participant could list from 0 to 95 challenges/needs. A 'yes' answer in "need for support" reflected that participants experienced a challenge which they needed external help and support to manage. A high amount of challenges/need for support could indicate a high disease severity, but it could also be related to other personal or contextual factors, such as acceptance, coping, and support from family and friends.

Statistical analyses

Data were analyzed using IBM SPSS statistics 29 [37]. Individuals were excluded if they had left the questionnaire without answering any of the questions or only the initial questions on age. Categorical variables were presented using numbers (n) and percentages (%). Mean and standard deviation (SD) or range (min-max) were used for normally distributed continuous variables, and median and range were used for abnormal distributed continuous variables. Differences in challenges and rehabilitation needs according to influence of gender, age, and years with MG (years since diagnosis) were calculated using Kruskal-Wallis test; the significance level was set as p equal or less than .05. Gender was defined based on how the participants viewed themselves (man/woman/other) [34], age was divided into groups (from 18 to 39, between 40 and 59, from 60 years and up) and years with MG (less than three years, between three and five years, and more than five years). The number of total challenges and rehabilitation needs across all domains were divided into three groups: from zero to five, between five and 10, and more than 10 challenges or rehabilitation needs. The number of total physical challenges, physical rehabilitation needs, and psychological challenges were divided into groups corresponding to zero, between one and five, and more than five, respectively.

Results

A total of 348 adults with MG were invited and 265 responded. Sixty-eight respondents were excluded from the analysis because of duplicates or because they had only filled in demographic data. The overall response rate was 56.6% ($n = 197$).

Participant characteristics

In total, 126 women and 71 men participated. Women were younger (55.4 years) than men (61.5 years) ($p < .001$), mean age of all participants was 57.6 years (14.7). Women were also younger (39 years) than men (50.4 years) at disease onset ($p < .001$), with a mean age at disease onset for the participants of 43.1 years (17.8). The mean years with MG was 14.4 (range 0–70.5) with 77% of the women and 63.4% of the men who had been living with MG for more than five years. Seventy-nine (40%) participants were diagnosed with acetylcholine receptor (AChR) antibody, and 95 (47%) were unfamiliar with their MG sub-diagnosis. One hundred-and-eight (54.8%) participants had ocular onset symptoms. One hundred-and-thirty-nine (69%) participants received symptomatic treatment (Mestinon) and more than half of them ($n = 118$, 59%) received between two and six MG therapies. Sixty-five (32%) participants had retired, and 36 (17.9%) worked reduced hours: 26 (72.2%) women and 10 (27.8%) men. Thirty (15%) participants were on early retirement: 24 (80%) women and six (20%) men. Eighty-seven out of 196 (44%) participants had experienced changes in employment status because of MG, but there were no differences in gender (p=.183), age (p=.801) or years with MG (p=.361). One hundred-forty-four (72%) participants were married/co-habiting/in a relationship (Table 1).

Challenges and rehabilitation needs across all domains

The median number of total challenges across all domains was 15 out of 95 possible with a higher prevalence in women than in men (p=.001). There were no differences in number of challenges according to age subgroups (p=.383) and years with MG subgroups (p=.185); 48% of the women and 68.6% of the men who reported more than 10 challenges were between 40 and 59 years, and from 60 years and up, respectively. Seventy-seven % of the women and 57% of the men who reported more than ten challenges had lived with MG for more than five years. Table 2 illustrates the median (range) number of challenges and rehabilitation needs across all domains according to subgroups within the following categories: gender, age and years with the disease.

The median number of total rehabilitation needs was 3 out of 95 with a higher prevalence in women than in men (p=.024). There were no differences in number of rehabilitation needs according to age subgroups (p=.583), and years with MG subgroups (p=.968); 77% of the women and 44.4% of the men who reported more than 10 rehabilitation needs had lived with MG for more than five years. The largest groups of women (60%) and men (44.4%) reporting more than 10 rehabilitation needs were between 40 and 59 years old.

The ten most frequently reported challenges and rehabilitation needs across all domains, measured in highest proportion score, were extracted (Table 3).

Physical challenges and rehabilitation needs

The median number of total physical challenges was 6 out of 25 (range 0–22). Multiple physical challenges (more than five) were reported by 110 (56%) participants, with a higher prevalence in women that in men: 7 (range 0–22) vs. 4 (range 0–14) (p=.010). There were no differences in number of physical challenges according to age subgroups (p=.826), and years with MG subgroups (p=.233). However, 76% of the women and 53% of the men reporting more than five physical challenges had lived with MG for more than five years. The largest group of women and men reporting more than five physical challenges were between 40 and 59 years and from 60 years and up, respectively. Table 4 displays the number of physical challenges and rehabilitation needs according to subgroups within the following categories: gender, age and years with MG.

The median number of total physical rehabilitation needs was 1 out of 25 (range 0–21). Seventy-five (38%) participants reported between one and five physical rehabilitation needs. There were no differences in number of physical rehabilitation needs according to gender subgroups (p=.063), age subgroups (p=.445), and years with MG subgroups (p=.784). Most of the women (71%) and men (60%) reporting more than five physical rehabilitation needs had lived with MG for more than five years. Sixty-two percent of the women reporting more than five physical rehabilitation needs were between 40 and 59 years old whereas 60% of the men were from 60 years and up. Fourteen (7%) participants reported no physical challenges. Many participants experienced various challenges but did not necessarily need support to handle these. This could be seen in the drop in numbers (percentages) from challenges to rehabilitation needs e.g.: muscular strength dropped from 131 (66%) participants to 35 (18%), persistent fatigue from 116 (59%) participants to 49 (25%) and memory/concentration from 83 (42%) participants to 25 (13%) (appendix, A.1).

Table 1. Participants' demographic.

	Total $n=197$ (100%)	Men $n=71$ (36%)	Women $n=126$ (64%)
Age. Mean (range)	57.6 (23–92)	61.5 (23–92)	55.4 (24–89)
Age at disease onset. Mean (range)	43.1 (10–85)	50.4 (18–79)	39.0 (10–85)
Marital status $n=196$			
Married/in a relationship, cohabiting	141 (71.9)	59 (83.1)	82 (65.1)
Widow/single	38 (19.4)	6 (8.5)	32 (25.4)
Divorced/separated	17 (8.7)	6 (8.5)	11 (8.7)
Highest completed education			
Higher education (academy or bachelor)	87 (44.2)	19 (26.8)	68 (54.0)
Higher education (master)	41 (20.8)	20 (28.2)	21 (16.7)
Primary and lower secondary school	30 (15.2)	11 (15.5)	19 (15.1)
Skilled	28 (14.2)	16 (22.5)	12 (9.5)
Upper secondary school/vocational education or training/other out-of-school education	5 (2.5)	3 (4.2)	2 (1.6)
Other adult education	6 (3.0)	2 (2.8)	4 (3.2)
Employment			
Retirement	63 (32.0)	34 (47.9)	29 (23.0)
Full-time job	37 (18.8)	21 (29.6)	16 (12.7)
Reduced hours-job	36 (18.3)	10 (14.1)	26 (20.6)
Early retirement pension	30 (15.2)	6 (8.5)	24 (19.0)
Other	22 (11.2)	–	22 (17.5)
Part-time job	5 (2.5)	–	5 (4.0)
Job seeking	2 (1.0)	–	2 (1.6)
Student	2 (1.0)	–	2 (1.6)
Have children $n=196$			
Yes, I have children living on their own	102 (52.0)	42 (59.2)	60 (48.0)
Yes, I have children living at home	51 (26.0)	13 (18.3)	38 (30.4)
No, I do not have children	30 (15.3)	16 (22.5)	14 (11.1)
I have children both living at home and on their own	13 (6.6)	–	13 (10.4)
MG subdiagnosis			
Do not know	95 (47.3)	37 (52.1)	56 (44.4)
Acetylcholine receptor (AChR) antibody	79 (40.1)	25 (35.2)	54 (42.9)
Muscle-specific kinase (MUSK)	8 (4.1)	4 (5.6)	4 (3.2)
Seronegative (SNMG)	8 (4.1)	2 (2.8)	6 (4.8)
Other	8 (4.0)	3 (4.2)	5 (4.0)
Lipoprotein receptor-related protein 4 (LRP4)	1 (0.5)	–	1 (.8)
Symptom onset			
Ocular	108 (54.8)	42 (59.2)	66 (52.4)
Generalized	69 (35.0)	21 (29.6)	48 (38.1)
Other	20 (10.2)	8 (11.3)	12 (9.5)
Current treatment			
Symptomatic	139 (69.2)	43 (60.6)	94 (74.6)
Immuno-suppressive	123 (61.9)	48 (67.6)	74 (58.7)
Glucocorticoid	44 (21.9)	21 (29.6)	23 (18.3)
Thymectomy	35 (17.8)	7 (9.9)	28 (22.2)
Other	27 (13.4)	8 (11.3)	19 (15.1)
No treatment	16 (8.1)	3 (4.2)	13 (10.3)
Plasmapheresis	10 (5.1)	2 (2.8)	8 (6.3)
Intravenous immunoglobulin	10 (5.1)	2 (2.8)	8 (6.3)
Biological therapies	8 (4.1)	3 (4.2)	5 (4.0)

Table 2. Number of challenges and rehabilitation needs according to gender, age and years with myasthenia gravis.

	Gender		Age			Years with MG			
	Men $N=71$	Women $N=126$	18–39 years $N=30$	Between 40–59 years $N=77$	60 years and above $N=90$	Less than 3 years $N=35$	Between 3–5 years $N=19$	More than 5 years $N=143$	Total $N=197$
Challenges (n) Median (range)	10 (0–38)	17 (0–53)	18 (0–41)	15 (0–53)	13 (0–46)	18 (0–44)	10 (0–32)	14 (0–53)	15 (0–53)
Rehabilitation needs (n) Median (range)	2 (0–25)	4.5 (0–31)	2 (0–21)	3 (0–31)	3.5 (0–27)	3 (0–28)	3 (0–15)	3 (0–31)	3 (0–31)

MG (myasthenia gravis). Years with MG = years since diagnosis.

Psychological/cognitive challenges and rehabilitation needs

The median number of total psychological/cognitive challenges was two out of 17 (range 0–15) (hereafter psychological challenges). Multiple psychological challenges (more than five) were reported by 57 (29%) participants, with a higher prevalence in women than in men: 45 (36%) vs. 12 (17%) ($p=.005$). Fifty-two (26%) participants did not experience any psychological challenges. No differences were found between psychological challenges and age subgroups. However, 20% of the women and 35% of the men who reported between one and five psychological challenges were between 40 and 59 years old and from 60 years and up, respectively. The participants who had lived with MG for less than three years reported more psychological challenges than those who had lived with MG for more than five years, (*p*=.025). Table 5 presents the number of psychological challenges according to subgroups within the following categories: gender, age and years with MG.

Of the 17 psychological items, the three variables with the highest scores were mental fatigue *n*=85 (43%), concerns *n*=73 (37%), and frustration *n*=68 (34%) (appendix, A.2). Of the 141 responses on psychological rehabilitation needs, 87 (62%) participants responded that they did not receive the necessary support, but no differences were found between gender subgroups (*p*=.185), age subgroups (*p*=.342) or years with MG subgroups (*p*=.109). Sixty-four (74%) out of 87 participants were women, 75 (86%) participants were from 40 years and up, and 66 (76%) participants had lived with MG for more than five years.

An overview of all results on challenges and rehabilitation needs from the questionnaire are listed in the Appendix.

Discussion

In this study, we collected self-reported data on MG-related challenges and rehabilitation needs from 197 adults with MG referred to RCFM in Denmark. Currently, 1853 people live with a verified MG diagnosis in Denmark [38] and 373 (20%) of them are referred to RCFM. This current study population represents 53% of the RCFM cohort. Results showed that only few (8%) participants did not receive medical treatment. This treatment rate is considerably lower than in a study by Andersen (2021) where 24% of 779 participants did not receive treatment, even though the mean number of years of living with MG in the two study samples were almost the same (14.4 vs. 13.6 years) [4]. The difference may be explained by the fact that our sample consists of people with MG referred to RCFM, a highly specialized outpatient rehabilitation hospital, by the neurological departments or general practitioners, and this may indicate that our population of adults with MG represents those who have a more complex disease trajectory than people with MG who are not referred.

Results showed that gender can influence the way MG is perceived and managed, e.g., women experienced more challenges and rehabilitation needs across the domains than men. These results are supported by previous studies on MG showing objectively measured gender differences in disease severity, level of disability and quality of life [4,39]. We found that women had a higher prevalence of physical challenges than men which aligns with other studies showing that women with MG tend to have more severe symptoms compared to men [27,40–43]. For instance, Lehnerer (2022) found that women more frequently reported a medium to high disease severity than men, and that women reported higher levels of difficulties in activities of daily living [40]. Results showed that most women who reported multiple

Table 3. The 10 most frequently reported challenges and rehabilitation needs across all domains listed in order of highest to lowest proportion score.

	Total n (%)	Men n (%)	Women n (%)
10 challenges			
Muscular strength	131 (66.5)	39 (54.9)	92 (73)
Physical tiredness	123 (62.4)	38 (53.3)	85 (67.5)
Fatigue that does not vanish/mental fatigue	116 (58.9)	31 (43.7)	85 (67.5)
Exercise	107 (54.3)	30 (42.3)	77 (61.1)
Medical side effects	84 (42.6)	32 (45.1)	52 (41.3)
Sleep	74 (37.6)	22 (31.0)	52 (41.3)
Concerns	73 (37.1)	17 (23.9)	56 (44.4)
Hot flashes	71 (36.0)	13 (18.3)	58 (46.0)
Vision	70 (35.5)	23 (32.4)	47 (37.3)
Cramps	68 (35.5)	23 (32.4)	45 (35.7)
10 rehabilitation needs			
Physical tiredness	59 (29.9)	16 (22.5)	43 (34.1)
Fatigue that does not vanish	49 (24.9)	11 (15.5)	38 (30.2)
Knowledge about available help/support	48 (24.4)	9 (12.7)	39 (31.0)
Maintenance	47 (23.9)	15 (21.1)	32 (25.4)
Medical side effects	43 (21.8)	15 (21.1)	28 (22.2)
Exercise	38 (19.3)	8 (11.3)	30 (23.8)
Sleep	35 (17.8)	8 (11.3)	27 (21.4)
Muscular strength	35 (17.8)	11 (15.5)	24 (19.0)
Navigating the system	31 (15.7)	8 (11.3)	23 (18.3)
Knowledge on alternative treatment	28 (14.2)	7 (9.9)	21 (16.7)

The variables are presented by numbers (n) and percentages (%).

Table 4. Total number of physical challenges and rehabilitation needs according to gender, age and years with myasthenia gravis.

	Gender		Age			Years with MG			
	Men *N*=71(%)	Women *N*=126(%)	18 to 39 years *N*=30(%)	Between 40–59 years *N*=77(%)	60 years and above N = 90(%)	Less than 3 years *N*=35(%)	Between 3–5 years *N*=19(%)	More than 5 years *N*=143(%)	Total *N*=197 (%)
Physical challenges									
None	6 (8,6)	8 (6)	4 (13)	7 (9)	3 (3)	1 (3)	1 (5)	12 (8)	14 (7)
Between 1 and 5	33 (46)	40 (32)	9 (30)	25 (32)	39 (43)	9 (26)	9 (47)	55 (38)	73 (37)
More than 5	32 (45)	78 (62)	17 (57)	45 (58)	48 (53)	25 (71)	9 (47)	76 (53)	110 (56)
Median (range)	4 (0–14)	7 (0–22)	6 (0–19)	6 (0–22)	5 (0–16)	8 (0–17)	4 (0–15)	5 (0–22)	6 (0–22)
Physical rehabilitation needs									
None	38 (53)	58 (46)	18 (60)	35 (45)	43 (48)	17 (49)	9 (47)	70 (49)	96 (49)
Between 1 and 5	28 (39)	47 (37)	12 (40)	27 (35)	36 (40)	10 (29)	8 (42)	57 (40)	75 (38)
More than 5	5 (7)	21 (17)	0 (0)	15 (19)	11 (12)	8 (23)	2 (10)	16 (11)	26 (13)
Median (range)	,0 (0–7)	1 (0–21)	0 (0–4)	1 (0–21)	1 (0–13)	1 (0–13)	2 (0–7)	1 (0–21)	1 (0–21)

MG (myasthenia gravis). Years with MG=years since diagnosis. The variables are presented by numbers (n) and percentages (%).

Table 5. Total number of psychological challenges according to gender, age and years with myasthenia gravis.

	Gender		Age			Years with MG			
	Men *N* = 71 (%)	Women *N* = 126 (%)	18 to 39 *N* = 30 (%)	Between 40–59 years *N* = 77 (%)	60 years and above *N* = 90 (%)	Less than 3 years *N* = 35 (%)	Between 3- 5 years *N* = 19 (%)	More than 5 years *N* = 143 (%)	Total *N* = 197 (%)
None	25 (35)	27 (21)	7 (23)	19 (25)	26 (29)	4 (11)	7 (37)	41 (29)	52 (26)
Between 1 and 5	34 (48)	54 (43)	11 (37)	32 (42)	45 (50)	17 (49)	6 (32)	65 (45)	88 (45)
More than five	12 (17)	45 (36)	12 (40)	26 (34)	19 (21)	14 (40)	6 (32)	37 (26)	57 (29)
Median (range)	2 (0–15)	3 (0–15)	4 (0–15)	2 (0–15)	2 (0–12)	4 (0–15)	2 (0–10)	2 (0–15)	2 (0–15)

MG: myasthenia gravis. Years with MG = years since diagnosis. The variables are presented by numbers (n) and percentages (%).

(more than five) physical challenges were between 40 and 59 years old and had had MG for more than five years. A prospective cohort study on people with MG receiving standard of care treatment over a period of seven years illustrated that women improved less compared to men on objective measures and patient-reported outcomes, and that women improved more on objective measures than patient-reported outcomes [39]. The fact that remission is more common in women (and juvenile) [44] and that women tend to have more severe symptoms, emphasize the importance of acknowledging that both objective and subjective factors influence on the experience of disease impact in both women and men [12]. Gender bias in healthcare and gendered norms have been found in a theory-guided literature review on men and women with pain, showing 'brave men' and 'emotional women' [45]. To counteract gender bias and provide more equitable care, it is important that healthcare professionals are aware of this bias [45].

We found a high number of total challenges (median 15), but a low number of total rehabilitation needs (median 3). The difference between challenges and needs can be regarded as a continuum going from complete self-care to a need for professional care due to a disability/dysfunction [46]. Where the individual line between going from self-care to professional care is drawn depends on many and different issues, for instance personal resources, coping strategy, personal experience and information along with the character and degree of the challenge and potential consequences [46]. Based on our results, there were no statistically significant relationship between years with MG and number of challenges and rehabilitation needs. However, participants aged 60 years and older showed a tendency to report more rehabilitation needs than younger persons. Our data do not reveal the reason for this, but it is known from other studies that people aging with a disability experience several impacts on their everyday lives which may generate a need for constant adaptations [47,48].

A study on illness perception among people with MG showed an association between disease duration and disease understanding, indicating that time helps people with MG accept the chronic nature of the disease and cope with it [49]. Enhanced disease understanding might explain the discrepancy we found between numbers of challenges vs. rehabilitation needs, as becoming familiar with one's MG symptoms and triggers make people proactively adapt to their everyday routines and cope with the challenges posed by the disease which, in turn, enhances their resilience and well-being [12,17].

Our results support previous studies showing that MG causes physical challenges for most people diagnosed with MG [12,15,17,40,50]. We found that the participants who were newly diagnosed (less than three years) reported more total challenges compared to those who had lived with MG for more than five years, even though this was not significant (p=.185). Interestingly, the men with most rehabilitation needs had lived with MG between three and five years which may be explained by results from a systematic review on men's help-seeking for depression [51]. The review showed that some men feel a pressure to adhere to notions of masculinity which may deter men's help-seeking behavior [51]. Similar findings have been found in cancer research [52]. Perhaps this pressure had also influenced some of our male-participants' help-seeking behavior during the initial disease phase. Again, we did not find any significant difference between the number of total challenges or physical challenges and years with MG which is interesting as muscles usually weaken during the first few years [53]. We would thus expect to see more challenges in those who had lived with MG for less than four years compared to those who had lived with MG for four years or longer who may have been in remission [3]. Even without treatment, MG normally has an active phase followed by an inactive phase [53]. A study of the life course of MG showed that most people have one remission, but up to 5% have 2–4 remissions with most remissions occurring within one year following diagnosis [44]. The fluctuating nature of MG symptoms underlines the need for regular and continuous support from specialists throughout the lives of people with MG.

The participants were psychologically impacted by MG which align with previous studies showing that living with MG can evoke a range of emotional responses, including frustration, anxiety, depression and grief over the loss of physical abilities [27,50]. In fact, 29% of the participants in our study perceived more than five psychological challenges, especially men from 60 years and up, women between 40 and 59 years old, and women who had lived with MG for more than five years. People may face stigma and social perception challenges related to their disease which may cause feelings of low self-esteem, isolation, and psychological distress [54–56]. In fact, self-stigma is found to be a stronger predictor for poorer quality of life among people with neuromuscular diseases compared to enacted stigma, meaning that people have more fear of being discriminated by others than what they actually experience in everyday life [54]. A systematic review shows that people with MG experience worse health-related quality of life compared to the general population [27]. Another study on quality of life among people with MG found that 53% and 26% of the participants reported mild and severe restrictions in their daily routines, respectively, which had a negative impact on their quality of life [15]. Despite the high number of psychological challenges among our participants, the majority (62%) did not receive the necessary psychological support, with slightly more women (64 out of 98, 65%) than men (23 out of 43, 53%). Several hormone-related and pharmacokinetics-related factors have been reported as potential explanations for the association between female gender and worse self-reported quality of life among people with MG [57]. More than 50% of the women between 40 and 59 years of age and from 60 years and up reported more than five psychological needs which is in line with another study showing that female gender and higher age are associated with lower health related quality of life in MG [40]. A study on patient-acceptable symptom state (PASS) found that female gender, unemployment and disease severity were associated with having a negative symptom state [58]. However, full resolution of all MG symptoms may not be necessary for all people to feel well [58]. For instance, coping style, marital status and educational level have been found to be important factors regarding disease perception among adults with MG [49]. Johansen (2021) also found that social support appeared to play a stronger role as a protective factor for mental distress in younger women compared to young men and older people [59]. An integrative review on coping with multiple chronic conditions also showed an association between social support and coping [60]. Overall, this may indicate that experience of challenges and rehabilitation needs may be a complex dynamic interplay of individual characteristics, life circumstances, and sociocultural factors, and that time, lived experiences and social support positively may impact people with MG's ability to adapt to and live with limitations and challenges posed by MG. Researchers and clinicians should therefore adopt a holistic approach to fully understand the varying needs of people with MG, as this may help them target and initiate services to support the people affected [19,61,62].

In this study, selection bias may have affected participation as people with a more severe disease course or proactive people might be more willing to fill out the questionnaire than people in remission or with few symptoms. Another selection bias could be the digital data collection, favoring digitally confident people and people without severe ocular or dexterity problems. We tried to minimize these selection bias by allowing all people with MG referred to RCFM to be enrolled in the study and giving them the alternative to fill out the questionnaire on paper, but we cannot rule out that those with more resources and higher health literacy were overrepresented in the study as the education level of the participants was high compared to the general Danish population (Table 1) [63]. Nevertheless, our sample represents people of different gender, age, years with MG, and number of symptoms.

Our participants had three weeks to fill out the questionnaire. Prolonging the window of data collection has not been associated with increased response rates [64,65]. Currently, there is no specified value for what constitutes an adequate response rate [66]. On average, a reasonable response rate of an online survey is 44% within education-related fields [67], and the response rate for this current study was 56.6%.

Through a process of patient and partner involvement to target items and domains to adults with MG in Denmark, we adapted a questionnaire which was subsequently pilot tested on adults with MG. Unfortunately, some items in the questionnaire had been combined, for example the memory/concentration item, and it was therefore difficult to interpret these results. The adapted questionnaire helped extract a holistic, nuanced and coherent picture of challenges and rehabilitation needs among adults with MG, from a person-centered perspective. No other validated MG-instruments were found applicable for that [68]. A recent article on expert consensus recommendations for improving and standardizing the assessment of patients with generalized MG emphasizes the need for a holistic approach that goes beyond the disease itself, recognizing the broad impact of MG [68].

As discussed, attention should be paid to generalizability as our sample may represent a sample with a more severe disease course compared to the 'general' MG-population who are not referred to RCFM [4]. Furthermore, comparisons of our results with other data from available studies were hampered by our use of an adapted questionnaire to investigate challenges and rehabilitation needs in adults with MG, providing different insights into everyday life challenges and rehabilitation needs among people with MG. Nevertheless, we believe that our results to some degree can be generalizable to other neuromuscular disorders, as such conditions impact on various aspect of everyday life causing challenging and, in some cases, rehabilitation needs for the people affected. The assessment questionnaire covered a broad spectrum of domains, which may also be applied to other diseases to help healthcare professionals unfold the focus areas for rehabilitation. This cross-sectional study did not provide information on causality of the challenges and rehabilitation needs experienced by the participants which could be relevant to investigate in future studies.

Conclusion

MG significantly impacts on everyday functioning and activities. Disease-related challenges and rehabilitations needs manifested differently across genders; women experienced more challenges and rehabilitations needs than men which may be ascribed to a combination of biological, psychological, and social factors. MG led to psychological and cognitive symptoms like mental fatigue, feelings of frustration, and concerns, and unmet psychological rehabilitation needs especially in women, participants from 40 years old and up and participants who had lived with MG for more than five years. A profound difference was found between the number of challenges and rehabilitation needs reported across all domains. By investigating, understanding, and addressing the unique challenges and rehabilitation needs experienced across gender, lifespan, and years with MG, healthcare professionals can target more equitable and supportive initiatives. This will empower adults with MG to navigate and cope with their disease-related challenges with resilience and dignity, enhancing their well-being and quality of life.

Acknowledgements

The authors gratefully thank all the people with MG who participated in this study. We also thank Annette Faber Mahoney for proofreading the article and the patient organization the Danish Foundation for Neuromuscular Diseases for their financial support. The founder was not involved in this study.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by Muskelsvindfonden, Denmark.

ORCID

Charlotte Handberg http://orcid.org/0000-0002-1378-2449
Ulla Werlauff http://orcid.org/0000-0002-5294-2046

References

[1] Pedersen EG, Hallas J, Hansen K, et al. Late-onset myasthenia not on the increase: a nationwide register study in Denmark, 1996-2009. Eur J Neurol. 2013;20(2):309–314. doi:10.1111/j.1468-1331.2012.03850.x.

[2] Rousseff RT. Diagnosis of Myasthenia Gravis. J Clin Med. 2021;10(8):1736. doi:10.3390/jcm10081736.

[3] Hehir MK, Silvestri NJ. Generalized Myasthenia Gravis: classification, Clinical Presentation, Natural History, and Epidemiology. Neurol Clin. 2018;36(2):253–260. doi:10.1016/j.ncl.2018.01.002.

[4] Andersen LK, Aadahl M, Vissing J. Fatigue, physical activity and associated factors in 779 patients with myasthenia gravis. Neuromuscul Disord. 2021;31(8):716–725. doi:10.1016/j.nmd.2021.05.007.

[5] Gilhus NE, Tzartos S, Evoli A, et al. Myasthenia gravis. Nat Rev Dis Primers. 2019;5(1):30–30. doi:10.1038/s41572-019-0079-y.

[6] Ruiter AM, Verschuuren J, Tannemaat MR. Fatigue in patients with myasthenia gravis. A systematic review of the literature. Neuromuscul Disord. 2020;30(8):631–639. doi:10.1016/j.nmd.2020.06.010.

[7] Beghi E, Antozzi C, Batocchi AP, et al. Prognosis of myasthenia gravis: a multicenter follow-up study of 844 patients. J Neurol Sci. 1991;106(2):213–220. doi:10.1016/0022-510x(91)90260-e.

[8] Keesey JC. Clinical evaluation and management of myasthenia gravis. Muscle Nerve. 2004;29(4):484–505. doi:10.1002/mus.20030.

[9] Bubuioc AM, Kudebayeva A, Turuspekova S, et al. The epidemiology of myasthenia gravis. J Med Life. 2021;14(1):7–16. doi:10.25122/jml-2020-0145.

[10] Mahic M, Bozorg AM, DeCourcy JJ, et al. Physician-Reported Perspectives on Myasthenia Gravis in the United States: a Real-World Survey. Neurol Ther. 2022;11(4):1535–1551. doi:10.1007/s40120-022-00383-3.

[11] Frost A, Svendsen ML, Rahbek J, et al. Labour market participation and sick leave among patients diagnosed with myasthenia gravis in Denmark 1997-2011: a Danish nationwide cohort study. BMC Neurol. 2016;16(1):224. doi:10.1186/s12883-016-0757-2.

[12] Gilhus NE, Verschuuren J, Hovland SIB, et al. Myasthenia gravis: do not forget the patient perspective. Neuromuscul Disord. 2021;31(12):1287–1295.

[13] Attarian S. New treatment strategies in Myasthenia gravis. Rev Neurol (Paris). 2024;180(9):971–981. doi:10.1016/j.neurol.2024.09.006.

[14] Bozovic I, Ilic Zivojinovic J, Peric S, et al. Long-term outcome in patients with myasthenia gravis: one decade longitudinal study. J Neurol. 2022;269(4):2039–2045. doi:10.1007/s00415-021-10759-4.

[15] Aggelina A, Karampli E, Mavrovounis G, et al. Evaluation of the Quality of Life of Patients with Myasthenia Gravis in Greece. J Pers Med. 2023;13:1–12.

[16] Andersen LK, Jakobsson AS, Revsbech KL, et al. Causes of symptom dissatisfaction in patients with generalized myasthenia gravis. J Neurol. 2022;269(6):3086–3093. doi:10.1007/s00415-021-10902-1.

[17] Hartford CA, Sherman SA, Karantzoulis S, et al. Experience of Daily Life with Generalized Myasthenia Gravis: a Qualitative Investigation and Assessment of Instrument Content Validity. Neurol Ther. 2023;12(6):2079–2099. doi:10.1007/s40120-023-00544-y.

[18] Devlin I, Williams KL, Shrubsole K. Fragmented care and missed opportunities: the experiences of adults with myasthenia gravis in accessing and receiving allied health care in Australia. Disabil Rehabil. 2023;45(15):2488–2496. doi:10.1080/09638288.2022.2094481.

[19] World Health Organization W. The international classification of functioning, disability, and health: ICF; 2001. [cited 2023 18. January]. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

[20] Maribo T, Ibsen C, Thuesen J, et al. Hvad er rehabilitering? ed. Hvidbog om rehabilitering. Vol. 1. Aarhus: rehabiliteringsforum Danmark. 2022;21–30.

[21] Gilhus NE, Andersen H, Andersen LK, et al. Generalized myasthenia gravis with acetylcholine receptor antibodies: a guidance for treatment. Eur J Neurol. 2024;31(5):e16229.

[22] World Health Organization. Rehabilitation. 2024. https://www.who.int/news-room/fact-sheets/detail/rehabilitation.

[23] Andersen H, Gaist D, Hansen K, et al. Guidelines for myasthenia treatment in Denmark 2017. [Retningslinjer for myastenibehandlingen i Danmark 2017]. Selskab DN, editor. 2017. p. 43. https://rcfm.dk/wp-content/uploads/sites/2/2024/04/MYASTENI-RETNINGSLINJER-2017.pdf#:~:text=Organiseringen%20af%20diagnostik%20og%20behandling%20af%20patienter%20med,%C3%A6ndret%20med%20Sundhedsstyrelsens%20nye%20specialevejledning%20for%20neurologi%20%282017%29

[24] Narayanaswami P, Sanders DB, Wolfe G, et al. International consensus guidance for management of Myasthenia Gravis: 2020 update. Neurology. 2021;96(3):114–122. doi:10.1212/WNL.0000000000011124.

[25] Corrado B, Giardulli B, Costa M. Evidence-Based practice in rehabilitation of Myasthenia Gravis. A systematic review of the literature. J Funct Morphol Kinesiol. 2020;5(4):1–13. doi:10.3390/jfmk5040071.

[26] Berrih-Aknin S, Claeys KG, Law N, et al. Patient-reportedimpact of myasthenia gravis in the real world: protocol for a digital observational study (MyRealWorld MG). BMJ Open. 2021;11(7):e048198. doi:10.1136/bmjopen-2020-048198.

[27] Gelinas D, Parvin-Nejad S, Phillips G, et al. The humanistic burden of myasthenia gravis: a systematic literature review. J Neurol Sci. 2022;437:120268. doi:10.1016/j.jns.2022.120268.

[28] Maribo T, Ibsen C, Thuesen J, et al. Hvidbog om rehabilitering. Vol. 1. Aarhus: Rehabiliteringsforum Danmark; 2022.

[29] Maggi L, Bernasconi P, D'Amico A, et al. Italian recommendations for diagnosis and management of congenital myasthenic syndromes. Neurol Sci. 2019;40(3):457–468. doi:10.1007/s10072-018-3682-x.

[30] Handberg C, Werlauff U. Cross-sectorial collaboration on policy-driven rehabilitation care models for persons with neuromuscular diseases: reflections and behavior of community-based health professionals. BMC Health Serv Res. 2022;22(1):1168. doi:10.1186/s12913-022-08557-3.

[31] The National Rehabilitation Center for Neuromuscular Diseases [RehabiliteringsCenter for Muskelsvind]. The National Rehabilitation Center for Neuromuscular Diseases [RehabiliteringsCenter for Muskelsvind].; 2020. https://rcfm.dk/

[32] WMA. A Declaration of Helsinki – Ethical principles for medical research involving human subjects; 2018. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

[33] ICMJE. 2021 International committee of medical journal editors.

[34] Heidari S, Babor TF, De Castro P, et al. Sex and gender equity in research: rationale for the SAGER guidelines and recommended use. Res Integr Peer Rev. 2016;1(1):2. doi:10.1186/s41073-016-0007-6.

[35] Ramboll. SurveyXact - a shortcut to knowledge; 2023. https://rambollxact.com/surveyxact.

[36] Regionmidtjylland. Vurder dine behov -lige nu; 2013. https://www.rm.dk/api/NewESDHBlock/DownloadFile?agendaPath=%5C%5CRMAPPS0221.onerm.dk%5Ccms01-ext%5CESDH%20Data%5CRM_Internet%5CDagsordener%5CRegionsraadet%202013%5C24-04-2013%5CAaben_dagsorden&appendixId=45320

[37] IBM. IBM SPSS Statistics; 2023. 29.0.1.0. https://www.ibm.com/products/spss-statistics.

[38] [Landspatientregistret] TDNRfPwMG. Diagnosis [Diagnoser]. 2024 https://www.esundhed.dk/Emner/Operationer-og-diagnoser/Landspatientregisteret-Avanceret-udtraek#tabpanel5951E82D767242D28F4FBF4B3DD7CD48

[39] Thomsen JLS, Vinge L, Harbo T, et al. Gender differences in clinical outcomes in myasthenia gravis: a prospective cohort study. Muscle Nerve. 2021;64(5):538–544. doi:10.1002/mus.27331.

[40] Lehnerer S, Jacobi J, Schilling R, et al. Burden of disease in myasthenia gravis: taking the patient's perspective. J Neurol. 2022;269(6):3050–3063. doi:10.1007/s00415-021-10891-1.

[41] Cutter G, Xin H, Aban I, et al. Cross-sectional analysis of the Myasthenia Gravis Patient Registry: disability and treatment. Muscle Nerve. 2019;60(6):707–715. doi:10.1002/mus.26695.

[42] Lee I, Kaminski HJ, Xin H, et al. Gender and quality of life in myasthenia gravis patients from the myasthenia gravis foundation of America registry. Muscle Nerve. 2018;58(1):90–98. doi:10.1002/mus.26104.

[43] Boldingh MI, Dekker L, Maniaol AH, et al. An up-date on health-related quality of life in myasthenia gravis -results from population based cohorts. Health Qual Life Outcomes. 2015;13(1):115. doi:10.1186/s12955-015-0298-1.

[44] Grob D, Brunner N, Namba T, et al. Lifetime course of myasthenia gravis. Muscle Nerve. 2008;37(2):141–149. doi:10.1002/mus.20950.

[45] Samulowitz A, Gremyr I, Eriksson E, et al. "Brave Men" and "Emotional Women": a theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. Pain Res Manag. 2018;2018:6358624–6358614. doi:10.1155/2018/6358624.

[46] Hjortbak BR, Hjortbak BR. Behovsvurdering : grundlag og praksis. 1. udgave. 1. oplag. ed. Kbh: Munksgaard. 2017.

[47] Widerström-Noga E, Finlayson ML. Aging with a disability: physical impairment, pain, and fatigue. Phys Med Rehabil Clin N Am. 2010;21(2):321–337. doi:10.1016/j.pmr.2009.12.010.

[48] Møller LA, Martinsen B, Werlauff U, et al. Ageing with neuromuscular disease: getting lost in transitions. Disabil Rehabil. 2022;44(16):4311–4318. doi:10.1080/09638288.2021.1902577.

[49] Xu L, Wang X, Cui Y, et al. Illness perception characteristics and influencing factors in adult patients with myasthenia gravis in China. Brain Behav. 2022;12:e2451.

[50] Berrih-Aknin S, Palace J, Meisel A, et al. Patient-reported impact of myasthenia gravis in the real world: findings from a digital observational survey-based study (MyRealWorld MG). BMJ Open. 2023;13(5):e068104. doi:10.1136/bmjopen-2022-068104.

[51] Seidler ZE, Dawes AJ, Rice SM, et al. The role of masculinity in men's help-seeking for depression: A systematic review. Clin Psychol Rev. 2016;49:106–118. doi:10.1016/j.cpr.2016.09.002.

[52] Handberg C, Lomborg K, Nielsen CV, et al. Understanding male cancer patients' barriers to participating in cancer rehabilitation. Eur J Cancer Care (Engl). 2015;24(6):801–811. doi:10.1111/ecc.12358.

[53] Estephan EP, Baima JPS, Zambon AA. Myasthenia gravis in clinical practice. Arq Neuropsiquiatr. 2022;80(5 Suppl 1):257–265. doi:10.1590/0004-282X-ANP-2022-S105.

[54] van der Beek KM, Bos I, Middel B, et al. Experienced stigmatization reduced quality of life of patients with a neuromuscular disease: a cross-sectional study. Clin Rehabil. 2013;27(11):1029–1038. doi:10.1177/0269215513487234.

[55] Froehlich L, Hattesohl DB, Cotler J, et al. Causal attributions and perceived stigma for myalgic encephalomyelitis/chronic fatigue syndrome. J Health Psychol. 2022;27(10):2291–2304. doi:10.1177/13591053211027631.

[56] Fernandez-Araque A, Gomez-Castro J, Giaquinta-Aranda A, et al. Mishel's model of uncertainty describing categories and subcategories in fibromyalgia patients, a scoping review. Int J Environ Res Public Health. 2020;17(11):3756. doi:10.3390/ijerph17113756.

[57] Dong D, Chong MK-C, Wu Y, et al. Gender differences in quality of life among patients with myasthenia gravis in China. Health Qual Life Outcomes. 2020;18(1):296. doi:10.1186/s12955-020-01549-z.

[58] Mendoza M, Tran C, Bril V, et al. Patient-acceptable symptom states in myasthenia gravis. Neurology. 2020;95(12):e1617–e1628. doi:10.1212/WNL.0000000000010574.

[59] Johansen R, Espetvedt MN, Lyshol H, et al. Mental distress among young adults - gender differences in the role of social support. BMC Public Health. 2021;21(1):2152. doi:10.1186/s12889-021-12109-5.

[60] Cheng C, Inder K, Chan SW. Coping with multiple chronic conditions: An integrative review. Nurs Health Sci. 2020;22(3):486–497. doi:10.1111/nhs.12695.

[61] Stucki G, Kostanjsek N, Ustün B, et al. ICF-based classification and measurement of functioning. Eur J Phys Rehabil Med. 2008;44(3):315–328.

[62] Leonardi M, Raggi A, Antozzi C, et al. Disability and functional profiles of patients with myasthenia gravis measured with ICF classification. Int J Rehabil Res. 2009;32(2):167–172. doi:10.1097/MRR.0b013e32831e4587.

[63] Universities_Denmark. Notat: Uddannelsesniveauet i Danmark er gennemsnitligt. 2022. https://dkuni.dk/publikationer-og-notater/notat-uddannelsesniveauet-i-danmark-er-gennemsnitligt/

[64] Sammut R, Griscti O, Norman IJ. Strategies to improve response rates to web surveys: A literature review. Int J Nurs Stud. 2021;123:104058. doi:10.1016/j.ijnurstu.2021.104058.

[65] L'Ecuyer KM, Subramaniam DS, Swope C, et al. An Integrative Review of Response Rates in Nursing Research Utilizing Online Surveys. Nurs Res. 2023;72:471–480.

[66] American association for public opinion research. Standard definitions. Final dispositions of case codes and outcome rates for surveys; 2016. https://aapor.org/wp-content/uploads/2022/11/Standard-Definitions20169theditionfinal.pdf

[67] Wu M-J, Zhao K, Fils-Aime F. Response rates of online surveys in published research: A meta-analysis. Comp Hum Behav Rep. 2022;7:100206. doi:10.1016/j.chbr.2022.100206.

[68] Meisel A, Saccà F, Spillane J, et al. Expert consensus recommendations for improving and standardising the assessment of patients with generalised myasthenia gravis. Eur J Neurol. 2024;31(7):e16280. doi:10.1111/ene.16280.