



Assessing Prevalence, Complications, and Risk Factors of Uterine Fibroids and Perceived Impact on Women's Lives in Rural Haiti: Cases from the Out-Patient Department (OPD) of Mirebalais University Hospital (MUH)

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**Assessing Prevalence, Complications, and Risk Factors of Uterine Fibroids and Perceived
Impact on Women's Lives in Rural Haiti: Cases from the Out-Patient Department (OPD)
of Mirebalais University Hospital (MUH)**

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Assessing Prevalence, Complications, and Risk Factors of Uterine Fibroids and Perceived Impact on Women's Lives in Rural Haiti: Cases from the Out-Patient Department (OPD) of Mirebalais University Hospital (MUH).

Abstract

As a benign tumor of the uterus, uterine fibroid profoundly affects the quality of life of women and their families.¹ The cumulative incidence higher among the black population is 59% based on ultrasound screening.² Haiti has significant biosocial factors that can impact care for uterine fibroids and struggled the women's daily lives. However, little is known about uterine fibroids in Haiti. Therefore, we conducted a convergent mixed method study³ to evaluate the prevalence, complications, risk factors, and the impact of uterine fibroids on the quality of women's lives at Mirebalais University Hospital(MUH) at the Out-Patient Department (OPD).

Contents

Part 1: Background.....	1
Vignette.....	1
Background.....	2
Thesis Statement.....	3
Global Surgery.....	4
Overview of global surgery.....	4
The Three Delays framework for addressing surgical care for fibroids.....	6
Haiti.....	7
Biosocial factors that hamper surgical care for fibroids.....	7
The reality of surgical care in Haiti, including fibroids.....	10
Surgical care at Partners In Health (PIH) in Haiti.....	12
Surgery at the University Hospital in Mirebalais (MUH), including for fibroids.....	13
Part 2: Publishable Paper.....	15
INTRODUCTION.....	15
METHODS.....	17
Study setting.....	17
Study design.....	18
Data collection.....	18
Data analysis.....	19
Measures.....	19
Data collection and analysis.....	20
RESULTS.....	21
Quantitative.....	21
Qualitative.....	24
Health system failure.....	24
Long journey for incomplete services.....	25
Gender disparity.....	26
Fear/lost relationship and social rejection.....	27
Poverty.....	27
Care seeking drivers.....	28
DISCUSSION.....	29
CONCLUSION.....	33

Part 3: Publishable Paper (Qualitative).....	35
Abstract.....	35
Background.....	36
History.....	37
Methodology.....	40
Data analysis.....	42
Findings.....	44
Patient journey when looking for care for uterine fibroids.....	44
Health system failure.....	46
Dilemma of an overcrowded hospital.....	47
Gender inequity.....	48
Bio-psychosocial consequences of uterine fibroids.....	49
Social consequences of uterine fibroids.....	50
Uterine fibroids and the family life.....	50
Economic exclusion because of uterine fibroids.....	51
Exclusion to social goods because of uterine fibroids.....	52
Exclusion to social production because of uterine fibroids.....	53
Exclusion from civil society and access to healthcare for uterine fibroids.....	53
Factors that impact the care for uterine fibroids.....	55
Accompaniment.....	56
Discussion.....	56
Conclusion.....	62
References.....	64
Appendices.....	70
Appendix 1.....	70
Appendix 2.....	70
Appendix 3.....	71
Appendix 4.....	72
Appendix 5.....	73
Appendix 6.....	75
Appendix 7.....	77
Appendix 8.....	81

Tables

Table 1: Sociodemographic, clinical history and economic characteristics of women receiving care for uterine fibroids at Mirebalais University Hospital’s outpatient department between October first, 2019 to January 31, 2020 (n=116).....73

Table 2: Joint display table for signs, symptoms, and complications of women with uterine fibroids in Haiti accessing care at the outpatient department at Mirebalais University Hospital (n =116)..... 75

Table 3: Bivariate analysis looking for risk factors associated with uterine fibroids among social demographic and clinical variables at MUH age greater or equal to 20 years old (n=193)..... 77

Table 4: Multivariate analysis of the association with uterine fibroids and social demographic and clinical variables at the OBGYN out-department at MUH age greater or equal to 20 years old (n=193)..... 81

Figures

Figure 1..... 43

Figure 2: The patient journey..... 45

Figure 3: Relationship between the exclusion of women with uterine fibroids from civil society
and access to health care..... 54

Figure 4: Poverty wheel of uterine fibroids suffering..... 58

Figure 5: Pathway of exclusion to social goods..... 59

Figure 6: Pathway of exclusion too social production..... 59

Figure 7: Uterine fibroid suffering tree..... 62

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Abbreviations

MUH: Mirebalais University Hospital

OPD: Out-Patient Department

OR: Odds Ratio

IDI: In-depth -Interview

ZL-DSI: Zanmi Lasante Depression Symptom Inventory

OBGYN: Obstetrics and Gynecology

GYN: Gynecology

WHO: World Health Organization

Part 1: Background

Vignette

On Friday, November 24, 2017, I left Port-au-Prince in the morning to go to Mirebalais University Hospital. Arriving at the hospital at the out-patient clinic for gynecological care, a patient with a large abdomen approached me in desperation, saying, “Doc, I know you are the chief here. Look at me. I did all my exams in 2016, and my physician told me I am ready for surgery. He sent me to the nurse scheduler to schedule me for surgery. The nurse said, ‘I will call you.’ One year later, I am still here with my big fibroid, suffering from pain and discomfort—without sleeping—and waiting for access to surgery. Doc, I was in an in-private clinic in PAP. They asked me so much money I left with my suffering, and I went back here with the expectation I can [sic] meet someone to help me. Today you are here, please did [sic] something for me.”

Due to large waiting lists of those looking for gynecologic surgery for fibroids, many people are familiar with this issue. This situation brings me to ask the following critical question, “Why can’t people access definitive care for something as common and treatable as uterine fibroid?” This situation is an example of the failure of the Haitian health system. People have argued that in building a large hospital in rural Haiti that provides service free of charge, that Zanmi Lasante “created a demand” for high-quality care—including gynecological surgery--that we cannot address. However, as I will show here, the demand for gynecological surgery already existed. The long waiting list and ongoing suffering are due to a general lack of access to high-quality health care in Haiti.

The lack of these services—in the case of uterine fibroid, an eminently treatable condition--is an example of the market’s failure to address the health needs of the poor. I will

study the impact of this market failure, particularly in addressing the surgical needs of poor women who require definitive treatment for uterine fibroids.

Background

Uterine fibroid is a benign tumor of the smooth muscle of the uterus. The fibroid is the most common reason for gynecology surgery.⁴ This pathology is widespread, and its prevalence ranges from 4.5 to 68.6%.⁵ The cumulative incidence in premenopausal women is around 51% among those whose complaint leads to an ultrasound screening.² In the United States, the cumulative incidence of fibroid is higher among women of African descent compared to women of European descent (59% and 43%, respectively).² Further, by their late 40s, the cumulative incidence among women whose complaint leads to an ultrasound may be up to 70% for white and 80% for Black women.² Uterine fibroids are a cause of maternal mortality and morbidity with direct implications on women's quality of life.^{1,6} Although there are controversies about risk factors of the fibroid, potential risk factors identified include: age, obesity, lifestyle, diet, family history, contraception, diabetes, hypertension, smoking, and hair relaxers.^{5,7-9} While uterine fibroids may be asymptomatic women with fibroids may present with: pelvic mass, bleeding responsible for anemia, pelvic pain, dysmenorrhea, dyspareunia, pelvic pressure, and infertility.^{6,9-11} Other presentations and complications include infection, deep vein thrombosis, chronic constipation, hydronephrosis, mictional dysfunction, sarcoma, abortion, premature delivery, and growth retardation.¹²⁻¹⁴

Women with fibroid are more likely to have heavy bleeding compared to those who do not have a uterine fibroid, and as a result, severe anemia occurs.¹⁴⁻¹⁶ This anemia could profoundly impact their lives, particularly in a country where the blood supply is sparsely

available. In our practice at MUH, we have difficulty treating acute and chronic anemia for our patients, including those with fibroids. Sometimes we receive patients with severe anemia who died because of this issue—this study will give us an idea about the anemic contribution of fibroids. Eventually, it will help us to come with a proper strategy to handle this situation.

The treatment of fibroids can be radiological, medical, and surgical.^{10,13} Access to surgery represents a significant challenge to surgical treatment, including for uterine fibroids. For instance, 11.16% of diseases can be treated with surgery.¹⁷ We can prevent 25.6% of deaths by illnesses just by providing access to surgical care.¹⁷ For instance, in low-income countries, approximately 288.2 million people annually need surgical care, and 5.6 million deaths could be prevented accordingly.¹⁷

While developed countries have achieved remarkable improvements in the treatment of uterine fibroids (e.g., laparotomy and robotic surgery), developing countries lag, with many relying solely on laparotomy.^{10,18,19} Medical technology in high-income countries has incredibly improved, creating various options for women who want to conserve their fertility.^{10,12} Overall, there is not enough equipment, staff, space, or system capacity available to provide medical or surgical therapy for fibroids in developing countries. Unlike developed countries, laparotomy remains the only surgical procedure used in the developing world. This is also true at Mirebalais University Hospital.

Thesis Statement

At Mirebalais University Hospital (MUH), fibroids represent the second most frequent pre-operative diagnostic in the OB-GYN department. It is the most frequent surgical pathology at the outpatient clinic of the obstetrics and gynecology (OB-GYN) department at the hospital.

Although fibroids accounted for about 50% of our gynecologic surgeries, as a national referral hospital with just six operating rooms, the list of women waiting for gynecology surgeries, including uterine fibroids, is growing every day. Because of the continuously growing number of women with uterine fibroid who need surgery presenting at MUH's outpatient department, addressing the growing need for surgical care for this pathology represents a big challenge for the leadership of the hospital. Moreover, there is the paucity of evidence in the literature about the prevalence and impact of fibroids in Haiti to guide our plan. This thesis project was undertaken to propose a plan to alleviate social suffering and improve the quality of life for women with fibroids. This study seeks to understand the prevalence and complications in the out-patient clinic (OPC) at the OB-GYN department at MUH in Haiti.

Global Surgery

Overview of global surgery

Surgical care is an indivisible part of health care. It contributes significantly to improve the health of a population. When a population of a country is in good health, this country will have a workforce that is essential to improving its social-economic condition.^{19,20} Furthermore, creating an infrastructure for surgical care is a critical element that can promote job creation to deliver income among people in the country, giving them the possibility to look for care for their disease, including fibroids. In contrast, health infrastructures in developing countries are sparse.

²⁰ To make the matter worse, the Lancet commission estimated that the annual catastrophic expenditure for surgical care reached USD 32.2 million in low-income countries.¹⁹

Approximately 3.7 billion people around the world are subjected to catastrophic expenditures for surgical care.¹⁹ Also, the health system needs to respond to its obligations of fulfilling the right

to health care.²¹ The violation of this right leads to mortality, morbidity, orphan kids, no healthy workforce with significant social and economic impact.^{19,20} This situation will create more poverty and specifically in low-income countries, such as Haiti, where the right to health care is sparsely respected. It is a moral obligation to create access to surgical care in low-income countries to promote wellbeing among these people who are suffering in desperation.

However, addressing surgical care, including fibroid, represents a significant challenge around the world. The Lancet Commission estimates that at least 5,000 surgical procedures are needed for 100,000 people and to reduce maternal mortality by 70 per 100,000 live births by 2030,¹⁹ whereas the staff, stuff, space, system, and social gap are huge.²² Besides obstetrical causes of maternal mortality, fibroids represent a significant contributor to maternal mortality in poor settings, particularly in Haiti. Filling the gap for human resources, training, surgical equipment, and surgical care represents the key elements to improve access to surgical care, and specifically in obstetric gynecology when we consider uterine fibroids.^{19,23}

Because the workforce is a critical element in addressing surgical care issues of fibroids, a minimum density of 20 to 40 surgeons, anesthetists, OB/GYN doctors per 100,000 population is considered a reference value to support surgical care. This study hopes to address the availability of fibroid treatments with other surgical procedures.¹⁹ Strategies to address the workforce gap for surgery in OBGYN, especially for uterine fibroids in resource-poor settings, could be task shifting—for instance, training nurse anesthetists when there are not enough anesthetist doctors, task sharing, and sustainable workforce planning for long.^{20,23,24}

In addition to the workforce, spaces, and biomedical equipment for addressing surgical care in OB/GYN, especially for fibroids represent a turning point in the endeavor of making surgical care available toward universal health coverage.²⁵ Partnership with the international

biomedical companies, innovation, NGOs, states reinforcement, the implication of the private sector, and research represent some valuable ways to address these issues of surgery overall and in OB/GYN, especially for fibroids.^{19,23,25,26}

Uterine fibroids are the most frequently encountered surgical pathology in gynecology.²⁷ As a surgical disease, the treatment of uterine fibroid requires pharmaceutical access, health workforce, and systems in place for surgical care.^{22,23,25,28} These elements represent a challenge in poor resource settings like Haiti.²⁹

The Three Delays framework for addressing surgical care for fibroids.

The three delays framework represents a vital tool to address access to maternity care.³⁰ It can also be a framework for access to surgical care, in this case, uterine fibroids. For women with fibroids, three delays would be the first delay of decision-making in seeking care for fibroids, the second delay of reaching care at the facility, and the third delay of receiving care at the health facility.³⁰ Addressing needed and timely medical and surgical care for fibroids will require action to reduce barriers that result in these three areas of delay.

To address the first delay, a broad set of interventions are needed, including campaigns and counseling about the causes of uterine bleeding and pain, the fact that fibroids may be the cause, and that they are treatable. However, women's understanding is only one part of the first delay. Many women delay care-seeking because they do not have the resources for transportation or user fees, or the facility is far from where they live, resulting in a loss of 1 or 2 days' work. Also, women delay care because they do not believe (often from experience) that their concerns will be addressed with available staff, appropriate treatments, or high-quality care. Therefore, to address this first delay, more than just patient education is needed, it is important to reduce

financial and geographic barriers, and provide services for the diseases that will engender trust in the system..^{30,31}

To address the second delay, actions should be taken to improve the transportation system from the community to the health facility.³⁰ This is especially true for emergency care so that women with massive hemorrhage from fibroids can get to the health facility quickly. For instance, having a good ambulance network, creating a road, having a well-organized public transport system, and improving the economic condition of the population represent some key points to decrease this delay.^{23,30}

The third delay implicates actions within the facility. Needed services should be available and accessible quickly.³⁰ From blood banks to operating rooms, well-trained staff, adequate supply-chain, good governance, and ethical leadership are critical to providing comprehensive high health quality care in the facility.^{20,23,30,32} We can use this three-delays-framework to analyze and improve surgical care for fibroids in Haiti.

Health care overall is complex. Uterine fibroids are a chronic and treatable condition that impacts women who are the pillars of Haitian society. We will evaluate the prevalence of and access to care for uterine fibroids in Haiti. Because the treatment for this condition is medical, surgical, and radiological, the disease and its treatment provide a lens in which we can evaluate the political, economic, and social context of Haiti and its health care system.

Haiti

Biosocial factors that hamper surgical care for fibroids.

The biosocial factors of surgery for fibroids refer to some historical, political, and economic factors that can hamper the surgical for fibroids in Haiti. These factors are intertwined.

I will present them in bloc in this paper.

Firstly colonized by the Spanish in 1492, Haiti, the first Black independent republic of the Hispaniola island was a French colony from 1697 and 1804.^{33,34} The French colonizers, via the transatlantic trade brought enslaved people from Africa to cultivate the plantation without health facility with surgical capacity for such complex diseases as uterine fibroids.^{34,35} In the 18th century, the wealthiest French colony had around 500,000 enslaved people and was called the Jewel of the Antilles, whereas these enslaved people died by physically abused and inhuman working conditions on the groundwork without surgical care accessibility and availability.^{34,36} During this period, the French masters mostly focused on maximizing the harvest to send to the metropole. Therefore, under the pressure of the French masters, enslaved people abandoned their spirituality and culture; such emotional and spiritual suffering struggled, even more, their life with any disease, including fibroids.^{37,38}

During this period, the health facilities in the colony, though inadequate, were maintained for the French masters alone.³⁶ In a big plantation, if it happened to have a health facility for enslaved people, the facility was administered by a woman without any formal medical knowledge.^{34,36} In 1791, inspired by the French Revolution, enslaved people started the revolt, and Haiti became independent in 1804, creating the first black independent republic.³³ The revolution itself was associated with the destruction of a vast majority of goods, including the inadequate health infrastructures created during this period.^{34,36} In addition to that, in 1825, French colonizers after stealing a substantial part of the natural resources of the country pressured Haiti by the threat of recolonization to pay for its sovereignty about 21 billion dollars as reparation.³⁹ Forty-nine years later, the United States government recognized Haiti as an independent nation. The social, economic, and health effect of the colonization overtime is

immeasurable on the physical and mental of people in the colony.

Further, the American occupation from 1915 to 1934 worsened the poverty effect of the French colonization period. However, the U.S. government created some health infrastructures for primarily taking care of American militaries on the ground, with a small part of the population leaving the highest part without access to surgical care, including for fibroids.^{34,36,40,41} After this period, Duvalier's father (1957-1971) and sons (1971-1986) took power from 1957 to 1986. During the Duvalier presidential time, the population was theorized by political power and continued to suffer profoundly by increasing people's death by oppression. After the departure of Jean Claude Duvalier, we had recurrent state coups, a riot that lasted for few years, and the embargo of the international community, which increased the level of poverty, weakening the capability to deliver surgical care, especially for fibroids. In 1990, Haiti democratically elected its first president: Jean Bertrand Aristides. Aristides was deposed eight months later by a state coup, plunging the country once more into economic and political instability and limiting its capacity to rebuild its health system to deliver care for fibroids. Aristides came back to power in 1994 after a collapsing economic embargo weakened the country's economy and its health system. In 1996, Rene Preval replaced Aristides, showing a little horizon of political stability.

Indeed, the French and American colonization periods, the state coups, the social and political instability, and the embargo of the international community, in addition to the severe politic neoliberalism, played an essential role in the collapse of the economy. They broke down the agriculture system, which was the motor of the economy, creating the penury of food, and lack of income, creating a lack of access to social goods like health care. As consequences, we observed social suffering, disease, death, malnutrition, poverty, inequity, and a weak health system with incapacity to deliver surgical care, including for fibroids.

After independence in 1804, Haitian authorities could not start building a health system that can fulfill the needs in surgical care for the population, including for fibroids.³⁶ In 1818, the tentative to create the academy of medicine in Port-au-Prince was unsuccessful.³⁶ In 1827, Haiti created the school of medicine in the post-colonial era to train health care providers for all of the country.³⁶ In 1838, the country recognized the hospital school as the National School of Medicine.³⁶ In 1888, they separated the school from the hospital. In 1906, they connected the hospital and the school.³⁴ In 1914, the Port-au-Prince maternity was created to teach obstetrics and gynecology. The school trained health care providers, including surgeons, to address surgical care overall. However, this achievement was not able to cover surgical care for the whole population, including those with uterine fibroids.

The population also struggled to get access to surgical care for fibroids because of neoliberalism. This climate of suffering is rooted in the history of colonialism, the political economy context, racial discrimination is called by Paul Farmer structural violence.⁴² This situation of structural violence constructed the social reality of the misery of the Haitian population. It confirmed the theory of social construction of the reality by Peter Berger and Thomas Luckman.⁴³ The political and economic instability, the deficit of leadership, and the system of corruption affect the capacity of Haiti profoundly to build its health system with comprehensive capacity for surgical care including for uterine fibroids.

The reality of surgical care in Haiti, including fibroids

A good health system supposes to provide universal health coverage, social protection for its population, social-economic improvement, and response to the needs of every member of its population.²¹ However, in Haiti, the situation is entirely different for the reasons previously

cited. In 2013, the country had 907 health care infrastructures, 25% for-profit institutions in the private sector, 18% of private nonprofit institutions, 38% state institutions, and 20% mixed.⁴⁴ Only 250 of these facilities have inpatient capacity.⁴⁴ Haiti has only 1.3 beds for 1000 people in Haiti,⁴⁴ whereas the world health organization recommends 3.5 beds for 1000 people. It has 0.25 physicians for 1000 population, which represents 10% of the US physician ratio.⁴⁴ It has only 4.7 specialists, including OBGYN, general surgeon, anesthetist, orthopedist for 100000 people ⁴⁴. In contrast, the Lancet Commission recommends 20-40 anesthetists and OBGYN specialists for 100000 people.¹⁹ 80% of the health care professionals are located in the western department⁴⁵, and 70% of the population in the countryside have sparse access to health care.^{44,45} The health care services, including for fibroids, are unavailable for 40 to 60% of the population.⁴⁴

Furthermore, after the earthquake, the health system was collapsed in Haiti.⁴⁶ The state university hospital (HUEH), the most significant teaching hospital, which had the highest surgical capacity, collapsed. The OBGYN department that provided care for fibroids was damaged. The faculty of medicine, the state nursing school, the midwife school collapsed, limiting the capacity to continue to train health resources and to deliver adequate surgical care overall, and for fibroids.⁴⁶ Many health care providers—including obstetricians and gynecologists, lab technicians, nurses, surgeons, and anesthetists—were among the 200,000 people who died in the earthquake, devastating the health care’s capacity to treat uterine fibroids.

⁴⁶ The situation of the country was worst after the earthquake. We understand entirely that surgical care, specifically for fibroids, represents a challenge in Haiti. How did PIH help to address that before and after the earthquake?

Surgical care at Partners In Health (PIH) in Haiti

As we previously see, surgical care, including surgery for fibroids, is an indivisible part of health care.¹⁹ Partners in Health, an NGO co-founded by Paul Farmer, has been working very hard to alleviate the suffering of people roaming for health care, especially surgical care for fibroids in many countries, including Haiti.⁴⁷ In 1985, PIH started in Cange with a little clinic that developed surgical capacity in 1993 and became quickly one of the most frequented hospitals for general surgery and gynecologic surgical care, mostly for fibroids in Haiti.⁴⁷ In this hospital, there were general surgeons, obstetricians and gynecologists, pediatricians, internal medicine specialists, ophthalmologists, and psychosocial support.⁴⁷ After building the hospital, the number of consultations and surgeries increased exponentially.⁴⁷ From 2002 to 2005, they realized more of 2400 surgeries with half for general surgery and one third for obstetric and gynecologic surgery with a significant amount of cases of fibroids.⁴⁷ Observing this market failure, PIH scaled up its experiences by supporting and reinforcing the capacity of several government health facilities.^{35,47}

In 2003, PIH started working with government health facilities to support the health system. These hospitals were like a medical desert without human resources, equipment before the presence of PIH.^{35,47} The results were spectacular when PIH started working with them.³⁵ The model of PIH is based on the principle that poor people are less likely to get access to social goods like health, education and followed the principle of a preferential option for the poor, which originates from the liberation theology of Gustavo Gutiérrez.^{35,48} PIH has helped eliminate some barriers that hamper poor people's ability to access health care, including surgery for fibroids.³⁵ Through a staff, stuff, and space approach, they connected these hospitals as a network.²² Finally, PIH supported five hospitals with surgical capacity for fibroid and eight health centers. Of these hospitals with surgical capacity for fibroid, two of them are teaching

hospitals. First, Saint Nicola de Saint Marc Hospital (HSN) with high-capacity for surgery, was the first hospital in the network that hosted a family medicine residency program. Second, Mirebalais University Hospital (MUH), which is the real tertiary level teaching hospital with five teaching residents programs, including the training program in OB/GYN. These training programs graduated general surgeons and gynecologic surgeons to reinforce the surgical capacity of the network and in the country. Since 2018, Mirebalais University Hospital has graduated the obstetricians and gynecologists who went to other hospitals with surgical capacity in the PIH network and in the country for addressing the surgical needs in OB/GYN specially for fibroids a disease highly prevalent in the country as a black population and in these health facilities.

Surgery at the University Hospital in Mirebalais (MUH), including for fibroids

After the disastrous earthquake on January 12, 2010, the Haitian government asked PIH to build Mirebalais University Hospital in central plateau rural Haiti. It is the biggest Partners In Health-created and supported facilities in rural Haiti. It is a three-hundred-bed facility. The hospital started providing care in March 2013. In 2018, the hospital hired around 1200 employees, including 65 attending physicians and 80 residents in training. Now, 122 health professionals have graduated from our training program, including eight obstetricians and gynecologists. In this hospital, we have the first emergency residency program in the country in the history of medicine in Haiti. This hospital has several services: internal medicine, surgery, pediatrics, OBGYN, ICU, emergency medicine, and a center for primary care. This hospital has three core functions, which are health care delivery mainly for the poor population, training a new generation of physicians, and doing research. The hospital has six operating rooms with four fully operational.

The OBGYN department assumes these three core functions, as mentioned above. It was designed to represent one-third of MUH and composed of several sectors: triage area, labor and delivery, pre- and post-partum wards, and one gynecology ward. The department offers prenatal care, family planning, cancer screening, ultrasounds, gynecological and obstetrical care, and surgery, including for fibroids. The number of deliveries a month is 500 with 25% of C/S. 16 to 20% of his admission to obstetric are HTA. Fibroid represents around 50% of gynecologic surgery. We had a waiting list of a growing number of patients who have been looking for gynecologic surgery, and most of them are the fibroids. Fibroid represents the most frequent pre-operative diagnostic at MUH and the most frequents gynecologic surgeries at the OB-GYN department at MUH.

However, little is known about the social demographic profile of fibroids and its impact on the quality of Haitian women's lives. I aim to conduct a mixed-method study to assess the prevalence of uterine fibroids, the frequency of their complications, the risk factors, and the effect of fibroids on the quality of life of these women with uterine fibroids attending the outpatient department of obstetrics-gynecology at Mirebalais University Hospital. To our knowledge, this will be the first study to address this issue in Haiti. By doing this assessment, we will have a better comprehension of the uterine fibroid management in the hospital, and we will come up with evidence to make programmatic decisions at MUH to further alleviate the suffering of these women with fibroids.

Part 2: Publishable Paper

INTRODUCTION

Uterine fibroids are benign tumors of the smooth muscle of the uterus. They are the most common tumors of the uterus and are the primary reason that surgery is performed in gynecology

.⁴ Uterine fibroids are readily treated through surgical intervention, but without treatment, this condition leads to significant chronic morbidity - and even mortality. In communities that lack sufficient or ready access to medical care, uterine fibroids have been shown to affect a woman's quality of life deeply.^{1,6,7}

Studies have identified a variety of risk factors for fibroids, including age, race, family history, and comorbid conditions such as diabetes and hypertension.^{5,8,9} Clinical manifestations of fibroids can range from asymptomatic presentations to more severe conditions such as bleeding, dysmenorrhea, and fertility problems.^{5,9,11} Fibroids—when left untreated—is associated with several debilitating complications such as chronic pelvic pain, anemia, persistent infections, hydronephrosis, and even premature delivery and fetal intrauterine growth retardation¹²⁻¹⁴ The far-ranging biological effects associated uterine fibroids can result in devastating psychological, economic, and social effects for affected women.

The prevalence of uterine fibroids across populations varies widely – with rates ranging from 4.5% to 68.6%.⁵ Notably, several studies in the United States have indicated that fibroids are more prevalent in the Black population. One study indicated that the cumulative lifetime incidence of uterine fibroids is 59% among Black women compared to 43% among white women.² The same study in communities across the United States has reported rates of uterine fibroids as high as 74% and 80%, respectively, by the age of menopause.² The prevalence of uterine fibroids in many populations across the globe is unknown—this is the case for Haiti where rates of uterine fibroids have not been documented.

There are several methods of treatment currently available for uterine fibroids – including radiological, medical, and surgical interventions.^{17,20} Developed countries have achieved remarkable improvements in the treatment of uterine fibroids, including the emergence of

laparotomy, laparoscopy, and robotic surgery. These treatment options available to women in high-income countries have helped many women in these settings conserve their fertility.^{24,32} In contrast, access to modern fibroid care is largely out of reach for most women in low and middle-income settings because the medical equipment, infrastructure, and specialized personnel required for such interventions are not widely available.^{10,18,19}

This gap in the treatment is highly correlated to the weaknesses of the health system in developing countries. In Haiti, there are only 1.3 beds per 1,000 people⁴⁴—a fraction of the 3.5 beds per 1,000 people recommended by the WHO. The availability of specialized care is even direr, as Haiti only has 4.7 specialists per 1,000 people,⁴⁴ in marked contrast to the 20-40 anesthetist and OBGYN specialists per 1,000 people recommended by the Lancet Commission.¹⁹ The geographic distribution of these services is extremely uneven—with 80% of health care professionals centered in the capital city of Port-au-Prince, which is home to just 30% of Haiti's population⁴⁵ of the country where about 30% of the population lives. The majority of Haitians live in rural areas and have limited access to basic health care and even less access to surgical care.^{19,44} This deep divide in health care access was further exacerbated by the 7.2 magnitude earthquake that hit Haiti in January 2010. In an effort to reshape the health system, the Haitian government and Partners In Health (PIH) locally known as Zanmi La Sante(ZL) built Mirebalais University Hospital (MUH) in the central department to improve care delivery to Haiti's rural poor. As tertiary care teaching hospital with 6 fully-functional operating rooms now, patients from across Haiti seek the care of MUH's OBGYN department.

Uterine fibroids represent the most common illness among women presenting at the MUH OPD at the OBGYN ward. Fibroid represents around 50% of the gynecologic surgery at the hospital, representing the most frequent gynecologic surgery and the most prevalent pre-

operatory diagnostic at MUH. With such high demands, the waitlist for surgical fibroid treatment has increased. Clinically, women who are presenting to MUH for surgical care are presenting with severe complications, and several have died shortly after arriving at MUH because of severe anemia.

However, little is known about the epidemiological profile in the Haitian context of these women who present with fibroids, and the impact of uterine fibroids on their quality of life is not well understood. To address this gap, we conducted a convergent mixed methods study—the first of its kind to address uterine fibroids in Haiti. We undertook a cross-sectional study to examine the prevalence, complications, and risk factors associated with uterine fibroids. We also undertook a qualitative study to explore patients’ illness experience and care-seeking trajectories, to understand the impact of uterine fibroids, and identify the structural barriers that shape access to fibroid care.

METHODS

Study setting

The study took place at Mirebalais University Hospital from October 2019 to January 2020. MUH is a three-hundred-bed facility located in the Central Plateau build and supported by Partners in Health in collaboration with the government of Haiti. The primary catchment area of MUH is 187,077 persons, and the secondary catchment area serves more than 3.1million Haitians.⁴⁹ MUH has 350 beds now, 6 operating rooms, and performs 6000 surgeries per year and about 250000 visits per year overall. About 40% percent of surgeries are for GYN conditions , and about 12% of outpatient visits are for GYN. The OBGYN includes a triage area, labor and delivery, pre- and post-partum wards, and one gynecology ward (add bed numbers) The hospital

offers a broad range of women's health services including prenatal care, family planning, ultrasound, gynecological care, complete emergency obstetrical care, gynecological surgery (including fibroids), and cancer screening.

Study design

This study used a convergent mixed methods design in which qualitative data were collected to provide elaboration, clarification, and explanation for the quantitative results³ for women with uterine fibroids. The study included all women aged at least 20 years old who were seeking gynecological care at MUH's outpatient gynecology ward. A sixty to ninety minutes individual, a semi-structured interview was carried out with 17 women of 15 to 20 expected women who had sought care at MUH for uterine fibroids, and 7 family members of 5 to 10 expected family members both selected purposefully.⁵⁰ The interview covered the following topics explore (a) women's experience with fibroid; (b) their care-seeking journey; (c) the meaning that women attribute to the fibroid; (d) the effect of fibroid on the family's social and economic life, and e) women's workload.

Data collection

All women >20-year-old presenting to MUH for gynecological consultation between Oct 1, 2019, and Jan 31, 2020, were considered for enrollment. Women were included in the study if they had had a current ultrasound documented in their records. Women meeting this criterion were invited to participate in the study. Excluded from the study were women who: were less than 20 years old, presenting for prenatal care at MUH, refused to consent, did not speak Creole, did not have an ultrasound in their record. In addition, women who had a medical emergency or

who otherwise were not able to participate due to medical considerations were excluded.

Data analysis

Measures

A conceptual framework (*Appendix 1*) was used to inform the survey questionnaire, which included significant covariates including age, parity (number of births), menopause, patient status (i.e., initial visit or a follow-up visit), confirmed diagnostic of uterine fibroids, employment, monthly income, income decline reported after the diagnosis of uterine fibroids, and reported excessive expense for transport to look for care for uterine fibroids. These expense categories are where patients expensed their money on things such as education, food, self-care, and medical care. Zone of residence, the average time to get to the hospital, primary method of transport, main profession, health insurance status, education level, and family conflicts were also taken into consideration. Family conflict was assessed by problems, of communication and attitude, and fight between the women and their husbands after the diagnostic of uterine fibroids. Further, the data of the most clinical symptoms were collected including constipation, dysmenorrhea (pain during menstruation), acute pelvic pain (less than 3 months), chronic pelvic pain (more than 3 months), menorrhagia (abundant bleeding during menstruation), metromenorrhagia (bleeding between period), mictional difficulty (pain with urination), pelvic pressure, pelvic infection, infertility (defined as > 1 year without conceiving a child while being sexually active and not on family planning); related conditions including deep vein thrombosis, urinary stones, hydronephrosis, anemia (Hb<12 mg/dl). We also measured self-reported stress and depression (using a validated depression screening tool-no depression < 13, mild depression 13-17, moderate depression 18 to 27. and severe depression 28-39.⁵¹ anemia (less than 12g of

hemoglobin).

Data collection and analysis

We designed a tablet-based survey using the CommCare application. A 30-45-minute survey was used by a quantitative research assistant to collect quantitative data. A chart review was performed to extract additional information. Data were cleaned, and string variables were converted to numeric for the analysis. Participants were eliminated for relevant missing data about the primary outcome. Descriptive statistics, including frequencies, means, and standard deviations, were used to report the social demographic characteristics, signs and symptoms, and complications of uterine fibroids. Bivariate and multivariate logistic regression were used to identify the risk factors associated with uterine fibroids. Variables with a p-value of less than 0.2 were used to build the multiple logistic regression model respectively for demographic variables and clinical variables. Potential confounders were integrated into the model to force the model. In both models, we exclude variables that could potentially be collinear based on prior knowledge. For the depression score, we used the cut-off score for depression on the ZL-DSI previously used in the Rasmussen study.⁵¹ All analyses were performed using Stata, version 16.2

Interviews were transcribed and translated into English by the first author and a trained research assistant. A general narrative analysis overview of all transcripts was done to think about eventual key concepts or theories related to the research question. Then, transcripts were analyzed in-depth using an inductive, narrative, and content analysis approach.^{52,53} Transcripts were reviewed in full, and a subset of transcripts was open-coded in order to identify a set of emerging concepts that explained women's perceived impacts of uterine fibroids. These initial

concepts were used to develop a draft codebook, which was then piloted and revised into a final codebook that was then used to code the entire dataset. The coded data were analyzed using an iterative inductive process that sought to identify an initial set of key concepts with supporting quotes as evidence. These initial concepts were then revised through an iterative approach to the data, resulting in a final set of descriptive categories that appear in Results, which were merged with the quantitative results and presented by using a joint display technic (*Appendix 4*). A summarized methodology is in *Appendix 2*.

RESULTS

Quantitative

Of 193 included in the analysis, 60.1% had uterine fibroids. Of these, 70 (60.3%) were between 35 to 49 years old (*Appendix 3*). Sixty-one (52.6%) were coming from the Central department (primary catchment area) area, whereas 47.4% were coming from other areas of the country. Fifty-seven (57.8%) reported that they experienced a decline in household income Table 1 described demographics and characteristics of all study participants. The most-reported clinical symptoms included stress 92(79.3%), dysmenorrhea 73(62.9%), acute pelvic pain 72(62.1%), pelvic mass 56(48.28%), polymenorrhagia 50(43.1). Additionally, 22 (15.6%) screened positive for depression with 11.4% mild depression (ZL score ≥ 13 - ≤ 17) and 4.2% with moderate depression (ZL score ≥ 18 - ≤ 27) (4.2%) (*Appendix 5*) Anemia 61(52.6), infertility 39(33.6%), deep vein thrombosis 18(15.52%), urinary stone 17(14.66%), and hydronephrosis 6(5.17%) were described as major complications. (*Appendix 6*)

Women aged 35 to 49 years were 2.6 times more likely to have uterine fibroids than those aged 20-34 years old, (95%CI.1.33 - 5.03, $p=0.005$), the odds of those who were out of

central plateau was 2.3 times the odds of those who were in the central plateau (95%CI. 1.22 - 4.17, p=0.01), the odds of those who are in follow-up visits was 3.2 times the odds of those who were in initial visit (95%CI. 1.14 - 8.84, p=0.026), the odds of those who experience excessive expense for transport was 3.8 times the odds of those who did not experience excessive expenses for transport (95%CI. 1.65 - 8.74, p=0.002), the odds of those who used public transport was 3.1 times the odds of those who walked (95%CI. 1.34 - 7.28, p=0.008).

Further, the odds of those who had higher education was 0.4 time the odds of those who had primary education (95%CI. 0.18 - 0.96., p=0.044). The odds of women with uterine fibroids who are farmer was 5.1 time the odds of those with no specific profession (95%CI. 1.04 - 25.29, p=0.044), the odds of those who experienced income decline was 3.0 time the odds of those who did not (95%CI. 1.64 - 5.54, p<0.001), the odds of those who had a family history with fibroids was 5.1 time the odds of those who did not (95%CI. 2.11 - 12.33, p<0.001), the odds of those who had micro polycystic ovary is 0.2 time the odds of those who did not have (95%CI. 0.12 - 0.41, p<0.001), the Odds of those who experienced family conflict is 2.6 time the Odds of those who did not (95%CI. 1.12 - 6.16, P=0.026), the odds of those who had pelvic mass is 2 time the odds of those who did not (95%CI. 1.10 - 3.67, p=0.024). However, there is no significant association between uterine fibroids with the number of pregnancies, number of births, health insurance, mictinal difficulty, menorrhagia, metrorrhagia, dysmenorrhea, infertility, chronic pelvic pain, acute pelvic pain, stress anemia and depression in the bivariate analysis (*Appendix 7*).

Controlling for potential confounders, including age, patient status, insurance, education level, income decline, and the number of births the odds of women with fibroids who experienced excessive expense for transport is 4.4 times the odds of women with fibroids who

did not experience excessive expense for transport (95%CI. 1.55-12.38, $p=0.005$), after adjusting for the variables age, patient status, insurance, excessive expense for transport, income decline, and the number of births the odds of women with higher education is 0.3 times the odds of those with primary education (95%CI. 0.09-0.87, $p=0.021$) then higher education appears to have a protective effect after adjusting for the variables age, patient status, insurance, excessive expense for transport, education level and the number of birth the odds of women with fibroids who experienced income decline is 4.7 times the odds of those who did not (95%CI. 2.05-10.93, $p<0.001$).

Further, for the multi logistic regression model for clinical variables (*Appendix 8*) after adjusting for variables family conflicts, pelvic infection, micro polycystic ovary, pelvic mass, polymenorrhagia, deep vein thrombosis, depression categories low and moderate the odds of women with fibroids who had a family history of fibroids was 4.6 times the odds of those who did not have a family history of fibroids (95%CI. 1.58 - 13.56, $p=0.005$), and finally after adjusting for variables family conflicts, pelvic infection, family history of fibroids, pelvic mass, polymenorrhagia, deep vein thrombosis and depression category the odds of women with uterine fibroids diagnosed with micro polycystic ovary was 0.3 times the odds of those who did not diagnose with micro polycystic ovary (95%CI. 0.10 - 0.97, $p=0.044$) then micro polycystic ovary appears to be protective against uterine fibroids.

However, we did not find an association between uterine fibroids and age, patient status, health insurance, number of births, family conflict, polymenorrhagia, deep vein thrombosis, or depression categories in the multivariate model (*Appendix 8*).

Qualitative

A set of themes describing women's experiences living with fibroids were identified. Many structural and contextual factors that shape the process of seeking care for fibroids were highlighted. Emerging themes described the complications and consequences of women's care-seeking journey.

Health system failure

Many women reported in their interviews that the Haitian health system did not deliver adequate care for their fibroids. While some participants indicated that they began their care-seeking journey by consulting with a traditional healer close to their home, most eventually sought care for their symptoms within the public or private health system. Women explained that before arriving at MUH, they undertook a large number of visits to different care providers – “roaming” from one hospital or clinic to the next in an attempt to seek care for their condition. They explained that at each stage, they were unable to obtain adequate treatment. For many, the protracted search for care led to significant delays, increasing pain, and mounting health care costs.

“I knew I had fibroid at General Hospital in Port-Au-Prince. The « Medsen fey » (leaf doctor/herbalist and shaman) told me I was pregnant. Well, there was a « Medsen Fey » who told me I was going to have twins. I said God knows everything. I know nothing. I spent money over, over, and over again, and nothing worked out. I got really sick on July 26, 2019. They rushed at the Emergency room of General Hospital with me. I came here after I left the Emergency room of General Hospital. They asked me to bring the sonography result back but, I could not find a doctor. I finally found one at 9:00 AM. I was sent to *Rue Monseigneur*

Guilloux. And it was 10:00 AM. When I got to the place I was sent, the receptionist told me no, there is no doctor here for this disease and I have to come back the day after at 6:00 AM. My cousin could not come with me because she had to drop her children off to school. My other cousin told me she would come to take me and bring me here. They came here with me. General Hospital did not transfer me to MUH. My cousins and I came here ourselves. I consulted several times.” (Woman with fibroids)

Long journey for incomplete services

Participants detailed an arduous journey, often going to many different places to access care even before they attempted to reach MUH. Those who traveled to Mirebalais from the central plateau via public transport often had to leave their homes a full day before the medical appointment because the journey from their homes to the hospital was so time-consuming. Women explained that once they arrived at the hospital, they would have to endure multiple long queues. A hospital visit required visits to many different services within the hospital, and each service entailed a long wait. In some cases, participants reported spending an entire day waiting for their medical consultation, only to be told to leave the hospital and return on the next day. For these women, the wait for a single consultation resulted in a days-long commitment with significant social and economic implications.

“I usually leave home at 6:00 AM. I arrive at the hospital at 8:00 AM because I take the bus in Delmas 33 to go to Croix-Des-Bouquets. I take another bus there so that I get to the hospital by 8:00 AM. Well...when I get there, I have my records released, I have my vital signs checked and, they transfer my records to

the doctor. I wait for the doctor if he has not arrived yet. I always get to see the doctor. There is a lot of people. There is a lot of people for gynecology. This process is very long because I started since January... I started on January 17th, 2019. I do not like to sleep at the hospital. There is nowhere to sleep there. If I do a test today at the hospital, I must come take the results tomorrow. So, I go to Port -Au-Prince, and I return back to Mirebalais. So, that costs me money.” (Woman with fibroids)

Gender disparity

Women with uterine fibroids explained that they often felt pressured to perform routine housekeeping activities with no support or minimum support from their spouses or partners. The effects of uterine fibroids made it exceedingly difficult to carry out the physical labor expected of them, but they nonetheless attempted to keep up with the duties they were expected to fulfill.

“Usually, I do everything. I wash clothes. I make sure that my husband’s clothes are ready, I make sure that my child’s clothes are ready, I make sure they have food, and I give the maid instructions while I am not at home.”(Woman with fibroids)

Women reported that the effects of the gendered expectations related to fertility were particularly painful for them. Fertility challenges caused women's sadness, but infertility also led to social exclusion. Women explained that they were blamed for the fertility challenges that they experienced as a result of untreated fibroids:

“I am unhappy, and so is my husband because of the fibroid because most Haitian men would like to have children. As soon as you cannot, their family members

start naming you: “Manman Milet” (A local reference to identify a woman who is sterile).” (Woman with fibroids)

Fear/lost relationship and social rejection

Women voiced the fear of losing their relationships due to uterine fibroids. Women described how her pain affected their relationship because the partners get hangry when women said they could not have intercourse because of the pain.

“My boyfriend complains about my illness because I cannot get pregnant. When I cannot have sexual intercourse with my boyfriend because of the pain I feel, he gets angry. He does not curse or yell, but my incapability to have sex troubles him .” (Woman with fibroids)

Poverty

Women indicated in their interviews that the physical effects of fibroids imposed on them by many social and economic consequences. Notably, women with fibroids were largely excluded from social and economic opportunities. Women recounted how the effects of their fibroids made them lose their job or have to give up their business. The loss of income severely impacted their ability to meet their most basic needs—including their ability to secure food and housing or to pay for their children’s school fees. Women explained that they had to scale back or eliminate participating in social activities, such as church or sporting events, which led to further isolation.

“I don’t have a job, I don’t have money, I cannot rent a decent place to live, and sometimes, I spent three days without eating because of my fibroids. I sometimes

choose to suffer hunger to save the money for coming to my acquaintances with the doctors to the hospital.” (Woman with fibroids)

“Sometimes, I feel like going to church, and I cannot. I stay home, and I lie down.” (Woman with fibroids)

Care seeking drivers

The interviews reveal that because women hope to be healthy, have kids, and work, they are motivated to endure the challenges inherent in navigating the health system and securing care for their fibroids. Factors that discouraged women included long wait times, poor provider communication, and a lack of availability of surgical care at the hospital. They advised the staff to have a better communication style, attitude, and behavior with women with fibroids. However, several of them like the quality of care at the hospital.

“I want the doctors to take good care of the patients by listening to them, helping them, and seeking care for them, and talk to them, advise them — speaking with the patients to explain what they have.” (Woman with fibroids)

“Advantages...I like the quality of care here. The only thing that bothers me is the wait. It takes too long to have a surgery. I thought I would have it faster.” (Woman with fibroids)

“When I find a solution, I will be in good health; I will be able to take care of myself, my family; I will be able to manage a business and take care of my family

, my daughter, and my parents.” (Woman with fibroids)

From the quantitative and qualitative findings of the study, the concept of the poverty cycle of uterine fibroids emerged.

DISCUSSION

The study found results of the quantitative and the qualitative part of the study are interconnected, and we merged them under the concept of the poverty cycle of uterine fibroids (Figure 4). The concept of the poverty cycle of uterine fibroids is processual, nonlinear, where one aspect interacts with another. The concept implies that poverty limits the capacity of the health system to deliver care for fibroids. As a consequence, the uterine fibroids become complicated, making women lose their job and business. Therefore, women do not have income and savings and become poorer and poorer. This cycle is rolling toward morbidity and mortality and negative social consequences and can be applied for diseases with suffering similarity with fibroids or worse.

The study revealed a high prevalence of uterine fibroids at the MUH’s OPD. This high prevalence was expected because the population is a surrogate and Black population, and the majority of women in the study were between 35 and 49 years of age – the age bracket with the highest prevalence of uterine fibroids.⁵⁴ Further, ultrasound was used as the reference method to select our population. The sensitivity of ultrasound for the diagnosis of fibroid is around 94.5%, and the accuracy is 94%.³⁰ This prevalence is similar to the cumulative incidence in the Baird study, which was 59% among the black population while coming for ultrasound screening.²

The study found that the two most frequently reported symptoms are stress and dysmenorrhea, whereas Zimmermann's study reported that heavy bleeding and prolonged

bleeding are the most frequent.⁵⁷ Because of political instability, women with fibroids are more likely to be stressed. The two most frequent complications reported in our study are anemia and infertility. In contrast, a previous study mentioned other complications.⁵⁸ Understandably, anemia is frequent because of bleeding associated with uterine fibroids but also current parasite infection, nutritional deficiency in Haiti. The lack of specialized care for infertility could be the cause of this high rate of infertility.

The study did not find an association between age and uterine fibroids in the multilinguistic regression model. However, study before demonstrated that people greater or equal to 40 years old are more likely to have fibroids, and in menopause, uterine fibroids are less likely to appear.⁵ However, the study found a statistically significant association in the bivariate analysis. The study showed the health insurance coverage in Haiti is about 7 times lower than the health insurance coverage in the USA and 6 to 8 times in Europe.⁵⁹ This lack of assurance coverage in Haiti explains why women were exposed to out-pocket expenditure and why they cannot afford care in a private clinic. Most of the women with uterine fibroids are in follow-up, and the majority are for more than 12 months whereas study shown the surgical time from consultation to gynecologic surgery for fibroids in the USA at Brigham and Women's Hospital is around 21.6 weeks, and 14.6 hours for treatment by high-intensity focus ultrasound.⁶⁰ This finding supports the long waiting time mentioned in the qualitative part of the study and explains the growing number of patient in the waiting list. About half of our women with uterine fibroids are coming from five other departments in the country, and most of them are coming from the western department, whereas this department has the highest ratio of specialists and health facilities with surgical capacity⁴⁴. These findings, aside from the lack of human resources and biomedical equipment in the Haitian health system and confirmed the qualitative findings that

the Haitian health system fails to deliver care for its citizens. This finding supports the concept of health system failure in the poverty cycle of uterine fibroids.

The study findings that more than four-fifths of the population studied are poor. In contrast, women with uterine fibroids are more likely to experience excessive expenses to go to a hospital and are more likely to experience a decline in their income are in the same direction of previous studies, which have shown that women with uterine fibroids are more likely to miss days at work. Those with lower incomes are more likely to experience severe disease and have a negative experience with higher education.^{57,61,62} These findings are connected with the bad economic condition of the country. This study revealed that women with uterine fibroids with higher education are less likely to have uterine fibroids. This finding can be because women with higher education are more like to look for care and economically powerful compared to women with lower education. This study supports that women with fibroid are more like to be impoverished by the disease, which is not at odd to the qualitative finding that women with fibroids are excluded economically and subjected to social exclusion to social goods and social production. once again, these findings support the concept of the poverty cycle of uterine fibroids in the results.

The findings of the quantitative part of the study support the concept of social exclusion from social goods like health care and education because of fibroids. However, it did not explain all the factors that affect the care of women with fibroids whereas the qualitative part provided a deeper explanation of how women with fibroids are excluded from social production by the fact that sometimes they cannot participate in a social activity like going to church or a soccer game. However, the quantitative literature studies highlighted the negative impact of fibroids on housekeeping, performance at work, social activity, attendance at work, or high education.⁵⁷

Although the study did not find an association in the multi logistic regression model, the bivariate analysis shows a significant association between women with uterine fibroids and the experience of conflict in the family. Once again, this part also supports the concept of the poverty wheel of uterine fibroids.

The qualitative component of the study underscores the importance of social determinants, which are contributing factors in women's suffering from fibroids. On a family level, findings show that uterine fibroids affect the intimate partner and sexual lives of women living with the disease and can arrive to divorce. However, other quantitative studies have shown negative consequences for sexual life and relationship for women with uterine fibroids.⁽³¹⁾ The qualitative part of the research has shown that the suffering of fibroids is also rooted in gender inequity. This section also supports the concept of the poverty wheel of uterine fibroids.

In the study, women with micro polycystic ovary were less likely to have uterine fibroids, and this result confirmed the results of a previous study realized by Huan.⁶³ Previous studies show that family history is an important risk factor for uterine fibroids in the literature,⁶⁴ and this study is moving in the same direction. However, stress, anemia, depression, menorrhagia, metrorrhagia, dysmenorrhea were not associated with fibroids, whereas the previous study has shown a significant association between these variables.⁵⁷ The absence of association of uterine fibroids between Stress and anemia can be explained by the fact that both are broadly distributed in the Haitian population linked to an inequitable distribution of social determinants of health and structural violence.⁴² Further study is needed to look at the burden of uterine fibroids among the whole Haitian population. This study has several limitations. As a cross-sectional study using a hospital-based surrogate population, it is not formally generalizable. The qualitative data is also not generalizable, but it offers important insight into the myriad social and economic effects that

women living with uterine fibroids face in settings where access to care is limited. Other clinical conditions may have been misdiagnosed as fibroids - a possible confounder resulting in an underestimation of prevalence. To mitigate misdiagnosis, we used clinical signs and ultrasound, which have high specificity and sensibility to establish the diagnosis. The prevalence may also be overestimated because symptomatic individuals may be more likely to pursue care. We expect the study was overpowered because our population is black and is more likely to develop uterine fibroids.

CONCLUSION

The prevalence of uterine fibroids in this population of rural women in Haiti is high, and the social and economic consequences associated with fibroids are deeply rooted in a vicious cycle of poverty and physical and social suffering. Women are motivated to pursue care for this treatable disease, but they encounter costly delays as they navigate a health care system that is fragmented and overwhelmed by a dearth of equipment and qualified health professionals. Health system strengthening, and programming that actively redresses the fragile economic and social conditions facing women with fibroids are key elements to improving the health and quality of life for women with uterine fibroids in Haiti.

Part 3: Publishable Paper (Qualitative)

Uterine fibroids: A socially malignant neglected illness

Abstract

As a benign tumor of the uterus, uterine fibroid profoundly affects the quality of life of women and their families.² The cumulative incidence higher among the black population is 59% while using ultrasound for diagnosis.² Haiti has significant historical, social, and economic factors that can impact care for uterine fibroids worsening the women living with the disease. However, little is known about the impact of uterine fibroids on the quality of women living with fibroids in Haiti in their voices in a social context. As part of a concurrent mixed-methods study, we have done a qualitative study on the effects of uterine fibroids on women's lives at Mirebalais University Hospital (MUH). This qualitative research explored how and why patients seek surgical care for uterine fibroids at MUH by (1) exploring and tracking the patient's care-seeking journey for uterine fibroids at MUH; (2) Understanding women's and family's experiences including meaning and perception of living with uterine fibroids and their complications; (3) Assessing the socio-economic impact of uterine fibroids; (4) Exploring structural barriers limiting access to care.

Methodology

In-depth interviews lasting 60 to 90 minutes were recorded and translated into English on a subset of seventeen women (at least 20 years old) with uterine fibroid selected from the quantitative sample of the mixed-method study, along with seven family members of women with uterine fibroids (at least 12 years old). Also, we conducted home visits of 2 to 4 hours with two women with complicated uterine fibroids, including participant observation and recording

field notes. Content analysis and narrative analysis were realized through an iterative inductive process to come up with the results.

Findings and discussion

The journey of care-seeking, the failure of the health system, and gender inequity in Haiti make women with uterine fibroids suffer physically, psychologically, and socially. The concepts of the health-seeking journey (*pèrelinage*), the poverty wheel of uterine fibroids, a pathway of exclusion to social goods, and social production, the dilemma of an overcrowded hospital, and the fibroids social suffering tree emerged

Conclusion

Strategic planning to strengthen the health system, improve the economic situation of the community, create mechanisms of accompaniment for women with uterine fibroids to get access to social goods, and participate in the community activities are critical to addressing the suffering by uterine fibroids in Haiti.

Background

As a benign tumor of the uterus, uterine fibroid profoundly affects the quality of life of women and their families.¹ This pathology is widespread, and its prevalence is between 4.5 to 68.6%.⁵ The cumulative incidence in premenopausal is around 51% among women without a diagnosis before coming for an ultrasound screening exam.² This cumulative incidence is higher among the women of African descent compared to women of European descent (59%, and 43% respectively).² By the late 40s, the cumulative incidence among screened women is up to 70%

for white and 80% for Black.² Several risk factors have been studied including race, family history of uterine fibroids, menorrhagia, age, hypertension, obesity, caffeine intake, and early menarche.^{5,65} Other factors appear to be protective such as multi-parity, polycystic ovarian disease, use of hormonal contraception, diabetes, and a diet rich of soya.^{5,63,65,66} Without treatment, uterine fibroids can exist for years and result in both acute and chronic complications including hemorrhage, anemia, chronic pelvic pain, acute pelvic pain, infertility, infection, deep vein thrombosis, chronic constipation, hydronephrosis, mictional dysfunction, sarcoma, abortion, premature delivery, and growth retardation.¹²⁻¹⁴ The treatment of fibroids can be radiological, medical, and/or surgical.^{10,13} The treatment implies as well the treatment of the previously mentioned complications. Because of these complications and the chronicity of this condition, fibroids can have devastating physical, psychological, economic, and social effects.

History

The physical, psychological, economic, and social impacts of this disease are more significant in countries that cannot address the health care needs of their citizens. The historical and political context of Haiti has led to a fragile health system, and the result of this is enormous suffering from otherwise treatable conditions.

In 1791, inspired by the French Revolution, enslaved Africans led a revolt against the French plantation masters. The Haitian revolution sent shock waves around the world when the formerly enslaved people beat Napoleon's Army and won independence for Haiti in 1804. Haiti was the first black independent republic, the second sovereign nation in the Western Hemisphere, and the only nation founded by a rebellion of enslaved people.³³ Haitians went farther than any other country in fighting for the abolition of slavery and supported uprisings and liberation

struggles throughout the hemisphere. The revolution itself was economically devastating for the country, destroying a vast majority of goods, including the inadequate health infrastructures created mainly for colonizers.^{34,36} In addition, as all major powers of the day, relied on enslaved Africans to generate wealth, France, England, and the United States embargoed Haiti. Without the benefit of international trade, Haiti's fortunes dwindled. Then, in 1825, French colonizers, after stealing a substantial part of the natural resources, asked Haiti in 1825 under the French pressure of the threat of warships strike to pay about 21 billion dollars for its sovereignty.³⁹ The Haitian people continued to pay this odious debt through the 1940s, including during the United States' occupation of Haiti 1915-1934. This 200-year history of the pillage of Haiti for empire and economic sanction and embargos to punish the liberated nation has had an immeasurable impact on the physical and mental well-being of Haitian people.

Because Haiti was developed as a plantation, there was no substantial medical infrastructure built during the colonial period.^{34,36} The life expectancy of enslaved Africans was around just 20 years.⁶⁷ The health infrastructures were built for colonizers and the military health^{34,36}. On rare occasions, a specialized hospital was built in a rich plantation for the enslaved people of the colony to take care of this workforce—by an unqualified health care provider who was herself an enslaved woman without medical education.^{34,36} While the revolution, few health facilities existed were destroyed.^{34,36} After independence in 1804, Haitian authorities did not have the economic or human capacity to start building a health system.³⁶ In 1827, Haiti created the school of medicine in the post-colonial era to train health care providers all over the country.³⁶ Nevertheless, by 1827, Haiti had suffered 23 years of an international embargo because of the revolution and was in a 100-year debt to France. There was no money in the Haitian treasury to pay workers or build the health system.

During the American occupation, some health infrastructures were created for the American military, but the majority of the population had no access to even basic medical care, no less surgical services.^{34,36,40,41} Under the long Duvalier family rule of Haiti (1957-1986), wealth was further concentrated in the hands of a small number of elite families, and the majority of the population suffered poverty and political repression. A democratic movement sparked the removal of the Duvalier family. In 1990, Haiti elected democratically its first president Jean Bertrand Aristide, who ran on a platform of improving health, education, and wages. But as he promoted this social contract for the long-neglected poor, Aristide rejected neoliberalism and looked for collaboration from other governments, including Cuba. Based on his anti-capitalist rhetoric, Aristide was embargoed and deposed by a U.S. backed coup d'état just eight months after his inauguration. This cycle has now been repeated multiple times, flouting the democratic will of the Haitian populace through foreign intervention in Haiti's electoral process. The fear of this independent Black republic and promotion of privatization over investment social structures has made stability and improvement in the public provision of health care virtually impossible.

Today, the ratio Bed by population is 1.3 beds for 1000 people in Haiti whereas the recommended World Health Organization's ratio is 3.5 beds for 1000 people.⁴⁴ Hospital beds and health care providers are disproportionately higher in the western department, where we found 80% of health care providers compared to the remaining part of the country⁴⁵ Therefore, in the countryside, 70% of the population are living with minimal access to health services.⁴⁴ The surgery field required specialists to deliver care. In Haiti, the ratio specialist specialists, including obstetricians, general surgeons, anesthetists, and orthopedists are only 4.7 specialists per 100000 people,⁴⁴ whereas 20- 40 surgical specialists per 100000 represent the recommended ration by the Lancet commission recommends.¹⁹ This situation became worse after the 7.2 magnitudes

earthquake on January 12, 2010 collapsed the health facilities, medical teaching institutions, and killing health care professionals of the country.

To rebuild the Haitian health system, the government asked PIH to build Mirebalais University Hospital (MUH) in central plateau rural Haiti. MUH is the biggest hospital built and supported by PIH in rural Haiti with a capacity of 300 beds. One-third of the hospital is represented by the OBGYN department, which is composed of several sectors: triage area, labor and delivery, pre- and post-partum wards, and one gynecology ward. Services delivered are prenatal care, family planning, ultrasound, gynecology care, complete emergency obstetrical care, gynecology surgery including for fibroids, and cancer screening program. Although about 50% of the gynecologic surgeries at the hospital were uterine fibroids, the waiting list for uterine fibroids surgery was growing during the past years and the first preoperative diagnosis at the OBGYN MUH'S OPD was uterine fibroids. There is no previous study published in Haiti on uterine fibroids. To cover this gap, which hampers good planning for care for fibroids, we conducted a concurrent mixed-methods study in which the qualitative part made visible the effects of uterine fibroids on women live at Mirebalais University Hospital (MUH) at the outpatient department (OPD) of the OBGYN service. This qualitative part of the study explored how and why patients seek surgical care for uterine fibroids at MUH by (1) exploring and tracking patient's care-seeking journey for uterine fibroids at MUH; (2) Understanding women's and family's experiences including meaning and perception of living with uterine fibroids and their complications; (3) Assessing the socio-economic impact of uterine fibroids; (4) Exploring structural barriers limiting access to care.

Methodology

Semi-structured interview guides and recorded notes from participant field observations were used to collect the qualitative data. In-depth interviews, which lasted for about 60 to 90 minutes, were aimed to be realized with a subset of 15 to 20 women with complicated uterine fibroids at least 20 years old from the quantitative sample and 5 to 10 family members at least 12 years old referred by 5 to 10 women from the qualitative part of the study. These women were selected purposively based on their agreement to participate in the interview, that they have been suffering from the disease, and could share their experiences with the disease according to the following criteria: (1) Having fibroids for at least two years; (2) A complicated fibroid like fibroids with chronic pain, hemorrhage with severe anemia, chronic constipation, etc.; (3) Waiting for at least two years to get access to care for your fibroids while living in or out of the Mirebalais community; (4) Having a giant fibroid (5) Are willing and capable to describe their experiences with the disease

During the in-depth interview the following topics were covered (a) Women's experience with fibroid; (b) Women's journey in seeking care for fibroid; (c) The meanings the women have about having a complicated fibroid; (d) Effect of fibroid on the family life; (e) Effect of fibroid on the women's workload; (f) effect of fibroids on the expense in the family for basic needs.

In addition, a subset of two women with giant fibroids and/or with a complicated fibroid who have been suffering for at least two years with the disease were selected purposively based on their consent from the qualitative part of the study for participant field observation. The purpose of the participant observation was to have a better comprehension of the effect of the fibroid on daily life. The following topics were covered (a) women who are suffering from fibroids while at home (b) The implication of fibroids on the woman's family activity; (c) Family support for the woman with the disease; (d) The influence of fibroids on the interaction of the

woman with her family members, such as her children, partner or other people at home. To understand the qualitative aims: women's and family's experiences including meaning, perception about living with uterine fibroids, complications, and assessment of the socio-economic impact of uterine fibroids, data were collected during the field observation about inactivity by, e.g., over bed rest because of the disease, incapacity for preparing food in the house, for sending children to school and cleaning the house during their suffering with the uterine fibroid. Fieldnotes were used to report the data during the participant observation.

Seven adult family members who knew the women's experiences with uterine fibroid supported her over time and referred by the women to the investigator were selected purposively based on their consent to participate in the qualitative in-depth interviews. During the interview we covered the following topics: (a)Economic impact of the fibroid on the family life; (b)Family experiences with the women fibroid; (c)Effect of fibroid on the sexual life if possible; (d) Women's journey in seeking care for fibroid; (e)Effect of fibroid on the women workload in the house; (f)Women waiting time to get access to care for the fibroid.

Data analysis

After having the recorded in-depth interview in Creole, it was transcribed into English. After transcription, content analysis⁵³ was done iteratively using an inductive process to come up with the findings. Before that, a general analysis overview of all transcripts, including narrative analysis,⁵² was done to come up with key concepts or theories related to the research question (How and why patients seek surgical care for uterine fibroids at MUH). The findings that support these key concepts and theories were developed iteratively via an inductive process starting by narratives, meaning summarizing key information in the transcripts, open codes by highlighting

the important portion of text in the transcript related to the research question, codebooks by labeling important portion of text to create multiple different labels or codes in a word documents, and grouping labels into broader categories. Processual methods were used.⁶⁸ This model was built as it follow.⁶⁹

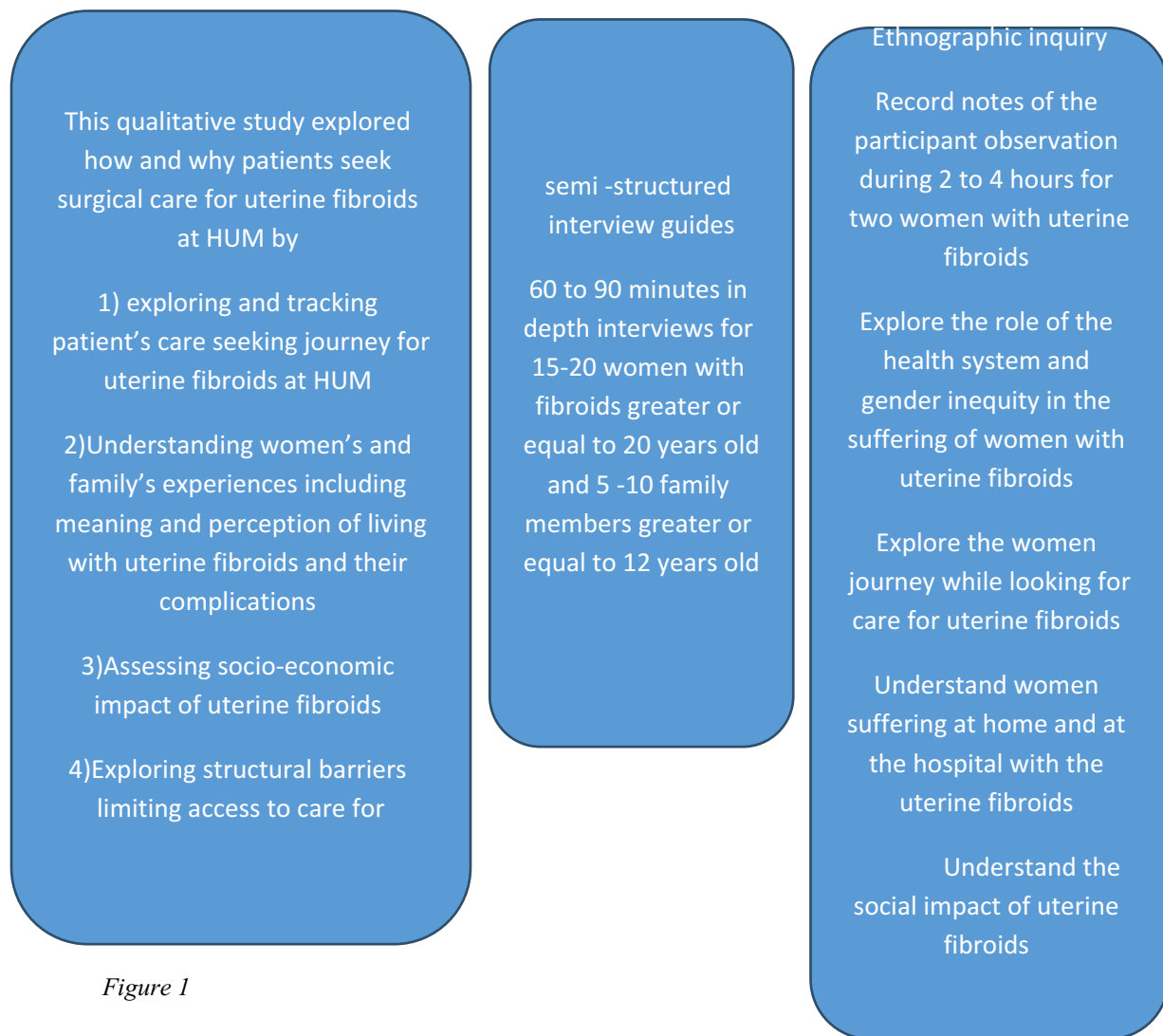


Figure 1

Ethical consideration

This research was approved by the Harvard University Internal Review Board and Zanmi Lasanté internal review board. Consent was obtained for all participants.

Findings

We interviewed 17 women with uterine fibroids, 7 family members, and did 2 participants field observations. The qualitative interviews and the fieldnotes of participant observations of the study indicate that women struggle while living with uterine fibroids. Women describe during the interviews gender disparities, and the health system did not help them to get care for their uterine fibroids, and consequently, they have been affected physically, psychologically, and socially with the disease. The results of the study focus on the arduous journey of patients with uterine fibroids, the physical, psychological, and social effects of the disease and factors that can impact on the patients care for uterine fibroids.

Patient journey when looking for care for uterine fibroids

Women in the interviews described an arduous journey in several steps to look for care before getting to MUH. They took the first available public transport to get to Mirebalais. Most of the time, they came the day before the consultation to Mirebalais University Hospital in the outpatient department. At the hospital, they went to the archive to have their records and to see the doctors. They reported that they could stay the whole day at the hospital waiting to see the doctor and sometimes needing to stay to be seen by the doctor the next day. Women required some money for transportation, feeding, and hotel for those who came outside of the Mirebalais community. In addition to that, women with complicated fibroids are transported in adverse conditions. At MUH, sometimes, they can stay for more than 6 hours. This is not a linear journey but includes the several places the women went to before coming to MUH. This journey is a “*pèrelinaje*” for a fundamental human right that women deserve

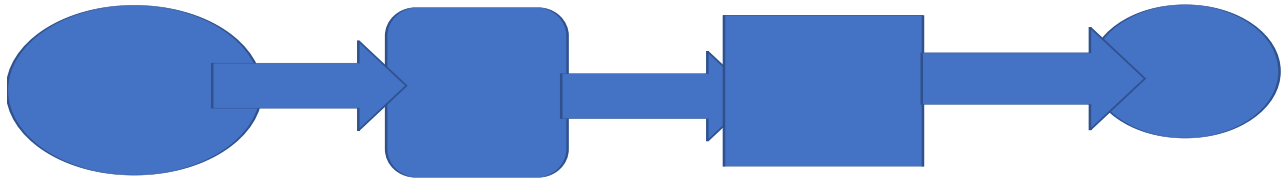


Figure 2: The patient journey

“I take a motorcycle that drops me at ‘Carrefour Marin, Port-Au-Prince.’ When I get there, I walk to ‘Carrefour Shada, Port-Au-Prince,’ and I take a ‘Camionette’ to go to ‘Croix-Des-Bouquets, Port-Au-Prince.’ When I get there, I take a bus at the station to go to Mirebalais, and I take a motorcycle from the Mirebalais station to go to the hospital. Hen I come to the hospital; I bring money for all my expenses. It never happened but...if I had no money left, my family would send me money. I usually bring with me 5000-7500 Gourdes in case I have to do some tests.” (woman with fibroids)

Further, the journey of the patient is much longer because before coming to the hospital, they roamed from place to place to find a solution for their suffering. In addition to the private clinic, they went to see traditional healers find a cure. While going through the journey of these women, it is evident that their lives are miserable. The health system of the country needs to be shaped to respond to the need of the countries’ citizens.

“I knew I had fibroid at General Hospital in Port-Au-Prince. The ‘Medsen fey’ (leaf doctor/herbalist and shaman) told me I was pregnant. Well, there was a ‘Medsen Fey’ who told me I was going to have twins. I said God knows everything. I know nothing. I spent money over and over again, and nothing worked out.” (woman with fibroids)

Health system failure

The interviews show a health system that is not responding to the need for care for women with uterine fibroids. There is not health coverage for these women who look for care. It also does not provide social protection to prevent out pocket expenses for care for fibroids. The interviews show that women went to several health facilities without getting access to care for their uterine fibroids. Women mention that when they went to a private clinic, they could not pay for the surgery because it is too expensive. The journey of women with uterine fibroids is additional proof of the failure of the health system.

“I discovered I had fibroids several years ago...in 2010. I always feel pain on the right side of my belly when I am about to have my period. I used to feel a little pain. And, after I told someone about that, he said I would need to see a gynecologist to examine me and see if there is something growing inside me. So, the doctor I consulted in Port-Au-Prince asked me to do a sonography test, and I did. I consulted the doctor in HUP, Port-Au-Prince. He told me to go to do the test at a private laboratory. I brought the results back to him. He told me I have three (3) fibroids. The biggest one was 4 centimeters large. As for the two (2) others, one was 2 centimeters, and the other one was one (1) centimeter. I did the sonography in 2010. I did the test once again in 2015. I discovered I had five (5) fibroids. I consulted and did the test at PROFAMIN. This is a Health center of the state located in Delmas 31. When I came to seek care for fibroids here, the doctor asked me to do the test again. I never got medications. I always ask the doctor to prescribe me medications to make the fibroid stop developing. He said no. All he

can prescribe me are pills to reduce the pain. In 2015, the doctor who consulted me at the PROFAMIN Health Center told me to do everything I could to have surgery and remove them so that I could get pregnant. He told me that I could get pregnant if I had surgery. I never had the chance to have that surgery because the doctors working at a private hospital ask a lot of money. God put this hospital for us because it takes care of us; it does not ask us too much money. Doctors practice surgery on patients. God put it on our way. I learned about MUH while someone was talking about it. And I said I would like to go there. But I always hear people saying the roads are bad. I am scared of the roads because of ‘Morne à Cabri.’ And, the first time I came here, my husband came along with someone else who drove us. Someone referred me to this hospital. He used to be a director at the hospital. He left the country. I have been consulting at MUH since January 2019.” (woman with fibroids)

Dilemma of an overcrowded hospital

Because the health system is broken, the concept of the dilemma of an overcrowded hospital emerged. This concept implies that a well-equipped hospital such as Mirebalais University Hospital with good quality of care in the Haitian broken health system faces the difficulty of maintaining the standard of quality with a growing number of patients with a long waiting time.

“Advantages...I like the quality of care here. The only thing that bothers me is the wait. It takes too long to have a surgery. I thought I would have it faster. The doctor told me I cannot have surgery right away, as I have to consult from time to

time first. I gave blood for the surgery. He could call me, but he never did. The country has been facing issues. Perhaps this prevented me to pay nothing. The medical tests are for free, and so does the care provided because I would need money to consult in a private hospital. I would need money for medications for everything.” (woman with fibroids)

Gender disparity

The interviews show that women with fibroids and family members think the Housework like washing clothes, preparing foods, cleaning the houses are the responsibility of women in the community. Sometimes, although they suffer deeply with the uterine fibroids, they might try to do these works to satisfy their husband. Sometimes, the partners think women should get pregnant when they get married without thinking that for being pregnant, both partners need to be fertile. Sometimes they get angry with their partners who refuse to have sex with them because of the disease.

“I have a boyfriend. We have sexual encounters. But I am still not pregnant. I have one sister and four brothers. They support me. My boyfriend supports me. My boyfriend complains about my illness because I cannot get pregnant. When I cannot have sexual intercourse with my boyfriend because of the pain I feel, he gets angry. He does not curse or yell, but my incapability to have sex troubles him .” (woman with fibroids)

“When I was coming to Mirebalais, I left my husband with my child...I left the maid...I organized the house. Usually, I do everything. I wash clothes, I make

sure that my husband's clothes are ready, I make sure that my child's clothes are ready, I make sure they have food, and I give the maid instructions while I am not home.” (woman with fibroids)

Bio-psychosocial consequences of uterine fibroids

Throughout most of the transcripts, women with fibroids expressed their physical suffering because fibroids are sometimes responsible for mictional difficulty, bleeding, anemia, abnormal menstruation, infertility, and much more than that. Women with fibroids appeared very stressed according to what people said, and their body language showed that during the interviews. They mentioned that they are very stressed because of the long waiting time to get access to the treatment, whereas some of them recognized some so many patients are waiting for surgery. Women are very anxious because of the cultural belief that family should have kids, whereas the fibroids make them unable to give birth. Sometimes they were depressed and expressed the desire for suicide because fibroids make them very dependent. We can see while doing this research that women with fibroids were stressed, anxious, depressed, and even felt suicidal.

“Because of that, I will have difficulties to get pregnant. This stressed me a lot. It still worries me. And day after day, the fibroid is getting bigger. When I underwent the test for the first time, it revealed the size of the fibroid was 3 centimeters. Then, it got up to 5 centimeters. Now, it is 7 centimeters. And until now, I have not been able to get pregnant. This frightens me so much.” (woman with fibroids)

“My period lasts eight (8) days. And it used to last three (3) days. When I have my period, I bleed a lot and, I have anemia. Consequently, I cannot stand a lot, sometimes I cannot urinate, and I cannot be involved in any activity. And I have four (4) children. By mentioning “activity,” I mean, I should be able to work somewhere or own a business so that I can help the children financially. Because of the fibroid, I cannot support them. That makes me feel bad because their father is the only one working to care for them but, should I have a job or a business, I would be able to help him provide for the children when he runs out of money.” (woman with fibroids)

“I am very depressed and considers myself useless. The humiliations that I endure day after day has affected me so badly. Sometimes, I do not find a sense to my life. I should be able to work and take good care of myself like a normal person. I tend to lose hope when my life gets too complicated.” (woman with fibroids)

Social consequences of uterine fibroids

Uterine fibroids and the family life

This research shows us that fibroids can be very painful for the family and even can lead to separation. Women with fibroids mentioned that the disease limits their ability to have intercourse with their husbands. Sometimes they could not do housekeeping, prepare food, and wash their clothes to live in bad hygiene conditions because of the biological effect of the disease. The fibroids also affected other members of the family, like the husband, the mother,

brothers, and sisters.

“The disease has affected all my brothers and sisters. They are afraid I cannot have children. Also, they are afraid because some people say that this disease kills people, as it generates other diseases. That was one of the reasons why I rushed to the hospital in the beginning. I am waiting. I am being patient. But the complications of fibroids really stress me out.” (woman with fibroids)

“I sometimes would like to wash clothes but, I cannot wash a lot, and I cannot bend down, I cannot clean my house. I cannot cook. If I am cooking, I do what I can because my waist hurts so bad.” (woman with fibroids)

Economic exclusion because of uterine fibroids

Women mentioned that the suffering of the fibroids interferes with their job and their business and impoverishes them. They reported that sometimes they lost their work because of the disease. Women with uterine fibroids mentioned that sometimes they did small businesses, and the fibroids made them abandon them because of the disabling biological effects whereas, they spend what little money they have in other places like traditional healers, exams in private Labs for care. Finally, they did not make money to decide to look for care, and they stayed at home with the disease.

“My work used to drain my energy out of my body. I used to sell goods for a living. This job required me to walk over the streets carrying the merchandise. As I cannot lift and carry anything heavy, I had to stop selling goods for a living. Consequently, I have had no income or savings because of my fibroids.” (woman with fibroids)

“ I am unemployed. The pain I feel because of the disease really stresses me out. Last year, I was working. Because of the symptoms of the fibroids, I was having. My supervisor had me replaced by someone else, which makes my situation even worse as I lose credit before my supervisor. He sees me as unreliable.” (woman with fibroids)

Exclusion to social goods because of uterine fibroids

Women with fibroids sometimes cannot send their kids to school and pay the fee for transportation to go to the hospital to receive care for their fibroids. Further, because of the disease, they cannot buy a decent place to live, they cannot buy food, as consequences, their fundamental rights are violated. Fibroids make women excluded from essential social goods.

“I don’t have a job, I don’t have money, I cannot rent a decent place to live, and sometimes, I spent three days without eating because of my fibroids. I sometimes choose to suffer hunger to save the money for coming to my acquaintances with the doctors to the hospital.” (woman with fibroids)

“I am still in school. I am currently in 9th grade. I could say that the fibroid of my mother affects my life...I would not like the disease to get worse. I would not like her to develop another disease because I am still in High school. I do not want her to die. She is the only one I have. I have a father, but it is like he does not exist. My mother is the one who helps me. She pays my school fees, everything for me. When she has to pay the monthly school fee, she talks with the director, and then,

she organizes herself to pay. Sometimes, she borrows money. She speaks with the school director so he can wait for her to pay. So, she borrows money so I can go to school. The disease affects her.” (Family member, daughter)

Exclusion to social production because of uterine fibroids

Women with fibroids mentioned that the disease hampers their capacity to participate in social activities. They related that sometimes they could not go to church to express their faith to God. One woman in the interviews mentioned that she likes soccer, but she could not go to a soccer game because of her fibroids.

“Sometimes, I feel like going to church, and I cannot. I stay home, and I lie down.
” (woman)

“I am really in bad shape. This fibroid tries to kill me. I cannot wait to have my fibroid removing.” She said, "things are worse when I must cross these unpaved roads to go to the school to teach. Sometimes, arriving at the school, I am tired, I had pain and bleeding. I must go back home without doing the job that I like so much. This is my life, Doc, with the disease hum mm"with a big sigh. The patient sometimes said, "I could not go to church or any social activity because of the pain and the bleeding associated with the disease." (Field note observation)

Exclusion from civil society and access to healthcare for uterine fibroids

Women reported that when they tried to get care for their uterine fibroids, they waited too long, and they wanted the hospital to take their cases more seriously. They mentioned that

when they went to a private clinic, they were asked to pay so much money and could not afford the care that they needed. They reported that medical professionals did not take enough time to communicate with them. It is evident that the mechanisms of the health system to address fibroids' care are not appropriate, and these mechanisms exclude many women with uterine fibroids.

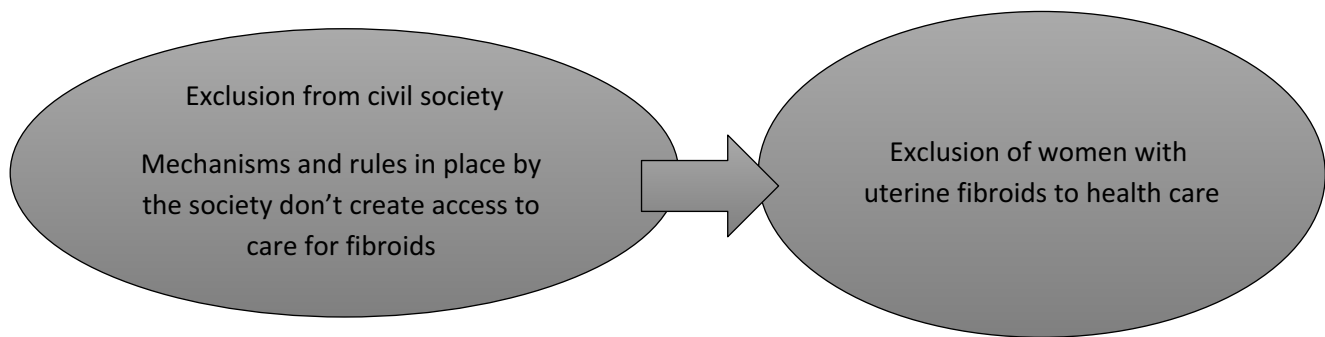


Figure 3: Relationship between the exclusion of women with uterine fibroids from civil society and access to health care

“Before I got married, I used to have pain, but I never consulted a doctor to know the cause of the suffering. Sometimes my husband reflects on that. We even went to see other surgeons. They asked 200,000 Gourdes in order to remove the fibroid. My husband did not have the financial means to support the expenses. Neither did I. So I remained...suffering.” (woman with fibroids)

“The hospital could help me by providing care faster. About surgery, the hospital could help me have surgery faster. I would like the hospital to improve the communication between its staff and the patients by helping them find their way inside the hospital, and by telling them what to do so, they do not waste time.” (woman with fibroids)

Factors that impact the care for uterine fibroids

Although women are struggling to survive by navigating this broken health system as we saw earlier in the paper, women with fibroids reported that they decided to look for care because they want to be healthy, to have kids, to work. They mentioned the long waiting time, attitude of the staff, non-accessibility to surgery are some factors that can discourage them from coming to the hospital. Further, they recommended that when they came to the hospital that the staff help them to get the surgery done, and they wanted the staff to communicate, explain, help, listen, and talk to them. They want them to be welcoming. However, they mentioned the positive side is the care that the hospital delivered is satisfactory, and they do not pay for care, they said the quality of care is good. The sign of hope is a woman with fibroids envisions their life as a healthy woman who can have kids and who can take care of their family. The idea in this section reinforces the findings that social exclusion from the civil society hampers care for fibroids because the mechanisms, system, and procedures in place did not allow women with fibroids to get access to care as they would for fibroids.

“I will be happy. I will no longer be sick. My life will change. I will be able to work and organize myself. I will be able to go to church. I will go back to work. I will start to live again.” (woman with fibroids)

“Once you get access to care, you get good quality healthcare because there are qualified doctors. They can do the job efficiently. Sometimes, doctors might be careless but, as soon as they take you in charge, they proceed with your case. You get access to care, and you do not pay for it. Elsewhere, you would pay for everything. My husband and I cannot afford to go elsewhere. We have MUH that provides good care. The biggest advantage is to get free access to care.” (woman with fibroids)

Accompaniment

In this research, interviews define accompaniment by the engagement of a person as an *accompagneur* for a woman with fibroids to intervene, provide information and support for her emotionally, financially, physically over time. In the interviews, we observed that women with fibroids are supported mainly by their family, husband, friends, caregivers.

“My fiancé and my mother-in-law support me. They always cheer me up. They told me not to stress about it. Fibroid is a disease. Any woman could have it. They told me not to worry. They help me out. They support me financially.” (woman with fibroids)

“My husband asks for a few days off at work to come with me. When he comes with me, he supports me, he fixes my bed, he takes the test’s results, he helps me go take a shower, he goes buy food for me.” (woman with fibroids)

Discussion

The findings in this study show that the Haitian health system is broken because it cannot respond to the need and provide social protection to its citizens²¹ for the most frequent tumor in gynecology.²⁷ This broken health care system is also rooted in the history and the political economy in the country. While going through the journey of these women, it is evident that their lives are miserable. My reflection is these women do not have other choices to risk their lives in a taxi or motorcycle to look for care where they can find it because the availability of surgical care in the country is sparse for a woman who does not have money to go to a private clinic. However, the dilemma is that Mirebalais University Hospital cannot provide care for the whole

country.

We can imagine how this situation will impact the quality of care. The health system of the country needs to be shaped to respond to the needs of the country's citizens. The patient journey supports the idea that the failure of the health system hampers access to care for uterine fibroids because, as we have seen, women roamed in the health system without getting access to health care before going to MUH. MUH, which delivers good quality care, faces the dilemma of an overcrowded hospital mentioned earlier. This broken health system, aside from gender inequity, makes the women suffering worse. Gender inequity is dangerous because it is rooted by disequilibrium of the economic power toward men in Haitian society, making women very dependent on men.⁷⁰ In society, men are more likely to be in the labor workforce, whereas women are more likely to be involved in domestic activity.⁷⁰

This study supports the fact that women with uterine fibroids are affected biopsychologically, and that was demonstrated in previous studies.^{27,38} A qualitative study realized by Ghant has shown that uterine fibroids favor psychological distress, affect women's sexual life, and women think they are helpless.³⁸ The impact of the fibroids on the family is severe because a situation like the disruption of the family that fibroids can be the cause can have significant social consequences. For instance, the consequences can be on the mental health and education of the kids and, as we see in this research worsening the psychological effect of the fibroids and even on the future generations^{71,72} supporting the idea of professor Paul Farmer that "Fibroids are socially malignant."

As diseases are rooted socially and have numerous social consequences,⁷³ in this research, we observed that uterine fibroids follow the rules. Women are excluded economically, and they are excluded from access to social goods, from social production and excluded from civil society

. From this research, the concept of a poverty wheel of uterine fibroids, the pathway of exclusion to social goods by fibroids, and social production have emerged. The leading cause of illness suffering in poverty.⁷³

The poverty wheel of uterine fibroids

The concept of the poverty wheel of uterine fibroids is processual; one aspect interacts with another. It is not linear/causal but intertwined. The concept implies that poverty can hamper the operationalization of a good health system capable of providing surgery for fibroids. Therefore, women stay with their fibroids, which become complicated and sometimes create disability. Then they lost their job and business and as a consequence, no income and saving, and they became poorer and poorer. This wheel is running toward morbidity and mortality and negative social consequences.

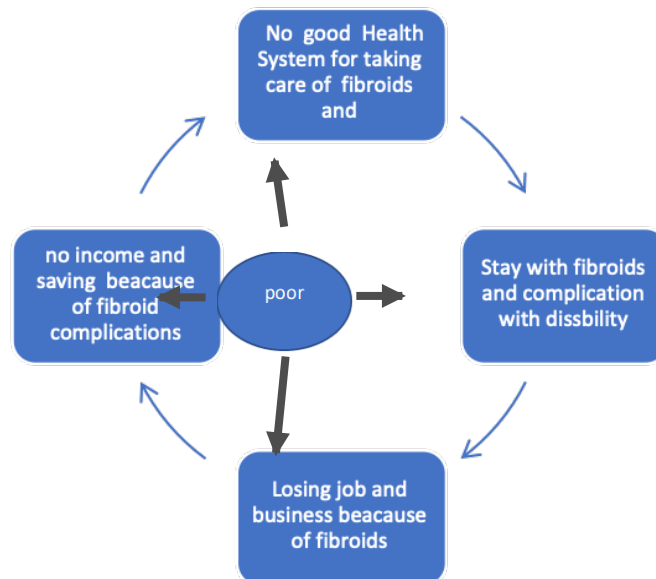


Figure 4: Poverty wheel of uterine fibroids suffering

The pathway of exclusion to social goods because of uterine fibroids

The pathway demonstrates that women with fibroids lose their jobs and businesses. Therefore, they cannot afford social goods, then no access to social goods. As a consequence,

there is no education, no decent house to live in, no access to healthy food, no access to good transportation

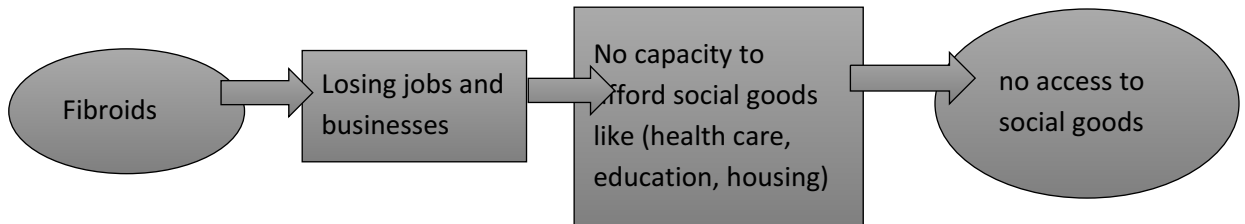


Figure 5: Pathway of exclusion to social goods

Pathway of exclusion to social production because of uterine fibroids

This concept implies that uterine fibroids are associated with economic exclusion and physical and social suffering and therefore exclude women from participating in the community activity such as social production.



Figure 6: Pathway of exclusion to social production

Accompaniment

In this research, we observe that accompaniment, as a form of social support, is not enough to counterbalance the devastating effect of other social suffering consequences of uterine fibroids. However, this could be a source of motivation to continue to innovate, to create long

term partnerships as PIH did, to come up with a structured way to make the family support more effective like the creation of mutual de solidarity⁷⁴ to limit the out-pocket expenditures for the disease. The notion of accompaniment is going further according to Professor Paul E. Farmer who emphasizes that the term implies a commitment to long term support and pragmatic solidarity for fundamental human rights.⁷⁵

Social suffering and structural violence

My belief is that the political drivers did not put health care for fibroids as a top priority on their agenda. The value of these women's lives does not matter for the politicians in my country. How can a government that received 4.2 billion dollars from the Petrocaribe fund did not do anything to alleviate the suffering of these women? By looking at the devastating effects of uterine fibroids on women's lives, it should be considered as a global health priority. This very prevalent disease can be used as a model to address suffering for a broader set of reproductive illnesses with the same or even worse consequences than uterine fibroids. Technology and innovation are growing quickly but disproportionately when comparing developed and developing countries to address fibroids' care in resource-poor settings. The demand for care for fibroids is high, and the complications are disastrous. The world market and the Haitian market fail to address fibroids because no social protection to cover care for fibroids in Haiti. Women roam inside the health system in Haiti without getting answers for their fibroids issues. In my thinking, the global market fails to provide economic support to strengthen the health system to address the issue of fibroids, and systematically the health system of the country fails to fulfill the needs of the citizens creating biological, psychological, and social suffering. Therefore, fibroids, for me, is considered a biopsychosocial disease and actions should be made in this

direction. Further, the political neoliberalism without specific consideration for health care for all will continue to have a devastating effect on women living with fibroids. We demonstrated that suffering from fibroids is rooted in the lack of access from social determinants of health such as housing, feeding, sound health system, poverty, social exclusion, gender inequity, unemployment, the politics of neoliberalism, the lack of mechanisms, rules that favor care for fibroids. Further, the historical context is a critical element that provides insights about how colonialism, political instability, recurrent state coups created a climate of poverty, limiting the capacity to alleviate the suffering of these women. This study shows us that uterine fibroids are socially malignant, although they are benign tumors.

Therefore, this study supports the theories of social suffering and structural violence developed by the professors Arthur Kleinman and Paul Farmer years ago.⁴² We finally come up with the concept of the fibroid suffering tree (Fig. 7) in which the roots of the tree are the inequitable distribution of social determinants of health and the branches are biological and psychological effects of uterine fibroids, and the stem of the tree is the uterine fibroid. To challenge this situation of suffering, we need to destroy the tree by destroying first the roots to hamper them, nurturing the stem and the branches. It implies the fight against social exclusion, poverty, corruption, neocolonialism, and political instability. Innovation, research, win-win partnership, pragmatic solidarity, creation of systems, social support, including accompaniment, are some essential elements to consider broadly. Developing surgical competence aside staff, staff, and socially supported in gynecology can deeply address the medical issue of uterine fibroids. Therefore, strengthening of the health system toward delivery of good quality of care for uterine fibroids can significantly diminish this social malignancy.



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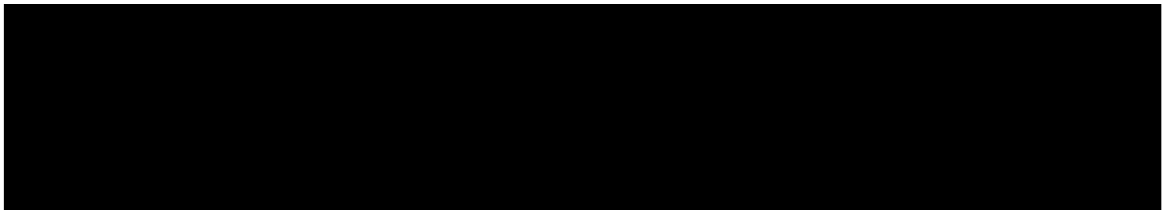


Figure 7: Uterine fibroid suffering tree

Conclusion

In conclusion, uterine fibroids are a socially malignant disease. It impacts the quality of life of women in Haiti profoundly. Uterine fibroid suffering is rooted in a vicious cycle of poverty supported by the unequal distribution of the social determinants of health, which

themselves grounded in the biosocial factors of the Haitian context making the women's lives miserable with the disease. The findings of this research support the social suffering and the structural violence theory.⁴² Strengthen the health system, in addition to mechanisms of accompaniment and social support, and the improvement of the economic condition of women with fibroids can be the solution for this social malignancy.

Conflicts of interest

There was no conflict of interest in this research. This research was financed by Harvard Medical School's Department of Global Health and Social Medicine.

References

- ADDIN ZOTERO_BIBL {"uncited":[],"omitted":[],"custom":[]} CSL_BIBLIOGRAPHY 1.
Downes E, Sikirica V, Gilabert-Estelles J, et al. The burden of uterine fibroids in five European countries. *Eur J Obstet Gynecol Reprod Biol.* 2010;152(1):96-102. doi:10.1016/j.ejogrb.2010.05.012
2. Baird DD, Dunson DB, Hill MC, Cousins D, Schectman JM. High cumulative incidence of uterine leiomyoma in black and white women: ultrasound evidence. *Am J Obstet Gynecol.* 2003;188(1):100-107. doi:10.1067/mob.2003.99
 3. John W. Creswell, Vicki L. Plano Clar. *Designing and Conducting Mixed Methods Research.* Thousand Oaks: SAGE Publications; 2017.
 4. El-Balat A, DeWilde RL, Schmeil I, et al. Modern Myoma Treatment in the Last 20 Years: A Review of the Literature. *BioMed Research International.* 2018. doi:10.1155/2018/4593875
 5. Stewart EA, Cookson CL, Gandolfo RA, Schulze-Rath R. Epidemiology of uterine fibroids: a systematic review. *BJOG.* 2017;124(10):1501-1512. doi:10.1111/1471-0528.14640
 6. Stewart EA, Lytle BL, Thomas L, et al. The Comparing Options for Management: PATient-centered Results for Uterine Fibroids (COMPARE-UF) registry: rationale and design. *American Journal of Obstetrics and Gynecology.* 2018;219(1):95.e1-95.e10. doi:10.1016/j.ajog.2018.05.004
 7. Wise LA, Palmer JR, Reich D, Cozier YC, Rosenberg L. Hair Relaxer Use and Risk of Uterine Leiomyomata in African-American Women. *Am J Epidemiol.* 2012;175(5):432-440. doi:10.1093/aje/kwr351
 8. Pavone D, Clemenza S, Sorbi F, Fambrini M, Petraglia F. Epidemiology and Risk Factors of Uterine Fibroids. *Best Practice & Research Clinical Obstetrics & Gynaecology.* 2018; 46:3-11. doi:10.1016/j.bpobgyn.2017.09.004
 9. Sparic R, Mirkovic L, Malvasi A, Tinelli A. Epidemiology of Uterine Myomas: A Review. *Int J Fertil Steril.* 2016;9(4):424-435.
 10. Islam MS, Protic O, Giannubilo SR, et al. Uterine Leiomyoma: Available Medical Treatments and New Possible Therapeutic Options. *J Clin Endocrinol Metab.* 2013;98(3):921-934. doi:10.1210/jc.2012-3237
 11. McCool WF, Durain D, Davis M. Overview of Latest Evidence on Uterine Fibroids. *Nursing for Women's Health.* 2014;18(4):314-332. doi:10.1111/1751-486X.12137
 12. Zaima A, Ash A. Fibroid in pregnancy: characteristics, complications, and management. *Postgraduate Medical Journal.* 2011;87(1034):819-828. doi:10.1136/postgradmedj-2011-130319

13. Schirf BE, Vogelzang RL, Chrisman HB. Complications of Uterine Fibroid Embolization. *Semin intervent Radiol.* 2006;23(2):143-149. doi:10.1055/s-2006-941444
14. Bachmann GA, Bahouth LA, Amalraj P, Mhamunkar V, Hoes K, Ananth CV. Uterine fibroids: Correlations of anemia and pain to fibroid location and uterine weight. *The Journal of reproductive medicine.* 2011;56(11-12):463-466.
15. Fuldeore MJ, Soliman AM. Patient-reported prevalence and symptomatic burden of uterine fibroids among women in the United States: findings from a cross-sectional survey analysis . *Int J Women's Health.* 2017;9:403-411. doi:10.2147/IJWH.S133212
16. Marret H, Fauconnier A, Chabbert-Buffet N, et al. Clinical practice guidelines on menorrhagia: management of abnormal uterine bleeding before menopause. *European Journal of Obstetrics & Gynecology and Reproductive Biology.* 2010;152(2):133-137. doi:10.1016/j.ejogrb.2010.07.016
17. Gupta S, Groen RS, Kyamanywa P, et al. Surgical care needs of low-resource populations: an estimate of the prevalence of surgically treatable conditions and avoidable deaths in 48 countries. *The Lancet.* 2015;385:S1. doi:10.1016/S0140-6736(15)60796-6
18. Pérez-López FR, Ornat L, Ceausu I, et al. EMAS position statement: Management of uterine fibroids. *Maturitas.* 2014;79(1):106-116. doi:10.1016/j.maturitas.2014.06.002
19. Meara JG, Leather AJM, Hagander L, et al. Global Surgery 2030: evidence and solutions for achieving health, welfare, and economic development. *The Lancet.* 2015;386(9993):569-624. doi:10.1016/S0140-6736(15)60160-X
20. Kim JY, Farmer P, Porter ME. Redefining global health-care delivery. *The Lancet.* 2013; 382(9897):1060-1069. doi:10.1016/S0140-6736(13)61047-8
21. Atun R, de Andrade LOM, Almeida G, et al. Health-system reform and universal health coverage in Latin America. *The Lancet.* 2015;385(9974):1230-1247. doi:10.1016/S0140-6736(14)61646-9
22. Mullan F. Health, Equity, And Political Economy: A Conversation With Paul Farmer. *Health Affairs.* 2007;26(4):1062-1068. doi:10.1377/hlthaff.26.4.1062
23. Grimes CE, Bowman KG, Dodgion CM, Lavy CBD. Systematic Review of Barriers to Surgical Care in Low-Income and Middle-Income Countries. *World J Surg.* 2011;35(5):941-950. doi:10.1007/s00268-011-1010-1
24. Anderson MW. The Metrics of Workforce Planning. *Public Personnel Management.* 2004; 33(4):363-378. doi:10.1177/009102600403300402
25. Hallo De Wolf A, Toebes B. Assessing Private Sector Involvement in Health Care and Universal Health Coverage in Light of the Right to Health. *Health Hum Rights.* 2016;18(2):79-92.

26. Malkin R, von Oldenburg Beer K. Diffusion of Novel Healthcare Technologies to Resource-Poor Settings. *Ann Biomed Eng.* 2013;41(9):1841-1850. doi:10.1007/s10439-013-0750-5
27. Vilos GA, Allaire C, Laberge P-Y, et al. The Management of Uterine Leiomyomas. *Journal of Obstetrics and Gynaecology Canada.* 2015;37(2):157-178. doi:10.1016/S1701-2163(15)30338-8
28. Lipnick M, Mijumbi C, Dubowitz G, et al. Surgery and Anesthesia Capacity-Building in Resource-Poor Settings: Description of an Ongoing Academic Partnership in Uganda. *World J Surg.* 2013;37(3):488-497. doi:10.1007/s00268-012-1848-x
29. Suryanto, Plummer V, Boyle M. EMS Systems in Lower-Middle Income Countries: A Literature Review. *Prehospital and Disaster Medicine.* 2017;32(1):64-70. doi:10.1017/S1049023X1600114X
30. Barnes-Josiah D, Myntti C, Augustin A. The “three delays” as a framework for examining maternal mortality in Haiti. *Social Science & Medicine.* 1998;46(8):981-993. doi:10.1016/S0277-9536(97)10018-1
31. Khan MS, Hashmani FN. Political and technical barriers to improving the quality of health care. *The Lancet.* 2018;392(10160):2146-2147. doi:10.1016/S0140-6736(18)32075-0
32. L.W F, Roa L, B. C, et al. Obstetrics and gynecology in global health: Lessons learned for advancing public health to achieve universal health care. *Bulletin of the American College of Surgeons.* May 2018.
33. Girard PR. The Haitian Revolution, History’s New Frontier: State of the Scholarship and Archival Sources. *Slavery & Abolition.* 2013;34(3):485-507. doi:10.1080/0144039X.2012.734089
34. Parsons RP. *History of Haitian Medicine.* New York: PBHoeber, inc; 1930. chapter 2, p.19, chapter 4, p.53, 73.
35. Mukherjee J. *An Introduction to Global Health Delivery: Practice, Equity, Human Rights.* Oxford University Press; 2018. chapter 1 p. 4-5, chapter 3, p.74-77, chapter 6, p.137.
36. Bordes A. *Évolution des sciences de la santé et de l’hygiène publique en Haïti.* Port-au-Prince? Centre d’hygiène familiale; 1980. chapter 1 p.6, 8-9, chapter 2, chapter 5 p.60
37. Joseph CL. The Religious Philosophy of Jean Price-Mars. *Journal of Black Studies.* 2012; 43(6):620-645. doi:10.1177/0021934712440449
38. Ghant MS, Sengoba KS, Recht H, Cameron KA, Lawson AK, Marsh EE. Beyond the physical: A qualitative assessment of the burden of symptomatic uterine fibroids on women’s emotional and psychosocial health. *Journal of Psychosomatic Research.* 2015;78(5):499-503. doi:10.1016/j.jpsychores.2014.12.016
39. Phillips A. Haiti, France, and the Independence Debt of 1825. :24.

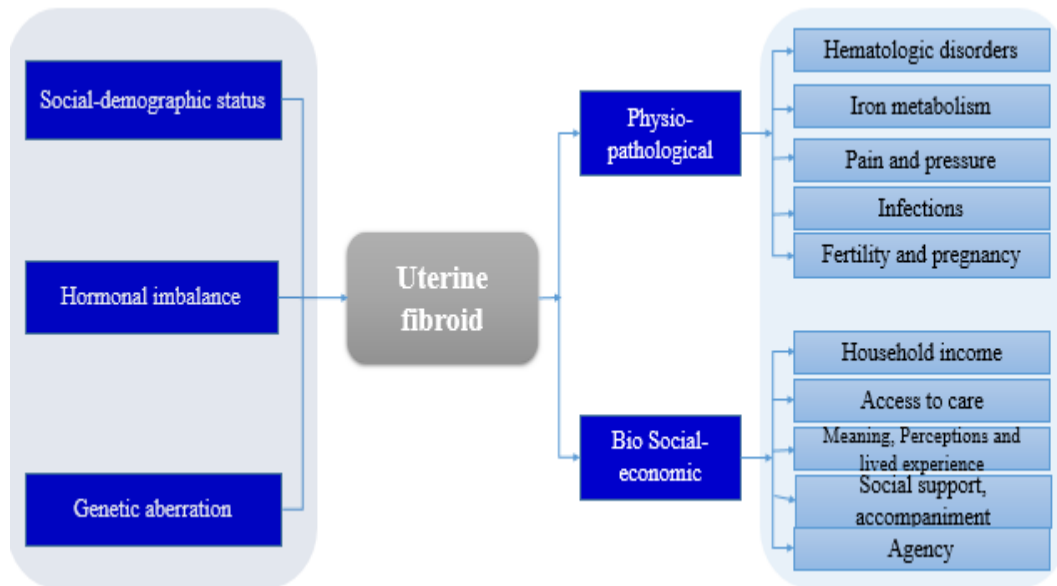
40. Bauduy J. The 1915 U.S. Invasion of Haiti: *Social Education*.:6.
41. Best RA. The U.S. Occupation of Haiti, 1915-1934. :7.
42. Farmer P, Kim J, Basilio M, Kleinman A. *Reimagining Global Health: An Introduction*. Berkeley, UNITED STATES: University of California Press; 2013. <http://ebookcentral.proquest.com/lib/harvard-ebooks/detail.action?docID=1337905>. Accessed January 23, 2020 . chapter 2 p.30-31
43. Parton N. Review of The Social Construction of Reality: A Treatise in the Sociology of Knowledge. *The British Journal of Social Work*. 2008;38(4):823-824.
44. Kaplan RS, Mistry B, Bertrand K. Hôpital Universitaire de Mirebalais, Partners In Health in Haiti. :25.
45. Arvisais D. Expérience 2008 de collaboration internationale en Haïti. June 2009. <https://papyrus.bib.umontreal.ca/xmlui/handle/1866/2886>. Accessed January 23, 2020.
46. Farmer P. *Haiti after the Earthquake*. 1st ed. New York: PublicAffairs; 2011. chapter 1 p. 11 other voice p.320
47. Ivers LC, Garfein ES, Augustin J, et al. Increasing Access to Surgical Services for the Poor in Rural Haiti: Surgery as a Public Good for Public Health. *World J Surg*. 2008;32(4):537-542. doi:10.1007/s00268-008-9527-7
48. Elias JL. *Paulo Freire: Pedagogue of Liberation*.; 1994. chapter 6 p.80,87, Chapter 7 p.98-99, 101, chapter 10 p.137
49. Estimats_poptotal_18 ans_menag_2015, Institut Haïtien de Statistique et d'Informatique. March 2015.
50. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health*. 2015;42(5):533-544. doi:10.1007/s10488-013-0528-y
51. Rasmussen A, Eustache E, Raviola G, Kaiser B, Grelotti D, Belkin G. Development and validation of a Haitian Creole screening instrument for depression. *Transcult Psychiatry*. 2015;52(1):33-57. doi:10.1177/1363461514543546
52. Katz AM, Mishler EG. Close encounters: exemplars of process-oriented qualitative research in health care. *Qualitative Research*. 2003;3(1):35-56. doi:10.1177/1468794103003001767
53. Hsieh H-F, Shannon SE. Three Approaches to Qualitative Content Analysis. *Qual Health Res*. 2005;15(9):1277-1288. doi:10.1177/1049732305276687
54. Parker WH. Etiology, symptomatology, and diagnosis of uterine myomas. *Fertility and Sterility*. 2007;87(4):725-736. doi:10.1016/j.fertnstert.2007.01.093

55. J.C E, A.C U, A.C I. The Value of Ultrasonography in the Diagnosis of Leiomyomas in Southeast Nigeria. In: ; 2013.
56. Dipi RM, Amin MS, Islam MN, Khan NA, Chaiti MM, Hossain MM. Comparison of transabdominal and transvaginal sonography in the evaluation of uterine mass with histopathological correlation. *Mymensingh Med J.* 2013;22(1):69-74.
57. Zimmermann A, Bernuit D, Gerlinger C, Schaefer M, Geppert K. Prevalence, symptoms and management of uterine fibroids: an international internet-based survey of 21,746 women. *BMC Women's Health.* 2012;12(1):1-11. doi:10.1186/1472-6874-12-6
58. Mettler L, Schollmeyer T, Tinelli A, Malvasi A, Alkatout I. Complications of Uterine Fibroids and Their Management, Surgical Management of Fibroids, Laparoscopy and Hysteroscopy versus Hysterectomy, Haemorrhage, Adhesions, and Complications. *Obstetrics and Gynecology International.* doi:https://doi.org/10.1155/2012/791248
59. Ortiz-Ospina E, Roser M. Financing Healthcare. *Our World in Data.* June 2017. <https://ourworldindata.org/financing-healthcare>. Accessed March 17, 2020.
60. Fennessy FM, Kong CY, Tempany CM, Swan JS. Quality-of-life assessment of fibroid treatment options and outcomes. *Radiology.* 2011;259(3):785-792. doi:10.1148/radiol.11100704
61. Stewart EA, Nicholson WK, Bradley L, Borah BJ. The Burden of Uterine Fibroids for African-American Women: Results of a National Survey. *J Women's Health (Larchmt).* 2013;22(10):807-816. doi:10.1089/jwh.2013.4334
62. Marsh EE, Al-Hendy A, Kappus D, Galitsky A, Stewart EA, Kerolous M. Burden, Prevalence, and Treatment of Uterine Fibroids: A Survey of U.S. Women. *Journal of Women's Health.* 2018;27(11):1359-1367. doi:10.1089/jwh.2018.7076
63. Huang H, Kuang H, Sun F, et al. Lower prevalence of non-cavity-distorting uterine fibroids in patients with polycystic ovary syndrome than in those with unexplained infertility. *Fertil Steril.* 2019;111(5):1011-1019.e1. doi:10.1016/j.fertnstert.2019.01.020
64. Donnez J, Dolmans M-M. Uterine fibroid management: from the present to the future. *Hum Reprod Update.* 2016;22(6):665-686. doi:10.1093/humupd/dmw023
65. Khan AT, Shehmar M, Gupta JK. Uterine fibroids: current perspectives. *Int J Women's Health.* 2014;6:95-114. doi:10.2147/IJWH.S51083
66. Abdel-Gadir A, Oyawoye OO, Chander BP. Coexistence of polycystic ovaries and uterine fibroids and their combined effect on the uterine artery blood flow in relation to age and parity. *J Reprod Med.* 2009;54(6):347-352.
67. Swanson RA. Country Profile: Haiti. 2006:23.

68. Moore SF. Explaining the Present: Theoretical Dilemmas in Processual Ethnography. *American Ethnologist*. 1987;14(4):727-736.
69. Suffrin, D. Suffrin, D., (2016)“Attitudes and Perceptions of Health Providers and HIV Positive Mothers on Adopting Breastfeeding for HIV Exposed Children: A Qualitative Study in Rural Haiti.” MMSc GHD, HMS. 2016.
70. Padgett A, Warnecke T. Diamonds in the Rubble: The Women of Haiti: Institutions, Gender Equity, and Human Development in Haiti. *Journal of Economic Issues*. 2011;45(3):527-558. doi:10.2753/JEI0021-3624450301
71. McLanahan S, Bumpass L. Intergenerational Consequences of Family Disruption. *American Journal of Sociology*. 1988;94(1):130-152. doi:10.1086/228954
72. Steele F, Sigle-Rushton W, Kravdal Ø. Consequences of family disruption on children’s educational outcomes in Norway. *Demography*. 2009;46(3):553-574. doi:10.1353/dem.0.0063
73. Marmot M. Social determinants of health inequalities. *The Lancet*. 2005;365(9464):1099-1104. doi:10.1016/S0140-6736(05)71146-6
74. Donfouet HPP, Mahieu P-A. Community-based health insurance and social capital: a review. *Health Economics Review*. 2012;2(1):5. doi:10.1186/2191-1991-2-5
75. Farmer PE. Foreign affairs. *Partners in Help: Assisting the Poor Over the Long Term*. 2011

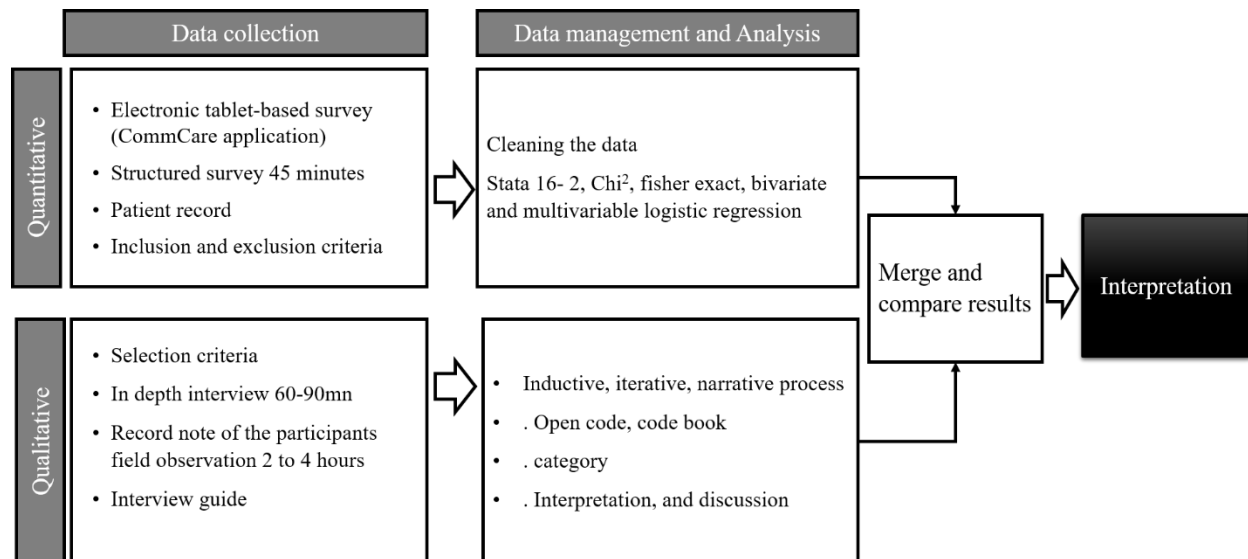
Appendices

Appendix 1.



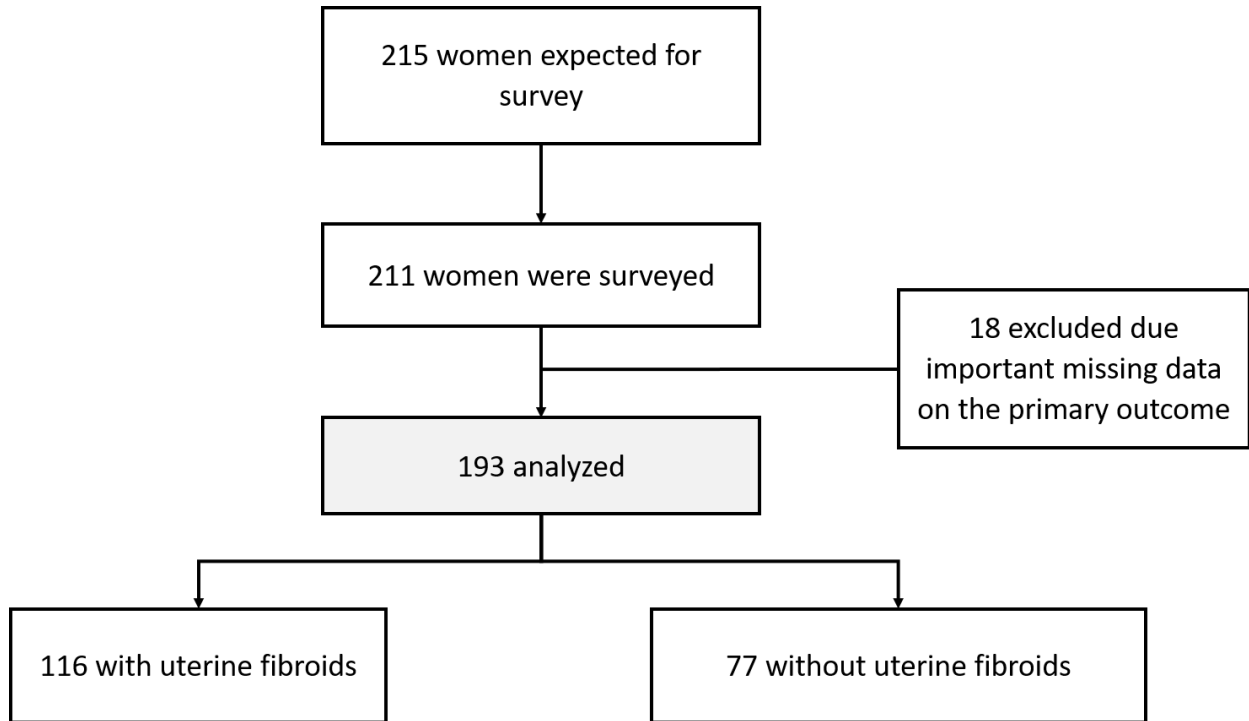
Appendix 2.

Diagram of the methodology of the study



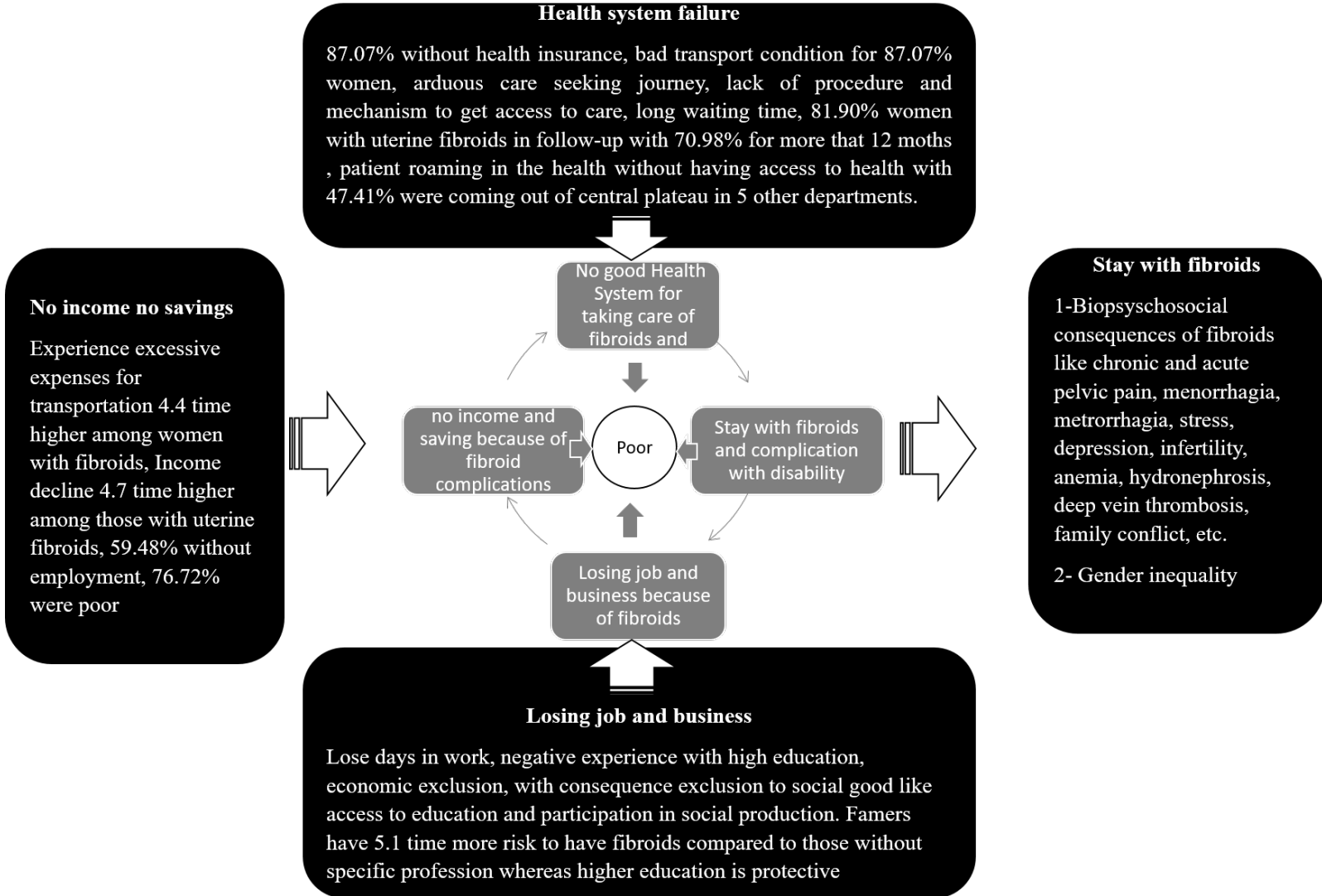
Appendix 3.

Data flow



Appendix 4.

Joint display results under the concept of the poverty cycle of uterine fibroids suffering



Appendix 5

Table 1: Sociodemographic, clinical history and economic characteristics of women receiving care for uterine fibroids at Mirebalais University Hospital's outpatient department between October first, 2019 to January 31, 2020 (n=116)

Characteristics	n (%)
Age category	
20-34	28 (24.1)
35-49	70 (60.3)
50+	18 (15.5)
Number of pregnancies (n=100)	
No pregnancy	28 (24.1)
1-3 pregnancies	52 (44.8)
>3 pregnancies	20 (17.2)
Number of births (n=101)	
No childbirth	43 (37.1)
1-3 childbirths	47 (40.5)
> 3 childbirths	11 (9.5)
Menopause (n=101)	
No	81 (69.8)
yes	20 (17.2)
Family history of fibroids(n=83)	
No	25 (21.6)
Yes	58 (50)
Pelvic infection (n=113)	
No	31 (26.7)
Yes	82 (70.7)
Patient status	
Follow-up visit	95 (81.9)
Initial visit	21 (18.1)
If follow-up patient (n=95)	
<6 months	8 (5.7)
6-12 months	15 (9.8)
>12 months	72 (70.9)
Zone of Residence	
Centre	61 (52.6)
Out of central plateau	55 (47.41)
Type of residence	
Urban	91 (78.5)
Rural	25 (21.6)
Average time per medical appointment/visit (Time to go to the hospital) (n=	

≤2h	92 (79.3)
>2h	22 (18.9)
Means of transport(n=115)	
Public transport	100 (87.1)
Walk	10 (8.6)
Private transport	4 (3.5)
Main profession	
Small business /market	48 (41.4)
Educator	15 (12.9)
Nurse	13 (11.2)
Farmer	12 (10.3)
Other	28 (24.1)
Health insurance	
No	101 (87.1)
Yes	15 (12.9)
Education (n=101)	
Primary	27 (23.3)
Secondary or higher	74 (63.8)
Family conflicts(n=113)	
No	86 (74.1)
Yes	27 (23.3)
Employment status	
Not employed	69 (59.5)
Employed	47 (40.5)
Monthly income (n=113)	
15.4 USD- ≤206 USD	102 (87.9)
>206USD	11 (9.5)
Income decline	
No	49(42.2)
yes	67(57.8)
Degree of income decline if income decline observed	
High	49 (61.5)
Moderate	21 (32.3)
Low	4 (6.2)
Major expense categories	
Medical care	23 (19.8)
Non-medical care	93 (80.2)
Excessive transport expenses (n=101)	
No	10 (8.6)
Yes	91 (78.4)
<hr/>	
Clinical diagnostics and complications	
<hr/>	
Confirmed fibroids	(60.1)
<hr/>	
Anemia	
No	55 (47.4)

Yes	61 (52.6)
Infertility (112)	
No	73 (62.9)
Yes	39 (33.6)
Deep vein thrombosis (n=115)	
No	97 (83.6)
Yes	18 (15.5)
Urinary stone	
No	99 (85.3)
Yes	17 (14.7)
Hydronephrosis	
No	110 (94.8)
Yes	6 (5.2)

Appendix 6

Table 2: Joint display table for signs, symptoms, and complications of women with uterine fibroids in Haiti accessing care at the outpatient department at Mirebalais University Hospital (n=116)

Description of Signs and symptoms		%
Characteristics	(n=116)	quotes
Stress (n=114)	92 (79.3)	<p>“I feel like I am desperate because knowing I have fibroids usually torments me. It stresses me. Because I am unable to sleep at night. I would spend the whole night thinking.” (woman with fibroids)</p> <p>“I think a lot about this disease because imagine that...I have no children...I have no children, and the fibroids hurt, and I do not know what effects this will have on me; I do not know what is going to happen to me because I have always heard people saying it kills people. I stress a lot about it because I have no kids. I still want to have surgery” (woman with fibroids)</p>
Dysmenorrhea (115)	73 (62.9)	<p>“When I have my period, I have severe pain.” (woman with fibroids)</p> <p>“I have severe pain when I have my period. My lower belly and my waist hurt. They always hurt. And, people cannot touch me; people cannot touch my belly because it is sensitive. I still work, and I do all my activities. When I have pain, I take a « Parafortan » pill. I rest a little after that I feel little pain.” (woman with fibroids)</p>
Acute pelvic pain (112)	72 (62.1)	<p>“I start feeling pain. The intensity of the pain makes me scream! And I have cramps. I am unable to walk.</p>

		<p>Sometimes, the pain is so terrible that I cannot even sleep at night. I just lay down on the bed wide awake.” (woman with fibroids)</p> <p>It is because I had pain. I had pain all of a sudden. (woman with fibroids)</p>
Pelvic mass (n=113)	56 (48.3)	<p>“So, I went to the hospital, and the doctor asked me to make a pap test and a sonography. I did. And the sonography revealed that I have a mass inside my lower belly. The doctor told me that the disease is called Fibroid.” (woman with fibroids)</p>
Polymenorrhagia	50 (43.1)	<p>“Well... sometimes, I have my period twice a month, and I was told fibroids might be the cause.” (woman with fibroids)</p>
Metrorrhagia (115)	49 (42.2)	<p>“After that, my blood is watery... then blood clots start coming out. After that, the blood stops flowing for five (5) days; after that, it starts flowing again during the same month”. (woman with fibroids)</p>
Menorrhagia (n=114)	49 (40.5)	<p>“Sometimes, when I have my period, I bleed a lot... and it lasts eight days” (woman with fibroids)</p> <p>“If I put pads during my period, the pad will not stop the blood. I sometimes put a bathing towel on the bed when I am sleeping, and I end up soaked with blood. I also have severe pain while I am bleeding. I was worried. So, I decided to come to seek care at the hospital.” (woman with fibroids)</p>
Mictional difficulty	49 (40.5)	<p>“I could not urinate. My lower belly was swollen because I could not urinate. So, I rushed to the hospital, and as soon as I arrived, I explained how I felt. They did a sonography test for me right away. When they got the results, they told me I have fibroid.” (woman with fibroids)</p>
Chronic pelvic pain (n=115)	33 (28.5)	<p>“I felt little pain in 2018. But, in 2019, it got worse. The pain became more severe. It is because of this pain I felt I decided to come to seek care and understand what was happening to me. Also, I wanted to understand why I kept losing the babies while I was still pregnant. I did a test that revealed I had fibroid.” (woman with fibroids)</p> <p>“I started feeling pain in my vagina in November 2018. After this, I came to the Hospital. The doctor asked for an ultrasound. I could not afford the exam, so I did not go. When I felt the pain again, I ran into the Boucan Carré Health Center, which asked to get</p>

		an ultrasound at a private Health Center. That ultrasound led me to discover I had a fibroid” (woman with fibroids)
Pelvic pressure (n=114)	33 (28.5)	“It bothers me because I feel something heavy inside my belly.” (woman with fibroids)
Abdominal pelvic mass (n= 113)	9 (7.8)	“My belly has become big. It is getting bigger. All of a sudden, my belly has changed. The disease was located on my lower belly at first, and I suddenly saw my belly changing.” (woman with fibroids)
Mild and Moderate depression (ZL score 13-17 and ≥18 -≤27)	22 (15.6)	“I used to suffer so much with fibroid that I thought of hurting myself just to put an end to my agony.” (woman with fibroids)
Description of complications		
Anemia	61(52.6)	“Her anemia (level of blood: 5g) makes her unable to stand”. (Family member, daughter) “Then, I did a blood analysis. The result revealed that my level of blood was 3g, which explained why I was feeling that way and why I could not speak. My arm was swollen, really swollen.” (woman with fibroids)
Infertility (112)	39(33.6)	“I got married in June 2015. And I had sex on my honeymoon. And, on the 7th of this month, I had my period. So, because I was in my menstrual cycle, I was unable to pursue the honeymoon. During my ovulating cycle, I had sex, but I never got pregnant. That really affected me.” (woman with fibroids)

Appendix 7

Table 3: Bivariate analysis looking for risk factors associated with uterine fibroids among social demographic and clinical variables at MUH age greater or equal to 20 years old (n=193)

Characteristics	Odd ratio	95% CI	P-value
Age			
20- 34	-		
>35-49	2.6	(1.33 - 5.03)	0.005
50+	1.2	(0.53 - 2.90)	0.611
Zone of residence			
Central plateau	-		
Out of central plateau	2.3	(1.22 - 4.17)	0.01
Number of pregnancies			
No pregnancy	-		
1-3 pregnancies	0.6	(0.29 - 1.32)	0.216

>3 pregnancies	0.9	(0.34 - 2.41)	0.848
Number of births (101)			
No childbirth	-		
1-3 childbirths	0.6	(0.30 - 1.14)	0.115
> 3 childbirths	1.1	(0.35 - 3.64)	0.844
Menopause			
No	-		
Yes	1.3	(0.57 - 2.88)	0.551
Patient status			
New patient	-		
Follow up	3.2	(1.14 - 8.84)	0.026
If follow-up patient			
<6 months	-		
6-12 months	1.4	(0.25 - 7.89)	0.699
≥12 months	0.4	(0.11 - 1.63)	0.208
Type of residence			
Rural	-		
Urban	1.5	(0.75 - 2.83)	0.267
Average time per medical appointment			
≤2h	-		
>2h	1.6	(0.69 - 3.50)	0.287
Excessive transport expenses			
No	-		
Yes	3.8	(1.65 - 8.74)	0.002
Means of transport			
Walk	-		
Public transport	3.1	(1.34 - 7.28)	0.008
Private transport	1.4	(0.29 - 6.27)	0.694
Health insurance			
No	-		
Yes	0.5	(0.24 - 1.12)	0.098
Education level			
Primary	-		
Higher education	0.4	(0.18 - 0.957)	0.039
Main profession			
Other (no specific employment)	-		
Small business	1.4	(0.67 - 2.79)	0.384
Educator	1.8	(0.64 - 5.24)	0.256
Farmer	5.1	(1.04 - 25.29)	0.044
Nurse	0.8	(0.31 - 2.02)	0.631
Employment			
No	-		
Yes	1.1	(0.61 - 1.99)	0.744
Income			
15 USD- ≤206USD	-		
>206USD	1.9	(0.60 - 6.42)	0.262
Income decline			
No	-		
Yes	3.0	(1.64 - 5.54)	<0.001
Degree of income decline			
Low	-		

Moderate	1.1	(0.09 - 11.56)	0.968
High	0.6	(0.06 - 5.33)	0.610
Expenses category			
Medical	-		
Non-medical	0.7	(0.35 - 1.60)	0.455
Family conflicts			
No	-		
Yes	2.6	(1.12 - 6.16)	0.026
Family history with fibroids			
No	-		
yes	5.1	(2.11 - 12.33)	<0.001
Pelvic infection			
No	-		
Yes	0.6	(0.30 - 1.24)	0.170
Ovarian micro polycystic			
No	-		
Yes	0.2	(0.12 - 0.41)	<0.001
Constipation			
No	-		
Yes	1.6	(0.80 - 3.05)	0.191
Pelvic mass			
No	-		
Yes	2.0	(1.10 - 3.67)	0.024
Abdominal-pelvic mass			
No	-		
Yes	1.6	(0.46 - 5.25)	0.475
Mictional difficulty			
No	-		
Yes	1.7	(0.92 - 3.16)	0.091
Pelvic pressure			
No	-		
Yes	1.5	(0.77 - 3.02)	0.225
Acute pelvic			
No	-		
Yes	1.75	(0.97 - 3.17)	0.062
Chronic pelvic pain			

No	-		
Yes	1.3	(0.65 - 2.48)	0.476
Polymenorrhagia			
No	-		
Yes	1.6	(0.89 - 3.04)	0.111
Menorrhagia			
No	-		
Yes	1.6	(0.89 - 3.04)	0.111
Metrorrhagia			
No	-		
Yes	1.6	(0.89 - 3.01)	0.111
Dysmenorrhea			
No	-		
Yes	1.6	(0.89 - 2.89)	0.113
Infertility			
No	-		
Yes	1.5	(0.80 - 2.89)	0.198
Stress			
No	-		
Yes	1.4	(0.68 - 2.75)	0.376
Anemia			
No	-		
Yes	0.9	(0.52 - 1.64)	0.789
Deep vein thrombosis			
No	-		
Yes	14.1	(1.84 - 108.02)	0.011
Urinary stone			
No	-		
Yes	1.0	(0.45 - 2.30)	0.972
Hydronephrosis			
No	-		
Yes	4.1	(0.49 - 35.13)	0.192
Depression			
No	-		
low (score 13-17)	1.6	(0.60 - 4.06)	0.350

Moderate (score 18-24)

(0.62 - 42.73)

0.130

Appendix 8*Table 4: Multivariate analysis of the association with uterine fibroids and social demographic and clinical variables at the OBGYN out-department at MUH age greater or equal to 20 years old (n=193)*

Characteristic	Adjusted OR	95% CI	P-value
Age			
<35	-		
≥35-≤49	1.7	(0.76 - 4.02)	0.189
≥50-≤77	0.4	(0.11 - 1.50)	0.174
Patient status			
Initial Visit	-		
Follow -up visit	2.8	(0.79 - 9.95)	0.110
Expense for transport			
No	-		
Yes	4.4	(1.55 - 12.38)	0.005
Health Insurance			
No	-		
Yes	1.2	(0.44 - 3.30)	0.709
Education level			
Primary	-		
Higher education	0.3	(0.09 - 0.87)	0.021
Income decline			
No	-		
Yes	4.7	(2.05 - 10.93)	<0.001
Number of births			
No childbirth	-		
1-3 childbirths	0.6	(0.26 - 1.30)	0.188
4+ childbirths	0.9	(0.19 - 3.99)	0.866
Family conflicts			
No	-		
Yes	3.1	(0.54 - 17.9)	0.206
Family history of fibroids			
No	-		
Yes	4.6	(1.58 - 13.56)	0.005
Pelvic infection			
No	-		
Yes	0.4	(0.09 - 1.80)	0.233
Micro polycystic ovary			
No	-		
Yes	0.3	(0.10 - 0.97)	0.044
Pelvic Mass			
No	-		
Yes	2.2	(0.72 - 6.85)	0.164
Frequent menstruation			
No	-		
Yes	0.4	(0.14 - 1.16)	0.094

No	-		
Yes	3.0	(0.29 – 31.89)	0.352
Depression			
No	-		
Low	5.7	(0.56 - 59.18)	0.142
Moderate	2.4	(0.17 - 36.03)	0.513
