Poster Number 132

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]
- 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

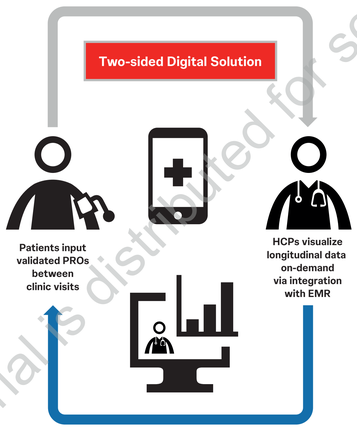
FIGURE 1: Study design

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

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

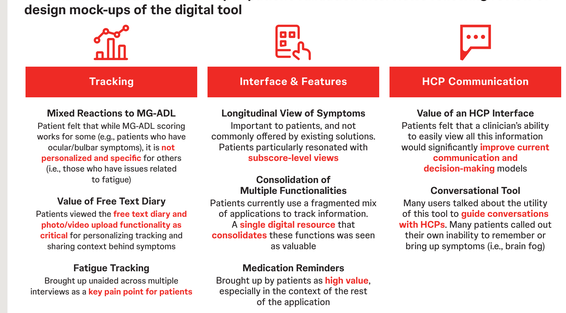


EMR, electronic medical record; **HCP**, healthcare provider; **PRO**, patient-reported outcome.

FIGURE 3: Insights from structured HCP workshops

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

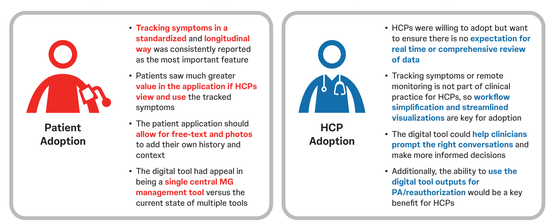


HCP, healthcare provider; **MG-ADL**, Myasthenia Gravis Activities of Daily Living.

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

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



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

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**

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Disclosures

SM has served on advisory boards for Alexion, AstraZeneca Rare Disease, argenx, Horizon Therapeutics/Amgen, and Ra Pharmaceuticals (now UCB). **JA** has served as a paid consultant for Alexion Pharmaceuticals, argenx, and UCB; he has served on speakers' bureaus for Alexion Pharmaceuticals, argenx, and UCB. **AELA** has served on a speaker's bureau for Alexion Pharmaceuticals and has served on advisory boards and as a paid consultant for Johnson & Johnson. **N Silvestri** has served as a paid consultant for Alexion Pharmaceuticals, Amgen, Annexon, argenx, UCB, and Immunovant; he has served on speakers' bureaus for Alexion Pharmaceuticals, argenx, and UCB. **N Streicher** has served as a speaker for Alexion and AstraZeneca Rare Disease. **AVP**, **HJ**, and **AG** are employees of ZS Associates, a company paid by Johnson & Johnson to undertake the analyses for this study. **NC** and **ZC** are employees of and hold stock in Johnson & Johnson.

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Autoantibody: MG