

Patient and Care Partner Preferences Related to Treatments for Myasthenia Gravis

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BACKGROUND

- Generalized myasthenia gravis (gMG) is a rare, chronic autoimmune disorder that causes muscle weakness and fatigue¹
- The goals of gMG management are to control symptoms and achieve remission; however, patients often experience significant treatment burden and dissatisfaction²⁻⁴
- As the gMG medication management and treatment landscape is rapidly changing, it is important to understand what patients and care givers want from a gMG treatment

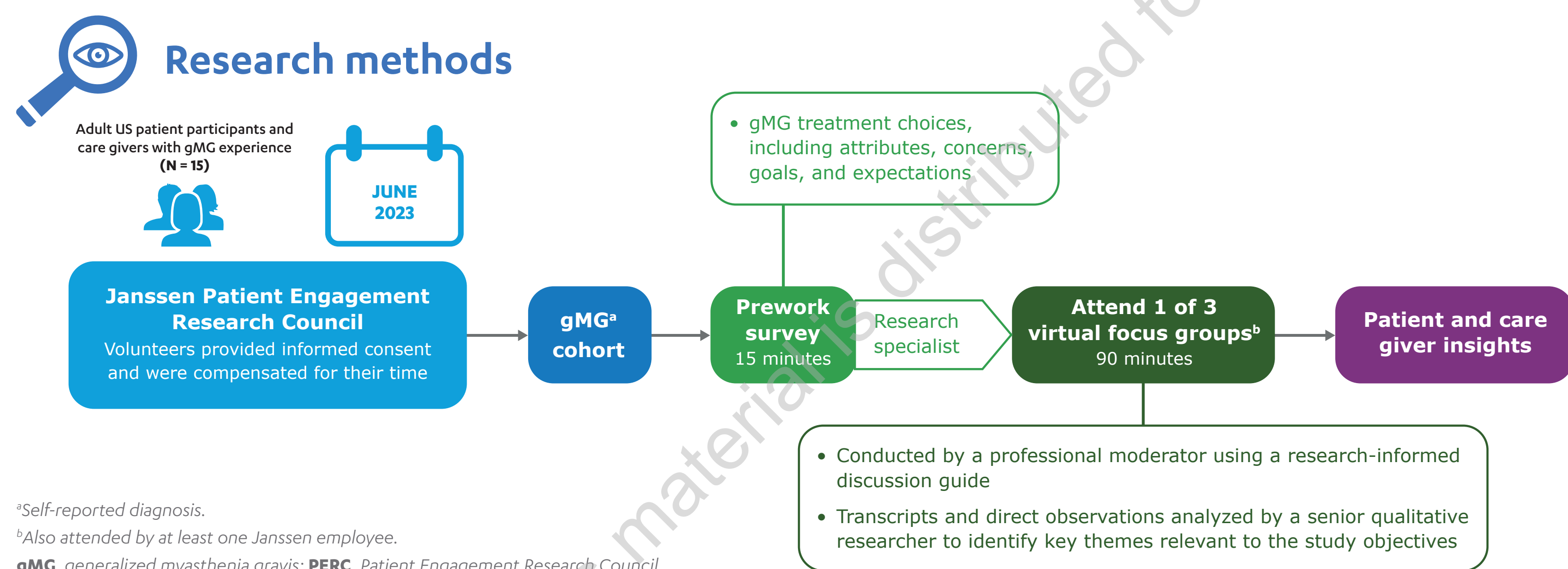
PURPOSE

- The purpose of this study was to apply mixed methods to further understand patient and care giver preferences related to treatments for gMG

METHODS

- Three virtual focus groups, consisting of people living with gMG and those providing care to people with gMG, were conducted (June 12–14, 2023)
- Participants were from Janssen's Patient Engagement Research Council (PERC) program (Figure 1)
- The PERC represents a diverse group of people living with chronic health conditions who can provide their insights and feedback around a specific set of structured activities, with variety in age groups, sex, time since gMG diagnosis, disease severity, educational backgrounds, treatment experiences, and time since diagnosis⁵
- A brief, eight-item prework survey centered around gMG treatment choices (e.g., attributes, concerns, goals, expectations) was given to participants prior to the focus groups
- The prework survey results, along with a targeted literature review and input from a steering committee of clinical experts and a patient advocate, were used to develop a discussion guide to facilitate active input during the focus group sessions
- Survey results were aggregated and reported descriptively. Qualitative data from the focus groups were recorded, transcribed, and analyzed using a thematic analysis approach to better understand patient preferences in gMG treatment

Figure 1. Research methodology of the gMG PERC

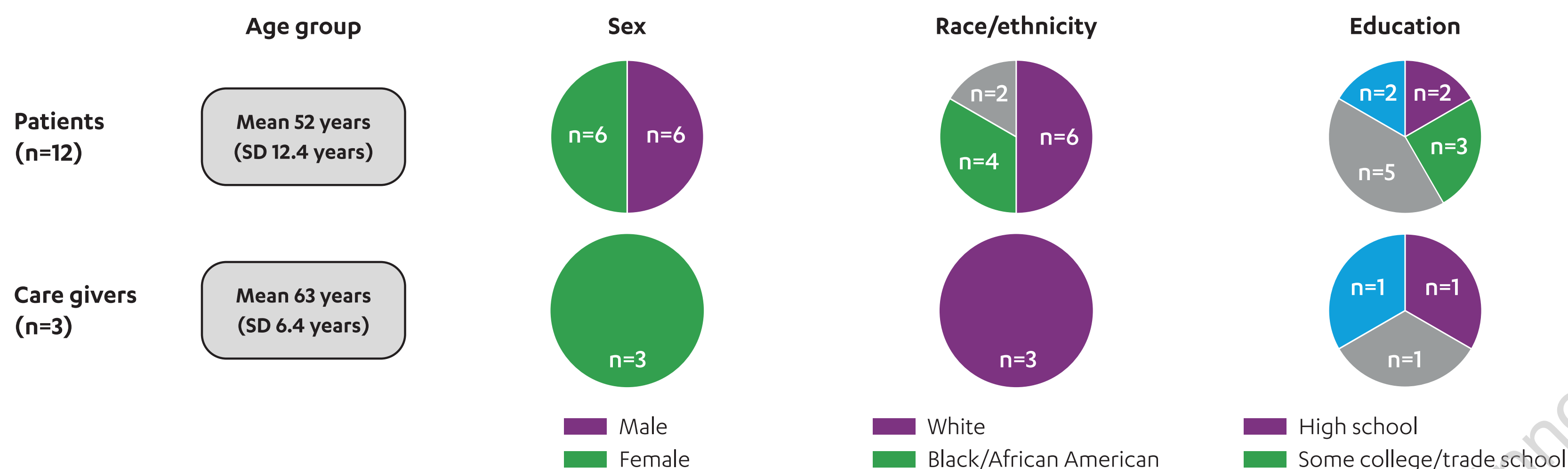


¹Self-reported diagnosis.
²Also attended by at least one Janssen employee.
 gMG, generalized myasthenia gravis; PERC, Patient Engagement Research Council.

RESULTS

- A total of 15 PERC members completed the eight-item prework survey, and 14 participated in the virtual focus group sessions (Figure 2)

Figure 2. Demographics^a



^aIncludes 15 participants who completed the prework survey; one of the 15 was unable to attend a focus group. SD, standard deviation.

Prework survey results

- Participants were asked to rank gMG treatment attributes in order of importance; the top three were avoiding or preventing a crisis, controlling symptoms and reducing side effects from treatment (Table 1)

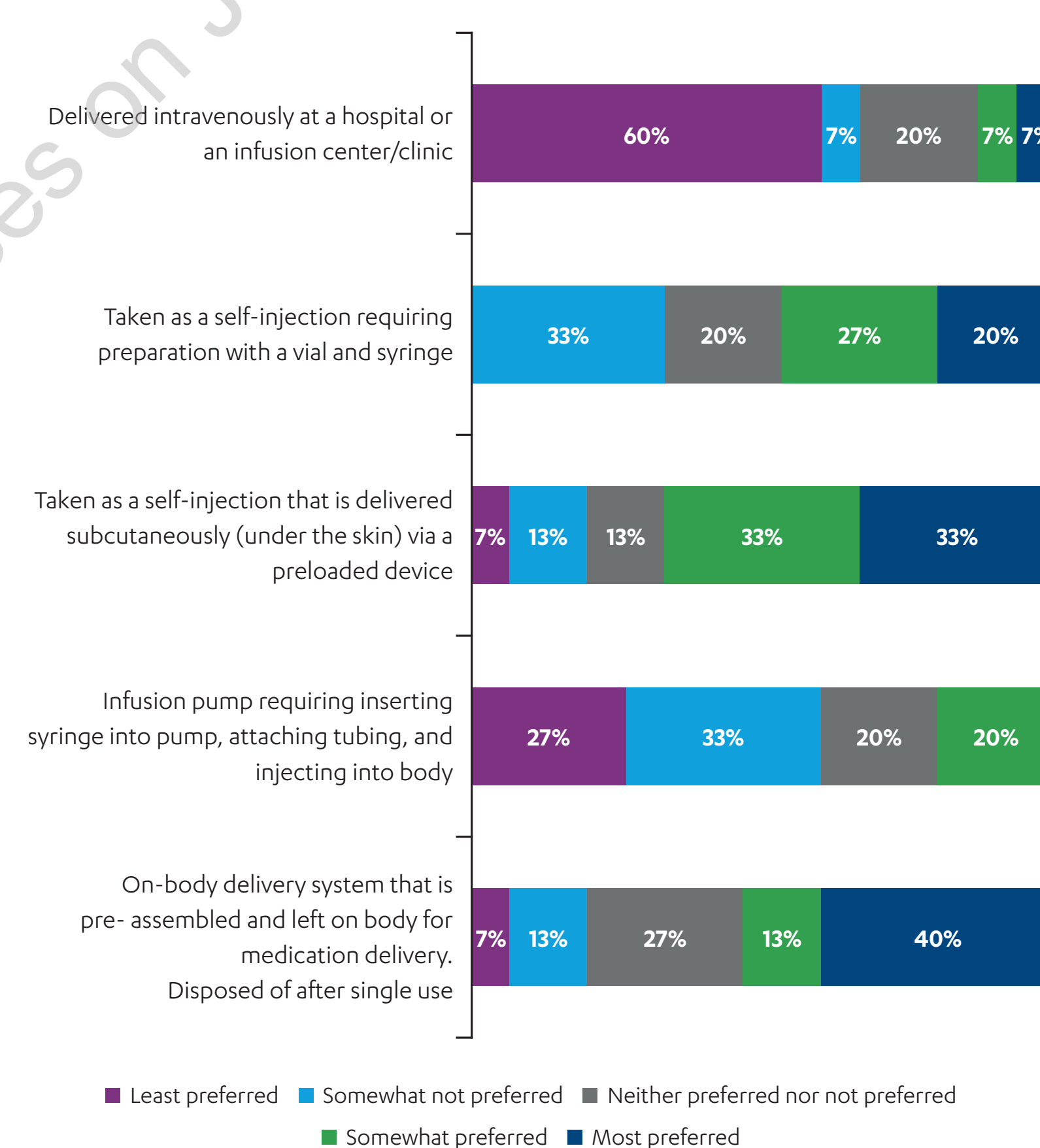
Table 1. Importance of treatment attributes^a

Rank	Treatment attribute	Mean score ^b
1	Avoiding or preventing a crisis	3.3
2	Controlling symptoms	3.8
3	Reducing side effects from treatment	4.7
4	Expected length of time the treatment will work	5.1
5	Cost of treatment	5.3
6	How long it takes before improvement starts	5.8
7	Impact on quality of life	6.3
8	Where the treatment is given	6.5
9	How often the treatment needs to be given	6.5
10	How the treatment is given	7.8

^aIncludes 15 participants who completed the prework survey; one of the 15 was unable to attend a focus group.
^bLower scores indicate attributes that were more important to participants.

- Patient/care giver expectations about new or emerging gMG treatments were also explored; the most important factors were fewer gMG crises and a longer duration of medication response (87% and 80%, respectively; data not shown)
- For emerging gMG treatment administration options, 40% preferred an on-body delivery system (OBDS); an additional 13% somewhat preferred OBDS; convenience was also a key factor, since 60% reported that intravenous delivery of treatments was the least preferred option (Figure 3)

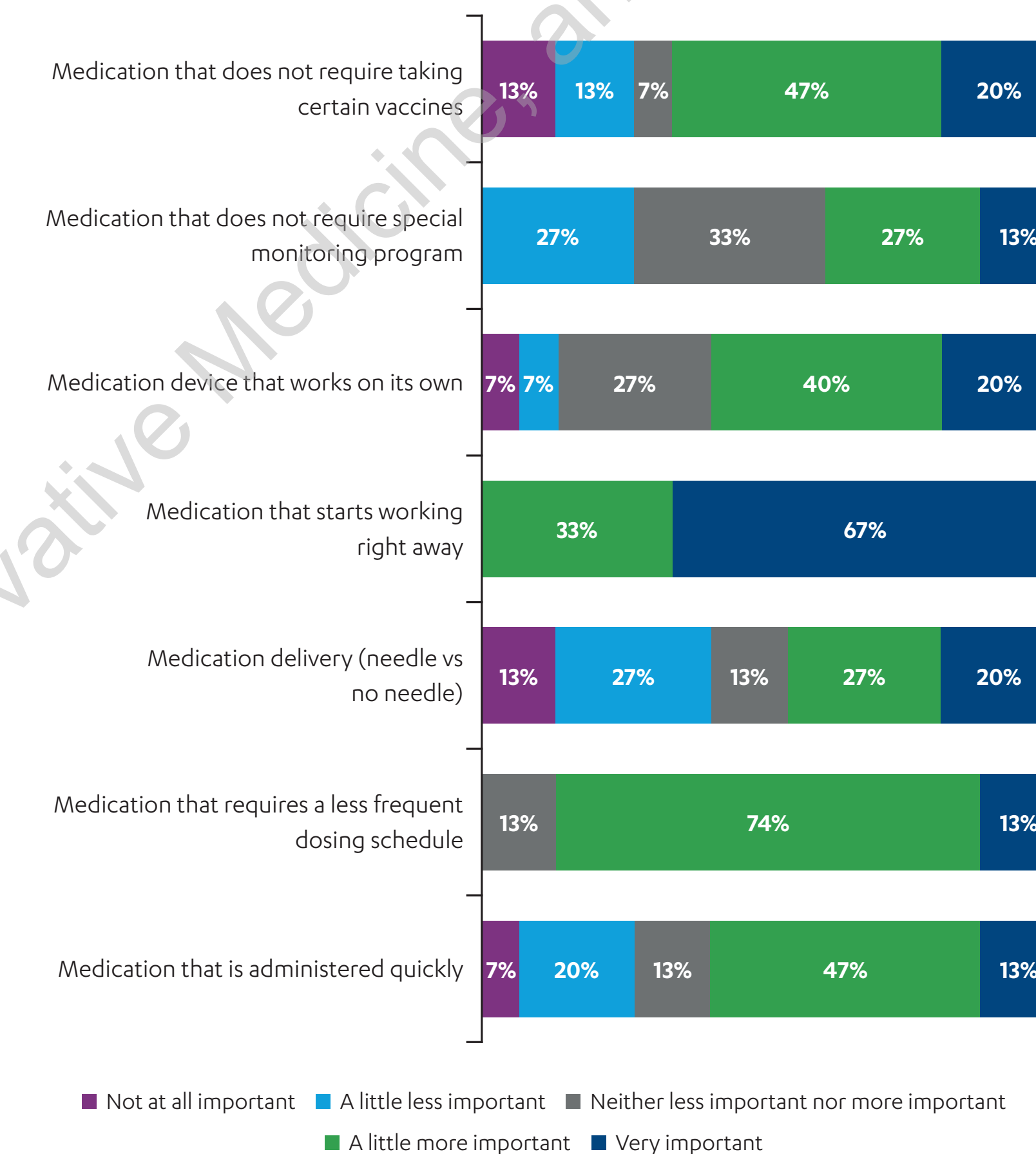
Figure 3. Preferred emerging myasthenia gravis treatment administration options^a



^aIncludes 15 participants who completed the prework survey; one of the 15 was unable to attend a focus group. Note: due to rounding percentages may not add to 100%.

- All participants somewhat preferred or most preferred a medication that worked rapidly, and many felt that a less frequent dosing schedule was important (Figure 4)
- All participants indicated preference for a "medication that starts working right away", and the majority felt that a "medication that requires a less frequent dosing schedule" was important (Figure 4)

Figure 4. Important factors for emerging myasthenia gravis treatments^a



^aIncludes 15 participants who completed the prework survey; one of the 15 was unable to attend a focus group. Note: due to rounding percentages may not add to 100%.

- Approximately 80% of participants preferred to share treatment decisions with the treating physician or make their final selection after considering the physician's opinion, 13% wanted to make their own treatment decisions, and 6.7% preferred to leave all treatment choices to the physician

Focus group results

Select quotes from patients attending the focus groups

“Some of the treatments that I've been on are 6, 7, 8 hours long, and that's a whole entire day. So, the length of it, how it's given, if it's something that I can do on my own, that's amazing ...”

Female patient with generalized myasthenia gravis

“... a lot of these things kind of roll into each other, so, if we're looking at side effects or symptoms that aren't controlled, that's going to automatically have an impact on quality of life ...”

Female patient with generalized myasthenia gravis

- In the prework survey, participants did not prioritize quality of life in their treatment decisions. However, when this was explored further in the focus groups, participants did not make a distinction between quality of life and other treatment factors (e.g., reducing side effects, avoiding crisis); most participants felt if a treatment attribute or concern was addressed, quality of life would also improve

- Consistent with results from the prework survey, controlling symptoms was important in current treatment decisions; this could lead to a better quality of life, prevent potential MG crisis or flare, and have an impact on other aspects of MG, including mental and physical fatigue
- Additionally, treatment convenience and home-based administration options were prioritized for both current and new MG treatments
- Expectations of new treatments included increased effectiveness, less dosing frequency, faster treatment onset, and fewer side effects. While a less frequent dosing schedule was an important factor according to the prework survey (Figure 4), participants were willing to have more frequent dosing if it resulted in more control (e.g., home-based administration, less symptom fluctuation, fewer side effects, fewer crises/flares)
- When asked about new methods of delivery, participants were receptive to an on-body delivery system
- Patients agreed that they wanted direct involvement, so they could make collaborative treatment decisions with their care team, family, and care givers

CONCLUSIONS

- This research provides important insights into patient and care giver treatment preferences in gMG
- Participants were open to new treatments, including new methods of delivery, and they desired new treatments with increased effectiveness, less frequent dosing, capacity for home-based administration, and fewer side effects
- Understanding patient and care giver preferences in treatments for gMG will lead to more personalized treatment plans that are considerate of patient values
- Most patients desired a collaborative approach to facilitate shared decision-making when selecting their treatments, which would enhance their overall well-being and their treatment experience and outcomes
- A larger scale study is needed to fully understand the preferences of individuals with gMG and the treatment attributes that drive their treatment decisions

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Disclosures

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