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Patient Voices in ATTR-CM: Driving Change in Diagnosis, Referral, and Support

Announcer:
You're listening to *On the Frontlines of ATTR-CM* on ReachMD. And now, here's your host, Ryan Quigley.

Ryan Quigley:
This is *On the Frontlines of ATTR-CM* on ReachMD. I'm Ryan Quigley, and joining me to discuss his recent findings on patient experiences in transthyretin amyloid cardiomyopathy, or ATTR-CM, is Dr. Quan Bui. He's a cardiologist and an Assistant Professor of Medicine at UC San Diego Health. Dr. Bui, thanks so much for being here today.

Dr. Bui:
It's my pleasure.

Ryan Quigley:
So if we start off with some background, Dr. Bui, what motivated you to focus on the patient experience in ATTR-CM?

Dr. Bui:
Overall, there's a lack of data exploring the transthyretin amyloid patient journey. And so I think understanding their lived experiences will really improve the care of these patients in areas that matter most to them. So that's really what motivated me to do this study.

Ryan Quigley:
And now, to dive a little bit deeper on that, who did you include in your study, and what were you hoping to learn from their stories?

Dr. Bui:
So we conducted semi-structured interviews with patients diagnosed with transthyretin amyloidosis—including those with wild type as well as hereditary—in addition to at-risk family members with positive TTR genetic variants.

We really hoped to learn insights into the amyloid patient perspective on diagnosis, access to specialized care, emotional responses, and ultimately, use of support groups.

Ryan Quigley:
Thank you for that. And now, let's turn to your findings. What were some of the key themes that emerged across these interviews with these patients who have had these experiences?

Dr. Bui:
So overall, there were four central themes from the study. First, amyloid patients were quite knowledgeable about their disease, with many patients participating in self-education. Second, diagnostic delays were common and often a source of frustration for patients. Third, patients recognized disparities in care, mostly around access to specialized amyloidosis centers. And fourth, while peer support groups were more often viewed positively, patients in our study shared mixed experiences.

Ryan Quigley:
And, Dr. Bui, looking specifically now at diagnostic delays and disparities in care, what patterns did you observe in these patients who are dealing with these experiences?

Dr. Bui:
One of the things that struck me was that nonspecialist providers were often able to recognize that something was wrong. The patients were able to recognize this, but they said that these providers often struggled with initiation of appropriate diagnostic workup and timely

referrals. So a few patients mentioned that they underwent repeated cardiac evaluations, including stress tests and angiograms, trying to find out the cause of their symptoms, and they ultimately were unrelated to ATTR-CM.

And so these findings really suggest an opportunity for improved education amongst nonspecialist providers, strengthened partnerships with amyloidosis centers, and lower thresholds for referral. And hopefully, with these strategies, we can help address healthcare challenges, not only with underdiagnosis and undertreatment, but also with overdiagnosis and overtreatment.

Ryan Quigley:
For those just joining us, this is *On the Frontlines of ATTR-CM* on ReachMD. I'm Ryan Quigley, and I'm speaking with Dr. Quan Bui about patient perspectives on living with ATTR-CM.

So, Dr. Bui, I do want to ask, how did patients describe their experiences with support groups and online communities?

Dr. Bui:
So I think peer support groups are generally viewed as helpful for patients with chronic illnesses and really offering a sense of community for disease management. However, I was interested in how, in our study, patients shared that sometimes these groups can be overwhelmingly negative and bring about retraumatization. So it should be noted that these unregulated nature of these platforms increases the risk of misinformation. I think providers should be mindful of both the benefits and limitations of these peer support groups when recommending such resources to patients.

Ryan Quigley:
And, Dr. Bui, before we wrap up, how do you see your findings informing the future of care for patients with ATTR-CM?

Dr. Bui:
One thing that was interesting to me was that patients recognize disparities in amyloidosis care. We really need to focus on strategies that will improve access to these specialized amyloidosis centers. And so, as I mentioned, this could be done through strengthened partnerships with the community or lowering thresholds for referrals. For example, I've seen success with dedicated heart failure with preserved ejection fraction or thick heart clinics and lowering the thresholds for referrals and identifying more patients with ATTR-CM.

So ultimately, timely and accurate diagnosis is essential because the prognosis worsens and the efficacy of therapies declines in later stages of this disease.

Ryan Quigley:
That's a great comment for us to think on as we come to the end of today's program. And I want to thank my guest, Dr. Quan Bui, for joining me to discuss how patients' experiences can reshape care in ATTR-CM. Dr. Bui, it was great having you on the program.

Dr. Bui:
Thanks for having me. It was a lot of fun.

Announcer:
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