



BLACK WOMEN'S
HEALTH IMPERATIVE

SPARE ME:
REAL TALK
FOR COMPASSIONATE CARE
FOR BLACK WOMEN WITH
UTERINE FIBROIDS

Discussion Guide

Supported by



THE WHYS: THE NEED FOR THE UTERINE FIBROID CONVERSATION

As Black women, we often know enough about fibroids to know that we don't want to be diagnosed with them, but often not enough to make informed decisions about management of them or to explain them to our loved one. Even so, we are often asked to do just that. This discussion guide is made not just for Black women, but by Black women.

THE WHY

BWHI'S WORK AND THE NEED FOR THE UTERINE FIBROID CONVERSATION

80% BLACK WOMEN SUFFER FROM UTERINE FIBROIDS

QUALITY OF LIFE TREAT THE WHOLE PERSON

missed OPPORTUNITY NOT DIAGNOSED EARLY ENOUGH

CHANGE THE CYCLE

BE THE EXPERT OF YOUR OWN BODY!

DR. CHARIS CHAMBERS, M.D. PEDIATRIC & ADOLESCENT GYNECOLOGY

“THE PERIOD DOCTOR”

RECOMMENDATIONS

- SIZE AND LOCATION
- COPY OF RECORDS
- get the doctor's notes

WHAT I SHOULD ASK?

THE SIZE OF YOUR fist

IS THERE A TREATMENT OPTION THAT YOU'RE NOT OFFERING?

REASONS FIBROIDS DEVELOP OVERGROWTH

- ESTROGEN
- HEREDITARY?

NO, BUT *FIRST MEMBERS (MOTHER, SISTER) INCREASED RISK

NON-CANCEROUS MUSCLE WHERE FIBROIDS GROW

UTERINE 101 fibroids

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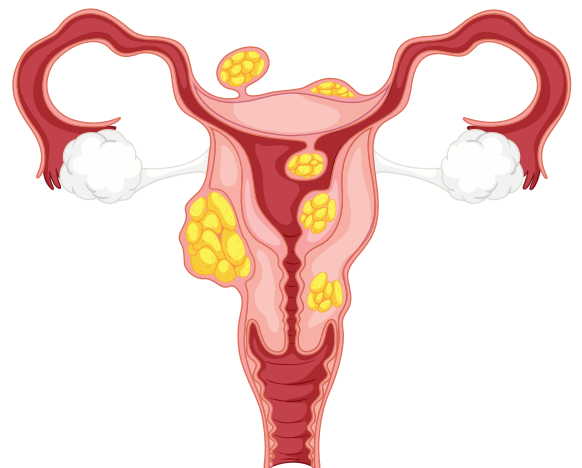
September 21, 2022

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THE BASICS: UTERINE FIBROIDS 101

WHAT ARE FIBROIDS?

- Fibroids affect the uterus, so it's important to know what the uterus is first. The uterus is a reproductive organ that is situated low in the pelvis and is typically about the size of your fist during childbearing years. It sits above the vagina and connects to the vagina via the cervix. The cervix is what dilates to 10cm to allow for a vaginal birth.
- Fibroids grow from the muscle layer of the uterus. The uterus is comprised of muscle which is why it contracts and why we get uterine cramps. Fibroids are abnormal growth of the muscle layer.



WHAT ARE THE SYMPTOMS OF UTERINE FIBROIDS?

Symptoms of uterine fibroids depend on the size and location of the fibroids. For reasons not fully understood, Black women with fibroids tend to be more symptomatic. Fibroid symptoms include abdominal pain, abdominal distension, heavy bleeding, early satiety, pain with intercourse, constipation, urinary urgency, and more.

IF YOU'RE DIAGNOSED WITH FIBROID WHAT ARE SOME OF THE FIRST QUESTIONS THAT YOU SHOULD ASK?

- Ask about size and location and see if you can get your ultrasound or imaging report. The withholding of medical records is intrinsic to the patriarchal history of the healthcare system. Historically, doctors could decide whether they felt you needed to know certain information about your care. Fortunately, this has changed with updated laws and policy. You now have every right to your medical record and by obtaining this, you gain the power to track changes as well as to back up any future concerns with tangible diagnostic evidence that you have already been diagnosed with uterine fibroids.



- Ask about their recommendations and next steps. This is a good way to ensure that your provider is thinking of next steps and planning for follow up instead of just giving you unactionable information. Sometimes next steps are just surveillance, but it can also be medication or even surgery.
- Ask “Is there something else that you are not offering me, that another doctor or specialist, would offer me?” This is a critical question to ask, because doctors tend to offer what they can do, what they were trained to do, and what they do most often. This question really lays the groundwork for seeking a second opinion. Second opinions are amazing and are every patient’s right.

WHAT IS ONE OF THE BIGGEST MISSED STAGES OF INTERVENTION?

The opportunity to be make sound judgement on next steps without the burden of profound anemia, pain, or fatigue. When we are diagnosed too late with fibroids, the burden of the disease can be so significant that we make urgent decisions that may not serve us best in the long-term. They also may not fully consider all of our personal, financial, or family planning goals. The truth is that we don't make our best decisions when we're in an urgent state of mind. When we've been worn down and are just barely making it, we may often choose the option that gives us relief the fastest. That may contribute to the disproportionate rate of hysterectomies in black women, not just because we may elect for them, but also because they may be more readily offered based on the severity of our symptoms at the time. In these settings, we may fail to have an honest appraisal of our fertility desires, our cultural needs, and our personal priorities.

ARE UTERINE FIBROIDS HEREDITARY?

While there isn't a specific gene that we can identify that will tell us whether you are at higher risk for uterine fibroids, we do know that you are at higher risk if you have a first degree relative with uterine fibroids. This should serve is motivation to have conversations about fibroids and share details about our experiences with our family members, so they can be better positioned to recognize signs or symptoms in their own bodies. Hopefully, this may allow for them to seek out earlier intervention and evaluation.

HER STORY

HOW DO FIBROIDS AFFECT QUALITY OF LIFE?



Quality of life must be considered to provide effective and compassionate patient care. Without the consideration of a patient's quality of life, that patient is often reduced to just lab values, number ranges, imaging findings, and second-hand interpretations. Unfortunately, medical record documentation is primarily the patient's words filtered through the clinician's bias and what they decided was important enough to document. Quality of life reporting can often be excluded. When we include quality of life points, we can gather an account that captures the whole patient. If a doctor fail to improve that patient's quality of life, they have failed that patient.

Her-Stories

IN the SPOTLIGHT
THE MEDIA and

ADRIANNA HOPKINS
BRING OUR DAUGHTERS WITH US TO OUR GYNECOLOGY VISITS
BUT, WILL THEIR STORIES RESONATE?
DECISION-MAKERS CAN BE BARRIERS TO SHARING STORIES
EDUCATE OUR GIRLS EARLY

LENEE' REDUS-CARSON
MY BODY DID THE BEST SHE COULD!
BELIEVE IN YOU!
ANGER LOSS
I FOUND A BLACK OBGYN WHO JOINED WITH ME
ADVOCATED FOR ME
MYOMECTOMY 3X
DOCTORS WHO DON'T PROVIDE ENOUGH INFORMATION ABOUT MY OPTIONS

CYNTHIA BAILEY
YOU OWN IT TO YOURSELF TO LIVE A QUALITY LIFE!
40's
FIBROIDS AFFECT EVERYONE AROUND YOU!
ANEMIA
PAIN
UTERINE FIBROID EMBOLIZATION
HOW SHOULD THIS TOPIC BE COVERED?
MORE MALE ADVOCATES
INCLUDE STORIES OF YOUNG WOMEN

TANIKA GRAY VALBURN
YOUR STORY IS YOUR POWER. PURPOSE...
15 YRS OLD
PAIN
BLEEDING 27 FIBROIDS REMOVED
YOU DON'T HAVE TO SUFFER IN SILENCE
CONVERSATIONS TO NORMALIZE THESE DISCUSSIONS!
BUILD TRUST WITH WOMEN BEFORE CAPTURING THEIR STORY
EMOTIONAL IMPACTS MUST BE ADDRESSED
RACIAL DISPARITIES IN HYSTERECTOMY CARE
BLACK WOMEN ALABAMA
STRUCTURAL BARRIERS OBGYN ACCESS LACKING
MORE SYMPTOMATIC & SEVERE

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IN THE SPOTLIGHT: THE MEDIA AND HER-STORIES

HOW CAN JOURNALISTS AND PROFESSIONALS IN THE MEDIA CHANGE HOW THEY REPORT ON UTERINE FIBROIDS?

- Use the platform you're given. Connect with those who are doing the work and speak your truth.
- If you're interested in the work, but are more of an outsider (Non-Black, with no personal experience of history of uterine fibroids), acknowledge the history, get to know the facts, and understand that for a lot of women, this is a deeply personal and sometimes private issue.
- There needs to be an effort to build trust and to be equally transparent. Be willing to answer as many questions as you ask.
- Another sad truth is that fibroid stories don't get the coverage that they deserve because they primarily involve Black women.



INVITING OUR POLICYMAKERS AS PARTNERS

WHAT ARE POLICYMAKERS DOING IN THE FIBROID SPACE?

- They are trying to pass legislation, The Stephanie Tubbs Jones Uterine Fibroid Research and Education Act 2021, which will provide \$150M to the National Institute of Health to address the fibroids public health crisis.
- The bill, specifically, expands and intensifies research. It also establishes a database where we can collect data. It also creates a public awareness campaign and provides providers with evidence-based care guidelines.

WHAT CAN WE AS CONSTITUENTS DO TO MAKE A DIFFERENCE?

- Write and call your elected officials to let them know that this is important to you and to the community.
- Take advantage of Fibroid Awareness month (July) and spread awareness.



WHY ARE BLACK WOMEN TREATED DIFFERENTLY WHEN IT COMES TO FIBROIDS?

It's fundamentally about racism and sexism. Unfortunately, we live in a world where biases affect the work that we do. Clinicians and even researchers are not above this. This shapes what research questions are asked, how we answer them, and what methodology we use. This also affects how doctors treat patients and how we offer these treatments to our patients.

WHAT IS THE BEST TREATMENT FOR FIBROIDS?

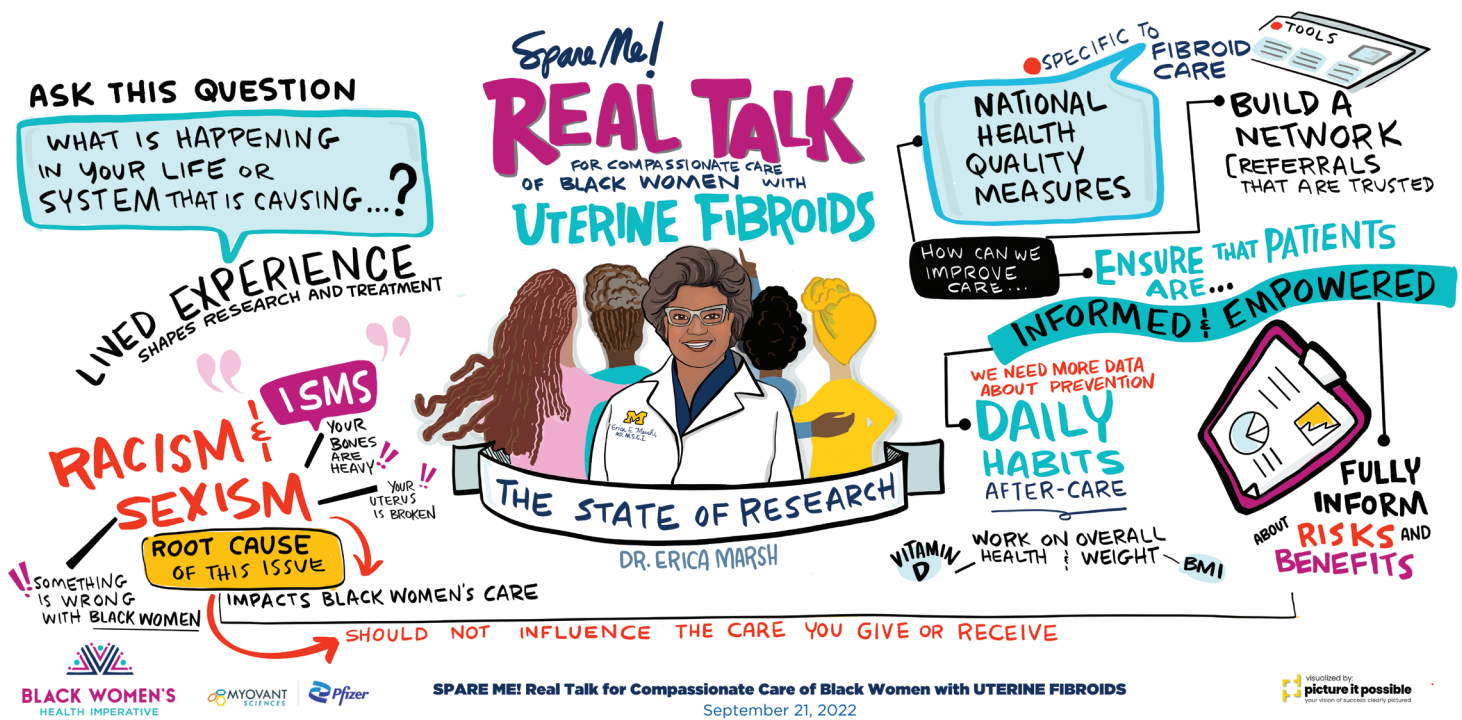
It's important not to demonize any treatments. For some people, hysterectomy is the right treatment, for others, medication may be best, for another uterine artery embolization may be best. The issue arises when the options aren't fully presented. We should be empowering patients to make informed decisions that are best for them.

INTERSECTION BETWEEN PATIENTS, RESEARCH AND TREATMENT

WHAT RESEARCH IS BEING DONE ON FIBROIDS?



Dr. Erica March (clinician, researcher, and fibroid patient) does research on this topic at the university of Michigan. Recently published research done by Dr. Marsh, showed that Black women actually pick minimally invasive options for surgery more often than not. It's important to highlight that these studies were done at centers of excellence for fibroids (these are not necessarily representative of typical healthcare settings where the majority of women are getting their fibroid care). These centers are places where patients are privileged to received high level, evidence-based, multidisciplinary care. The key takeaway of the paper was that, when we have the choice and are given the options, we choose the more uterine sparing option. It doesn't mean that Black women aren't still getting hysterectomies at a higher rate. It does beg the question, however, of how we make sure everyone is getting access to the full list of options, regardless of where they live and where they get their care.



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ARE BLACK WOMEN JUST BIOLOGICALLY DIFFERENT?

There's a long history of race and genes and genetic inferiority, and how we view different groups based on the color of their skin or physical feature. This has been used to justify some of the greatest atrocities in world history. These beliefs, held by our community as well as by folks outside of our community, have sometimes led us to believe that we are broken. This isn't to say that there is no genetic component to fibroids, but the question we should be asking is why. Why do they occur? What is happening in the system and in our lives that drives our bodies to make fibroids at younger ages that are larger? What are the stressors that cause our body to physicalize these things as fibroids?

ARE THERE CHANGES WE CAN MAKE DAILY, LIKE WITH FOODS OR ENVIRONMENTAL EXPOSURES, TO HELP DECREASE FIBROIDS OR PREVENT FIBROID RECURRENCE?

- What we do day-to-day drives the peaks of the highs and the depth of the valleys of our health, but there is limited research on fibroid prevention. We think that obesity is associated with fibroid growth. So working on our overall health and keeping our BMI between 19 and 25 may be helpful. There's also data that shows an association in Vitamin D and fibroids. We know that women of African ancestry, because of the physiology of how Vitamin D is processed in our skin, tend to have lower levels of Vitamin D. There are important questions being asked around whether vitamin D supplementation may help to lower the risk or recurrence of fibroids.



- After fibroid surgery, there isn't a lot of information on what prevents recurrence. What we know is that 89% of women who are of African Ancestry will have fibroids by the age of 50. If we remove the fibroids, about half of those women are going to have a recurrence. And about half of those women will opt to have another procedure. There isn't great information on what can be done to prevent the need for another procedure. Again, a few things we think may be affecting our risk of fibroids are obesity and Vitamin D levels. There are also some questions being asked around whether taking certain types of medications after fibroid removal helps prevent recurrence.

WHAT IS HAPPENING IN THE ADVOCACY SPACE FOR UTERINE FIBROIDS?

- Tanika Gray Valbrun of The White Dress Project – Her fibroids started around age 15. She never wore any white clothing and always had heavy menstrual bleeding which really took a toll on her life. Her Mother taught her that she should figure out how to not embarrass herself. She also went to a doctor who told her to save her money and get a surrogate because her uterus was too compromised to carry a pregnancy. She had 27 fibroids removed at her first myomectomy. It was during her recovery where she realized that she couldn't be the only one experiencing this. Therefore, she ended up creating an organization to tell women that they did not have to suffer in silence.
- Cynthia Bailey of the Real Housewives of Atlanta- Has also suffered significantly from fibroids. She first heard of fibroids during her pregnancy. They said it was nothing to worry about. She gave birth and continued to have the heavy cycles that she has always had. As she got older, they got worse. Around age 40 she was anemic, exhausted all the time, and had abdominal distension. She noted that a bunch of her other cast mates were suffering from it too, but no one was talking about it. She decided to share her story about fibroids and about UFE.
- You don't have to be a doctor or a celebrity to be an advocate for fibroid awareness. Anyone can share their story. Often by sharing our story, we invite others to share theirs. We're all in community together.

Remember, you are your own best advocate, and everyone deserves to have a quality life. The doctor may be the expert in medicine, but you are the expert in your body.