

MONTHLY Feature

Improving Outreach and Care of Our Spanish-Speaking Community

According to recent demographic statistics of registered MDA families, almost a third are of Hispanic or Latino ethnicity. Historically, this demographic has been shown to get less treatment for their neuromuscular diseases, leading to worse outcomes.

To address this community's unique needs, MDA spoke with Yaacov Anziska, MD, associate professor of Neurology and director of the MDA Care Center at SUNY Downstate Health Sciences University in Brooklyn, New York. Dr. Anziska sees a number of patients who would be considered underserved — of a lower socioeconomic status — and many of them come from Central and South America. Here, he discusses unmet needs and shares best practices in caring for this community.

Unmet Needs

Some of the largest unmet needs of the Hispanic or Latino patients who come to the MDA Care Center include a language barrier, access to treatment, and less treatment. "One problem is clearly language, but that's not the only problem," Dr. Anziska says. Even though SUNY clinic's patient coordinator was Spanish-speaking, patients still had trouble understanding their disease, genetics and prognosis. "Educational barrier is more a problem than language barrier," he says.

Addressing the Educational Barrier

To address the educational issue, Dr. Anziska typically uses existing materials that he simplifies to leave out some of the details, "which can be good and bad," he says. While MDA offers disease-specific educational materials — some of which are already translated to Spanish, others of which are in the process of being translated — these can often be overly complex.

Dr. Anziska emphasizes the use of diagrams and employs a translator to help explain the materials to patients. Most patients do come to an understanding of their disease and the course of treatment, but it is often with help from members of their own community. "When patients speak to each other and other families, they can communicate it better," he says.



Best Practices for Caregivers

Other factors that contribute to the challenges of caring for this community include issues related to poverty. For example, patients and their families may experience food and housing insecurity, making it hard for them to afford insurance co-pays, take time off work to meet with specialists, and purchase mobility aids needed to get to and from appointments.

Dr. Anziska advises fellow clinicians to be more empathetic around these unique issues, offering the following best practices to caregivers and clinicians:

- Hire coordinators who understand the community and speak the language.
- Understand patients' social, economic and financial barriers, and tailor treatment to these vulnerabilities.
- Check in regularly with patients, even if they skip office visits.
- At every visit, confirm patients' understanding of their disease and course of treatment.

Dr. Anziska also makes an effort to alert patients to support networks such as social media communities, MDA Engage events and others. "I think this community feels isolated," he says, noting that they don't fully appreciate the role MDA plays in patient advocacy and care. "They don't feel part of the greater community, and some of that may be language, but not all."

MDA recognizes the importance of inclusion and is continuing to build upon its advocacy and outreach for all patients, including adding more MDA Engage events for the Spanish-speaking community, holding virtual events, and creating appropriate and targeted patient materials, among others.