

Background

Myasthenia gravis (MG) is a **rare autoimmune disease** that clinically manifests as muscle weakness and fatigability¹

There are few published data on the **patient perspective** of how MG impacts life

Objective

This study set out to reveal the lived experience of MG from the patient perspective

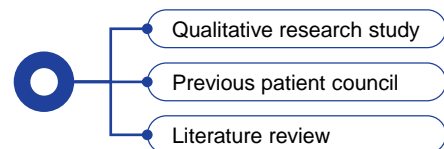
Methods

The qualitative analysis was led by an international patient council (see page 2 for method overview)

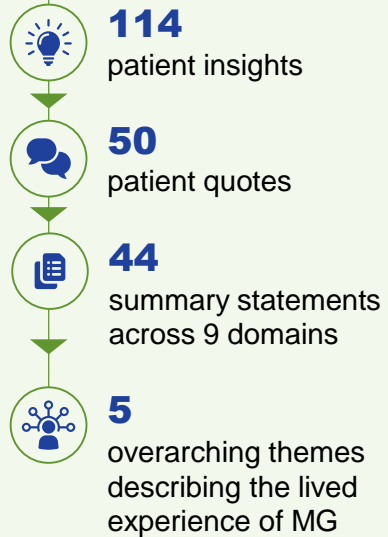


9 individuals living with MG who serve as local or national patient advocates across Europe and the United States

3 data sources analyzed:



Results



Summary

This patient-driven analysis enriches our understanding of the reality of living with MG



A greater understanding of what it means to live with MG could help health care professionals (HCPs) to better communicate with patients



Patient insights were organized into **9 domains**: (see page 4 for summary statements)

- Physical
- Psychological
- Social
- Reproductive & parenting
- Activities & participation
- Controlled & not controlled
- Flare-ups & myasthenic crises
- Treatment burden
- Unmet needs

^aRepresentative quote by person living with MG

Reference: ¹Ruiter AM, et al. *Neuromuscul Disord* 2020;30:631–9. **Author Contributions:** All authors contributed to preparation of the poster.

Author Disclosures: NL, KD: members of the patient council; MB, KS: employees of UCB Pharma, which funded the study. **Acknowledgments:** We give special thanks to the people with MG who participated in the qualitative research survey and patient councils. This study was sponsored by UCB Pharma. The authors acknowledge Veronica PorKess, PhD, UCB Pharma, for publication and editorial support. Medical writing support was provided by Sarah McSorley, Envision Pharma Group, Wilmslow, UK, and funded by UCB Pharma, in accordance with Good Publications Practice (GPP3) guidelines (<http://www.ismpp.org/gpp3>). All costs associated with development of this poster were funded by UCB Pharma.

Overarching themes identified by patient authors

(see page 3 for detailed themes)

1 Living with fluctuating and unpredictable symptoms

“Every patient will have muscle weakness, but the difficulty to live with is that it is so unstable, the fluctuation is even worse to live with than the muscle weakness itself”^a

2 A constant state of adaptation, continual assessment, and trade-offs in all aspects of life

“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”^a

3 Treatment inertia, often resulting in undertreatment

“Yes, if you don’t know something is going to work, and it doesn’t work, you feel like you’ve wasted 6 months, which can be very frustrating”^a

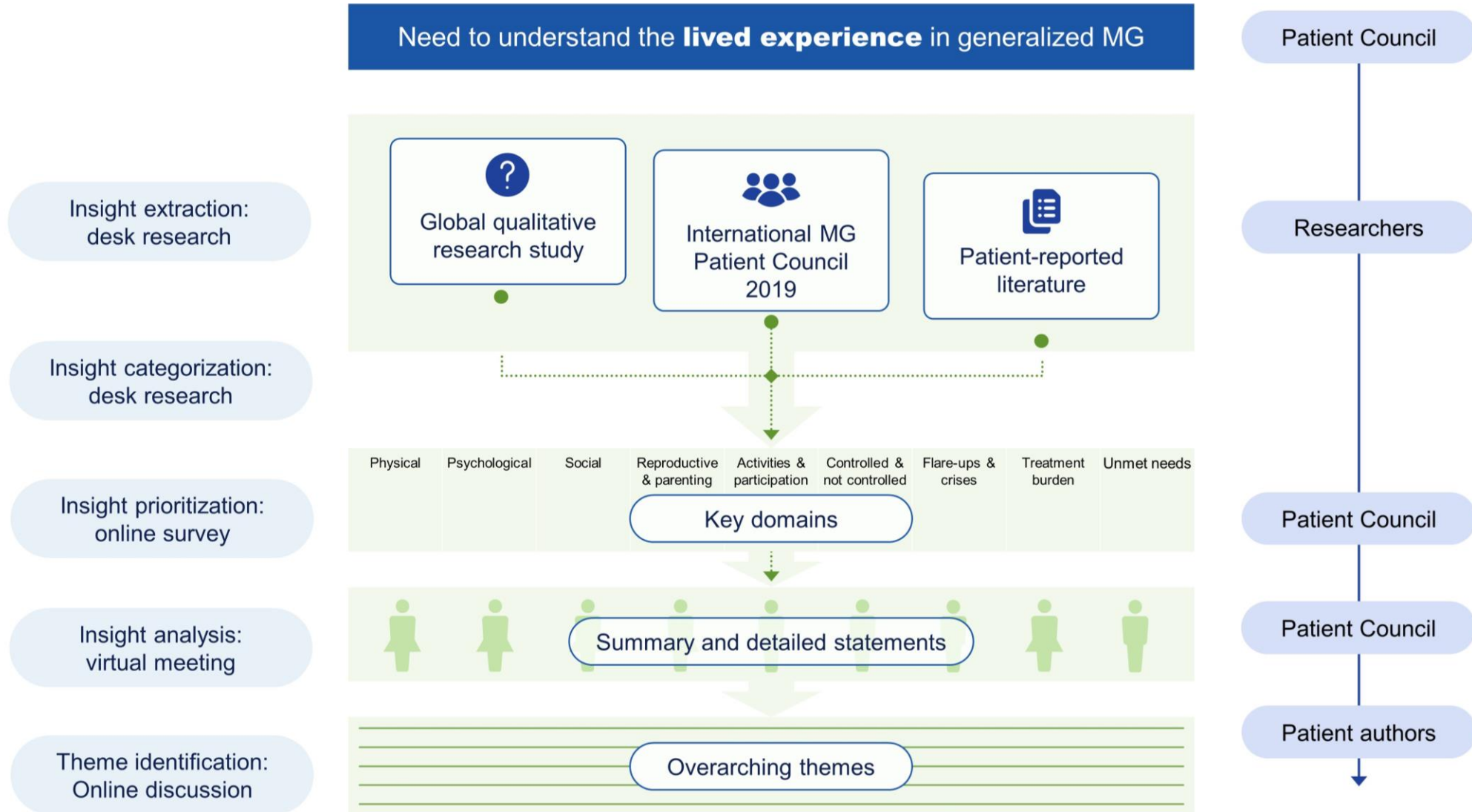
4 A sense of disconnect with HCPs

“He may think I’m in remission, but I’m taking 20-30 mg of prednisone, I have all these side effects. It’s not adequate control”^a


5 Feelings of anxiety, frustration, guilt, anger, loneliness, and depression


“I remember a time when I couldn’t go out for dinner with friends after the theatre because I was so exhausted. I cried a lot that evening”^a


The patient-led process followed for insight identification, collation, prioritization and analysis





Detailed themes identified by patient authors

- 

1 The challenge of living with MG extends beyond managing the characteristic muscle weakness. The fluctuating and unpredictable nature of symptoms, with periods of worsening and remission, has a substantial impact on the lives of people with MG.
- 

2 As a consequence of living with fluctuating symptoms, people with MG navigate a constant state of adaptation to their muscle weakness. They have to make continuous assessments and trade-offs in all aspects of their life, including crucial areas such as work, family planning and treatment.
- 

3 Despite sub-optimal disease control, there can be a reluctance among both patients and HCPs to alter their comfort zone of MG treatment. Multiple factors contribute to this “treatment inertia,” which can result in people with MG being under-treated.^{1,2} These include a lack of consensus on what constitutes optimal disease control, concerns over potential additional side effects and the time needed to see the benefits of a change in treatment. These factors can lead to a reluctance to “rock the boat.” Furthermore, some patients who are not treated by a specialist can feel that their HCP does not fully understand their disease.
- 

4 People with MG may feel a sense of disconnect with their HCPs. This feeling is largely driven by barriers to communication such as limited time, a gap in the perception of both disease and treatment burden and differences in treatment goals. Although HCPs may focus on managing clinically relevant symptoms and side effects, this management may not address the impact that MG has on people’s lives and the degree to which they must compensate in order to live with their symptoms.
- 

5 MG can lead to feelings of anxiety, frustration, guilt, anger, loneliness and depression. These feelings may be driven by multiple factors, from the burden of MG symptoms themselves to social isolation, loss of control and a lack of support.

Summary statements describing the lived experience of MG by domain

Domain	Summary statements and representative quote
Physical	<ul style="list-style-type: none"> Muscle weakness and fatigability are experienced by almost all people with MG Muscle weakness in MG is unstable, fluctuating, and unpredictable, which is difficult to live with and reduces quality of life Generalized fatigue manifests as exhaustion in people with MG People with MG have disrupted sleep The experience of MG is different between and within individuals MG is not always progressive – it can improve <p><i>“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”</i> – Patient advocate, Patient Council</p>
Social	<ul style="list-style-type: none"> Living with MG means it can be a struggle to make plans, resulting in feelings of loneliness MG can negatively impact relationships People find comfort in connecting with other people with MG who understand <p><i>“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 into the solitude of my mind”</i> – Patient advocate, Patient Council</p>
Activities & participation	<ul style="list-style-type: none"> Activities can take longer and may need to be limited for people with MG Activities need more planning for people with MG MG can negatively impact employment and schooling People with MG (perhaps younger people in particular) feel a sense of loss due to restrictions in activity and limitations in life choices <p><i>“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”</i> – Person with MG in qualitative study</p>
Flare-ups & myasthenic crises	<ul style="list-style-type: none"> People with MG fear a crisis There are barriers to presenting early for medical help for a flare-up Concerns about potential flare-ups can make travel a challenge <p><i>“Whenever I think about joining in on strenuous activities with friends...I’m never sure how far I’ll make it”</i> – Person with MG in qualitative study <i>“Turns out stress is my main trigger, and it’s what caused those first symptoms to show up”</i> – Person with MG in qualitative study</p>
Unmet needs	<ul style="list-style-type: none"> The ultimate goal is a cure for MG, but better longer-term treatment efficacy and tolerability would be an improvement for patients There is a need for improved treatment options for MG People with MG want to hear about new treatments in development Broad access to effective treatment for MG is critical There is a need for better understanding from HCPs on treatment goals of people with MG Technology can improve engagement and education in MG Psychological support for people with MG could be improved <p><i>“Achieving a sustained effect so patients don’t have to take so much medication”</i> – Person with MG in qualitative study</p>

Domain	Summary statements and representative quote
Psychological	<ul style="list-style-type: none"> MG is largely an “invisible” illness, so other people may not understand its impact The unpredictability and uncertainty of MG make it hard for people to plan Living with MG can lead to feelings of anger, frustration, and depression People with MG may have feelings of guilt Living with MG can bring out optimism, hope, and resilience Emotional support is very important <p><i>“You don’t know how you will feel from one day to the next or what the future holds”</i> – Person with MG in qualitative study</p>
Reproductive & parenting	<ul style="list-style-type: none"> People with MG have concerns about pregnancy Concerns about the impact of MG and its treatment on their ability to cope as a mother can deter women from planning a pregnancy Concerns about the impact of MG on the ability to cope as a father can deter men from planning for pregnancy with their partner MG leads to “trade-offs” for people with children More education and guidance are needed regarding family planning for people with MG <p><i>“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”</i> – Patient quote from literature review¹</p>
Controlled & not controlled	<ul style="list-style-type: none"> MG could be better controlled in a significant proportion of people There are differences in the level of control achieved for different people living with MG There is a level of inertia around switching treatments, even when they are not optimized People with MG adapt to poorly or moderately controlled MG by developing coping strategies Flare-ups or crises after a period of stability or remission are discouraging Resilience helps people with MG cope <p><i>“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”</i> – Patient quote from literature review²</p>
Treatment burden	<ul style="list-style-type: none"> People with MG make trade-offs between treatment efficacy and burden People with MG perceive a lack of communication of treatment burden from HCPs Steroids have many adverse effects Current treatments are very slow to take effect <p><i>“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 20 mg instead of 5 mg, people are living with that trade off and that’s why we need better treatments and not after everything else has failed you”</i> – Patient advocate, Patient Council</p>