



Original Research

Exploring impairments and allied health professional utilisation in people with myasthenia gravis: A cross-sectional study

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ABSTRACT

This study aimed to explore how people with myasthenia gravis experience impairments in vision, dizziness, hearing, and fatigue, and how these relate to balance confidence, community participation, and health-related quality of life. Additionally, this study investigated the utilisation and perception of the allied health role in managing these impairments in the Australian context. Visual and hearing impairments, along with fatigue, were found to be correlated with health-related quality of life and community participation to varying degrees, while visual impairment and dizziness were correlated with balance confidence. Perception and utilisation of allied health professionals was variable; common barriers to better utilisation included participant perception of clinicians having poor knowledge around myasthenia gravis, previous poor experiences with clinicians, uncertainty about the clinicians' role, and lack of awareness that symptoms were associated with myasthenia gravis. Further research exploring clinicians' knowledge of myasthenia gravis is recommended, along with education for people with the disease about symptoms associated and how to appropriately access care.

1. Introduction

Myasthenia gravis (MG) is a rare chronic autoimmune disorder caused by the presence of antibodies directed at components of the neuromuscular membrane [1]. Consequently, the primary clinical impairment is weakness of skeletal muscles [2,3]. The annual estimated prevalence of MG is 150 to 250 cases per 1 million people worldwide, typically occurring in women under 40 and men over 60 [4], with older people usually experiencing more severe symptoms [5].

The disease presents in the form of ocular or generalised muscle weakness [6]. Ocular symptoms are the most common initial presentation, which progress to other muscles in 80% of cases [1]. Muscle weakness involving the eyes produces symptoms of blurred vision and variable diplopia and ptosis [7], and potentially leads to the experience of dizziness [8]. Generalised muscle weakness of the limbs and body can contribute to impaired balance and walking, lead to a sense of

disequilibrium and result in an overall decline in functional abilities and an increased risk of falls [9–11]. Additionally, the risk of functional decline following a fall [12] may be increased for people with MG as they tend to be generally sedentary, physically inactive [13] and experience muscle weakness and fatigue [2,3].

Less obvious symptoms of MG include effort-induced fatigue, difficulties with breathing, chewing, swallowing, and speech [6]. Disease progression of MG can also be associated with clinically evident hearing dysfunction from irreversible cochlear damage caused by autoantibody influence on acetylcholine receptors in outer hair cells [14,15]. This hearing dysfunction may go unnoticed in people with MG [16]. The impairments affecting symptoms of vision [17], dizziness [8], hearing [18], balance [19], fatigue [20], and weakness [21] may be more impactful in people with MG over 60, given these impairments tend to worsen with increasing age in the general population [4].

Due to the multiple impairments that people with MG experience,

Abbreviations: MG, Myasthenia Gravis; HRQoL, health related quality of life; AHP, allied health professionals; GP, General Practitioner.

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there tends to be a notable reduction in health-related quality of life (HRQoL) in this population [22–24]. Consequently, in addition to medical management, coordinated multidisciplinary rehabilitation is recommended in this population [2]. Allied health professionals (AHP), such as optometrists, audiologists, and physiotherapists, form a key part of the multidisciplinary team, as they are keenly placed to identify and manage symptoms and functional impacts which may affect people with MG directly because of the disease and/or due to comorbidities. For example, with the provision of prism lenses for intractable double vision by optometrists [7], hearing aids to improve hearing for socialisation and communication by audiologists [16], or exercises to improve strength, balance, fatigue, and independence by physiotherapists [25–28].

Despite the importance of a multidisciplinary model of care, there is limited information available to identify uptake of allied health involvement in the management of MG symptoms and no current practice guidelines for treatment by AHP for people with MG. An Australian survey on MG in 2013 identified that 88% of participants experienced symptoms associated with MG in the prior year, with most of those (92%) attending appointments with neurologists and specialists while only 19% reported accessing AHP in the same year [29]. Similarly, referral to AHP mirrors the low uptake with a recent Australian study finding that only 26% of people with MG are referred to a speech pathologist [30]. Given the positive benefits of engagement with AHP for people with MG [7,31–34], and the apparent low referral and attendance rates, further research is needed to investigate why people with MG do or do not choose to access allied health services.

This study aimed to explore symptoms and impairments experienced by people with MG living in Australia related to vision, dizziness, hearing, and fatigue and the correlation to balance confidence, community integration, and HRQoL. A secondary aim was to explore the perception and beliefs of people with MG as to allied health service utilisation and benefit, in the Australian context.

2. Methods

2.1. Design

The study was an online, mixed-methods cross-sectional survey that was constructed and distributed using Qualtrics survey software. Ethical approval was granted by The University of Queensland Health and Behavioural Sciences Human Research Ethics Committee approval number: 2020000677). The survey was designed and reported as per the Checklist for Reporting Results of Internet E-Surveys [35].

2.2. Participants and recruitment

A non-probability purposive sampling strategy was chosen to recruit participants [36]. Recruitment involved advertisements on social media platforms and newsletters through local and national MG associations. The advertisement included a web link to the participant information and consent form, which contained contact details of the research team should prospective participants have any questions. Participants were required to indicate consent prior to entering the survey. Participants were eligible to participate if they were aged 18 years and over, currently living in Australia, had a diagnosis of MG, and had sufficient English skills to participate without requiring a translator. People born in Australia but living overseas at the time of the survey were excluded.

2.3. Survey

The survey included questions designed by the research team and patient-reported outcome measures, and had a mixture of Likert scales, binary and multiple-choice questions, with open-ended comment fields to elicit more detail as required. Development was informed by a broad review of the literature and the study aims. A pilot was undertaken with

3 people: 2 members of the Myasthenia Gravis Association of Queensland and 1 undergraduate allied health student. They provided feedback on the length of the survey and understanding of the questions. Following feedback, minor changes were made to improve the clarity of questions and reduce the survey length. The final survey took approximately 45–60 min to complete and consisted of 103 questions. The survey collected data relating to demographics, clinical history, symptoms, and function. Participants were required to read the participant information sheet attached to the online survey and provide consent in the first survey question and were able to withdraw their consent at any time. The survey was open for participants to respond between June and August 2020 and participants were able to use a bar code or web link to access the survey through the advertisements. Data was de-identified to preserve anonymity. To assist with fatigue, participants were able to complete the survey over multiple sittings. The survey is available in full in [supplementary file 4](#).

The outcomes measured were incorporated to explore symptoms related to vision, dizziness, hearing, fatigue, and the impact of MG on balance confidence, community participation, and HRQoL. The outcomes covered the three main components of the International Classification of Functioning, Disability, and Health [37]. Wherever possible, measures were used that have been validated in people with MG, and when this was not possible, measures validated in other neurological populations were utilised.

Vision symptoms were captured via the Impact of Visual Impairment Scale – 5 (IVIS), a 5-item questionnaire that measures the effect of visual impairment on restrictions of participation [38]. Scores range from 0 to 15, with higher scores indicating a greater impact of visual impairment in daily life. Symptoms of dizziness were captured via the Dizziness Handicap Inventory (DHI), a 25-item questionnaire that measures the degree of impairment an individual experiences with dizziness, on physical, emotional, and functional domains [39]. Scores range from 0 to 100, with higher scores indicating greater perceived disability and lower scores indicating no perceived disability. Scores of 0 to 16 indicate no handicap, 16–34 a mild handicap, 36 to 54 a moderate handicap, and over 54 a severe handicap. Symptoms of hearing were captured via the Hearing Handicap Inventory for Adults (HHIA), a 25-item questionnaire that assesses the impact of hearing dysfunction with emotional and situational subscales [40]. Scores range from 0 to 100, with 0–16 indicating no handicap, 17–42 mild to moderate handicap, and over 43 indicating a significant handicap. Symptoms of fatigue were captured via the Modified Fatigue Impact Scale (MFIS), a 21-item questionnaire used to measure the impact of fatigue in physical, social, and psychosocial domains [41]. A higher score indicates a larger impact of fatigue on everyday life, with a maximum score of 84. Scores higher than 38 can be used to distinguish between fatigued and non-fatigued individuals [42]. Self-reported balance confidence was captured using the Activities-Specific Balance Confidence (ABC) scale, a 16-item questionnaire in which patients rate their balance confidence in performing daily activities [43]. The score ranges from 0 to 100, with 0 representing no confidence and a score of 100 representing complete confidence in performing the activity. Scores can indicate the level of physical functioning; under 50 indicates low level, 50–80 moderate, and over 80 high [44]. Community participation capacity was captured via the Community Integration Questionnaire-Revised (CIQ-R), an 18-item questionnaire that explores the relationship between meaningful participation, with health and wellbeing [45]. It explores 4 subscales: home integration, social integration, productivity, and electronic social networking. The total CIQ-R score ranges from 0 to 35, with higher scores indicating fewer disease impacts on participation. Normative values for healthy adults aged 18–64 have been reported as 22.3 ± 4.7 [46]. Finally, HRQoL was captured via the Myasthenia Gravis–Quality of Life 15, a 15-item scale that measures HRQoL and incorporates physical, social, and psychological components [47,48]. Scores range from 0 to 30, with a higher score indicating lower HRQoL.

To determine allied health engagement of people with MG, questions

designed by the research team collected information on clinical symptoms, referral/attendance to AHP, and experiences with allied health services across optometry, audiology, and physiotherapy. Information obtained about referrals included the referral source, to which allied health services participants were referred, and whether participants attended. The participants were also asked to comment on their awareness and understanding of the AHP roles. A brief description was provided on how optometrists, audiologists, and physiotherapists could assist the participants with symptoms of MG, followed by whether participants would attend an AHP in the future. Participants also had the option to write free-text responses on their perceptions of AHP.

2.4. Data analysis

Survey data was analysed with SPSS v27 (IBM Corporation). Descriptive statistics were examined for participant characteristics, frequency and type of symptoms, and referral and access to allied health services. Data was tested for normality using The Shapiro-Wilk test. Patient Reported Outcome Measures (PROMS) were scored according to published scoring procedures [38–42,44,46]. Correlations were examined using relevant parametric (Pearson’s r) or non-parametric analysis (Spearman’s rank) and categorised as very strong (0.8–1.0), strong (0.6–0.79), moderate (0.4–0.59), or weak (0.2–0.39), with statistical significance set at $p > 0.05$.

Responses to open-ended questions were analysed using content analysis [49]. After reading through responses, the first author (NC) derived codes that were commonly occurring in the responses and captured key meanings, and then further sorted the codes into categories. Another author (KS) cross-checked these categories and discussed them with the first author (NC) until a consensus on the final categories was reached.

3. Results

Participant characteristics can be found in Table 1, symptom prevalence is reported in Table 2 and PROMS are reported in Table 3. A high

Table 1
Participant demographic characteristics.

| Measure | Participants (n = 101) |
|---|------------------------------|
| Age Mean Years (SD) Median (IQ) | 62.1 (16.2) 64.7 (56 – 73.5) |
| Range | 20.6–89.6 |
| Age, Years n (%) | |
| 18–50 | 18 (17.8) |
| 51–60 | 20 (19.8) |
| 61–70 | 31 (30.7) |
| 71–80 | 27 (26.7) |
| 81–90 | 5 (4.9) |
| Gender n (%) | |
| Female | 67 (66.3) |
| Birthplace n (%) | |
| Australia | 81 (80.2) |
| Elsewhere | 20 (19.8) |
| Education level n (%) | |
| Primary School &/or High School | 36 (35.7) |
| Trade | 27 (26.7) |
| University Graduate and/or Postgraduate | 38 (37.6) |
| Age at diagnosis mean years (SD) median (IQ) | 50.9 (17.7) 55 (38.5–64.5) |
| Range | 1–85 |
| Age first experienced MG symptoms Mean Years (SD) Median (IQ) (n = 100) | 46.1 (19.8) 50 (30.5–62.0) |
| Range | 0–80 |
| Form of MG n (%) | |
| Ocular | 12 (11.9) |
| Generalised | 69 (68.3) |
| Unsure | 18 (17.8) |
| Congenital | 2 (2) |

Note: SD = standard deviation; IQ = Interquartile; MG = myasthenia gravis.

Table 2
Frequency of symptoms reported by participants.

| Visual symptoms as a result of MG | Participants (n = 99) |
|--|-------------------------------|
| Weak or droopy eyelids | 88 (89%) |
| Blurry vision | 70 (71%) |
| Double vision | 79 (80%) |
| Reading headaches | 34 (34%) |
| Others | 16 (16%) |
| None | 2 (2%) |
| Hearing symptoms as a result of MG | Participants (n = 101) |
| Reduced hearing/hearing loss | 28 (28%) |
| Tinnitus | 27 (27%) |
| Dizziness/vertigo | 44 (44%) |
| Others | 10 (10%) |
| None | 39 (39%) |
| Sensory/physical symptoms as a result of MG | Participants (n = 82) |
| Muscle weakness | 80 (98%) |
| Muscle fatigue | 74 (90%) |
| General fatigue (n = 101) | 93 (92%) |
| Dizziness | 60 (73%) |
| Balance issues | 59 (72%) |
| Vertigo | 35 (43%) |
| Blurred vision | 48 (59%) |
| Unsteady gait | 60 (73%) |
| Walking difficulties | 68 (83%) |
| None | 1 (1%) |

Note: Multiple answered permitted; MG = myasthenia gravis.

Table 3
Descriptive of patient reported outcome measures.

| Patient-reported outcome measure | Scores |
|---|------------------------------|
| Impact of Visual Impairment Scale-5 (n = 99) | |
| Total Score (Mean (SD) Median (IQ)) | 3.7 (4.5) 3 (0–5) |
| Hearing Handicap Inventory for Adults (n = 101) | |
| Total Score (Mean (SD) Median (IQ)) | 13.0 (22.5) 2 (0–15) |
| Emotional Score | 6.8 (11.7) 0 (0–9) |
| Situation Score | 6.3 (10.9) 0 (0–7) |
| Dizziness Handicap Inventory (n = 80) | |
| Total score (Mean (SD) Median (IQ)) | 38.8 (27.7) 42 (14.5–62) |
| Physical Score | 9.3 (6.9) 10 (4–14) |
| Emotional Score | 11.6 (9.9) 10 (2.5–20) |
| Functional Score | 17.9 (12.9) 19 (6–28) |
| Activities Specific Balance Confidence (n = 81) | |
| Total (Mean (SD) Median (IQ)) | 65.8 (24.5) 67.5 (44.4–84.4) |
| Modified Fatigued Impact Scale (n = 96) | |
| Total Score (Mean (SD) Median (IQ)) | 44.9 (20.6) 48 (31.5–60) |
| Physical Score | 22.9 (9.2) 24.5 (19–29) |
| Cognitive Score | 17.7 (10.5) 19 (10–25) |
| Psychosocial Score | 4.3 (2.4) 4 (4–6) |
| The Community Integration Questionnaire – Revised (CIQ-R) (n = 96) | |
| Total Score (Mean (SD) Median (IQ)) | 20.2 (5.8) 21 (16.5–24) |
| Electronic Social Subscale | 3.8 (1.6) 4 (3–5) |
| Productivity Social Subscale | 2.9 (2.2) 2 (1–5) |
| Home Integration Subscale | 7.1 (2.9) 7 (5–9.5) |
| Social Integration Subscale | 6.4 (2.1) 7 (5–8) |
| Myasthenia Gravis–Quality of Life 15 – Revised (n = 96) | |
| Total Score (Mean (SD) Median (IQ)) | 12.5 (7.8) 12 (6–17) |

Note: SD = standard deviation; IQ = Interquartile.

proportion of participants reported blurry vision (71%), ptosis (89%), and diplopia (80%). The mean score of the visual outcome was low (3.7 ± 4.5), indicating a mild impact of visual impairments on daily life. Nearly three-quarters of participants reported dizziness. A mean score of 38.8 ± 27.7 was recorded for the dizziness handicap outcome with severity ratings indicating that 35% of participants had a severe handicap, 40% had a mild or moderate handicap and 25% had no handicap. Participants reported experiencing hearing dysfunction (28%), with a mean score of the hearing impairment outcome of 13.0 ± 22.5 . Severity ratings showed that 76% of participants had no hearing handicap, 14% had a mild to moderate handicap and 10% of participants had a severe hearing handicap. Most participants reported having experienced muscle weakness (98%), general fatigue (93%), muscle fatigue (90%), and balance dysfunction (72%). The fatigue impact outcome indicated a moderate level of fatigue in over 65% of the cohort (44.9 ± 20.6). Balance confidence was moderately low, with a mean score of 65.8 ± 24.5 . This corresponds to over 25% of participants classified to have a low level of physical functioning, 41% a moderate level, and 33% a high level. The community integration outcome's mean (20.2 ± 5.8) showed slightly lower scores than a healthy aged population (22.3 ± 4.74) [45], with subscales scores following a similar pattern. The mean HRQoL score was 12.5 ± 7.8 , indicating a moderate impact.

All correlations are shown in Table 4. The visual impairment outcomes captured a weak negative correlation with balance confidence ($r = -0.228, p = 0.041$), a moderate positive correlation with HRQoL ($r = 0.41, p < 0.001$), and no correlation with community integration, indicating visual impairment had a negative association with HRQoL and balance confidence. No correlations were captured between dizziness and HRQoL or community integration, however, a strong negative correlation to balance confidence was noted ($r = -0.68, p < 0.001$), indicating the perception of dizziness is associated with lower balance confidence. Hearing impairment noted a weak correlation to HRQoL ($r = 0.24, p = 0.02$), and community integration (CIQ-R Productivity) ($r = -0.25, p = 0.02$), indicating that more severe hearing symptoms were associated with reduced HRQoL and community participation. As with hearing, fatigue was not correlated to balance confidence. Higher fatigue was significantly associated with lower community participation ($r = 0.79, p < 0.001$) and HRQoL ($r = -0.41, p < 0.001$).

Content analysis revealed that nearly a quarter of participants (23.8%) had never been referred to any AHP (Table 5). Over 70% of participants had previously been referred to and attended an optometrist, with the most common referral methods being self and general practitioner (GP) referrals (both 39%). Nearly three-quarters who attended an appointment reported it helpful in managing their visual concerns. Free text responses revealed that participants found receiving assistance with acquiring the correct prescription of glasses ($n = 27$), and education on management strategies for visual symptoms ($n = 4$),

Table 4

Correlations between patient reported outcome measures of vision, dizziness, hearing, and fatigue, with balance confidence, community integration and health related quality of life scores.

| | ABC | CIQ-R | MG-QoL-R |
|------------|----------|----------|----------|
| IVIS | -0.23* | -0.14 | 0.41*** |
| DHI Total | -0.68*** | -0.02 | 0.12 |
| HHIA Total | 0.02 | -0.07 | 0.02* |
| MFIS Total | -0.12 | -0.41*** | 0.79*** |

* $p = 0.05$ to 0.02 ; ** $p = 0.01$ to 0.001 ; *** $p < 0.001$; Spearman's Rho.

Note:

ABC = Activity specific balance confidence.

CIQ-R = The Community Integration Questionnaire – Revised.

MG-QoL-R = myasthenia gravis-quality of life-revised.

IVIS = Impact of Visual Impairment Scale-5.

DHI = Dizziness Handicap Inventory.

HHIA = Hearing Handicap Inventory for Adults.

MFIS = Modified Fatigued Impact Scale.

Table 5

Allied Health referral and attendance rates and perception.

| Participants referred to allied health professional (multiple answers permitted) | Participants |
|---|--------------|
| Optometrist (n = 99) | 72 (73%) |
| Referral Method (n = 72) | |
| Self-referred | 35 (48%) |
| GP referred | 35 (48%) |
| Other | 15 (20%) |
| Audiologist (n = 101) | 78 (77%) |
| Referral Method (n = 22) | |
| Self-referred | 14 (64%) |
| GP referred | 8 (36%) |
| Physiotherapy (n = 81) | 42 (52%) |
| Referral Method (n = 42) | |
| Self-referred | 12 (28%) |
| GP referred | 22 (51%) |
| Other | 9 (21%) |
| Participants that attended an appointment with an allied health professional | |
| Optometrist (n = 99) | 73 (74%) |
| Appointment managed concerns (n = 73) | 54 (74%) |
| Audiologist (n = 101) | 15 (15%) |
| Appointment managed concerns n = 15) | 9 (60%) |
| Physiotherapy (n = 81) | 38 (47%) |
| Appointment managed concerns (n = 38) | 27 (71%) |
| Aware of the role of the allied health professional | |
| Optometry (n = 99) | 79 (80%) |
| Audiology (n = 100) | 31 (31%) |
| Physiotherapy (n = 80) | 56 (70%) |
| Likelihood to attend an appointment in the future | |
| Optometry (n = 19) | |
| Definitely Yes | 9 (47.37%) |
| Probably Yes | 6 (31.58%) |
| Might or might not | 0 |
| Probably not | 4 (21.05%) |
| Definitely not | 0 |
| Audiology (n = 69) | |
| Definitely Yes | 12 (17.4%) |
| Probably Yes | 13 (18.8%) |
| Might or might not | 17 (24.6%) |
| Probably not | 15 (21.7%) |
| Definitely not | 12 (17.4%) |
| Physiotherapy | |
| Definitely Yes | 2 (8.33%) |
| Probably Yes | 4 (16.66%) |
| Might or might not | 9 (37.5%) |
| Probably not | 8 (33.33%) |
| Definitely not | 1 (4.17%) |

Note: GP = general practitioner.

helpful to manage their visual concerns. Participants also identified that optometrists were helpful in referring to other relevant medical or AHP ($n = 15$), with only a small number reporting that optometrists were well versed in MG treatment ($n = 5$).

Similar to optometry, 77% of participants had been referred to an audiologist with self-referral being the most common method of referral at 64% and only 36% being referred from a GP. However <15% of participants reported attending an appointment. Self-referral was the most common method of referral at 64%, with only 36% receiving a referral from a GP (Table 5). Of those who attended an appointment, 60% reported it helped manage their hearing concerns, commonly via identifying the need for hearing devices ($n = 7$). Participants who found their audiology appointment unhelpful ($n = 4$) felt the audiologist was unable to diagnose or treat complex issues ($n = 2$) and could only prescribe hearing devices ($n = 2$).

Only half of the participants had been referred to a physiotherapist (52%), with 51% of this group receiving a referral from a GP and 28% self-referring. Below half had attended an appointment and just under

three-quarters of those who attended reported the consultation was helpful in managing their concerns (Table 5). Participants who were satisfied with their appointment reported that physiotherapists prescribed exercises to increase general strength and balance ($n = 16$), provided advice and education ($n = 6$), or provided management for vestibular symptoms ($n = 4$).

In terms of perception and awareness of how AHP could assist in symptom management, most participants were aware that optometrists (80%) and physiotherapists (70%) could assist them (Table 5). However, only 31% were aware that audiologists could assist them in managing their MG-related hearing concerns, with another 33% of participants unsure of the audiologists' role, and 8 were unaware that hearing difficulties could be related to MG.

After being provided with a role definition, the majority (80%) of participants responded that they would be willing to attend an optometrist appointment if required but were more mixed in their willingness to see an audiologist (35% probably/definitely) or physiotherapist (24% probably/definitely). The most common reasons for high willingness to attend allied health services in the future included the realisation that the practitioner can assist in managing MG symptoms ($n = 3$), already currently receiving treatment ($n = 7$), currently experiencing symptoms that can be managed by the relevant practitioner ($n = 6$), and a newfound understanding of the AHP role ($n = 5$). The most common reasons for participants' unwillingness or neutrality to attend allied health services included the perception of poor practitioner knowledge on MG ($n = 5$), poor previous experiences ($n = 5$) and currently experiencing no symptoms ($n = 26$). For full results from the free text responses see [supplementary files 1–3](#).

4. Discussion

This study explored how people with MG experience impairments in vision, dizziness, hearing, and fatigue, and the correlation of these to balance confidence, community participation, and HRQoL. The perceptions and beliefs of people with MG on AHP service utilisation and benefit were also explored. This is the first study to comprehensively explore the engagement of people with MG with optometrists, audiologists, and physiotherapists, with one recently published study exploring this with speech pathologists [30]. We found that visual and hearing symptoms had a lower incidence than symptoms of dizziness and fatigue, but all were commonly reported. Low balance confidence was a frequent concern with community participation and HRQoL both reduced in this cohort. Despite the high frequency of symptoms experienced by people with MG, engagement with and awareness of relevant AHP was variable.

MG-associated visual symptoms such as blurry vision, ptosis, and diplopia were commonly reported in the present study (70–90% of participants). In contrast, a 2015 Australian study found only 65% of people with MG reported ptosis and diplopia [23]. While the age of participants was similar to our cohort, there was a higher proportion of males in the 2015 study. In the general population, literature shows females reported higher levels of visual impairments than males, which may account for this discrepancy [50–52]. Though the IVIS showed that these visual impairments only had a mild impact on functioning, visual impairment was correlated with lower HRQoL, a finding consistent with the literature in the general population [53,54]. Though the correlation between the impact of visual impairment on HRQoL in people with MG has not been explored comprehensively, Richards et al. did find that the presence of ptosis alone in people with MG is correlated to lower HRQoL and community participation [55]. Contrary to this, our study did not find any correlation between visual impairment and community participation, which could be due to the IVIS covering a more comprehensive evaluation of visual impairment than ptosis alone.

The correlation between visual impairment and dizziness is commonly reported in the literature [56] along with the increased frequency of dizziness in older individuals [57,58]. To our knowledge, this

is the first study to explore the prevalence of dizziness in people with MG. We found 75% of participants reported experiencing dizziness to some degree, which is higher than reported in the general population (23%) [59]. This impairment warrants further investigation, particularly given 35% of those experiencing dizziness in the present study reported scores consistent with severe impact on daily life. Despite this, we found no correlations between dizziness and HRQoL or participation. In similar neurological disorders, the presence of dizziness can substantially impact HRQoL and participation [60,61]. The lack of correlation of our study may be reflective of the measures used, or the structure of the survey, as dizziness was explored towards the end of the survey where there was a considerable reduction in responses likely due to the length of the survey. Those reporting less dizziness reported better balance confidence; reflective of previous literature that dizziness impacts balance confidence [62] and contributes to increased risks of falls in both general [63] and neurological populations [64]. Research into falls rates of people with MG is currently limited and warrants further investigation given the presence of these impairments and previous case reports indicating this may be a concern for this population [65,66].

Hearing dysfunction incidence in our cohort was at a similar level to previous reports on MG [14] and was correlated to a reduced HRQoL. Reported hearing dysfunction was higher in the present study than the general population of Australian adults, at over 25%, compared to 12–15%, respectively [67]. There is a lack of research surrounding the relationship of hearing dysfunction to HRQoL in people with MG, however, the presence of hearing dysfunction has been shown to have moderate to severe impacts on HRQoL in the general population [68–70]. Hearing dysfunction often goes unnoticed by people with MG [31], which could contribute to why the correlation with HRQoL was only weak, and why there was no correlation to community participation.

Our study showed that nearly all of the participants experienced muscle weakness, with global muscle weakness and muscle fatigue reported at over 90%, which is unsurprising as fatiguability of muscle weakness is the key clinical manifestation of MG [71]. Over 90% of our participants reported fatigue, similar to previous studies citing up to 82% [72]. Our study found strong correlations between fatigue and decreased HRQoL and community participation. Previous literature on people with MG supports these findings that high fatigue negatively impacts HRQoL [73–75]. Fatigue in other neurological populations can be a disabling factor in community participation [76,77].

Most participants reported reduced community participation and HRQoL, with participation (CIQ-R) marginally lower than healthy age-matched norms [46]. Our study was the first to investigate community participation using the CIQ-R, but previous research has shown people with MG experience restrictions on community participation and activities of daily living [73,75], with one study finding moderate to severe restrictions of activities of daily living and participation [78]. The present study showed moderate reductions in HRQoL compared to a previous Australian study of people with MG which showed a greater impact on HRQoL in a younger cohort with a higher proportion of females [79]. Some evidence suggests that younger people with MG [47] and women [75] have significantly worse HRQoL than older men, which could account for this difference.

Our study identified 67% of participants experienced a lower level of balance confidence as compared to a previous study with a younger cohort of people with MG who reported a higher level of balance confidence [79], which supports previous literature that balance deteriorates with age [80]. Symptoms explored in our study such as vision [17,81], dizziness [8], hearing [18], and fatigue [20] also are shown to deteriorate with age as found in the present study and previous research [1,2,6]. Considering the trend towards increasing incidence of late-onset (>65 years) MG [82,83], the older adult with MG may be subject to compounded disease and age-related impairments and thus particularly require intervention to optimise outcomes. Optometrists [7,17], audiologists [16,31], and physiotherapists [32–34,84] have established roles

in managing impairments related to age and symptoms experienced by people with MG. Previous research has found allied health intervention can manage symptoms that impact balance confidence, HRQoL, and community participation [7,26,27,34,85], but despite many of our participants experiencing reductions in above, the utilisation of services was variable. Our study indicates that utilisation of AHP may be attributed to poor understanding of AHP role in care, a perceived lack of clinician knowledge about MG, and poor previous experiences with AHP.

Potential underutilisation of allied health services for people with MG can be seen with <16% of participants having attended an appointment with an audiologist, despite 24% experiencing some degree of handicap from hearing-related symptoms. Similar evidence of low engagement with audiology services exists in the general population with Donahue et al., reporting that only 20% of adults with hearing dysfunction seek assistance. A possible contributor to why audiologists seem to lack engagement from both the general hearing-impaired population and in people with MG may be a lack of trust or knowledge of audiologists. Kochkin et al. 2017 found that lack of trust in audiologists impacted the decision in 25% of people to seek help [86]. Many of our participants' associated audiologists primarily as salesmen of hearing aids or thought them to be unhelpful, a key concern cited in the general population [86]. One participant in the present study stated: *'I've heard many negative stories about audiologists, i.e. they get patients to buy expensive aids that they don't find helpful.'* It is also possible the lack of engagement may stem from a low understanding of the audiologists profession, as identified by 30% of our cohort, with one participant stating they *'didn't know they existed'*. Additionally, people with MGs' understanding of the impact of the disease on hearing is likely to be a contributing factor, with hearing deficits often not noticed by people with MG [31] and the general population [87].

Optometry and physiotherapy had higher rates of utilisation than audiologists with nearly 75% having attended an appointment with an optometrist; indicating higher usage of these services than in the general population (25%) [17]. This is likely attributable to the higher prevalence of visual symptoms experienced by people with MG. Physiotherapy utilisation was higher than previous reports [29] with three-quarters of participants having attended an appointment. A previous survey of people with MG reported 45% of participants were receiving treatment from a physiotherapist [29], but this difference may be attributed to the previous study looking at attendance in the last 12 months, whereas our study looked at any point in time.

Despite the higher rates of utilisation of optometry and physiotherapy, many participants perceived AHPs to lack knowledge surrounding MG which left some participants dissatisfied with their care and less willing to attend again. One participant stated, *'They [physiotherapist] didn't understand that the exercises they wanted me to do made my weakness worse.'* Given the low incidence of MG, it is possible some physiotherapists are ill-equipped to manage the disease, however, this has not been investigated to date. It is known that individuals with rare and heterogenous disorders can often face the challenge of health care professionals who know less about the disorder than the individuals themselves [88]. A 2021 study on patient perspective found people with MG may feel disconnected from their health care professionals and a lack of understanding from health care professionals may discourage individuals from seeking care [89]. There is a need to establish if upskilling of AHP, could optimise confidence in seeking these services by people with MG. In contrast to audiology, 70% of participants indicated that they understand the role of physiotherapy in the management of MG symptoms, but only 25% would attend an appointment in the future. Optometry, on the other hand, had similar rates of understanding and willingness to attend in the future. This suggests that it may not solely be the lack of understanding of an AHP role but a combination of elements that influences a person with MG to attend allied health services, which should be explored further.

An additional barrier to appropriate multi-disciplinary care may be

the referral process to AHP. The present study indicated that nearly 75% of participants had been referred to an optometrist, 77% had been referred to an audiologist and only 52% had been referred to a physiotherapist. Referral rates from GPs varied (39%, 36%, and 51% respectively), with many participants indicating that they are self-referred. It must be noted that referrals are not required in Australia to access AHP services, but active engagement in multidisciplinary practice may promote individuals to engage with AHP more and improve awareness of the profession. Previous research on AHP management for people with Parkinson's Disease indicates that the referral process to AHP may be suboptimal, and people with impairments, that can be potentially managed by AHP, are often not being referred [90,91]. Additionally, when referred by a GP, Australian people have subsidised AHP appointments, which could have the potential to improve utilisation, especially for people with a disease with such a wide variety of symptoms. The role and perceptions of GPs were outside of the scope of this study, however, given their imperative role as often first-contact providers in the primary care setting, further research into their role within the multidisciplinary team in managing people with MG is warranted.

The findings of this study should be interpreted with consideration of several limitations. Firstly, the cross-sectional online survey design comes with limitations which may include sampling bias and selection bias. As participants self-selected to complete the survey, it is possible they were more engaged with the topic and more comfortable with the use of technology (younger) [92]. Concurrently, further cohort bias may have been present in reference to population heterogeneity of MG and the high levels of uncertainty of diagnosis reported by participants (18%). Therefore, this study may not be comprehensively reflective of the Australian population with MG. There was a noted drop-off throughout the survey, with fewer participants completing the section of physiotherapy (15%) as this was towards the end of the survey, perhaps representing fatigue. The nature of the survey also does not lend itself to assign causality or relationships thus correlations should be interpreted with this in mind.

As is possible when utilising established PROMs, some question redundancy may also have occurred. Concurrently participants may not have directly been reflecting on the highlighted symptom when providing an answer or responses may have been influenced by other co-morbidity symptoms, such as depression or be reflective of other pathologies. A cross sectional survey design limits controlling for these biases. In an attempt to limit length of the survey and participant engagement fatigue medical history, including surgical management of MG and co-morbidities were not directly captured. Open text answers were offered to participants to express other symptoms and concerns, with only a handful utilized this opportunity. Future studies and surveys should directly capture this information and encompass face to face functional and laboratory-based assessments of symptoms to provide a more encompassing and targeted representation of symptoms experienced by people with MG.

5. Conclusion

MG is a rare chronic autoimmune disorder with various disease manifestations including visual symptoms, fatigue, and balance deficits [6], with emerging evidence on hearing impairments [7] and dizziness. Lack of evidence currently exists around dizziness for people with MG, but our study showed that prevalence is high, and warrants further investigation. Our study highlighted the prevalence of these symptoms including the impacts they have on balance confidence, community participation, and HRQoL. Awareness of the role and utilisation of relevant allied health services was variable in people with MG. One of the strengths of this study was establishing a qualitative groundwork on perspectives of AHP from the lens of Australian people with MG. Highlighted barriers to increased utilisation include lack of knowledge of the role of the health professional, perceived practitioner lack of knowledge of MG, and poor previous experiences. Future research

should further explore people with MGs knowledge of AHP and if education on the role of certain AHP increases utilisation. Investigation into AHP knowledge on disease processes and management, and how GPs perceive their role in the referral process would be beneficial.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: KS has myasthenia gravis and is a member of the Myasthenia Gravis Association of Queensland, a volunteer consumer-led organisation. Authors NC, TA, and KW report no conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jocn.2023.05.012>.

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