A study exploring women's experiences, knowledge, attitudes, and perceptions of fibroids in Diepsloot, South Africa.

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ABSTRACT

This study is an exploration of women’s experiences, knowledge, attitudes, and perceptions of fibroids. It is underpinned by social constructionism and the common-sense model of self- regulation theoretical frameworks. Eight in-depth semi-structured interviews were conducted with women in Diepsloot, South Africa. The study aimed to include diverse perspectives, thus participants included women who consulted biomedical and cultural practitioners or both. The findings of the research reveal that women’s experiences with fibroids are complex because of the many decisions they have to make about the diagnosis and treatment options and the multiple, and sometimes intersecting temporary disruptions, caused by fibroids. Furthermore, the low levels of awareness about fibroids and the prevailing culture of silence surrounding women’s reproductive health have negative consequences for women living with fibroids as this can result in delayed diagnosis and treatment. The findings highlight the importance of raising awareness about fibroids in communities such as Diepsloot where awareness initiatives are insufficient, given the high prevalence of fibroids among reproductive age black women.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

Uterine fibroids are the most common benign tumours of the uterus affecting women of reproductive age (Khan*,* Shehmar & Gupta, 2014: 95; Ghant, Sengoba, Retcho, Cameron, Lawson & Marsha,2015: 499). They are non-cancerous growths that develop in the smooth muscle of the uterus (Igboeli, Walker, McHugh, Sultan & Al-Hendy, 2019: 2). Fibroids affect between seventy to eighty per cent of women worldwide, and black women are affected at higher rate than other races (Khan *et al*., 2014; Ghant *et al*., 2016; Igboeli *et al*., 2019; Millen, Manzi, Katz, Gilbert, Fawzi, Farmer & Mukherejee 2021; VanNoy & Zota, 2021). Depending on how big they are and where they are located in the uterus, symptomatic fibroids can manifest with a variety of symptoms (Millen *et al*., 2021: 4). They are often associated with abnormal, heavy, painful, and prolonged bleeding (Zimmermann, Bernuit, Gerlinger, Schaefers & Geppert, 2012: 2). As the sizes of the fibroids increase, other symptoms may include dyspareunia (pain during intercourse), pelvic pain, constipation, abdominal swelling (bloating), low back pain, bowel dysfunction and urinary retention (Aubuchon, Pinto & Williams,2002; Buttram and Reiter 1981; Stewart 2001; Zimmerman *et al*., 2012). Biomedical treatments of fibroids include hysterectomy, myomectomy, uterine fibroid embolization, and hormonal therapies (Khaund & Lumsden, 2008: 75; Myles, 2013: 13; De la Cruz & Buchanan, 2017:104).

Research on fibroids has historically placed a strong emphasis on quantitative approaches, with little attention paid to the exploration of women's subjective experiences, knowledge, and perceptions of this health condition (Stewart, 2001; Fortini, Panobianco, Sabino-de-Freitas, Barbosa, Azevedo, Brito & Candido-dos-Reis, 2018; Giuliani, As-Sanie & Marsh, 2020; Morhanson-Bello & Adebamowo, 2022). The few studies that examine the subjective aspects of the illness experiences of women with fibroids do not consider the cultural aspects and the intersection of biomedicine and culture in shaping women's experiences of fibroids (Myles, 2013; Hunsche, Rakov, Scippa, Witherspoon & McKain, 2022; Begho & Waterman, 2023). Furthermore, given that a significant proportion of studies is carried out in the Western context, where women predominantly seek biomedical practitioners for diagnosis and treatment, there is frequently a need for more exploration into the diverse factors influencing women's decisions regarding diagnosis and treatment options. As a result, this study seeks to bridge these gaps by offering insights into women’s experiences, knowledge, and decision-making processes, taking into account elements including healthcare accessibility, personal values, and socio-cultural influences.

The study employed a qualitative design, using in-depth semi-structured interviews for data collection. Thematic analysis was used to analyse the data. The study took place in Diepsloot, a township in the north of Johannesburg, South Africa. The sample consisted of six women who consulted biomedical practitioners and/or traditional healers, and two were cultural practitioners.

1.2 Objectives

1.2.1 Primary Objective

The primary objective of this study is to explore women’s experiences of fibroids.

1.2.2 Secondary objectives

The secondary objectives include:

a) To identify factors influencing women’s decisions related to diagnosis and treatment;

b) To assess women’s level of awareness and knowledge of fibroids;

c) And to explore how cultural factors shape women's experiences with fibroids.

1.3 Thesis outline

The thesis is divided into six chapters; the first is an introduction, and the second is a literature review that provides the research context. The third chapter outlines social constructionism and the common-sense model of self-regulation, two theoretical frameworks underpinning the study. Chapter four discusses the research methods and the justification of why these methods are appropriate for this study. The fifth chapter presents an analysis of the data, and the last chapter is the conclusion and limitations of the study.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In the past, most studies on fibroids have been overwhelmingly conducted within quantitative or biomedicine frameworks, which tend to ignore women's experiences, knowledge, and perceptions of fibroids. As a result, these studies have yet to adequately capture the subjective aspects of this condition and how it affects women living with fibroids (Myles, 2013). The few studies that examine the subjective aspects of the illness experiences of women with fibroids do not consider the cultural aspects nor the intersection of biomedicine and culture in shaping women's experiences of fibroids. The purpose of this chapter is to contextualise women's experiences of uterine fibroids by exploring and examining existing literature on fibroids and identifying research gaps. The chapter begins by exploring the biomedical definition of fibroids, symptoms, diagnosis and treatment options. From there, the chapter explores how intersectional stigma burdens women with fibroids. Lastly, the chapter discusses the different and often intersecting *biographical disruptions* caused by fibroids (Bury, 1982).

2.2 Uterine fibroids

2.2.1 Definition, prevalence and risk factors

Uterine fibroids (also known as leiomyomas or myomas) are the most common benign tumours in women of reproductive age (Khan *et al*., 2014: 95). They are non-cancerous growths that develop in the smooth muscle of the uterus (Igboeli *et al*., 2019: 2). Studies reveal that up to seventy per cent of women will be affected by fibroids before they reach menopause (Ghant *et al.,* 2016; Igboeli *et al*., 2019; Khan *et al*., 2014; Millen *et al*., 2021; VanNoy & Zota, 2021). Of these, black women are disproportionally affected at rates that are three to four times higher than those of their counterparts of other races (VanNoy, Bowleg, Marfori, Moaward & Zota, 2021: 2). It is estimated that seventy to eighty per cent of black women will be affected by fibroids during their lifetime (Igboeli *et al*., 2019: 2). Although the cause of fibroids remains unknown, there have been efforts to identify epidemiological risk factors associated with fibroid growth (Morhason-Bello & Adebamowo, 2022). Several studies have found that race plays a significant role in the prevalence of fibroids (Okolo, 2008; Sarkodie, Botwe, Adjei & Ofori., 2016; Stewart, Cookson, Gandolfo &Schalze-Rath,2017). As already indicated, fibroids affect black women at higher rates than other races. They frequently exhibit more symptoms and have multiple and larger fibroids, and they tend to be much younger at the time of diagnosis (Okolo, 2008: 578). It has been argued that this is the case because black women have a higher prevalence of oestrogen receptor gene polymorphism, which is the genotype responsible for the genetic risk factor for fibroids (Okolo, 2008: 578).

Another epidemiological risk factor that has been identified is age. Studies report that women aged forty to sixty are more at risk of fibroids than women between the ages of twenty and thirty (Morhanson-Bello & Adebamowo, 2022: 1). Other risk factors include obesity, high blood pressure, early menarche, late menopause, nulliparity, and family history of fibroids (Giuliani *et al*., 2020; Walker & Stewart, 2005). Although much of the research on fibroids tends to focus on the biological or genetic risk factors, some studies link the risk of fibroids with social determinants. For example, studies by Boynton-Jarett, Rich-Edwards, Jin, Hilbert & Wright (2011) and Wise, Palmer & Rosenberg (2013) found that fibroids were more prevalent in women who reported experiencing sexual and physical abuse during their childhood and teenage years.

2.2.2 Symptoms and Diagnosis

Up to seventy per cent of fibroids are asymptomatic and are only incidentally detected during unrelated radiologic procedures, but they, in most cases, remain undiagnosed, leaving some women to suffer in silence with an unidentified condition (Giuliani *et al*., 2020: 4). Depending on how big they are and where they are located in the uterus, symptomatic fibroids can manifest with a variety of symptoms (Millen *et al*., 2021: 4). Symptomatic fibroids are often associated with abnormal, heavy, painful, and prolonged bleeding (Zimmermann *et al*., 2012: 2). As the sizes of the fibroids increase, other symptoms may include dyspareunia (pain during intercourse), pelvic pain, constipation, abdominal swelling (bloating), low back pain, bowel dysfunction and urinary retention (Aubuchon *et al*., 2002; Buttram and Reiter 1981; Stewart 2001; Zimmerman *et al*., 2012). Although fibroids are benign tumours and only less than one per cent may result in cancer, they can still negatively affect one's quality of life, cause pregnancy complications, and, in some cases, cause infertility (Igboeli *et al*. 2019; Stewart, 2001).

Fibroids are usually diagnosed by a physician during a pelvic examination where manual palpitation or medical tools such as ultrasound, Magnetic Resonance Imaging (MRI), and hysteroscopy are used to detect the presence, size and shape of fibroids (McLucas, 2008: 635; Myles, 2013: 12). Most studies on women’s experiences of gynaecological pathologies (endometriosis, polycystic ovarian syndrome, uterine fibroids, etc.) are conducted in North America and Europe and thus tend to only focus on women who have access to a diagnosis from a physician (Brito *et al.*, 2014; Denny, 2004; Myles, 2013; Simoens *et al.*, 2012; Zarbo *et al.*, 2022). Even the few existing studies in developing countries focus on women with a diagnosis from a physician, neglecting the experiences, knowledge, perceptions and attitudes of women without access to a gynaecological diagnosis (Adegbesan-Omilabu, Okunde, Gbadegsan,2014; Millen *et al.*, 2021). Women, particularly in Africa, experience massive healthcare inequalities, especially those who live in rural areas, have little to no formal education, are unemployed, have no access to media, and are single are affected the most (Tessema *et al.*, 2022: 4). Thus, there is a great number of women who do not have access to a gynaecological diagnosis of fibroids. These women either suffer silently from fibroids without knowing what they are or find alternative ways to get a diagnosis, such as from traditional healers or older women in their communities (Coulidiaty, Youl, Some & Nadembega, 2021: 2). These women have knowledge and experiences that have been neglected in research on fibroids. As a result, this study aimed to explore how these women go about seeking a diagnosis from traditional healers or other women in their communities and the knowledge that those who give the diagnosis have about the condition.

2.2.3 Management and Treatment Options

There are various biomedical treatment options for fibroids depending on their size and location, the patient's age, the symptoms, and the desire to maintain fertility (De la Cruz & Buchanan, 2017: 102). Treatment options include surgical procedures, radiological intervention, and medical and hormonal therapies (De la Cruz & Buchanan, 2017: 102; Giuliani *et al.*, 2020: 5). One of the most common methods of treating fibroids is through a hysterectomy. A hysterectomy is a surgical procedure to remove the uterus. Hysterectomy is the only definitive option for treating fibroids because the reoccurrence of fibroids is impossible if the uterus is removed (Myles, 2013: 13). This treatment option is the most preferable to individuals who do not wish to preserve their fertility (De la Cruz & Buchanan, 2017: 104). Myomectomy, a surgical procedure to remove fibroids while preserving the uterus, is the surgical alternative to hysterectomy. It is most common for women who wish to preserve their uteruses and fertility (Khaund & Lumsden, 2008: 751). Another available option is uterine fibroid embolization (UFE). UFE is one of the minimally invasive procedures for treating fibroids. It is a procedure that involves the injecting of sand-size particles into the arteries supplying blood to the fibroids to cut off their supply (John Hopkins Medicine, 2023). The fibroids shrink once the blood supply is cut off, easing the symptoms or causing them to go away over time (John Hopkins Medicine, 2023). Hormone therapies such as oral contraceptives and Gonadotropin-Releasing Hormone Agonists (GnRH) may also be prescribed to manage fibroids. These hormonal therapies are used to shrink the sizes of the fibroids and, in some cases, suppress menstrual periods to relieve heavy menstruation-related symptoms (Hillard, 2014: 631).

Alternatively, an increasing number of people are turning to complementary and alternative medicine (CAM) to manage and treat their fibroids (Dalton-Brewer, 2016; Karunagoda *et al*., 2021; Mehl-Madrona, 2002; Rubio *et al*., 2023). It has been reported that traditional Chinese medicine has been found to be effective in eliminating or reducing the size of fibroids (Dalton- Brewer, 2016: 112). It has also been argued that green tea has ingredients that reduce fibroids' size (Dalton-Brewer, 2016: 113). Mehl-Madrona (2002) found that although some CAM treatments were more expensive than the treatment options discussed above, they had lower risks of complications and higher patient satisfaction. In Africa, alternative medicine is by no means alternative because the majority of the population relies on it to meet their basic healthcare needs (Sobiecki, 2014: 1). It has been reported that eighty per cent of South Africans use traditional African medicine (ATM) because it is affordable and its providers are easily accessible (Molebatsi, Breed & Stafford, 2020). Traditional healers possess knowledge of the practises and values of the communities in which they practise, which contributes to their respectable social standing, allowing more people, especially in rural and urban informal settlements, to consult them before or over Western medical practitioners (Molebatsi *et al*., 2020). Few studies focus on the role played by traditional healers in the treatment and management of fibroids.

A study by Coulidiaty *et al*. (2021) explored the traditional management of uterine fibroids by a well-known traditional healer in Burkina Faso. This traditional healer uses stem bark and roots of plants which are sun-dried and later ground into fine powder, which is mixed in cold water to be drunk three times a day and used as a vaginal bath (Coulidiaty *et al*., 2021: 2). Other herbs are boiled for ten hours and patients drink half a litre of the concoction daily for two months (Coulidiaty *et al*., 2021: 2). Other treatments used by the traditional healer include vaginal cleaning with gloved hands and the extraction of the fibroids from the uterus through the vagina (Coulidiaty *et al*., 2021: 2). As noted earlier, there is a need for more African studies that explore the knowledge on fibroids that traditional healers who help women cope with their fibroids have of the condition. As a result, this study aimed not only to identify the mechanisms women who do not seek biomedical treatment use to cope with fibroids but also to identify the knowledge of the cultural practitioners that the women consult. This is an important enquiry considering that the majority of women in Sub-Saharan Africa do not have access to biomedical healthcare or health insurance to cover the cost of managing or treating fibroids, which means they rely on traditional medicine or other alternatives (Igboeli *et al*., 2019: 5).

2.2.4 The cost of managing and treating fibroids

The high prevalence of fibroids significantly impacts healthcare expenses worldwide (Giuliani *et al*., 2020: 3). Annual costs related to fibroids in South Africa are not readily accessible. However, it is estimated that the annual direct and indirect costs related to fibroids are around $34.4 billion in the United States of America (USA), $348 million in Germany, $120 million in France, and $86 million in England (Giuliani *et al*., 2020: 3). Undergoing surgeries and hormonal therapies can be costly for the affected individuals. According to Khan *et al*. (2014:107), women who suffer from fibroids have to bear the financial burden of paying for various medical procedures such as diagnostic tests, hospital admissions, surgeries, hormonal therapy and prescribed medication. Moreover, the surgical removal of fibroids is a delicate procedure with a relatively high risk of complications (Khan *et al*., 2014). Unfortunately, in case of complications such as adhesions or infection, women may incur additional costs for corrective surgeries. For example, in the USA, fibroid complications are estimated to contribute between 4% and 23% of annual costs related to fibroids, as reported by Al-Hendy, Myers & Stewart (2017:474). In addition, due to the fact that fibroids may result in pregnancy complications or infertility, women who desire to have biological children may need to allocate additional funds for fertility treatments (Fortin *et al*., 2018: 33). Furthermore, women who suffer from fibroids frequently experience severe and prolonged menstrual bleeding, which can add to their financial burdens (Hunsche *et al*., 2022: 292). On average, these women purchase more sanitary products per cycle than the average woman. According to the average price, a woman in South Africa spends between R300 and R600 per year on sanitary pads, and if she chooses to use tampons, the cost might increase to between R500 and R600 per year (Mitchell & Lewin, 2018). These costs may be two to three times higher for women whose fibroids cause severe and prolonged menstrual bleeding.

2.3 The social aspect of fibroids: stigma and silence

This section delves into the social dimensions of fibroids, a health condition frequently perceived as solely biological or physical within quantitative and biomedical frameworks. It sheds light on the intersecting stigmas that many women endure due to their fibroid symptoms. Additionally, the chapter addresses the culture of silence prevalent in certain cultures and communities regarding women's health, where speaking openly about such issues is often deemed taboo. The discussion explores the profound consequences these beliefs have on those who suffer from fibroids.

2.3.1 Menstruation as a stigmatised condition

Fibroids not only have a biological aspect, but they also have a social aspect with significant social consequences attached to certain natural processes, such as menstruation. As a form of resistance, several artists, such as American artist Vanessa Tiegs, German artist Petra Paul, and Spanish artist Jasmine Alice Carter, use their menstrual blood to create art (Johnston-Robledo & Chrisler, 2020: 181; McFarlane, 2020). In response to their art, people have expressed shock at their audacity, admiration of their creativity and disgust at their willingness to display one of nature's most stigmatised fluids (Johnston-Robledo & Chrisler, 2020: 181). Johnston-Robledo and Chrisler (2020: 183) argue that these artists' work seems to want to make people ask themselves why a mundane product of nature is so shocking, given that most women experience the menses and manage their menstrual flow for many years in their lifetime. These artists want people to consider why menstruation, a benign process essential to the production of human life, evokes fear, disgust, and comparison to toxic waste (Johnston & Chrisler, 2020: 182). Johnston and Chrisler (2020: 181) further argue that people have negative reactions to Tiegs, Paul and Carter's art mainly because menstrual blood is a stigmatised substance.

Like other types of stigma, menstrual stigma impacts women not just in one domain of their lives but it affects other areas of their lives - it has a significant impact on their emotional, mental, social and economic status (Olson, Alhelou, Kavattur, Rountree & Winkler, 2022: 2). Menstrual stigma has long-lasting implications, and it hinders meaningful discussions on menstruation. As a result, many people have misconceptions about the causes of menstruation because there is a lack of trustworthy, easily accessible information (Olson *et al*., 2022: 3). Because of this, people do not have an understanding of the menstrual cycle, biological processes, and meanings associated with menstruation, all of which are necessary for understanding socio-cultural practises and contexts (McCammon, Bansal, Hebert, Yan, Menendez & Gilliam, 2020: 297). It is this lack of knowledge that fuels the misconceptions that exclude and degrade women throughout their monthly cycles (Litman, 2018). For example, in Venezuela, many women are forced to sleep in huts for the duration of their menstruation, and in certain areas of rural Ghana, menstruating women are forbidden from entering a house with men or cooking food (Litman, 2018). Menstruation stigma also contributes to the reinforcement of misogynist stereotypes. As a result, during menstruation, women are often seen as being 'irrational', 'too emotional', 'hysterical', or 'less capable', and this affects their ability to participate in public life, including job prospects (Roberts, Goldenberg, Power & Pyszczynski, 2002: 132). For example, a social experiment found that women who dropped a tampon in front of others to indicate that they were menstruating were rated as less competent and liked than those who dropped an object that was seen as neutral, like a hairpin (Roberts *et al.*, 2002: 131). This study also found that menstrual-related teasing and bullying had a considerable negative impact on females' educational experiences and outcomes. Consequently, the daily social and physical activities of menstruators are severely limited by menstruation stigma (Roberts *et al.*, 2002: 132). The stigma surrounding menstruation also has an impact on health outcomes. For example, medical textbooks continue to be biased against menstruating bodies, and this may continue as healthcare professionals interact with menstruators (McCammon, Bansal, Hebert, Yan, Menendez & Gilliam, 2020).

In her study, Seear (2009: 1225) found that women with conditions associated with heavy and abnormal bleeding, such as fibroids and endometriosis, conceal their menstrual problems because they anticipate sanctions from employers, partners, family, and friends who do not view menstruation as an inherently normal and non-pathological process. These women feared that other people would trivialise their pain and criticise or ostracise them as a result. Furthermore, women's experiences and conversations with doctors and other people about their painful or abnormal periods violate menstrual etiquette – the act of concealing menstruation to avoid stigma (Myles, 2013: 27; Seear, 2009). This results in the stigmatisation of those who have endometriosis and fibroids, normalising the pain of menstruation and making it difficult to distinguish between normal and abnormal periods (Myles, 2013: 27; Seear, 2009).

2.3.2 Infertility stigma

Infertile women experience various forms of stigma – e.g. self and public, felt and enacted - and the stigmatised woman may feel ostracised, stereotyped, or labelled by others, which is known as felt stigma (Sternke & Abramson, 2015: 5). In response, an individual may self-stigmatise in response, which could lead to negative self-beliefs, a loss of self-esteem and self-efficacy, and a tendency to isolate oneself from others (Sternke & Abramson, 2015: 5). The actual status decline and particular instances of discrimination against a person are referred to as ‘enacted stigma’ (Sternke & Abramson, 2015: 6). Therefore, it is not surprising that studies have found that infertile women feel marginalised and judged as abnormal or deviant because of the continuous emphasis on biological motherhood in many cultures (Bornstein, Gipsona, Failing, Bandad & Norrise, 2020; Whiteford & Gonzalez, 1995: 27). Furthermore, in cultures where parenthood is highly valued, infertility may be viewed as a personal failure or a sign of weakness, which may negatively impact women's ability to seek medical attention or have discussions about their infertility (Bornstein *et al.*, 2020: 4). This may lead to feelings of shame and isolation. This also leads many women with severe cases of fibroids to refuse to have a life-saving hysterectomy, as the removal of the uterus signals the permanent inability to have children biologically (Becker, 1994: 391). A study found that some women view fibroids as a 'thief' of motherhood because they may, in some cases, cause infertility (Bejekal & Li, 2000). These women not only fear that their dreams of motherhood will be shattered, but they also fear the social and cultural stigma and exclusion that is associated with infertility (Becker, 1994: 387). A study in Malawi found that one of the socially damaging aspects of infertility was the exclusion from the normative transition into adulthood marked by parenthood (Bornstein *et al.*, 2020: 7). Infertility can also be stigmatised because it is frequently regarded as a personal issue that is rarely discussed in public (Sternke & Abramson, 2015: 7). People may feel alone as a result of this closed-off communication, which makes it challenging for them to ask for help and support and guidance from infertile women (Whiteford & Gonzalez, 1995: 30). Finally, stigma attached to infertility can have significant negative influence on women's relationships, support networks, and their mental and emotional health (Bornstein *et al.*, 2020: 7).

2.3.3 Silence on Reproductive Health Issues.

In addition to the stigma attached to some of the symptoms of fibroids, there is often silence around reproductive health issues in some cultures. From a social constructionism perspective, social and cultural norms surrounding reproductive health may influence some women's reluctance to openly discuss this topic (Tiwari, Wu, Citrin, Bhatta, Bogati, Halliday & Maru, 2022). How women express themselves is often shaped by gender roles and expectations, and discussing these intimate issues is sometimes influenced by cultural taboos or perceived social judgments (Kennedy, Bulu, Harries, Humphreys, Malverus & Gray, 2014; Metusela, Ussher, Perz, Hawkey, Morrow, Narchal, Etsoesta & Monteiro, 2017). Additionally, reproductive health discourse can also be influenced by historical background and societal conceptions of women's roles. For example, a study by Metusela *et al.* (2017: 840) that explored barriers to sexual and reproductive health found that some women were limited or forbidden to discuss cultural norms and values on reproductive health. Women are not allowed to discuss sexual-related issues until they get married, as such discussions were viewed as harmful to the cultural and religious beliefs of the community (Metusela *et al*., 2017: 840). Tiwari *et al*. (2022) also found that unsupportive family norms and lack of open communication, especially between mothers and their daughters, limited women's access to health care, especially young women. This lack of open communication about sexual and reproductive health was the reason why some women delayed seeking medical help for fibroids and other conditions as symptoms were normalised (Orellana, Riggan, DeSouza, Stewart, Venable, Balls-Berry & Allyse, 2022). This shows that the social and cultural setting of women living with fibroids is important because they not only influence how they perceive their illness but also influence their ability to seek medical diagnosis and treatment.

2.4 Women’s lived experience with fibroids

While they are non-cancerous, the impact of fibroids on the lives of women can be profound and multifaceted. This chapter delves into the lived experiences of women who have been diagnosed with fibroids, focusing on the various disruptions these growths cause in their lives. Through the lens of biographical disruption, this section seeks to uncover the intricate ways in which fibroids affect women physically, socially, financially, and mentally.

2.4.1 Biographical disruption

The concept of 'biographical disruption' refers to how the experience of chronic illness disrupts a person's social life and sense of self (Bury, 1982). Chronic illness disrupts the norms and forms of knowing that guide everyday life (Bury, 1982: 169). Furthermore, illness and chronic illness necessitate the acknowledgement of "the worlds of pain, suffering and possibly death", which are typically only imagined as remote possibilities or the misery of others (Bury, 1982: 169). Subsequently, the expectations and plans that people have for the future must also be re-examined. Charmaz (1983: 168) notes how people living with chronic illnesses typically witness the disintegration of their former self-images without the concurrent creation of equally valuable new ones. People no longer have access to the events and meanings on which they had previously based their positive self-images (Charmaz, 1983: 168). As a result, it may impact how individuals perceive themselves and believe others perceive them, frequently resulting in social isolation and a sense of being different from their peers (Green *et al*., 2007: 525). Mathieson and Stam (1995: 293) have aptly conceptualised this state of being as ‘disrupted feelings of fit’.

Although fibroids are not considered a chronic illness, the concept of *biographical disruption* can be applied as women suffering from fibroids experience a temporary disruption. Morden, Jinks & Ong (2017: 358-59) advocate for the extension of the concept of biographical disruption to include the disruptions that non-chronic illnesses create in people's lives. As the participants' fibroid narratives in the current study show, their lives were temporarily disrupted from the moment they started experiencing severe symptoms until the successful completion of their treatment or until they adopted coping mechanisms.

In the present study, women’s lived experiences of fibroids are framed within the concept of biographical disruption because it captures the profound and multifaceted impacts of this health condition on their lives. Biographical disruption allows for a deep exploration of the different ways in which fibroids alter and reconfigure the personal identities, life trajectories, and societal roles of sufferers (Engman, 2019). It provides a valuable lens through which to consider the major adjustments and changes that women have to deal with, such as disruptions to their daily routines, personal and professional goals, and relationships.

Moreover, biographical disruption is consistent with the Common-sense model of self-regulation (CSM) and social constructionism theoretical frameworks, which serve as the foundation for this study (see chapter 3). Social constructionism highlights the influence of cultural and societal factors on women's perceptions and accounts of their experiences with fibroids, whereas biographical disruption investigates the transformative effects of these interpretations (Houston & Houk, 2011; Olafsdottir, 2013). Social constructionism and biographical disruption both rely on illness narratives, which provide rich, qualitative insights into how women interpret their conditions in relation to society. CSM, on the other hand, emphasises how people's perceptions and beliefs about their condition influence their self-management and coping mechanisms (Diefenbach & Leventhal, 1996: 29). This is enhanced by biographical disruption, which draws attention to the larger lifestyle modifications and mental health adjustments necessary for managing a condition such as fibroids (Engman, 2021: 121).

Through the lens of biographical disruption, the study sheds light on the whole range of effects fibroids have on women's lives, taking into account their cultural backgrounds, coping strategies, and subjective experiences (Olafsdottir, 2013). This ensures a comprehensive understanding that goes beyond the clinical symptoms by addressing the often-taken-for-granted aspect of living with fibroids.

2.4.2 The physical disruption of women's lives

Women with symptomatic fibroids experience various forms of pain, which sometimes affects them physically. For example, in a study by Hunsche *et al.* (2022: 291), 87% of the participants reported experiencing intense fatigue in the first few days of menstruation. Some of those women said they could not get out of bed or stand up due to fatigue (Hunsche *et al.*, 2022). Other studies have also found that women with symptomatic fibroids struggle to carry out their domestic and professional duties during their menstrual cycles due to fatigue, severe cramping and heavy bleeding (Brito *et al.*, 2014: 3; Dykstra, Laily, Marsh, Kasting & DeMaria, 2023: 7; Fortin *et al.*, 2018: 34). For example, women with moderate to severe symptoms stated that they miss at least one day of work per month (Fortin *et al.*, 2018: 34). As a national survey by Stewart, Nicholson, Bradley and Borah (2013) found that 77% of African American women are likely to miss work due to the severity of their symptoms. This results in a 36% reduction in overall productivity. A study found that approximately 68% of women with fibroids felt self-conscious and embarrassed about the weight gain due to fibroids, and between 68% and 88% of women with fibroids feel self-conscious about the size and appearance of their stomachs (Fortin *et al.*, 2018: 34). Another study found that the women's negative self-evaluation of their bodies tend to have a negative impact on their romantic relationships and sexual intimacy (Sayer-Jones & Sherman, 2021: 469). This shows that the physical disruptions experienced by women with fibroids also disrupt nearly all aspects of their lives.

2.4.3 The social disruption of women's lives

In addition to the physical limitations that prevent women with fibroids from participating in certain physical activities and the stigma associated with fibroids, menstruation, and infertility, women's lives are also socially disrupted in various ways. Women with fibroids may feel ashamed or self-conscious about their condition and refrain from engaging in social activities or social situations (Hunsche *et al.* 2022: 293). This has led to some women planning their lives around their menstrual cycles (Begho & Waterman, 2023: 21). While some women noted that living with fibroids has strained relationships with their partners, family and friends (Fortin *et al.*, 2018). Other women said that how they felt about their symptoms and other people's lack of empathy and understanding occasionally caused conflict within the family and friendship (Begho & Waterman, 2023: 21; Seear, 2009: 1255). A study found that 46% of the participants said that fibroids impacted their ability to care for their families, and 47% believed that fibroids impacted their relationships with friends and families (Fortin *et al.*, 2018: 35).

2.4.4 Impact of fibroids on mental health

Many studies have focused on the physical impact of fibroids on women's health and lives, and few studies have considered the mental and emotional impact of fibroids (Ghant *et al*., 2015: 499). As discussed above, symptomatic fibroids can have a severe impact on women's daily lives, which may lower their quality of life (Fortin *et al*., 2018: 36). This means that women are also emotionally affected by these benign tumours, which may increase the anxiety about their general health, their ability to manage the symptoms, and ability to live meaningful lives (Ghant *et al*., 2015: 499). A study found that fibroids impact the mental health of women during the different phases of their illness experiences (Begho & Waterman, 2023: 22). The level of emotional distress advanced as women transitioned through various phases: pre-diagnosis, diagnosis, therapy, and recurrence (Begho & Waterman, 2023: 22). Women who have fibroids may experience frustration about the lack of control over their bodies and the effects they have on their lives. In one study, some women reported feeling a sense of helplessness when it came to controlling their fibroids (Ghant *et al*., 2015: 501). These women described feeling like they were 'out of control' as there was nothing they could do to manage their symptoms and enhance their quality of life (Ghant *et a*l., 2015: 501). Studies have also found that women with severe fibroids are more susceptible to depression due to chronic pain (Fortin *et al*., 2018: 36; Ghant *et al*., 2023: 501). Finally, the social (e.g. stigma), financial and physical disruptions experienced by women with fibroids have a negative impact on their mental health.

2.5 Conclusion

The chapter contextualised women's experiences of fibroids by reviewing existing literature on the topic. It highlighted the biomedical understanding of fibroids and identified that there is a gap in the literature in that there are no studies that explore how women, especially in Africa where the majority of the population does not have access to healthcare or health insurance, understand and seek a diagnosis from traditional healers or elders in their communities. The lack of literature on African women's experience of fibroids sidelines and privileges the experience of women who are biomedically diagnosed and treated. In addition to physical and emotional suffering, women with fibroids are also burdened with the stigma attached to menstruation and infertility. Finally, the chapter explored how the lived experiences of women with fibroids are marked by a disruption in their biographies, forcing them to acknowledge and continue to come to terms with 'the world of pain, suffering and possibility of death (Bury, 1982; Charmaz, 1983).

CHAPTER 3: THEORETICAL FRAMEWORKS

3.1 Introduction

This chapter outlines *social constructionism* and the *common-sense model of self-regulation* as they complement each other in understanding and explaining the livid experience of an illness, which extends beyond biomedical explanations. Using these theories is important as the study explores knowledge, experience, attitudes and perceptions, which are subjective phenomena.

3.2 Social constructionism

Social constructionism is a theoretical framework that challenges the positivist idea of an objective and external reality independent of human perception. Social constructionists assert that reality is both objective and subjective and that language, cultural practises, and shared meanings all contribute to the social construction of reality (Andrews, 2012: 40; Conrad & Barker, 2010: 67). From this perspective, knowledge, like reality, is considered a social product, as social constructionists argue that social interactions and institutions play a crucial role in shaping knowledge (Burr, 1995: 3). Institutions such as the media, education, and science are powerful forces in defining and reinforcing certain types of knowledge as valid while marginalising or excluding others. Furthermore, social constructionists view knowledge as being dependent on the historical and cultural setting in which it is created (Burr, 1995: 3). This, therefore, means that there is a multiplicity of interpretations and perspectives of knowledge and reality as we shift from one social context to the next.

3.2.1 Social constructionism and illness

One of the key findings of social constructionism is that all illnesses have biological, social, and cultural aspects (Barker, 2010: 148). In this regard, it suggests that our understanding of illness and disease is not solely based on medical knowledge but is also significantly influenced by our cultural beliefs, values, practices, and social context (Barker, 2020: 148). Social, cultural and historical factors significantly influence how people perceive, experience and respond to illness (Olafsdottir, 2013: 47). Different communities and cultures have different definitions of health and illness. Social constructionists emphasise that these cultural meanings not only shape how illness is perceived but also how sufferers react to their illnesses and how communities respond to them (Olafsdottir, 2013: 47). Although the social and cultural meanings of illnesses are often ignored or taken for granted, they may influence the illness experience of individuals, and have independent consequences on access to health care (Conrad & Barker, 2010: 69). For example, some illnesses are stigmatised whilst others are not, and some are contested whilst others are not (Conrad & Barker, 2010: 67). Furthermore, certain illnesses may be considered as a normal part of life in some cultures, but may be viewed as embarrassing conditions, which are stigmatised (Olafsdottir, 2013: 43). The more stigmatised or contested the illness is, the less likely that an individual will seek treatment for the condition, and the less likely they are to receive support from their families and communities.

Social constructionism is used as a theoretical framework because it allows the researcher to recognise that women's experiences of fibroids are subjective and influenced by broader forces, thus departing from the dominant biomedical perspective that prioritises the objective over the subjective (Conrad & Barker, 2010: 67). Social constructionism also encourages the inclusion of diverse perspectives and voices in research (Barker, 2020: 148). Thus, it is the appropriate theoretical framework because it allows the researcher to give voice to women's experiences and knowledge by understanding how their narratives, knowledge and perceptions differ across cultural and social contexts (Brown, 1995: 49).

One of the fundamental insights of social constructionism is that all illnesses have biological, social, and cultural meanings (Barker, 2010: 148). Moreover, cultural analysts note that illnesses may also have metaphoric undertones. For example, in her book titled Illness as a Metaphor (1978), Susan Sontag stated that negative metaphorical interpretations of cancer as evil and repressive are common, and they have negative impacts on the illness experiences of sufferers.

Medical sociologists who have examined the cultural meanings embedded in illnesses conclude that not all illnesses are the same (Barker, 2010: 148). For example, Conrad and Barker (2010: 67) note that some illnesses are stigmatised while others are not; some are disputed while others are not; and some are regarded as disabilities while others are not. These disparities are significant because they are based on societal factors rather than biological ones (Conrad & Barker, 2010: 67). The cultural meanings of illness influence the way an illness is experienced, how it is portrayed, how society reacts to it, and what policies are made concerning the illness (Brown, 1995: 49). Similarly, fibroids also have social and cultural meanings, which affect the women's experience of this condition. People with fibroids may experience multiple stigmas, some associated with the condition itself and others with its symptoms. For example, menstruation and infertility have a social and cultural stigma attached to them (Johnston-Robledo & Chrisler, 2020). An individual with fibroids might have to navigate these intersectional stigmas on a daily basis.

3.3 The common-sense model of self-regulation

The common-sense model of self-regulation (common-sense model) is a widely accepted theoretical framework developed by Howard Leventhal and colleagues to understand how people perceive, interpret and respond to their illnesses (Huston & Houk, 2011: 270). Leventhal *et al*. (2016: 935) argue that the common-sense model outlines a dynamic, multi-level process that generates an understanding of how people perceive health threats and the management procedures they adopt to deal with them. Furthermore, it provides a framework for understanding how individual symptoms and emotions experienced during a health threat or diagnosis influence the perception of illness and guide subsequent coping mechanisms (Breland, Wong & McAndrew, 2020: 2). Unlike other models of illness and health, the common-sense model conceptualises the individual as a problem solver grappling with two phenomena: the perceived reality of a health threat and the emotional responses to that threat (Diefenbach & Leventhal, 1996: 20). The model is based on three key premises: first, the person is an active problem-solver who actively seeks information and takes action to test hypotheses about the meaning of their symptoms, physical state, and the relevance of these meanings to media and interpersonal messages about health risks. Second, the illness representation is the primary cognitive construct that directs coping mechanisms and the evaluation of action outcomes. Third, representations vary greatly from person to person and might not correspond to medical facts (Diefenbach & Leventhal, 1996: 20).

3.3.1 Illness representations

Central to the common-sense model is the idea of illness representations or 'lay' beliefs about illness, which are integrated into the existing normative beliefs about illnesses, allowing the individual to interpret their symptoms and guide any coping mechanisms they may employ (Hale, Treharne, & Kitas, 2007: 904). These illness representations have concrete and abstract aspects. The concrete aspect of the illness representations refers to the physical experience of the health threat, such as fatigue or numbness (McAndrew, Martin, Friedlander, Shaffer, Breland, Slotkin & Leventhal, 2018: 500). The abstract aspect, on the other hand, refers to the cognitive ideas or perceptions that describe the health threat (McAndrew *et al.*, 2018: 500). The abstract aspect of illness representations are shaped by an individual’s lived experiences of the health threat, their cultural background, and the information they gathered about the health threat from the media, social networks, and healthcare professionals (Hale *et al.*, 2007: 905).

The common-sense model has five key components of illness representations: identity, cause, timeline, consequences and curability or controllability (Hale *et al.*, 2007: 904). The identity component includes the name or label given to the condition and the symptoms accompanying it. According to Hale *et al.* (2007: 904), most people like to have labels for their symptoms for legitimisation purposes. However, people are likely to interpret diverse symptoms as evidence of the label once applied. This component takes into account the influence of culture, past experiences, information from the media and healthcare professionals, and the opinions of significant others on how individuals interpret, react, and label their symptoms. The cause component speaks to the individualistic ideas about the perceived cause of the illness, which may not be completely biomedically accurate (Diefenbach & Leventhal, 1996: 22). The timeline connects the stimulus to an expected timeframe, and it answers questions whether the stimulus is acute, chronic, or cyclic (Diefenbach & Leventhal, 1996: 20). The consequences component speaks to the individual's beliefs about the consequences of the condition and how this will have an impact on them physically and socially (Huston & Houk, 2011: 273). Finally, curability or controllability highlights the beliefs about whether the condition can be cured or kept under control and the degree to which the individual plays a part in achieving this (Diefenbach & Leventhal: 1996: 21).

3.4 Social Constructionism and the common-sense Model

Social constructionism and the common-sense model are used as theoretical frameworks because they allow for a comprehensive exploration of the different factors that shape women's experiences, perceptions, attitudes and knowledge of fibroids, thus contributing to a nuanced understanding of the research topic. Both theories position the individual as a knower and a problem solver. For example, a study on the illness experience of women with fibroids applied the common-sense model and found that women are agents of knowledge, but often, this knowledge is taken for granted by healthcare providers (Nicholls, Glover & Pistrang, 2004: 299). The common-sense model was used to prioritise women's knowledge of fibroids and their impact on their bodies (Nicholls *et al.*, 2004). The current study used the common-sense model and social constructionism to privilege women's knowledge and experiences above biomedical explanations and treatment. This is consistent with the interpretivist epistemology, which is concerned with in-depth variables and factors that are context-specific (Alharahsheh & Pius, 2020: 41). An interpretivist epistemology considers the fact that humans are different from physical phenomena because they create meaning, and it operates on the assumption that human beings cannot be explored in a similar way to physical phenomena (Alharahsheh & Pius, 2020: 41). Knowledge from an interpretive perspective is, therefore, interpretive and subjective. The interpretive approach caters to the different experiences that women from different cultures have because the qualitative researcher using this approach is interested in factors, conditions, and people's personal views and opinions instead of approaching the research as if only one form of experience and knowing exists (Sarantakos, 2012: 40).

3.5 Conclusion

The chapter set out to discuss the theoretical framing of the study. Social constructionism and the common-sense model are appropriate theoretical frameworks because they are complementary in that they offer a multi-level analysis and understanding of an individual's illness experience. Social constructionism allows for an exploration of how women construct their illness experiences from their interactions with medical professionals and social actors in their communities. The common-sense model is concerned with illness representations or lay beliefs about illnesses, and it conceptualises the individual as a knower and a problem solver. This is important for this study because to understand the participants' illness experiences, there is a need to acknowledge that there are multiple ways of knowing. Therefore, applying social constructionism and the common-sense model of self-regulation offers a comprehensive framework for exploring women's experiences with fibroids. This integration considers the impact that society has on knowledge and processes of self-regulation in the management of fibroids.

CHAPTER 4: RESEARCH METHODS

4.1 Introduction

This chapter outlines the research methods and processes that were followed in the data collection and analysis of this study. The first section of the chapter discusses qualitative research and its connections to social constructionism and the common-sense model of self-regulation. This is followed by a discussion on data collection and analysis and, finally, ethical considerations.

4.2 Research approach

This research follows a qualitative research approach whose goal is to gain an understanding of the social phenomenon in its natural environment (Denzin & Lincoln, 2017: 50). It relies on the first-hand experiences of people as the meaning-making agents in their daily lives and emphasises the ‘why’ rather than the ‘what’ of social phenomena (Denzin & Lincoln, 2017: 50). Qualitative research involves an interpretive and naturalistic approach to the research subject (Aspers & Corte, 2019: 142). This means that qualitative researchers seek to understand social reality by interpreting the meanings that research participants attach to the phenomenon under study (Aspers & Corte, 2019: 145).

The main aim of this study was to explore women's knowledge, experiences, attitudes, and perceptions of fibroids. This is why the qualitative approach was appropriate in this study, as it allowed the researcher to understand the personal views of the research participants and enabled an appreciation of participants' subjective knowledge. The qualitative approach is ideal in studies like the current study, which privileges participants' voices. It is also consistent with the theoretical framework (social constructionism and the common-sense model of self-regulation) underpinning this research. Qualitative research principles align with the emphasis that social constructionism and the common-sense model of self-regulation place on subjective experiences, contextual knowledge, and the importance of in-depth exploration. Qualitative research methods allow for the flexibility and depth needed to explore the nuanced aspects of illness highlighted by social constructionism and the intricacies of people's self-regulation processes of health threats (e.g. fibroids).

4.3 Data collection

4.3.1 Study setting

The study was undertaken in Diepsloot, a township in the northern periphery of Johannesburg, South Africa. Diepsloot has an estimated population of half a million people, with the majority (97%) being black, hailing from different parts of the country, as well as other countries in Southern Africa, representing a diversity of ethnic backgrounds (Cahill, 2019; Maronga-Feshete, 2022; 21). Diepsloot was selected as the research site due to its convenient accessibility, being just twenty minutes away from the researcher’s current place of residence. Furthermore, the researcher has intimate familiarity with the cultural and linguistic dynamics of the area, stemming from over 15 years of residency in the area. This intimate familiarity and understanding of the research site was crucial for both data collection and analysis.

4.3.2 Sampling

Purposive and snowballing sampling were used to recruit women above the age of 18 years who have or have had fibroids and those who have culturally dealt with fibroids (cultural practitioners). The latter were recruited because they had knowledge and experiences of fibroids either as women living with fibroids or as traditional practitioners who diagnose and treat fibroids. Finding the women started with the researcher purposively identifying and recruiting three women who met the study criteria. The women are known by the researcher and had previously shared their experiences with fibroids with the researcher. Snowball sampling was then used to recruit the remaining participants. Purposive and snowballing sampling methods were suitable for this study because fibroids are a sensitive topic and a hidden condition that requires an insider's knowledge to locate participants who are not readily identifiable or associated with fibroids research or clinics and organisations (Biernacki & Waldorf, 1981: 141).

One of the major disadvantages of snowball sampling is that it can result in a homogenous sample because individuals tend to identify with others with similar experiences and characteristics, which might result in repetitive findings that do not provide new or significant insights (Parker, Scott, & Geddesl., 2019: 4). To remedy this challenge and to ensure diversity in the sample, the initial three participants were deliberately selected from different cultural backgrounds and different age groups. One of these participants was a cultural practitioner specialising in treating women with fibroids. The researcher is grateful for her service as she helped recruit participants who had previously consulted her. Having a diverse group of participants to initiate snowball sampling from ensured an ideal study sample. A diverse sample was important for this study because people from different ages and cultural backgrounds meant that participants' experiences were shaped by different values, norms, beliefs, and societal and cultural expectations.

The sample size was eight, which was justifiable as the study sought to gain an in-depth understanding of women's knowledge, attitudes, perceptions, and experiences of fibroids. Thus, a larger sample size may have resulted in a loss of participants' nuanced perspectives, which may have resulted in the oversimplification of the findings (Faber & Fonseca, 2014).

Conversely, a smaller sample size may have been inadequate to capture the diversity within the population, and it would have been challenging to identify meaningful patterns in the data.

4.3.3 In-depth semi-structured interviews

While focus groups, surveys and questionnaires might have been useful data collection tools, in-depth semi-structured interviews offer unique advantages in exploring sensitive and complex topics like women's experiences with fibroids. Semi-structured interviews are adaptable to accommodate different participants, and the questions can be tailored based on their responses, allowing the researcher to probe for more details and explore unexpected avenues of enquiry (Ritchie & Lewis, 2003: 79). This flexibility allowed the researcher to capture the different experiences and perspectives represented in the sample (Bryman, 2012: 716). In-depth interviews allow participants to express their experiences and perspectives in their own words, providing the researcher with rich and detailed data (Ritchie & Lewis, 2003: 79). Some of the disadvantages of in-depth interviews are that they are time-consuming and the sample size tends to be smaller (Rahman, 2017). However, in-depth interviews were the most suitable data collection method because this allowed participants to provide detailed responses about their knowledge, perceptions, and experiences on fibroids. They provided information that might have been difficult to gather through open-ended survey questions or group discussions (Smithson, 2000: 105). Furthermore, surveys and focus groups tend to treat participants as a collective, which can make it challenging to fully capture each person's unique perspective (Smithson, 2000: 105). In-depth interviews, on the other hand, allowed the researcher to explore each participant's experiences and attitudes extensively, ultimately resulting in a more detailed and comprehensive understanding of their fibroid experiences (Ritchie & Lewis, 2003: 79).

By delving deep into the insights and viewpoints of each participant, the researcher gained a more nuanced understanding that goes beyond surface-level conclusions obtained from aggregated data from surveys and focus groups (Sim & Waterfield, 2019). The sensitive nature of fibroids can make some women feel vulnerable and emotional. In-depth interviews provided a secure and confidential space where participants could openly express their thoughts and feelings (Mahat-Shamir, Niemeyer & Pitcho-Prelorentzos 2021: 85). The one-on-one interviews allowed for a more natural degree of comfort and trust than in group settings or standardised surveys, making the interview process a comfortable and safe space for empathy and understating thus creating a meaningful and supportive research experience (Mahat-Shamir *et al.*, 2021: 85). Moreover, the in-depth interview process empowered both the researcher and participants because it gave them the confidence to freely express their opinions and actively participate in the research project (Sim & Waterfield, 2019). In turn, this built rapport between the participants and the researcher, which was marked by increased involvement and cooperation, ultimately resulting in a more rewarding research experience (Ritchie & Lewis, 2003: 78).

The interviews ranged from thirty minutes to an hour and were conducted in the language that the participants were most comfortable with. The researcher knows all the languages (English, Tshivenda, XiTsonga, Sepedi, and SeSotho) that participants spoke and, therefore, did not use translators. Using participants' language of choice allowed them to express themselves freely and in greater detail. Furthermore, the researcher gained insights into context-specific meanings and cultural references that might have otherwise been difficult to express in, for example, English. All the interviews were recorded, translated into English, and transcribed.

4.4 Data analysis

Data was analysed using thematic analysis, which involved searching for recurring ideas or themes in a data set (Riger & Sigurvinsdottir, 2016: 33). The identification of themes from the data allowed the researcher to uncover rich and nuanced insights, leading to a comprehensive understanding of the topic and presentation of findings (Riger & Sigurvinsdottir, 2016: 35). The identification of themes was done by way of coding, which involved designating sections of text as belonging to particular categories in a way that enabled later retrieval and analysis of the data (Joffe & Yardley, 2003: 58). The first step of thematic analysis involved data familiarisation. Here, the researcher immersed herself in the data by reading and re-reading the transcripts (Vaismoradi, Jones, Turunen & Snelgrove, 2016: 103). This step helped the researcher to become familiar with the content and gain an initial understanding of the main issue of the phenomenon under study (Terry, Hayfield, Clarke & Braun, 2017: 23). This understanding prepared them to focus on the most important constructs identified and presented in data (Vaismoradi *et al.*, 2016: 103). After this, the researcher started the coding process, where she identified meaningful data units and assigned them descriptive labels or codes (Terry *et al.*, 2017: 23). The codes represented different data set elements and captured the essence of the content. Thereafter, the researcher searched for recurring concepts, ideas, or topics to establish connections and patterns across the data set (Castleberry & Nolen, 2018: 808).

The common-sense model of self-regulation, one of the theoretical frameworks underpinning the study, also helped in the generation of themes during the interview and analysis processes. For example, the five illness representations outlined in the model allowed the researcher to explore and understand how women identified their symptoms, the labels they attached to them, and their beliefs about the aetiology of fibroids.

4.5 Ethical considerations

Research ethics addresses issues related to the moral problems of research (Mirza, Bellalem, & Mirza, 2023: 442). It is an inquiry into the 'rights' and 'wrongs' of research as well as the conduct that researchers should follow (Bos (2020) cited in Mirza *et al*., 2023: 442). In line with good research conduct, the present study received ethical approval from the Rhodes University Human Ethics Committee (ref. 2023-7370-7940) before fieldwork could commence. Thereafter, the study adhered to all the guidelines set by the committee.

In line with the ethical guidelines of the ethics committee, the first step, once fieldwork commenced, was to recruit participants and gain their voluntary and informed consent. The purpose of the research, the nature of participation and the risks and benefits of participation were explained to all potential participants. This information allowed potential participants to make informed decisions about whether or not they wished to participate in the study. The participants who expressed their interest in participating in the study were given informed consent forms detailing all the information about the research to sign. The researcher verbally translated the consent form to participants who do not speak or read English in their mother tongue. Furthermore, it was explained to the participants during the recruitment stages and the day of interviews that participation was voluntary and that they could withdraw at any stage in the research should they wish to.

Ensuring that participants are not harmed as a result of their participation in research was an ethical consideration that was not taken lightly throughout all the stages of the current study, especially considering the sensitive nature of fibroids. As already mentioned, the potential risks of participating in the study were made known to the participants before granting their consent to participate in the study. The participants were made aware that participating in the study might trigger emotional responses as they have to revisit some of their experiences (the emotional, social, financial, and physical aspects of fibroids). The interviewer made it a point to let all the participants know of free counselling services available in Diepsloot should they need professional help. None of the participants wished to use counselling services after the interviews. Furthermore, the researcher ensured that the list of interview questions was age and culture-sensitive. This is because it is considered disrespectful for a younger person to ask certain questions to their seniors in some cultures. The researcher also ensured that the interview questions were not repetitive, or accusatory, and did not perpetuate stereotypes. The researcher's supervisor reviewed the interview questions before participants were interviewed to ensure that they adhered to the ethical guidelines.

Lastly, confidentiality and anonymity guidelines were strictly adhered to throughout the research process. The researcher avoided asking questions or information that could be easily linked to the participants. The interview data was kept in a safe storage cloud to which no one but the researcher and supervisor had access.

4.6 Conclusion

This chapter aimed to outline and justify the research methods used in the study. It highlighted that the qualitative research approach is suitable for this study because it allows for exploring subjective knowledge and experience, which is consistent with social constructionism and the common-sense model of self-regulation. It further outlined the different methods used to collect and analyse the data and briefly discussed ethical considerations underpinning the study.

CHAPTER 5: DATA ANALYSIS

5.1 Introduction

This chapter explores the complex nature of women's experiences, knowledge, attitudes, and perceptions of fibroids. The analysis is centred around four main themes: the symptom experience, the decision-making process, knowledge and awareness of fibroids, and cultural influences. The first theme; the symptom experience, explores the different symptoms that women experienced and the social, financial and emotional impacts of those symptoms. The second theme, the decision-making process, sheds light on the factors that influenced participants' choices about their diagnosis and treatment. The third theme, knowledge and awareness, explores women's knowledge and assesses their level of awareness regarding fibroids. The last theme, cultural influences, explores the cultural factors that shaped women's experiences of fibroids. These four themes correspond with the study's four secondary objectives, and their collective synthesis contributes significantly to addressing and achieving the main objective.

5.2 A distinction between two groups of participants

5.2.1 Biomedical and cultural diagnosis of illness

Two groups of participants are represented in the data sample: those who consulted a biomedical practitioner and those who consulted a cultural practitioner. It is important to make this distinction because biomedical and cultural beliefs about health and illness are not always the same. Cultural practitioners, such as traditional healers or individuals within specific cultural or indigenous practices, may have their methods of diagnosing health conditions, including what they might refer to as ‘fibroids.’ However, it is important to recognise that these cultural diagnoses are not the same as medical diagnoses provided by biomedical practitioners. While a biomedical healthcare professional will base their diagnosis and treatment plan on the patient's disease history, a cultural practitioner hardly ever requests this kind of background information (Sodi, 2009: 63). Rather, the latter makes a diagnosis and develops a treatment plan through their ancestral spiritual connections, throwing of bones, interpretation of dreams, etc. (Louw & Duvenhage, 2016: 460). The health care provided by most cultural practitioners is holistic and easily accessible. However, it does not always rely on accurate diagnosis, and unlike biomedicine, the cultural/traditional healing practice is not regulated, and the medical knowledge is not easily accessible (Louw & Duvenhage, 2016: 460; White 2015: 6). Therefore, diagnosis and treatment options offered by cultural practitioners may also not be the same, depending on factors such as the nature of the healer’s training, their beliefs about health and illness, and their preferred methods of diagnosis. This is consistent with one of the key tenets of social constructionism about illnesses, that our understanding and experience of illness is not solely based on medical knowledge but also on our cultural beliefs, values and practices (Barker, 2020: 148).

Highlighting the distinction between biomedically and culturally diagnosed participants is important in this study because it creates room to appreciate the nuances between the two approaches. It also provides context for participants’ narratives and perspectives.

To make it easy to distinguish the two groups of participants, tags such as 'biomedical, ' cultural, ' 'self-help, ' and 'cultural practitioner' are inserted at the end of each participant's account. Biomedical' refers to participants who consulted a biomedical practitioner, and 'cultural' refers to participants who consulted a cultural practitioner. 'Self-help' refers to participants who employed coping strategies independently without consulting a healthcare practitioner, and lastly ', cultural practitioner' refers to participants who are cultural practitioners.

5.2.2 A brief description of the participants

A total of eight participants were interviewed: six women living with fibroids and two cultural practitioners (one identifying as a trained traditional healer and another identifying as 'just' an expert in certain cultural illnesses and healing practices). Three participants had consulted cultural practitioners, one had only consulted a biomedical practitioner, and the other two had consulted a biomedical practitioner and used alternative therapies for treatment.

To maintain anonymity and confidentiality, participants will be referred to as Participant One, Participant Two, etc. The referencing of the participants follows the order in which they were interviewed, and the table below is a graphic representation of the participants.

Participant	Consulted cultural practitioner	Consulted biomedical practitioner	Used alternative therapy	Cultural practitioner
One		X		
Two	X			
Three				X
Four				X
Five	X			
Six		X	X	
Seven	X			
Eight	X	X	X	

5.3 The symptom experience

The symptom experience refers to the collection of symptoms that a sufferer experiences when dealing with a medical condition or illness (Erikson & Risor, 2014). For some women, the fibroid symptom experience also includes grappling with self-diagnosis as they try to understand their health and well-being. Furthermore, fibroid sufferers are burdened with the physical, emotional, mental, social, and financial consequences of their symptoms. Thus, making the symptom experience more than just the physical aspect of a condition or illness.

5.3.1 Physical symptoms

As already highlighted in the literature review, up to seventy percent of fibroids are asymptomatic and may remain undiagnosed and may need little to no medical intervention (Giuliani *et al*., 2020: 4). However, the lives of the thirty percent of women with symptomatic fibroids are characterised by various forms of pain, suffering, questioning, the making of life-changing decisions, acceptance, and non-acceptance of their condition. In severe cases, the symptoms disrupt the lives of women not just physically but emotionally, socially, and financially. Some women are fortunate enough only to start experiencing symptoms after a professional diagnosis. Therefore, the symptoms and their severity do not come to them as a surprise, and they do not have the mental pressure of trying to figure out what could be causing the symptoms. This was the case with Participant Six, who was not aware of her fibroids because she had never experienced any symptoms before the diagnosis:

> I didn't know anything about it. I only found out from the results that there was something growing. So, I got the diagnosis before experiencing any symptoms. So, by the time I started experiencing the symptoms I knew it was because of the fibroids that were growing inside of me. (Participant Six, biomedical consultation; self-help).

In contrast, other women endure painful symptoms without knowing their source, as was the case with Participant Eight. She initially attributed sharp pains near her rib cage and left arm to the heavy lifting she did at work. However, as the pain intensified, she and her family realized there was a more serious underlying issue. Participant Eight recounted:

> My family said to me as the pains progressed that I should go to the clinic and get checked for all sorts of illnesses. So, I went to the clinic with my sister. I got tested for Covid-19, HIV and AIDS, and they took a pregnancy test. The results came back and I did not have Covid-19, or HIV and I wasn't pregnant. It was then that my mother said that I should also get a pap smear. (Participant Eight, biomedical & cultural consultation; self-help).

The common-sense model of self-regulation proposes that people go through a series of emotional and cognitive processes to interpret their symptoms and choose the best course of action (Diefenbach & Leventhal, 1996: 23). Initially, participant Eight interpreted her symptoms as physical exhaustion from work, believing that rest would alleviate her pain. However, when the symptoms persisted, she and her family entered a state of panic, struggling to accurately interpret her symptoms... The difficulty of Participant Eight and her family in identifying and labelling the source of her pain underscores the challenges faced by those attempting to navigate uncertain and distressing health experiences.

Fibroid symptoms can be acute or chronic, incapacitating one day and bearable the next (Myles, 2012: 68). When fibroids become symptomatic, they can present with a range of symptoms, which often include irregular and heavy bleeding, intense pain, and unusually long periods (Zimmermann *et al*., 2012: 2). These are the most documented symptoms in the literature. However, as the fibroids grow in size, they can lead to various symptoms which include dyspareunia, which refers to the experience of pain during sexual intercourse, pelvic pain, constipation, abdominal swelling (also known as bloating), low back pain, bowel dysfunction, and urinary retention (Aubuchon *et al*., 2002; Buttram & Reiter 1981; Stewart 2001; Zimmerman *et al*., 2012). This is illustrated in the following detailed symptom narratives of the participants:

> I've had period problems from when I was like nine, I think I had my first period when I was around nine years old. I was very young when I started my period. So, basically, with that, it became hectic from there. So, I've had long periods. So, uh, chronic pain with period pains and having to take very heavy painkiller medication and stuff like that. And progressed, as I grew up into my teenage years. I think the peak of it was when I got to high school… that's when it became a little bit more like progressive in terms of like it growing and becoming worse and everything. I remember, I think I was in grade nine, when I had my first long period, because I went through my period for like, "I think it was like 17 days. And it stopped for two days. And then I went on my period again for like another week or so, like almost a full month. Yeah, almost a full month I went on my period. It was the longest period I've ever had, like bleeding one way. So that kind of contributed to the excessive losing blood because obviously, periods is blood. (Participant One, biomedical consultation).

Participant Eight's pain in her left arm and ribcage were linked to fibroids after a pap smear and a diagnosis of fibroids. In addition to the pain, she had lost a lot of weight, and she also explained that the problem was related to whatever was growing in her uterus (fibroids). She also spoke about how she experienced intense pain during sexual intercourse to the point that the activity was no longer enjoyable for her:

> It felt as if my uterus was hanging low. …experiencing pain in the uterus. The pain affected my ability to walk, I had to lean on something in order to walk. (Participant Eight, biomedical & cultural consultation; self-help).

Participant Six had the following to say about her fibroid symptoms:

> It wasn't showing before then but as time went by they started growing and my stomach also started growing big. It was very hard. Sometimes you'd sleep with a big tummy but wake up okay. So, I guess that's what disturbed me the most because I looked pregnant even though I wasn't pregnant. And I also couldn't eat certain foods. I could always feel that something wasn't alright with me. I had gained weight and was constantly tired. (Participant Six, biomedical & self-help).

The physical symptoms experienced by Participants One, Six and Eight are similar to those reported by the majority of women in the reviewed literature. Studies have shown that women with severe cases are physically burdened by their fibroids (e.g. heavy bleeding, severe cramping and fatigue) to the extent that they are unable to carry out day-to-day mundane tasks because of the heavy bleeding (Brito *et al*., 2014: 3; Dykstra *et al*., 2023: 7; Fortin *et al*., 2018: 34). As a study by Sayer-Jones and Sherman (2021: 469) found that some women were self-conscious about their bodies as a result of the negative self-evaluations of their bodies from the weight gain which also negatively affected their romantic relationships. Participants in this study explained that they had the support of their partners, which is what made their experiences a little less daunting (Sayer-Jones & Sherman, 2021). This shows that having the support and understanding of your partner and loved ones is important in shaping the illness experiences of women. However, Participant Eight explained that her partner was very understanding, but she did not tell him that she "…experienced pain during sex and no longer enjoyed it". She reasoned that she still had a duty to him even though she experienced pain during sexual intercourse. She was putting the needs of her partner before her pain, which shows how the physical burden of fibroids can, in some cases, add to women's suffering. Some women have no choice but to put the needs of their families above their pain, go to work because they cannot afford not to or simply exist in communities where women are supposed to be strong and show up to their roles and give their 100 per cent without fail.

The three participants who consulted cultural practitioners reported having different symptom experiences. For example, Participant Two had not experienced any symptoms, the only indicator she had was after the birth of her child. As she explained:

> I did not experience any symptoms. I only found out after giving birth to my first child. I was alerted by the elders around me that there was something wrong with the child.

> They discovered that she had a red mark at the back of her head and told me that I had what you call fibroids. So, that's how I found out. (Participant Two, cultural consultation).

Participants Five and Seven also had a similar experience of their children being born with a red mark at the back of the head and this was an indication that something was wrong with both the mother and child. Unlike Participant Two, they had an itchy rash around the vaginal area, which was a signal to the attending traditional midwives that the participants had growths (the meaning of these growths will be explored in section 4.5.1.2). When asked if there were other symptoms besides the red mark and the baby's behaviour (constant crying), such as heavy bleeding or cramping, one participant had this to say:

> There isn't. With period pains, there is a different way of treating them. Some people go on their period for seven days, that's not normal. It's not normal for a person to menstruate for seven days, three to four days is normal. You can go to a healer and they'll give you traditional herbs to reduce your period days. It's a disease if you have your period for over four days and it can get cured. (Participant Five, cultural consultation).

Participant Three, a cultural practitioner, shared Participant Five's beliefs. She explained how the women who seek help from her do not complain about heavy and abnormal bleeding because "that is something that can be cured." She also believes that a longer menstrual cycle is an indication of a different disease.

5.3.2 Impact on everyday life

The previous section detailed some of the ways that the symptoms of fibroids burden women physically, but as mentioned in the literature review and earlier parts of this chapter, the symptoms also burden women emotionally, socially, and financially.

5.3.2.1 Social impact

Aside from the physical impact that fibroids have on women, these benign tumours can also create social disruptions. Participants who reported a shift in their social lives mainly spoke about feeling abnormal, the frustrations of having to explain their symptoms and condition, the limitations that the symptoms placed on their bodies, and the negative feelings they had toward their bodies as a result.

Participant One described her experience as being 'weird' and did not feel like she was normal:

> Socially, I'll say maybe when I was in school, when I started my period, not everyone had started their period. So, it was more like abnormal, so you become the like, the centre of attention. Like “you have a period, how does that feel?”. And everyone else started a period when they were like in grades What? Maybe grade seven? Grade Eight, maybe, you know, when they were like 14,15. And I started when I was nine. All these people are only starting to discover their bodies. And I'm sitting there like,. “You guys only getting here now?”… It was a little bit weird. Because then I didn't realise that I wasn't normal, until I realised that other people only started at that age. Like, I have a cousin who only started her period when she was 18. And I was like, "Wait, so you're only starting in this field now?". I've been suffering for years. So, it's socially it's not something you realise until you actually realise that listen, wait, so I'm actually going through this and people haven't even got there yet. So why is my body in a rush? Like, why is it doing all these things. (Participant One, biomedical consultation).

Participant One's experience is similar to studies that found that women with benign gynaecological conditions often share a concern about feeling abnormal because of the negative stereotypes associated with their symptoms and “the perceived transgression of womanhood” (Sayer-Jones & Sherman, 2021: 468). This is especially true when women compare themselves to friends and relatives who are not afflicted by benign gynaecological conditions (Sayer-Jones & Sherman, 2021: 468).

For Participant Six, the social impact was felt mostly because of the attention that her symptomatic body attracted, especially the curiousness of others, which she found frustrating:

> The thing is, everywhere you went people asked, "how far along are you?" and you have to explain. I hated having to answer such questions and I can't always explain that no, I'm not pregnant it's fibroids (Participant Six, biomedical consultation & self-help).

Similarly, other studies have also found that women experienced negative emotions about appearing pregnant and overweight (Ghant *et al*., 2015; Hunsche *et al*., 2022; Sayer-Jones & Sherman, 2021). These negative emotions are usually coupled with shame and embarrassment associated with their symptomatic bodies, which sometimes pressurise women to conceal themselves physically (Sayer-Jones & Sherman, 2023: 547). For example, those who experience abdominal bloating often resort to wearing loose clothes to conceal their changed bodies (Sayer-Jones & Sherman, 2021; Sayer-Jones & Sherman, 2023). This was the case for one participant, who said:

> …when you go out nothing sits well on you. So, it affected me a lot, my self-confidence…I’d wear bigger clothes so that I hide this thing. (Participant Six, biomedical consultation & self-help).

Participant Six's experience highlights a strong connection between one's sense of self and one's physical appearance, in particular, changes in appearance due to an illness can have profound emotional and psychological impacts. However, contrary to Participant Six's experience, four participants were not socially burdened by their condition because they acted fast and avoided severe symptoms such as a bloated abdomen.

These narratives highlight the importance of considering the social disruptions that ill health causes, not only in research but also in the care of the afflicted. It is insufficient to treat only the physical symptoms while neglecting the impact that these social disruptions may have on the recovery process. A truly effective treatment plan must address the full spectrum of challenges faced by women with fibroids.

5.3.2.2 Financial impact

The financial burden of fibroids can be substantial and may vary from person to person depending on variables such as the severity of symptoms, the treatment of choice, and the accessibility of health insurance. Contrary to what other studies found, the majority of the participants in the current study stated that they were not as financially burdened by the fibroids treatment/therapy (Al-Hendy *et al*., 2017; Fortin *et al*., 2018; Giuliani *et al*., 2020; Khan *et al*., 2014). Participants cited various reasons why fibroids were not expensive to treat, which included having medical insurance, treating symptoms before they became too severe, and 'spacing out doctor's appointments' that could be planned. For example, a participant said:

> I wouldn't say it was that much of a burden because it wasn't something that was constant. It was something that happened over the years. It didn't necessarily progress over time that I would say, every single day I was in the hospital or every other month I was in the hospital. So, it didn't really bother me so much financially because I guess it was spaced out enough to know that I can set an appointment… Although gynaes are expensive and stuff like that, but it's not necessarily something that was so ... Yeah, it was spaced out so it was easier to plan. (Participant One, biomedical consultation).

For Participant Five, having medical insurance saved her from the financial burden of paying huge hospital costs:

> I fortunately had a medical aid so I wasn't financially burdened. But the bill for a three-day stay at the hospital was R 45 000. So, imagine if I didn't have medical aid. Where was I going to get the R 45 000? (Participant Six, biomedical & self-help).

However, millions of South Africans are not as fortunate as Participant Six. Although some participants in the study reported not being heavily burdened financially, it is important to highlight that this is not always the case for the majority of South Africans who do not have medical insurance and who live in poverty. Statistics show that 82 out of every 100 people, or approximately 45 million South Africans, do not have medical insurance (Mhlanga & Garidzirai, 2020: 2). This means that most women with fibroids rely on complimentary/alternative therapy, traditional treatment or the public healthcare system. Two participants in this study went to public healthcare facilities for their diagnosis and treatment.

Participant One spoke about the good and efficient service that she received from a public hospital in Johannesburg. Participant Eight, on the other hand, went to a public clinic in a rural area in Limpopo province that lacked resources, and she was referred to a nearby hospital within the province. She was booked for an appointment at the hospital, but it took almost a year for her to be seen. As she recounted:

> I had already lost hope because they took a while to call. I thought they were not going to call. I even had to quit my job because I was always sick (Participant Eight, biomedical & cultural consultation; self-help).

It is clear from the experiences of these two participants that the inequality between rural and urban healthcare services significantly influenced their treatment options. After the negative and unsuccessful treatment at the hospital, Participant Eight turned to a cultural practitioner, and when this also failed, she resorted to self-help. She shared:

> I wouldn't say that it burdened me that much financially because I found it in the early stages, it hadn't gotten that severe... I also made a few trips to the hospital, so I can't say I spent a lot on transport. Especially compared to some who have been going to the hospital back and forth for months (Participant Eight, biomedical & cultural consultation; self-help).

At the time of the interview, Participant Eight was still undergoing treatment, and she did not expect further financial costs because she explained that the current treatment was effective in alleviating her symptoms.

On the issue of healthcare costs, Participant Four, a cultural practitioner, believes that getting a diagnosis and treatment need not be financially burdensome whether a woman/individual consults a biomedical or cultural practitioner. She had the following to say on the matter:

> I don’t think it could be that costly because we have government hospitals that have doctors and traditional healers. I don’t think there is a traditional healer that would charge someone thousands of rands for treatment because when you’re treating someone, you're supposed to tell them that they should only pay a little just to thank the

> ancestors for the medication. Even if someone is unwell and they don't have money, I know that as traditional healers, we're supposed to help them. It's only when they are well that they should come back and say thank you with whatever little they can afford (Participant Four, cultural practitioner).

Unfortunately, even when public healthcare services and cultural practitioners costs are low, some women may still be unable to afford them, which can impact their overall financial well-being. This was the case for one participant who explained that the costs for consultation and treatment were too much for her, but she had no other choice because she ‘wanted it to be over’:

> I was not financially stable when it happened, to be honest. So, it was too much to the extent that my family had to help. I paid R800, including treatments and consultation (Participant Two, cultural consultation).

This participant's experience of seeking help from her family shows that it is not only the woman who is financially burdened but her loved ones are also affected.

5.3.2.3 Emotional and psychological impact

5.3.2.3.1 The role played by the physical, social and financial burdens of fibroids on sufferers' emotional and psychological well-being.

A careful analysis of the data and a review of the literature reveal that fibroids significantly impact the emotional and psychological well-being of sufferers. This is primarily because the physical, social, and financial impacts of fibroids can exacerbate sufferers’ already-existing emotional and psychological load. This shows that different disruptions can overlap in different ways, meaning that those who experience them have numerous burdens.

As highlighted in the literature review, fibroid sufferers experience a temporary biographical disruption (Bury, 1982) in different aspects of their lives. Those with severe cases of fibroids mourn their former selves because life ceases to be the same as they knew it (Charmaz, 1983: 168). They are forced to mourn their former selves and re-evaluate their future plans to accommodate their new realities, and this process of mourning can be a profound and complex emotional experience, not just for the sufferers but their social networks as well. The physical limitations and pain due to fibroids frustrate women to the point of sometimes feeling betrayed by their bodies (Sayer-Jones & Sherman, 2023). This is a complex emotional phase that most women experience. Additionally, the financial burden of living with fibroids can add to the women's stress, especially those who do not have health insurance (see Section 5.3.2.3). The social experience of illness might also add another layer of emotional stress, especially the stigma attached to fibroids (see Section 5.3.2.1). The 'loss of self' and self-confidence as a result of a symptomatic body might also trigger negative emotions (Charmaz, 1983). This is mainly because changes in appearance may represent the passing of one's former identity and a grieving process might be triggered as they grapple with their new reality and identity (Charmaz, 1995: 657).

5.3.2.2.2 Diagnosis, treatment decisions, and future expectations and their impact on the emotional and psychological impact.

In their study, Begho and Waterman (2023: 22) found that women experienced different emotions, and the severity of their mental distress varied as their fibroids experience progressed from one stage to the next. Participants in that study reported experiencing a significant amount of stress in the pre-diagnosis period because of the uncertainty surrounding their symptoms, fears of fibroids progressing into cancer and fears of fertility complications (Begho & Waterman, 2023: 22). Similarly, Participant Eight recalled feeling anxious because she was struggling to fall pregnant long before she started experiencing symptoms and was worried that a diagnosis of fibroids might shatter her dream of becoming a mother. It was this fear that later led her to try different coping strategies, which included consultations with biomedical and cultural practitioners, as well as self-help strategies blogged on the internet by other women.

Once diagnosed, women may feel a sense of relief because they are given treatment options and are told that fibroids are benign in the majority of cases (Begho & Waterman, 2023: 22). However, this period of relief is often brief as women are faced with decision-making regarding treatment options and the implications associated with them. This process may add to their emotional stress, as one participant illustrates:

> I would be thinking about what if the surgery doesn’t go well. With surgery, they remove a part of you, what if I lose too much blood during the surgery? There was just a lot of what-ifs. Things like what if I don’t take them out they end up causing cancer. What if I don’t make it out of the surgery? So, I was not okay. I was always worried until I went for my surgery. (Participant Six, biomedical consultation & self-help).

There is also a moment of relief after treatment decisions have been made and carried through. How long that moment of relief lasts is mostly determined by the choice of treatment. As highlighted in the literature review, hysterectomy is the only definitive way of treating fibroids (Myles, 2013: 13). As a result, only those who get a hysterectomy can rest assured that there is zero possibility of fibroids reoccurring (Martin-Merino *et al.*, 2015). There is usually a concern about the recurrence of fibroids for women who go for less invasive surgery, hormonal therapy or alternative therapy (Frisch *et al*., 2023). In addition, these women are concerned about their future plans and what their diagnosis might mean for those plans (Frisch *et al*., 2023). Some participants acknowledged that their diagnosis might mean that they might never have children or have complicated pregnancies, as illustrated in the following account:

> And then obviously, as you get older, they start telling you the severity of stuff like… you might have this and that and this and that is gonna probably hinder you from getting pregnant and stuff like that. So obviously, as you get older, you start thinking about your future that wow, okay, wait. So, this means that maybe in the future, I might not even be able to have kids, or I'm going to struggle to have kids or what if I find a boyfriend or husband and wants to have kids and then you know, you only one child. (Participant One, biomedical consultation).

Less than one percent of fibroid cases result in cancer, however, this does not stop women from worrying, as a participant noted:

> So, I was scared because not removing the fibroids could result in cancer but then removing your womb also has negative consequences because it could also cause cancer. (Participant Eight, biomedical & cultural consultation; self-help).

Another participant shares the above concern because she has a history of both cancer and fibroids in her family:

> …because some of it is genetic. I know my grandmother also had also had it… my great-grandmother passed on from womb cancer. So, you start thinking about those things. Okay. So, this means it might be coming down the family. (Participant One, biomedical consultation).

Furthermore, participants were also worried about the possibility of their daughters having fibroids as a history of fibroids increases the chances of passing it on:

> The danger with that is that it will continue from generation to generation, even your children will also have it. (Participant Five, cultural consultation).

Another participant explained:

> Say if I were to have a daughter right now, she would start having those problems. Now you start thinking about, Okay, what if she inherits what I have? What if she's never able to have kids, stuff like that. (Participant One, biomedical).

The conversation about future expectations post-diagnosis and treatment led to participants reflecting on the effectiveness of their chosen treatment. All participants said that their treatment was effective. Participant Two, who had only consulted a traditional practitioner, was certain her treatment was effective, but if there was a recurrence, she would opt for the biomedical treatment These reflections highlight a complex interplay between participants' mental and emotional well-being and the perceived effectiveness of their treatment options. For most participants, the confirmed effectiveness provided a sense of relief and hope, reinforcing their trust in their chosen treatment methods. However, the possibility of recurrence and the possible need to move to biomedical treatment point to underlying anxiety and uncertainty about what lies ahead for Participant Two.

As highlighted above, the impact that the different decisions have on participants was further highlighted by the contemplation of future outcomes. Numerous feelings, from readiness and resilience to worry and anxiety, were evoked by the possibility of a recurrence or the requirement for alternative treatment options. This range of emotions is representative of the larger difficulty in making health-related decisions that combine cultural, medical, and personal beliefs.

To summarise, the discussion on diagnosis, treatment choices, and future expectations not only sheds light on the perceived effectiveness of different treatment options but also emphasises the profound emotional and mental impact these decisions have on individuals. These insights can help healthcare professionals better understand and meet the holistic healthcare needs of their patients, resulting in treatment programmes that support their mental and emotional health in addition to being medically effective.

5.3.2.2.3 The role of support

It was evident that support from family played a crucial role in participants' illness experiences. The support they received from their loved ones provided a space of emotional understanding and a sense of solidarity. The understanding and presence of loved ones helped some participants escape depressive thoughts about their pain, possible complications, and uncertainties about the future. For example, Participant Six explained that she was often at peace when surrounded by her loved ones, but when she was alone, the questioning and negative feelings overwhelmed her:

> It didn't affect me that much because I had support. But it did affect me when I was alone because I would be thinking about what if the surgery doesn't go well. With surgery, they remove a part of you, what if I lose too much blood during the surgery? There was just a lot of what-ifs. (Participant Six, biomedical & self-help).

The role of family support in healthcare experiences is well-documented across various contexts. Studies show that familial emotional support can promote resilience, improve psychological outcomes, and increase general well-being (Cohen, 2004; Umberson & Montez, 2010; Holt-Lunstad, 2018; Patterson & Smalley, 2019). Begho and Waterman (2023) and Dykstra *et al*. (2023), found that women leaned on family members and online groups to cope with their fibroids. This emphasises how important it is for medical professionals to take into account the social and emotional aspects of patient care and to promote family participation in the course of treatment and recovery.

The previous sections discussed emotional and psychological stress related to fibroids, adding to the social and financial challenges that women face. In addition, women are also faced with decision-making challenges, which are explored in the following sections.

5.4 Decision-making process: diagnosis and treatment

The majority of studies on fibroids are conducted in Western settings where biomedicine is the default and only option for diagnosis and treatment (Khan *et al*., 2014; Ghant *et al*., 2016; Giuliani *et al*., 2020; VanNoy *et al*., 2021; Bhego & Waterman, 2023). So, there is rarely ever consideration of the factors that influence women’s choices about their diagnosis and treatment.

This section looks at how sufferers made their decisions on which practitioners to consult and their treatment options.

5.4.1 Diagnosis

The South African healthcare system is notably pluralistic, offering a variety of healthcare options to its citizens (Moshabela *et al*., 2016: 85). This diversity of choices plays a crucial role for women seeking a diagnosis of fibroids. During the interviews, it emerged that the participants' decisions about seeking a diagnosis when they first noticed symptoms were primarily influenced by the accessibility of healthcare practitioners and facilities, as well as the severity and nature of their symptoms, such as heavy prolonged bleeding or a bloated abdomen. Women often sought help from the most readily accessible sources, guided by their perceptions of different healing systems and their religious beliefs.

Participant Six (biomedical and alternative therapies consultation) had an unplanned fibroid diagnosis, as she had spontaneously decided to get a pap smear at a clinic near her workplace. However, she explained that she still sought a biomedical diagnosis because she is a born-again Christian who does not believe in “cultural things”.

For Participant One (biomedical consultation), it was a matter of what was easily accessible and what made more sense to her. When asked why she decided to seek a biomedical diagnosis, she responded:

> So, my mother took me to a doctor, like any normal person, like any other person would. The first thing you would do if you fell sick right now. The first place you're gonna go is to the doctor before you think about traditional methods of how to treat your stuff. So yes, I did go the medical way (Participant One, biomedical consultation).

She believes that a 'normal' person goes to the doctor the moment they feel sick because it is the 'normal' thing to do. However, going to a biomedical practitioner was not the first thing that came to Participant Five's mind, even though she had access to public and private hospitals in Johannesburg, where she lives. She believed that biomedical doctors would not help her, so she went to Limpopo to see a cultural practitioner. She explained:

> Because it is a cultural condition, you have to use cultural methods… even if you use Western medicine without first being treated culturally, it won't get cured (Participant Five, cultural practitioner).

Another participant shares the above view:

> To be honest, I did not know that this thing existed in Western medicine. I thought it was a cultural disease (Participant Two, cultural consultation).

Unlike the participants diagnosed by cultural practitioners, Participant Two's decision was based on what was easily accessible to her since the cultural practitioner who diagnosed and treated her was a family member.

The various pathways taken by women to obtain the diagnosis of a fibroid highlight the important role that cultural backgrounds, personal views, and the availability of healthcare options play. These early diagnostic choices are crucial because they provide the foundation for the later actions women take to manage their condition. The next section explores how these women make critical decisions about their treatment options by weighing biomedical treatments against traditional practices, and the factors that shape these important decisions.

5.4.2 Treatment

As highlighted in the literature review, there are multiple options for treating and managing fibroids (De la Cruz & Buchanan, 2017: 102; Giuliani *et al.*, 2020: 5). However, there are many factors that women consider when deciding which treatment option is the best for them. Previous studies found that factors such as maintaining fertility, discomfort with surgery, and finding a long-lasting solution were key in the participants' decision-making process (Babalola *et al.*, 2023: 981; Myles, 2012).

In the current study, women's consultation with cultural practitioners included ancestral spiritual guides who revealed suitable treatment options. Spiritual guidance was also dependent on the severity of the women's symptoms. As a participating practitioner explained:

> I ask my ancestors who gave me my gift so that they can advise me on which herbs to use as treatment (Participant Three, cultural practitioner).

The other cultural practitioner also consults spiritual guides to determine the best treatment options for her patients. Her range of treatments includes burned herbs, vaginal steaming concoctions, herbal liquid mixtures, and the removal of vaginal growth with a razor. For this reason, Participants Two, Three, and Five, who had only consulted cultural practitioners, did not make decisions about treatment options as they trusted the practitioner’s prescribed treatment. Similarly, Participant One did not have the burden of deciding on her treatment option because her fibroids were not big enough for a surgical intervention:

> So luckily for me, mine were small enough to be treated with medication. So they shrunk mine medically with medication (Participant One, biomedical consultation).

Studies show that some women wait for a long time (four to ten years) before having surgery because of the desire to preserve their fertility and the fear of surgery and its potential risks (Adegbesan-Omilabu *et al.*, 2014: 4; Pollack *et al.*, 2020; VanNoy *et al.*, 2021). It has been argued that women’s fear of surgery is most likely a result of misinformation from mass media (Adegbesan-Omilabu *et al.*, 2014: 4). For one participant, it was her friends’ stories which caused her fear of surgery:

> ...but you know how it is when you have to tell your friends, Yoh! They will scare you. So, I ended up being confused. Some people will tell you that somebody else did it and it didn't work, or someone died, and you get scared. Some will tell you that your husband will get bored because you'll be cold. So, the information that you get from the outside world is not always right. So, that kind of information made me postpone my surgery date (Participant Six, biomedical consultation & self-help).

In their study, Adegbesan-Omilabu *et al.* (2014: 4) found that the majority of their participants sought alternative treatment because of the fear of complications that come with surgery. Participant Three, a cultural practitioner, had such cases of women who were told at the hospital that their fibroids needed surgical removal or hysterectomy, but they instead went to her for help. The women’s fear of surgery and loss of potential children after a hysterectomy were the main reasons for consulting the cultural practitioner. As she explained:

> Sometimes I send them to get checked by a doctor or at the hospital before I help them to confirm if my diagnosis is indeed correct. Some patients go and come back to me and confirm that my diagnosis was indeed correct. Most of them come back to me for help after being told at the hospital that they will need to undergo surgery and are afraid of surgical procedures. What I then do is tell them that I will try to treat them using my traditional methods. In most cases, the patients lead healthy lives with no problems after I help them (Participant Six, biomedical consultation).

The above discussion shows that some women consult both biomedical and cultural practitioners because they avoid treatment options that they deem risky or which do not align with their long-term goals of having children. Some women avoid surgery and are prepared to endure pain longer than they have to just to preserve their chances of having children. However, it also became apparent that some women sought help from other practitioners because of failed treatment, so the only option was to move to a different practitioner. For example, when Participant Three was asked if she had treated women who had unsuccessful biomedical treatment, she responded:

> I had one case last year. I also tried to help her but was unsuccessful because she had a severe case of fibroids. She explained to me that she had been diagnosed with fibroids. I tried fighting them using my methods but was unsuccessful because they had gotten too big. I ended up sending her back to the hospital for a surgical operation (Participant Three, cultural practitioner).

The cultural practitioner further explained that the woman never returned for further treatment and that she didn't know whether the woman had gone back to the hospital for a second surgery or not, as she had had surgery before.

For one participant, factors such as the severity of her symptoms, a family history of fibroids, and having children with no desire to have more helped her decide to have a hysterectomy. Regardless of these factors, the decision to have a hysterectomy was not an easy one, as illustrated in the following account:

> The fact that they can come back after I get surgery done, there's no guarantee that they won't re-grow. So, the only way to remove them is to get the uterus removed. So, then I had to decide if I must go for surgery for taking everything or if I must just go for surgery to only remove the fibroids, it was not easy to decide. Remember, I booked an appointment, and they told me to come back three weeks later, so it wasn't an easy treatment. But then, by the grace of God, I decided to go and take everything out except for my ovaries (Participant Six, biomedical consultation & alternative therapy).

Researchers have found that women with fibroids and other gynaecological abnormalities are sometimes not given options, and hysterectomy is presented to them as the only option or they will die (Carey *et al*., 2023; Verwoerd, 2023). Therefore, it was important to ask Participant Six whether she had been offered other options besides a hysterectomy or if she had decided which option she wanted after doing her research. She answered:

> Yes, they gave me options. They said to me these are the options,… but because I had sterilized, the procedure of getting your tubes tied. So, I had the procedure done when I had my second child. So, I had already made the decision that I was not concerned about the womb. So, keeping it … they were still gonna regrow so what was the use of keeping it? So, they told me that I could only get the fibroids removed or get a hysterectomy (Participant Six, biomedical consultation & self-help therapy).

Before deciding to get a hysterectomy, Participant Six engaged in a range of self-help therapies because of the severity of her symptoms. She was constantly admitted to the hospital when she was expecting her last born:

> The nurses used to say to me, "Did the doctor tell you that you need prayers because fibroid babies don't get to live" But I had faith in God, so I had my baby, but he was so small because of that fibroid. So, the fibroid kept on growing until I discovered Forever products… So, I started using the Forever Living fibroid combo, and it helped me. The fibroid started shrinking, and when it shrunk, I started looking much better (Participant Six, biomedical consultation & self-help therapy).

However, the relief she had after using the Forever products was temporary because the symptoms eventually got worse, and she finally decided to have a hysterectomy. Her experience confirms the findings of previous studies, which found that women with severe symptoms make their treatment decisions based on the severity of their symptoms and which option would best lessen or end their pain, which often means having myomectomy or hysterectomy (Murji, 2020; Schlaff *et al*., 2020; Senogoba *et al*., 2017; Soliman *et al*., 2017).

Participant Six was not the only one who had resorted to self-help therapy. Participant Eight (biomedical & cultural consultation; self-help therapy) had also bought similar self-help products after numerous unsuccessful hospital visits. It is important to note that Participant Eight was not formally diagnosed with fibroids at this stage. She had taken a pap smear test at a clinic, and the results indicated that there was a growth in her uterus. She was referred to the hospital for a formal diagnosis because the clinic did not have the resources. However, she started treating the growths as fibroids after conducting her research. When the biomedical treatment failed, she consulted a prophet (healer) who helped her for a while, and then she started using Yoni products:

> I had forgotten about getting help from the hospital and was focused on getting help traditionally. But then, I still experienced pain during sex and no longer enjoyed it. From there, I met a woman who was selling products for treating things like fibroids and cysts. I had also seen reviews, and people were saying that it worked. The product is called Yoni Detox. The products were R 350. I ordered the products. So, I started using the treatment (Participant Eight, biomedical & cultural consultation; self-help).

Although Participant Eight had earlier said that Yoni products were effective, she nevertheless went back to biomedical treatment:

> But I'm now back in Venda and decided not to just trust that the products have worked. So, I went back to the clinic yesterday, but they didn't have a scan. So, they gave me some pills. They also gave me an injection, but I didn't ask what it was for (Participant Eight, biomedical & cultural consultation; self-help).

The common-sense model of self-regulation, one of the theoretical frameworks underpinning this study, conceptualizes the individual as a problem solver who develops or adopts coping strategies to address the threat to their health (Leventhal *et al.*, 2016: 935). These coping strategies are informed by their prior knowledge of the health threat, their personal experiences, beliefs, and information from loved ones, doctors, or the media (Hale *et al.*, 2007: 905). Both Participants Six and Eight were proactive and used their 'common sense' to adopt coping strategies by taking herbal products to relieve pain from fibroids. Participant Eight went as far as labelling her condition 'fibroids' after a self-analysis of her symptoms long before a biomedical diagnosis. From a common-sense model of self-regulation perspective, these women need validation for their experiences, especially when a name is given to the painful condition – fibroids. This validation allows them to understand that what they are going through is not a figment of their imagination but rather a tangible reality that deserves attention and care. It reassures them that their suffering is real and dispels self-doubt about their experiences and what others might have. However, it is also important to note that using 'common sense' might lead to a misdiagnosis and unnecessary or incorrect treatment.

This discussion of treatment decisions and the various factors influencing them highlights the complexity and deeply personal nature of managing fibroids. Each woman's journey is shaped by a mix of medical advice, cultural beliefs, personal experiences, and individual goals. Understanding these decision-making processes provides valuable insights into the broader context of women's healthcare choices.

The following section delves deeper into the participants' understanding of fibroids. This will provide a clearer picture of how their perceptions and knowledge about fibroids influenced their healthcare decisions and overall approach to managing their condition.

5.5.1 Women’s Knowledge of fibroids

Women's knowledge about fibroids can vary significantly, as it is influenced by various factors such as their unique experiences, level of education, and access to relevant information. It is, therefore, important to acknowledge that each woman's understanding of fibroids may differ greatly from another, creating a diverse range of perspectives on this subject.

The Common-sense model is useful for examining women's knowledge of fibroids. The five key components of illness representations; identity, cause, timeline, consequences, and controllability or curability which are part of the model allow for the exploration of the labels and language they use to describe fibroids, their beliefs about the causes of fibroids, their understanding of how fibroids may progress over time, their beliefs about the consequences of fibroids and their ability to control or manage them. The analysis in the next sections focuses on three of these illness representations: identity, cause, and controllability.

5.5.1.2 Identity

Women use different words to describe fibroids. A study by Venugopal *et al*. (2022: 878) found that some sufferers described fibroids as an embryo, a liquid buildup, or blood clots. In the present study, the majority of participants described them as a ball or a meaty ball.

> So what fibroids are is basically a growth in your womb, that literally turns into, it's like a little ball. It can grow into a big ball, like for some severe pain, but it's literally little balls in your womb that attach themselves to your uterus, and they sit there sometimes they can attach themselves to your ovaries. (Participant One, biomedical)

Participant Eight recalled something that was like "little balls of meat" coming out of her vagina after she used herbal products that claim to treat fibroids, cysts, and other gynaecological conditions:

> I removed the cleaning point after three days, something like dirt fell out when I removed the cleaning point. It was something like little balls of meat. I think they were blocking the womb. (Biomedical, cultural & self-help)

Participant Three, a cultural practitioner, described it as a sort of "wound" that grows in the womb:

> In Tshivenda, we describe it as a sort of wound that grows in the womb because when you consult a healer, they usually tell you that you have balls in the womb, and in English, they call them fibroids. When it's severe, we say they have huge balls in the womb.

The common trend is that participants described fibroids in terms of their appearance and location. Although some participants referred to them as "balls" or "meaty balls," they also had specific names for these "balls" in their languages. Participant Five said that the "balls" are called *lekone* in Sepedi, and Participants Two, Four (cultural practitioner), and Seven said they are called *goni* in Tshivenda. It is important to note that all these participants were diagnosed and treated culturally and believed their condition was fibroids, often referring to their condition as "fibroids" during the interview process.

However, it became apparent during Participant Three's interview that *goni*/*lekone* and fibroids were two different conditions:

> Interviewer: Some people have told me that they call them *'goni'*. Do you all refer to them as *goni*, or are these two different things?
>
> Participant Three: *Goni* and fibroids are two different things. They are different in that the positions of *goni* and fibroids are different. We are able to cut/remove goni. It does not grow at the same rate as fibroids; we cut *goni* on a woman's private part. It does not grow on the uterus where we cannot see it, and it does not grow to the extent that it prevents you from delivering a baby. Goni is itchy and sometimes affects a child if you are a new mother. If the newborn is not treated for goni, they might unexpectedly die without being sick. (Participant Three, cultural practitioner)

Culturally diagnosed participants believe that a red mark appearing on the back of a new baby indicates the growths in their vagina, which are then removed by a cultural practitioner using a razor or herbs. Research on *goni/lekone* shows that the condition is often biomedically labelled as unknown or ill-defined because laboratory tests fail to detect it (Rikhotso, 2017: iv). *Goni/lekone* is found in infants whose mothers have been diagnosed with a sexually transmitted infection (Lekgothoane & Ross, 2020: 3). Rikhotso (2017) found that Indigenous African beliefs hold that this condition can only be treated by traditional healers. Mulaudzi and Rasweswe (2022: 152) note that some Western scholars associate the red mark with Mongolian spots, which are congenital birthmarks.

Reflecting on the interviews with Participants Two, Four, Five, and Seven, it became clear that they may have confused *goni/lekone* with fibroids due to the similarities in symptoms. Both conditions can lead to infertility if untreated and can be treated or managed by surgical removal or shrinking the growths. The fact that participants referred to them as "balls" or "balls of meat" might also contribute to the confusion if the position of the growths is not clarified.

These findings support social constructionists' views that the understanding of illness is not solely based on biomedical knowledge but is also influenced by cultural practices and beliefs (Barker, 2020: 148). Similarly, from a common-sense model perspective, illness representations vary from person to person and do not always correspond to biomedical facts (Diefenbach & Leventhal, 1996: 20). This, however, does not diminish the importance of the experiences and knowledge of the sufferers.

5.5.1.2 Women's beliefs about the cause of fibroids

As highlighted in the literature review, the cause of fibroids remains unknown. However, previous studies have revealed that some women believe that fibroids are caused by spiritual forces (Adegbesan-Omilabu *et al.*, 2014: 4), hormonal imbalances and pregnancy (Krishnan *et al.*, 2020: 508). All the women in this study reported not knowing what caused fibroids and that it is a natural condition that affects women without being triggered by anything. Participant Three explained it like this:

> Eish… I don't want to lie. I don't know what causes them. But also, from what I've observed, we women suffer from many diseases and I think fibroids are just a growth on the inside. It's a condition that just comes, it's not caused by what you eat or what you don't eat. (Cultural practitioner).

Participant Six also expressed uncertainty about the cause but speculated on a possible link with contraceptive use altering hormonal balance:

> According to me, because I used to use Evra patch for prevention, I think it somehow contributed to the growth of fibroids. I didn't have them when I had my firstborn in 2013 but then in 2017 I was using the prevention and had fibroids. So, I think it increased the hormones or something. I don't know. But that might not be accurate, it's just what I think. (Biomedical & self-help).

The participants' beliefs about the cause of fibroids significantly influenced their perceptions and attitudes towards the condition. Many acknowledged the natural occurrence of fibroids, recognizing the limited control over their development. While some expressed sadness, there was also a noticeable shift towards acceptance, viewing fibroids as a natural phenomenon experienced by many women. Participant Two reflected on this acceptance:

> I think it's a natural thing, it's like an accident. You don't choose to be in an accident, it's the same with fibroids, you don't choose to have them. (cultural).

Participant One offered a nuanced perspective, emphasizing the inevitability of health conditions:

> There is no negative or positive. There isn't because it's an experience. You can hate it… you can't hate something for happening to your body. If it was meant to happen, it will happen. And then you get also there isn't a positive, it happens. So, you can't necessarily say you like fibroids. A disease is a disease, you understand? You can hate something you gave to yourself… It doesn't have anything to do with the positive or negative if, if it was gonna happen, it is going to happen. There's nothing you can necessarily do about it. (biomedical).

These varied points of view demonstrate the nuanced views that women have concerning fibroids, which are influenced by both cultural and personal experiences. Participants share a similar thread of acceptance and resilience in the face of this health crisis, despite uncertainties surrounding its aetiology.

5.5.1.3 Cultural practitioners' knowledge of fibroids

Two cultural practitioners were interviewed to examine their knowledge of fibroids and the treatment options or coping mechanisms they recommend to their patients. However, since it has been established that what Participant Four believed to be fibroids are not fibroids, this section will only detail Participant Three's beliefs and the coping mechanisms she recommends to her patients.

Participant Three's background

Participant Three is a trained traditional healer. She attended a traditional healer's training school after discovering that she had an ancestral calling. At the school, she was exposed to a wide range of illnesses from patients who consulted with the healer who was training her, and she learned the different methods and medicinal plants used to treat those conditions:

> I fell ill and later found out that I had an ancestral calling. I then went to school to get trained as a traditional healer. At the school that I went to, we had patients coming in with different conditions. Some came suffering from fibroids and we would observe and help the traditional healer teachers/trainers. They would teach us to treat the condition and which medicinal plants to use. So, that's how I got my knowledge of fibroids because we had experience from interacting with patients at the traditional healer school I went to. Another this is, as a traditional healer, if I don't see a way to treat a patient, I ask from my ancestors who gave me my gift so that they can advise me on which herbs to use as treatment.

Although the participant had been practising as a traditional healer for many years, she revealed that she only started working with patients with fibroids in 2021 after realising that many of her patients came to her complaining about womb and stomach problems and struggling to have children. It was then that she consulted with her ancestral guides, and it was revealed to her that the women had growths in the womb.

Traditional Management of Fibroids

Studies on how cultural practitioners manage fibroids are very few. The few studies that exist usually detail how different cultural practitioners make use of medicinal plants and the benefits of those plants. The majority of cultural practitioners who work with fibroids rely on medicinal plants to treat their patients (Balick *et al*., 2000; Mehl-Madrona, 2002; Dalton-Brewer, 2016). Similarly, Participant Three also relies heavily on medicinal plants that her ancestors revealed to her to treat her patients:

> So, I started asking my ancestors about how I should be helping someone who comes with such problems. I found that since I'm not a doctor that works with machines, I work through the spirit, the solution should be using something that the patient can drink or something that I can burn and the patient steams through their vaginal opening.

Participant Three further explained that:

> The smoke prevents the fibroids from getting bigger in size and weakens them. It stops the pain that the patient is experiencing and helps to shrink them. The herbal medication that I give the patients also prevents the fibroids from getting bigger.

Participant Three reported that these methods are often successful, and most of her patients give good reports of the medications having restored them to good health or having helped them conceive in cases where the fibroids were causing infertility. However, she is also aware that her methods may offer temporary relief for some sufferers, especially those with severe symptoms.

A study by Coulidiaty *et al*. (2021) explored the traditional management of uterine fibroids by a well-known traditional healer in Burkina Faso. It revealed that the traditional healer, in addition to using medicinal plants, also extracted the fibroids from the uterus through the vagina. Participant Three, however, explicitly stated that she did not remove the fibroids; her methods only shrank and weakened the fibroids and targeted the pain:

> I don't know how to cut them but I do recommend my patients to go to a hospital and have them surgically removed if I'm successful in helping them fall pregnant. What I like most about hospitals is that they can surgically cut them from their roots, preventing any chances of them regrowing.

Collaboration with Biomedical Treatment

Participant Three recognizes the limitations of her methods and does not delay sending her patients to the hospital if needed. She explained that biomedical treatment is very helpful, and she does not look down on it. She sometimes sends her patients to the hospital for a second opinion after she has diagnosed them.

It can be concluded that Participant Three's knowledge of fibroids is mainly from her training and what her ancestral guides reveal to her about her patients' diagnosis and the appropriate treatment options. She did not mention consulting other sources of information, such as medical and biomedical textbooks or professionals. Her ancestors guide her on which medicinal plants to use and where to get them. The cultural practitioners did not reveal which plants they used or where they found them, as such information is regarded as sacred, and only specific people may know about it.

5.5.2 Women’s level of awareness

Previous studies have reported a high level of awareness among respondents (Adegbesan-Omilabu *et al.*, 2014; Krishnan *et al.*, 2020; VanNoy *et al.*, 2021; Venugopal *et al.*, 2022). Contrary to these findings, the present study found that the level of awareness of fibroids among participants was very low. Most participants did not know about fibroids before their diagnosis. This is consistent with findings by Nicholls *et al.* (2004), where the majority of respondents first learned about fibroids after being diagnosed.

Women's lack of awareness of fibroids is one of the reasons many delay seeking medical attention (Carey *et al.*, 2023). Studies show that this lack of awareness can lead to uncertainty about abnormal symptoms or the normalization of disruptive menstrual symptoms and pain associated with fibroids (Ghant *et al.*, 2014; Stewart *et al.*, 2021; Carey *et al.*, 2023). Nicholls *et al.* (2004) argue that this uncertainty can be best understood using the Common-sense Model's framework of illness representations. Women who are unaware of fibroids before diagnosis do not have an existing illness schema to explain their symptoms.

For example, Participant One experienced long periods and severe pain from a young age, requiring heavy painkillers. It was only in grade nine that her mother took her to a doctor to investigate:

> Before then it seemed normal… Besides I was young. So even when I told my mom, I think I only started telling my mom when my period started getting severely painful, especially when she started getting worried. Like, okay, no, this is an ongoing thing because you know, like parents they'll tell you periods are supposed to be painful or they'll give you a hot water bottle, a painkiller there. It was only when she started realising that the pains got so painful that they would even send me home from school. You Understand? So, it was only until then when my periods went on for longer, my mother asked me like, Okay, why are you still on your period? (Biomedical)

Participant Six also had no prior knowledge of fibroids until she was diagnosed:

> I started reading about it and doing research. I didn't know about them, so I went through the internet and googled. So, I started teaching myself about it. (Biomedical & self-help).

Access to healthcare impacts women's awareness of fibroids. Participant Six recounted that her grandmother, who lacked medical aid, received treatment too late and died of fibroids. After being diagnosed and educated, Participant Six realized her grandmother's condition was fibroids:

> …So, yeah, from my mom's family, my mom's mom had a growth but back then they didn't have medical aid to find out if it was a fibroid or not. But now that I've had a fibroid removed, I understand that what she had was a fibroid and she got treatment late and unfortunately she couldn't make it. She started bleeding and she was old.

Community and social settings play an important role in women's awareness of fibroids (Krishnan *et al*., 2020; VanNoy *et al*., 2021). Women are more likely to be aware if others in their community are aware. Most participants believed only a few women in their communities were aware of fibroids. Participant Three explained:

> A lot of women don't know about this condition because when they experience the symptoms they treat it like a minor illness because of the fear of going for a check-up at the doctor. A lot of women don't know why most of them only find out when their fibroids have increased in size. They don't like going to a doctor to find out exactly what's happening. When they are unwell, they just think that they should buy Panado and all will be well without first consulting a doctor. That's why some of them seek help too late when they have become dangerous. (Cultural practitioner).

This aligns with Nicholls *et al*. (2004) and Carey *et al*. (2023) who noted that women often normalize fibroid symptoms because they lack mental representations of the condition. Without awareness, they cannot associate their symptoms with fibroids, leading to continued patterns unless women are educated about fibroids and their symptoms.

Other participants believed it could be fifty-fifty in that some women were aware and others were not. Participant Eight was one of them, she even referenced herself as one of those women who only became aware after their diagnosis. She stated, "I think some women are aware and some aren't. I also didn't know about it. I only went to the clinic after I experienced some pain." Participant Six was also of the view that most women did not have awareness of fibroids. However, it was apparent from her response that she was not aware of the prevalence of fibroids. She was of the view that fibroids only affected a few people:

> I don’t think people understand or even know about it. It doesn’t happen to a lot of people. It happens to 2 out of 10 people. Some people have it but don’t know that it is fibroids. They would have bloated stomachs and think that it’s just a big belly. (Biomedical & self-help).

This shows that women are not only not aware of the condition, but they are also not aware of its prevalence. As already highlighted in the literature review, research has shown that fibroids affect between 70% and 80% of women worldwide, which means that it affects seven to eight out of every ten women instead of two out of ten people, as expressed by Participant Six.

From Participant One's point of view, most people are aware of fibroids, but they prefer not talking about them or disclosing that they are sufferers or were sufferers:

> Not everyone is as vocal, okay. It's the same. I think it's right up there with things like, like you said, people don't always really want to talk about it. Their difficulty. You know, no one wants to talk about what they’re lacking. Nobody wants to talk about what they cannot do. Everyone wants to seem like okay, I'm able, I have money, I am working. I can have kids, you know, I’m healthy. It's the same way. People will never necessarily come to you and say, Hey, dawg I’m HIV positive. Nobody's gonna come up to you and say, Listen, I cannot have kids. And it's just not in me. Because the minute you say something like that, people look at you weirdly. It's just how people are. It's either people put to you or they look down on you or so people frown on talking about it. I wouldn't say serious things like this, but It's people look down on actually just talking about anything that reflects negatively about their lives. So, nobody's going to come to you and tell you it's right up there with telling people that… people can see that you’re big and then they'll ask you why don't you lose weight, only to find that maybe you have a genetic disease, that you cannot lose weight. And it's, it's not necessarily that you don't want to, it's just that you just can't. So, it's just also one of those things. People know about it. But it's not necessarily someone, something someone is prepared to discuss. (Biomedical).

This culture of silence will be discussed later, but it is clear that cultural influences play a role in women's illness experiences. Older women, who should teach or discuss reproductive issues, often avoid these discussions due to cultural reasons.

All participants agreed on the need to raise awareness and educate about fibroids. Other studies support this conclusion (Ghant *et al*., 2015; Marsh *et al*., 2018; Aninye *et al*., 2021). Raising awareness can help women recognize fibroid symptoms early, allowing for timely medical intervention and preventing complications. Education empowers women to make informed health decisions and prevents confusion with other conditions.

Participants were then asked what strategies they thought would be effective in raising awareness. The majority suggested that healthcare providers need to educate women not just about fibroids but about all the different kinds of reproductive illnesses that affect women. Ghant *et al*. (2016: 849) found that it would be effective if healthcare providers educated women in both clinic and community settings. Taking the education campaigns to the community setting will allow reach to those who do not go to clinics for medical treatments (Ghant *et al*. 2016: 849).

Participant Six suggested that there needs to be workshops aimed at raising awareness about fibroids:

> I think it's important that there be presentations on women's health every other month. The presentations need to touch on other conditions affecting women and not just fibroids. It should be like how they do it with things like cancer awareness…that will then make people aware because some people think that they're pregnant when they are not. I had a cousin of mine who had a big tummy for a while and she thought she was pregnant because at times you'd feel it moving as if there was a heartbeat but it wasn't pregnancy but fibroids. (Biomedical & self-help).

Participant Three suggested that women need to be open about having conversations about fibroids with other women and educate one another:

> According to me, I think that as women, if we live near each other, we should gather and have conversations and educate each other about fibroids. We need to encourage each other to go to clinics and get checked regularly. There are things like pap smear. A woman needs to get a pap smear regularly because that is where they find out if they have fibroids or any other condition affecting women. (Cultural practitioner).

The significance of raising awareness and providing education about fibroids, treatment options, and the different steps women need to take to stay informed about their reproductive health cannot be overstated. As highlighted by the cultural practitioner above, breaking the culture of silence, especially regarding reproductive health issues such as fibroids due to their high prevalence, is crucial. Women and those possessing knowledge should take responsibility for their counterparts who may lack awareness. Educating or opening up about one's experiences with fibroids might save the next person who is unaware or ashamed to seek help.

5.6 Cultural and social influences

As previously mentioned, health and illness are deeply intertwined with cultural concepts. Our cultural backgrounds profoundly shape how we perceive, manage, and experience health and illness (Ravindran & Myers, 2011: 312). Cultural influences are evident in our health behaviours, affecting where and when we seek medical attention, the duration of our care, and how we assess treatment effectiveness (Ravindran & Myers, 2011: 312). Additionally, beyond their biomedical definitions, illnesses carry significant social and cultural meanings (Conrad & Barker, 2010: 69). These meanings, often overlooked or underestimated, profoundly impact individuals' experiences with illness (Conrad & Barker, 2010: 69). What may be considered a natural part of life in one culture can carry shame or stigma in another. Recognizing and comprehending these social and cultural dimensions is crucial for understanding the diverse perspectives and experiences of those affected.

5.6.1 A culture of silence

A study by Orellana *et al*. (20221) illustrates how cultural and familial factors significantly influence women's perspectives on diagnosis, management, and treatment options for health issues. For instance, some women in the study discovered their family's history of fibroids only after being diagnosed, as women's health issues were not openly discussed within their cultures or families, leading to delayed diagnosis in some cases (Orellana *et al*., 20221: 1188). Participants reported that discussing such intimate matters could be perceived as disrespectful, particularly towards elders, thus inhibiting open conversations about women's health:

> The reason for them not to talk about it is it’s how they were also brought up. They grew up believing that once they start talking about private parts or intimate stuff the respect flies out of the window. Elders want to be respected so they think that once they start telling the young ones where children come from and stuff like that there won’t be that respect anymore. That’s also how we were brought up. That’s why we were afraid to tell them when we started our period but nowadays you're able to talk to me about it. Back then, we used to bleed and hide it until they saw us because we knew that telling them meant there was no longer respect. (Participant five, cultural).

Similarly, participant one also explained:

> …Back home we have old women who don't necessarily talk about the fact that these things happen to women. We have old woman who doesn't who don't necessarily

> discuss their personal lives within the maternal… Because they don't talk about those things. So, you don't necessarily get the kind of help that you want. (Biomedical).

This cultural silence extends to intergenerational conversations about reproductive health. Participant Six, despite her personal experience with fibroids, had not discussed them with her daughter due to cultural norms:

> No. You know that we as black people don’t talk about such things with our children. I don’t know why but I can say that we talk about it when it happens. (Biomedical & self-help).

Furthermore, Orellana *et al*. (20221: 1189) found that cultural factors influence women’s perceptions of symptom severity and the decision to seek medical treatment. Some women reported downplaying symptoms due to familial normalization of heavy bleeding and pain, which could delay seeking necessary treatment. Many were unaware of their family's history of fibroids until diagnosis, further complicating early symptom recognition (Orellana *et al*., 20221: 1189).

Participant One, for example, delayed seeking medical attention for heavy bleeding and pain, believing it to be normal until a diagnosis was made years later. She suspects a familial history of fibroids, noting:

> All you know is that your aunt is 45 and has five kids or you have an aunt or *gogo* somewhere who only ended up having two kids. You don't know if the rest of the kids died young or she miscarried? Because they don't talk about those things.

While cultural norms of silence around women's health persist, they significantly impact how individuals perceive and manage health issues within their families and communities. The reluctance to openly discuss reproductive health can delay diagnosis and treatment, perpetuating misconceptions and inhibiting access to necessary care. The following section explores how cultural beliefs and practices shape women's experiences with health and illness, shedding light on the diverse perspectives that influence their healthcare decisions.

5.6.2 Cultural beliefs and practices influencing women’s experiences of fibroids.

Participants were asked if their cultural beliefs and practices influenced their experiences of fibroids. Participants reported that their cultural beliefs and practices did not influence their illness experiences, citing reasons such as being a Christian who did not believe in cultural practices and having opted for the biomedical route. Participant Six, for example, stated:

> I don’t have cultural beliefs. I am a born-again, I believe in God. Cultural things didn’t bother me much. (biomedical &self-help).

Participant One explained: "No. Everything was still Western. So yeah, everything was factual and wasn't necessarily based on belief or who did what." (Biomedical).

Interestingly, even the three participants who consulted cultural practitioners reported that their cultural beliefs and practices did not influence their experiences with fibroids. Participants were unable to elaborate on why they thought their cultural beliefs and practices did not affect their illness experiences. This could be because participants were not fully aware of cultural influences. After all, cultural practices might be deeply ingrained and perceived as normal, resulting in participants being less likely to recognise them as influential factors. Furthermore, participants may have been hesitant to disclose their personal and cultural beliefs because of factors such as social desirability bias.

Additionally, participants were asked how they or the people in their social and/or cultural settings view other women with fibroids. All participants agreed that women with fibroids are the same as those without fibroids. Participant One put it like this:

> It's normal. I wouldn't say it's good, right? But at the same time, we cannot judge people, we are all built differently. We all have certain diseases. I think it's right up there with people who don't want to have kids. I mean, people get stereotyped and looked at just for saying that… If God didn't bless you with kids, then God didn't bless you with kids… Not everyone's going to be able to have kids. (biomedical).

Participants understood that fibroids occur naturally, thus enabling them to view sufferers with compassion. Participant One used the example of having children to illustrate that having fibroids is not something the sufferer chooses thus, the sufferer should not be treated differently. However, just as women who are naturally unable to have children, women with fibroids also get stereotyped. These stereotypes are often harmful and may hinder sufferers from seeking help for their fibroids. For example, in a study by Akpenpunn *et al.* (2019: 20) looking at the health-seeking behaviour of women with fibroids in Nigeria, it was found that the cultural value placed on the uterus and children led to women not wanting to get a hysterectomy even if it is the best treatment option in their cases because of the belief that not having a uterus or children makes one less of a woman. Furthermore, other studies have found that childlessness and the removal of the uterus might lead to social isolation in some cultural contexts (Hsieh, Lu, & Liang, 2021). Contrary to the findings of these studies, Participant Six, who had a hysterectomy, expressed that:

> I still see you as a full woman if you had the surgery to remove the womb and even if you didn’t. I see you a woman who had her reasons. (biomedical & self-help).

These insights underscore the profound impact of cultural and social environments on individuals' experiences with fibroids, highlighting the need for policies that consider these contexts and their implications.

5.7 Conclusion

This chapter illuminated the intricate nature of women’s experiences with fibroids, encompassing their knowledge, decision-making processes regarding diagnosis and treatment, and the profound influence of culture. The analysis revealed that women with fibroids endure multifaceted and sometimes overlapping disruptions in their lives due to symptoms. These symptoms not only affect them physically but also impose social constraints, requiring them to plan their lives around their condition. Financial burdens and significant emotional and psychological impacts were also evident.

Moreover, the chapter underscored the challenging and emotionally taxing decisions women face in selecting healthcare providers for diagnosis and treatment. Accessibility and affordability emerged as critical factors influencing their choices. Cultural and religious beliefs further shaped their decisions, particularly concerning fertility preservation, treatment effectiveness, and the likelihood of recurrence.

Another key finding was the disparity between participants' knowledge about fibroids and biomedical accuracy. While some women demonstrated awareness, there was a recognized need for greater community education. Cultural norms influenced how participants approached discussions about fibroids and reproductive health more broadly.

Lastly, this chapter has illustrated the myriad factors influencing women’s experiences with fibroids, transcending mere physical symptoms to encompass profound social and cultural dimensions. It emphasises the importance of holistic approaches to healthcare that consider these diverse influences, ensuring more comprehensive support and treatment for affected individuals.

CHAPTER 6: CONCLUSION

6.1 Conclusion

This study explored women's experiences, knowledge, attitudes, and perceptions of fibroids, focusing on a community in Diepsloot, South Africa. Utilizing a qualitative research design framed by social constructionism and the common-sense model of self-regulation, the study examined how cultural norms and societal expectations shape individuals' perceptions and responses to fibroids. The findings highlighted significant gaps in awareness and knowledge about fibroids, underscoring the need for targeted educational initiatives and community awareness programs. The depth of understanding gained from this research offers a critical perspective that extends beyond the biomedical focus typically found in Western studies, providing a comprehensive view of the socio-cultural dimensions of fibroid experiences.

The study revealed concerning levels of awareness about fibroids among women in Diepsloot. Most participants were only aware of fibroids post-diagnosis, which often led to delayed treatment and potentially more severe health outcomes. This underscores the necessity for increased education and awareness campaigns to promote early detection and timely medical intervention. Furthermore, the impact of fibroids on women was found to be profound, affecting them physically, socially, financially, emotionally, and psychologically. These findings echo existing literature on the burdens of living with fibroids and highlight the need for comprehensive support systems that address the multifaceted impact of this condition on women's lives. By recognizing the extensive challenges faced by women with fibroids, healthcare providers and policymakers can better design interventions that provide holistic support.

Cultural and religious beliefs played a significant role in shaping women's health-seeking behaviours. Participants' decisions on whether to consult biomedical or cultural practitioners were influenced by factors such as cultural beliefs, access to healthcare, and affordability. This points to the importance of culturally sensitive healthcare approaches that respect and integrate patients' beliefs and practices. Moreover, participants' knowledge about fibroids often came from non-biomedical sources, including cultural practitioners who rely on ancestral spiritual guides and medicinal plants for treatment. This highlights the need for healthcare professionals to acknowledge and incorporate diverse perspectives and sources of knowledge in their practice. By bridging the gap between biomedical and cultural understandings, healthcare providers can foster more inclusive and effective care environments.

The study also uncovered a generational culture of silence surrounding women's reproductive health, contributing to delayed recognition and treatment of fibroid symptoms. Breaking this silence and de-stigmatizing reproductive health issues are crucial steps toward improving women's health outcomes and encouraging open discussions about these conditions. This generational culture of silence inadvertently normalizes the pain caused by these symptoms, leading some women to seek treatment only in advanced stages, which may require invasive procedures like hysterectomy. Addressing this cultural barrier requires concerted efforts to promote open dialogue and education about reproductive health, empowering women to seek timely medical attention and make informed decisions about their health.

This study provides valuable insights into the lived experiences of women with fibroids in a developing country context, offering a perspective that is often overlooked in biomedical research focused on Western populations. By highlighting the social, cultural, and emotional dimensions of fibroid experiences, the study challenges the dominant biomedical narrative and calls for a more holistic approach to women's health. Given the findings, there is a clear need for more research on fibroids in diverse cultural and socioeconomic contexts. Such research should aim to uncover the unique challenges faced by women in different settings and develop tailored interventions that address their specific needs.

Future studies should explore the effectiveness of community-based education and awareness programs on fibroids, investigate the interplay between biomedical and cultural healing systems in fibroid treatment, examine the long-term impact of fibroids on women's quality of life, including fertility and mental health, and assess the role of healthcare professionals in supporting women with fibroids, particularly in resource-limited settings. Addressing these gaps through continued research and education initiatives can improve early diagnosis, treatment outcomes, and overall quality of life for women affected by fibroids. By expanding our understanding of fibroid experiences across different contexts, we can develop more effective strategies to support women's health globally.

In conclusion, this study underscores the critical need for increased awareness and education about fibroids, culturally sensitive healthcare practices, and further research into the diverse experiences of women living with this condition. By addressing these gaps, we can improve early diagnosis, treatment outcomes, and the overall quality of life for women affected by fibroids. This research not only contributes to the existing body of knowledge but also paves the way for future studies to build upon these findings and continue to advocate for the health and well-being of women worldwide

6.2 Limitations

A key limitation of this study is the relatively small sample size, which might impact the generalizability of the findings. The cultural context explored in this study is specific to Diepsloot, and as such, the findings may not fully capture the diversity of experiences in other cultural settings. Furthermore, due to the reliance on participants' self-reported data, social desirability bias may be present in this study (Grimm, 2010). Participants might have given answers that they thought were socially acceptable, which affected the accuracy of the data collected. Additionally, this study could have benefited from follow-up interviews to further explore certain concepts and provide deeper insights into the participants' experiences. However, this was not possible due to time constraints. Finally, this study's assessment of cultural elements is based on the researchers' perceptions. Various interpretations might be possible, and the reliability of the cultural insights could be improved by including the opinions of various researchers or including participants in the interpretation process.

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APPENDICES

Appendix A: Participant informed consent form

PARTICIPANT INFORMED CONSENT DECLARATION

(To be signed by research participant/s)

Project Title: *A study on the experiences, knowledge, perceptions, and attitudes of women towards fibroids in Diepsloot, South Africa.*

Moreblessing Itani Nwanamidwa from the Department of Sociology, Rhodes University has requested my permission to participate in the above-mentioned research project.

The nature and the purpose of the research project and of this informed consent declaration have been explained to me in a language that I understand.

I am aware that:

1. The purpose of the research project is *to explore how women construct knowledge, attitudes, and perceptions of fibroids as they interact with biomedical and/or cultural practitioners*
2. Rhodes University has given ethical clearance to this research project (2023-7370-7940) and I have seen/may request to see the clearance certificate by contacting the Ethics Coordinator (ethics-committee@ru.ac.za)
3. By participating in this research project, I will be contributing towards *expanding the knowledge on women's experiences of fibroids and the factors that shape their knowledge and perceptions of and attitudes towards fibroids.*
4. I will participate in the project by *engaging in a one-time interview lasting between one to two hours.*
5. My participation is entirely voluntary and should I at any stage wish to withdraw from participating further, I may do so without any negative consequences.
6. I will not be compensated for participating in the research, but my out-of-pocket expenses will be reimbursed.
7. The following risks are associated with my participation:
8. The Researcher intends to publish the research results in the form of *a master's thesis that will be made electronically available via the Rhodes University library.* However, confidentiality and anonymity of records will be maintained and my name and identity will not be revealed to anyone who has not been involved in the conducting of the research ***unless I indicate to the contrary/recognize that as a public figure, my identity will inevitably be/become known, in which case I agree to accept the loss of anonymity.***
9. In terms of the Protection of Personal Information Act (No. 4 of 2013) it remains my right to request the Researcher to provide me with a detailed explanation of exactly how confidentiality and anonymity of the data I provide will be achieved. I may also request to know exactly how my personal information will be stored securely, and for how long it will be stored.
10. If any data collected from me for this research project is to be used by the Researcher for any further study, I am to be informed in writing and my written consent is requested again. I need not give consent for the new research if it is incompatible with the initial purpose of the

present study (POPIA, s15(3)). Equally, I can simply reject the request. In such cases, a formal request needs to be made to me by the researcher via the Ethics Coordinator (ethics-committee@ru.ac.za).

11. In terms of the POPI Act, I possess the right to receive feedback about this research. This will take the form of an email with the pdf version of the final research project unless ***I elect not to receive this feedback.***
12. Any further questions that I might have regarding the nature of the research and/or my participation in it will be answered by Moreblessing Itani Nwanamidwa at g19n2390@campus.ru.ac.za
13. By signing this informed consent declaration, I am not waiving any legal claims, rights, or remedies. A copy of this informed consent declaration will be given to me, and the original will be kept on record by the Researcher.
14. I ***agree/disagree*** (delete inapplicable) to the Researcher's request to take photographs, or videoing me as part of this research project, recognizing that agreement here is likely to raise the risk of compromising my anonymity and that steps will be taken to ensure this will not happen it my consent is given.
15. I ***agree/disagree*** (delete inapplicable) to the Researcher's use of voice recording of my comments and opinions during interviews, the purpose of which is to ensure the accurate recording of my views/responses. Furthermore, I have the right to request a copy of the interview transcriptions to confirm that my opinions are accurately recorded.

I, ……………………………………………………………………….., have read the above information / confirm that the above information has been explained to me in a language that I understand and I am aware of this document's contents. I have asked all questions that I wished to ask, and these have been answered to my satisfaction. I fully understand what is expected of me during the research.

I have not been pressurised in any way and I voluntarily agree to participate in the above-mentioned project.

…………………………………… ………………………… ……………………………

Participant's signature **Witness** **Date**

Appendix: Interview Questions

1. What symptoms did you experience or how did you first come to realise that something was happening in your body, and you needed to seek help?
2. What were your thoughts when you first experienced the above-mentioned symptoms, what was your self-diagnosis?
3. Did you have any conversations with your loved ones about what you thought was happening to you? If so, would you mind sharing how those conversations went?
4. Did you seek your initial diagnosis from a biomedical or cultural practitioner?
5. What influenced your decision to seek a diagnosis from the practitioner you consulted?
6. What were your thoughts after your consultation, did the practitioner confirm your self-diagnosis or did the diagnosis come as a shock to you?
7. What were some of your concerns after you found out you had fibroids?
8. How did your loved ones respond to the diagnosis? Did they raise any concerns?
9. Did you feel like you had a strong support system around you?
10. Did the practitioner you consulted recommend support groups you could join?
11. What coping strategies did your practitioner recommend? What were your feelings or concerns about those strategies?
12. Do you have a positive or negative attitude towards fibroids and why?
13. Would you say that your culture influences how you view fibroids?
14. To the women who have consulted both biomedical and cultural practitioners, which one did you consult first and what motivated you to consult the other?
15. Women who consulted cultural practitioners, what are your thoughts on the medical treatment of fibroids?
16. Women who consulted biomedical practitioners, what are your thoughts on the non-biomedical treatment of fibroids?

17. Are your experiences of fibroids shaped by biomedical or cultural values and beliefs or both?
18. How did you first become aware of fibroids? Was it through personal research, conversations with healthcare professionals, or other sources of information?
19. How did fibroids affect your life, physically, financially, socially and emotionally?
20. Did you face any stigma as a result of your fibroids?
21. What are your thoughts on the current level of awareness and understanding of fibroids in the general public?
22. How do you perceive the impact of fibroids on women's reproductive health and fertility?
23. Are there any cultural or societal factors that you believe influence the experiences and perceptions of women with fibroids?
24. Have you encountered any challenges or barriers when seeking medical care or treatment for fibroids? If yes, could you elaborate on those experiences?
25. Are there any specific concerns or questions you have regarding fibroids that you would like to see addressed through research or educational initiatives?
26. In your opinion, what strategies could be effective in raising awareness and improving education about fibroids among women and the general public?

Questions for cultural practitioners only (they will also be asked the above questions if they once were fibroids sufferers)

27. How long have you been working with women with fibroids and how did you get started?
28. How do you diagnose fibroids, what symptoms do you look out for?
29. How do you know that certain symptoms signal that the patient has fibroids?
30. What coping strategies do you recommend to your patients?

31. How did you come to know of these coping strategies and if they would be effective in treating fibroids?
32. Is your knowledge of fibroids solely based on your cultural upbringing, values, beliefs and practices or has biomedicine also played a role?
33. What are your thoughts on the biomedical treatment of fibroids?
34. Do you ever recommend some of your patients to seek biomedical care?