

The Impact of Uterine Fibroids on African American

Women's Quality of Life

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November 21, 2016

## **Introduction**

Uterine fibroids are benign tumors found inside of or on uterine muscle tissue and can be the size of a pea or grow to the size of a small soccer ball. These tumors are often a painful and distressing burden to bear (Okolo, 2008). Fibroids, or leiomyomatosis, are a public health issue as they are widespread throughout much of the American female population; by the age of fifty, 80% of African American women and 70% of white women had reported cases of leiomyomatosis (National Institute of Health, 2013). This percentage might be even higher because 20-50% of women who have uterine fibroids do not feel any side effects. Women who do experience these side effects do so with varying severity- often based on race, age, genetics, and behavioral factors. Although fibroids often become a large burden for any individual, that holds true most often for African American, pre-menopausal, overweight women whose mothers or sisters also have the disease (Eisinger, 2015).

This paper will examine the disproportionate ways African American women acquire and experience uterine fibroids compared to white women, and analyze the ways in which access to healthcare information and health behaviors typical of their built environment heightens the burden of disease for these women.

## **Epidemiologic Data**

The morbidity of fibroids may be shocking, as more than three-quarters of African-American women will get them; however, the mortality is very low. Fibroids are benign tumors, and very rarely become malignant, which leads to leiomyosarcoma. Less than one in one thousand fibroids will be cancerous and will arise on its own- not from a preexisting fibroid

(Eisinger, 2015). As previously stated, it is difficult to determine the incidence of this disease because many people do not feel side effects and do not get screened routinely. A study by Okolo reported 59% of African American women tested at random had one or more fibroids, and the incidence reached 75% in African American women aged 45 or older (Okolo, 2008). These African-American women suffer the highest burden of this disease, as the same study by Okolo reported 45% of white women tested at random had fibroids, which is significantly less than the previously stated prevalence for African American women. This is correlated to the reported increased intensity to which African American women experience fibroid symptoms. Most women of childbearing age are at risk, unless they take preventative measures such as hormonal birth control or vitamin D supplements to regulate their hormone fluctuations and decrease the chances of getting fibroids (Nagel et al., 2013).

### **Biomedical Understanding**

Uterine fibroids are controlled by estrogen and progesterone levels, which rise during the ages of 20-35. Thus, the women most at risk are of childbearing age when these levels are highest. Alternatively, the tumors can either disappear or shrink when a woman goes through menopause, has recently been pregnant, or uses an anti-hormone medication, such as birth control (National Institute of Health, 2013). There is also a genetic link, so African American women with family members who have had fibroids have a threefold risk of acquiring the disease than they would have if it did not run in their family (Eisinger, 2015).

The two distinct stages of fibroid growth includes the transformation to an abnormal tumor cell and the further proliferation of those cells (Okolo, 2008). Therefore, each tumor originates from one single cell, creating greater risk of a greater amount of tumors for women

with a higher predisposition for leiomyoma (Okolo, 2008). These fibroids grow in muscles inside the uterine wall and can vary greatly in size; they range from about 1 cm to 16 cm. Both size and location of these tumors can also adversely impact pregnancy and fertility in women with the disease, and pregnancy loss during the first trimester is twice as common in patients with fibroids in the submucosal membrane than those without (Elthouki et al., 2014).

A study by Sharan et al. examined the level of vitamin D in a person's diet and its tendency to decrease the level of COMT mRNA expression (Sharan et al., 2011). Both HuLM and LM298, which are known to proliferate into tumors, have a sensitivity to vitamin D and tend not to rapidly divide in its presence (Sharan et al., 2011). Even though there are known and potential causes of fibroid development, more research needs to be done about the interaction between those factors to gain a better understanding of why they grow, and why they grow more frequently in African American women. There is currently no one necessary cause for uterine fibroids to develop. Current research suggests that their development is dynamic, and that hormone levels and genetics are contributing factors to their growth, shrinkage, and potential disappearance over time (Nagel et al., 2013). There is a relatively small amount of information about the genetic basis of uterine fibroids in African American women, as earlier studies on the disease were conducted in countries like Japan, where there is an underrepresented population of women of African descent (Elthouki et al., 2014). As studies continue in the United States and are organized to include more of these women, we can gain a greater understanding of the nature of leiomyoma and how African American women may respond differently to treatment based on their genetic differences to women of other races (Elthouki et al., 2014).

### **Risk Factors Associated with Social Determinants of Health**

A study by Stewart et al. discusses self-reported discrepancies regarding impairment of quality of life between white and African American women due to uterine fibroids, in which the latter are significantly more impaired in various aspects of their lives. In addition to the difficulty of dealing with, on average, more severe symptoms, they more often had to seek medical care and miss work to mitigate them, impacting them financially (Stewart et al., 2013). There is also a significant difference in anxiety regarding missing work and fibroid symptoms impacting personal relationships, which African American women are more worried about and think about more often (Stewart et al., 2013). A major concern is morbidity of fibroids negatively affecting close relationships (Stewart et al., 2013). African American women are more self-conscious than white women about the side effects of fibroids, such as the appearance of their stomachs and weight gain (Stewart et al., 2013). Uterine fibroids also interfere with many physical activities African American women partake in as part of their daily lives, so they also can affect physical health more so than they do in white women (Stewart et al., 2013). The list of all hindrances that leiomyomatosis causes African American women is even more extensive than the aforementioned examples, demonstrating that fibroids affect these women throughout several important aspects of their lives, and potentially affecting quality of life in a way that women with fibroids do not experience (Stewart et al., 2013).

In terms of their built environment, African-American women experience many cultural differences from women of other ethnicities; from the food they eat to the social support systems they rely on. This can affect the rate at which they acquire fibroids and also how they manage them. A correlation has been found between diets rich in red meat and the number of fibroids a woman has, with average consumption of red meat being slightly higher for African-American

women than white women (Eisinger, 2015). Additionally, these meat-heavy diets can also be extremely calorically dense and therefore a contributing factor to obesity. Obese women are twice as likely to get uterine fibroids, underscoring the relevance of the genetic, dietary, and physical activity components of both states of morbidity (Nagel, 2013). A woman who is both obese and African-American has an extremely high risk for acquiring the disease due to both behavior and genetics, but community interaction still must be accounted for.

There may be underlying cultural differences in the communities that African American women live and work in as a result of systemic racism in the United States. Economic stability and access to quality healthcare are often linked, and African-American women belong to two minority groups facing drastic economic inequality. Latina and African-American women are at the highest risk for low wages and living in a state of poverty (DeNavas-Walt et al., 2015). Medical care and access to medical information can be expensive; a lack of funds in addition to African-American women's historically limited reproductive health can reduce knowledge and therefore treatment options for painful or dangerous uterine fibroids (Stewart et al., 2013).

Due to African-American women's complicated relationship with the American healthcare system, many of them are less likely to seek out treatment for fibroids (Stewart et al., 2013). Detection, treatment, and reduction of uterine fibroids are fairly expensive, and potentially include invasive medical procedures. From a study of both insured and employed women, uterine fibroids cost affected individuals an average of \$4,624 annually via direct and indirect causes. A direct cause would be undergoing an MRI for detection or hormone treatment for shrinking, while an indirect cause would be money lost from having to miss work on a regular basis (Nagel, 2013). According to the 2014 US Census, 15,553 African-American

women were living under the poverty line, and this extra spending is a large burden to bear for many women (DeNavas-Walt et al., 2015).

### **Why the Focus Needs to be on African American Women**

Not having access to this type of medical care and information can hinder women from taking preventative measures so they do not have to wait until their symptoms become unbearable and resort to hysterectomy, the most common and most extreme treatment chosen by African American women for fibroids. Hormonal treatments such as estrogen-progesterone birth control have proven highly effective for regulating fibroid growth and development, but the issue, and why this community is so heavily affected by leiomyomatosis and needs more attention, is access to this medication (National Institute of Health, 2013).

Many African-American women with access to information about uterine fibroids reported that this was insufficient for them to make treatment and prevention decisions. These women were twice as likely to want more information than white women were (Stewart et al., 2013). This lack of education and access to quality information may be a reflection of the discrimination against African Americans in healthcare. This is an example of “stratified biomedicalization,” in which public health information and interventions may bypass groups of individuals and entire communities (Ranell, 2013). Although 14% more African American women look to the internet or ask family and friends about advice regarding health issues than white women, it is possible that the correct information specific to the African American community is either very difficult to find, or that individuals are socialized against this extensive exterior search for more efficacious treatment for their individual situation by their community (Ranell, 2013). Even with the existing options of several less invasive procedures available, such

as myomectomy or hormonal therapies, African American women are most likely to opt for hysterectomy. The decision to get a hysterectomy is potentially a result of a lack of effective discourse with physicians and others in the community, as well as the environment they live in (Eisinger, 2015).

Addressing the social aspect of managing fibroids, a recent study found that African-American women tend to build strong communities with each other and often seek out others who are in similar situations to themselves (Stewart et al., 2013). They are more likely to seek out peer support than white women, often in the form of chat rooms and women's health organizations. African American women are 25% more likely than white women to join a uterine fibroid support group, creating a community in which these women can look to each other for support (Stewart et al., 2013). This is perhaps due to the severe symptoms they experience in addition to the norms of the communities in which they were raised, where reaching out to others and talking freely about pain is a norm, as compared with white communities (Stewart et al., 2013). These cultures and communities also propagate beliefs about appropriate treatment for fibroids, which may, in fact, not be very effective for every individual woman with differing symptoms.

For many African American women at a reproductive age, leiomyomatosis is a fairly common condition, as demonstrated by the high incidence rate. However, there are many forms of treatment and even more forms of prevention that aim to minimize the burden of this disease for these individuals. These strategies, specifically eliminating possibility of fibroids with hysterectomy, use of estrogen-progesterone hormones for cycle regulation, and increasing

awareness of the importance of vitamin D in one's life, all work most effectively when the specific needs of the holistic individual is taken into account.

### **Public Health Interventions in the Framework of the Social Ecological Model**

#### **Individual Level Intervention:**

Due to African American women's likelihood of earlier onset and more severe symptoms of fibroids than other racial groups, these individuals are 2-3 times more likely to opt for a hysterectomy to remedy their fibroid tumors (Elthouki et al., 2014). Hysterectomy is a surgery to remove the uterus and sometimes the cervix as well, which is considered a total hysterectomy (Temkin & Kho, 2014). Therefore, after the procedure, women no longer have menstrual periods, are unable to have children, but also have no possibility of leiomyoma. Recovery time averages around 6-7 weeks but varies by person, just as eligibility and reasons to get the surgery do as well. For the women who are eligible, can pay, and have made decisions about their reproductive future, hysterectomy often results in reportedly improved quality of life of individual African American fibroid patients (Temkin & Kho, 2014).

Although socioeconomic status and race often determine the type of treatment that African American women can select rid themselves of their fibroids, or at least alleviate symptoms, hysterectomy is a personal choice based on knowledge, self-concept, and future life plans. This intrapersonal intervention is more common in African American women than less invasive, but more expensive, laparoscopic procedures, which white women often opt for (Elthouki et al., 2014). In one large cohort study, even when median household income and "indication of fibroids" was the same, African American women, as well as women of other racial minorities were more likely to choose abdominal procedures (Qi et al., 2013). This same

study reported significant differences in specifically education level in women who opted for hysterectomy and those who did not. The women with lower levels of education were more likely to make the decision to get a more invasive hysterectomy (Qi et al., 2013). In the previously mentioned study by Stewart et al., African American women were more likely to report receiving inadequate information about alternative treatment options, leaving hysterectomy to be one of only a few options (Stewart et al., 2013). Additionally, they reported wanting additional resources to facilitate more effective patient-provider discussions (Stewart et al., 2013). It is possible that, in addition to a lack of sufficient information, this discrepancy between treatment decisions between African American women and women belonging to other racial groups may be caused by the different ways that these women experience fibroids.

Some studies suggest that the racial difference in treatment choice accounts for the differential burden of fibroids experienced by African American women, as they tend to grow larger fibroids at a higher frequency (Elthouki et al., 2014). Although hysterectomy definitely eliminates further burden from fibroids, African American women were also more likely to suffer from postoperative complications, such as excess bleeding or infection, which was potentially due to their larger fibroids (Qi et al., 2013). For some individuals, however, this procedure is the only option when fibroids become an unbearable burden, leading to other health complications, including problems with infertility, preventing them from being able to conceive (Myles, 2013). Total removal of the uterus is more common in African American women than women of other races potentially because most abdominal procedures, like hysterectomy, are covered through public insurance, such as Medicare (Elthouki et al., 2014). This insurance is more accessible to African Americans, who have been systematically misrepresented in the

United States healthcare system (Singh & Belland, 2014). However, hysterectomy is not an ideal choice for many African American women, but it is one that many women choose of their own accord.

The financial impact of hysterectomy on both the United States healthcare system and the individual receiving treatment are steep, and accounts for over \$5 billion annually (Wright et al., 2012). This is the result of the approximately 600,000 hysterectomy procedures that are performed annually (Al-Hendy, 2014). In terms of the individual, this cost is measured by direct cost of the actual procedure and indirect cost of time spent recovering and not working. For some patients, either or both costs are unsustainable, and unfeasible to pay that much for symptom elimination (Myles, 2013). Additionally, some African American women may choose not to get a hysterectomy to preserve fertility. Even though hysterectomy is the most common intervention for African American women, other more minor surgical options exist that spare the uterus, as do medical treatments such as hormone regulation.

### **Societal Level Intervention**

Estrogen-progesterone birth control has been proven to regulate hormone levels in reproductive age women to aid in the prevention of uterine fibroids (Nagel, 2013). Fibroids often occur in uterine environments with inconsistent levels of estrogen and progesterone. Several studies have shown that various types of regulatory birth control can effectively decrease the risks and severity of fibroids developing (Singh & Belland, 2014). However, this intervention is not always accessible to women for financial and cultural reasons, and is on the societal level of the socio-ecological model because of the underlying discriminatory factors and historical unequal treatment of African Americans compared to white people (Singh & Belland, 2014).

African American women have historically not had a very positive relationship with the American healthcare system, but instead a rather restrictive one. For generations, the healthcare system has been defined by the white majority, and there remains a residual mistrust in African American women of that system due to “fear and negative experiences” (Murray, 2015). This cycle perpetuates health disparities, as African American women’s mistrust of the healthcare system often results in poor health outcomes (Murray, 2015). A positive patient-physician relationship has been shown to be beneficial for facilitating open communication regarding the individual’s needs and how the physician can help (Murray, 2015). In addition to mistrust of the system, many African American women cannot afford birth control and may feel compelled to mitigate social stigmas against the medication.

According to a 2014 census report, 26.2% of African Americans live below the poverty line, and an even higher percentage do not have adequate health insurance that would cover a hormonal birth control prescription (DeNavas-Walt & Proctor, 2014). For those who do have insurance or are able to pay, social stigmas and “historical reproductive injustices” often get in the way of access (Myles, 2013). Fortunately, the Affordable Care Act implemented by the Obama administration ensured women access to oral contraceptives without a copay in 2010, making them much more accessible and a viable option for fibroid prevention and treatment (Elthouki et al., 2014). However, as made evident by its colloquial name, birth control’s sole purpose is not to regulate hormone levels to prevent uterine fibroids, but to control fertility. The choice of reproduction through various contraceptive methods is a continuous discussion throughout the nation. Even though breakthroughs are being made in terms of a woman’s choice regarding her own fertility, controversy and stigma around contraceptives are other factors that

may prevent women from utilizing these hormones to alleviate fibroid symptoms (Hausman, 2013).

This intervention would require a large amount of societal work to increase acceptance and accessibility of birth control for African American women, potentially including the restructuring of the American healthcare system. Regardless, contraceptives would be very effective for premenopausal women with insurance under recent health care policy changes, specifically the Affordable Care Act (Hausman, 2013). Another group that could benefit from this medication is African American women with enough financial stability to pay for the medication who are also not actively trying to conceive a child. Regulating the hormones that can lead to fibroids is a very effective and relatively harmless (as most medications have minimal side effects) way to reduce the chances of being affected by this disease (Radin, 2013). However, due to variable accessibility based on systematic racial disparities in healthcare, it would be very difficult to apply this intervention to the entire population of pre-menopausal African American women. In addition to differential treatment in the United States healthcare system, African American women also experience differential likelihoods of acquiring fibroids due to a genetic predisposition, which may be mediated by increased public awareness of prevention.

### **Community Level Intervention**

Due to the facts that birth control is not always accessible and that hysterectomy is costly and includes major surgery, increased understanding of African American women's need for increased intake of vitamin D on the community level is an effective mode of leiomyoma prevention (Sharan et. al, 2011). African American women are about 10 times more likely to be

vitamin D deficient than Caucasian women due to differential sunlight absorption and potentially dietary differences as well (Brakta et al., 2015). Although vitamin D can be obtained through dietary sources such as dairy products and fatty fish, the most common and consistent source of this vitamin is through direct sunlight on the skin (Brakta et al., 2015). Various factors affect levels of absorption of the photons from sunlight, including levels of exposure, use of protective sunblock, and differential skin pigmentation. African American women have a genetic predisposition to dark skin because of the deposition of melanin, therefore decreasing their absorption of sunlight and their acquisition of vitamin D (Brakta et al., 2015). Vitamin D supplementation for African American women is relevant, as recent studies have shown that the presence of vitamin D significantly reduces growth of HuLm cells, which could, if unregulated, proliferate into tumors in the uterine wall (Sharan et al., 2011).

Vitamin D supplements are most effective in the form of a long-term maintenance therapy. Analogs of this vitamin have been synthesized to reduce the possibility of toxicity from high levels of vitamin D<sub>2</sub> or D<sub>3</sub>. These supplements have been shown to be an effective measure for both prevention and treatment of leiomyoma (Sharan et al., 2011). Discussion centered around this medication and which African American women should take it and also how they should take it is crucial to the efficacy of this intervention. The recommended, nontoxic dosage is about 1,400 IU per day and would cost an individual about \$32 yearly, making this treatment accessible to African American women of variable levels of income and education (Sharan et al., 2011).

A community approach to the acceptance and understanding of this treatment involves active discussions in groups where African American women of reproductive age are

represented. Local television programming, social support groups, and women's centers are viable options for this educational campaign to emphasize the importance of vitamin D in the prevention of fibroids (Myles, 2013). This utilizes a familiar and comfortable environment to promote health and well-being throughout a community, potentially making the information more accessible than if it came from the mouth of a physician (Myles, 2013). This approach is focused on community support to enhance general understanding of fibroids and the importance of a healthy amount of vitamin D. It encourages African American women to undertake a continuous and active approach to prevention and treatment, as vitamin D supplementation is often most effective when taken in regular doses over long periods of time (Sharan et al, 2011).

This community support is also a preservative factor for the mental health of African American women with fibroids, as the aforementioned study by Stewart et al reported that fibroid symptoms interfering with personal relationships were more likely to be a source of stress in African American women than in women of other races (Stewart et al., 2013). Through the creation of strong relationships enriched with positive affirmations towards each other through community-based organizations such as women's centers and fibroid support groups, women have felt more secure in their relationships outside of those groups (Myles, 2011). African American women in this study also reported more overall concerns with the potential repercussions of their fibroids and higher rates in impairment of quality of life, and "did not know who to talk to" about their symptoms (Stewart et al., 2013). They tended to turn to friends or family as well as health brochures more often than white women, but also found this information to be "inadequate," emphasizing the need for community-based education from trusted professionals (Stewart et al., 2013).

**Recommendation for Most Appropriate Intervention:**

Conversations between women in the same community in the form of neighborhood associations or meetings with community leaders can be effective in spreading awareness of an evidence-based, relatively minor lifestyle change. As previously mentioned, African American women were more likely to report mistrust of the current United States healthcare system, and having information delivered from a more trustworthy source, such as a peer or a healthcare professional from their own community, has been proven to be more effective than information from a potentially unrelatable physician (Murray, 2015).

Some of the advantages of this intervention, specifically for reproductive-age African American women, outweigh those of the other proposed interventions. The 2014 Census report noted that 37.1% of African Americans fall below the poverty line, which is a large increase from the 33.7% the previous year in 2013 (DeNavas-Walt & Proctor, 2015). This underscores the necessity for an intervention with an acceptable cost for effective continuation of treatment. In 2014, the Affordable Care Act under the Obama administration required that more healthcare services specific to women's health be provided in every healthcare plan (Elthouki et al., 2014). Additionally, it aims to improve coverage to "unsinsured and underinsured" women, to grant more access to services required to decrease the burden of fibroids. Maintenance prevention with long-term medications can become a large burden for women, but \$32 a year is feasible for many of those women, and can ultimately help them evade potentially painful fibroids, expensive surgery or other complications involved with leiomyoma (Sharan et al., 2011).

There are large number of counties in the United States that have women's centers that are free and accessible to all women. In this community-based intervention, these spaces would act as sources of information about fibroids in a low-stress setting, where African American women can share their own experiences and knowledge about leiomyoma, and learn new information from formal talks (Murray, 2015). Mission statements of these centers often involve the "promot[ing] well being of women and girls, and to build positive connections among people and organizations that do the same" (Women's Community Center of Central Texas, 2016). Many also emphasize equity and intersectionality, which is specifically relevant to the healthcare disparities that African American women experience while living in America. These spaces welcome and encourage discussion with people of similar experiences. They would facilitate small communities of support groups or occasional educational talks by local health care professionals about the burden of uterine fibroids, what one can do to reduce their risks, and the importance of vitamin D as a cost-effective mode of prevention and treatment (Myles, 2011).

In summation, increasing both awareness and resources to a traditionally underserved population has been proven to be an effective method of intervention (Stewart et al., 2013). Both of those aspects are crucial, as one without the other would not likely provide a change in outcome for most women at high risk for developing uterine fibroids. This is exemplified by the women Stewart et al studied, stating that they did not have access to acquire and process appropriate resources for fibroids (Stewart et al., 2013). Providing knowledge about risk factors for uterine fibroids and methods of prevention alongside the option for accessible vitamin D therapy would be the most effective proposed intervention, as it directly addresses the complex needs of pre-menopausal African American women.

**Conclusion**

African-American women need much more attention than they are currently getting to minimize the burden of leiomyomatosis. They bear a disproportionate prevalence of uterine fibroids than women of other ethnicities as well as a disproportionate impact in terms of symptoms, effects on employment, and general quality of life (Stewart et al., 2013). Their fibroids tend to be larger and occur in greater quantities. Because of this, in addition to African-American women's tendency to have an early onset of this disease, fibroids have a more profound effect on a woman of color's reproductive health, child-rearing capabilities, and how she perceives those issues (National Institute of Health, 20) (Eisinger, 2015).

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