PANEL DISCUSSION

UFE: Reaching More Patients and Meeting Their Needs

A conversation about awareness and access needs for uterine fibroid embolization, including what is holding it back from the mainstream, the intersection between disparities and access, barriers to care, effective awareness initiatives, and more.

With John C. Lipman, MD, FSIR, and Jessica K. Stewart, MD

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First, how would you describe overall levels of patient awareness of uterine fibroids?

Dr. Lipman: It is clear from our experience and from surveys that the Society of Interventional Radiology (SIR) has performed that there is a lack of public awareness of uterine fibroids. This is rather surprising given how common fibroids are in women; particularly, African American women disproportionately have these benign tumors. Fibroids are the number one cause of heavy uterine bleeding and the number one reason why women undergo hysterectomy.

Dr. Stewart: In my opinion, awareness of uterine fibroids and the impact that they can have on the lives of so many women is low but seems to have recently been increasing, in part related to sharing of experiences on social media, including in patient support groups on Facebook comprised of tens of thousands of people. I think these are great resources for patients to learn from each other and hear more about a variety of treatment options from a patient's perspective, helping them to better advocate for their own health.

And the levels of uterine fibroid embolization (UFE) awareness?

Dr. Stewart: UFE has been a well-established minimally invasive treatment for many years, and yet it remains underutilized. In fact, a recent analysis of inpatient data from 2011-2020 indicated that only 2.9% of patients nationwide were treated with UFE, with no increase in utilization over the decade.[1] Many patients are not told about UFE during initial consultations and only come to find out about the treatment by doing their own searches online or by word of mouth. Studies, including surveys of women who had a consultation for UFE, have found that the majority of these patients were self-referred. This may be partly due to misconceptions about the procedure held by referring physicians, such as concerns regarding the procedure's effectiveness for fibroids of different sizes/locations or for adenomyosis, pain management after the procedure, potential effects on future fertility, or exposure to radiation. We can do more as interventional radiologists (IRs) to help dispel these myths.

Dr. Lipman: Despite the fact that UFE has been available throughout the United States for > 25 years, with a long track record of proven safety and efficacy, it has languished in obscurity. In 2008, the American College of Obstetricians and Gynecologists endorsed UFE with level A scientific evidence, but this has not had an effect on the number of gynecologists mentioning UFE as a treatment option for the treatment of symptomatic uterine fibroids. Hysterectomy

is the second most common surgery performed in the United States, and this high hysterectomy rate is a direct reflection of the public's lack of awareness of UFE.

With UFE already a relatively established procedure, what is holding it back from breaking through to more mainstream awareness?

Dr. Lipman: Gynecologists are the gatekeepers of women's health. When women have symptoms due to fibroids, they naturally seek a gynecologist's opinion and care. However, it is clear that many gynecologists are not informing women about all of their fibroid treatment options. Women are entitled to know all of their treatment options for symptomatic fibroids—not just the surgical options.

Dr. Stewart: It should be standard practice for physicians to use shared decision-making aids when discussing treatment options with fibroid patients to ensure that the treatment options offered align with the individual patient's values. For example, one patient may value a speedy return to work and minimal downtime over a more invasive procedure, even if the minimally invasive procedure may involve some chance of symptom recurrence. A study in collaboration with The Fibroid Foundation performed semistructured interviews with 47 patients regarding fibroid diagnosis, treatment, experiences with providers, reproduction, and perception of care.[2] This study found that patients had feelings of dismay when only surgical options were offered and that the treatment choices offered were incongruent with patient treatment goals. For women to be able to make informed, collaborative treatment decisions, accurate information regarding the side effects of UFE must be clarified with gynecologists, who are often the first clinicians undertaking shared decision-making with patients with uterine fibroids. The information also needs to be implemented accurately into fibroid treatment decision aids. Short of this shift, the best way to reach more patients, in my opinion, is to directly reach patients through online educational resources as well as conventional media and social media.

How do disparities in prevalence intersect with those in access to care?

Dr. Lipman: As previously mentioned, fibroids disproportionately affect women of color. With so many of these women impacted, the cause of and treatment for uterine fibroids deserve our attention for the crisis that it is, despite any "inconvenience" related to referring to a different type of medical doctor (ie, IRs) to inquire about UFE.

Marginalized populations and people of color continue to be denied the reproductive freedoms available to other women and entitled by all. Not informing women who have uterine fibroids about UFE reflects what has happened historically to cause people of color to mistrust the medical establishment and other forms of authority that continue to perpetuate health care disparities. This leads to women delaying medical treatment for their fibroids, which often involves years of prolonged and unnecessary suffering. A landmark study from the Mayo Clinic in 2013 studied approximately 1,000 women with fibroids, demonstrating that most of these women waited > 3 years for treatment and 25% waited > 5 years. This was largely due to not informing patients of nonsurgical treatment options like UFE. Hysterectomy is no longer the first-line or only treatment option; it should be relegated to a last resort option given the outstanding results of UFE.

Keep in mind, the average age of hysterectomy is < 40 years. Therefore, one needs to ask, "Why are so many young women, including a disproportionate percentage of Black women, undergoing a permanent surgical procedure for benign disease, without being presented UFE as an option?" UFE is very effective and much safer, much less invasive, and with a much shorter recovery than hysterectomy. There are also consequences for women losing their uterus, particularly young women, and this is underappreciated by many gynecologists. I often hear patients tell me that their gynecologist told them that their uterus was worthless if they were not interested in future fertility. However, women who've undergone hysterectomy often struggle psychologically (similar to a castrated male), struggle sexually (loss of libido, loss of orgasm), leak urine (check the packaging for adult diapers), have significant bone loss, and even have an increased cardiovascular risk (particularly for hysterectomy in those aged< 50 years). This has to stop!

Dr. Stewart: Black women have a higher prevalence of uterine fibroids compared to White women. Black women are also more likely than White women to have more and larger fibroids, be diagnosed at a younger age, and indicate a preference for uterine-sparing treatments such as UFE. The COMPARE-UF registry, comprising 1,141 White women and 1,196 Black women, found that Black women were more likely than White women to undergo UFE (17.6% vs 5.5%).[3] As the authors of these results discuss, the reasons for this difference are likely multifactorial and could relate to distrust as a result of historical racial inequities regarding hysterectomy, preference for a rapid recovery with little downtime, or desire for future childbearing (Black patients were younger than White patients undergoing treatment). However, COMPARE-UF had limited inclusion of women in rural locations. These prefer-

ences may or may not be similar in rural populations, and which procedures patients ultimately undergo may be more related to availability in rural areas rather than true patient preference. However, given that available data indicate that Black women find minimally invasive, uterine-sparing treatments for fibroids seemingly align best with their goals, it is unacceptable that UFE is not routinely discussed by gynecologists as an alternative to hysterectomy with these patients.

What kinds of initiatives have shown progress in creating greater awareness, and what has been most effective?

Dr. Stewart: Groups like the Fibroid Foundation and The Society for Women's Health Research have been promoting awareness of UFE as a treatment option. These organizations create resources such as webinars, informational brochures, and advocacy materials that reach both patients and medical professionals. Several institutions have also established multidisciplinary fibroid clinics where patients can be seen by IRs and gynecologists simultaneously to discuss the spectrum of treatment options available to them. In addition, when patients have positive experiences with UFE, they often share their stories in support groups, on blogs, or in interviews. Word-of-mouth recommendations from those who have undergone the procedure can have a powerful impact on spreading awareness. Continuous education for doctors through conferences, webinars, and direct outreach by IRs is crucial to overcoming the lack of awareness among health care professionals. The more knowledgeable physicians are about the procedure in general, the more likely they are to recommend UFE as a treatment option.

Dr. Lipman: We need greater medical research into what causes fibroids, which hopefully will lead to a better understanding of preventive measures and can change the lives of millions of women in the United States. This highlights another disparity that needs to be corrected. In 2020, $18 million were spent on fibroid research. This ranks in the bottom 50 out of 300 common medical conditions, despite the fact that it affects one in every three adult women and up to 80% of African American women in this country. Fibroids have an estimated yearly cost to society of $35 billion. Therefore, with roughly 26 million women affected, the amount of research funding is approximately 69 cents per person with fibroids. Contrast this with cystic fibrosis, a medical condition that affects primarily Caucasians. In 2020, cystic fibrosis commanded $94 million in research funding and has a much lower impact to society than fibroids (approximately $1 billion/year). With 30,000 people affected by cystic fibrosis, this results in > $3,000 per person affected versus 69 cents per person for fibroids. This is unacceptable.

As a first step, Congress should pass the Stephanie Tubbs Jones Uterine Fibroid Research and Education Act of 2021 (H.R. 2007). My hope is that with this, the National Institutes of Health will get much-needed funding, which should include women of color who are often underrepresented in medical research. It will also direct the Centers for Disease Control and Prevention to educate physicians and the general community at large on all treatment options for uterine fibroids, including UFE. With this, women will be empowered to make the best, most informed decision about their reproductive health and well-being.

When speaking to patients, what barriers do they describe in their processes of seeking and receiving care for their fibroids?

Dr. Lipman: Many patients appreciate the time they spend with us (30-45 minutes of physician time). They feel heard, and I spend a lot of time listening to their symptoms and their fibroid journey. Many of these women suffer needlessly because their previous doctor didn't spend the necessary time with them or only offered surgical options that the woman did not want. They describe their doctor trivializing or dismissing their symptoms, saying it's part of being a woman or natural aging and perimenopause or that they don't need their uterus if they're not interested in future fertility.

There are > 1 million women in the United States who we call the silent sufferers. These women are suffering with symptomatic fibroids and have been told by their gynecologist that their only treatment option is hysterectomy. They don't want a hysterectomy, so they endure the miserable bleeding and pain each and every month, not knowing that UFE could literally transform their life back to normal.

Dr. Stewart: Patients often express disappointment and frustration that they had to learn about UFE themselves through their own online searches, rather than being told about this up front by their physician, and that they were often told inaccurately that hysterectomy was the only reasonable treatment option. These patients often have been through a long process to finally be seen for a consultation to discuss UFE, suffering a great deal from their symptoms in the meantime.

Reflecting on your successful work with referrers, how have you learned to meet their needs? What are the first steps in establishing

that trust, and ultimately, how do you prove yourself and your offerings in a way that's truly meaningful to them?

Dr. Stewart: In building my practice, the first step is outreach to referring physicians. I visit them in their offices and have an informal conversation about their patient population and what their needs are. Many of them are unaware of the procedures that IRs offer and that we see patients in clinic and follow patients ourselves. I also make sure that these physicians have my cell phone number so that they can reach me easily to discuss challenging cases and answer questions quickly. I let them know about innovations in patient care that improve the patient experience, such as superior hypogastric nerve blocks to reduce pain after the procedure. I also build trust by offering my services to help care for their most challenging patients, whether that be patients with adenomyosis who want to avoid hysterectomy, patients who aren't candidates for general anesthesia, or patients with pelvic pain of unknown origin that I can help work up and treat. Helping to take on cases they find challenging or difficult is a surefire way to build a fruitful relationship.

Dr. Lipman: When you show people that you care, then trust usually follows. That's true with patients, as well as the referring physicians. I do see a number of gynecologists refer their patients to me for UFE because our practice has established a high level of trust over many years of collaboration. Our clinic sees fibroid patients every day; it's my life's work. I take a lot of pride in what the Atlanta Fibroid Center has accomplished in the 20 years we've been around. I also refer a lot of patients to gynecologists, and oftentimes we work together on caring for these women.

How are you using social and traditional media to increase awareness?

Dr. Stewart: My institution has had success with creating patient-oriented YouTube videos that are posted to the radiology department website for a variety of interventional radiology procedures. Many patients find our physicians this way during their online searches. These videos include how to get in touch with our team to schedule a consultation to streamline the process. We also have brochures available in our waiting room so that patients undergoing other imaging procedures (such as mammograms) can see that this is a treatment offered by our IRs in case they or someone they know might benefit from a consultation.

Dr. Lipman: UFE is one of the biggest medical breakthroughs for women. Patients get the relief of symptoms that they're looking for, avoid the risks and long recovery of surgery, and get to keep their uterus (and even have children afterwards). This is a tremendous story, and we spend a great deal of time telling it to anyone who will listen, through any and all channels. We create a lot of content, attend health and women's events, do interviews/podcasts, post on social media channels, and occasionally participate in segments with traditional media (TV, radio, print) as well.

What collaborations with other providers are you currently working on?

Dr. Lipman: Last year, with the help of the SIR Foundation and the Women's Health Clinical Specialty Council of the SIR, we established the Annual James B. Spies Fibroid Research Summit and the Scott C. Goodwin Adenomyosis Research Grant. In addition, I have been working with the Outpatient Endovascular and Interventional Society on an embolization registry that we hope to launch this spring. I'm also working with Dr. Pratik Shukla from Rutgers and the Radiology Health Equity Coalition on a 1-page patient educational flier on fibroids and UFE.

Dr. Stewart: Our institution has a monthly benign gynecologic Zoom meeting where we discuss challenging cases with our minimally invasive gynecologic surgeons. I was also honored to serve as the junior lead investigator for the James B. Spies Fibroid Research Summit on reproductive outcomes of patients undergoing UFE (generously funded by Dr. Lipman). This was an invaluable opportunity to collaborate with gynecologists and other experts to help guide future research efforts on this important topic. I also collaborate with gynecologists on ongoing research initiatives, which is a great way to engage these physicians as partners to learn more about issues impacting patients with fibroids. ■

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Disclosures
Dr. Lipman: None.
Dr. Stewart: Consultant to Terumo Interventional Systems, Medtronic, Varian, and Crannmed; advisory board member for Microbot Medical; consultant and advisory board member for Cook Medical.