

# IN CONVERSATION:

## CONNECTING ART, HEALTH, AND LASTING CHANGE

*Transcribed conversation between Hayveyah McGowan & Tasha Burton*

HM:

How do you think sharing personal stories through creative mediums can empower individuals who have been affected by uterine fibroids to speak out?

TB:

The more we realize and recognize that other people share similar stories or experiences, the more we're able to reach a place where we can become a little bit more vulnerable, either by acknowledging the truth with ourselves or finally feeling some sense of relief that there is someone else out there, and we're not alone. Sometimes, conversation alone makes it difficult to arrive at that place. Not everyone is going to sit down and read a whole story or book, but visual arts are just a different way of disseminating information.

We must consider how people engage in different ways with different types of information when it comes to statistical facts and other data. Sometimes it depends on someone's level of education, for example, as to whether or not they're able to readily process certain information. It can be difficult to figure out what it is you're looking at. But when it's presented creatively, in a way where someone can see a reflection of themselves or witness someone speaking about their story creatively, I believe it touches a different part of the heart. It connects with a different part of our mental space, allowing us to let down our guard and really immerse ourselves in what we're seeing.

In the health care space, the arts are not often presented as a means to say, "Hey, this is what you're experiencing." However, with more artists beginning to talk about their health issues—especially physical health issues, which don't come up as often as mental health issues—we can now fill a niche area of how that information is conveyed. Collaborating with the health care space is very necessary, and I believe it can be incredibly helpful, especially with the younger generation. The way they receive, and access information is a lot different these days. When you're able to go online and see an infographic, photo, or other visual art representation of something deeply personal, it touches you in a unique way. I believe this approach is extremely beneficial and helpful to the community at large.

HM:

In your view, how has the legacy of racism and bias in the health care system affected the diagnosis and treatment of uterine fibroids for Black women and other marginalized groups?

TB:

Unfortunately, it has had such negative consequences on the health of Black women who experience uterine fibroids. I spoke with an obstetrician in Phoenix, Arizona, while starting this project. She shared that she's making the decision to leave her field because it has been very difficult for her, as a Black woman physician in reproductive health. She has to do a lot of labor and education with her colleagues to help them recognize and address their biases.

She told me a story about a woman, an immigrant from Africa, whose first language is not English. This woman needed a lot of help, assistance, and resources to navigate the health care system in America. Unfortunately, her physician was very cold to her and did not give her full information. Thankfully, the obstetrician I spoke to had a conversation with her colleague, which revealed the situation. She reached out to the patient, essentially saying, "I can't be your doctor, but I suggest you look here for services and resources." She felt that if she hadn't intervened, the woman might have faced even greater difficulties.

That's just one example of how health care bias works, even in situations where someone isn't experiencing uterine fibroids but is bringing life into the world while dealing with them. Because the symptoms vary so much from person to person, uterine fibroids are sometimes dismissed as something trivial.

For instance, I'll use myself as an example. My symptoms were relatively mild. I had weight gain, frequent urination, and heavy cycles. Almost all the Black women I spoke with said, "I thought that was just normal." They assumed heavy periods, back cramps, and fatigue were common experiences. When I went to the doctor, my physician, a Filipino woman, immediately suspected fibroids after an exam and referred me for an ultrasound.

Many of the stories I've heard differ. Women told me they were informed they had fibroids and were immediately recommended for surgery without being given alternative options. Others shared that their symptoms were so severe they had to take backup clothes to work, put towels down on chairs, or make other concessions throughout their day. These women often struggled to advocate for themselves because their symptoms were downplayed or misdiagnosed.

The historical legacy of racism adds another layer to this. From slavery to eugenics, Black women's reproductive systems have been controlled and exploited. Fannie Lou Hamer referred to forced sterilizations as "Mississippi appendectomies" because they were so common, often conducted without consent under the guise of medical necessity. This history contributes to a deep mistrust in health care among Black women.

Even today, forced sterilizations occur, such as in California's prison system or at the border with immigrants. Addressing this mistrust and systemic racism is essential. Women should feel empowered to advocate for

themselves, recognize bias, and seek second opinions when necessary. It's equally important for health care providers to confront their biases and improve their training so they can better serve diverse communities.

HM:

What are your thoughts on the advancements needed in the medical field to ensure early detection and improved treatment options for uterine fibroids?

TB:

I work in the clinical research space in addition to my art practice, so I'm familiar with the processes involved in hypothesizing and theorizing ways to gain more information scientifically. I understand that this requires putting together grant proposals and trying to secure funding because research is expensive.

When it comes to uterine fibroids, what I've realized recently is that more women are becoming proactive about visiting the doctor and getting diagnosed. However, these diagnoses—and the subsequent surgeries or treatments—cost the health care industry a significant amount of money. When these costs become burdensome for the healthcare and health insurance industries, they often trickle-down mandates, saying, "Figure out what's causing this, and start the research."

The problem is that when someone proposes to study a specific issue, particularly concerning Black women's bodies and minds, funding requests are often rejected across the board. Without funding, research can't happen. For example, last year, when articles came out about microplastics potentially contributing to uterine fibroids or chemical hair relaxers being linked to uterine cancer, it was because someone recognized a pattern and pushed for research. However, we need to go further.

One of the subjects I photographed for this project has rare genetic diseases and is an advocate for early genetic testing during infancy. The idea is that early testing could enable proactive health care. In oncology, for instance, if someone has a family history of leukemia and gets genetically tested, they can be monitored closely by an oncologist. This means early detection and treatment, which improves survival rates.

If genetics play a role in uterine fibroids—and they likely do, as many women have mothers, aunts, and grandmothers who've also dealt with fibroids—we should explore how to prevent or delay their development. Alongside medical advancements, there's also work to be done within the community. Talking about reproductive health in Black and Brown communities is still somewhat taboo.

People might say, "Looks like you're gaining weight," or "You need to go on a diet," without considering that a woman might have fibroids causing an enlarged uterus. Other advice might include, "Drink this tea for your cramps," or "Take this for heavy flow." These dismissals prevent meaningful conversations about what's really happening.

In some cases, subjects I spoke with didn't even know their mothers had undergone hysterectomies. They just knew their mothers went to the hospital and came back. There wasn't any discussion. When I asked about conversations they had with their mothers about reproductive health as they approached puberty, many said there wasn't much dialogue. It was usually, "Okay, it's here. Here's how to use pads."

There's a lot of shame associated with discussing reproductive health issues. No one wants to feel like something's wrong with them. Systemic racism also plays a huge role—women fear that voicing their concerns about reproductive health will automatically lead to hysterectomies without other options being discussed. And hysterectomy isn't the only solution.

Some women I spoke with found support when discussing their issues with friends, but others faced dismissal. The truth is, no one truly understands how uterine fibroids impact someone unless they've experienced it themselves. Fibroids are an invisible condition, and the lack of visibility makes them harder for others to empathize with.

We need to utilize support systems more effectively. Whether that's someone watching your kids so you can rest, or a friend bringing you a care package after a tough week dealing with symptoms, small gestures can make a big difference.

Personally, I've experienced pain so severe that it woke me up in the middle of the night—even when I wasn't on my cycle. These experiences underscore the importance of community and open conversations. At the same time, we need to be cautious about misinformation. Social media often promotes inaccurate advice about shrinking fibroids or detoxing the vagina.

While lifestyle changes like diet adjustments may help some people, they aren't a universal solution. I've had two surgeries to remove fibroids. Despite going vegan, exercising, and making other lifestyle changes, the fibroids returned. Genetics may play a role, and without research to understand the root causes—whether environmental factors, stress, or diet—we're left guessing.

Right now, the literature often suggests that fibroids could be a result of personal failings, like eating the wrong foods or gaining weight. This blame isn't helpful, especially when we lack definitive answers. That's why research is essential. We need hard data to identify the real factors at play so we can provide clear guidance and solutions.

For the future of reproductive health and overall well-being, we need collective efforts at the community, clinical, and research levels. These advancements require time, funding, and collaboration. Most importantly, they require an acknowledgment that Black women face unique challenges that are too often dismissed until they become societal issues.

If Black women are frequently calling out of work due to health problems, for example, their labor is missed, and only then might someone say, "Let's investigate this issue." Funding research is a crucial first step. Our future depends on people showing up, caring, and working together to address these challenges.

