Design of a Digital Solution to Improve Myasthenia Gravis Patient Symptom Tracking in Routine Clinical Care

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Background

- Myasthenia gravis (MG) is a chronic, debilitating, antibody-mediated autoimmune neuromuscular disease characterized by fluctuating, fatigable muscle weakness[1–3]
- The fluctuating nature of MG symptoms creates challenges for disease management[1]
- Validated patient-reported outcomes (PROs) are utilized in clinical research to assess symptom changes over time, but symptom monitoring in clinical practice could be improved[1,3]
  - Limitations of MG PROs include infrequent collection of data and the inability to gather a holistic picture of patients' disease burden[3]

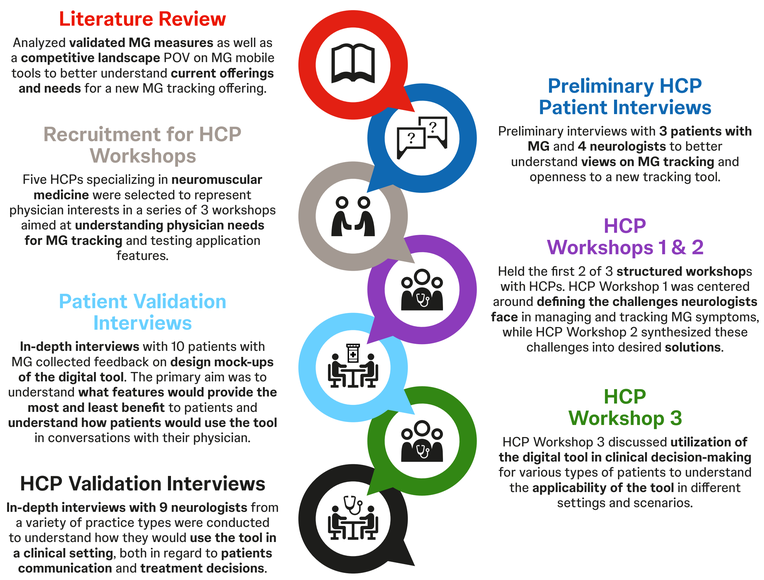
Objective

The objective of this study was to determine design requirements for a digital tool that utilizes validated PROs to improve symptom tracking and communication between patients with MG and healthcare providers (HCPs) in routine clinical practice

Methods

- A literature review was carried out and preliminary interviews with US-based patients with MG (n=3) and HCPs (n=4 neurologists) were conducted to assess the current state of MG symptom tracking and identify opportunities for improvement (**Figure 1**)
- Structured workshops with HCPs (n=5 neuromuscular neurologists) and validation interviews with patients with MG (n=10) and HCPs (n=9 neurologists, academic- and community-based) were held to design a novel digital tool and understand factors influencing adoption (**Figure 1**)
- Transcripts were analyzed for themes regarding challenges, preferred solutions, and benefits and applications of the proposed digital tool

Figure 1. ***Study design***



Participating patients and HCPs were US-based.
***HCP**=healthcare provider, **MG**=myasthenia gravis, **POV**=point of view.*

Key Takeaway

A two-sided digital solution was designed that would support evidence-based care management of patients with MG

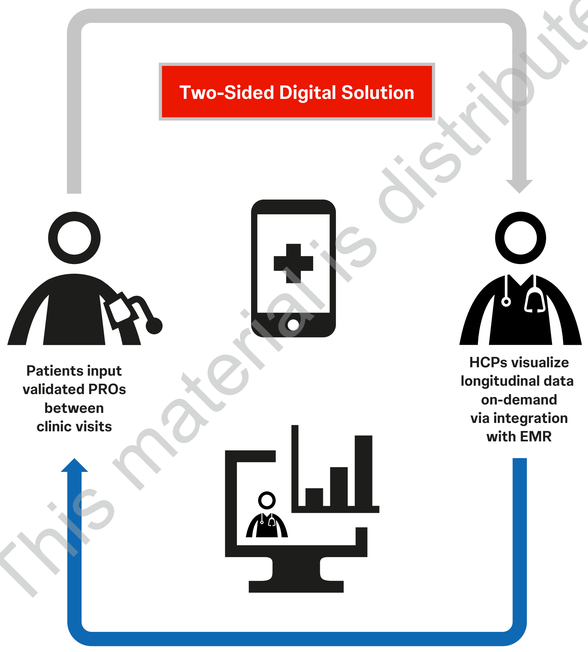
Conclusions

- **The designed solution would allow patients to input validated PROs between clinic visits, and HCPs to visualize longitudinal data on demand via integration with electronic medical records**
- **Patients and HCPs agreed that the proposed digital solution would enhance clinical care by improving MG symptom tracking and, ultimately, treatment decisions**
- **These results support continued development of the digital tool and studies investigating its clinical utility**

Results

- The result of the study was the conceptual design of a two-sided digital solution that enables patients to input validated PROs between clinic visits and helps HCPs visualize longitudinal data on demand via integration with electronic medical records (**Figure 2**)
- Findings from the literature review and preliminary patient and HCP interviews confirmed that opportunities exist to improve the current state of MG symptom tracking
  - Patients noted that they felt neglected in their MG journey, mostly regarding their experiences outside of the clinic; HCPs who manage a high volume of patients with MG saw the greatest value in a new digital tool
- The Myasthenia Gravis Activities of Daily Living (MG-ADL) scale, Patient Acceptable Symptom State (PASS), and Quality of Life in Neurological Disorders (Neuro-QOL) – Fatigue subscore were measures identified for inclusion
  - MG-ADL had strong advantages in ease of administration and utilization/validation in clinical trials, but lack of fatigue assessment was identified as a weakness; inclusion of Neuro-QOL – Fatigue and PASS would fill this gap
- HCPs preferred the MG-ADL scale as their primary visual, with ability to overlay subscores and other contextual data (i.e., PASS, Neuro-QOL – Fatigue, hospitalizations, and medications; **Figure 3**)
- Free text patient diary entries with artificial intelligence-generated summaries for HCPs were desired for additional contextualization and personalization (**Figures 4** and **5**)
- Factors influencing patient adoption of the digital solution included HCP use and the potential to have a single central MG management tool (**Figure 6**)
- HCPs noted adoption of the tool would be facilitated by electronic medical record integration and streamlined visualizations enabling quick data synthesis to support treatment decisions and features to simplify insurance prior authorization/reauthorization (**Figures 3** and **6**)

Figure 2. ***Key design requirements***



***EMR**=electronic medical record, **HCP**=healthcare provide, **PRO**=patient-reported outcome.*

Figure 3. ***Insights from structured HCP workshops***

HCP Workshop 1 Current Challenges	HCP Workshop 2 Desired Solutions	HCP Workshop 3 Utilization and Applicability of the Proposed Solution
Though ultimate treatment goals may be shared, there is an opportunity to enhance the way patients and clinicians **set goals**, **track progress**, **and communicate** using objective data	**MG-ADL should be "center piece"** of the digital tool, since it's perceived as the most clinically useful tool for managing MG	The digital tool would be very valuable to manage **patients on infusion therapy**, informing dose and switching decisions
MG-ADL is the best PRO measure but has limitations, including a lack of **personalization**, lack of surrounding **patient context**, and the need for up-front patient **education** to ensure correct usage	The digital tool should allow clinicians to view **individual questions/ subscores of MG-ADL**	For patients with **unstable or new MG** who may experience more fluctuations in symptoms, the digital tool would help **identify trends** and help clinicians **select the best treatment** on an accelerated timeline
Given the **fluctuating** nature of MG and issues with **recall and recency bias**, HCPs have blind spots regarding symptom volatility between clinic visits	In addition to visualizing MG-ADL trends, the digital tool should be able to **overlay important information** such as hospitalizations and infections to provide clinicians with **greater context**	With novel therapies entering the market and uncharted PA processes, the tool could **demonstrate patient need** and also track improvements while on treatment to **aid insurance reauthorizations**
Although fatigue, quality of life, and mental health data are important, this **information does not directly influence MG treatment decisions** and is therefore useful only in specific instances	**Inclusion of the one question PASS** could help quickly assess patient level of satisfaction with disease control and current treatment	HCPs would **not be expected** to perform live data review or read all patient entered text, which would be **important** for both **HCP** and **patient to understand**
Accessing patients' MG symptom data in a convenient way within their EMR would enable HCPs to **make informed treatment decisions**	**In-EMR accessibility** is critical for the utility of the tool and for clinician adoption	HCPs appreciated a **streamlined interface** with the ability to hover over icons or data and **reveal additional patient data**, such as medication information, dosing data, and data timestamp
	The patient interface should include **educational** content to ensure proper use of MG-ADL, along with a **free text diary** for patients to log important information	Although symptoms other than MG-ADL do not typically prompt a change in therapy, tracking them can **empower patients and prompt conversations**; when relevant, **fatigue should be captured**, but consider a single question trigger before a more detailed PRO (ex. Neuro-QOL – Fatigue)

***EMR**=electronic medical record, **HCP**=healthcare provider, **MG**=myasthenia gravis, **MG-ADL**=Myasthenia Gravis Activities of Daily Living, **Neuro-QOL**=Quality of Life in Neurological Disorders, **PA**=prior authorization, **PASS**=Patient Acceptable Symptom State, **PRO**=patient-reported outcome.*

Figure 4. ***Feedback from in-depth patient validation interviews following review of design mock-ups of the digital tool***

Tracking	Interface & Features	HCP Communication
Mixed Reactions to MG-ADL Patient felt that while MG-ADL scoring works for some (e.g., patients who have ocular/bulbar symptoms), it is **not personalized and specific** for others (i.e., those who have issues related to fatigue)	**Longitudinal View of Symptoms** Important to patients, and not commonly offered by existing solutions. Patients particularly resonated with **subscore-level views**	**Value of an HCP Interface** Patients felt that a clinician's ability to easily view all this information would significantly **improve current communication and decision-making** models
Value of Free Text Diary Patients viewed the **free text diary and photo/video upload functionality as critical** for personalizing tracking and sharing context behind symptoms	**Consolidation of Multiple Functionalities** Patients currently use a fragmented mix of applications to track information. A **single digital resource** that **consolidates** these functions was seen as valuable	**Conversational Tool** Many users talked about the utility of this tool to **guide conversations with HCPs**. Many patients called out their own inability to remember or bring up symptoms (i.e., brain fog)
Fatigue Tracking Brought up unaided across multiple interviews as a **key pain point for patients**	**Medication Reminders** Brought up by patients as **high value**, especially in the context of the rest of the application	

***HCP**=healthcare provider, **MG-ADL**=Myasthenia Gravis Activities of Daily Living.*

Figure 5. ***Themes that emerged from in-depth HCP validation interviews on applicability of the digital tool in a clinical setting***

Patient Benefits

- Provides comfort to patients to **be in control** of tracking symptoms
- Helps **validate qualitative symptom tracking** and provides **objective data** showing that symptoms in fact are worsening
- Helpful for patients with **poor recall of symptoms** at the time of visit by **allowing them to both track symptoms accurately and time of onset**
- Particularly useful for **new or newly diagnosed patients** who may have **less controlled symptoms** or **change treatments more frequently**

> *"I have been wanting an application like this for about 10 years. I think many more patients would track this information and benefit from tracking if there was an easy way of doing it."*

Applicability for Infusion Patients

- Provides **baseline data before starting infusions** to **understand effectiveness** of infusion once started
- Provides objective data particularly in **advanced patients** such as those who are **running out of treatment options or are on infusions**
- Helps clinicians make treatment decisions based on objective data indicating **how patients are handling MG symptoms during and after infusions**

> *"This is particularly useful for infusion patients. Currently we have to wait until the patient calls us with concerns, but having access to this data helps us see trends and determine how often the infusions should be given."*

Clinical Decision-Making

- Allows both patient and HCP to be **alerted early & make quicker decisions** about changes in symptoms
- Makes HCPs **aware of non-MG causes of symptom exacerbation**, such as other illnesses or medications, resulting in the **avoidance of unnecessary treatment escalation**
- When patients call about symptoms, the digital tool can help validate if symptoms are MG related and reduce **unnecessary patient visits**
- For patients with **vague complaints like fatigue**, the digital tool provides **objective data** and **AI summaries** to better differentiate MG related vs non-MG related symptoms

> *"Things like fatigue are 'squishy' complaints that are hard to find on an exam. Now we have an app to validate this and show objective evidence of symptoms that are not well controlled, allowing us to change treatments more quickly."*

HCP Benefits

- Helps provide **objective data to support the prior authorization process** since MG-ADL baselines and any worsening of symptoms will be captured in the data and can be copied into a PA form
- Clinicians, ideally, want to be **reimbursed for usage of the tool** – if used during the clinic visit, the time should be reimbursable (RPM codes seem less likely)
- HCPs want to **quickly read the graphic and text summary** and not have to spend time manipulating HCP dashboard – the generative AI and a clear default graph were important

> *"Sometimes apps like this are tricky because I don't get reimbursed for my effort using them. If I were able to get that reimbursement, I'd be more likely to use it."*

***AI**=artificial intelligence, **HCP**=healthcare provider, **MG**=myasthenia gravis, **MG-ADL**=Myasthenia Gravis Activities of Daily Living, **PA**=prior authorization, **RPM**=remote patient monitoring.*

Figure 6. ***Key factors influencing patient and HCP adoption of the digital tool***

Patient Adoption

- **Tracking symptoms in a standardized** and **longitudinal way** was consistently reported as the most important feature
- Patients saw much greater **value in the application if HCPs view and use** the tracked symptoms
- The patient application should **allow for free text and photos** to add their own history and context
- The digital tool had appeal in being a **single central MG management tool** versus the current state of multiple tools

HCP Adoption

- HCPs were willing to adopt but want to ensure there is no **expectation for real time or comprehensive review of data**
- Tracking symptoms or remote monitoring is not part of clinical practice for HCPs, so **workflow simplification and streamlined visualizations** are key for adoption
- The digital tool could **help clinicians prompt the right conversations** and make more informed decisions
- Additionally, the ability to **use the digital tool outputs for PA/reauthorization** would be a key benefit for HCPs

***HCP**=healthcare provider, **MG**=myasthenia gravis, **PA**=prior authorization.*

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