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ORIGINAL RESEARCH

What Patients Don't Say and Physicians Don't Ask: A Needs Assessment in Myasthenia Gravis Integrating Patient and Healthcare Professional Perspectives

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ABSTRACT

Introduction: Myasthenia gravis (MG) is a rare, autoimmune neuromuscular disease characterized by unpredictable fluctuating muscle weakness. This unpredictability makes effective patient–healthcare professional (HCP) dialogue essential for optimal diagnosis and management, with communication as a key component of shared decision-making (SDM). We designed a needs assessment to understand the differences between HCP and patient communication needs and perspectives on the impact of MG.

Methods: A mixed-methods approach was utilized, comprising a survey and semi-structured interviews with HCPs and patients with MG. Quantitative data from the survey were extracted and analyzed to understand trends of knowledge, skills, and attitudes toward patient–HCP dialogue and SDM in MG. Interviews were transcribed and analyzed using principles of thematic analysis to identify

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perspectives on the impact of MG and challenges in communication.

Results: Completed survey data were collected from 47 HCPs and 122 patients. There were discrepancies and areas of alignment in the priorities each group placed on knowledge, skills, and attitudes in MG management. Patients valued HCPs' listening skills and knowledge of treatment history, whereas HCPs prioritized knowing what matters to a patient with MG, including providing support to the patient and their family/carer. Both groups agreed on the necessity of a compassionate and informed approach to care. Interviews (10 HCPs; 10 patients) revealed key themes, including the multifaceted way in which symptoms impact patients' lives and challenges patients face while communicating their experiences.

Conclusion: This needs assessment indicated general alignment between patients and HCPs on MG symptoms; however, notable disparities were found in relation to the perceived impact of these symptoms on patients' lives, and communication. While some HCPs expected patients to volunteer information on symptoms and MG-related challenges, patients expected their HCPs to ask. This highlights a need for improved communication strategies, which will foster SDM approaches.

Keywords: Collaborative research; Immersive learning experience; Myasthenia gravis (MG); Needs assessment; Patient engagement; Patient perspective; Patient–physician communication; Shared decision-making (SDM); Behavioral analytics

Key Summary Points

Why carry out this study?

Myasthenia gravis (MG) is a chronic autoimmune neuromuscular disease that causes muscle weakness, leading to significant social, professional, and emotional strain due to the unpredictable fluctuations of symptoms.

The study investigated whether there are gaps in the communication needs of both patients and healthcare professionals (HCPs) that could be limiting patient–HCP dialogue and shared decision-making (SDM) in the management of MG.

To the best of our knowledge, existing needs assessments in MG include either the patients' perspective or the HCPs' perspective; this study uniquely incorporated both to define a learning intervention that aims to increase HCP empathy, enhance patient–HCP communication, and improve SDM practices.

What was learned from the study?

Though HCPs are knowledgeable about MG and its symptoms, there are differences in how patients and HCPs perceive the impact of these symptoms on patients' daily lives; these differences lead to suboptimal patient–HCP communication, experiences and outcomes.

Our findings revealed critical evidence and actionable insights that can directly inform and enhance HCP training, ensuring it promotes more effective communication and collaboration between HCPs and patients with MG. Integrating patient and HCP perspectives of how symptoms impact patients' daily lives may serve as a model to enable more empathetic, personalized care.

INTRODUCTION

Myasthenia gravis (MG) is a rare, chronic, autoimmune neuromuscular disease characterized by damage at the neuromuscular junction and impaired synaptic transmission [1–3]. The condition causes patients to experience fluctuating muscle weakness and fatigue, which impair the ability to carry out activities of daily living [4, 5]. The unpredictability of these fluctuations often makes it difficult for patients to plan daily activities and contributes to emotional, professional, and social strain. Patients can feel frustrated and isolated by their MG [6, 7], and this makes effective and empathetic patient–healthcare professional (HCP) dialogue essential for optimal disease diagnosis and management [7, 8].

Research has demonstrated that, by actively listening and empathizing with their patients, HCPs are in a better position to acknowledge the nuanced ways in which MG affects their lives [7, 8] and to maintain adaptive dialogue [9]. Empathetic communication assists in creating an environment where patients feel encouraged to discuss the full spectrum and impact of their symptoms [7, 10]. Further, inadequate communication can have detrimental effects on early and accurate disease diagnosis. It can lead to misunderstandings that prevent patients from sharing their experiences or expressing concerns. This, in turn, can create long-term challenges in disease management for both patients and HCPs [11]. Effective communication is a key component of shared decision-making (SDM), aligning disease management choices with patients' values and ensuring that decisions are patient-centered and collaborative [12, 13]. Studies have consistently shown that patients who are actively involved in their own care tend to experience better health outcomes and greater satisfaction with their treatment [14–16].

This publication reports Phase 1 of the three-phase ENGAGE educational pilot program. ENGAGE was conducted between July 2022 and December 2023 across Denmark, Germany, the United Kingdom (UK), and the United States of America (USA) and encompassed a needs assessment conducted with HCPs and patients with MG (Phase 1), a virtual reality (VR) educational intervention (Phase 2) and an outcome evaluation (Phase 3). The ENGAGE educational pilot program was designed to explore whether immersive learning using VR is an effective educational tool for neurologists to bridge the sense of disconnect between patients and HCPs. The program aimed to increase HCPs' understanding of the patient experience, thereby improving patient–HCP dialogue and SDM in MG. The design of the VR learning intervention and the outcomes of the ENGAGE program (Phases 2 and 3) will be reported in a separate publication.

This needs assessment aimed to elucidate the commonalities and disparities between patient and HCP perspectives on the impact of MG symptoms on patients' daily lives and how effectively symptoms and their impact are communicated. By uniquely featuring both HCP and patient perspectives, this needs assessment sought to enhance the relevance of educational content and was a crucial step in designing the immersive educational intervention for HCPs involved in the management of patients with MG.

METHODS

Study Design

The three-phase ENGAGE program design is presented in Fig. 1. The purpose of the needs assessment (Phase 1) was two-fold: (1) to gather information on MG symptoms and their impact on patients' daily lives from both patient and HCP perspectives, and (2) to provide benchmark data for the outcome evaluation. The study design was presented at the 9th Congress of the European Academy of Neurology 2023, and the 15th Annual European Continuing Medical Education Forum 2022, demonstrating the framework that guided the program's development [17, 18].

The needs assessment followed a mixed-methods approach consisting of surveys and semi-structured interviews with both HCPs and patients. This pilot was led by a steering committee, which consisted of four patients, some of whom were representatives of patient organizations, and five MG specialist physicians. The survey was distributed via physician and patient members of the steering committee. Semi-structured interviews were carried out with HCPs and patients with MG, all of whom were selected with the help of the steering committee. Target recruitment numbers were 80 HCPs and 80 patients for completion of the survey, and 10 HCPs and 10 patients for participation in the interviews.

Measurements

The survey consisted of two parts; part one comprised six questions, starting with an open-ended question exploring the skills and

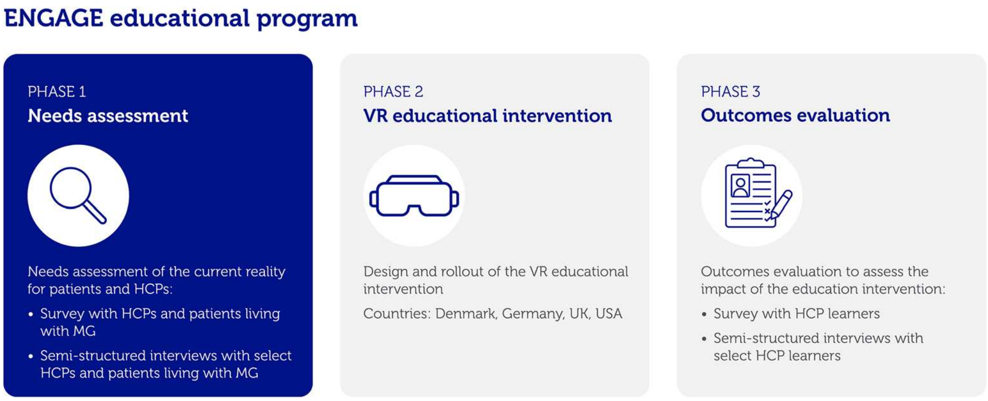

Fig. 1 Study design of ENGAGE. *HCP* healthcare professional, *MG* myasthenia gravis, *UK* United Kingdom, *USA* United States of America, *VR* virtual reality

knowledge necessary for SDM. Participants were presented with a list of 24 pre-defined domains covering essential SDM-related knowledge, skills, and attitudes, and were asked to select all options that they felt were essential to achieve effective SDM. Participants then rated readiness across each of these 24 domains on a 10-point Likert scale from 1 (no ability) to 10 (expert ability). Patients rated their HCP's readiness, while HCPs rated their own readiness (Supplementary Material). This component of the survey was used to inform the content of the immersive learning application and detect differences and commonalities between patients and HCPs. Part two of the survey consisted of questions drawn from the Theoretical Domains Framework (TDF); items were selected from the original Huijg et al. (2014) 79-item questionnaire [19]. The items were tailored to the context of MG and patients' experiences with patient–HCP dialogue and SDM in clinical settings. In total, 31 items representing 14 TDF domains were included. The TDF component of the survey was intended to serve as a baseline data point for the outcome evaluation survey that was distributed among HCPs after participation in the immersive learning experience.

In addition to survey data, qualitative data on MG symptoms, challenges, and barriers to patient–HCP dialogue were collected through interviews with HCPs and patients with MG. The interviews were conducted using a discussion guide tailored to fit the needs of HCPs and patients within the context of MG. The questions in the discussion guide were established based on prior literature research on MG and its symptoms [7, 20], alongside a review of relevant articles published online (e.g., MG forums, blog and web posts with patient stories and patient stories featured on public social media accounts). Overall, with the help of the qualitative interviews, data were collected on: (1) the patient journey living/working with MG; (2) the most common and most troublesome symptoms of MG; (3) the most significant challenges of living with MG; (4) challenges in patient–HCP dialogue; and (5) best practices of engaging with patients and managing MG. The results of this needs assessment were then reviewed by the steering committee members. The insights gained upon completion of the data analysis formed the basis of designing the VR learning intervention (Phase 2), which will be published separately.

Data Analysis

Quantitative and qualitative data for the needs assessment were analyzed separately. Quantitative data from the survey were extracted to understand trends of knowledge, skills, and attitudes toward patient–HCP dialogue and SDM within the context of MG. Quantitative survey data were collected via Qualtrics (www.qualtrics.com), downloaded from the platform and then analyzed using SPSS Statistics 26.0. Data cleaning consisted of removing responses with more than 50% of the data missing. Categorical responses were represented as proportions, with ratings used to capture subjective assessments with greater nuance. The quantitative data results were used to illustrate common trends among HCPs and patients in terms of domains relevant to patient–HCP dialogue (e.g., knowing about the patient and their symptoms, the impact of these symptoms, the patient's ideal treatment outcomes, and worries and concerns, as well as aspired qualities to foster adaptive dialogue).

An artificial intelligence-assisted service (www.otter.ai) was used to transcribe the qualitative interviews. Interview data were then analyzed manually by the researchers using thematic analysis [21]. In our analysis, a hybrid coding approach was employed [22], beginning with a deductive framework that outlined key organizing themes based on theoretical expectations [23]. This approach allowed broad themes to be established, while also enabling an inductive process that helped refine subthemes as new insights emerged from the data [24, 25]. For instance, while many subthemes were identified a *priori,* others, like symptoms resulting in shame for some patients, surfaced as we iterated through the interview material. To simplify presentation of the most significant differences between HCPs and patients, quotes were subsequently reorganized around specific symptom types and key categories.

HCP and patient interviews were initially coded manually by the researchers on a case-by-case basis illustrating occurring themes by extracting indicative quotes for reference. Once this step had been completed, interview data from HCPs and patients were condensed into one coding sheet allowing for a holistic picture of emerging themes and respective quotes. A count of occurrences by subtheme was also performed to allow depiction of the relevance of occurrences to create realistic content for the VR experience that resonated with both stakeholder groups alike.

Ethical Consideration

Institutional Review Board approval for the overall ENGAGE program, including this needs assessment, was granted by the University of Warwick, UK (Ethical Application Reference: HSSREC 41/22-23). The needs assessment was carried out in accordance with the principles of the Declaration of Helsinki. Surveys were designed in accordance with both the Data Protection Act 2018 and the General Data Protection Regulation. Informed consent was captured from the participants prior to their participation in the interview, and survey data were captured anonymously, password protected, and stored on a secure server. Interviews were conducted following consent from participants. Primary data were only available to essential members of the research team at LLH Concepts unless explicit consent was received from the respective participant. Participants consented to the publication of their insights.

RESULTS

What Patients Don't Say, and Physicians Don't Ask

In total, 55 HCPs and 133 patients with MG agreed to participate in the survey, of whom 47 HCPs and 122 patients provided responses. Respondents were from Denmark, Germany, the UK, and the USA. Among the HCPs who responded and completed the demographic section of the survey ($N = 47$), 59.6% ($n = 28$) were neurologists or neuromuscular specialists and 10.6% ($n = 5$) were nurses, including specialist nurses. Other HCP respondents included physiotherapists (2.1%; $n = 1$), alternative practitioners (10.6%; $n = 5$) and 'Other' (17.0%; $n = 8$). Responses from two HCPs had more than 50% of their data missing and were excluded from part one; 71 patients completed all required sections and were included.

Analysis of the survey data from part one exploring HCP and patient perceptions of the impact of various MG symptoms on patients' daily lives revealed that there were significant discrepancies as well as areas of strong alignment in the priorities each group placed on certain knowledge, skills, and attitudes in the management of MG (Fig. 2). The most notable discrepancies were that patients placed a much higher value on ability of the HCP to listen to them, have knowledge of their medical and treatment history, and engage them in discussions about their preferences and personal knowledge of the illness. On the other hand, HCPs prioritized knowing what matters to a person living with MG, providing support to the patient and their family/carer, offering suggestions for future and family planning, and asking what might interfere with treatment. The strong alignment on patience, sharing treatment information, understanding the impact of MG, and empathy showed that both parties agree on the necessity of a compassionate and informed approach to care.

The comparison of HCPs' self-assessments with patient ratings revealed both disparities and alignment in their perceptions of knowledge, skills, and attitudes (Fig. 3). Differences were particularly apparent in areas where HCPs underestimated their performance, such as knowledge of the patient's treatment history and appreciating the patient's medical history. HCPs rated themselves highest in showing empathy and being a good listener, reflecting confidence in their interpersonal skills. Notably, HCPs and patients were closely aligned in areas such as appreciating how patients feel about their illness and treatment, having a good understanding of how the illness impacts a patient's life, and sharing information on treatment options and outcomes.

Key Symptoms and Challenges That Characterize Patient Experience in MG

A total of 20 semi-structured interviews were carried out (10 HCPs and 10 patients with MG). The qualitative data from these

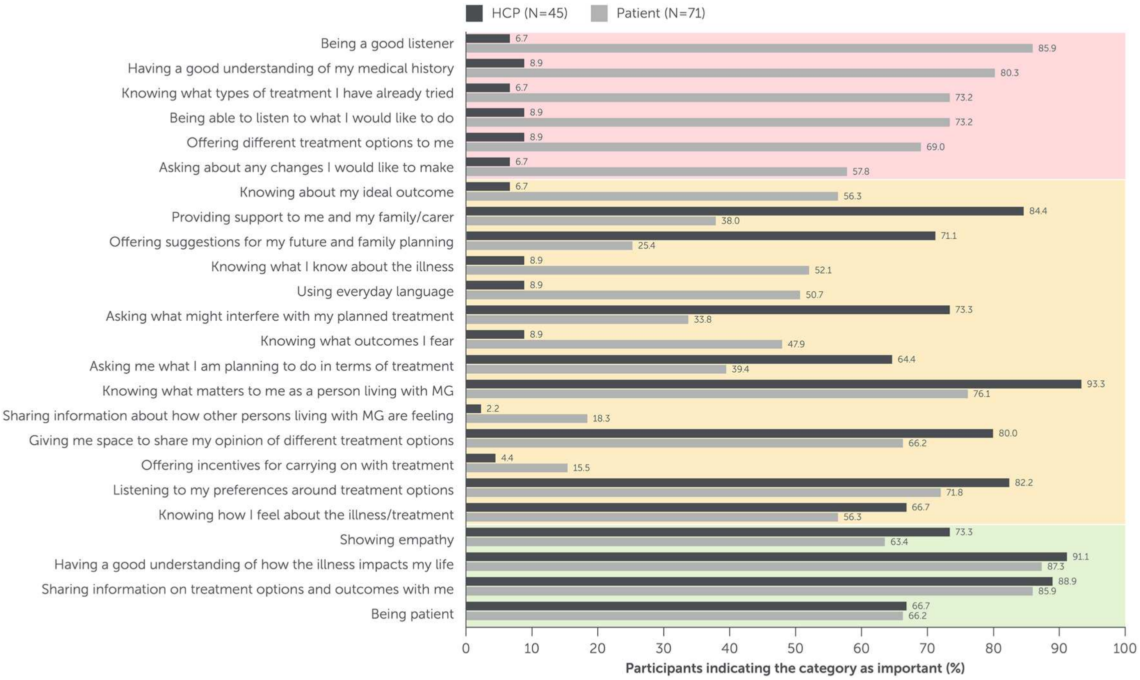

Fig. 2 Survey data comparison (patient versus HCP)—importance of knowledge, skills, and attitudes. The reported categories individually represent types of knowledge, skills or attitudes. Categories are ordered from least aligned to most aligned between HCPs and patients; difference > 50% (*red*), difference ≥ 10%–50% (*yellow*), difference < 10% (*green*). *HCP* healthcare professional, *MG* myasthenia gravis

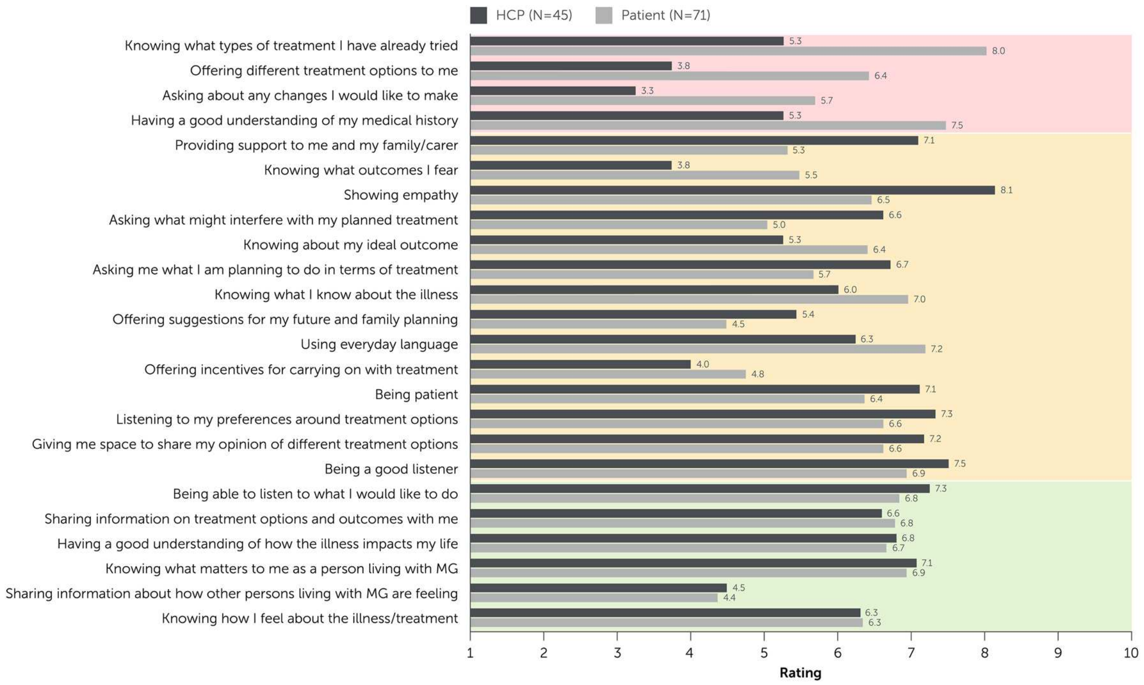

Fig. 3 Survey data comparison (patient versus HCP)—rating of HCP readiness*. The reported categories individually represent types of knowledge, skills or attitudes. Categories are ordered from least aligned to most aligned between HCPs and patients; difference > 2.0 (*red*), difference ≥ 0.5–2.0 (*yellow*), difference < 0.5 (*green*). *Readiness was defined as the subjective evaluation of an HCP's preparedness and confidence in their knowledge, skills, and attitudes. *HCP* healthcare professional, *MG* myasthenia gravis

interviews revealed significant complexities in patient–HCP interactions in MG. Key themes that emerged included the variability and multifaceted way in which symptoms impact patients' lives, the challenges patients face in fully communicating their experiences, and the vital role of specialist HCPs, including specialist nurses, physiotherapists, and psychologists, in bridging these gaps, particularly in the areas of mental health and emotional support. There was strong alignment between HCPs and patients in recognizing the importance of understanding how MG affects patients' lives.

MG Symptoms and Challenges—The HCP Perspective

A full juxtaposition of HCP and patient perspectives on MG symptoms and challenges is presented in Table 1. HCPs noted specific symptoms that need to be addressed in a patient consultation, covering the most common symptoms of MG: ocular, bulbar, respiratory, and muscle fatigability, particularly in the limbs. HCPs stated that patients consistently mentioned fatigue as a prevalent and troublesome symptom of MG. As a result, HCPs highlighted the need to differentiate between fatigue and muscle fatigability. Many HCPs emphasized the risk of hospitalization as a particular concern when there is a risk of myasthenic crisis.

HCPs reported depression as a frequent comorbidity in patients with MG, reflecting the psychological impact of the disease. However, HCPs may lack expertise in dealing with such comorbidities, which may require collaboration with clinical psychologists, psychiatrists or HCPs in other specialties. Additionally, many HCPs reported challenges supporting patients diagnosed at a younger age. Due to the chronic nature of the disease, these patients need more help accepting their diagnosis and incorporating the disease into their daily routines than those diagnosed later in life.

Table 1 Juxtaposition of MG symptoms and challenges from HCP and patient perspectives

Aspect	Perspective		Supporting quote
Ocular symptoms	HCP	HCPs highlight ptosis (drooping eyelid), diplopia (double vision) and other visual impairments as common concerns in patients with MG	*“Patients could present with double vision […], many of them simply have blurred vision. Patients describe this in such a variety of ways; some say that they must make an exaggerated effort to focus their vision on something, which is exhausting, or they feel a certain pressure on the eye.”*
	Patient	Patients often report on their symptoms in conjunction with how these symptoms add complications to their daily lives (e.g., how symptoms affect their appearance and confidence in social settings)	*“I didn’t want to complain more about the suffering that seemed to relate only to my aesthetic. […] But at the same time […] it’s a symptom that affects also my work because, of course, when I had to go to my shift I had to talk to people”* *"Then I also had double vision and then I couldn’t do the work any longer […] I saw the rows of teeth double.”*
Muscle fatigability	HCP	Muscle weakness, especially in the limbs and bulbar muscles, is a significant focus for HCPs, as it can impact mobility, independence and daily function	*“[…] the problem with fatigue is that it’s also used in myasthenia to refer to a very specific sign in which weakness worsens with exercise, and it’s often termed fatigable weakness. So, patients hear us talk, ‘you’ve experienced chronic fatigue’, [but] to try to understand that symptom is really difficult.”*
	Patient	Patients experience progressive muscle weakness in their limbs, arms and other areas, which restricts their ability to walk, move and complete daily tasks independently	*“[…] I could only walk with walking sticks. [Now] I am also dependent on a wheelchair, and I am practically unable to walk any longer. [I] was getting continuously worse […] so there is the weakness of the arms, difficulty speaking, my lung volume got really bad also.”* *“I love to cut my husband’s hair. And just that was becoming impossible.”*

Table 1 continued

Aspect	Perspective		Supporting quote
Bulbar symptoms	HCP	HCPs are particularly concerned about dysphagia (difficulty swallowing) and dysarthria (speech issues), as they significantly impair a patient’s ability to eat and communicate	*“[...] within the first year or so, they can develop, slurring of speech and difficulty in swallowing. [...] once they have passed that acute stage [...] patients will mainly complain of the swallowing and speech problems as and when they develop relapses.”* *“I would say the more serious symptoms. [...] the ones that I get most concerned about are swallowing troubles and breathing troubles, because that’s what’s going to land people in the hospital.”*
	Patient	Patients find swallowing and speech difficulties very frustrating, impacting their ability to engage in conversations and enjoy meals with others	*“[...] sometimes like, at nighttime, I can wake myself up because of stopped breathing and swallowing. Like I... I choke on my own saliva and stuff like even lying down at night. And that’s quite horrible when that happens. And bending over can really affect my breathing, with my diaphragm not fully working.”*
Fatigue	HCP	Fatigue is one of the most challenging symptoms for HCPs to differentiate, as it can either be a result of muscle weakness or psychological factors, and it requires careful assessment	*“So, one of the first things patients usually flag is that they are exhausted/fatigued, they are always completely drained. This is something we describe as ’fatigue’ and this is something we have to differentiate from exhaustion that stems from muscle weakness.”*
	Patient	Patients emphasize how fatigue affects their daily life and social activities, causing exhaustion after even minimal exertion, which reduces their quality of life	*"[...] So the one thing that’s a real handicap is that I need a lot of sleep and I get less out of my day [...] I simply can’t do some things. Like for example some people my age go out in the evenings, but for me that’s either not possible anymore or I can start the next day only in the afternoon then.”*

Table 1 continued

Aspect	Perspective		Supporting quote
Respiratory issues	HCP	HCPs express major concern over respiratory issues, as they can lead to hospitalization or the need for mechanical respiration in severe cases	“*Even the controlled patients when they have stress, surgical or pregnancy, being in labor that sort of things they are at risk of being ventilated.*”
	Patient	Patients fear respiratory complications, noting the decline in lung function and the necessity of assistance with breathing	“*[I] was getting continuously worse [...] so there is the weakness of the arms, difficulty speaking, my lung volume got really bad also now in hospital [sic], swallowing, I am often choking. I once had a really bad choking fit which weakened me even more.*”
Mental health	HCP	HCPs acknowledge that depression and anxiety are prevalent comorbidities in patients with MG, adding an extra layer of complexity to care, but they often feel unequipped to manage these psychological aspects	[**Relating to one HCP’s patient**]: “*One of my patients [...] his double vision lasted for a bit longer and he became suicidal, because he cycles about 150 miles a week and he held a very high, top managerial job, a young chap. And double vision was completely upsetting his life, because he couldn’t cycle.*”
	Patient	Patients may not directly express concerns about depression or mental health challenges, however the emotional toll of MG becomes evident in how they describe the impact of the disease and its symptoms (e.g., limiting their ability to work, minimized opportunities for a fulfilling social life)	“*I was employed by a large international law firm [...] and I was actually about to become the first female partner for that particular office. And then [...] I realized I’m gonna have to resign, I can’t keep going. [...] that was devastating. And it also felt I’ve worked so hard to get to it, and it all came crashing down.*”

Table 1 continued

Aspect	Perspective		Supporting quote
Age/gender-related challenges	HCP	HCPs highlight that younger patients often have a harder time accepting their diagnosis due to concerns about treatment side effects, such as weight gain from steroids or reproductive health issues related to immunosuppressants	"*Age and sex are clearly relevant. So, for example, a female patient should be considering reproductive history and also reproductive plans, that's going to turn out to be really important in that group. What medications do they… can they take? Are they able to take given the contraindications and so on?*"
	Patient	Younger patients often resist treatments due to fears of side effects (e.g., weight gain, acne), adding another challenge to coping with the disease itself. For younger women, the illness is often reported as affecting them in different ways, as it may interfere with their plans to have children, and symptoms can worsen during their menstrual cycles	"*[E]specially in the first day before my period and during the period I have a very bad worsening of symptoms, but just for the days.*" "*[F]or example they mentioned about me being a young woman and flagged that pregnancy might become a topic one day.*"
Daily living and independence	HCP	HCPs aim to prevent MG crises but recognize that even with treatment, the disease can severely limit a patient's ability to live independently, affecting their ability to work and engage in daily activities	[**Relating to one HCP's patient**]: "*So due to [symptoms] they are also at higher risk of having a fall, they cannot drive anymore, but even as a pedestrian or cyclists they are not fully able any longer, they can't read anymore, they can't work and are constantly depending on help.*"
	Patient	Patients often report a loss of independence, with some needing to reduce work hours or rely on others for assistance, which they find difficult to accept	"*I moved back in with my parents, which is a very surreal situation to […] being that child again, if you like, no matter what you just revert to somehow your childhood self in some ways, when you live with your parents again, but I needed a lot of help.*"

Table 1 continued

Aspect	Perspective		Supporting quote
Communication and trust	HCP	HCPs express concern over communication issues, as some patients omit critical information due to stress or mistrust, leading to incomplete symptom reporting and a more challenging diagnosis and treatment process	*“I think we as doctors have an idea of what information we want to get out of a patient for every visit. […] and I am very tempted to say ’Tell me this, tell me this, tell me this’ […] But what I have learned to do is to just have people talk […] And then it’s better for the relationship because patients feel heard rather than me just checking a list.”* *“If you ask them directly, they will also say ’Yes I have difficulty going down the stairs so I try to stay most of the time downstairs’ […] So you need to ask ’Are you back to your normal life? Is this what you want? Are you happy with how things are?’ and often if there is a husband or a wife they will say ’No I think he doesn’t really help out in the house and when he comes home from work, he is always tired.’”*
	Patient	Some patients feel dismissed or not heard by their physicians, leading to frustration and a sense that their individual needs are not being addressed	*“…because I was looking at my medical history. I had a lot of other symptoms. They were like screaming myasthenia gravis, and she, she knew about it, but she doesn’t miss so I thought OK, maybe it’s not? […]”* *“[…] [I]t didn’t seem to me he had any interest to look at a patient as an individual, I think he followed a bit of a cookie-cutter approach, and he was simply not willing to look at an individual patient and take time to understand what is this person’s specific situation.”* "[…] a major issue was communication. I simply had the feeling that this physician didn’t understand what I was telling him about my condition. […] that was a situation where I thought I’m just not in good hands there.”

Table 1 continued

Aspect	Perspective		Supporting quote
Treatment and side effects	HCP	HCPs are aware of the toll that side effects, such as weight gain and increased fatigue from treatments like steroids, have on patients, and they strive to guide patients through these challenges as best they can	*"[Patients] don't want to go on steroids, because they don't want to put on weight and they don't want to have acne [...] and they don't want to go on immunosuppressive therapy because they are interested in their reproductive health [...] so it's a real challenge for them to accept the disease and then to accept the side effects."*
	Patient	Patients feel the need for clearer communication about how treatments will affect them, expressing concerns over side effects and the time it takes for medications to work effectively. Many patients feel overwhelmed by the uncertainty of how long it will take for treatments to show results, or whether they will be effective at all	*"I think I need to have the doctor take that time to tell me OK, what is actually going to happen? And tell me how I am supposed to take the medicine and which kind of side effects they see the most."* *"The other thing that I tell people is with MG you need to be patient, because some of the treatments don't work overnight. However, you also need to be assertive, and if something isn't working, ask for another option."*
Uncertainty and fluctuations in symptoms	HCP	HCPs find it difficult to track the progression of MG due to the unpredictable and fluctuating nature of the symptoms, making it challenging to monitor patients' responses to treatment consistently	*"A lot of questions, a lot of uncertainty, especially when it concerns younger patients, because it affects so many areas of their lives, their social life, their working life, also communication with employers."*
	Patient	Patients experience unpredictability in their symptoms, causing significant stress as they cannot plan their daily activities or anticipate how they will feel from one day to the next	*"So for about six, seven weeks, I would go every Friday to this ophthalmology clinic [...]. And they would do these tests. And they would always show different results. So what they got was that it was fluctuating."*

Table 1 continued

Aspect	Perspective		Supporting quote
Coaching and emotional support	HCP	Some HCPs acknowledge that they may lack the skills needed to provide adequate emotional support to patients, recognizing that treating MG requires more than just managing physical symptoms—it involves helping patients navigate complex emotions	*"The thing that I personally struggle with is probably the mental health element [...] obviously I've had a bit of training, but I'm not a clinical psychologist."*
	Patient	Patients frequently express the need for more emotional and psychological support from their healthcare providers, especially in terms of managing side effects and coming to terms with their diagnosis	*"What I would find useful is to be given a plan, for example to be told "OK listen, we will keep going with this until then and either it will starting working by then, but if not we will do this and that." This would give you a bit of a perspective, because I find it really hard to being presented with this void of "Let's wait and see" because I find that too unspecific."* *"I think I need to have the doctor take that time to tell me OK, what is actually going to happen? And tell me how I am supposed to take the medicine [...]? Which kind of side effects are the side effects that they see the most?"*

HCP healthcare professional, *MG* myasthenia gravis

HCPs were aware that a comprehensive appreciation of the symptoms within the context of patients' daily lives is necessary, but they often lacked the time or skills to address these aspects. Accurately recording complete information about symptoms was sometimes difficult. While not explicitly queried, stress, shame, lack of trust and insufficient consultation time were mentioned in HCP interviews as factors that may explain why listening to patients and fully understanding their medical history can be challenging. Keeping abreast of a patient's MG journey also proved challenging. Inconsistencies in collecting data about patients' well-being and their response to treatment may lead to unnoticed declines in health, emphasizing the need for improved communication between patients and HCPs. Several HCPs mentioned that utilizing tools such as symptom monitoring devices or apps that send patients prompts to monitor and report their symptoms could help address this problem. In overcoming these multifaceted challenges, HCPs play a pivotal role in enhancing the overall care and well-being of patients.

MG Symptoms and Challenges—The Patient Perspective

In their interviews, patients reported a range of known MG symptoms, including dysphagia, dysarthria, ocular symptoms, and muscle weakness (Table 1). Patients who reported respiratory issues were concerned that these symptoms would reoccur or worsen in future. Fatigue and the need for increased rest were also prevalent among those interviewed. The most challenging aspect of the condition as communicated by patients was the impact of muscle weakness on their independent daily living, including participation in social and leisure activities. Additionally, patients reported concerns about the impact of MG on their work and ability to sustain financial independence. This included worries about decreased productivity, mobility issues impacting their commute and whether employers would be understanding of their illness. Many found themselves forced to reduce working hours or cease working altogether.

The struggle to maintain a normal life post-diagnosis is a common experience among patients. Notably, symptoms such as ptosis and facial drooping have an aesthetic impact, raising concerns about others' perceptions. While comorbidities were not directly discussed, some patients alluded to the broader implications of living with a chronic illness, including its effects on mental health and overall well-being, emphasizing the strain it puts on planning and engaging in various activities. Furthermore, side effects from medication complicated the pursuit of hobbies.

Establishing effective communication with HCPs emerged as another prominent hurdle. Some patients recounted experiences of unhelpful interactions; for example, sometimes HCPs appeared disinterested in listening to symptoms and other times challenged or misinterpreted reported symptoms. Some patients failed to mention issues like ptosis, assuming it was 'only' cosmetic or expecting the HCP would ask if it mattered. Additionally, some patients, like one who felt sad about no longer being able to run marathons, hesitated to share their true feelings, believing they should be content with the treatment's results. This led to missed opportunities for adjustments to disease management, as HCPs assumed the patients were satisfied and did not inquire further—only discovering these needs by chance. Although both groups mentioned HCP–patient communication as an important aspect of patient care, different points were made. Patients shared mixed reports on experiences with their HCPs, with some HCPs being a very positive force in their care and others leaving the patients feeling unheard. HCPs noted the challenges that can arise in HCP–patient communication and the fact that trust, the ability of patients to communicate their symptoms and needs, and HCPs' skills to ask the right questions are all important for SDM.

Enhancing the HCP's empathy and appreciation of MG was seen as a potential remedy to improve accurate reporting of symptoms by patients. The prolonged and sometimes life-threatening symptoms endured before receiving an MG diagnosis contribute to the patients' struggles. While acknowledging the rarity of MG, patients expressed concerns about the delayed referral to specialty HCPs. The lengthy diagnostic process underscores the need for expedited access to specialized care. A significant source of concern arose from the potential side effects of medications used to manage MG. Patients often grapple with the dual burden of coping with the physical symptoms of the disease, while simultaneously navigating the adverse effects of their prescribed medications.

An additional consideration in disease management is patients' apprehension about side effects, including weight gain from steroid use. Patients emphasized the need for better assistance in planning treatment, including information on how long it might take for medication to take effect, while at the same time receiving reassurance on how to best navigate side effects.

Differences in how Patients and HCPs Report on Symptoms and Challenges

Patients and HCPs were generally aligned on the symptoms prevalent in MG. However, patients focused more on the impact these symptoms have on their daily lives, including their ability to work, maintain independence, and participate in social activities, than did HCPs (Table 1). Additionally, patients expressed concerns about the aesthetic aspects (e.g., concerns about what others may think). In contrast, HCPs prioritized symptom monitoring based on clinical parameters to manage the risk of hospitalization and to prevent patients from deteriorating to a myasthenic crisis. This difference in focus explains the varying priorities of patients and HCPs when it comes to managing symptoms and challenges. Key challenges for HCPs included distinguishing between muscle fatigability and fatigue, addressing comorbidities such as depression, and the uncertainty surrounding symptom fluctuations.

While patients were keen on finding the best treatment to improve their condition, they were also concerned about medication side effects such as weight gain and increased fatigue. Additionally, patients struggled with the uncertainty of how long it will take for medications to work and whether they will be effective at all. HCPs were aware of patients' worries about side effects and often found themselves needing to coach and support patients through their treatment journey, with some HCPs feeling inadequately skilled to provide this level of support. Due to the uncertainty of MG, its chronic nature, and the resulting impact on quality of life and well-being, younger people in particular require careful monitoring. Effective communication with HCPs and trust issues remain key challenges for patients.

DISCUSSION

Rare autoimmune diseases like MG require lifelong management [1], with collaboration between patients and HCPs needed to minimize the disease's impact on patients' lives. Our approach, which aimed to provide a greater understanding of HCP and patient communication needs in the management of MG, was novel, integrating both HCP and patient perspectives and critically comparing their views to obtain a more accurate understanding of MG symptoms' impact on patients' lives. This research indicated that patients and HCPs are generally aligned on the most challenging symptoms of MG; however, assessments of these symptoms and their severity can vary significantly. HCPs often focus on clinical indicators, rather than patients' personal experiences and the subtle ways in which these symptoms affect patients' daily lives.

Patients prioritize maintaining an independent and fulfilling life, striving to continue their professional activities and hobbies despite their disease. Symptoms that patients feel may seem minor to some HCPs can significantly impact a patient's quality of life (e.g., ptosis). Hence, HCPs should take extra time to thoroughly explore the full impact of symptoms on patients, creating a safe environment for patients to express themselves openly and honestly. Our data suggest that, while HCPs feel confident in their interpersonal skills, there is a gap in how they perceive their knowledge and information-sharing abilities compared with patients' impressions. The expectation that patients will communicate what matters to them may result in important questions not being asked by HCPs. The nature of questions asked can have a strong influence on the HCP's perception of the disease impact and thus how it is managed [7]. Equally, HCPs seemed to overestimate their listening skills compared with patients' perceptions, suggesting that a greater awareness of the importance of listening to patients is required; patients may avoid voicing issues if they feel that the HCP is not interested. HCPs noted the challenges that can arise in patient–HCP communication and highlighted trust, the ability of patients to communicate their symptoms and needs, and the skill of the HCP to ask the right questions as important for SDM and patient care. This research reinforces that there is an ongoing need for patient and HCP education to improve communication about how patients' symptoms impact their daily lives and goals, and the perception of what classes as successful SDM. Patients shared reports on the quality of their care, and HCPs confirmed that an unmet need remains for patients living with MG. This research also illustrates that there is a need for consensus among HCPs on the overall care of patients with MG to comprehensively improve outcomes for all patients and to elevate the standard of care in MG.

This needs assessment adopted a patient-centric approach, by engaging both patients and HCPs, building on insights from previous phenomenological studies [7, 26, 27]. HCPs provided their responses from a broad perspective based on the MG population and subpopulations that they care for, and patients reported on their individual and personal perspectives. By integrating the voice of patients as well as of HCPs, who were the target learners in the ENGAGE pilot program, this needs assessment went beyond traditional educational design practice, which typically assesses only the learner's perspective. This deep understanding of patient and HCP needs in MG allowed the VR experience to be designed in a way that truly reflected the experiences of patients and addressed the educational needs of HCPs, including those identified by patients.

Limitations of this needs assessment have been identified. Participating patients and HCPs were identified by the steering committee. To recruit patients, the committee distributed invitations to members of their respective patient organizations. HCPs from participating hospitals who were involved in the ENGAGE educational program were invited to participate. While this ensured a level of expertise and engagement, it may have introduced selection and inclusion bias. When considering the implications of this needs assessment, it is important to reflect on the participant numbers. Although significant efforts were made to maximize response rates, target HCP response rates (80 HCPs) were not met. To avoid potential bias and low response rates, future studies could employ broader recruitment strategies, such as random sampling or open calls for participation. Further, although the study was conducted in four countries, it was only conducted in English, which may impact its generalizability.

Outlook and Future Research

This study highlighted a significant disconnect between patients with MG and HCPs regarding the disease's impact on patients' daily lives, communication challenges, and the effectiveness of SDM. Actively involving patients in the development of educational interventions bridges this gap, fostering better understanding and alignment between patient needs and HCP perspectives. For instance, the operationalization of Patient Advisory Councils, as described by Nielssen et al. [28], demonstrates how structured patient engagement can improve healthcare delivery by aligning interventions with patient priorities, while offering practical lessons for sustaining such initiatives. Additionally, Ferra et al. [29] emphasized the success of participatory advisory boards in mental health research, highlighting their value in shaping research agendas and ensuring patient-centered outcomes.

Other approaches to enhance patient–HCP communication, such as innovative telemedicine services, could supplement subjective perceptions with measurable, objective parameters, thereby providing HCPs with a more comprehensive overview of patients' symptoms and response to treatment [30].

CONCLUSIONS

To the authors' knowledge, this is the first HCP and patient co-led, co-authored needs assessment that examines the alignment between HCP and patient perspectives on the impact of key symptoms of MG on patients' daily lives, patient–HCP communication challenges, and SDM in MG. This study revealed that informed and compassionate care is essential in managing MG and directly impacts patient outcomes. For example, understanding how symptoms affect patients' daily lives builds trust and improves treatment adherence. Without this, patients may feel misunderstood, compromising their well-being and the effectiveness of care. We hope that it will enhance the recognition and appreciation of the impact of MG and inspire future approaches to HCP educational interventions, SDM, and patient outcomes.

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Declarations

Conflict of Interest. Cornelia Reyes Acosta has nothing to disclose. At the time of the study, she was a Consultant for LLH Concepts GbR. Since manuscript development, she further holds a position in the Digital Health & Applied Tech Assessment research division at the Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, UK. Ivo Vlaev has received consulting fees, research or institutional support and educational grants from AtomicPR, Barclays Bank, Boehringer Ingelheim, Ernst & Young, Kindred Agency, MC&T, McDonald's, Ogilvy, Pfizer, Prime Global Medical Communications, Swiss Re Ltd. and UCB. He has received speaker fees from Teva UK Limited. Alexis Rodriguez has nothing to disclose. Allison Foss is part of the argenx Leadership Council. Ashwin Pinto has received funding for consultancy on scientific or educational advisory boards for argenx, Terumo BCT and UCB. Channa Hewamadduma has received funding for consultancy on scientific or educational advisory boards for argenx, Biogen, Lupin, Roche and UCB, and has received an investigator-led research grant from UCB. His study activities were supported by a Sheffield NIHR BRC UK centre grant. He is a Trustee of the myasthenia gravis patient organization Myaware. John Vissing has been a Consultant on advisory boards for Amicus Therapeutics, Biogen, Edgewise Therapeutics, Fulcrum Therapeutics, Genethon, Horizon Therapeutics (now Amgen), Lupin, ML Biopharma, Novartis, Regeneron Pharmaceuticals, Roche, Sanofi Genzyme (now Sanofi), Sarepta Therapeutics and UCB. He has received research and travel support and/or speaker honoraria from Alexion Pharmaceuticals, argenx, Biogen, Edgewise Therapeutics, Fulcrum Therapeutics, Lupin, Sanofi Genzyme (now Sanofi) and UCB. He is a Principal Investigator in clinical trials for Alexion Pharmaceuticals, argenx, Atamyo Therapeutics, Genethon, Horizon Therapeutics (now Amgen), Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine), ML Biopharma, Novartis, Regeneron Pharmaceuticals, Roche, Sanofi Genzyme (now Sanofi) and UCB. Nicholas J. Silvestri is a Consultant/Adviser for Alexion Pharmaceuticals, Amgen, Annexon Biosciences, argenx, Immunovant, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine) and UCB; he is a Speaker for Alexion Pharmaceuticals, argenx, Takeda Pharmaceuticals and UCB. Sophie Lehnerer has received speaker or consultancy honoraria or financial research support (paid to her institution) from Alexion, argenx, Biogen, Hormosan, HUMA, Johnson & Johnson, Merck, Roche and UCB. Marc De Backer, Natasha Monin and Sophie Barry are employees and shareholders of UCB. Ina Weisshardt has received consulting fees from Heel, ILAE, ISHH, Janssen and UCB.

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