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**Original Research Article**

# "The Pain is Just Too Much:" Understanding the Burden of Uterine Fibroid on Quality of Life among Women Diagnosed with Fibroid in a Tertiary Hospital

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**Abstract:** ***Background:*** While current information on uterine fibroid (UF) includes mostly quantitative approaches, there is limited information known about women's personal experiences and symptoms of UF described in their own words. ***Objective:*** This study explored the understanding of symptoms experienced by women diagnosed with UF and the burden of the disease on their quality of life. ***Methods:*** This was a qualitative exploratory study. Purposive sampling was used to select 10 women diagnosed with UF between March and April 2022. The study used semi-structured interviews, guided by the common-sense model of illness, during which they described UF symptoms they experienced and the different ways in which UF affected their life before presenting at the hospital. Thematic analysis, as described by Braun and Clark was used for data analysis. ***Results:*** Seven symptoms of UF experienced by participants emerged: menorrhagia, chronic pain, dysmenorrhea, abdominal bloating, pelvic pressure, pelvic mass and micturition difficulty. The burden of UF was felt across six areas of life: psychological, social, physical, socioeconomic/financial, employment and sexual life. ***Conclusion:*** The results reported in this current study illustrate that participants consider the burden of UF to be too much.

**Keywords:** Uterine Fibroids, Women, Symptoms, Burden, Quality of life.

## BACKGROUND

Globally, uterine fibroids, also known as leiomyomas (UF), are the most prevalent benign gynaecological tumours affecting fertile women [1]. Fibroids can vary in size from less than one inch to more than eight inches across, and a woman may have a single fibroid or clusters of numerous. A lot of fibroids are not noticed until they start to show signs [2]. In contrast to the 5–11% recorded in Europe and the US, the incidence of fibroid in Nigeria ranges between 17.9–26% [3]. Furthermore, unfavourable repercussions of uterine fibroid are reported in less-resourced countries particularly countries in Sub-Saharan Africa [4]. Compared to women of other races, black women experience uterine fibroids at a significantly higher rate [5]. According to Ford [6], social life restrictions, anxiety related to not knowing when menstruation will start, embarrassment caused by breakthrough bleeding, lack of control over plans and social activities, uncertainty about fertility-preserving treatment options, a sense of losing control over overall health, and complaints of exhaustion and depression are some of the ways that UF can cause a burden. On the other hand, UF is a chronic and progressive illness that is becoming a greater public health concern due to the detrimental effects its symptoms can have on the quality of life, the higher risk of UF development among women who have it, and the increased strain UF treatment places on healthcare systems [6].

While current information on the topic of interest includes mostly quantitative approaches [6, 7,8], there is limited information known about women's personal experiences and perspectives on the symptoms and impacts of UF described in their own words. Patient interviews reported in this present study aimed to gather patient experience data through open-ended questions, rather than from a survey with predefined answering options. This study sought to provide new insights into UF burden and capture a robust understanding of fibroid

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patient experiences in terms of patient-relevant symptoms and their impacts on the different aspects of quality of life, including social life, financial, psychological, sexual, daily activities functioning, and well-being.

## MATERIALS AND METHODS

### Study Design

This was an exploratory qualitative study using thematic analysis, as described by Braun and Clark [9]. Between March and April 2022, we conducted semi-structured interviews for ten women diagnosed with UF. Semi-structured interviews allowed for discussion with women diagnosed with UF to understand their personal experiences and perspectives on the symptoms and impacts of UF before seeking care in the hospital.

### Study Setting

This study was conducted in Afe Babalola Multisystem Hospital Ado Ekiti, Ekiti State Nigeria (AMSH). AMSH is located in Ado Ekiti, southwest Nigeria and was founded in March 2018. It is a private hospital that offers a tertiary level of care with over 400-beds. The variety of patients at this treatment facility, together with its standing for providing high-quality medical evaluations, treatments, care, and equipment, all played a part in the decision to select it as a referral hub for patients with a range of illnesses. Nigerians from both rural and urban areas flock to the hospital for assessment and care.

### Study participants and sampling

A purposive sampling was utilized to select ten (10) women who had UF principally confirmed by ultrasound visiting the obstetrics and gynaecology unit of AMSH. The sample size in this study was guided by the saturation principle. According to Thorne [10], theoretical saturation is reached when the researcher can anticipate responses to the questions being asked and realizes that no new information that could enrich the emerging pattern is forthcoming.

### Interviews

Semi-structured face-to-face interviews in English language was conducted per respondent visit but at a time of convenience to the participants during hospital visits. A top building (a private room) just above the obstetrics and gynaecology department was used for all interview sessions. Before the interview began, information about the study was reviewed with each participant. The interviews aimed to explore concepts i.e., symptoms and burdens associated with UF. Interviews were based on a semi-structured interview guide and included open-ended questions to encourage spontaneous responses, followed by targeted probes as needed. Women were asked to describe symptoms and impacts they experienced as a result of UF before seeking care in the hospital. Each interview was audio recorded, with the woman's prior consent. All Interviews were conducted in English. However, the availability of Yoruba (the indigenous local language in Ado Ekiti) interviewer was made ready depending on the participant's preference. The interview lasted an average between 30 to 45 mins and no repeat interviews were carried out. Each interview was audio recorded, transcribed, and translated into English before being kept on a secure cloud platform to which only members of the study team had access. No transcripts were given back to the participants for their evaluation.

### Data Analysis

We utilized Braun & Clark's approach to data analysis [9]. First, we transcribed interviews verbatim to retain the 'original nature' of the verbal accounts. Then we transitioned into the initial phases of analysis by conducting an immersive data content review to ensure uniform familiarity among members. A deductive/inductive approach for the codebook to foster greater representation of the data was developed based on interview guides, initial reading of transcripts, and existing literature. This continued until saturation was reached. Two team members (K.P & E.K) lead the codebook development. Upon coding completion, themes/subthemes were generated. The same was refined in subsequent analysis meetings until the patterns of meaning were clear. Of note, the total number of burdens identified could be greater than the total number of women who reported the concept, because some women provided multiple examples and descriptions of how UF impacted their lives.

### Data trustworthiness

The four standards developed by Lincoln and Guba [11] for assuring the reliability of findings in a qualitative study—credibility, applicability, consistency, and confirmability were applied to this study. To establish credibility, we reflexively engaged in the process, asked clarifying questions both during and after the interview to make sure the points were understood, shared preliminary data interpretations with the participants to make sure they aligned with their experiences and held consultations and discussions with the research team. Throughout the research process, expert consultations were consulted to maintain consistency. Applicability was ensured by providing a detailed description of the research context. Confirmability was guaranteed by utilising participant quotes, ensuring that the study findings were based on the data, and having the study participants validate the data interpretations.

### Theoretical framework

This study utilised the common-sense model of illness described by Leventhal *et al.,* [12] to characterise women's experiences with UF. Five characteristics of cognitive illness representations are proposed by the Common-Sense Model: identification, encompassing views regarding the diagnosis of the ailment, the naming of those experiences, and which experiences are indicative of the sickness and which are not; views about the course of the illness, including when it started and will finish; beliefs about the effects the health condition will have on a person's life; and timelines cause or underlying mechanism is a category of beliefs related to the perceived reasons for the development of the illness and the mechanism behind the manifestation of the symptoms; and control, which includes the individual's beliefs of how much he or she can manage or control the illness and its symptoms as well as representations of how control should be achieved.

# RESULTS

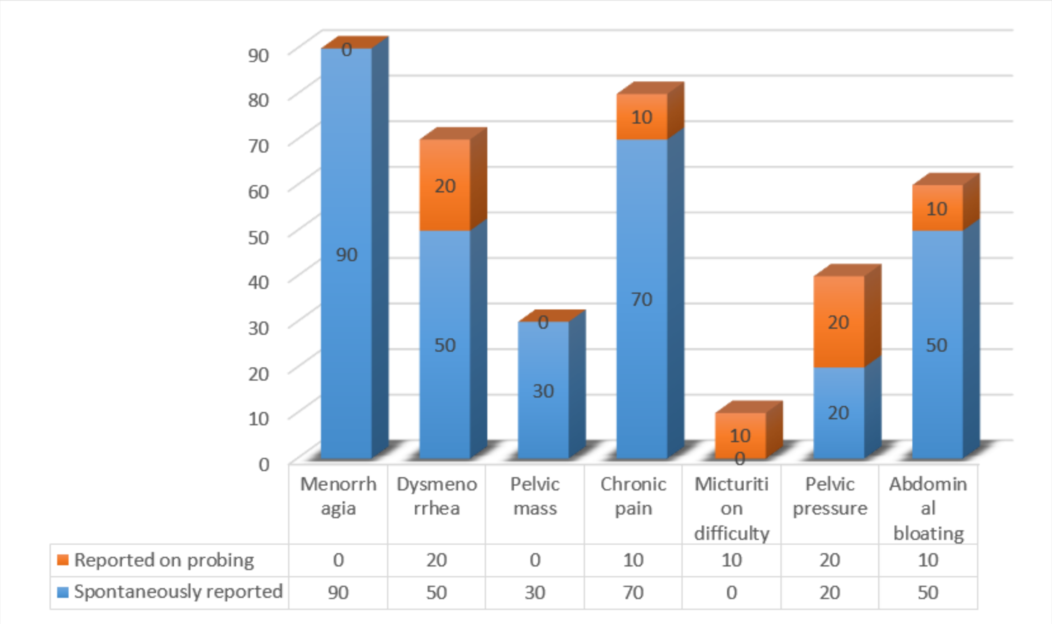
**Table 1: Participant characteristics**

| Variables | N (%) |
|---|---|
| **Age** | |
| (Mean±SD) | 33±7.208 |
| **Marital status** | |
| Single | 3 (30.0%) |
| Married | 7 (70.0%) |
| **Parity** | |
| 0 | 7 (70.0%) |
| 1 | 2 (20.0%) |
| 2 | 1 (10.0%) |
| **Education** | |
| Primary | 0 (0.0%) |
| Secondary | 2 (20.0%) |
| Tertiary | 8 (80.0%) |
| **Occupation** | |
| Employed | 10 (100%) |
| Not employed | 0 (0.0%) |
| **Family history of Uterine fibroid** | |
| No | 80 (80.0%) |
| Yes | 20 (20.0%) |

### Experienced symptoms of UF

Descriptions of 7 unique UF symptoms emerged from interviews (Fig. 1). The most commonly reported symptom of UF was Menorrhagia (n=9 of 10; 90.0%); one woman characterized menorrhagia as ''*the bleeding is usually heavy and drop down like a river, most especially outside menstruation days*". A thirty-three-year-old woman expressed *"I can tell you, at some point, there was no difference between my menstruation days and normal day, almost every day I bleed. It was just too much"*. Frequently reported among women was chronic pain (n=8 of 10; 80.0%). A participant expressed it like this "*Whenever I start to feel the pain, it is as if I want to die, as if my belle is turning. I don't wish the pain for anyone"*. A 42yr old woman one woman described chronic pain as ……. "*and other symptoms I felt was pain in the pelvic area, it is usually sharp like this and render me useless for sometimes"*. Of the percentage of women expressing chronic pain, when asked to rate the pain on a scale of 1-10, (1=low, 10=high pain), all the participants rated their pain as 8/10. Furthermore, dysmenorrhea symptoms were another frequent symptom reported among participants (n=7 of 10; 70.0%) of the participants. Women provided statements such as: *"my period is usually a disaster because i am always in pain"*. Another woman explained that "…….even during my period, I will cry sometimes, rolling on the floor when I start to feel the pain".

Abdominal bloating was reported by half of the women (n=5 of 10; 50.0%), A participant described bloating as "*A lot of the time I look pregnant as if there is a baby in my uterus*" Almost half of the participants reported pelvic pressure as the symptoms they felt. A 39yr old woman verbalized that ….*i feel great pressure when I sit too much and before I know it my two leg will be heavy"*. Pelvic mass was also reported by one third of the participant (n=3 of 10; 30.0%), Descriptions provided included: "*sometimes I felt heaviness in my tigh, but after a while it goes down. During this time I could rarely do anything"*. Furthermore, micturition difficulty was described by just one participant. Comments included: "*Sometimes, I would have difficulty urinating. This happens when I feel the pressure in my leg"*.



| | Menorrhagia | Dysmenorrhea | Pelvic mass | Chronic pain | Micturition difficulty | Pelvic pressure | Abdominal bloating |
|---|---|---|---|---|---|---|---|
| 🟧 Reported on probing | 0 | 20 | 0 | 10 | 10 | 20 | 10 |
| 🟦 Spontaneously reported | 90 | 50 | 30 | 70 | 0 | 20 | 50 |

**Fig 1: Symptoms of UF experienced by women**

**Burden of UF on quality of life**

From the analysis of the participants' interview transcripts, the burden of UF on quality of life was clustered into 6 themes; psychological burden, social burden, physical burden, socioeconomic burden /financial burden, sex-related burden and employment burden.

**Psychological burden**

Participants reported negative effect of UF on their emotional well being. Majority (n=9 of 10; 90.0%) were depressed, feeling of embarrassment (n=5 of 10; 50.0%), Sad, hopeless/discouraged (n=6 of 10; 60.0%). The majority of the women expressed that they are always depressed and couldn't handle anything. One participant verbalised "*I would get depressed because I couldn't really do anything, just pissed off and uninterested in activities". *Another woman expressed:*" I get angry, anytime I think of the bleeding so I'm constantly irritated and sad".* Another participant commented …. "*And I was always depressed…depressed because I'm spotting, even outside my menstruation days"*

Feeling of being embarrassed as an impact was mentioned by half of the participants (n=5 of 10; 50.0%), For example, one woman expressed *''it is embarrassing really, the fact that my step wife laugh at me calling me big tummy without pregnancy/child. So I just stay indoor almost every time."*

**Social Burden**

The majority of the participants described that UF impacted their social life. Women described missing family activities (n = 8 of 10; 80.0%), thorough selection of clothes due to bleeding (n = 6 of 10; 60.0%), and Inability to go out due to menorrhagia and bloating (n = 5 of 10; 50.0%). A 43 year old woman expressed ''*I was unable to go to my friend naming ceremony as a result of bleeding, even though my friend understand but I still feel sad about it*''. One participant expressed: "*Sometimes I will have to select, select and select what to wear to avoid being stained when going outside"*.

Another woman expressed that *"going out or engaging in social whatever is cancelled whenever I experience pain and bleeding, you just cant help it"*.

A participant who has been suffering from UF for 3yrs+ verbalized .. "*It is really embarrassing to bleed through your clothes in public. With time I had developed this feeling of self conscious whenever I am in public to avoid being embarrassed which has reduced my social interaction."*

**Physical Burden**

The majority experienced weakness (n = 7 of 10; 70.0%), tiredness (n = 8 of 10; 80.0%), feeling of drowsiness (n = 6 of 10; 60.0%). Women provided statements such as: ''*Whenever this bleeding starts before I know it, I start feeling weak*".

Another woman verbalized "*I was driving one day when I started bleeding, I had to park because I was experiencing this serious drowsiness that I had to call my husband to come and pick me up*".

Furthermore, one participant expressed that "*generally, (I) can say my physical strength has reduced, I am always exhausted and tired with little activities"*.

**Socioeconomic/financial burden**

Half of women (n = 5 of 10; 50.0%) described a negative impact on finances. Eight women (n = 8 of 10; 80.0%) mentioned that this was a result of excessive spending on feminine hygiene (n = 8 of 10; 80.0%), borrowing to sustain self and family, high cost of drugs (n = 9 of 10; 90.0%), high cost of concoction (n = 2 of 10; 20.0%) with one woman saying ‘‘*I had to borrow from my friend who introduced me to the herbalist for concoction money when it was draining me*”.

Another woman expressed “*The amount of money I was spending on buying for pads and tampons also affect my personal needs*’’.

**Sex-related Burden**

When asked about the effect of UF on sexual life, eight (n= 8 of 10; 80.0%) reported they avoided sexual activity. One woman expressed *“you see….when this bleeding starts, sincerely, sex is the last thing you will ever think of, I avoid sex at all cost”*. Diminished sexual desire was recorded among study participants (n= 2 of 10; 20.0%). For example, one woman expressed that … *“even though I am not bleeding, the urge to be intimate with my husband is off”*

**Impact on employment**

Regarding the effect of uterine fibroid on employment status of the participants. It was noted that few experienced loss of job (n= 2 of 10; 20.0%), majority experienced complaint from boss and reduced work efficiency (n= 7 of 10; 70.0%). One participant expressed “*this thing (UF) almost made me lose my job because i am always feeling weak and couldn’t cope with work stress again.”* Additionally, four women (n= 4 of 10; 40.0%) expressed that they missed work as a direct result of uterine fibroid symptoms. For example, one woman verbalized that *“I was seriously bleeding one Monday morning and presentation at office was my turn, I was soaked repeatedly from the bleeding… I had to call in sick which almost got me fired from work.”*

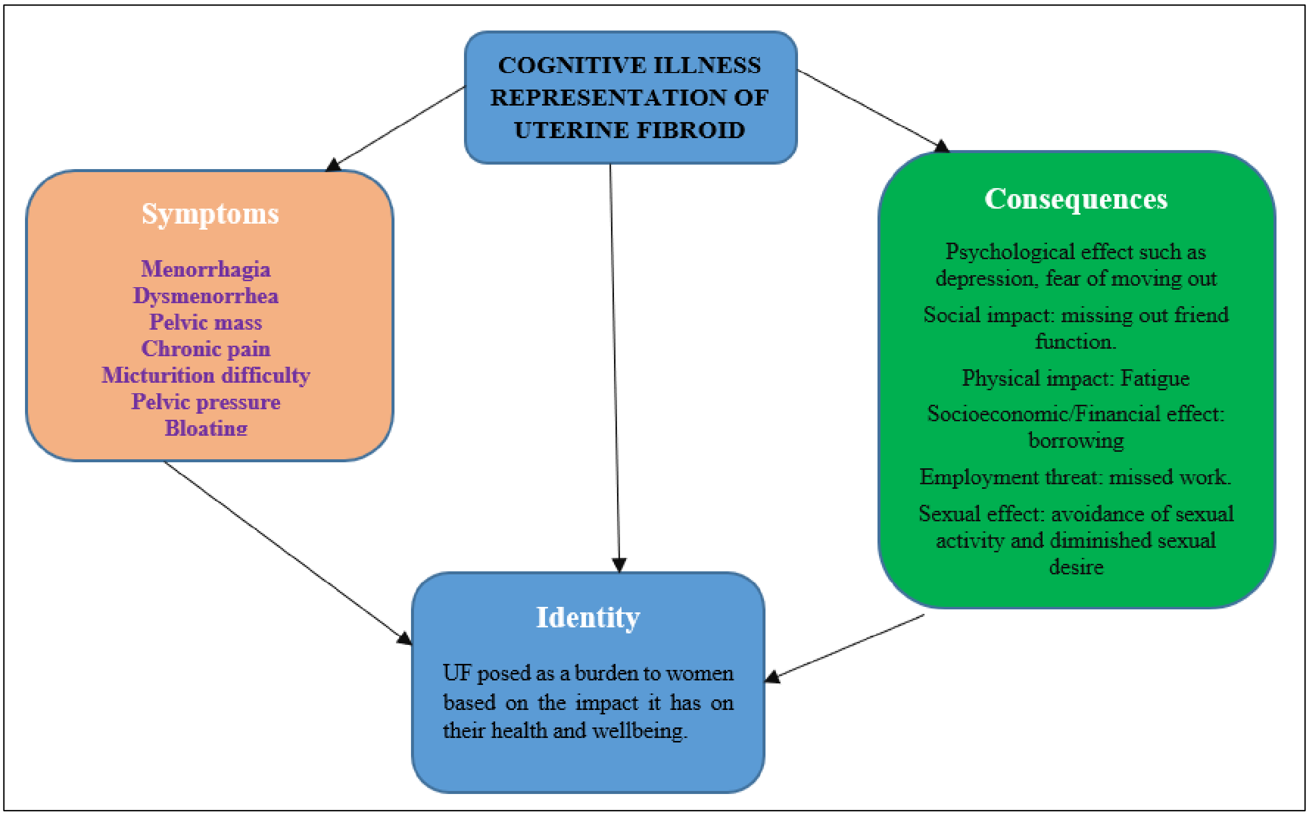


**Fig. 2: Common-sense model of illness for women with UF in a tertiary hospital**

## DISCUSSION

This study aimed to understand the UF symptoms experienced by women diagnosed with UF and the burden of the disease process on their quality of life. The mentioned UF symptoms were menorrhagia, chronic pain, dysmenorrhea, abdominal bloating, pelvic pressure, pelvic mass and micturition difficulty. The UF symptoms described in the present study are in agreement with those described by other authors [13-15]. Similarly, results from this present study align with the UF symptoms such as menstrual bleeding or spotting, cramping, fatigue, bloating, and fibroid-related pain reported by participants in Deal *et al.,* [16] study.

Also, women in this present study subsequently described how UF impacted their physical functioning, social life, psychological life, sexual life, socioeconomic life, and employment. The psychological burden described by participants in this study agrees with Lerner *et al.,* [17] findings which described that women settled they were depressed because of the pain, and constant bleeding they experienced as a direct effect of UF. Overall, findings from this present study revealed that the impact of UF symptoms experienced influenced almost all spheres of women's lives which aligns with other studies on UF [6, 17, 18].

The strength of this study lies in the methodology used. Women answered open-ended questions with minimal probing, giving women the opportunity to freely share their experiences and the burden that UF imposes on their lives. This study contributes to the understanding of the experiences and the burden of UF on the lives of women with UF in south-western Nigeria, an area where such data is scarce. However, results should be interpreted in light of some potential limitations. Participants in this study were only screened for UF by ultrasound. Objective confirmation of UF by menstrual blood loss of ≥160 mL during one cycle or ≥ 80 mL per cycle for two menstrual cycles, as measured by the alkaline haematin method was not carried out. Also, due to limited geographic recruitment, this study may not be generalizable across all locations or sociodemographic groups.

# CONCLUSION

This qualitative study reports women's personal experiences regarding the symptoms and impacts of UF, as described in their own words. The most commonly reported symptoms of UF were menorrhagia, dysmenorrhea and chronic pain. Symptoms experienced reportedly affected almost all their spheres of life, including psychological, physical, social, financial life, employment and sexual life. Importantly, these findings demonstrate the debilitating consequences of UF symptoms, which translate into reduced quality of life. The findings presented here demonstrate that patients believe UF to have an excessive impact. This study may help clinicians uncover significant effects of UF that patients may not be willing to address and may also help them better understand how women with UF view their condition.

# DECLARATIONS

## Ethical approval

The ethical approval to conduct the study was sought from AMSH research ethics and review committee (ref: AMSH/RQ/EEA/045). The study was conducted according to the guidelines of the Declaration of Helsinki.

## Author's Contributions

Conception and design of the study: K.P & E.K
Writing: All authors
Data analysis and interpretation of data: All authors
Supervised the conduct of the study: K.P & E.K
Revising the paper critically for important intellectual content: All authors
Participated in final approval of the version submitted: All authors
Takes responsibility for the paper as a whole: All authors

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**Conflicts of interest:** None

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