

## **FIBROIDS: A SILENT HEALTH PROBLEM AFFECTING WOMEN IN TRINIDAD AND TOBAGO**

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Uterine fibroids are described as benign tumours of the womb. Conventional medicine states that only 20% of women have fibroids when they reach the age of menopause. This figure is not however representative of the Caribbean community, where the statistics are much higher. In Trinidad and Tobago, women between the ages of 25-44 show the highest incidence of fibroids, which are the most common tumour for women's admission to hospital. This paper examines the experiences of Trinidadian women with fibroids and argues that like HIV/AIDS, hypertension, diabetes or cancer, the occurrence of fibroids among women needs to be promoted as a public health concern.

The paper reviews the incidence and prevalence of fibroids internationally and within Trinidad and Tobago, and surveys current research findings for fibroids. Case studies that demonstrate the effects of fibroids on women and their quality of life illustrate the urgency of this issue. The article concludes by identifying a research agenda to develop preventative interventions for fibroids, and calls for building public awareness among the population of urgent matter involving women's health in Trinidad and Tobago.

**Keywords:** fibroids, women's health, Black women, Trinidad and Tobago

### **Introduction**

The health of women is an issue that requires focused attention today. Many concerns dominate the public agenda. Cancer, in particular breast and cervical cancer, affect women in Trinidad and Tobago. Diabetes, osteoporosis, complications of labour and delivery, and HIV/AIDS dominate health articles in newspapers and the general public is sensitised to prevalence, prevention and treatment of these various conditions. Uterine fibroids do not enjoy the same level of public awareness. Yet among women of Trinidad and Tobago, fibroids is an area of concern that is discussed among women in closed circles. Fibroids affect a larger proportion of Trinidad and Tobago women more than cancer, and HIV/AIDS. Fibroids usually do not occur before puberty and shrink after menopause. So frequent is its occurrence for women in Trinidad and Tobago, it has been described as a "rite of passage" along the biological timeline of growth phases (i.e. puberty → fibroids → menopause) in many women. Fibroids are perceived by the medical

profession as benign and harmless, and a problem that can be easily handled through surgical intervention for severe cases.

Uterine fibroids, medically termed leiomyoma uteri, are benign tumours of the smooth muscle of the uterus (Simms-Stewart & Fletcher 2012). They can range from one or two centimetres in length to uterine growths weighing over sixty (60) pounds. Fibroids may be located within the wall of the uterus to increase its size, expand towards the uterine surface, grow towards the uterine cavity or grow as a long stalk-like structure extending into the vagina (Cotran, Kumar and Collins 1999). Fibroids cause severe abdominal pain, excessive bleeding, constipation, involuntary urination, asymptomatic pelvic masses, infertility, preterm labor, and spontaneous abortion, but rarely cause cancer (Sunkara et al. 2010) and are the most cited indication for hysterectomies (Cardozo et al. 2012). Fibroid growth is stimulated by the sex hormones estrogen and progesterone (Rein, Barbieri and Friedman 1995), and may distort the uterine surface. Black women have more fibroids (Amant et al. 2003) and larger uteri that accounts for the higher incidence of complications. They are also diagnosed at an earlier age with more symptomatic tumors (Peddada et al. 2008).

Fibroids have a major impact on the quality of life that women enjoy in Trinidad and Tobago. It is important to recognise that the “lived” experiences of many women with fibroids are painful and very embarrassing. Many women with fibroids suffer in silence and only rarely is there public mention of this topic. This paper provides a brief review of the current research on fibroids. Using information provided from interviews with medical practitioners and women with fibroids, it explains the experiences of women and the perspectives of the medical profession towards fibroids as a health condition. It concludes with a justification for fibroids to be considered a public health concern. This paper hopes to raise public awareness of this problem and encourage further research to develop appropriate alternative approaches for non-surgical treatment and prevention of this condition.

### **The “lived” experiences of women with fibroids**

The following three (3) case studies illustrate the perspectives of women with fibroids.

#### **Case Study 1 - Alison**

Alison, a single parent with one child, was a 36-year old clerical assistant with a major corporation. At about thirty two (32) years she experienced heavy menstrual bleeding, pain around her uterus and extension of her stomach. When her period was due she was careful to dress appropriately so that there was no leakage. Given these sensitive changes taking place in her body, she decided to consult her medical doctor who diagnosed fibroids.

The doctor recommended the surgical removal of the fibroid via a myomectomy, a surgical procedure, considering her age, interest in having more children and desire to keep her womb. After the surgery, Alison felt great. However, she had no sensation where the incision was made. She did report that before and after the operation there was no negative effect on her relationships with her child, friends, family, employment or social activities.

She considered having fibroids to have been a “learning experience” in which she recognised the importance of being alert to changes in one’s body, keeping physically active and maintaining good health. She noted that there needed to be greater emphasis on educating women about fibroids because it seems to be very prevalent in Black women, both young and old, whether or not they have children.

### **Case Study 2 - Dora’s Story**

Dora was a 49-year old divorcee, with a 24-year old daughter, who lived in the eastern area of Trinidad. A trained primary school teacher by profession, she had recently been promoted at her workplace. Dora had benefited from the free education provided for the nation in the sixties and seventies. She was also very active in cultural groups in the community.

At age thirty, she experienced heavy, irregular menstruation and constant back pain. Her gynaecologist diagnosed fibroids. During this period Dora often felt exhausted and frequently was absent from work. She withdrew from netball, a sport that she played since teenage years.

Five years after being diagnosed with fibroids, Dora had a hysterectomy. Her husband at the time did not understand what she was experiencing, and accused her of not wanting to have any children for him. After frequent quarrels they divorced.

### **Case Study 3 - Mary-Anne’s Story**

Mary-Anne was a 36-year old university student with a sixteen year old son. After the relationship with her child’s father ended due to domestic violence and her partner’s infidelity, Mary-Anne concentrated on raising a good son and being independent. Her son was successful in the Caribbean Examination Council examination and became gainfully employed. After her son’s father, Mary-Anne did not pursue another relationship. She was very proud of having an organised and disciplined life where she adequately provided for her child, parents and herself. Mary-Anne was only able to enter university as a mature student due to these responsibilities, and she self-financed her tuition.

After entering campus she had to take days-off from classes and tutorials because of complications related to fibroids. She had difficulty concentrating and always felt weak and exhausted. She dropped out for a semester to attend to her medical condition.

Her constant question was “What could I have done to have avoided this? I have tried so hard to be careful.” Mary-Anne later died. It was not established if her death was related to fibroids.

The voices of women with fibroids come through these three cases illustrating the effect on the lives of women who develop symptoms. It affects their work life, reducing productivity through absenteeism and lowered morale. Family life can be more difficult for women with symptoms from fibroids. Their relationships with male partners may be strained and the feelings of tiredness inhibit activities with children. Mary-Anne’s story reinforces the point that educational and career development can be hindered by fibroids. Dora’s contribution to sport and youth development was curtailed during the time that she was incapacitated by fibroids. The ability of

women to be fully involved in productive, reproductive and social life directly relates to the progress of the society and the country. Fibroids may not be as fatal a disease as cancer or AIDS. Neither are the effects as striking and emotionally disturbing as the social diseases of suicide or murder. Their gradual development almost makes them invisible to the general public. Nevertheless, they are affecting the quality of life that Trinidad and Tobago women can enjoy.

Women, themselves, discuss fibroids in private settings. Even though as many as seventy (70) per cent of African women over forty (40) years have fibroids in the New World, there remains a public silence on this topic. A reason for this silence relates to the fact that a discussion of fibroids necessitates mention of the womb and other intimacy aspects surrounding human sexuality. Human sexuality is frequently kept out of discussions on social issues in public forums. Women also lack the courage to contradict established views of the status quo, and fail to voice their personal sufferings.

### **The perspectives of medical doctors**

Interviews with medical doctors in Trinidad and Tobago reinforce the views of health practitioners that are not “seriously concerned” about this condition. In cases where women are affected by heavy menstrual bleeding or pressure of the uterus on the bladder, the only option offered is surgical intervention. Medical emphases on women’s health prioritise breast and cervical cancer as key health issues affecting women. Even with gynaecologists there remains a silence on fibroids and its impact on women.

When asked about prevention or the causes of fibroids, responses were varied. One doctor proposed that women are not having enough children. He suggested that compared to mothers of yesteryear and their ancestors, there has been a reduction in the fertility rate which therefore influenced the production of fibroids in women today. This argument may help to explain why women without children or only one child develop fibroids, however the evidence shows that women with three or more children also have fibroids.

From all reports one pattern is clear. The doctors confirmed the literature statements that fibroids are most prevalent in women of African descent in the New World. Not only in Trinidad and Tobago has this pattern been observed. It was noted that as many as seventy-five per cent (75%) of African descended women over thirty (30) years are affected. East Indians have the next highest incidence level followed by Asians such as Chinese. Caucasians are the least affected, rarely reaching more than twenty-five per cent for women descended from that ethnic group. This indicates that there may be genetic links to the presence of fibroids. No evolutionary advantage has been identified for the presence of fibroids in women. The widespread presence in the African ethnic group may relate to generations of in-breeding in small populations. Fibroids are known to run in families. No cultural patterns are attributed to causing fibroids.

The doctors had no responses to questions of prevention. Other than surgical procedures such as embolization, there is no advice for the many young women who will be affected by fibroids in the future. Women in Trinidad and Tobago as young as fifteen years have been found to have fibroids. Will there be continued denial of the effect of fibroids on women? Surgical procedures are expensive, time consuming, and have associated risks: infection, damage to other organs, and

exposure to anaesthesia. Recovery from a hysterectomy can take four to six (4-6) weeks. This results in absenteeism from work and studies, and quality time away from family.

**Review of current information and data on fibroids**

Fibroids are the most common tumors seen in women between 25 to 44 and 45 to 64 age groups in Trinidad and Tobago. Incidence rates are based on discharge data from the Ministry of Health Annual Statistical Report, 2005 (Tables 1 and 2). The true incidence/prevalence is under-reported as the condition is probably not diagnosed in many women.

Incidence by hospital discharge data by diagnosis

Table 1. Discharges for Uterine Leiomyoma by Age Group and Length of Stay at All Hospitals

Year	Diagnosis	All Ages	Age at Admission in Years					Average Length of Stay
			1-4	15-24	25-44	45-64	> 65	
2004	Uterine Leiomyoma	621		6	343	266	6	4.4
2005		676	1	10	348	312	5	4.4

Excerpt from Republic of Trinidad and Tobago Ministry of Health Annual Statistical Report 2004 – 2005

Table 2. Discharges by Public Institutions for Females from 2004 to 2005

Institution ↓	Population →	2004	2005
Port of Spain General Hospital		256	214
San Fernando General Hospital		200	260
Sangre Grande Regional Hospital		62	62
Point Fortin Regional Hospital		47	42
Tobago Regional Hospital		51	94
Total		616	672

**NB.** Data from Eric Williams Medical Sciences Complex and Mt Hope Women’s Hospital are missing from this list.

Excerpt from Republic of Trinidad and Tobago Ministry of Health Annual Statistical Report, 2004 – 2005.

**Review of the literature on fibroids**

In order to explain the presence of fibroids, a brief literature search revealed that several researchers detected chromosomal defects that facilitate the growth of existing tumors or genetic mutations that initiate tissue growth (Marshall et al. 1997). Fibroids within the same woman have different growth rates within the same hormonal environment (Peddada et al. 2008) as solitary tumors grow faster than multiple tumors sharing a uterus possibly because of less competition for uterine blood. A hereditary predisposition also occurs in families (Vikhlyaeva, Khodzhaeva and Fantschenko 1995). Surprisingly, spontaneous fibroids regress in some premenopausal women as

shrinkage usually occurs after menopause. Although current practice encourages ultrasound or pelvic examination at 6 months to evaluate growth (Katz and Lentz 2007), the follow-up assessment may be extended as growth is less than 20% in 6 months, with a median rate of 9%.

### **Lifestyle risk factors**

#### *Non-modifiable risk factors*

Black women cannot alter factors such as age, age at menarche (Marshall et al. 1998), and ethnicity. Fibroid risk decreases as the age of menarche increases and increased weight prior to puberty is strongly linked to early menarche, which can be delayed by exercise (Claessens et al. 2003). Importantly, the greater fibroid burden observed in black women decline minimally with increasing age (Wise, Palmer, Stewart and Rosenberg 2005). An early-onset fibroid risk was observed in women with identical twins possibly due to a greater likelihood of fetal growth restriction (Peddada et al. 2008).

#### *Modifiable risk factors*

Body mass index (BMI, a measure of total body fat) may influence the risk of fibroids through changes in sex hormone metabolism and bioavailability (Wise et al. 2005a). There is an inverse association between BMI and circulating levels of sex hormone-binding globulin (SHBGs). Decreased SHBGs may increase the proportion of free estrogen available for biologic activity. Obesity is associated with an increased concentration of estriol estrogens which have a greater attraction for binding to uterine muscle than catechol estrogens. Also, central obesity, independent of BMI, is associated with hormonal and metabolic changes (altered estrogen metabolism, insulin resistance, elevated blood glucose concentrations (hyperinsulinemia), and decreased SHBG levels in premenopausal women (Wise et al. 2005a). Insulin is also associated with down regulation of SHBG and up regulation of insulin-like growth factor-1 (IGF-1), both of which can influence tumor development by promoting myometrial proliferation or enhanced ovarian hormone secretion. Hence higher BMI might be associated with greater symptomatology. The influence of elevated adult BMI and weight gain has a greater impact among child-bearing (parous) women than nulliparous women. Epidemiologic studies show that parous women are at lower risk of fibroids due to long-term reduction in hormones (including prolactin) associated with myoma growth (Terry, De Vivo, Hankinson and Missmer 2010). Similarly, The Black Women's Health Study and the Nurses' Health Study found that parity appeared to protect against uterine fibroids (Marshall et al. 1998).

Black women had an increased risk of early-onset fibroids in association with early-life factors, such as *in utero* gestational diabetes (D'Aloisio, Baird, DeRoo and Sandler 2012). *In utero* exposure to diabetes influences later risk of fibroids pertaining to the genes that regulate fibroid pathogenesis (D'Aloisio, Baird, DeRoo, & Sandler, 2010). Blacks in the United States have greater rates of type 2 and gestational diabetes (Savitz, Janevic, Engel, Kaufman and Herring 2008) and are more likely to have *in utero* exposure to hyperinsulinemia and hyperglycemia. Thus, *in utero* exposure to maternal diabetes may contribute to the elevated fibroid burden among U.S. black women. Long-term consumption of excess simple carbohydrates may lead to prolonged hyperinsulinemia and insulin resistance in the liver, muscle, and fat tissues. Studies of

blood samples from nondiabetic adults show that high concentrations of insulin correlate with increased free circulating concentrations of IGF-I and decreased SHBGs, thereby increasing estradiol levels (Radin, Palmer, Rosenberg, Kumanyika and Wise 2010).

Black women who exercised vigorously for at least 4 hours per week showed decreased tumor onset (Baird, Dunson, Hill, Cousins and Schectman 2006) as exercise reduces circulating sex hormones and insulin levels. The concentration of circulating estrogen might also be reduced by exercise-induced increases in SHBGs. Any decrease in menstrual cycling (at menopause) reduces the risk of fibroids by lowering levels of circulating sex hormones.

Many authors identified various risks associated with fibroids. The glycemic index (GI), an indicator of a food's insulin demand, quantifies the capacity of food to raise postprandial (after a meal) blood glucose concentrations (Radin et al. 2010). Glycemic load (GL), the product of food's GI multiplied by grams of carbohydrate in a serving, provides a more complete measure of the portion's effect on postprandial blood glucose. Positive associations of GI were observed with fibroid risk overall and of GL with fibroids in younger women (Radin et al. 2010). It was observed that females who were fed soy formula at infancy had longer menstrual bleeding and greater pain when menstruating (Strom et al. 2001), both of which are symptoms of fibroids. Soy formula might influence later risk of fibroids because of the high concentration of estrogenic isoflavones they contain (D'Aloisio et al. 2010). The risk of fibroids was positively associated with current consumption of alcohol, particularly beer (Wise et al. 2004). High dairy intake was inversely associated with fibroid risk among black symptomatic women (Wise, Radin, Palmer, Kumanyika and Rosenberg, 2010).

## **Treatment**

Treatment is individualized based on the severity of symptoms, size and location of fibroid lesions, age, proximity to menopause, and desire for children (Sabry and Al-Hendy 2012).

The goal of treatment is to relieve symptoms using any of the following:

- Vitamin D analogues may be used to prevent fibroids as there is a strong correlation between lower concentrations of Vitamin D and fibroid severity (Bläuer, Rovio, Ylikomi and Heinonen 2009).
- Green tea contains bioflavonoids that potentially block each stage in the pathogenesis of fibroids (Zhang et al. 2010b).
- Gonadotropin-releasing hormone (GnRH) antagonists suppress the release of gonadotropins and the sex hormones (Samant, Hong, Croston, Rivier and Rivier 2005), but have adverse side effects.
- Selective estrogen receptor modulators have the potential to prevent ovarian stimulation (Lingxia, Taixiang and Xiaoyan 2007). These drugs also have adverse side effects and are contraindicated in certain females with a prior history of stroke, etc.

- Aromatase inhibitors (AIs) suppress estrogen production. Aromatase is expressed to a greater extent in fibroids of black women (Ishikawa et al. 2009). AIs may be considered in women who want to avoid surgical intervention to preserve fertility (Parsanezhad et al. 2010), but may cause bone loss with prolonged use.
- Acupuncture (Zhang, Peng, Clarke and Liu 2010a).
- Many other novel agents (that inhibit steroidogenesis and with anti-estrogen/-progesterone receptor properties) to shrink fibroids are in development (De Leo, la Marca, Morgante, Severi and Petraglia 2001; La Marca et al. 2004; Yoshida et al. 2010).
- Surgery (Edwards et al., 2007; Sabry and Al-Hendy 2012). The surgical management options consist of dilation and curettage (D&C), resectoscopic endometrial ablation techniques<sup>i</sup>, myomectomy<sup>ii</sup>, hysterectomy<sup>iii</sup> and uterine artery embolisation<sup>iv</sup>.

This summary review of preliminary clinical studies of fibroids has not revealed definite answers to the concerns of Mary-Anne and Alison for advice on how to prevent fibroids or at least reduce the occurrence. The information in the “modifiable lifestyle risk factors” section alludes to associations with fibroids that may be explored. These include minimising the incidence of (gestational) diabetes, avoiding the use of soy products as infant formula and the consumption of alcohol. The importance of exercise, consumption of high fibre foods with a low glycemic-index/-load, Vitamin D, exercise, green tea, and use of a high dairy intake are positively linked to a reduced occurrence of fibroids. These insights require more research on larger populations before they can be recommended as preventative measures for fibroids.

## **Conclusion**

The last ten years has shown more interest by the research community into understanding fibroids and their effect on women. The Black Women’s Health Study, Wise et al., D’Aloisio et al. provide direction for further work. These efforts could be supported by public recognition of the urgency of this problem for women, and particularly for Black women. Methods of prevention and early detection have been identified for AIDS, cancer and diabetes. Changed sexual lifestyles, based on monogamy, abstinence and condom use contribute to reducing HIV/AIDS. Most women would at some time have received a pamphlet explaining the importance and method of self-examination for the early identification of breast cancer. Children’s television programmes have advertisements that promote the importance of eating five fruits and vegetables each day to reduce the occurrence of cancer. What advice is there to prevent fibroids?

Alison and Mary-Anne stated that they wanted to know how to avoid fibroids. Alison wanted more education on fibroids for women. However, what form is this education to take? It has not been possible to identify distinct causal relationships for fibroids that can be prevented. In a world with so many advances in science and technology, it remains a mystery that there does not exist any deep understanding of why so many women, especially those of African and East Indian descent develop fibroids, particularly those that result in hysterectomies. This is one area affecting women of colour that sorely needs attention.



This article argues that fibroids are a public health concern. While not being a communicable disease like malaria, HIV or polio; nor is it a lifestyle sickness like type 2 diabetes, it is a major form of disease affecting women in the age group 25-64 in Trinidad and Tobago. Easily one third (1/3) of these women would require surgical intervention in the form of a hysterectomy, myomectomy or embolization.

Women must express their feelings and experiences of having fibroids. They need to show that even though fibroids are not as life threatening as HIV and cancer, they do affect one's well-being and it is therefore essential to develop an understanding of how to prevent and/or reduce their occurrence. Fibroids affect women during their reproductive years. A collective consciousness of women, similar to that which identified domestic violence as a major social problem where women previously suffered in silence must take place. Women's groups must advocate for medical research into the prevention of fibroids. Non-surgical treatment must also form part of the research in this area. In an era when we are seeing the informed control of many diseases it is surprising that there have been limited advances in this area. The well-being of future generations of girls and women will be compromised unless there is an urgent response to this situation that affects the majority of our women.

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<sup>i</sup> This procedure entails the transcervical resection of the endometrium and has been the standard cure for menorrhagia for many years. The primary risk is uterine perforation.

<sup>ii</sup> Used for women who wish to maintain their uterus and/or fertility. It entails the removal of a single or few myomas or **fibroids**

<sup>iii</sup> The removal of the womb is considered the definitive cure for fibroids.

<sup>iv</sup> Uterine artery embolization is a procedure that works well for women who do not want a myomectomy or a hysterectomy. It consists of blocking the blood supply to the uterine body.