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ReachMD

www.reachmd.com

info@reachmd.com

(866) 423-7849

Health Disparities in the Management of Uterine Fibroids

Announcer:

Welcome to CME on ReachMD. This activity, entitled Health Disparities in the Management of Uterine Fibroids, is provided by Omnia Education and is supported by an independent educational grant from AbbVie prior to beginning the activity. Please be sure to review the faculty and commercial support disclosure statements as well as the learning objectives.

Dr. Mencia:

Welcome to our discussion on health disparities and the management of uterine fibroids. I'm Dr. William Mencia, and I'm joined today by Miss Sateria Venable, founder and CEO of the Fibroid Foundation. Miss Venable, welcome to the program.

Ms. Venable:

Thank you for having me. It's wonderful to be here.

Dr. Mencia:

Miss Venable, a patient's journey with uterine fibroids from the first onset of symptoms through diagnosis and ultimately finding an effective treatment can be very long and arduous. Can you walk us through what your personal journey was like and would you describe that is typical?

Ms. Venable:

I think my journey was very typical from what I've learned since I've started my work in advocacy. I grew up in a family of women who experienced heavy menstrual bleeding and they considered it normal and managed it as such. So as a little girl, I remember my mom doubling up on sanitary products to take me out places, when she was really in agony. And so that was my reality. So I endured my symptoms for a long time because I had seen that growing up. I was diagnosed at 26, and what took me to the doctor was the bleeding had just gotten so unmanageable and I was just really uncomfortable in a lot of pain. And I was diagnosed with fibroids. And I think another thing is typical is that when I was diagnosed, I had never heard the word fibroids. I hear that from quite a number of community members. In the process of treatment and seeking treatment, I also think was typical because my fibroid journey started off with the treatment options that I knew of at the time. I was immediately recommended to have a hysterectomy, which is sadly what a lot of women experience. And I found the physician who offered a hysteroscopy, but sadly that again, that physician was not really a minimally-invasive, gynecologic surgeon, so I had a very poor first treatment experience and unsuccessful. And I think my journey is also typical because, despite the fact that I've had four fibroid surgeries, the reason that there were four is because the fibroids returned for me in under a year each time. So I think that many, many women experience that. They experience trying to find the right provider, learning how to advocate for themselves, and trying to find treatments that will be effective for them over a longer period of time.

Dr. Mencia:

Thank you for sharing your personal journey with us, Miss Venable. And it sounds like you may not be alone and what you experienced. Would you say then that health equality or inequality as it be, plays an important role in determining how a woman's journey with uterine fibroids will unfold? How would you define health equality and with your experiences through your work at the Fibroid Foundation, what insights do you have on how its presence or absence affects patients outcomes?

Ms. Venable:

That's a great question and I think there are many facets to healthy quality. One is proximity. I think that there are many women who need treatment, who don't have access to a really skilled fibroid specialist, and that could be because they're in a rural area, or it could be because they're just simply in a location or town where none of those specialties exist, and that's worldwide. And I think that another aspect of health equality is that physician-patient dialogue and communication. I think sometimes physicians and people in our arena are too close to the medicine to have an appreciation for the fact that we're speaking with someone who has absolutely no knowledge of what we're talking about. And I'll give an example of that. I was, I think I was between surgeries two and three. I was in my doctor's office and he asked me if I had driven to my doctor's appointment. And I thought that was an odd question. And he said - I told him I had, and he said, I'm afraid that you might pass out behind the wheel driving home. And that was the first time that I really clearly understood the significance of my anemia as it relates to my day to day experience. I knew I felt badly. I knew I was inhaling with more shallow breaths, but I didn't understand that I could pass out and I just didn't understand the dynamics of anemia. I think it's also important too to not make assumptions and not treat any patient differently because of their access or insurance. And these are all incredibly important factors. There should be just a level playing field, a tremendous bedside manner, and that facilitates a much better treatment experience for patient and provider actually.

Dr. Mencia:

So following up on that, would you say that there are regional differences in terms of health equity?

Ms. Venable:

Absolutely. We've discovered during many of our research projects and studies that the incidences of hysterectomy in the South East are far higher than any other area of the country. Hysterectomy is offered far more often to women in the South East of the United States, and that is a definite health disparity. The numbers of hysterectomy are far greater, while in other areas of the country other treatment options are offered and it kind of balances out.

Dr. Mencia:

For those just joining us, this is CME on ReachMD, and I'm Dr. William Mencia. And I'm here today with Ms. Sateria Venable, founder and CEO of the Fibroid Foundation. We are discussing health disparities in the management of uterine fibroids. It's interesting, Miss Venable, you mentioned maybe the cultural challenges that you experienced as part of your patient journey, your diagnostic journey. And I want to explore that a little bit more. How can clinicians help women overcome the cultural barriers that may interfere with both how women recognize the need for medical attention and in how women can become stronger advocates for their own care?

Ms. Venable:

I think that there are many ways that we can improve the culture or overcome the cultural challenges. There are many aspects to that. I think that within the African-American community or communities of African descent, there is a fear of medical treatment that is very a very old fear that sadly stems from treatment experiences in the past that were biased or racially biased. And while I think and know that the medical community has evolved significantly beyond some of those old horrific experiences, generationally between families, there's still that fear so that when our community members reach out to us for fear of seeking treatment is one of the first things that they verbalize. And I think one of the ways that we can overcome those challenges is by listening to women reaching out. I think we host fibroid talks, and the reason we do that is because we create a setting, a social setting, where physicians and patients can communicate and congregate outside of the physician's office setting or a clinical setting. And then I know there are significant time constraints, oftentimes with physicians in their offices. And one way they can augment that is by partnering with a really knowledgeable and verified nonprofit organization that can help to provide information that they may not be able to share during the visit. And that also helps to overcome some of those health disparities.

Dr. Mencia:

You make a great point regarding the levels of communication between clinician and patient and how critical that is and ensuring a strong partnership. Do you have any suggestions on how clinicians can help patients open up to get them to describe their symptoms that maybe they might be embarrassed or uncomfortable bringing up?

Ms. Venable:

I think that there are many strategies that could be utilized to further engage the patient. And I think really the focus should be on giving her a level of comfort. And oftentimes patients don't realize that their symptoms are typical and very common, sadly. And I think sometimes when the questions are asked in the doctor's office, like, how many times do you change a sanitary napkin? There needs to be a conversation of don't feel bad. This is very common. There are so many women suffering through this. Don't be afraid. Uterine fibroids are benign tumors. Many women don't realize that initially, and they are very concerned about what's going to happen in their bodies there. They don't open up right away. And I think if there is a conversation around treatment and what needs to be done, they will

relax and be able to share more information that then can enable their healthcare provider to treat them.

Dr. Mencia:

And that's actually a great transition to my next question. Miss Venable, can you please share with our audience some additional information about the Fibroid Foundation, as well as the types of resources and programs that are offered to help address these health disparities?

Ms. Venable:

Sure. I started the foundation really seeking information. I was a frustrated patient. I had just had my second of four fibroid surgeries, and I could not find a provider. And I started speaking with women and then I started blogging about the challenges that I experienced and the solutions that I found for them. And those experiences transitioned into the mission of the Fibroid Foundation. So education is really preeminent area of focus. We seek to educate women on what fibroids are, dispel those fears, help them to know that they can advocate for their care, that there are solutions. We also consult because the patient voice in the consulting and medical device and development arena is critical when patients and physicians or clinicians have an opportunity to collaborate. Those are really two specialized viewpoints that I've seen time and time and time again have tremendously beneficial outcomes from collaboration. We also work in legislation. We actually just had a huge win because the Fibroid Bill was introduced in the House and in the Senate. And while because we're in an election year and it probably won't be reintroduced hopefully next year because of the logistics of the timing of everything, that is huge. We did a lot of advocacy work, met with over 50 legislative offices on Capitol Hill during the past year to try to bring that to fruition. And we will continue to advocate for funding. That bill will provide over, I think it's 30 million dollars per year for four years and NIH for research, which we desperately need in this arena. And then our final area of focus is research. We've designed research studies and we continue to be a voice in the research arena to help medical centers find unique ways to communicate with their patient community and to encourage women to participate in really verified and patient centric studies.

Dr. Mencia:

That's certainly exciting news coming out from Capitol Hill. Congratulations for that. Well, this has certainly been a fascinating conversation. But before we wrap up, if there was one key message that you'd like our audience to remember from this conversation, what would that be?

Ms. Venable:

It's that this is a partnership when we need the physician community to help women who are suffering with uterine fibroids. The community that is affected by this health concern is way too large. And we're there are millions of women who are suffering. And that message needs to be amplified over and over and over again because that suffering does not need to continue. We know too much now, and we have too many resources to be able to start to find out about new treatment options and methods. And I think the more that we share the urgency of this health concern from both the patient voice and the clinicians voice, the better off we will all be.

Dr. Mencia:

Unfortunately, that's all the time we have today. I want to thank our audience for listening in and thank my guest, Ms. Sateria Venable, for sharing her valuable insights. It was great speaking with you today.

Ms. Venable:

Thanks, Dr. Mencia, it was my pleasure.

Announcer:

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