SUPPLEMENTARY MATERIAL

The Lived Experience of Myasthenia Gravis: A Patient-led Analysis

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DATA SOURCES OF INSIGHTS FROM PEOPLE WITH MG

Qualitative Research Study

A qualitative research study of people living with MG was the primary source of insights for this study. The study was performed by researchers at Branding Science Ltd. on behalf of UCB Pharma (Smyrna, GA, USA). Consent was obtained from all participants prior to interview and the study was conducted in accordance with the EphMRA Code of Conduct, which provides comprehensive and up-to-date key ethical and legal guidance to support the execution of multi-country, primary and secondary healthcare market research. In addition, local market research guidelines were adhered to in each individual country included in the study.

Men and women from seven countries (Japan, United States, France, Germany, Spain, Italy, United Kingdom) who had been affected by MG (either patients or caregivers) were identified to take part in 75-min web-assisted telephone or in-home individual interviews. Participants were identified through a range of channels commonly used in qualitative research, including via HCPs, patient panels, patient support organisations and through referrals from other people with MG.

The interviews were conducted by trained market research moderators from Branding Science in the United States, United Kingdom and Italy. In Spain, Germany, France and Japan, interviews were conducted by trained moderators from local market affiliates with which Branding Science regularly collaborates.

Participants were selected for interview if they were aged ≥ 18 years, had experienced generalised symptoms of MG for ≥ 1 year and were currently receiving treatment.

The topic-guided interviews, designed following a review of relevant published literature and input from the Patient Council, investigated all aspects of the patient journey from first symptoms, initial HCP evaluation and diagnosis to initial treatment and ongoing management. For the purpose of this study, only patient insights and quotations focused on the ongoing management of patients receiving treatment for MG were extracted from the qualitative research study data.

Patient demographics and relevant clinical characteristics are provided in Table S1.

Table S1 Demographics of people with MG who participated in the qualitative research study

	Participants interviewed (*N* = 54)
Sex, *n* (%)	
Male	15 (28)
Female	39 (72)
Age, *n* (%)	
< 40 years	18 (33)
> 40 years	36 (67)
Geographic location, *n* (%)	
Japan	8 (15)
United States	15 (28)
France	6 (11)
Germany	7 (13)
Spain	6 (11)
Italy	6 (11)
United Kingdom	6 (11)
Diagnosed, *n* (%)	
< 5 years ago	17 (31)
> 5 years ago	37 (69)

MG myasthenia gravis

Prior Patient Council Outputs

Insights from a Patient Council meeting held in Brussels in September 2019, which discussed the lived experience of MG, supplemented insights from the qualitative research study. The meeting was attended by six individuals with MG who serve as patient advocates in their local communities across the globe, including in Europe and the United States. The meeting was conducted in English. Participating members of this Patient Council (September 2019) are listed in the acknowledgements of the primary article.

Only new insights not previously captured in the qualitative research study were extracted from the Patient Council meeting transcript.

Patient-Focused Literature Review

A comprehensive review of the published evidence of the lived experience of MG was performed to supplement the patient insights gathered during the qualitative research study and from the previous GMGPC meetings. A literature search was conducted (initially in June 2019 and updated in May 2020) using PubMed. Clinical studies, systematic reviews, meta-analyses, literature reviews and case studies were all eligible for inclusion, provided that they included information relating to patient experience or patient-reported outcomes within the abstract. Articles not published in English, or published more than 6 years ago, were excluded from the primary PubMed search. Search terms were carefully considered to allow for wide capture of patient-related outcomes and experiences, and are provided below.

As patient-reported qualitative research is not always published in indexed, peer-reviewed journals, we also included any relevant articles in the 'grey' literature. The PubMed search was further supplemented with hand searches of pre-determined patient and sociology journals not indexed in PubMed and other patient-authored literature, including a book authored by one of the authors, Kelly Davio.

Although initial searches identified 2675 articles, most were rejected during the screening process. Only 34 articles (32 peer-reviewed research publications, one newsletter and one book) were deemed by two researchers as being of direct relevance to the patient-reported lived experience of MG and were included in the final literature review.

The articles included are listed in Table S2.

Literature Review Search String

Literature search was performed using the following search string:

Myasthenia gravis AND (patient-reported OR patient-centred OR experience OR perspective OR satisfaction OR convenience OR quality of life OR preference OR emotion OR well-being OR psychosocial OR burden OR stigma OR anxiety OR stress OR fatigue OR tiredness OR weakness OR symptoms OR phenomenological OR relapse OR refractory OR crisis OR emergency OR hospitalization OR control OR treatment option OR home OR flexible

OR subcutaneous OR intravenous OR plasmapheresis OR oral OR surgery OR benefit OR value OR barrier OR challenge OR living OR illness OR work OR coping OR self-management OR psychology OR mood OR confidence OR reliance OR agency OR worsening OR intensive care OR rehabilitation OR steroids OR prednisone OR patient report experience measure OR mode OR method OR delivery OR administration OR qualitative). Limitations: English only; Since July 2014

Table S2 Articles selected for inclusion in the patient-focused literature review

Davio K. It's Just Nerves. In: Squares & Rebels. 2017. 144 pages
Keer-Keer T. The lived experience of adults with myasthenia gravis: a phenomenological study. AJON. 2015;25:40–6.
Diaz BC, et al. Myasthenia gravis and its comorbidities. J Neurol Neurophysiol. 2015;5:1–5.
Tanovska N, et al. Myasthenia gravis and associated diseases. Open Access Maced J Med Sci. 2018;6:472–78.
Lee I, et al. Gender differences in prednisone adverse effects: survey result from the MG registry. Neurol Neuroimmunol Neuroinflamm. 2018;5:e507.
Jeong A, et al. Factors associated with quality of life of people with myasthenia gravis. PloS One. 2018;13:e0206754.
Cioncoloni D, et al. Major motor-functional determinants associated with poor self-reported health-related quality of life in myasthenia gravis patients. Neurol Sci. 2016;37:717–23.
Chen YT, et al. Experiences of living with myasthenia gravis: a qualitative study with Taiwanese people. J Neurosci Nurs. 2013;45:E3–10.
Schneider-Gold C, et al. Understanding the burden of refractory myasthenia gravis. Ther Adv Neurol Disord. 2019;12:1–6.
Braz NFT, et al. Muscle strength and psychiatric symptoms influence health-related quality of life in patients with myasthenia gravis. J Clin Neurosci. 2018;50:41–4.
Tran C, et al. Fatigue is a relevant outcome in patients with myasthenia gravis. Muscle Nerve. 2018;58:197–203.
Hoffmann S, et al. Fatigue in myasthenia gravis: risk factors and impact on quality of life. Brain Behav. 2016;6:e00538.
Dill R, et al. The impact of motivational interviewing on self-perceived burden in patients receiving therapeutic plasma exchange. J Clin Apher. 2018;33:586–90.
Nagane Y, et al. Social disadvantages associated with myasthenia gravis and its treatment: a multicentre cross-sectional study. BMJ Open. 2017;7:e013278.

Richards HS, et al. The psychosocial impact of ptosis as a symptom of myasthenia gravis: a qualitative study. Orbit. 2014;33:263–9.

Frost A, et al. Labour market participation and sick leave among patients diagnosed with myasthenia gravis in Denmark 1997-2011: a Danish nationwide cohort study. BMC Neurol. 2016;16:224.

Barber C. Diagnosis and management of myasthenia gravis. Nurs Stand. 2017;31:42–7.

Koopman WJ, et al. Hope, coping, and quality of life in adults with myasthenia gravis. Can J Neurosci Nurs. 2016;38:56–64.

Beecher G, et al. Subcutaneous immunoglobulin in myasthenia gravis exacerbation: a prospective, open-label trial. Neurology. 2017;89:1135–41.

Bourque PR, et al. Subcutaneous immunoglobulin therapy in the chronic management of myasthenia gravis: a retrospective cohort study. PloS One. 2016;11:e0159993.

Utsugisawa K, et al. Health-related quality-of-life and treatment targets in myasthenia gravis. Muscle Nerve. 2014;50:493–500.

Megan Hunter. Myasthenia Gravis News: Exhaustion Means Being More Than Just a Little Bit Myasthenia Gravis News. Exhaustion Means Being More Than Just a Little Bit Tired. https://myastheniagravisnews.com/2019/07/24/exhaustion-chronic-illness-symptoms-tired-activities-friends/. Accessed July 2019.

Fernandes Oliveira E, et al. Sleep disorders in patients with myasthenia gravis: a systematic review. J Phys Ther Sci. 2015;27:2013–8.

Harris L, et al. Employment in refractory myasthenia gravis: a Myasthenia Gravis Foundation of America Registry analysis. Muscle Nerve. 2019;60:700–6.

Bogdan A, et al. Chronic stress, depression and personality type in patients with myasthenia gravis. Eur J Neurol. 2020;27:204–9.

Bacci ED, et al. Understanding side effects of therapy for myasthenia gravis and their impact on daily life. BMC Neurol. 2019;19:335.

Adiao KJB, et al. Efficacy and tolerability of subcutaneously administered immunoglobulin in myasthenia gravis: a systematic review. J Clin Neurosci. 2020;72:316–21.

Boscoe AN, et al. Impact of refractory myasthenia gravis on health-related quality of life. J Clin Neuromuscul Dis. 2019;20:173–81.

Xin H, et al. Examining the impact of refractory myasthenia gravis on healthcare resource utilization in the United States: analysis of a Myasthenia Gravis Foundation of America patient registry sample. J Clin Neurol. 2019;15:376–85.

Ohlraun S, et al. Impact of myasthenia gravis on family planning: how do women with myasthenia gravis decide and why? Muscle Nerve. 2015;52:371–9.

Boldingh MI, et al. An up-date on health-related quality of life in myasthenia gravis -results from population based cohorts. Health Qual Life Outcomes. 2015;13:115.

Cutter G, et al. Cross-sectional analysis of the myasthenia gravis patient registry: disability and treatment. Muscle Nerve. 2019;60:707–15.

Hehir MK, et al. Myasthenia gravis patient and physician opinions about immunosuppressant reduction. Muscle Nerve. 2020;61:767–72.

Sanders DB, et al. International consensus guidance for management of myasthenia gravis: executive summary. Neurology. 2016;87:419–25.

Table S3 Summary and detailed statements organised by domain

Summary statements by domain	**Quotes and detailed statement**
Physical	*'Having muscular weakness means that, on the worst days, holding up a hairdryer simply isn't possible, and that managing to get some mascara on without stabbing myself in the eyeball feels like a CV-worthy achievement. Putting on a dress with the zipper up the back, like in the dress in the ad? Not going to happen. Send in the leggings please'* – Patient advocate, Patient Council
Muscle weakness and fatiguability are experienced by almost all people with MG	Almost all people with MG experience muscle weakness, whereby muscles lose strength. They may also experience muscle fatiguability, where the more muscles are used, the weaker they become. This can affect many areas of the body, and can also lead to pain as a secondary issue (for example, pain that results from falls or injuries that result from weakness, neck/shoulder pain, eye pain)
Muscle weakness in MG is unstable, fluctuating and unpredictable, which is difficult to live with and	The muscle weakness associated with MG is unstable and fluctuating in nature: the weakness comes and goes. The fluctuations are particularly difficult to live with and can have a significant, debilitating impact on people's lives due to the

reduces quality of life	unpredictability, which affects their ability to plan and diminishes all aspects of their life
Generalised fatigue manifests as exhaustion in people with MG	As with many other auto-immune diseases, people with MG experience generalised fatigue, which manifests as ‘exhaustion’. Fatigue is a subjective and hard-to-measure symptom that can often be dismissed. However, fatigue can be debilitating and impact many aspects of life, such as the ability to work, exercise and concentrate (‘brain fog’).
People with MG can have disrupted sleep	People with MG often report sleep disturbances, in the form of poor night-time sleep, excessive daytime sleepiness or feeling that sleep is not restorative. They may manage their energy for upcoming activities by taking extra naps or sleeping for longer (described by them as a ‘hibernation’). Medication for MG, such as steroids, can also negatively impact sleep quality
The experience of MG differs between and within individuals	MG is a variable and unpredictable condition, which means that the experience is different for each person, and also differs for each individual at different times (‘good days’ and ‘bad days’) In addition, people with MG report that the importance of MG subtype (anti-MuSK and anti-AChR) for treatment decisions varies by country. There is an awareness amongst people with MG that anti-MuSK MG is more difficult to stabilise, leading to a greater physical toll compared with the anti-AChR subtype. People with MG may be categorised as ‘seropositive’ (testing positive for antibodies to anti-MuSK, anti-AChR or other relevant antibodies) or ‘seronegative’ (testing negative to one, more or all of the relevant

	antibodies)
MG is not always progressive – it can improve	MG is often, but not necessarily, a progressive disease, and there is the opportunity for patients with MG to see an improvement in their symptoms. Initial ocular symptoms often progress to generalised MG, but if an effective treatment protocol is found, their condition can stabilise and even improve over time. This is an important message to communicate to newly diagnosed people
Psychological	*'You don't know how you will feel from one day to the next or what the future holds'* – Person with MG in the qualitative study
MG is largely an 'invisible' illness, so other people may not understand its impact	Because MG is largely an 'invisible' illness that others cannot see, people with MG feel that other people do not understand it or take it seriously, leading to feelings of isolation
The unpredictability and uncertainty of MG makes it hard for people to plan	The unpredictability of MG impacts the ability of people living with MG to plan, in both the short- and longer-term. The feeling of not having any control over MG, and not knowing how they will feel on any given day, can lead to feelings of uncertainty and anxiety about the future
Living with MG can lead to feelings of anger, frustration and depression	People with MG experience anger and frustration, directed at both the condition and the burden of treatments, and sometimes toward other people who may offer unhelpful advice. In addition, people with MG may report feeling depressed
People with MG may have feelings of guilt	People with MG may have feelings of guilt, driven by different factors – for example, feeling they are letting family and friends down if they need to cancel plans, or wondering if they have done

		something to ‘cause’ MG
	Living with MG can bring out optimism, hope and resilience	Some people with MG view the future in an optimistic light, and have hope that newer, better treatments will benefit them. Living with MG can also develop people’s resilience. Consequently, people with MG may learn to maximise each day and find the ‘silver linings’ in their situation
	Emotional support is very important	Emotional support is very important for people with MG, whether through family relationships and friendships, faith-based groups, HCPs or other people living with MG People with MG also find huge value in support groups, reporting that it is helpful to know ‘they are not alone’ and to hear about how others in a similar situation cope. Such groups provide a forum to help them express and validate their concerns about symptoms, can fill knowledge and support gaps left through disconnects with HCPs, can enrich their social life and provide rewarding opportunities to help others. Support groups can also enhance communication within existing relationships, as they help to increase understanding of MG amongst those closest to the people with MG, in particular if they are also able to attend together. Different ways to participate, with both face-to-face and technology-enabled options, are important to facilitate the involvement of the broadest possible range of people living with MG
Social		*‘Soon I couldn’t breathe or speak well enough to chat with friends on the phone, much less meet for a social gathering. My world grew smaller and my close friends less numerous. I aimed my loneliness*

	at books – both the reading and writing of them. But when my eyes couldn't work well enough to read a page, and when my muscles were too wobbly to allow me to write for more than a few moments at a time, I retreated even further in to the solitude of my mind' – Patient advocate, Patient Council *'A lot of people don't understand what MG means. They don't know what it is and they also don't want to learn about it. People would just rather withdraw from you. This really makes your social circle much, much smaller. I used to have a lot of friends and business partners as well, but all of this has fallen away. I only have a handful of very old friends that I have had since childhood. Everyone else is gone.'* – Person with MG in the qualitative study
Living with MG means it can be a struggle to make plans, resulting in feelings of loneliness	The unpredictability of MG can make it hard for people to make plans in advance. Many learn to listen to their bodies and be honest with themselves. However, this often means cancelling plans at the last minute, needing to rely on others, and missing out on events with family and friends. People with MG can worry that others see them as unreliable, leaving them feeling frustrated and lonely
MG can negatively impact relationships	The invisible nature of MG makes it hard for others to understand, which can negatively impact relationships. MG may even be a contributing factor to divorce or relationship break-ups, although the extent of this is currently unclear. People with MG may even choose to live alone rather than having to explain their condition over and over. The concept of being thought of as a 'burden' by others can be

	stigmatising for some people with MG
People find comfort in connecting with other people with MG who understand	Many people with MG find comfort and empathy in connecting with others who share similar experiences and can act as a 'mirror' to reflect their own experience
Reproductive and parenting	*'I was really willing to look after my children, but that made me getting worse. It was too difficult to fulfil a mother's responsibility with MG. I did not bring up my children by myself, I feel regret for losing intimacy with them. Meanwhile because of my disease, I was abandoned by my husband'* – Patient quote from the literature review
People with MG have concerns about pregnancy	Many women with MG are fearful of going through a pregnancy with the condition, due to the unpredictability of MG and the possibility of a flare-up during pregnancy. There is also a belief that MG may have a negative impact on pregnancy. Women express concerns over the impact of any medication on a foetus, that they may pass MG on or that the child may develop neonatal myasthenic syndrome
Concerns about the impact of MG and its treatment on their ability to cope as a mother can deter women from planning a pregnancy	People with MG may consider abstaining from having children due to the condition. People with MG express concerns about adding additional stress on their relationships, or not having the physical strength to carry the baby or cope with its needs
Concerns about the impact of MG on the ability to cope as a father can deter men from planning for pregnancy with their partner	Decisions about having children are not confined to women with MG – men with MG are also concerned about the impact on fatherhood; for example, they are concerned about the impact on work or not being able to perform 'typical

		fatherhood tasks' such as playing football
	MG leads to 'trade-offs' for people with children	For people with MG who already had children pre diagnosis or choose to have children after diagnosis, there are often 'trade-offs' that have to be made, such as choosing whether or how much to work
	More education and guidance are needed regarding family planning for people with MG	People with MG need support with family planning, but express that this is largely unaddressed by HCPs. There is a need for more information and education for both HCPs and people with MG around MG and pregnancy and for better guidance on treatments during this time. Advice from HCPs can have a strong influence on people's decisions on whether or not to have children. This decision can, ultimately, have a consequential effect on relationships. There is an unmet need for effective treatments that allow women with MG to safely become pregnant
Activities and participation		*'You feel it from the moment you wake up and you have to adjust your routines and expectations, I live day by day. Those bad days you need to prioritize the most important activities, or the most basic, and try to work with your medication.'* – Person with MG in the qualitative study
	Activities can take longer and may need to be limited for people with MG	People with MG may need to factor in extended rest times before and after activities. They may not be able to do multiple activities in the same day and may need to carefully consider how much they are able to take on. It may be necessary for people with MG to plan additional time for activities – for example, extra time for meals, as chewing may take longer

Activities need more planning for people with MG	The unpredictable nature of MG and the limitations and challenges during flare-ups mean that all practical tasks need to be carefully considered and planned, requiring ‘mental calculus’ to manage life with MG. In addition to fatigue, there are practical challenges such as accessibility, and impact on activities and participation; people with MG always have to consider the potential impact of their condition on their plans
MG can negatively impact employment and schooling	Employment can present challenges for people with MG as they may not be able to manage a full-time role. Desk-based as well as manual jobs can be difficult; for example, people may have problems with eye fatigue, neck pain, ability to smile or speak, or staying alert. The impact of MG on their ability to drive can also be a barrier to employment and affect people’s sense of independence. People with MG are also often concerned about the emotional stresses of MG manifesting themselves in the workplace, or, conversely, the stress of work negatively impacting their condition. Employer attitudes can vary significantly by country and workplace and can even affect the treatments people with MG are able to commit to; for example, they may not feel able to take time away from work to receive IVIg treatment. Many of these issues are also relevant to the ability of both children and adults with MG to pursue educational activities
People with MG (perhaps younger people in particular) feel a sense of loss due to restrictions in activity and limitations in life choices	The impact of MG on activities and participation may be most significant in younger people, whose lives may be more focused on activities with peers, and who may look back at ‘life before diagnosis’ more often. Patient support groups report that

		teens and young adults living with MG may have particular difficulties coping with the demands of school/university, at an age where fitting in and peer relationships are very important. HCPs may underestimate the particular sense of loss amongst younger people with MG – for example, the ability to participate in the physical and social side of previously enjoyed sports
Controlled and not controlled		*'It is particularly frustrating [for people with refractory disease] to read that most people with MG are well managed on treatment, or have "normal" lives, when their experiences are quite the opposite'* – Patient quote from the literature review
	MG could be better controlled in a significant proportion of people with the disease	Many people with MG feel that they are sub-optimally controlled and could benefit from better treatment. Consistent with findings in the literature, some people with MG are living with ongoing symptoms that could be better managed – this is not always realised by HCPs. Some people with MG are believed to be unresponsive or 'refractory' to treatment
	There are differences in the level of control achieved for different people living with MG	People with 'well-controlled' MG are effectively treated with few or no residual symptoms. However, many people are living with inadequate levels of symptom control: People with 'moderately controlled' symptoms are adapting their lifestyle to compensate for sub-optimal treatment; where this is not sufficient, people with 'poorly controlled' MG are experiencing symptoms that restrict their lives, despite their adaptations. The level of severity of 'poorly controlled' symptoms can be high (and dangerous), especially for those who are very good at compensating. People with MG that is not 'well

	controlled' are experiencing symptoms, in some cases severe, which could be due to either undertreatment or unresponsive disease
There is a level of inertia around switching treatments, even when they are not optimised	There is a level of inertia, from both people with MG and HCPs, with respect to changing treatment. Some people live with 'poorly controlled' MG for extended periods; they may be under-treated but do not switch treatments. This can be driven by many different factors, such as waiting to see if they improve; fear of the process and time to optimise a new treatment and/or of leaving an imperfect 'comfort zone' of the current medication; lack of access to new medications; and concerns over starting steroid treatment when the duration is unknown and there are long-term adverse effects
People with MG adapt to poorly or moderately controlled MG by developing coping strategies	People with MG adapt to their new reality by implementing coping strategies to overcome MG-related restrictions when their condition is not fully under control. They may even 'over-adapt' and seem that they are coping well, when in fact they may be able to live with fewer adaptations if their treatment was optimised. They rely on these adaptations and coping mechanisms, such as long-term planning, allowing for more frequent breaks, changing or reducing the amount or type of work they do, proactively cancelling plans if necessary and adapting the ways in which they conduct activities of daily living such as eating or personal hygiene. The fluctuating nature of MG means there may be a need for constant 'mental calculus' involving calibration of activities and coping strategies
Flare-ups or crises after a	When the condition is stable or in remission, people

	period of stability or remission are discouraging	can begin to resume their pre-MG activities – and can even 'forget' they have MG. This can make flare-ups or crises even more discouraging and depressing, as they are forced to adapt all over again
	Resilience helps people with MG cope	Some people seem to be able to cope with the challenges of MG and still maintain a positive outlook on their lives. It would be helpful to have a better understanding of how the characteristics and behaviours of those who are resilient by nature might be learned and adapted by others, and how support systems might contribute
Flare-ups and myasthenic crises		*'Whenever I think about joining in on strenuous activities with friends…I'm never sure how far I'll make it.'* – Person with MG in the qualitative study *'Turns out stress is my main trigger, and it's what caused those first symptoms to show up. Being in a situation where I can get stressed suddenly, like driving, immediately causes the muscles in my lungs, throat and mouth to stop working, so I can't breathe or speak or swallow.'* – Person with MG in the qualitative study
	People with MG fear a crisis	People with MG fear a crisis, especially if they have had previous traumatic experiences such as being intubated, which can leave people with PTSD-like psychological distress and a reluctance to return to hospital in future. The fear of inducing a crisis can leave both people with MG and their HCPs reluctant to 'rock the boat' by changing medication. This can also impact willingness to participate in clinical trials
	There are barriers to	When people with MG begin to experience a flare-

	presenting early for medical help for a flare-up	up, it is difficult for them to know objectively when or how they should seek medical help, as this is not well defined. There is a feeling amongst some people with MG that HCPs, particularly those with less knowledge of the condition, do not understand or even believe MG symptoms, which can discourage people from seeking help. People with MG may wait to seek assistance, either to be sure it is a real flare-up, or because following previous bad healthcare experiences they may be reluctant to present with symptoms that they worry an HCP may consider to be 'too mild'. Some people don't like to 'bother' their HCPs, and for some the distance involved is a barrier to early presentation. In the current pandemic, fear of contracting COVID-19 in a healthcare facility is also a deterrent from seeking medical intervention
	Concerns about potential flare-ups can make travel a challenge	Travel can be a challenge for people with MG, as it can require a significant amount of extra planning in case of a flare-up. People with MG may be concerned about a lack of access to MG specialists and treatments, in case of an emergency, at their travel destination. Some of their concerns, such as the requirement for live vaccines, impact of crossing time zones on medication doses and difficulty obtaining travel medical insurance, may limit travel options. Travelling for work may be even more challenging than travelling for leisure, as people with MG may not be able to factor in as much rest time as they really need
Treatment burden		*'Living with the idea these medicines have bad side effects, you want to get by on the lowest meds you can even if you know you could be stronger on*

	20mg instead of 5mg, people are living with that trade off and that's why we need better treatments and not after everything else has failed you.' – Patient advocate, Patient Council
People with MG make trade-offs between treatment efficacy and burden	Many people with MG are living with trade-offs between feeling better and having adverse effects from their treatments that diminish their quality of life. Some are willing to accept a greater treatment burden in exchange for greater efficacy. For example, although IVIg can be an effective treatment, some people experience intolerable adverse effects. There is also a significant time commitment to receive the intravenous treatment, and it may not be available in all locations There are concerns around IVIg shortages, particularly considering the decrease in plasma donations during the current COVID-19 pandemic
People with MG perceive a lack of communication of treatment burden from HCPs	Information from HCPs on treatment burden, in terms of adverse effects and monitoring, is typically lacking from the perspective of people with MG. Some HCPs may lack sufficient knowledge to clarify the risk–benefit balance of treatments. They may sometimes prioritise other comorbidities over MG, and there is a need for understanding and consideration of the impact of the treatments for these comorbidities on treatment for MG
Steroids have many adverse effects	Adverse effects of steroids are a real concern for many people with MG. Steroids have several negative effects such as weight gain, change in appearance, acne, disrupted sleep, mood swings and impact on mental health (which is often underestimated). Long-term negative effects can also include loss of bone density, poor wound

		healing and pre-diabetes or diabetes. The adverse effect profile of steroids can lead many people with MG to make trade-offs, choosing less control instead of risking adverse effects brought on by steroid use.
	Current treatments are very slow to take effect	Some chronic treatments for MG can be very slow to take effect, sometimes with a delay of several months, even as long as a year or more in some cases, before the benefit is evident. People with MG may feel they are having to take on a large treatment burden for potentially no benefit. This can lead to frustration if the treatment does not ultimately prove helpful, as people feel they have wasted time
Unmet needs		*'Achieving a sustained effect so patients don't have to take so much medication.'* – Person with MG in the qualitative study
	The ultimate goal is a cure for MG, but better long-term treatment efficacy and tolerability would be an improvement for patients	The ultimate goal of research for people with MG is to find a cure; however, treatments that achieve remission, or maintain their effects over the longer term, with fewer adverse effects, would be seen by patients as an important improvement
	There is a need for improved treatment options for MG	There is a recognised need for more research into treatments with a better clinical efficacy/adverse effect profile and improved convenience and autonomy of administration (for example, at-home options). New treatment options that prevent crisis/need for rescue therapy, that avoid the need to increase steroid dose if not well controlled and that give people with MG enough control and predictability that they can make plans would also be welcomed by people with MG

People with MG want to hear about new treatments in development	Many people with MG want to be kept informed of clinical trial developments. This would help to alleviate the perception that progress is not being made
Broad access to effective treatment for MG is critical	Some patients are unable to access the most effective treatments, with many being used off-label. Many on-label treatments, notably some high-cost biologics, are difficult or impossible for people with MG to access. Accessibility and reimbursement are key to ensuring the broadest possible group of people with MG can access the most highly effective treatment options
There is a need for better understanding from HCPs on treatment goals of people with MG	There are differences in perception between people with MG and their HCPs in what is considered to be satisfactory symptom control and quality of life. There is a need for education for both patients and HCPs that increases communication about treatment goals, and the perception of what is successful treatment and satisfactory quality of life. The nature of questions an HCP asks people with MG can have a strong influence on the HCP's perception of the impact of the disease and thus how it is managed
Technology can improve engagement and education in MG	There is an opportunity for technology to improve the experience of people with MG; for example, smartphone apps may help patients to engage and monitor their MG, and technology may also be able to support the education of HCPs and the whole multidisciplinary team on the impact of MG
Psychological support for people with MG could be improved	The diagnosis of MG creates psychological as well as physical challenges. People with MG and their family members report an array of emotions,

	including depression, anger, anxiety and fear. Psychological support can help, but it can be difficult for people to find mental health professionals who understand the burden of chronic illness, in particular the nuances of the rare disease that is MG. Poor-quality psychological support, for example, from a therapist who does not have a deep understanding of MG, may be worse than no support

AChR acetylcholine receptor, *HCP* healthcare provider, *IVIg* intravenous immunoglobulin, *MG* myasthenia gravis, *MuSK* muscle-specific tyrosine kinase, *PTSD* post-traumatic stress disorder

Statements reflect the consensus of the lived experience of MG from the perspective of people with the condition. They do not necessarily apply to everyone, nor to a specific individual all of the time, but all statements reflect the experience of some people with MG.