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RESEARCH ARTICLE

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Economic burden of myasthenia gravis in China: a nationwide registry-based study

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ABSTRACT

Background: The long-term treatment of myasthenia gravis (MG) and impaired productivity related to physical decline incur significant economic burdens on affected populations and society. This study aims to evaluate the costs of MG in China from a societal perspective and to identify the cost-driving factors.

Methods: A web-based survey was conducted on 1020 MG patients recruited through a national registry system in China. Respondents reported their socio-demographic and disease-related information and annual expenses related to MG under direct medical and non-medical costs. Indirect costs were estimated among 268 working respondents based on hours of missed work and their annual income. Generalized linear models were used to identify factors associated with different categories of costs.

Results: Among all respondents, the median annual direct medical cost was US$2219.0, with a median of $1860.2 contributed by medical costs and a median of $248.2 by non-medical costs. Higher education, unemployment, hospitalization, use of mechanical ventilation, and use of multiple medications were significant driving factors of direct medical and non-medical costs. Among respondents who are at least part-time employed, the indirect costs were generally minimal. Older age, physical burden of disease, and use of multiple medications were significant predictors of higher income loss.

Conclusion: Population with MG in China reported heavy economic burdens related to medication. Disease severity is a major driving factor of both direct and indirect costs. Targeted policies are needed to alleviate the financial burden of MG on patients and society at large.

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Myasthenia gravis; economic burden; direct and indirect costs; China; disease severity

Introduction

Myasthenia gravis (MG) is a rare autoimmune disease associated with the impairment or failure of neuromuscular junction transmission, which results from autoantibodies that react with specific proteins involved in neuromuscular junction signaling[1,2]. The disease is characterized by weakness of eye muscles, difficulty in swallowing and breathing, and weakness in limbs and other muscles[3]. The incidence rate of MG ranges from 1.7 to 21.3 cases per million person-years globally[4] and is estimated to be 6.8 in China after adjusting for age and sex[5].

Although there is no cure for MG to date, most MG patients can have a good prognosis under long-term treatment, which often involves pharmacological treatment, plasmapheresis, thymectomy, and critical illness management[6]. However, the costs associated with hospitalization and the long-term, complex treatment regimen for MG may be substantial. A systematic review has reported that the use of intravenous immunoglobulin (IVIg), plasmapheresis, mechanical ventilator support, MG crisis, and hospitalization are associated with higher direct medical costs[7]. In addition to the costs related to treatment, studies from Europe have shown that only less than one-third of the MG population are employed[8], and that MG population are more prone to an absence in labor market and long-term sick leave compared to the general population[9]. This suggests that the impaired work productivity due to MG may lead to a significant socio-economic burden on MG individuals and their families.

Most of the existing studies on economic costs associated with MG are from Europe, North America, and Asia, with large variability in cost estimates within and between

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countries[10]. In China, the economic cost of MG has been estimated from a healthcare perspective, and the results showed an increasing trend in the proportion of out-of-pocket expenses for MG, indicating a growing economic burden on Chinese patients over time[7]. However, this approach fails to take into consideration the costs incurred outside of healthcare setting (e.g. those due to caretaking, assistive devices, productivity loss) that can significantly affect the patient and the society. Adopting a societal perspective can, therefore, provide a more comprehensive picture of the economic burden of MG on affected populations and the society as a whole. This study aims to evaluate the economic costs associated with MG in China from a societal perspective and to identify the socio-demographic and disease-related drivers of these costs.

Methods

Study design and data collection

A web-based cross-sectional survey was conducted among individuals with MG between June and July 2022 in China. Beijing Aili Myasthenic Gravis Care Center, the largest national MG patient organization in China, established a registry system for individuals with MG in 2018. This registry is supported by The Rare Disease Real-world Data Lab from the Shenzhen Research Institute of The Chinese University of Hong Kong, medical experts and consultants, and regional patient societies and volunteers. All members are required to submit a proof of diagnosis, which are subsequently verified by the organization for registration. Up to March 2023, more than 7000 individuals with MG voluntarily registered. After pilot testing, a questionnaire was distributed by this organization to its registered patients through social network platform. The questionnaire collected the respondent's information on socio-demographic characteristics (age, sex, education level, employment status, personal and household income, household registration), disease-related characteristics (clinical characteristics, number of medications for MG currently in use, duration of disease, dependence on assistive devices, treatment), annual expenses related to MG, and information about work productivity and activity impairment. Number of medications for MG was evaluated for pyridostigmine, corticosteroids, azathioprine, mycophenolate mofetil, mycophenolic acid, tacrolimus, cyclosporine, cyclophosphamide, and methotrexate. Prior to the start of the online survey, an informed consent form was provided, and the respondent would be directed to the survey only if they agreed to participate and clicked the "next page" button. For patients who were aged under 18 or not able to complete the survey by themselves, primary caregivers of the patients were invited to complete a proxy-version of the survey. A total of 1,020 valid answers were collected, among which 935 were self-reported by the patients and 85 were proxy-reported. Ethical approval of this study was obtained from the Survey and Behavioral Research Ethics Committee of the Chinese University of Hong Kong (approval No. SBRE-21-0260).

Measurements

In addition to the socio-demographic and basic disease-related factors, we evaluated the respondent's physical burden using the MG Activities of Daily Living (MG-ADL), a validated, 8-item instrument that measures MG symptoms, with a higher score indicating more limitations in daily activities[11]. We used a cut-off score of 6 to categorize participants into groups with high (MG-ADL $\geq$ 6) or low disease burden (MG-ADL $<$ 6)[12]. The respondents were asked about the amount of total expenses they spent during the past 12 months (June 2021 to May 2022) on different categories, regardless of the amount claimed from insurance or fundraising.

Direct medical cost was measured by four components: (1) expenses on medication, including prescribed medications and Traditional Chinese Medicine; (2) expenses on outpatient, hospitalization, surgery, and intensive care unit, excluding medication; (3) other medical expenses, such as rehabilitation and physical therapy; and (4) caretaking expenses for formal care.

Direct non-medical cost was measured by three components: (1) traveling expenses related to treatment or follow-up checks, including transportation and accommodation; (2) expenses on assistive devices (e.g. shower chair, mobility aids, orthoses); and (3) other expenses associated with MG, such as nutritional supplements, sanitation products, or disability-related home remodeling/renovations.

Indirect cost was calculated among 268 patients who were employed at least part-time and reported individual income in the self-reported version of the questionnaire, based on the Work Productivity and Activity Impairment Questionnaire: General Health V2.0 (WPAI:GH)[13]. WPAI:GH is a six-item instrument that measures four domains of work productivity and activity impairment: (1) absenteeism: percentage of work time missed due to health problems in the past 7 days (referring to absence from work); (2) presenteeism: percentage of impairment experienced at work due to health problems in the past 7 days (referring to reduced productivity while at work); (3) overall work productivity loss: absenteeism plus presenteeism; and (4) daily activity impairment: percentage of impairment in daily activities due to health problems in the past 7 days. Scores for each domain were presented in percentages, with a higher percentage indicating greater impairment in work productivity and activity. We calculated the percentage of missed work based on the number of missed working hours in the past 7 days, assuming a 40-hour work week. Estimated annual indirect costs were calculated for the 268 patients by multiplying the percentage of missed work by the patient's annual income. The costs were presented in US dollars (USD$1 = CNY¥6.85).

Covariates

Covariates considered for analysis included age ($<$18, 18–30, 31–50, $>$50), sex (male, female), household registration (rural, urban), education attainment (below high school, high school or occupational education, university or above), monthly household income ($<$¥5,000, ¥5,000–10,000, $>$¥10,000; equivalent to $<$ US$729.93, $729.93–1459.85, $>$$1459.85), medical

insurance (no, yes), dependence on assistive devices (none, mild, moderate/substantial), MG-ADL (<6, ≥6), disease duration (in years), history of thymectomy (no, yes), relapse and hospitalization within the past six months (no, yes), number of medications for treating MG (0, 1–2, 3 or more), use of mechanical ventilation, IVIg, plasmapheresis (no, yes), and whether undergoing rehabilitation at the time of survey (no, yes).

Statistical analysis

Basic characteristics, direct medical cost, direct non-medical cost, and indirect cost were described. Continuous background variables were reported as mean ± standard deviation (SD) and categorical variables were reported in number and percentage. Given the non-normal distribution, costs were reported as median and interquartile range (IQR). We used generalized linear models (GLMs) with Tweedie distribution and log link function, which allows for inclusion of zero values in health care cost analysis[14] and has shown favorable performance in evaluating medical expenditure in China[15]. Univariable and multivariable models were conducted to identify socio-demographic and disease-related factors associated with direct medical cost, direct non-medical cost, and indirect cost of MG. The multivariable model included variables that were significant at $p < 0.10$ level in univariable analysis. For interpretation purposes, we reported the exponential coefficient estimates from GLMs, referred to as cost ratios, along with their 95% confidence intervals (CIs).

To test the robustness of our findings, we conducted sensitivity analyses by: (1) including an alternative indicator of physical burden, defined by MG-ADL score ≥6 with ≥50% of the score derived from non-ocular symptoms; (2) including employment status considering the involvement of MG (categorized into employed, unemployed due to MG, unemployed due to other reasons). The analyses were conducted using Stata 16.0 (Stata Corp LP, College Station, TX, USA) and R software (Version 4.0.0).

Results

Background characteristics

The socio-demographic and disease-related characteristics are described in Table 1. A total of 283 (27.8%) males and 737 (72.3%) females were included in the analysis. The respondents aged between 7 and 86 years, with a mean of 41.7 (SD = 12.5). Nine respondents (0.9%) were pediatric patients and more than half (57.1%) of the sample were aged between 31–50. Approximately two in three respondents (66.8%) were unemployed and less than half (40.6%) reported monthly household income of <¥5,000 (US$729.93). The median annual household income and disposable income were $8759.12 and $3503.65, respectively. The duration of disease ranged between 0–51 years, with an average of 10.7 years (SD = 8.0). Among all participants, 40.0% were considered with high physical burden, and 31.8% had experienced relapse during the 6 months prior to the time of survey. In terms of treatment, 8.9% were undergoing mechanical ventilation, 90.1% were taking at least one medication, 2.2% were using IVIg, and 20.1% were under rehabilitation at the time of survey. The clinical characteristics and medication use are presented in Supplementary Table S1.

Table 1. Descriptive characteristics of participants ($n = 1020$).

Variables	*n* (%)
Sex	
Male	283 (27.8%)
Female	737 (72.3%)
Age	
<18	9 (0.9%)
18–30	162 (15.9%)
31–50	582 (57.1%)
>50	267 (26.2%)
Household registration	
Rural	509 (50.1%)
Urban	508 (50.0%)
Education	
Below high school	392 (38.4%)
High school/occupational education	422 (41.4%)
University or above	206 (20.2%)
Employment at least part-time	
Unemployed	651 (66.8%)
Employed	324 (33.2%)
Monthly household income[a]	
<¥5,000	405 (40.6%)
¥5,000–10,000	405 (40.6%)
>¥10,000	188 (18.8%)
Insurance	
No	394 (38.6%)
Yes	626 (61.4%)
Dependence on assistive devices	
None	532 (52.2%)
Mild	419 (41.1%)
Moderate/substantial	69 (6.8%)
Physical burden	
Low (MG-ADL <6)	612 (60.0%)
High (MG-ADL ≥6)	408 (40.0%)
Duration of disease (years), mean (SD)	10.7 (8.0)
Relapse	
No	697 (68.3%)
Yes	323 (31.7%)
Mechanical ventilation	
No	929 (91.1%)
Yes	91 (8.9%)
Hospitalization	
No	847 (83.0%)
Yes	173 (17.0%)
Thymectomy	
No	609 (59.7%)
Yes	411 (40.3%)
Number of medications[b]	
0	101 (9.9%)
1–2	692 (67.8%)
3+	227 (22.3%)
Intravenous immunoglobulin	
No	998 (97.8%)
Yes	22 (2.2%)
Plasmapheresis	
No	1014 (99.4%)
Yes	6 (0.6%)
Rehabilitation	
No	815 (79.9%)
Yes	205 (20.1%)

Abbreviations. SD, standard deviation; MG-ADL, Myasthenia Gravis Activities of Daily Living.
[a]Equivalent to < US$729.93, $729.93–1459.85, >$1459.85 (USD$1 = CNY¥6.85).
[b]Medications included pyridostigmine, corticosteroids, azathioprine, mycophenolate mofetil, mycophenolic acid, tacrolimus, cyclosporine, cyclophosphamide, and methotrexate.

Table 2. Cost of MG in median (IQR) and range in USD$.

Cost category	Median	Interquartile range	No cost reported *n* (%)	Patients reporting costs	
				Median	Interquartile range
Direct medical cost (n = 1,020)	1860.2	438.0–4379.6	65 (6.4%)	2043.8	671.5–4700.7
Medication	1167.9	292.0–2919.7	69 (6.8%)	1459.9	438.0–2916.1
Outpatient, inpatient, surgical cost excluding medication	0	0–583.9	546 (53.5%)	729.93	145.99–2919.71
Other treatment (e.g. rehabilitation, physical therapy)	0	0–0	811 (79.5%)	291.97	145.99–729.93
Formal care	0	0–0	889 (87.2%)	291.97	145.99–729.93
Direct non-medical cost (n = 1,020)	248.2	0–729.9	260 (25.5%)	438.0	160.6–978.1
Traveling expenses	87.6	0–292.0	329 (32.3%)	219.0	73.0–438.0
Assistive devices	0	0–2.8	761 (74.6%)	116.8	47.9–291.6
Other cost: nutrition supplements, sanitation products, disability-related house renovation/remodeling	0.1	0–292.0	510 (50.0%)	291.6	145.9–729.2
Direct cost total (n = 1,020)	2219.0	656.9–5401.5	53 (5.2%)	2219.7	656.2–5405.8
Indirect cost[a] *(n = 268)*	0.0	0–54.7	200 (74.6%)	1313.9	580.4–2716.1

[a]Indirect cost was estimated by multiplying the percentage of missed work by the patient's annual income.

Costs related to MG

As described in Table 2, among all the 1020 respondents, the median of annual direct medical cost was USD$ 1860.2 (IQR = 438.0–4379.6), presenting about 20% of the median annual household income ($8759.12) and half (53.1%) of the median disposable household income ($3503.65). Specifically, the median of annual medication cost, outpatient/inpatient/surgery cost, other treatment cost, and caretaking cost were $1167.9 (IQR = 292.0–2919.7), $0 (IQR = 0–583.9), $0 (IQR = 0–0), and $0 (IQR = 0–0), respectively. The median of annual direct non-medical cost was $248.2 (IQR = 0–729.9), with the majority contributed by travelling expenses (annual median = $87.6, IQR = 0–292.0). The median annual costs on assistive devices and other relevant costs (e.g. nutritional supplements, sanitation products, disability-related housing renovation) were at $0 (IQR = 0–2.8) and $0.1 (IQR = 0–292.0), respectively. The median of annual total direct costs, including direct medical and non-medical costs, was $2219.0 (IQR = 656.9–5401.5).

Among the patients who reported any cost (i.e. the patients utilizing the corresponding services), the median annual medication cost, outpatient/inpatient/surgery cost, other treatment cost, and caretaking cost were $1459.9 (IQR = 438.0–2916.1), $729.93 (IQR = 145.99–2919.71), $291.97 (IQR = 145.99–729.93), and $291.97 (IQR = 145.99–729.93), respectively. One-third (32.20%) of all patients reported use of Traditional Chinese Medicine, with a median annual cost of $218.98 (IQR = 131.39–291.97). The median of the annual direct non-medical costs was $438.0 (IQR = 160.6–978.1).

Among the 268 respondents with a paid job, the average percentage for absenteeism, presenteeism, and activity impairment due to MG was 6.5% (range = 0–66.7%), 38.7% (range = 0–100%), and 46.8% (range = 0–100%) according to the WPAI:GH scale. Approximately one in four (25.4%) respondents reported missed work during the past week. The median of annual indirect costs calculated based on missed working hours in the past week was $0.0 (IQR = 0–54.7).

Factors associated with direct and indirect costs of MG

Three sets of models were tested to identify factors associated with direct medical, direct non-medical, and indirect costs of MG. In univariable analysis, insurance status, disease duration, relapse, IVIg, and use of plasmapheresis were not significantly associated with any of the three outcomes and were therefore excluded in multivariable models. In multivariable regression (Table 3), we found that those with education of university or above (cost ratio = 3.90, 95% CI = 1.84–8.30), unemployed (cost ratio = 2.44, 95% CI = 1.22–4.76), undergoing mechanical ventilation (cost ratio = 4.58, 95% CI = 2.20–9.53), had been hospitalized during the past 6 months (cost ratio = 3.22, 95% CI = 1.72–6.04), and taking three or more different medications (cost ratio = 3.35, 95% CI = 1.03–10.87) were more likely to report higher direct medical costs. Urban household registration (cost ratio = 1.83, 95% CI = 1.03–3.25), high education attainment (cost ratio = 3.68, 95% CI = 1.78–7.60), unemployment (cost ratio = 2.22, 95% CI = 1.20–4.00), use of mechanical ventilation (cost ratio = 6.08, 95% CI = 3.26–11.32), recent history of hospitalization (cost ratio = 2.97, 95% CI = 1.70–5.20), use of multiple medications (cost ratio = 3.93, 95% CI = 1.34–11.56), and rehabilitation (cost ratio = 2.91, 95% CI = 1.70–4.98) were associated with higher direct non-medical costs. For indirect costs, significantly higher costs were reported by those who were older (cost ratio = 3.23, 95% CI = 1.22–8.56 for age 31–50; cost ratio = 3.54, 95% CI = 1.05–11.92 for age >50, compared to age 18–30), with high physical burden (cost ratio = 5.18, 95% CI = 2.67–10.05), and using multiple medications (cost ratio = 3.47, 95% CI = 1.06–11.41). Sex, monthly household income, dependence on assistive devices, and history of thymectomy did not significantly contribute to any of the cost categories.

The results of the sensitivity analyses (Supplementary Tables S2 and S3) showed that employment status became non-significant after subdividing unemployment into "unemployed due to MG" and "unemployed for other reasons". This suggests that socio-economic background may have a stronger association with economic burden than disease-related job changes. The associations for other contributors remained largely consistent with the main analysis, supporting the robustness of our primary findings. To further explore the underlying drivers of costs, we conducted post-hoc interaction analysis between physical burden and mechanical ventilation and found a significant effect on direct medical ($\beta = -2.40$, $p = 0.001$) and non-medical ($\beta = -2.68$,

Table 3. Multivariable generalized linear models of factors associated with direct medical, direct non-medical, and indirect costs of MG.

Variables	Direct medical cost ($n = 1,020$)	Direct non-medical cost ($n = 1,020$)	Indirect cost ($n = 268$)
Sex	Exponential estimate (Cost ratio) (95% CI)	Exponential estimate (Cost ratio) (95% CI)	Exponential estimate (Cost ratio) (95% CI)
Male	——	NS	——
Female	——	NS	——
Age			
<18		——	——
18–30	——	——	Ref.
31–50	——	——	3.23 (1.22–8.56)*
>50	——	——	3.54 (1.05–11.92)*
Household registration			
Rural	——	Ref.	NS
Urban	——	1.83 (1.03–3.25)*	NS
Education			
Below high school	Ref.	Ref.	——
High school/occupational education	1.45 (0.75–2.82)	1.05 (0.55–2.00)	——
University or above	3.90 (1.84–8.30)***	3.68 (1.78–7.60)***	——
Employment at least part-time			
Employed	Ref.	Ref.	——
Unemployed	2.44 (1.22–4.76)*	2.22 (1.20–4.00)*	——
Monthly household income[a]			
<¥5,000	——	——	NS
¥5,000–10,000	——	——	NS
>¥10,000	——	——	NS
Dependence on assistive devices			
None	NS	NS	NS
Mild	NS	NS	NS
Moderate/substantial	NS	NS	NS
Physical burden			
Low (MG-ADL <6)	——	——	Ref.
High (MG-ADL ≥6)	——	——	5.18 (2.67–10.05)***
Mechanical ventilation			
No	Ref.	Ref.	——
Yes	4.58 (2.20–9.53)***	6.08 (3.26–11.32)***	——
Hospitalization			
No	Ref.	Ref.	——
Yes	3.22 (1.72–6.04)***	2.97 (1.70–5.20)**	——
Thymectomy			
No	NS	NS	——
Yes	NS	NS	——
Number of medications for MG [b]			
0	Ref.	Ref.	Ref.
1–2	1.54 (0.5–4.73)	1.87 (0.67–5.22)	1.27 (0.43–3.73)
3+	3.35 (1.03–10.87)*	3.93 (1.34–11.56)*	3.47 (1.06–11.41)*
Rehabilitation			
No	NS	Ref.	——
Yes	NS	2.91 (1.70–4.98)***	——

*$p < 0.05$; ** $p < 0.01$; *** $p < 0.001$;——, not included in model.
Abbreviations. NS, non-significant; MG-ADL, Myasthenia Gravis Activities of Daily Living.
[a]Equivalent to < US$729.93, $729.93–1459.85, >$1459.85 (USD$1 = CNY¥6.85).
[b] Medications included pyridostigmine, corticosteroids, azathioprine, mycophenolate mofetil, mycophenolic acid, tacrolimus, cyclosporine, cyclophosphamide, and methotrexate.

$p < 0.001$) cost but not indirect cost ($p = 0.97$), after controlling for other factors.

Discussion

This study has provided novel data on economic burden of MG in China from a societal perspective. The median annual direct medical cost was $1860.2, the majority of which derived from medications. This estimate is considerably lower than that reported in the US ($24,990 and $20,190)[16,17] but slightly higher than in Taiwan ($1780)[18]. The median total direct cost (including medical and non-medical costs) was $2219 in China, lower than in Germany ($15,050)[19] but higher than in India ($680)[20] and Bulgaria ($1559)[21]. The observed differences may be attributable to the heterogeneity in management of MG, operation of healthcare systems, as well as the perspective of analysis (healthcare vs. societal) and components of costs measured. For example, the estimate from Taiwan only reflected expenses on inpatient and outpatient services, and it is uncertain whether medication expenses were included in the measurement[18]. When compared to costs of other autoimmune diseases in China, our estimate of annual direct costs of MG ($2219) was comparable to that reported among patients with rheumatoid arthritis (median $2147.61)[22] and with systemic lupus erythematosus (median $2289.52)[23]. In our study, approximately one-third of the participants were employed at least part-time, a proportion comparable to Germany[8]. Among this working subgroup, the median indirect cost due to productivity loss was $0, with a third quartile of $54.7. This estimate is significantly lower than that reported in

Germany ($3550)[19] and India ($80)[20], but relatively comparable to Bulgaria ($0)[21]. While the large gap with Germany can be partially explained by the difference in hourly wage between developed and developing economies, we have found that the overall work impairment in absenteeism (6.5%) is relatively low compared to European countries (15.9%), despite a higher level of presenteeism (38.7% vs 29.9%)[24].

Mechanical ventilation and hospitalization were found to be significant drivers of both direct medical and non-medical cost in this study, consistent with previous findings[10]. Participants with higher education attainment reported higher direct medical and non-medical costs, probably because they are more aware of health management and more likely to seek professional medical care, leading to increased medical costs. Among the working participants, those who were older, with high physical burden, were prone to higher indirect cost. This indicates that disease severity and physical disability may be major contributors to income loss due to impaired productivity. Urban household registration was associated with greater direct non-medical costs, potentially due to higher transportation expenses and easier access to advanced assistive devices and nutritional supplements. Concurrent use of three or more medications predicted higher costs of all categories, suggesting that the complex regimen may not only increase medical expenses but also negatively impact productivity due to the burden of medication management. The significant interaction effect between physical burden and mechanical ventilation indicates that the direct costs associated with high physical burden tend to decrease when mechanical ventilation is utilized. This is likely because mechanical ventilation shifts the primary cost drivers from individual variations in physical burden to standardized, resource-intensive treatments.

In our study, approximately one-third of MG patients reported using Traditional Chinese Medicine, with a median annual cost of $218.98 (IQR = $131.39–$291.97). These expenses were reflected in the total medication costs, providing a comprehensive estimate of the financial burden associated with both modern and traditional treatments. In China, Traditional Chinese Medicine remains an integral part of the healthcare system, often reflecting cultural preferences and public attitudes toward health management. However, the adoption of such treatment often depends on personal beliefs, financial capacity, and the availability of medical insurance coverage.

This study is the first to evaluate the economic burden of MG in China with a large sample size and from a societal perspective, contributing to the existing knowledge of MG's global impact. The findings underscore an imperative need for targeted policies to alleviate the economic burden of MG, for example, increased insurance and security policies for MG treatment, particularly for medications. As rare disease patients often seek cross-region healthcare in China, providing subsidies for traveling may help relieve the financial burden on patients and reduce barriers to healthcare access. Moreover, the indirect cost estimation revealed that MG's progressive physical decline significantly affects the patients' ability to work which tends to marginalize them in the job market, calling for more attention and support for this rare disease population.

There are several limitations to this study. First, due to the lack of a sampling frame of MG patients in China, the participants were recruited through a registry system of a national patient organization with a non-probability sampling approach, which may affect the representativeness of the sample. Second, the data were self-reported by patients and may involve reporting bias. Third, the cross-sectional design has precluded establishment of the causal relationship between examined factors and costs. Third, the indirect cost was estimated among working participants with MG based on their individual income during the past year. The small sample size of indirect cost analysis ($n = 267$) may limit the statistical power and affect the generalizability of results. Despite the low proportion of participants (25.4%) reporting missed work over the past week, the indirect cost is likely underestimated because the reported annual income may already involve certain income loss due to absenteeism. The societal costs of MG are expected to be substantially higher when further including productivity loss due to presenteeism at work, income loss of patients who had completely lost their ability to work, and income loss of patients' informal caregivers due to caretaking responsibilities. Lastly, the patient-reported nature of our study limits the assessment of economic burden to the patient's perception. While we asked for total expenses incurred regardless of reimbursement or subsidies from various sources, other costs, such as those covered by the government, healthcare providers, or external organizations, as well as non-medical costs like caregiving expenses that may not have been fully perceived by the patient, were not captured in our study. In addition, our study did not evaluate the specific impact of health insurance plans and imbursement rates, which vary considerably in China, particularly for rare diseases and Traditional Chinese Medicine. These factors are closely related to out-of-pocket expenses, which directly affect household finances and individual healthcare-seeking behaviors. Research focusing on out-of-pocket expenditures could explore metrics like catastrophic health expenses and impoverishment due to illness to provide deeper insights into the financial burden borne by MG patients and their families. Future study may also consider adopting a more comprehensive approach to estimate the costs of MG from the perspectives of patient, caregivers, health providers, and broader societal stakeholders.

Conclusions

The economic burden of MG in China, as perceived by patients, is largely contributed by direct costs on medications. Indirect costs among working individuals with MG are relatively low compared to other settings. Disease severity is a consistent, significant driver for both direct and indirect costs of MG. The findings call for targeted policies to alleviate the economic burden of MG and increased support for patients who suffer from income loss due to physical decline.

Transparency

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Declaration of financial/other relationships

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. Peer reviewers on this manuscript have no relevant financial or other relationships to disclose.

Author contributions

JY: conceptualization, data interpretation, formal analysis, writing – original draft. HZ: conceptualization, data interpretation, writing – original draft. SC: methodology, writing – review and editing. DD: supervision, investigation, writing – review and editing.

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Data availability statement

All data generated or analyzed during this study are included in this article. Further enquiries can be directed to the corresponding author.

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