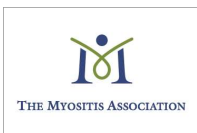


Integrating the “Lived Experience” of the Patient into the Training of Clinical Trial Investigators & Support Providers



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Introduction

Identifying a lack of general education on the patient “lived experience” by support providers in a myositis clinical trial, The Myositis Association (TMA) and Firma Clinical (Firma) partnered on an innovative approach to enhance nurse care provider training.

Additional feedback directly from myositis patients/care partners was also received to compare the program to topics most important to them.

Materials and Methods

- **Health Professionals** – (Ongoing) Up to 36 health professionals supporting patients in a myositis clinical trial will receive specialized information detailing myositis, the “lived patient experience”, and references to additional resources in addition to their standard protocol training.
- **Patients/Care Partners** – (Completed) A survey was distributed to 450 attendees at TMA’s Annual Patient Conference. 61 myositis patient and care partner attendees provided feedback supplementing this formal training to further detail their perspective & areas most important to them.
- **Assessment** – To assess the success and integration of this information, TMA and Firma developed a short evaluation to be completed by each trained health professional.

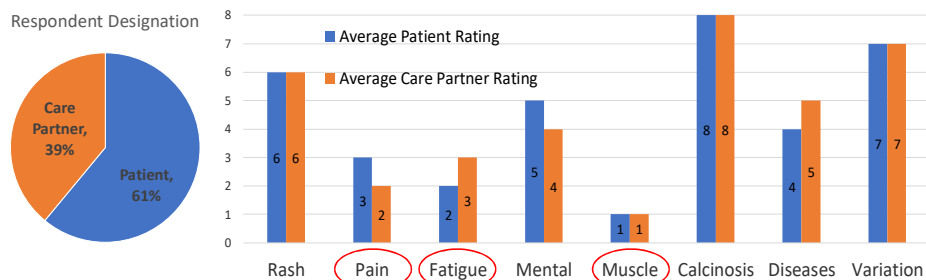
Results

Health Professionals – Feedback pending as enrollment and home health support assignments currently take place. Survey questions include:

“The supplemental training document enabled me to learn more about this condition and its impact on myositis patients and care partners?
 (Rank 1-5 – Strongly agree to strongly disagree)”

“Did you feel the need to seek out additional information on the disease condition beyond what was provided in the supplemental document? If yes, what additional information would be helpful for future training documents?”

Patients/Care Partners – 2019 Myositis Association Annual Patient Conference patients/care partners rating of the specialized training topics for home providers for relative importance (ranked 1-8) with 1 being most significant.



Verbatim response sample: What would you want a nurse/care provider who may be unfamiliar with myositis to know about you or your condition prior to supporting you?

- “How to assist a patient needing help (i.e. extending a hand or arm to help IBM patient get up is generally not helpful)”
- “Be aware of noise and light sensitivities with myositis”
- “Prone to fall, balance issues. Need assistance getting up from low center of gravity chair”
- “I’d like them to understand how...myositis affects not only me but impacts my entire family”
- “Fatigue/exhaustion are normal”
- “I cannot do things other patients can do: like get up on a step...get up from low chairs”

Conclusions and Next Steps

- **Perspective Counts** - Broadening perspective to include both patient and care partner input in patient support highlights important perspectives. In this case, there was alignment from patient and care partner with inclusion of top 5 items, though slight variation in ranking ‘Pain’ and ‘Fatigue’, noteworthy as these are top 3 rankings.
- **Verbatim Comment Key** – Verbatim comments highlight critical importance of “lived patient experience” to incorporate in home health training – especially as these perspectives are not captured in Pharma trial protocols.
- **Next Steps** – Firma and TMA to complete the survey of the health care professionals and then realign training documents to reflect the outcomes of these surveys.

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