UNIVERSITY of the WESTERN CAPE

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DEPARTMENT OF PSYCHOLOGY

Title: The lived experience of young women with endometriosis in South Africa: An exploration of chronic pain with regards to physical, psychological, and social wellbeing.

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01 February 2022

Keywords: *Young women, endometriosis, chronic pain, anxiety, intimate relationships, sexual intimacies, social wellbeing, psychological wellbeing, qualitative, phenomenology*

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Abstract

Endometriosis is a common disorder affecting many young women of reproductive age physically, socially, and psychologically. The disease is largely considered from a biomedical perspective and there is a paucity of literature on the psychological impact on women with endometriosis, particularly in South Africa. Women with endometriosis are often impacted physically in terms of infertility and chronic pain; socially in terms of their intimate relationships and sexual intimacies; as well as psychologically through their enhanced experiences of anxiety and stress. This study considered the lived experiences of young women in South Africa afflicted with endometriosis within a phenomenological theoretical framework, using a qualitative approach. Furthermore, the participants were between the ages of 25-35 years old, were of a female sex, and had been medically diagnosed with endometriosis. At the end of data collection, 17 participants were interviewed, 14 of which had their interview conducted in English, while 3 had their interview conducted in Afrikaans. This study was conducted online through Google Meets, using a semi-structured interview guide to understand the subjective lived experiences of women with endometriosis. The interviews were analysed according to a descriptive phenomenological analysis in this study's desire to understand participants' common narratives. Seven themes were generated out of the interview data with relative sub-themes, and these themes were termed: endometriosis in a nutshell; medical experiences; mental wellbeing; sexual intimacies; impact on women's lived experiences; social wellbeing; and coping mechanisms. Ethical considerations such as beneficence, non-maleficence, autonomy, anonymity, and confidentiality were considered within this research study. The limitations to the study were that the study was conducted online due to the COVID-19 pandemic, that the age range of 25-35 was used, thus excluding women with endometriosis outside of this age bracket, and lastly that this study was produced due to personal experience with endometriosis, thus resulting in potential bias in the research. The recommendations for future studies on this topic are the use of a face-to-face interview setting to ensure there is no loss of meaning during the interview process; inclusion of women of various age ranges (below the age of 25 as well as above the age of 35, rather than solely 25-35 years of age); and lastly, to ensure that debriefing opportunities are available.

Keywords: *Young women, endometriosis, chronic pain, anxiety, intimate relationships, sexual intimacies, social wellbeing, psychological wellbeing, qualitative, phenomenology*

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Chapter 1: Introduction

1.1. Context

Endometriosis is a common disorder in women of reproductive age, and it can often lead to issues of infertility and chronic pain (Berkley et al., 2005). Pain manifests through menstrual pain, sexual intercourse, and chronic pain (Sinaii et al., 2002; Giamberarino et al., 2001). According to literature, there is no cure for endometriosis, only an alleviation of symptoms (Petrelluzzi et al., 2008). Endometriosis occurs when cells that line the womb are found elsewhere in the body, usually inside the lining of the abdomen and pelvis, and in areas such as the ovaries, vagina, bowel, or bladder (Horne & Pearson, 2018). It has been emphasised that endometriosis affects 10% of women of reproductive age all over the world, while it affects 50% of women that are found to be infertile (Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010). In one study, 48.1% of women that underwent a laparoscopy for gynaecological issues were thereafter diagnosed with endometriosis (Fawole et al., 2015). South Africa has no fixed statistics on how many women are impacted by endometriosis, and there is a paucity of South African research regarding the psychological wellbeing of affected women (Roomaney et al., 2019).

Women with symptoms of endometriosis are more likely to be affected in their mental wellbeing, leading to dysfunctionality (Gaab et al., 2005; Galli et al., 2009). Aspects of mental wellbeing, such as anxiety, can potentially exacerbate experiences of pain through central sensitization, which results in the decrease in mental wellbeing impacting the chronic pain itself (Gaab et al., 2005; Galli et al., 2009). Central sensitization is defined as activity that occurs within the central nervous system which can cause pain responses, and thus can often occur and be amplified by the experience of anxiety due to increased activity within certain areas of the brain (Blackburn-Munro, 2004; May, 2011). Endometriosis is not recognised as being associated with central sensitization, and this results in therapies not considering this potential cause of pain experiences (Ren & Dubner, 2007; Woolf, 2007).

Endometriosis cannot be diagnosed until a laparoscopy is performed, which requires invasive procedures and exorbitant financial costs, which most women in South Africa cannot afford (Barbieri & Missmer, 2002; Endometriosis Research Center, 2006; Lemaire, 2004; Kang et al., 2006). There is a misconception that endometriosis affects women of a higher socioeconomic status more than those with a lower socioeconomic background (Wanyoike et al., 2017; Kyama et al., 2007). Many women from resource constrained communities cannot afford the costs of medical care, hence their underrepresentation in literature (Kyama et al., 2007).

1.2. Problem Statement

Many articles on endometriosis focus on a biomedical perspective, with a paucity of literature on the lived experiences of women with endometriosis (Lorencatto et al., 2006; Roomaney et al., 2019). Experiences of endometriosis in young women in South Africa is significant in how their social, psychological, and physical wellbeing is affected by experiences of chronic pain. Furthermore, they experience reduced mental wellbeing resulting in heightened anxiety (Culley et al., 2013). This study aims to understand the subjective experiences of women with endometriosis and chronic pain by bringing forth their voices.

1.3. Aims and Objectives

The aim of this research study is to explore the lived experiences of young women with endometriosis in South Africa. The objectives are to:

- explore the lived experiences of young women with endometriosis in relation to chronic pain;

- explore the lived experiences of young women with endometriosis in relation to their intimate relationships, and;
- explore the lived experiences of young women with endometriosis in relation to their mental wellbeing.

1.4. Rationale

Women who suffer from this disease are affected by physical and psychological symptoms, and in their intimate relationships. Although there is much recent research that addresses the diminished psychological wellbeing of women with endometriosis, there is not much awareness within the South African population around the disease and women are still struggling with this the psychological effects of endometriosis (Lorencatto et al., 2006; Fries et al., 2005; Culley et al., 2013; Gilmour et al., 2008). There is a need for research into the effects of chronic pain and endometriosis, as demographic reports of women with endometriosis come from those who are able to financially afford medical care (Kyama et al., 2007). This is significant in helping mental health professionals understand the disease and develop better treatment plans. According to the African Union (2006), young women are defined as being between 15-35 years of age. Moreover, the age of 25-35 years old is considered due to Erikson's psychosocial stages of development (McLean & Syed, 2017). The stage of intimacy vs isolation is considered and this stage examines the importance of how relationships develop. Furthermore, the development of identity is considered prior to intimacy vs isolation and thus, Erikson establishes intimacy vs isolation as significant once individuals have developed their identities. This stage focuses on sharing those developed identities with others, whether in romantic or platonic relationships (McLean & Syed, 2017). Reproductive age according to the World Health Organization's (2006) definition is constituted as between 19-40 years old, which aligns with the stage this study focuses on. The reasoning behind the focus on young women that are affected with endometriosis is due to the fact that this age range of 25-35 years old is incredibly critical for identity formation, and the formation of intimate relationships and thus, the effect that endometriosis has on women should have extensive focus in order to provide support for women during this stage of their lives. Furthermore, as aforementioned, endometriosis affects 10% of young women of reproductive age worldwide, emphasising the importance of a focus on young women (Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010).

Chapter 2: Literature Review

Endometriosis as a disease is significant to understand, particularly in the way it affects women of reproductive age both physically as well as psychologically. Literature on endometriosis is extensive from a biomedical perspective regarding how fertility and physical attributes of life are affected (Berkley et al., 2005; Kyama et al., 2007). Further, within the last few years there has been a growing body of literature that speaks to the psychological effect of endometriosis, as well as the way in which the physical experience of chronic pain impacts women's mental and social wellbeing, but women with endometriosis are still struggling psychologically and socially with minimal relief (Moradi et al., 2014; Kold et al., 2012; Denny, 2009). Thus, this study considers endometriosis as a physical disease that afflicts women with chronic pain, and considers various psychological and social impacts of the disease. Psychologically, endometriosis contributes to enhanced anxiety and stress, which can in itself influence the experience of chronic pain; and socially, endometriosis can often affect women's intimate and sexual relationships. Given the above, the psychological, social, and physical wellbeing of women affected by endometriosis are interlinked with women's experiences of the disease, thus there is the necessity to consider all three elements of wellbeing when understanding endometriosis.

The concept of wellbeing has continuously been disputed within literature and thus, it becomes "intangible, difficult to define, and even harder to measure" (Thomas, 2009, p. 11). Wellbeing is often constituted as incorporating three aspects: life satisfaction, pleasant affect, and unpleasant affect. The World Health Organization often uses "quality of life" and "wellbeing" interchangeably, and thus they define quality of life as a "concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment" (World Health

Organization, 1997). Therefore, wellbeing is largely considered in this paper as relating to physical health, psychological state, and social relationships.

2.1. Physical Wellbeing

Physical wellbeing is the ability to perform physical activities without limitations or experiences of pain (Capio, 2014). Symptoms of endometriosis include fertility complications and pain associated with menstruation, sexual activity, bowel activities or chronic persistent pain (CPP) (Sinaii et al., 2002; Giamberardino et al., 2001). Endometriosis affects the physical wellbeing of women through CPP, and there are three broad categories of endometriosis: superficial peritoneal endometriosis, deeply infiltrating endometriosis, and ovarian endometriosis (Nisolle & Donnez., 1997). There are further physical complications that can occur which contribute to chronic pain, however, many of these issues cannot be definitively diagnosed without surgery. Infertility is often associated with physical pain and affects women with endometriosis, and this ties into their social and psychological wellbeing (Dunselman et al., 2014). Chronic pain becomes the primary focus of this thesis due to the fact that infertility has often been investigated extensively in the literature on endometriosis. However, despite this, infertility is still largely considered in this paper due to its extensive involvement with endometriosis.

2.1.1. Chronic Pain

Pain is defined as a sensory or emotional experience that is unpleasant, and associated with tissue damage (Merskey & Bogduk, 1994). CPP is persistent pain that lasts beyond 3-6 months (Trioloa et al., 2013). CPP in the pelvis is characterised by negative cognitive, behavioural, sexual, and emotional consequences and can be linked to issues in the urinary tract, sexual, bowel, pelvic floor, or gynaecological dysfunction (Baranowski et al., 2012). 30-50% of women who experience CPP are found to have endometrial issues and Lorencatto et al. (2006) found that a third of women who underwent a laparoscopy due to CPP had endometriosis. CPP is assessed through whether: the pelvic pain is cyclic; endometriosis has been diagnosed via laparoscopy; and the pain persists despite surgery (Trioloa et al., 2013). The pain is said to usually begin one or two days before menstruation up until the end of menses when a woman has endometriosis, however, some women experience constant and debilitating pain, which results in a dysfunction in daily life, lending itself ultimately to the development of CPP (Cox, Henderson et al., 2004).

CPP is not just physical in nature but is connected to negative psychological states of wellbeing (Blackburn-Munro, 2004). Women who are affected by CPP are more likely to struggle with anxiety and depression (Dorn et al., 2009). Many studies support the same findings, however, there is little consensus on why this occurs, and most doctors and gynaecologists do not consider the mental wellbeing of individuals as being the potential cause of persistent pain. One such concept that is fundamentally relied on is that pain and the experience of it is due to activity within the central nervous system (CNS), often referred to as central sensitization (Stratton & Berkeley, 2011). Anxiety can amplify pain due to increased activity within certain areas of the brain (Quartana et al., 2009). Fauconnier & Chapron (2005) suggest that the actual lesions caused by endometriosis engage the CNS to produce this persistent pain by compressing nerves near the lesions and enhancing pain beyond that which is due to damage. Often medical professionals assume pain is due to physical dysfunctions, and there is a lack of a holistic understanding of the disease (Ballard et al., 2006; Denny, 2004; Huntington & Gilmour, 2005). This often leads to the trivialization of pain from medical professionals when no physical issue is detected, and often the pain is thus attributed to being a normal part of menstruation (Cox, Henderson et al., 2003; Denny, 2004; Huntington & Gilmour, 2005).

Furthermore, endometriosis has not been recognized as a disease that has a potential association with neural dysfunction, such as with central sensitization (Stratton & Berkeley, 2011). This increases the need for discussion around the topic, as therapies do not attempt to find treatments relating to the nervous system and have not undergone clinical trials and therefore, all therapies are medical in nature and much of the time, this does not help women with endometriosis and CPP (Stratton & Berkeley, 2011). Furthermore, this leads to depression and increased stress, as well as a feeling of isolation due to the lack of understanding of their condition (Cox, Henderson et al., 2003). These feelings increase the pain sensations experienced, and CPP individuals end up in a cycle of pain that they cannot break out of. Endometriosis is under-diagnosed and under researched, particularly in relation to women's experiences, and CPP thus becomes even less understood (Horne & Pearson, 2018). Based on the above, the contention is that understanding CPP in relation to endometriosis, as well as its connection/relation to psychological wellbeing in the theory of sensitization, is important.

2.1.2. Infertility

Infertility issues are associated with endometriosis, and women who have endometriosis are likely to be concerned with their fertility (Dunselman et al., 2014). Infertility is reported in an estimation of 25-50% of women with endometriosis (Meuleman et al., 2009; Ozkan et al., 2008). In South Africa, the prevalence of endometriosis in black African [1]women is unknown (Wanyoike et al., 2017), and has previously been believed to be relating to the idea that endometriosis is more prevalent in white women, however, this is not the case as it has been seen

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[1] Race is referred to here as many articles (Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010; Wanyoike et al., 2017) on endometriosis posit the idea that the lack of statistics available on black women that are afflicted with endometriosis is due to financial burdens of endometriosis surgeries, rather than due to endometriosis being more prominent in white women, as was posited by numerous authors cited in Kyama et al. (2007).

that medical care for endometriosis is incredibly extensive, resulting in rather those of a lower socioeconomic status being unable to afford medical care associated with endometriosis (Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010; Wanyoike et al., 2017). Thus, it posits that it is based on ability to afford medical care rather than race, as most reports regarding fertility issues are on white women, given their ability afford medical care given their higher opportunities during the apartheid era (Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010; Wanyoike et al., 2017). In a South African study, fertility issues in endometriosis patients resulted in women feeling depressed and anxious (Roomaney et al., 2019), and this had negatively influenced their relationships with regards to concerns of conception (Roomaney et al., 2019).

2.2. Social Wellbeing

Social wellbeing is conceptualised as encompassing characteristics such as social acceptance; social actualisation; social contribution; social coherence; and social integration (Keyes & Lopez, 2002). Social wellbeing is significant when considering the experiences of women with endometriosis, as physical aspects of the disease can affect the social characteristics mentioned. Although social wellbeing is affected in various friendships and family relationships when considering endometriosis, the greatest impact is upon intimate relationships and sexual intimacies.

2.2.1. Intimate Relationships

Endometriosis can impact romantic relationships with the inability to start a family; inability to be sexually intimate due to pain; and decreases in mental health resulting in an exacerbation of pain. These factors pose challenges within intimate relationships if the partner does not understand the disease. Women expressed frustration in feeling unable to speak to their partners, as often individuals assumed that pain symptoms these women felt were “in their head” (Denny, 2009). The experience of CPP can result in women becoming dependent on support, as women with CPP can experience limitations, such as in their social and work lives due to reduced physical performance (Lorencatto et al., 2006). Should this dependency affect their relationships, they experience lower self-esteem and social support, worsening the experience of pain (Dunselman et al., 2014). In a South African study, women felt depressed and frustrated in their inability to manage their pain, which reduced their confidence and resulted in isolation (Roomaney et al., 2019).

As self-esteem and confidence can often be reduced due to the nature of the disease, social isolation becomes increasingly prevalent (Roomaney et al., 2019). In a South African study, women were found to feel increasingly depressed and frustrated in their inability to manage their experiences of pain, which seemed to reduce their confidence and result in further isolation from partners, as well as friends (Cox et al., 2003; Gilmour et al., 2008). Thus, women with endometriosis enter a cycle in which they feel increasingly worse due to CPP and this results in women isolating themselves from support structures, which then increases feelings of frustration and depression, enhancing the already present pain.

2.2.2. Sexual Intimacy

Sexual intimacy can become difficult for women with endometriosis due to pain during or after intercourse, and decreased confidence and self-esteem, which could result in less sexual libido (Rossi et al., 2008). In Rossi et al.’s (2008) study, women with endometriosis reported that they experienced less satisfying sex lives and relationships than other women who did not suffer from endometriosis. Furthermore, they reported that they experienced poorer sexual functioning than women without endometriosis, largely due to experiences of dyspareunia (genitopelvic penetration disorder), which is often a symptom of endometriosis (Roomaney et al., 2019). Considering this issue, it can be understood how intimate relationships become impacted upon due to the experience of endometriosis, as sexual intimacies can be incredibly important for many intimate relationships. Should women with endometriosis be unable to be sexually intimate with their partners, this could lead to a dissatisfying intimate relationship and cause issues for women afflicted by this disease.

2.3. Psychological Wellbeing

Psychological wellbeing is the experience of feeling good while functioning effectively in various domains (Huppert, 2009), and this incorporates positive emotions such as happiness and confidence. If this is absent, the individual struggles to function effectively (Huppert, 2009). This can lead to decreased mental wellbeing in women with endometriosis, as chronic pain and infertility can lead to increased depression and anxiety, which affects intimate relationships.

A few studies noted a link between endometriosis, anxiety, and psychosocial stress, however, there is a need for further research on the association (Facchin et al., 2017). Women with endometriosis often report being dissatisfied with the health care they receive as they find it difficult to find doctors that take their condition seriously (Roomaney et al., 2019). There is much research attempting to understand how to rectify the condition in consideration of psychological wellbeing, but more research is needed (Roomaney et al., 2019).

Women with endometriosis who experience CPP often show symptoms of depression. According to Lorencatto et al.'s (2006) study, depressive symptoms were present in 86% of women with CPP. Cox et al. (2003) explain that women with endometriosis experienced higher levels of depression due to the lack of certainty and unpredictability of endometriosis.

Depression and anxiety are largely investigated within research, however, not much research is conducted on other forms of mental wellbeing.

Due to the generally biomedical consideration of the disease and paucity of research on psychological wellbeing and CPP in women with endometriosis, this study becomes significant. It further becomes significant in exploring the experiences of CPP in women with endometriosis.

2.4. Theoretical Framework

Phenomenology is a philosophical discipline and framework that emphasises the importance of self-awareness, particularly in relation to phenomena such as caring and healing explored through lived experiences (Wojnar & Swanson, 2007). Descriptive phenomenology understands that the meaning of lived experiences is only truly understood once one-on-one interactions are had, such as that between a researcher and participant (Wojnar & Swanson, 2007). As phenomenology relates to interpretivism, this theoretical framework becomes significant in this study's aim to explore the lived experiences of women with endometriosis by using interactions between the participant and researcher to develop meaning (Dudovskiy, 2018). Within a phenomenological study and use of a phenomenological framework, it is the researcher's obligation to ensure "bracketing" is maintained. Bracketing is defined as a "deliberate putting aside [of] one's own belief about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation" (Chan et al., 2013, p. 1). This method is exclusive to phenomenology and is a way in which to maintain validity of the data collection and analysis process. Phenomenology further calls for a production of meaning of lived experiences, as well as in-depth meaning production. Furthermore, self-awareness is a significant principle in phenomenology, which should be maintained in research (Chan et al., 2013).

Chapter 3: Research Methods

3.1. Research Approach

This study used a qualitative approach. Qualitative research considers how individuals attribute meaning to experiences (Hesse-Biber & Leavy, 2011). Due to the exploratory nature of this research, this facilitates understanding into unknown areas of research (Terre Blanche et al., 2006a). Interpretivism considers the world through individuals' experiences (Tanh & Tanh, 2015). Therefore, interpretivist research aims to present findings through emotional language and rich detail to explore subjective experiences (Terre Blanche et al., 2006a).

3.2. Participants

When using a phenomenological framework, studies can consider 4 participants (Maree, 2015), while others may consider up to 20 participants (Braun & Clarke, 2012). For the purposes of my study, I decided to consider 10 participants, contingent on data saturation. Data saturation is contested within qualitative research, as there are differing rules of when data saturation is reached. Within interpretivism, data saturation is reached when no new data, themes or coding is produced, and when there is an ability to replicate the study (Fusch & Ness, 2015). Thus, this study concluded data collection with a total of 17 participants. The use of probing questions in the semi-structured format allowed for data saturation to be reached as far as possible (Fusch & Ness, 2015).

This study used purposive sampling, which is a non-random form of sampling and allowed for the choosing of participants based on characteristics that met the inclusion criteria (Tongco, 2007). The inclusion criteria for participants were that they had to be female, they had to be between the ages of 25-35 years, they had to be of a South African nationality, and they had to have been medically diagnosed with endometriosis. The only exclusion criteria were women below 25 years old or above 35 years old, and women who had not been medically diagnosed with endometriosis.

As shown in table 1 below, the demographics of the participants varied greatly in age, race[2] and education level. Race discussed in this section is marked by the participants' own identification of their races. Most of the participants interviewed were of a white race (82.4%), while a few of the participants were of a coloured race (11.8%), and one participant was of an Indian race (5.6%). All participants were female. The lowest age interviewed was a female of 24-years old who was turning 25 in a month's time from the date of the interview, whilst the oldest female interviewed was 34-years of age. Participants vary in location, with participants from Cape Town (41.2%), Johannesburg (29.4%), general Western Cape area (11.8%), Durban (5.9%), North-West Province (5.9%), and one participant currently residing in the United Kingdom (UK), having only migrated from Cape Town within the last year (5.9%).

The education level amongst participants also varies, with some participants holding a postgraduate degree (29.4%), undergraduate degree (23.5%), a diploma (17.6%), a tertiary certificate (5.9%), a matric (11.8%), and one participant currently undergoing their undergraduate (5.9%), while one participant holds a N4 and N5 in Human Resource Management (5.9%). Most of the participants were employed (88.2%), while a few were students (11.8%). Most participants do not have children (82.4%), whilst only a few have children (17.6%). The majority of the participants have had fertility issues over the course of their lives (64.7%), whilst only a few have not experienced such issues (35.3%). Lastly, the

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[2] As discussed in the literature review, race became necessary to evaluate due to this paper's aim to understand socioeconomic differences across women with endometriosis and as mentioned prior, historically due to apartheid, most women of colour have been previously disadvantaged socioeconomically. Thus, this paper wished to understand whether this was a prevalent role in the diagnosis and presentation of endometriosis as a disease.

majority of the participants opted for their interviews to be conducted in English (82.4%), whilst a few preferred Afrikaans as their language of choice (17.6%).

Table 1

Table Showing Demographic Characteristics of Participants

Demographic Category	**Types**	**Percentage (%)**
Race	White	82.4
	Coloured	11.8
	Indian	5.6
Location	Cape Town	41.2
	Johannesburg	29.4
	Western Cape area	11.8
	Durban	5.9
	North-West Province	5.9
	UK	5.9
Education Level	Matric	11.8
	Diploma	17.6
	Tertiary Certificate	5.9
	Undergraduate Degree	23.5
	Postgraduate Degree	29.4
	Undergoing Undergraduate Degree	5.9

	Undergoing N4 and N5 in Human Resource Management	5.9
Employment Status	Employed	88.2
	Student	11.8
Children	Have Children	17.6
	Do Not Have Children	82.4
Fertility Issues	Have Fertility Issues	64.7
	Do Not Have Fertility Issues	35.3
Language of Interview	Afrikaans	17.6
	English	82.4

3.3. Research Setting

The setting of this proposed study was entirely online; thus, interviews took place using Google Meets. The use of an online research setting allowed for access to socially isolated groups, as endometriosis can lead to an inability to function in certain activities (Crete & Adamshick, 2011; Seymour, 2001). This online setting ensured safety between participant and researcher during the COVID-19 pandemic. Online settings can also bring some challenges, including a potential loss of meaning through the inability to properly read emotion through screens (Williams et al., 2015). Online interviews can hinder the comfort participants feel during the interview, and it causes potential ethics implications in a lack of privacy in the online setting. Should the participant be unable to have the interview in a private space, privacy could be hindered. I thus negotiated a time for the interview with the participant in which they were able to have a private setting and in which I had a private setting myself. A final issue around using an online space to conduct the interviews was the potential impact it had on the sample acquired, as there are issues related to accessibility and data costs that could impact who was able to participate in the research study, and who would not have been able to participate. Thus, in needing data to connect online for the interview, some individuals would have been unable to have the interviews online due to limited resources, which could bias the sample.

3.4. Data Collection Procedure

Ethics clearance was requested and granted from the Biomedical Research and Ethics Committee (BM21/7/9) as well as from higher degrees by providing them with my proposal for approval. After receiving the ethics clearance letter, I recruited participants from support groups on Facebook. I requested permission to post in the groups, which allowed for participants to volunteer to take part, and I was granted such permission. I then provided individuals with the requirements to participate within an advertisement (see Appendix C & D). Anonymity was maintained in the groups as individuals were requested to follow a google forms link (see Appendix E) and provide their email addresses and consent to participate in the study.

The google link incorporated an information sheet explaining the reasons for the study (see Appendix F & G) and a consent form they could sign if they wished to participate (see Appendix H & I). I requested permission to record the interviews for transcription and I was granted such permission. Furthermore, considering I offered the interviews in either English or Afrikaans, I further requested permission to bring an outside researcher that is fluent in Afrikaans to conduct the Afrikaans interviews on my behalf. Within the google form (see Appendix E), I acquired the necessary demographic characteristics of each participant. Once participants had consented to participate through initialing the online google form, I requested that they find a private space from which they could have the online interview with me, and this was done by conducting the interviews when it was convenient for them.

3.4. Data Collection Methods

Semi-structured online interviews were used due to its use of open-ended and closed-ended questions, which allowed the participant to guide the interview (Adams, 2015). An interview guide was structured for the interviews (see Appendix A & B). Each participant was given the option for the interview to be conducted in either English or Afrikaans. isiXhosa was not considered, due to the my inability to speak isiXhosa, as well as the lack of access to a researcher that could assist with the isiXhosa interviews for the research study. The researcher I used for the Afrikaans interviews is a member of my master's research class and therefore understood the importance of ethics. Interviews were conducted online via Google Meet. The shortest interview was 15 minutes long, while the longest interview was 59 minutes long. Thus, the average interview time was 33.1 minutes long ($\bar{x}$ = 33.1).

In using semi-structured interviews in this study, it allowed for one-on-one interactions to take place, which resulted in a production of meaning of the lived experiences of women with endometriosis, required of a phenomenological framework. Furthermore, the role of the researcher was to allow the participants to lead the interviews in order for their personal experiences to be heard and in-depth meaning production to be ensured. This was maintained by following a semi-structured format with the use of probes, dependent on the route the participant took regarding the interview. This allowed for the lived experiences of the participants to be incorporated in this research study without bias. Furthermore, self-awareness was maintained by using a reflective journal through the data collection process to ensure bias was kept to a minimum, as well as through maintaining open communication with the participants through occasional self-disclosure and reassurance in order to maintain a caring atmosphere.

3.5. Data Analysis

Once I had conducted the interviews, I transcribed the English interviews using the recorded audio, and used a transcription company for the Afrikaans interviews in which the names of the participants were concealed, as the files were marked by participant numbers. After the transcriptions were complete, the researcher I used to conduct the Afrikaans interviews translated the transcriptions. Once the transcriptions were completed, a descriptive phenomenological analysis was used in this research study. In reading the description, the researcher must read to understand the data prior to the analysis, and this was done by reading the transcripts prior to beginning my analysis (Girgoi, 2012). Constituting parts refers to marking parts of the transcriptions in which there is meaning, and this was done by coding the transcripts based on relevant experiences (Girgoi, 2012). Transforming the data revolves around expressing the data in a meaningful way, and this was done by grouping common experiences together to make meaning of the given phenomenon (Girgoi, 2012). The write-up thus should incorporate the sensitive experiences to adequately represent them, which was done by portraying the raw experiences as they were told to me and by including every participant’s experience in the analysis (Girgoi, 2012). The final step was interpretation, and the data was then used to explore and clarify the meaning of the experiences (Girgoi, 2012).

3.6. Ethics Considerations

Beneficence provides the participant with the maximum benefits, while non-maleficence is the researcher's obligation to do no harm to the participant (Jungers & Gregoire, 2013). Thus, questions were structured sensitively, and referrals were provided if they required support in the event the research evoked an emotional response. It was further made clear that the participants were not required to answer questions that made them uncomfortable. Autonomy allows participants to make their own decisions regarding research through voluntary participation and informed consent (Jungers & Gregoire, 2013). Participants were made aware that they were able to withdraw from the study at any time, and the interview guide allowed for participants to direct the interviews. Confidentiality was considered by ensuring that the interviews were conducted in a private space. Anonymity was maintained through consideration of the POPI Act by ensuring participants signed-up through the google forms link to maintain anonymity. Privacy was maintained by using participant numbers to ensure no data used in the research study was linked to participants interviewed. The transcriptions and recordings shall be kept in a password protected folder on my computer for 5 years, after which it shall be deleted.

3.7. Trustworthiness

Trustworthiness includes establishing credibility; transferability; dependability; and conformability (Pandey & Patnaik, 2014). Credibility is like internal validity and seeks to ensure the research study measures what it intends to (Pandey & Patnaik, 2014). This was established by developing a relationship of trust with the participants as well as using peer debriefing with my supervisor. Transferability investigates if a study has relevance to differing contexts (Pandey & Patnaik, 2014). This was established by providing a detailed description of the context, which is done through the google form that I provided. Dependability ensures the findings of the study are consistent and can be repeated (Pandey & Patnaik, 2014). This was done by ensuring methods and findings were as detailed as possible to allow for replication of the study (Pandey & Patnaik, 2014). Conformability maintains neutrality and reduces researcher bias (Pandey &

Patnaik, 2014). This was established by using audit trails and giving a step-by-step description of the study (Pandey & Patnaik, 2014).

3.8. Reflexivity

Reflexivity is the researcher's ability to be aware of their own values and perspectives to ensure they do not influence the findings (Pandey & Patnaik, 2014). I am a white female of a middle socioeconomic class and am English speaking. My ethnicity and socioeconomic status differed to some participants, and this could have hindered my ability to understand the participants' experiences. I managed this by being open-minded and taking intersectionality into consideration in the context of differing experiences. In being a fluent English speaker and despite my fair command of the Afrikaans language, I am not a fluent Afrikaans speaker. This could have biased my research in losing meaning through language, thus, I implored the help of a fellow classmate who understood the ethics behind research to conduct the Afrikaans interviews.

Bracketing was maintained in this study in various ways. Firstly, in being a female and having been diagnosed with endometriosis myself, I could potentially bias the research and thus, I ensured my own experience of the disease did not bias the research by using a semi-structured interview guide, in which participants guided me through their experiences. I further kept a journal documenting my thoughts during the process to remain open-minded. One positive regarding my own experience with endometriosis was that I was able to connect with my participants empathically. Secondly, with regards to bracketing, I made sure I maintained transparency with my participants about my own experiences when I was asked about it in the form of self-disclosure, and this led me to develop a relationship of understanding and trust, and my participants thus were able to feel comfortable with me. I further managed my own perceptions of endometriosis by remaining compassionate and understanding of their experiences despite my own. Despite having had previous knowledge regarding endometriosis prior to conducting this study, there was still much I did not understand about the disease. Thus, I allowed this study to be a learning process for myself and for my participants in listening to their experiences and debriefing them on my own knowledge post-interviews.

Research requires the researcher to be understanding of their own experience while still being transparent to the reader of the paper produced and thus, I shall debrief in this section regarding my experience of the interview process in being an individual diagnosed with endometriosis myself.

The interview process at times was emotionally evocative for myself, due to common experiences I shared with the participants, as I felt their struggles and understood their experiences. This led me to be emotional at points during the interview process and after data collection was completed. In order to manage my own bias and remain compassionate and representative of their experiences, I attempted to produce in-depth interviews of their experiences beyond the focus of my study so as to not focus on my own personal aspects of the disease. Thus, the raw experiences of participants are portrayed in the findings chapter of this thesis. Furthermore, after the interviews and the entire data collection process was completed, I made sure to check in with myself and take time for myself doing activities I enjoyed and debriefing with individuals close to me, sharing my emotions and what I had experienced during the process. By doing this, I was able to take on data analysis with fresh eyes and unbiased emotions. Furthermore, in deciding upon quotes to use within my study, I implored the perspective of my supervisor to reduce bias even further.

Chapter 4: Findings

The purpose of this study was to explore the lived experiences of young women with endometriosis in South Africa, with specific focus on their experiences of chronic pain, mental wellbeing, and intimate relationships. This indicates why a phenomenological framework was significant for this study, as it primarily focuses on the subjective lived experiences of young women. Thus, seven significant themes emerged from the interviews with various participants, each of which yielded their own relevant subthemes. These themes are: endometriosis in a nutshell; medical experiences; mental wellbeing; sexual intimacies; impact on women's lived experiences; social wellbeing; and coping mechanisms.

Table 2

Table Showing Themes and Relative Subthemes

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4.1. Theme 1: Endometriosis in a Nutshell

Endometriosis has many defining characteristics that affect women afflicted by the disease, and experiences that participants shared during the interviews varied in positive and negative experiences across a range of aspects. These experiences included infertility concerns, the typical symptoms associated with endometriosis, how endometriosis manifested physically for participants, chronic pain experiences in relation to endometriosis, genetic tendencies throughout families associated with the disease, as well as the lack of knowledge or understanding regarding endometriosis or how to deal with the disease.

4.1.1. Infertility Concerns

As has been discussed before, infertility concerns have been a big concern for many women struggling with endometriosis, and this was further emphasised through interviews with the participants. Many of the participants struggled with the inability to conceive, and these experiences ranged from struggling to conceive, to feelings of knowing they would not be able to conceive.

> **Participant 17:** *"I am someone who has always wanted children. I love children so, so much, so that broke my frame of mind completely down. It is after this week that I am finally starting to feel like half a person and, you know, sorting my process of accepting what happened."*

Women found it difficult to accept their inability to have children when they were hoping to conceive or have children at some point in their lives. Furthermore, participants expressed that the process of realising that they were not able to conceive was difficult to overcome and that it took a long time to deal with. Other participants shared their experiences of knowing prior to trying to have children that they would not be able to conceive due to having had experiences with endometriosis for a long period of time.

Participant 11: *"I always had this instinct that I will never have children. I dunno how it happened, and if anybody asked me like ya but when you get older you will have kids, and I'd always - I dunno - which was something weird to me because I'm not religious, I'm not superstitious, nothing. But for some reason I always knew I would never have a child, ever."*

Despite these experiences and concerns around fertility, there were some participants that expressed that they were able to conceive despite the doctor's warnings that they would not be able to conceive due to their diagnosis.

Participant 13: *"I found out I was pregnant with my daughter at 20...And he looked at me and he said to me, "you not supposed to be able to get pregnant, this is a miracle"."*

Thus, participants had varying experiences. While most of the participants either struggled to conceive or were unable to conceive, there were also a few participants that managed to conceive despite being diagnosed with endometriosis.

4.1.2. Symptoms of Endometriosis

Symptoms of endometriosis experienced by participants ranged across the board, with some participants experiencing multiple symptoms, while others only experienced one typical symptom of the disease. One of the most common symptoms that was expressed was being afflicted with either heavy or irregular menstrual cycles. Furthermore, pain during that time period was expressed as an enhancement of the symptom.

Participant 6: *"I literally did not stop bleeding, I think it was for like a month, and ya it was terrible, like you have all that pain and everything."*

Another symptom that was fairly common amongst participants was the experience of fatigue or lack of ability to concentrate in daily life, and this was further expressed in conjunction with experiencing mood swings and uncontrollable irritableness. Along with these symptoms, however, were a few participants that also experienced terrible headaches.

> **Participant 4:** *"I can feel myself being moody and I can feel myself lashing out at my husband when I don't want to... I had fatigue I had experienced a lot of pain, I would get really down... A lot of headaches…"*
>
> **Participant 17:** *"If someone just looked as if they were going to look at me a certain way, then I would totally lose my shit, to put it like that."*

Although endometriosis as a disease causes numerous symptoms, mood, fatigue and irregular or heavy menstrual cycles were the most prominently experienced by most participants.

4.1.3. Physical Manifestation of Endometriosis

Despite the symptoms women experience in relation to endometriosis, there were also ways in which endometriosis manifested physically for participants, which resulted in doctor's diagnosing them with the disease or needing to perform laparoscopies on the participants. One participant expressed that her ovaries and uterus mended together with her spine, which caused numerous issues with the nerves in her spine, causing her further chronic pain on top of the pain she experienced from her fibromyalgia.

> **Participant 5:** *"...my uterus and my ovaries was stuck to my spine, so that had to be cut loose, or loosened from there, so now I have a problem with my sciatic nerve as well... I was diagnosed with fibromyalgia as well…"*

Another common physical manifestation expressed by participants was the prominence of cysts on their ovaries and for some of the participants, those cysts had popped, which they explained was incredibly dangerous and painful.

> **Participant 11:** *"...he basically said you had a big endometriosis cyst, and it was very large and basically popped and filled with a lot of fluid and lost some blood... he said my one ovary was double the size of what ovaries and a womb combined should be, the other one was completely dead, it wasn't existent…"*

Other physical manifestations that were experienced were due to negligence from doctors, which made the diagnosis and removal of endometriosis and cysts incredibly difficult thereafter.

> **Participant 15:** *"When they performed the laparoscopy, they realised that my uterus and stomach were sewn together after the caesarean, and between the stomach and endometrium lining were many growths which then caused endometriosis. They then took a little bit out. Then they told me, my bladder and uterus has grown attached together, but they could not loosen it because they were afraid that if they loosen it, it will tear and so forth."*

Furthermore, these physical manifestations often resulted in the need for complicated surgeries or concerns that the doctors would inherently cause damage if they attempted to rectify the issue.

4.1.4. Chronic Pain

One of the most common presentations of endometriosis expressed by the participants was chronic pain and how it affected numerous aspects of their lives. Most of the participants interviewed experienced chronic pain on a daily basis, while few only experienced it occasionally. One of the most common experiences shared was how the extent of the pain caused them to miss out on general activities, as well as result in a need for painkillers.

> **Participant 6:** *"...when I was at school I remember actually, if I didn't like catch it in time, if I started my period before I'd taken painkillers I would actually like not be able to walk and like vomit and like have diarrhea and it was just terrible, so I remember I usually like would be fine if I'd catch the pain in time, but if I didn't, so like if I started my period when I was sleeping I'd wake up with proper pain, I'd literally have to like crawl to the bathroom, it was so bad…"*

Despite the uterine chronic pain expressed, participants also expressed that chronic pain affected them in different areas of their bodies, such as in their backs or due to general movement that occurred on a daily basis.

> **Participant 13:** *"...mainly it was the indescribable pain lingering down my back as well, so at first I thought it was sciatica, and then no they said it's not sciatica it comes from your endometriosis… The walking and the pain and knowing that I'm gonna be suffering for about two weeks after that one day. That killed me and I couldn't let her know that mommy is dreading celebrating your birthday because mommy knows what's [gets emotional], you know…"*

Other participants expressed that the laparoscopies that were generally used to treat the symptom of pain from endometriosis and attempts at reduction of the disease in general had in fact made their pain worse, while movement of any kind became too painful to endure.

> **Participant 11:** *"...walking, sitting, any physical activity like, ya, um, that I would say the pain has been my greatest thing over the past few years, and I would say that got progressively worse with the more surgeries they did... I can't go and walk with the dogs, I can barely do a kilometer at all, it's too painful, honestly...in*

> *March I actually went to the doctor. I said I'm in so much pain, I've got no quality of life, please, please can you just remove my uterus, remove my ovaries, remove it all. And he said no, because you can get pregnant. And then I said I cannot walk, so I can't take it anymore, I got no quality of life, and I'm at the point where it would be easier to kind of shoot myself because I'm bed ridden."*

Despite the physical experience of the pain by participants, there was also a mental toll that was expressed that resulted in participants feeling more depressed, anxious, or occasionally even suicidal.

4.1.5. Genetic Tendencies

An interesting subtheme that occurred during the interviews was that many individuals within the participants' close family had experienced symptoms of endometriosis or had in fact been diagnosed with endometriosis. This often resulted in participants believing that endometriosis is passed down through generations.

> **Participant 13:** *"... she's twelve and she's started with her period at ten. And she's also already in unforgivable pain so I already know it's coming for her and there's nothing I can do about it, she's twelve years old, what do I give her, how do I help her at twelve... But my cousin has the same as me and it's my cousin from my mother's side, you know…"*

Similarly, some participants had had close family members that had been prone to uterine or cervical cancer as well as having endometriosis, resulting in the necessity for hysterectomies.

> **Participant 1:** *"...my mom had to have a hysterectomy at the age of 38 years old. It was because they found pre-cancerous cells and the endometriosis was really bad as well."*

Furthermore, a common experience shared was the experience of miscarriages by close family members due to having endometriosis, which in turn resulted in their family members getting hysterectomies.

> **Participant 7:** *"...went to the gynae with my mom, and she spoke to her as well and it seems like we both had it, my mom had a hysterectomy 20 years ago, or earlier than that, so back then she didn't know that that was what it had been so ya, because she also, she got - I was pregnancy number 6, baby number 1."*

This subtheme was quite interesting as there were various understandings expressed around genetic tendencies of endometriosis.

4.1.6. Lack of Knowledge/Understanding

Women with endometriosis expressed either that they had a lack of knowledge around what the disease entailed when they were diagnosed, or that there was, and still is, a lack of knowledge amongst medical professionals and those not afflicted by the disease. One participant expressed that she had noticed that many white women get diagnosed for endometriosis fairly easily, while the diagnosis for black women in South Africa is not as prevalent, despite the experience of endometriosis symptoms.

> **Participant 9:** *"...it's not widely discussed and now it's chatting to the different specialists I've been to now, it hasn't been a priority in the South African market and definitely not… more African markets... it's not as volatile or picked up and only of recent years have they really put more of a focus on it."*

Other experiences around a lack of understanding and knowledge of endometriosis came from feeling like individuals in participants' lives attempted to reassure them that everything would work out for them, despite the fact that medical professionals do not know how to cure endometriosis. Thus, frustration was expressed around this experience in feeling as if others were incapable of reassuring participants when the diagnosis itself was so uncertain.

> **Participant 10:** *"...I find that like it's hardest to deal with your diagnosis when people are saying everything is gonna be okay, just stay positive it will all work out, because with endometriosis we don't know. Doctors don't know, we don't know. And when someone tries to reassure you, you kind of - I kind of feel like you can't reassure me because I don't know. Doctors don't know, so how could you know?"*

Furthermore, participants expressed that often women experience continuous reproductive issues, or struggles with conceiving, but do not know what is wrong or seek medical guidance in order to establish what the issue is. This was further expressed as endometriosis not being explained enough by doctors to women with reproductive issues despite the prevalence of the disease.

> **Participant 14:** *"Ya, I mean, I've, I've spoken to quite a few women with reproductive issues and like, continuous reproductive issues and I've asked them like have you ever - has your doctor like ever mentioned endometriosis to you and they like sorry, no they haven't mentioned any kind of reproductive issues... And for me it's, it's painful like, knowing like that so many people are just moving forward without knowing what to do or, getting proper guidance…"*

Thus, the common experience amongst participants is that there is not enough knowledge around endometriosis and how it affects women, nor is there enough understanding on how to rectify the issue women experience when it comes to endometriosis. This leads to a lack of understanding from those that are not afflicted by it.

4.2. Theme 2: Medical Experiences

The theme regarding medical experiences became quite prevalent amongst participants, particularly in relation to the experiences they had with doctors, gynaecologists and fertility/endometriosis specialists. While few participants had positive experiences, most of the participants had negative experiences. This theme considers the positive and negative experiences with doctors and specialists, attempts at treatment for endometriosis, as well as doctors providing participants with a timeframe of conception.

4.2.1. Experiences with Doctors and Specialists

Every participant interviewed had an experience with a general practitioner, gynaecologist, or fertility/endometriosis specialist. A few participants noted positive experiences particularly in relation to fertility/endometriosis specialists regarding the way in which they diagnosed and removed their endometriosis, while still being able to comfort the participants and reassure them throughout the process.

> **Participant 8:** *"He said, "you know, I've operated on girls with severe endo in their colon and I've never had to cut out a piece of their colon and I've never had to place them on tube feeding, that should have never*

> *happened to you." And that was quite a wake-up call, you know, to not just go to a gynae if you've got endo, because you think it's all much of a muchness and it isn't. Here I find a brilliant doctor, he's managed to do the minimum, without putting me out for weeks."*

Thus, positive perceptions of fertility/endometriosis specialists came out of the interviews with few participants, however, most of the participants had negative experiences, particularly with general practitioners and gynaecologists. One of the biggest issues that arose out of these interviews was the lack of sensitivity received from doctors and gynaecologists, specifically in relation to chronic pain experienced by the participants.

> **Participant 15:** *"...it is a lot of feedback that one got from the doctors, where the doctor told you that, yes, maybe there is something wrong with your head, but there is nothing wrong with my head, there's nothing psychological, because they say no, you are just addicted to pills because look at how many pills you already used but it did not work."*

As seen above, the inability to believe the experience of chronic pain led doctors to minimise participant experiences, while further insinuating potential mental illness due to the lack of understanding around the participants' experiences.

Other experiences expressed revolved around the inability to receive adequate care and treatment when it was requested, particularly due to the doctor's own beliefs of the participant's ability to have children. However, the participant in question expressed her desire for a hysterectomy despite those beliefs due to the lack of quality of life she experienced on a daily basis.

> **Participant 11:** *"I said I'm in so much pain, I've got no quality of life, please, please can you just remove my uterus, remove my ovaries, remove it all. And he said, "no, because you can get pregnant" ... At that point he admitted me to hospital, and he made me see a - a psychiatric person and they told me it's all in my head. The pain, the cysts, everything, I'm making it up… the psychiatric person she put me on anti-psychotics... I've got a lot of respect for people - for the transgender community, um, but I find it unfair how a woman can go and have a sex change for example and get her womb and all of that removed by saying that she um, is a man trapped in a woman's body, and how that is okay to remove her womb and her ovaries to change genders, but when I say I will sign whatever paper needed, please, please just take the pain away, like please take this out, it's my choice, then it is no…"*

There is further the belief that mental health is the issue with participants due to an inability to understand that pain remains despite numerous operations, which leads to a lack of sensitivity from doctors that women with endometriosis consult. Furthermore, an interesting perception that arose out of the interviews was around the concept of transgender individuals, in that the participant felt it was not fair for her experience of pain to not be validated and how she requested a hysterectomy and was denied, however, that nowadays transgender individuals can change genders and the doctors will not deny them that right. What was interesting about this perception was her inability to understand why her identification as a woman made her unable to have a hysterectomy due to her possibility of bearing children.

Thus, despite some positive experience's participants had, mostly negative experiences with medical professionals were expressed regarding the lack of sensitivity, belief in one's symptoms, or recognition of desired treatment.

4.2.2. Attempts at Treatment

Participants interviewed spoke about many types of attempts at treatment, however, the main treatment was a laparoscopy to remove the endometriosis and definitively diagnose the disorder. Further, some participants found that the laparoscopy helped with pain management or symptoms experienced due to the endometriosis.

> **Participant 12:** *"I mean it's not as heavy, I mean now I hardly get any cramps or anything like that, it's like when my period starts it's usually a surprise because usually I'd be cramping for the week before, um, so there definitely has been a positive thing from having the operation."*

There was affirmation that the laparoscopy helped in a few ways, either by reducing heavy menstrual flow, or by reducing pain associated with endometriosis. Other participants found that a full hysterectomy was the only way they received some relief, although they did emphasise that it was not a cure and did not remove endometriosis symptoms entirely.

> **Participant 11:** *"And look I'm not saying hysterectomy is a cure, I do have some pain every once in a while, but it's completely manageable..."*

Despite these positive experiences, there were participants that were under the impression that laparoscopies and surgeries would completely fix the endometriosis symptoms, however, were disappointed a few months after when their pain and other symptoms returned.

> **Participant 14:** *"...for me I thought that after the op everything would just like fix itself, I still continued with the diet but I just thought that magically I would have like no more pain and wouldn't have to be on hormonal treatment, um, you know, I wouldn't have to take pain meds anymore, but it lasted a couple of months and then it's just like back again."*

Thus, this shows that although laparoscopies are the primary surgery to diagnose and remove endometriosis, they were not a complete cure for the issues participants experienced regarding the disease.

4.2.3. Timeframe of Conception

Another common medical experience by participants is the perception that there is a timeframe on conception ability, and this is often explained to women by medical professionals as needing to start trying to conceive as early as possible should they want to have children.

> **Participant 3:** *"...my doctor did say though that we do need to seriously consider it within the next two to three years, um, he said after, he's giving us max five years, he says at that point in time also everything else starts counting down…"*
>
> **Participant 4:** *"...he said that we need to start trying as soon as possible, the younger you start the more likely you are to have a baby… the less chance of medical intervention like IVF and stuff."*

Furthermore, some participants personally felt like there was a deadline on when they were able to have children purely through having been diagnosed with endometriosis, which often made women feel pressured to get pregnant.

> **Participant 10:** *"...only now because I so badly want to have a child before it's too late almost. I feel like there's a deadline on when I can have a kid and, am I able to have a kid, you know?"*

As can be seen, many aspects around medical experiences were expressed during the course of the interviews with women, and many of the experiences shared were negative in nature, while few were positive perceptions.

4.3. Theme 3: Mental Wellbeing

This research paper outlined psychological wellbeing as one of its primary objectives regarding the experience of endometriosis, and as such, numerous aspects emerged from this endeavour. The most common experiences by participants interviewed was the experience of either a relationship, or no perceived relationship between their chronic pain and mental wellbeing; how endometriosis affected their mental wellbeing in general; as well as how they experienced a sense of diminished womanhood due to the disease.

4.3.1. Relationship Between Pain and Wellbeing

During the course of the interviews, a theme developed regarding the relationship between chronic pain and participants' state of mental wellbeing, albeit that some participants experienced a major relationship, while others did not feel there was a relationship between the two. With regards to a lack of relationship between mental wellbeing and chronic pain, participants mentioned that they felt other coping mechanisms assisted them when they had pain, such as taking a bath or engaging in self-care, rather than noting that there was a link between decreased mental health and heightened pain.

> **Participant 2:** *"If I'm having like a really rough day emotionally, I'll go bath, I'll get into bed, I'll put on a nice movie and that I would say lessens any type of pain... I can't really think of a time where I got more emotionally upset and noticed more pain in my general life…"*

On the other hand, however, some participants noted that when they felt heightened anxiety or stress in their lives, they tended to experience greater pain, or to notice the pain more frequently.

> **Participant 1:** *"I have found that when my anxiety is really really bad, I can feel the pain... I feel that pain more intense when I do have an anxiety or panic attack."*

Furthermore, other participants noticed the link between pain and mental health due to their experience of pain improving when their mental health improved, or vice versa, in which the pain became worse when their mental health was worse.

> **Participant 10:** *"I've always suffered with anxiety, so my anxiety shot through the roof which made me… I made the pain come... So the pain in my head when I wasn't actually feeling the pain. So when I was feeling anxious and I felt - and I let my thoughts run with me, then I would feel like I was in pain and I was suffering when I wasn't actually. Cause the minute someone would come and calm me down the pain would go away."*

Thus, regarding the relationship between chronic pain and mental wellbeing, it can be seen that participants differed in their experiences of this link, whether acknowledging there to be a relationship, or no relationship between the two.

4.3.2. Mental Wellbeing

The most common experience amongst participants was the heightened anxiety felt in association with endometriosis either due to the diagnosis itself having had a negative impact on wellbeing, or endometriosis facilitating heightened anxiety. Furthermore, some participants noted self-esteem issues that they struggled with which facilitated the increase in anxiety or low moods.

> **Participant 5:** *"...it's anxiety as well because you don't know when the next shoe is going to drop, you don't know where the next pain is going to come from... My mental wellbeing, I suffer from extreme self-esteem issues as well and I was actually excited that the other day someone actually told me that I was losing weight."*

Another experience regarding mental wellbeing was the decrease in mood and feelings of depression that participants experienced.

> **Participant 13:** *"... the depression and the anxiety really really went to a new level that I never, I never really understood what it was before then. I never really understood what anxiety was. I never really understood what depression was. And after I actually was diagnosed, then that's when the depression came…"*

Furthermore, the depression and low moods experienced led to suicidal thoughts and deep depression by some participants in feeling an inability to continue with general life due to endometriosis.

Participant 17: *"You don't know, you do not feel up to living. You just want to lay and cry the whole day."*

Mental wellbeing therefore is seen to be greatly associated with endometriosis as a disease and further manifests in various forms, such as stress, anxiety, depression, as well as feelings of diminished self-esteem.

4.3.3. Diminished Womanhood

An interesting sub theme that emerged throughout the interviews was a sense of diminished womanhood amongst the participants, and this was experienced in various ways, one of which being the inability to conceive and the experience of uterine issues feeling like a burden and a reduction of womanhood, pertaining to the inability to bear a child.

Participant 1: *"It makes me feel lesser of a woman, as women out there that don't have fertility issues, they don't have any baggage, so I'm taking this baggage into new relationships as well... So, um, it just made me feel like less of a woman because I am, I am a problem because I come with all this baggage."*

Other experiences regarding diminished womanhood related to feeling as though motherhood was not meant for some participants and that was the reason why they believed they were not able to conceive. This idea was further expanded upon to include diminished wellbeing experiences, as well as feeling a sense of the inability of "being a woman" as they felt they were stripped of being a "real" woman.

Participant 10: *"...there will always be that little voice in my head that says, you know, things are not okay, maybe you're not meant to be a mother... You know, I feel like the ladies that have been diagnosed with endometriosis are always the ones that feel like they were born to be a mother... especially if you want to have children and you feel like it's your right as a woman to have children, you almost feel like when you get the diagnosis that your right to have - to be a woman is taken away from you almost, you know."*

Another way in which this sub theme came about was in the form of feeling like less of a good wife in being unable to care for their husband or partner due to the physical inability to move around, and this further facilitated anxiety around relationships and being a “woman” in looking after their husband or partner.

> **Participant 16:** *“…and then I would lay and think, jeez, I must really get out of bed, because I have to look after my husband, because I mean, I am a woman, I am the woman of this house and… so I have to, and then I literally get an anxiety attack, because I think just if I don’t do this, my husband won’t love me anymore, you know.”*

Thus, diminished womanhood manifested in various forms, be it due to an inability to conceive, a feeling like they were not meant to be mothers, or by feeling like lesser wives in their inability to care for their partners.

4.4. Theme 4: Sexual Intimacies

One of the main themes that the interviews focused on with participants was their experiences of their sexual intimacies with their partners in relation to sexual pain and satisfaction. Some of the main subthemes were the common experience of sexual pain when engaging in intimate relations with a partner, a lack of libido due to endometriosis or lack of satisfaction during sexual intimacies, and how these aspects had an impact on their intimate relationships with their partners.

4.4.1. Sexual Pain

Participants throughout the interviews expressed experiencing sexual pain either during intimate relations, or afterwards, while few participants did not experience sexual pain with their partners due to endometriosis. A few participants noted that they generally have pain after they are sexual with their partners.

> **Participant 5:** *"I do have a little bit of pain, um, afterwards but, I tend to not focus - I try not to focus on the pain, my partner is very supportive when it comes to that and he's always worried that he will hurt me or there will be pain…"*

For some participants, the pain after sexual relations is bearable and they felt as if they do not place much focus on the experience, while other participants experienced extreme pain that was emphasised to generally come out of nowhere with no preemptive warning.

> **Participant 2:** *"So I will have no pain at all, have sex and then it's like this unbearable horrificness. So there's no sort of, like, preemptive thing to tell me okay, maybe it's not the best thing to do it now or whatever."*

Furthermore, some participants felt that they had never had an issue with sexual pain before being diagnosed with endometriosis and that since the diagnosis, they had started to experience it. Furthermore, feelings of discomfort around sexual relations due to the pain was fairly prevalent.

> **Participant 9:** *"And I was like no, I don't really have that problem, I'm relaxed and um, until sort of recently the sex has been very painful, which is, you know, it's not a lekker feeling like you said, you wanna be in the moment and you are cringing and you're being told to relax."*

Thus, it can be seen that sexual pain has been a common experience amongst participants interviewed and particularly for women with endometriosis. Although few participants noted that they experienced other aspects other than pain regarding sexual intimacies, there were very few participants that experienced no pain during sexual relations.

4.4.2. Sexual Dissatisfaction/Libido

Aside from sexual pain, other experiences were emphasised in relation to sexual intimacies, one of which primarily being libido or having a "mood" for sexual engagement. Furthermore, this was noted as a recent occurrence due to endometriosis.

> **Participant 12:** *"I almost felt like I wouldn't have much of a libido or interest in sexual activities either…"*

Some participants also experienced a lack of sexual satisfaction, with sexual activities not always being pleasurable either due to the experience of pain or a lack of satisfaction from said activities.

> **Participant 9:** *"...they want to try and please you and it's hard when you're just grinning and bearing it, and they want it to be pleasurable when it's not always…"*

Furthermore, other participants experience both a struggle with staying in the mood or just generally being in the mood, as well as struggling to reach orgasm during sexual activities as a result of endometriosis symptoms experienced.

> **Participant 13:** *"...sexual satisfaction, that I battle with constantly. So that's a big, big problem for me, you know, getting in the mood, staying in the mood, being able to, to finish, you know, is a big problem for me…"*

Thus, the experience of sexual issues regarding being intimate with a partner were commonly experienced by numerous participants, whether in the form of painful experiences, lack of mood in sexual activities, or inability to be satisfied or experience pleasure during sexual activities.

4.4.3. Impact on Intimate Relationships

The experiences participants had regarding sexual intimacies, whether from pain, lack of satisfaction or inability to sustain a mood for sexual intimacies, was explained to affect their intimate relationships/marriages with their partners to some extent. This was experienced in the form of strain on a new marriage and the inability to be sexually intimate.

> **Participant 4:** *"The effect on my new marriage was really difficult, it definitely had a massive toll on it... So, the less you have sex there would be more tension, I feel like when you having sex regularly it's a bit easier."*

Furthermore, participants were concerned that their partners might feel as if they are performing incorrectly or impacting them in a negative way, which was emphasised to cause issues within the relationship/marriage.

> **Participant 2:** *"It can be a bit difficult and also you know your partner starts to think they doing something wrong, you know, it's them, so that obviously impacts things…"*

Other participants emphasised that the thought of engaging sexually with a partner caused anxiety for them due to struggles to be intimate due to pain and lack of satisfaction, and this was further emphasised as bringing about arguments and pressure within the relationship.

> **Participant 1:** *"...brings up arguments and that brings more pressure to the relationship, so it's been I think two years since my last relationship and I haven't engaged in any kind of sexual intercourse or anything like that, just because the thought of it gives me anxiety."*

This shows that women with endometriosis experience various factors that affect their sexual intimacies, which in turn often result in affecting their state of mental wellbeing, or the partnerships/marriages they have.

4.5. Theme 5: Impact on Women's Lived Experiences

Endometriosis as a disease has a substantial impact on the lived experiences that women diagnosed experience on a daily basis, primarily due to symptoms of endometriosis as well as how it affects mental wellbeing. Some of the main aspects of their lived experiences that are affected in relation to endometriosis are the impacts on work life, the financial impacts it has, as well as the impact on daily functioning.

4.5.1. Impact on Work

One of the biggest issues that participants experienced in relation to their work lives was their inability to move around or have the energy or lack of pain to go to work in the mornings. Other participants mentioned that the endometriosis caused brain fog and lack of concentration for them, and that their inability to perform at work made them feel incredibly guilty.

> **Participant 4:** *"And then with work, you feel you can't get out of bed and you don't have energy and you can't think properly, it's like you have brain fog, and then you feel guilty, it's like you're not performing as well as you should, or not contributing as well as you should... I think I've taken all my sick leave just from recovery after surgery because it's been twice within the year…"*

Another experience that was mentioned was how difficult it was to be diagnosed with a disease such as endometriosis, and how the surgeries put the women out of work for weeks on end, which ends up being detrimental for their careers. The biggest issue voiced by one participant was around the fact that she had just come out of surgery, and still had to attend meetings regarding work because otherwise she felt she would not have a career.

> **Participant 11:** *"...I'm in the hospital, and I'm really struggling with my heart and everything, um, but still I got my laptop out and I'm working. You know and there's no really time to process what you've just gone through, cause it's kind of like okay this happened but okay I got a meeting tomorrow morning, so okay I need to get through this presentation and I need to do it tomorrow cause it is what it is... And the problem is if I didn't have my own business, um, I wouldn't have a career…"*

Furthermore, participants expressed that some employers were understanding of their struggles regarding endometriosis, while others were not and did not feel as if the disease should put individuals out of working for days on end.

> **Participant 13:** *"I mean at times you can't even get up to go to work. At my previous job, I had a boss that had endometriosis so he said I could work at home. But the boss that I had now, I was retrenched, he was a very big narcissist, so he didn't care, work was it, so."*

Thus, endometriosis is seen to have a major impact on women regarding their work lives and building of careers, whether it was due to an inability to concentrate and feelings of guilt due to lack of performance, or inability to attend work due to pain.

4.5.2. Financial Impacts

Other aspects of life that the disease tended to affect for participants was their financial wellbeing, as doctors and the surgeries that come along with endometriosis were explained to be incredibly expensive due to the need to go into the private sector for treatment for endometriosis.

> **Participant 9:** *"I'm also amazed by how much money people are spending, because this whole private enterprise is massively expensive."*

Other issues experienced regarding finances was the exorbitant costs of medication to treat the symptoms of the disease, and even though some participants explained that they had medical aid, they further explained that medical aid companies tended to not see endometriosis as a chronic illness and thus, would not cover their medication. This again leads to a potential lack of information around the disease.

> **Participant 14:** *"I've spent so much money like, I was literally just telling my gynae now that my medical aid isn't covering my Visanne anymore, cause it's not a contraceptive basically... I've tried to motivate – "Oh no, endometriosis isn't a chronic illness", okay but it, it kind of is a chronic illness. So now he's trying to tell me to go back onto an oral contraceptive but that comes with its own side effects."*

Furthermore, due to having endometriosis, participants explained that internal exams performed by a gynaecologist is needed often, and that costs related to this are incredibly expensive.

> **Participant 11:** *"I had to go for an internal exam every 2 weeks, which costs a fortune because I think he is 1400 rand and had to do that 2 times a month."*

Thus, finances end up being quite a difficult aspect for women with endometriosis to manage due to the inability to maintain treatment without having finances allocated to medical care for endometriosis.

4.5.3. Impact on Daily Functioning

The biggest impact that endometriosis was seen to have on participants regarding their lived experiences was the impact that the symptoms had on women's daily functioning. For some participants, it was incredibly difficult to get out of bed or to travel, as they felt a need to be near hospitals at all times due to the pain. Furthermore, another issue that was prevalent was the constant sense of fatigue.

Furthermore, other aspects tended to impact them, such as a lack of understanding from individuals believing that the symptoms were not as serious as the participants explained they were.

> **Participant 2:** *"...you can't get out of bed, you can't do anything, um, ya it prevented me from going out and really travelling and seeing the world like my friends were doing because I always had to be within sort of 20 minutes of a hospital because if the pain got that bad, I had to be on pain medication… I used to miss school a lot, um, and you know people just, they make you feel like the symptoms aren't there, or you just being dramatic or just being stupid…"*

Other aspects that tended to influence participants' daily interactions was the necessity to be careful in case hospitalisation was imminent, such as in the case of one participant, who cut out intake of alcohol entirely in case she ended up in hospital and they would not be able to help her if she were intoxicated.

> **Participant 11:** *"And I literally got to the point where I don't even drink anymore cause I don't know if I'm gonna end up in hospital that night and if I end up in hospital that night they can't help me…"*

Furthermore, endometriosis had an impact on participants' daily chores, and even in simple chores such as cleaning the house, as the pain would be too severe and would persist for weeks on end.

> **Participant 15:** *"At a point, I could not clean the house completely. A simple task. If I cleaned the house, then I could not walk for two weeks, and then I would be sore. And then your pains start and then you suddenly menstruate. And then you suddenly get inflammation and infections that you never thought you would get."*

Endometriosis was seen to affect participants in various ways, and much of the effect was seen in women's inability to perform daily tasks, engage in social alcohol intake, or even getting out of bed for work or a social event.

4.6. Theme 6: Social Wellbeing

Social wellbeing is a major factor that gets impacted by the diagnosis of endometriosis as the diagnosis and disease itself can lead to impacts on daily functioning as discussed, as well as impacts on bodily perceptions. Thus, the main factors of social wellbeing that came out of the interviews with participants was how endometriosis resulted in social isolation from friends, family, and partners, as well as the types of support systems received from friends, family, and partners, and how it assisted participants in dealing with endometriosis.

4.6.1. Social Isolation

A major sub theme that arose out of the interviews was the inability to find support in parents due to the generational differences experienced between the participants and their parents.

Experiences shared revolved around parents not believing in endometriosis as a disease, nor believing it should affect an individual's life due to endometriosis not having been a recognised disease within their own generation despite women around them suffering from the same symptoms.

> **Participant 2:** *"...still with my parents, they grew up in a very different generation, it - where I think there are people on my mom's side, my mom's one of eight kids, and I think some of my aunts had endo, but obviously they didn't have the tools and stuff to diagnose it so it was just like no you grin and bear it and you just get on with your life, um, so it can be difficult sometimes for parents to really understand the impact it has on your life I would say."*

Other experiences that arose revolved around the inability to explain to friends and family what participants were experiencing as there was a lack of understanding due to the lack of physical appearance of having endometriosis and the internal nature of the disease.

> **Participant 13:** *"You don't look sick so you're not sick. There's nothing wrong with you, why can't you come out with us. Why - ugh we are just going to go see a movie, ugh we are just going to braai, why can't you come to the braai. Or, when you feel, when you're having a good day and you're making plans because you're feeling good that day and then you cancel those plans because then when that day comes, you're having a really bad day. They just don't get it. Because you don't look sick so what bad day are you talking about? You're sharing stuff on Facebook, you're sharing stuff on Instagram, you look so happy. Because it's a fake happy, that's why."*

Furthermore, participants struggled with attending social gatherings or seeing friends due to the extreme pain they experienced from endometriosis and the inability to be social for extensive amounts of time. This resulted in participants socially isolating.

> **Participant 11:** *"I go to a social gathering and then you're there for ten minutes and then you're like ya, I think I'm gonna go lie down. I mean we went to my hubby's reunion and um, ya, I mean I was there for probably, I wouldn't even say 20 minutes, and the rest of the four hours I was lying in the car because I couldn't even move. So, it does take quite a bit of your life away and it does play a big role on your mental health and I think, I think it is overlooked quite a bit and I think even family members don't understand what you're going through, they can't see it or anything."*

As can be seen, social isolation was a prominent experience for participants, particularly in the beginning of their diagnosis, but for some participants it extended beyond the initial diagnosis throughout their journey with endometriosis. This in turn had an impact on their mental wellbeing in the inability to interact socially for various reasons, such as lack of understanding from others, generational differences, as well as inability to be social due to chronic pain.

4.6.2. Support Systems

Despite the social isolation participants experienced, participants also noted that the support systems that they did have made a major difference for them in dealing with their diagnosis of endometriosis. One experience was around finding other women who were also diagnosed with endometriosis and feeling connected to other individuals who understood what the participants were going through.

> **Participant 12:** *"...as I started talking about it, you know, other women were saying "oh, I've also had it", or "I've had a similar experience", so that really has helped me, um, and I'm not ashamed or anything like that to talk about it, and I've found when I've connected with other women, I've been like "oh my word okay, you need to [inaudible]" and the feeling of alone has surpassed me, but in the beginning it was quite difficult."*

Other support systems revolved around feeling grateful to have individuals around them that put in effort to understand the participants' diagnosis and disease in order to try and assist, understand, and be there for them when they needed it.

> **Participant 5:** *"But then you find that lucky few people that make the effort to research it once they hear that you've got it so they know a little more about it and they take the time out to ask you know, "how are you feeling, is there something you can do". Something that people don't realise is a little bit of compassion goes a long way, you might not be able to take my pain away but just acknowledging that it's there... it makes a very big difference."*

Lastly, partners were also explained to have been major support systems for the participants, particularly in supporting the participants in reassuring them that they were there for them, while also understanding that they would not be able to understand the disease the same way the participants do, but still being willing to listen and support them.

> **Participant 10:** *"I feel like if I didn't have him, I don't think I would have managed, if I can put it that way. So he was a giant support system and he knew the right things to say without feeling… without me feeling*

> *smothered or smothered in positivity, that kind of thing you know. He was the biggest support system um, being on the endo group I saw a lady whose husband left her because she got diagnosed with it…"*

Thus, participants shared that having support systems when dealing with their diagnosis of endometriosis, and even past the diagnosis stage, made a major difference to their wellbeing and social wellbeing in particular.

4.7. Theme 7: Coping Mechanisms

Numerous coping mechanisms were mentioned throughout the course of the interviews with participants, and many participants noted the use of various aspects that helped them cope with their endometriosis symptoms. These generally included the wide use of medication, diets, exercise as both a positive and negative affect on their bodies, as well as holistic treatments.

4.7.1. Use of Medication

Medication was noted as the most widely used coping mechanism amongst participants, mostly in relation to the use of painkillers for the chronic pain they experienced, however, there were a few interesting types of medications or medical treatments that seemed to help some participants. One participant noted that she had started using magnesium to level her hormones, which she felt had helped her with her experience of pain and general endometriosis symptoms, which was further extended with the occasional help of a heat or ice pack.

> **Participant 5:** *"...like I said, right now magnesium works when I need it, heating pad works when I need it, even an ice pack now and then, it all depends on what level of pain I am experiencing on a regular day."*

Other experiences shared was the use of the Mirena coil (a type of intrauterine device) which is generally used to help pain symptoms or, for some women, stop menstrual cycles altogether in order to stop the endometriosis from growing. Furthermore, the consumption of progesterone was further emphasised as a medication that assisted with endometriosis symptoms.

> **Participant 6:** *"I had my laparoscopy last year which has really, really helped me, um ya, also got the Mirena coil inserted as well, and I'm on medication I take monthly, it's like progesterone… it's helped but, yoh, you know how it is, just chronic pain all the time, it's helped so much but it's always there unfortunately."*

Another interesting medication that was used was prenatal vitamins, which is generally used for women that are pregnant or attempting to conceive, and one participant noted that research indicated to her that the vitamins were supposed to help with endometriosis as it can assist in balancing hormones.

> **Participant 10:** *"...I'm on the prenatal vitamins, um, I sort of did a little research on if it can help with your endo. And a lot of them say the vitamins that are in the prenatal vitamins actually help with your endometriosis if you wanna like fall pregnant, or just help balance your hormones."*

As can be seen, numerous types of medication were noted to be helpful to some extent with endometriosis symptoms, while others that were used were mentioned in passing as not assisting with the symptoms of endometriosis.

4.7.2. Diet and Exercise

Participants generally mentioned using an anti-inflammatory diet as being incredibly helpful regarding their endometriosis symptoms due to the way some foods enhance inflammation in the body and thus, exacerbate endometriosis. They further noted that it had assisted with aspects in their lives that had been affected by endometriosis.

> **Participant 4:** *"I've started eating an anti-inflammatory diet, so I've consulted a nutritionist and we've… cut out everything just to get your body in a good space. And that helped a lot, like, sex has been a lot less painful, my moods have been a lot better, I haven't - the pain has been a lot less... So I've cut out gluten, dairy, sugar, and alcohol, and then after a while I'm going to start introducing things and see how my body reacts, but I think I'm going to stick to it most of the time."*

Another experience noted by participants was that exercise had been incredibly helpful for reducing their symptoms, especially with regards to their pain, and occasionally also regarding their mental state

> **Participant 2:** *"I think definitely exercise to a certain degree. Um, especially if I'm in a lot of pain, I find if I get up and walk, I don't know if that actually lowers the pain or if my mind goes off it and I'm not thinking about it the whole time, so I'd say exercise definitely has something to do with it."*

However, for some participants they did not experience exercise as being a positive experience, but rather as a negative experience in which it enhanced their endometriosis pain. Furthermore, it was emphasised that this was the case despite exercise having been a big part of participants' lives prior to the diagnosis of endometriosis.

> **Participant 1:** *"...with regards to exercising, it's become an issue because I used to love doing leg day and squats and stuff and now, I've found I can't really go hard on the waist, because just like the motion of when you do squats going up and down, that's painful, that's really painful, on my lower back and especially on my bladder area. Uh so, I can't exercise as much as I wanted to and when I do have my period it is super painful."*

Experiences regarding diet and exercise were expressed by the majority of participants, with diet having helped most participants that had tried the anti-inflammatory diet, while exercise either positively affected participants, or negatively affected them.

4.7.3. Holistic Treatment

Aside from the attempts at coping mechanisms by using either medication, diet or exercise, there were some participants that had also attempted the use of holistic treatments. One of the most common holistic and natural treatments used by participants that helped endometriosis symptoms was the use of a heat pad, or just a general hot bath, but heat in any form seemed to assist with pain symptoms.

> **Participant 14:** *"Hot baths, that's a thing. I literally sleep with a, with a heat pad next to me, so that also, even though I've gotten the patchiness on my tummy from too much heat, that works, that helped a lot."*

Another experience that was mentioned by a few participants was either the use of marijuana in assisting with pain management or use of CBD oil for pain management. Participants noted that it assisted with their pain, but also assisted with any anxiety or stress they were feeling in relation to pain from endometriosis.

> **Participant 10:** *"...my doctor actually recommended that I take CBD oil, or smoke weed, because smoking weed is the purest form of it. And funny, scary enough, smoking has helped one hundred percent. I was never one of those big smokers or anything, but whenever I felt pain that was super uncomfortable at that time of a month, or if mentally I just felt like I was gonna go crazy, I would have like half a joint, or a joint, I would feel - or my brother would make me edibles - and I would feel so much better."*

There were also a few participants that mentioned other types of coping mechanisms, namely the use of acupuncture, a tens machine, and the use of a physiotherapist to assist them with pain management. Some participants noted that this helped them, while others noted that it assisted for a few hours and then the pain would return.

> **Participant 8:** *"...we can't figure out what this pain is, so I ended up going to a physio which sorted me out for about - she dry-needled and she did tens machine and everything. When I left, I felt better in my back, and about an hour later the back pain came back."*

Over the course of the interviews, participants expressed their attempts at various coping mechanisms, most of which worked for them in easing their pain from endometriosis, such as heat, CBD oil, and medication, while other aspects were not as effective, such as acupuncture and the use of a physiotherapist.

4.7.5. Impact of Social Media

Another interesting experience that was expressed during the interviews by some participants was the impact that social media had on their ability to cope with the diagnosis of endometriosis. Most of the participants that spoke about social media and its impact generally discussed the positive impact it had. Some participants mentioned how it assisted in creating awareness on endometriosis as a disease, which hopefully would be able to assist women diagnosed with endometriosis that were struggling with understanding the disease.

> **Participant 5:** *"The amount of awareness we are getting out on social media and the campaigns they got is incredible, and I said if it's, if it can help one person…"*

Other participants mentioned that the reason social media as a platform was helpful to them with regards to being diagnosed with endometriosis was through the ability to do research on the disease and learn more about it, as well as the ability to connect and speak to individuals also diagnosed with endometriosis and thus, develop a support network.

> **Participant 9:** *"...Ya then I'm online hey boy, I'm researching, trying to find out about bloggers, I email people directly, say can I speak to you, when's a good time. Some people reply and others don't…"*

However, some participants did not necessarily note social media as a positive platform, as they felt that it assisted in portraying an ideal perception of what a woman should be, especially with regards to being able to conceive and satisfy their partner in sexual aspects. Furthermore, this was emphasised as being negative as it had an effect on some participants' mental wellbeing in their inability to fit the stereotype.

> **Participant 1:** *"...social media portrays that a woman should be able to produce kids, should be satisfying in bed, all these other things…"*

Thus, social media was portrayed as both a positive and negative platform for some of the participants, particularly in relation to feeling supported and producing research on the topic through spreading awareness, or alternatively feeling pressured by society's stereotypes of what a woman "should" be.

Chapter 5

5.1. Discussion

The participants interviewed experienced a range of issues associated with endometriosis, and the issues they experienced were often linked with one another. One of the main experiences that came out of the interviews was concerns around fertility, or inability to conceive, and this was often linked with the experience of pain, as well as diminished mental wellbeing. Literature has shown that almost half of women diagnosed with endometriosis experience infertility or struggle to conceive, which correlates largely with the experiences of the participants in this study (Jones et al., 2001). Furthermore, infertility was often found to be associated with physical pain in consideration of endometriosis, which seems to be the case largely amongst the participants interviewed, as most of the participants that were interviewed struggled majorly with pain experiences, and the majority of the participants had issues with infertility or were struggling to conceive at the time of the interview (Dunselman et al., 2014). The use of Erikson's psychosocial stage of intimacy vs isolation becomes significant in this regard given that this stage largely focuses on creating intimate relationships, which becomes impacted by the inability to have children in their intimate partnerships.

Within the literature, it is notable that most women in South Africa that have been diagnosed with endometriosis are reported as white in race with unknown statistics on black women that have been diagnosed with endometriosis, which becomes incredibly interesting in consideration of this study (Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010; Wanyoike et al., 2017). The reason this is considered is due to the fact that this study primarily incorporated participants that classified themselves as white, while a few women classified themselves as coloured or Indian, however, none of the participants interviewed classified themselves as black. Amongst the literature, there is occasionally this perception that endometriosis only affects white women, which is not the case (Kyama et al., 2007; Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010; Wanyoike et al., 2017). Furthermore, this is generally due to the fact that white women are traditionally able to afford the extensive medical care that is associated with a diagnosis and disease such as endometriosis whereas women who were previously disadvantaged within South Africa due to apartheid are primarily women of colour and thus, there is this understanding that there are higher reports of diagnosis in white women due to their ability to afford medical care (Kyama et al., 2007; Zondervan et al., 2018; Shafrir et al., 2018; Giudice, 2010; Wanyoike et al., 2017). This is incredibly important as firstly, one of the most significant themes that came out of the interviews with participants was how expensive doctors' appointments and surgeries for endometriosis are, which supports the understanding that the medical care for endometriosis is incredibly expensive, and secondly, the majority of participants within this study were white. This further skewed demographics regarding race could have been influenced by the fact that online interview methods can result in a lack of accessibility for some individuals and thus, despite the aforementioned reasons, this is another contributing factor to the lack of reporting on endometriosis for women of colour.

Another important aspect around the theme of fertility was that the inability to conceive or concerns about fertility resulted in women feeling incredibly depressed or anxious, which is supported by the literature that indicates that many women that experience fertility issues experience decreased mental wellbeing, as well as negative impacts on their intimate relationships (Labinjo, 2020; Culley et al., 2013). As mentioned before, fertility issues were often associated with chronic pain experiences and thus, chronic pain was often discussed amongst participants. Yet again, the psychosocial stage regarding intimacy vs isolation is important here as depressed and anxious feelings around infertility and pain issues often resulted in women isolating from close friends and family members, which impacts their development of the intimacy vs isolation stage (Cox et al., 2003; Gilmour et al., 2008; Roomaney et al., 2019).

Chronic pain was one of the main symptom's participants experienced and this symptom affected their lives through various aspects, such as the inability to function effectively in daily life, impacts on work life, as well as diminished mental wellbeing and social isolation. Chronic pain is not largely considered in the literature and there are not many fixed statistics as to how many women experience chronic pain within South Africa. However, it is evident that a large majority of women who experience chronic pain generally have endometrial issues, which emphasises that much chronic pain is associated with gynaecological issues and often, endometriosis specifically (Baranowski et al., 2012; Fawole et al., 2015). Furthermore, participants interviewed emphasised the impact chronic pain had on their ability to work effectively, function in daily life, as well as how much the pain impacted their mental wellbeing. Sibande and Roomaney (2022) found that many women with endometriosis struggled greatly from fatigue, which inherently impacted their ability to function in daily activities. Furthermore, they found that women found that when attempting to find coping mechanisms for the fatigue, they became aware that what would work for them would not necessarily work for another woman struggling from endometriosis-related fatigue, indicating that the solution for endometriosis-related fatigue and impacts on daily functioning can be incredibly difficult and frustrating, as well as difficult to solve (Sibande & Roomaney, 2022). Dorn et al. (2009) found that women who experience chronic pain are more likely to struggle with mental health aspects such as anxiety and depression, however, that there is not much understanding as to why this occurs. This is further supported by the fact that many of the participants had not managed to find a coping mechanism that assisted them with their experience of pain, while the doctors primarily considered medical procedures to reduce it, without considering holistic treatment or treatment of mental wellbeing.

This leads to why chronic pain and its relationship with mental wellbeing was considered in this study, as chronic pain was seen to be associated with experiences of anxiety and low mood in some participants, while other participants did not recognise an association. Furthermore, some participants noted the opposite, in that when their pain was bad, their mental wellbeing would decrease, rather than their pain increasing due to diminished wellbeing. This is incredibly interesting as the literature speaks about central sensitization as linking mental wellbeing and pain together, which inherently has the ability to cause chronic pain (Sinaii et al., 2002). Thus, it is understood that anxiety has the potential to increase pain due to increased activity in certain areas of the brain (Tracey & Mantyh, 2007). This correlates with the discussion around chronic pain and wellbeing for some participants interviewed. The issue, however, lies in the fact that traditionally, medical professionals do not consider mental wellbeing as a potential cause of enhanced pain, and thus, this was further experienced by some participants in their interactions with doctors and specialists (Cox et al., 2003; Denny, 2004; Huntington & Gilmour, 2005). Furthermore, women who suffer from chronic pain in relation to endometriosis often suffer cyclically in the sense that at times they will suffer from the pain and experience symptoms, while at other moments they may not suffer symptoms. It is emphasised that when they experience the chronic pain symptoms, however, it impacts various elements of their daily functioning, including their mental wellbeing as it causes much frustration for women, as well as issues within their intimate partnerships (Denny, 2009; Butt & Chesla, 2007).

Interaction's participants had with doctors and specialists came out as a common experience, particularly in their inability to assist them with their endometriosis, or their lack of sympathy towards the participants. As mentioned, some participants had terrible interactions with medical specialists, particularly when discussing their pain symptoms, and doctors tended to assure participants that the pain was all in their head, or that they were in fact making it up. This becomes an issue, as it seems some doctors do not understand the holistic nature of pain and thus, it often leads to doctors diminishing participants' experiences of pain and leading them to be incredibly unsympathetic (Cox et al., 2003; Denny, 2004; Huntington & Gilmour, 2005). Furthermore, the literature also speaks of women with endometriosis often being dissatisfied with the healthcare they receive from medical professionals, and that it is often due to not taking women's symptoms seriously, nor being sympathetic towards them (Cox et al., 2003). This was emphasised in the interviews with participants, who mentioned that they had visited numerous different medical professionals, all of which had varying opinions or understandings of endometriosis, and some which were directly insensitive towards participants' experiences. This becomes an issue, as this suggests that some doctors do not understand the condition well enough given that participants feel that they tend to focus primarily on the biomedical and not on the psycho-social aspects of endometriosis. Thus, doctors end up being unable to assist women with endometriosis, and it seems to make women feel as if they are not understood (Denny, 2009). This leads to the need for further research around endometriosis.

Other issues that were prevalent in the interviews were issues around sexual intimacies, such as sexual pain and lack of satisfaction, as often the participants would experience sexual pain during intercourse and thus, would struggle to be intimate with a partner. For some of the participants, intercourse resulted in a lack of satisfaction either due to the pain, or general lack of pleasure. The literature has shown that women with endometriosis struggle to be sexually intimate with their partners due to the extensive pain they experience during or after engaging in intercourse, and thus, it is suggested that this could inherently influence levels of libido experienced in women with endometriosis (Mathias et al., 1996). This was incredibly prevalent amongst the participants interviewed, as some participants experienced immense sexual pain, resulting in a lack of desire to be sexually intimate with a partner, or anxiety around the idea of being sexually intimate with a partner, while other participants experienced a lack of satisfaction in their inability to achieve orgasm, or remain in the mood to be sexually intimate. This is supported by Rossi et al. (2008), in which they noted that women with endometriosis tended to report less satisfying sex lives and relationships than other women, and furthermore, that they struggled with poorer sexual functioning (Di Donato et al., 2015; Guiliani et al., 2016).

These issues around sexual intimacy further tended to influence women’s intimate relationships, as some participants mentioned that if their partners did not understand the struggle to be sexually intimate, it would result in conflict and tension within the relationship. Labinjo (2020) investigated this through evaluating multiple studies (Moradi et al., 2014; Alabi et al., 2013; Ajayi et al., 2016) that found that women felt unable to speak to their partners about their experiences around sexual intimacy, as often partners would assume that the pain was in their heads due to their inability to understand what the woman was experiencing. These experiences were further linked with the experience of diminished womanhood, in which some participants felt that if they could not be sexually intimate with their partners or “satisfy” their partners intimately, they were failing as women and as wives. Some women have felt incredibly depressed and frustrated in their inability to manage their experiences of pain, particularly in relation to sexual intimacies or social situations, and this tended to reduce their confidence and result in isolation from others (Cox et al., 2003; Gilmour et al., 2008). Some participants expressed frustration around their inability to engage in social situations or with their own partners due to their endometriosis, as well as the lack of understanding they would receive from friends, family members and partners around the resulting isolation they engaged in. The inability to be intimate with partners could ultimately result in a lack of connection with partners, and in many instances, it resulted in tension in partnerships for some women, indicating that this particular psychosocial stage within women's lives is incredibly significant (Trioloa et al., 2013).

Thus, there is the understanding that there are numerous common experiences amongst women with endometriosis and thus, further research needs to be conducted on the prevalent themes that have not gained enough attention or insight, such as the social wellbeing and ways to support the psychological wellbeing of women with endometriosis.

5.2. Limitations and Recommendations

Despite the necessity of this research on endometriosis and the necessity for understanding the relationship with the physical, psychological and social wellbeing, there are a few limitations that should be noted regarding this study.

One of the limitations is that the study had to be conducted online due to the global COVID-19 pandemic, and thus, in order to ensure safety of participants as well as allow them to be comfortable during the duration of the interviews, an online platform was necessary. Furthermore, this study was conducted in South Africa and thus, the online space allowed individuals from various provinces to participate in the study. However, online spaces can sometimes result in a loss of meaning due to the use of technology, and furthermore, an online space can sometimes make participants feel less comfortable or open during the course of the interview process, thus potentially biasing the research. It would therefore be recommended that further research on endometriosis and the aspects considered in this study should take place in a face-to-face setting to ensure that participants are comfortable and open, while ensuring that no meaning is lost through the online space.

Another possible limitation to this study is the exclusion of women below the age of 25 and above the age of 35, as this limited the study to a designated 10-year age range. This range was used due to the development stage considered (being that of intimacy vs isolation in Erikson's psychosocial stages of development, as discussed), as well as the limited scope of this paper. However, by excluding other ages, experiences amongst various ages cannot be understood or discussed and thus, this becomes a limitation to this study in only considering a particular age-range and therefore, a particular point in women's lives that experience endometriosis. Thus, it is recommended that future studies consider a larger array of ages across women with endometriosis, or potentially not limit the age range at all to allow for inclusivity amongst women with endometriosis and a further understanding of women with endometriosis across various age ranges.

The methodology of this research study was particularly useful for exploring women's experiences of endometriosis, specifically in relation to the use of phenomenology and online data collection. Usually, there are many limitations attached to online settings, however, this research study benefited from this particularly due to the ability to reach women across various provinces, as well as to not inconvenience the participants with travel costs. Furthermore, the use of phenomenology allowed for in-depth and deep understanding of endometriosis and participants' experiences with the disease due to its primary aim to portray experiences in a raw and meaningful way.

5.3. Recommendations for Future Research

Future research should perhaps consider fewer participants in order to provide more in-depth understanding into women's experiences of endometriosis, as the large sample size of this research study when considering phenomenology made it more difficult to present all experiences in detail.

Further, future research should consider other aspects of social and psychological wellbeing and extend on understanding sexual intimacies with partners in relation to endometriosis, as this topic is generally viewed as taboo and is not investigated as widely as other aspects of social wellbeing. Moreover, in terms of psychological wellbeing, future research should also provide insight into potential therapies for women with endometriosis from a holistic perspective and a psycho-social lens, rather than from a biomedical one.

5.4. Conclusion

Research on endometriosis is incredibly important and beneficial for women suffering from the disease, as well as for partners and loved ones of women affected by endometriosis. This study aimed to provide insight into women's experiences of endometriosis, with particular emphasis on experiences of chronic pain, anxiety and stress, and sexual intimacies. This research study brought to light the lack of psycho-social care that is given to women with endometriosis, by doctors, support systems, and therapies that are generated for the disease. The understanding is that most therapies and knowledge around endometriosis largely considers the disease within a biomedical lens and thus, therapies are developed to target these issues, however, they do not consider the mental wellbeing of women and how this could potentially impact experiences of endometriosis, particularly in relation to major symptoms such as chronic pain and anxiety. Future research and knowledge generation should focus on bringing forth the understanding that endometriosis is not only a physical disease, but a psychological disease as well and as such, therapies should be generated accordingly.

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Appendices

Appendix A: Interview Guide (English)

FACULTY OF COMMUNITY
AND HEALTH SCIENCES

Email: 4117797@myuwc.ac.za

Interview Procedure:

Time of interview: ______________________________

Date: ______________________________

Place of interview: ______________________________

Researcher: ______________________________

Interviewee: ______________________________

Interview Questions:

1. Can you tell me about when you were first diagnosed with endometriosis?
2. What kind of symptoms of endometriosis do you experience?
    a. Probe: physical symptoms, mental symptoms, social isolation etc
3. How have these symptoms impacted your daily functioning?
4. What is your personal experience living with endometriosis?
5. Has endometriosis had an impact on your physical health?
    a. Probe: chronic pain, ability to move, infertility etc.
6. Has endometriosis affected your mental wellbeing?
    a. Probe: Experiences of anxiety, increased stress, depressive moods etc.
7. What have your experiences of your intimate relationships been like in having been diagnosed with endometriosis?
    a. Probe: friendships, intimate partnerships, sexual satisfaction etc.
8. Have you found any methods of treatment to be particularly helpful for your symptoms?
    a. Probe: mindfulness, exercise, fertility treatments, medication etc.

Appendix B: Onderhoudsgids (Afrikaans)

UNIVERSITY of the
WESTERN CAPE

FACULTY OF COMMUNITY
AND HEALTH SCIENCES

Email: 4117797@myuwc.ac.za

Onderhoudsprosedure:

Tyd van onderhoud: ____

Datum: ____

Plek van onderhoud: ____

Narvorser: ____

Onderhoud gevoer met: ____

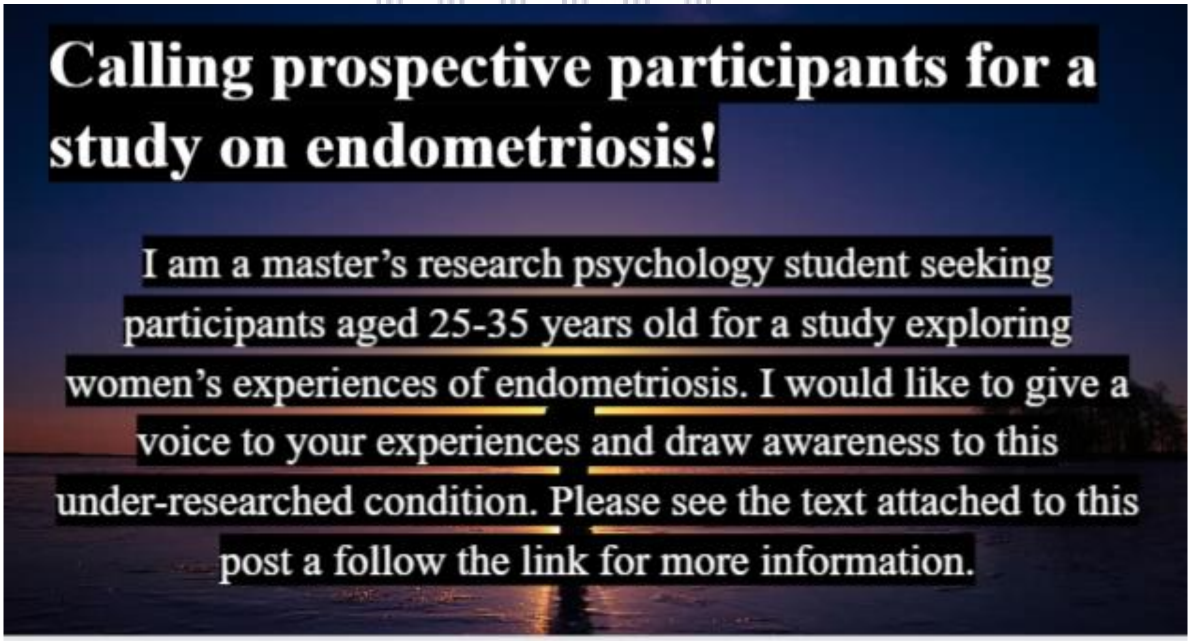
Onderhoudsvrae:

1. Kan jy vir my vertel die eerste keer vandat jy gediagnoseer is?
2. Watse tipe simptome van endometriose het jy ervaar?
    - Ondersoekende vraag: fisiese simptome, geestelike simptome, sosiale isolasie, ens.
3. Hoe het hierdie simptome jou daaglikse funksionering beïnvloed?
4. Wat is jou persoonlike ervaring om met endometriose te leef?
5. Het endometriose enige invloed gehad op jou fisiese gesondheid?
    - Ondersoekende vraag: kroniese pyn, vermoë om te beweeg, onvrugbaarheid ens.
6. Het endometriose jou geestelike welstand beïnvloed?
    - Ondersoekende vraag: ervaringe van angs, toenemende stres, depressiewe buie, ens.
7. Hoe ervaar jy jou intieme verhoudings vandat jy diagnoseer is met endometriose?
    - Ondersoekende vraag: vriendskappe, intieme vennootskappe, seksuele tevredenheid ens.
8. Het jy enige metodes van behandelinge gevind wat veral behulpsaam is vir jou simptome?
    - Ondersoekende vraag: 'mindfulness' gefokusde behandeling, oefening, vrugbaarheidsbehandelings, medikasie, ens.

Appendix C: Advertisement (English)

Hi everyone. I am a research psychology master’s student at the University of the Western Cape doing my thesis on young women’s experiences of endometriosis. I am interested particularly in the influence endometriosis has on young women’s wellbeing, particularly in relation to chronic pain, intimate relationships and anxiety. My topic was largely developed due to my own experiences with endometriosis and reproductive health-related issues, and I am passionate about hearing the lived experiences of women with endometriosis. I am looking for South African women who have been diagnosed with endometriosis and are between the ages of 25 and 35 years. Please note that this advert has been created in this way to protect your identity and as such, if you are interested in participating in my study, please see the advert below and click on the link for more information.

https://forms.gle/YcaDysSFDPXzJPJy7



Calling prospective participants for a study on endometriosis!

I am a master’s research psychology student seeking participants aged 25-35 years old for a study exploring women’s experiences of endometriosis. I would like to give a voice to your experiences and draw awareness to this under-researched condition. Please see the text attached to this post a follow the link for more information.

Appendix D: Advertisment (Afrikaans)

Hello almal. Ek is ‘n meesters navorsings sielkunde student by die Universiteit van die Wes-Kaap (UWK). Ek is tans besig met my navorsingsprojek wat fokus op vrouens se ervaringe met endometriose. Ek stel spesifiek belang in watter invloed endometriose het op jong vrouens se welstand, veral in verband met kroniese pyn, intieme verhoudings, en angs. My studie is grootliks ontwikkel deur my eie ervaringe met endometriose en reproduktiewe gesondheids probleme. Ek is passievol en luister graag na die geleefde ervaringe van vroue met endometriose. Ek soek vrouens van Suid-Afrika wat gediagnoseer is met endometriose en hulle moet tussen die ouderdom van 25 en 35 jaar wees. Let asseblief daarop dat hierdie advertensie geskep is om u identiteit te beskerm. As u belang stel om deel te wees van my studie, kyk asseblief na die advertensie was aangeheg is. U kan net klik op die skakel vir meer informasie.

https://forms.gle/YcaDysSFDPXzJPJy7

Ek soek vir voornemende deelnemers vir n studeer op endometriose!

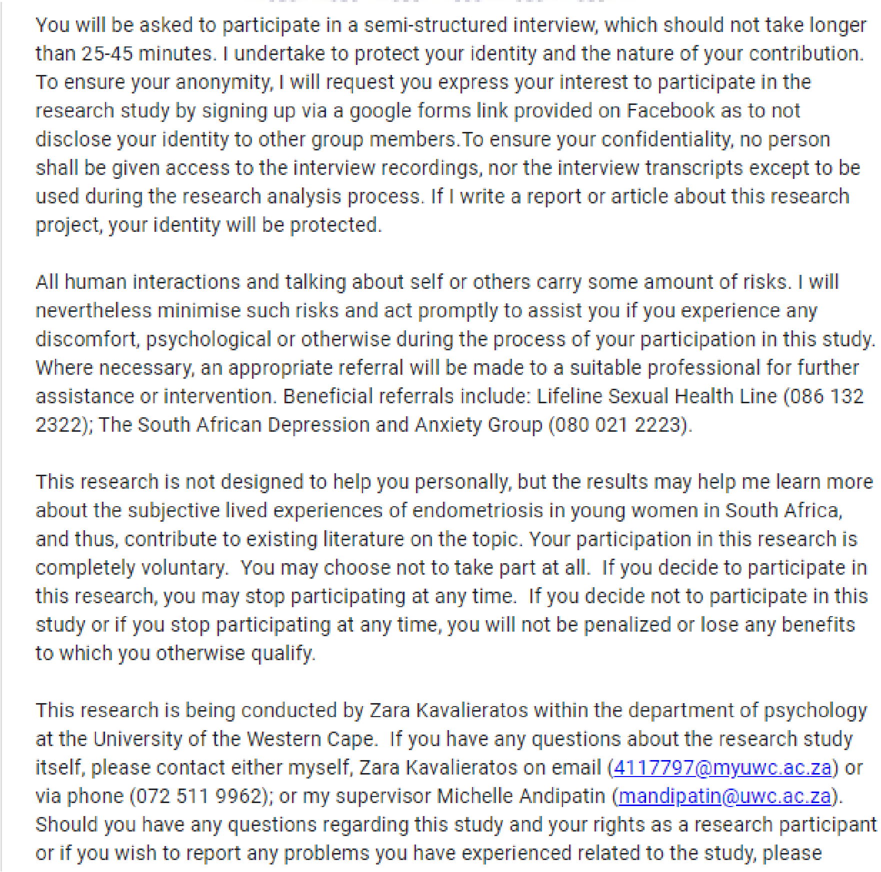
Ek is ‘n meesters navorsings sielkunde student en soek ek vrouens van Suid-Afrika wat gediagnoseer is met endometriose en hulle moet tussen die ouderdom van 25 en 35 jaar wees. Ek is passievol en luister graag na die geleefde ervaringe van vroue met endometriose. As jy belang stel om deel te wees van my studie, jy kan net klik op die skakel vir meer informasie.

Appendix E: Google Form

The lived experiences of young women with endometriosis in South Africa: An exploration of chronic pain with regards to physical, psychological and social wellbeing. (Die geleefde evaring van jong vrouens met endometriosise in Suid-Afrika: ‘n Verkenning van kroniese pyn in verband met fisies, sielkundig, en sosiale welstand.)

ENGLISH:

This is a research project being conducted by Zara Kavalieratos, a research psychology master’s student at the University of the Western Cape. I am inviting you to participate in this research project because you are of female sex, between the ages of 25-35 years old and have a medical diagnosis of endometriosis. The purpose of this research project is to explore the lived experiences of young women with endometriosis in South Africa.

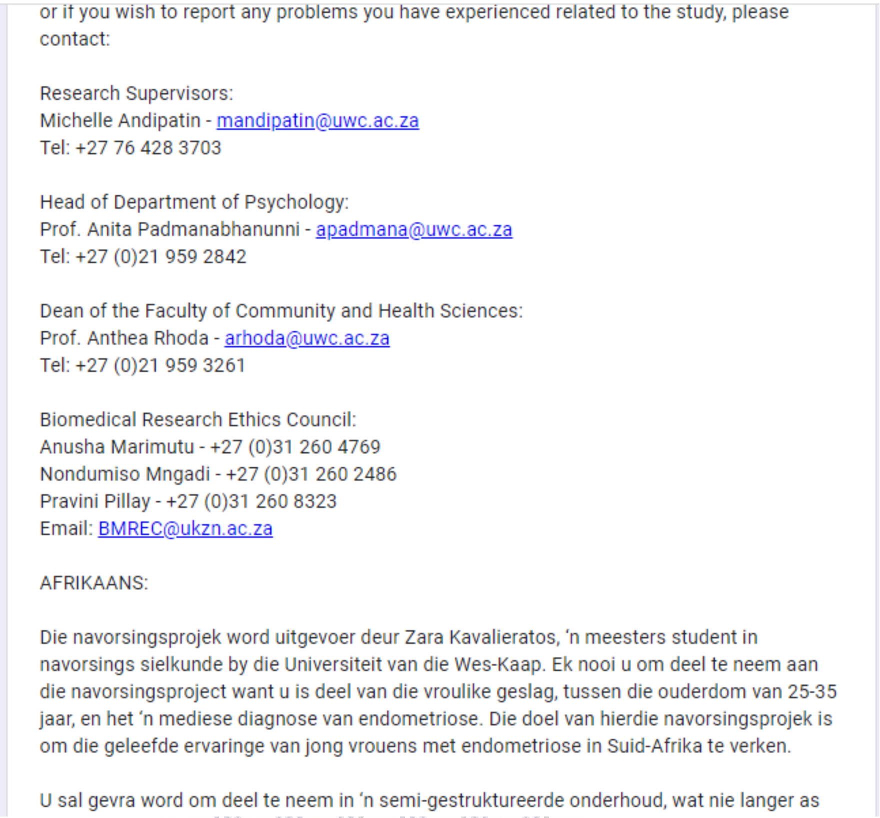


You will be asked to participate in a semi-structured interview, which should not take longer than 25-45 minutes. I undertake to protect your identity and the nature of your contribution. To ensure your anonymity, I will request you express your interest to participate in the research study by signing up via a google forms link provided on Facebook as to not disclose your identity to other group members.To ensure your confidentiality, no person shall be given access to the interview recordings, nor the interview transcripts except to be used during the research analysis process. If I write a report or article about this research project, your identity will be protected.

All human interactions and talking about self or others carry some amount of risks. I will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. Beneficial referrals include: Lifeline Sexual Health Line (086 132 2322); The South African Depression and Anxiety Group (080 021 2223).

This research is not designed to help you personally, but the results may help me learn more about the subjective lived experiences of endometriosis in young women in South Africa, and thus, contribute to existing literature on the topic. Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

This research is being conducted by Zara Kavalieratos within the department of psychology at the University of the Western Cape. If you have any questions about the research study itself, please contact either myself, Zara Kavalieratos on email (4117797@myuwc.ac.za) or via phone (072 511 9962); or my supervisor Michelle Andipatin (mandipatin@uwc.ac.za). Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please



or if you wish to report any problems you have experienced related to the study, please contact:

Research Supervisors:
Michelle Andipatin - mandipatin@uwc.ac.za
Tel: +27 76 428 3703

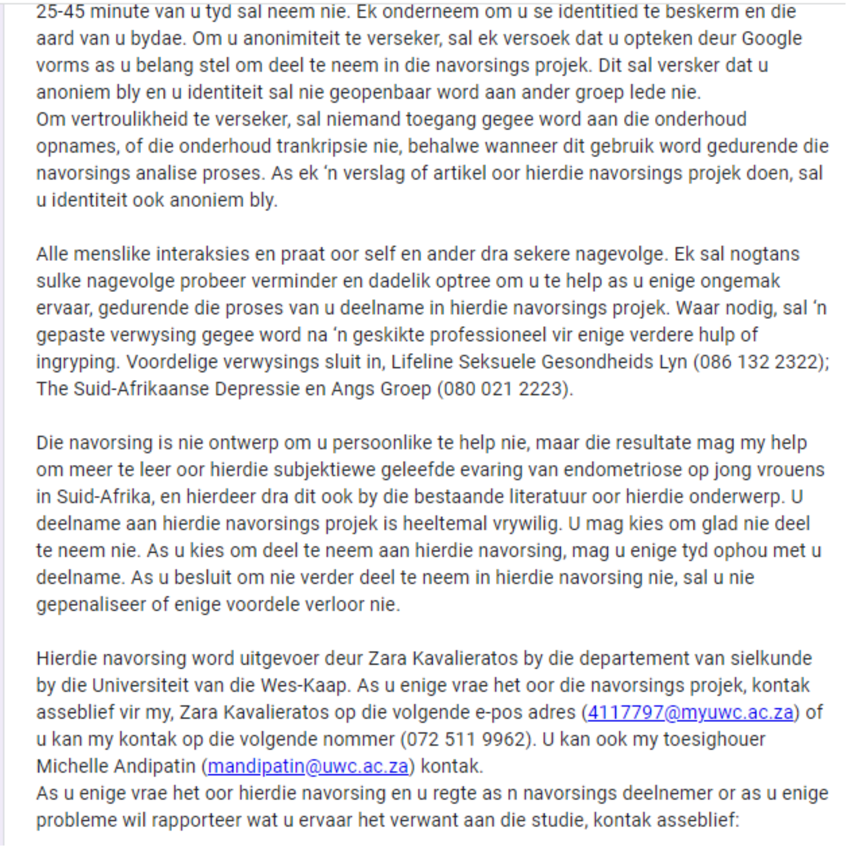
Head of Department of Psychology:
Prof. Anita Padmanabhanunni - apadmana@uwc.ac.za
Tel: +27 (0)21 959 2842

Dean of the Faculty of Community and Health Sciences:
Prof. Anthea Rhoda - arhoda@uwc.ac.za
Tel: +27 (0)21 959 3261

Biomedical Research Ethics Council:
Anusha Marimutu - +27 (0)31 260 4769
Nondumiso Mngadi - +27 (0)31 260 2486
Pravini Pillay - +27 (0)31 260 8323
Email: BMREC@ukzn.ac.za

AFRIKAANS:

Die navorsingsprojek word uitgevoer deur Zara Kavalieratos, 'n meesters student in navorsings sielkunde by die Universiteit van die Wes-Kaap. Ek nooi u om deel te neem aan die navorsingsproject want u is deel van die vroulike geslag, tussen die ouderdom van 25-35 jaar, en het 'n mediese diagnose van endometriose. Die doel van hierdie navorsingsprojek is om die geleefde ervaringe van jong vrouens met endometriose in Suid-Afrika te verken.

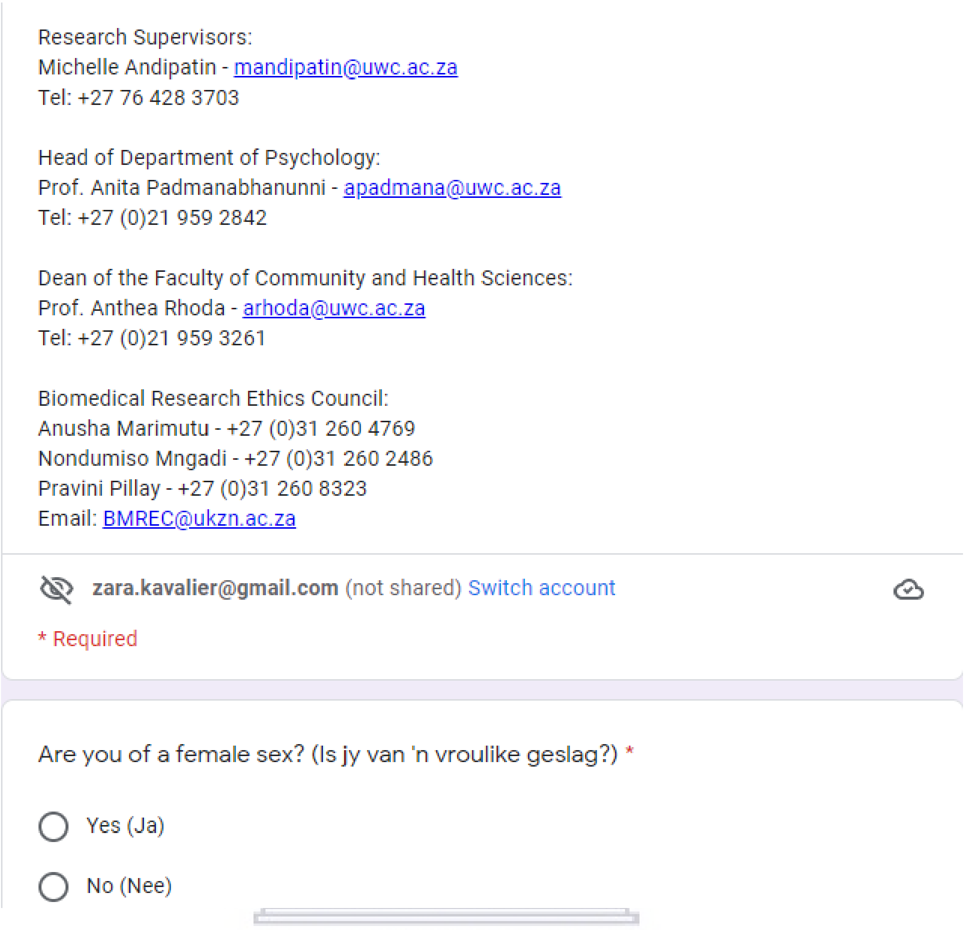


U sal gevra word om deel te neem in 'n semi-gestruktureerde onderhoud, wat nie langer as 25-45 minute van u tyd sal neem nie. Ek onderneem om u se identitied te beskerm en die aard van u bydae. Om u anonimiteit te verseker, sal ek versoek dat u opteken deur Google vorms as u belang stel om deel te neem in die navorsings projek. Dit sal versker dat u anoniem bly en u identiteit sal nie geopenbaar word aan ander groep lede nie.
Om vertroulikheid te verseker, sal niemand toegang gegee word aan die onderhoud opnames, of die onderhoud trankripsie nie, behalwe wanneer dit gebruik word gedurende die navorsings analise proses. As ek 'n verslag of artikel oor hierdie navorsings projek doen, sal u identiteit ook anoniem bly.

Alle menslike interaksies en praat oor self en ander dra sekere nagevolge. Ek sal nogtans sulke nagevolge probeer verminder en dadelik optree om u te help as u enige ongemak ervaar, gedurende die proses van u deelname in hierdie navorsings projek. Waar nodig, sal 'n gepaste verwysing gegee word na 'n geskikte professioneel vir enige verdere hulp of ingryping. Voordelige verwysings sluit in, Lifeline Seksuele Gesondheids Lyn (086 132 2322); The Suid-Afrikaanse Depressie en Angs Groep (080 021 2223).

Die navorsing is nie ontwerp om u persoonlike te help nie, maar die resultate mag my help om meer te leer oor hierdie subjektiewe geleefde evaring van endometriose op jong vrouens in Suid-Afrika, en hierdeer dra dit ook by die bestaande literatuur oor hierdie onderwerp. U deelname aan hierdie navorsings projek is heeltemal vrywilig. U mag kies om glad nie deel te neem nie. As u kies om deel te neem aan hierdie navorsing, mag u enige tyd ophou met u deelname. As u besluit om nie verder deel te neem in hierdie navorsing nie, sal u nie gepenaliseer of enige voordele verloor nie.

Hierdie navorsing word uitgevoer deur Zara Kavalieratos by die departement van sielkunde by die Universiteit van die Wes-Kaap. As u enige vrae het oor die navorsings projek, kontak asseblief vir my, Zara Kavalieratos op die volgende e-pos adres (4117797@myuwc.ac.za) of u kan my kontak op die volgende nommer (072 511 9962). U kan ook my toesighouer Michelle Andipatin (mandipatin@uwc.ac.za) kontak.
As u enige vrae het oor hierdie navorsing en u regte as n navorsings deelnemer or as u enige probleme wil rapporteer wat u ervaar het verwant aan die studie, kontak asseblief:



Research Supervisors:
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Pravini Pillay - +27 (0)31 260 8323
Email: BMREC@ukzn.ac.za

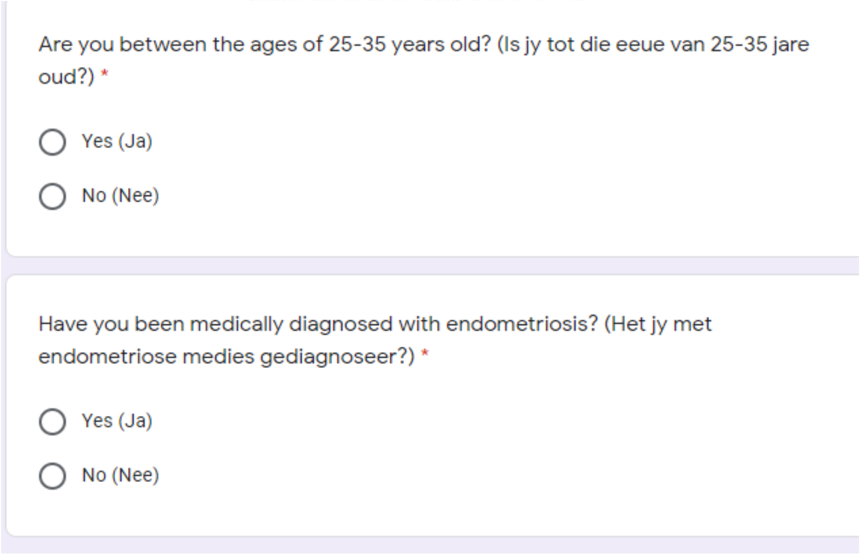
zara.kavalier@gmail.com (not shared) Switch account

* Required

Are you of a female sex? (Is jy van 'n vroulike geslag?) *

○ Yes (Ja)

○ No (Nee)



Are you between the ages of 25-35 years old? (Is jy tot die eeue van 25-35 jare oud?) *

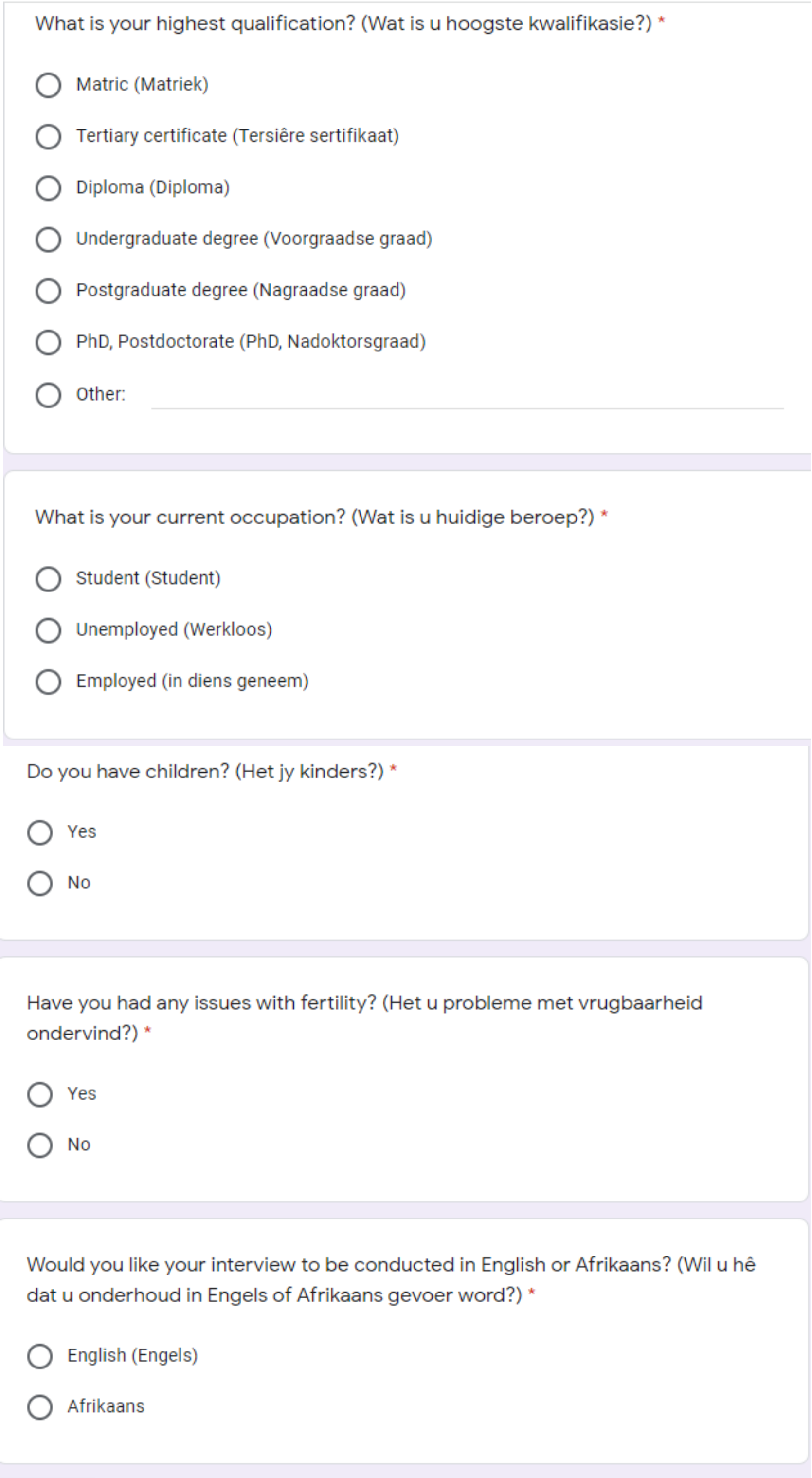
○ Yes (Ja)

○ No (Nee)

Have you been medically diagnosed with endometriosis? (Het jy met endometriose medies gediagnoseer?) *

○ Yes (Ja)

○ No (Nee)



What is your highest qualification? (Wat is u hoogste kwalifikasie?) *

○ Matric (Matriek)
○ Tertiary certificate (Tersiêre sertifikaat)
○ Diploma (Diploma)
○ Undergraduate degree (Voorgraadse graad)
○ Postgraduate degree (Nagraadse graad)
○ PhD, Postdoctorate (PhD, Nadoktorsgraad)
○ Other: ________________

What is your current occupation? (Wat is u huidige beroep?) *

○ Student (Student)
○ Unemployed (Werkloos)
○ Employed (in diens geneem)

Do you have children? (Het jy kinders?) *

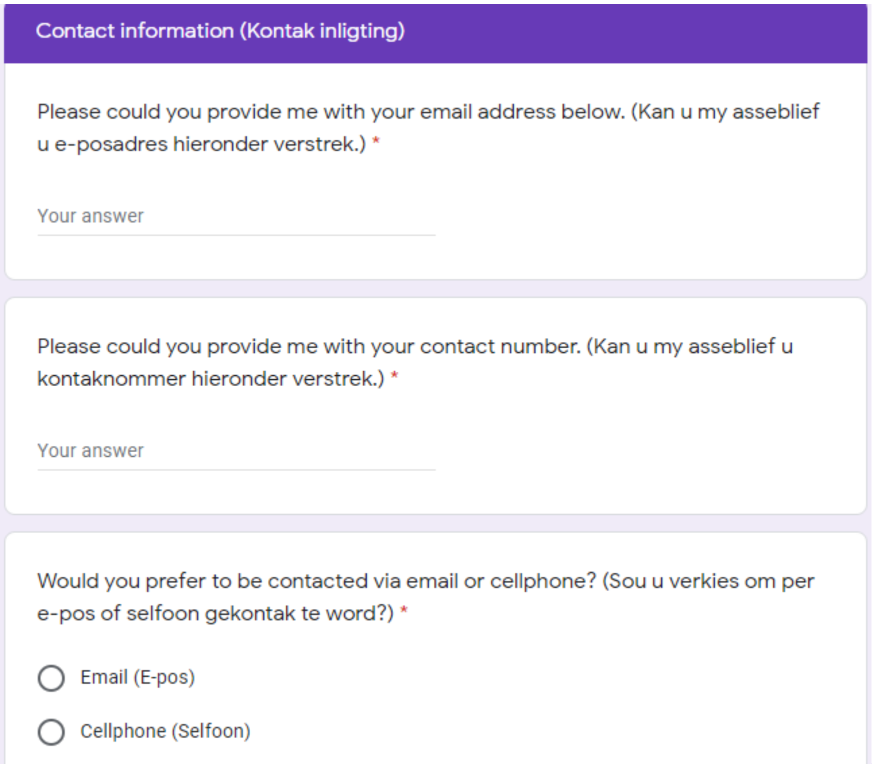
○ Yes
○ No

Have you had any issues with fertility? (Het u probleme met vrugbaarheid ondervind?) *

○ Yes
○ No

Would you like your interview to be conducted in English or Afrikaans? (Wil u hê dat u onderhoud in Engels of Afrikaans gevoer word?) *

○ English (Engels)
○ Afrikaans



Contact information (Kontak inligting)

Please could you provide me with your email address below. (Kan u my asseblief u e-posadres hieronder verstrek.) *

Your answer

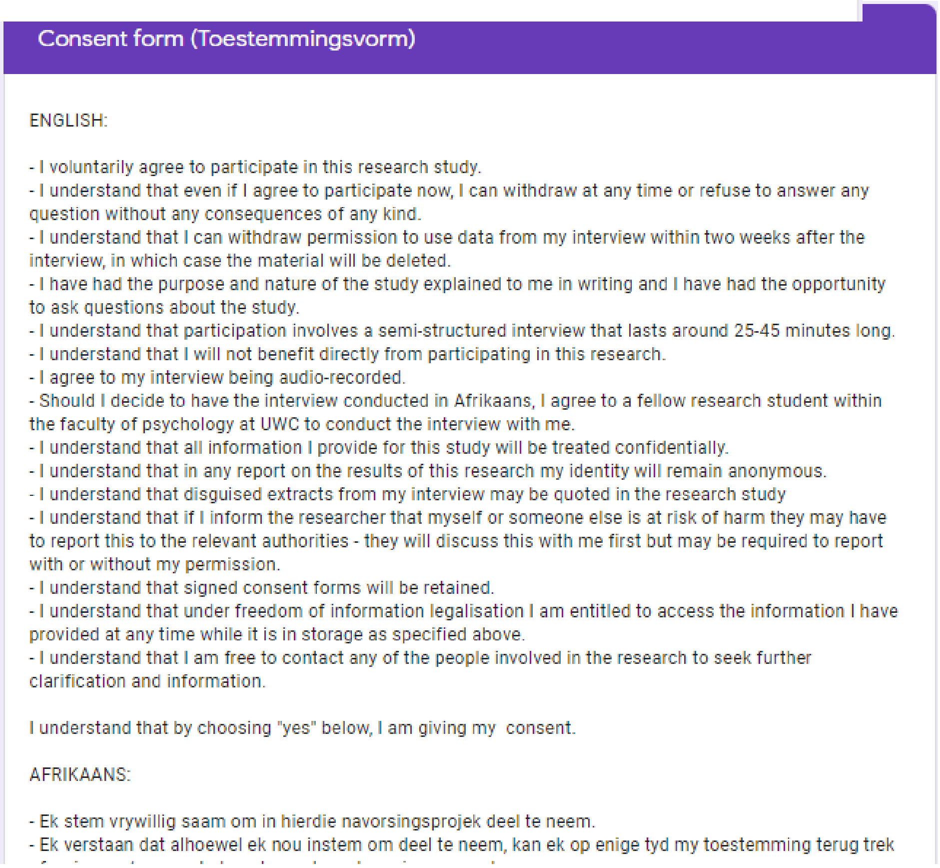
Please could you provide me with your contact number. (Kan u my asseblief u kontaknommer hieronder verstrek.) *

Your answer

Would you prefer to be contacted via email or cellphone? (Sou u verkies om per e-pos of selfoon gekontak te word?) *

○ Email (E-pos)

○ Cellphone (Selfoon)



Consent form (Toestemmingsvorm)

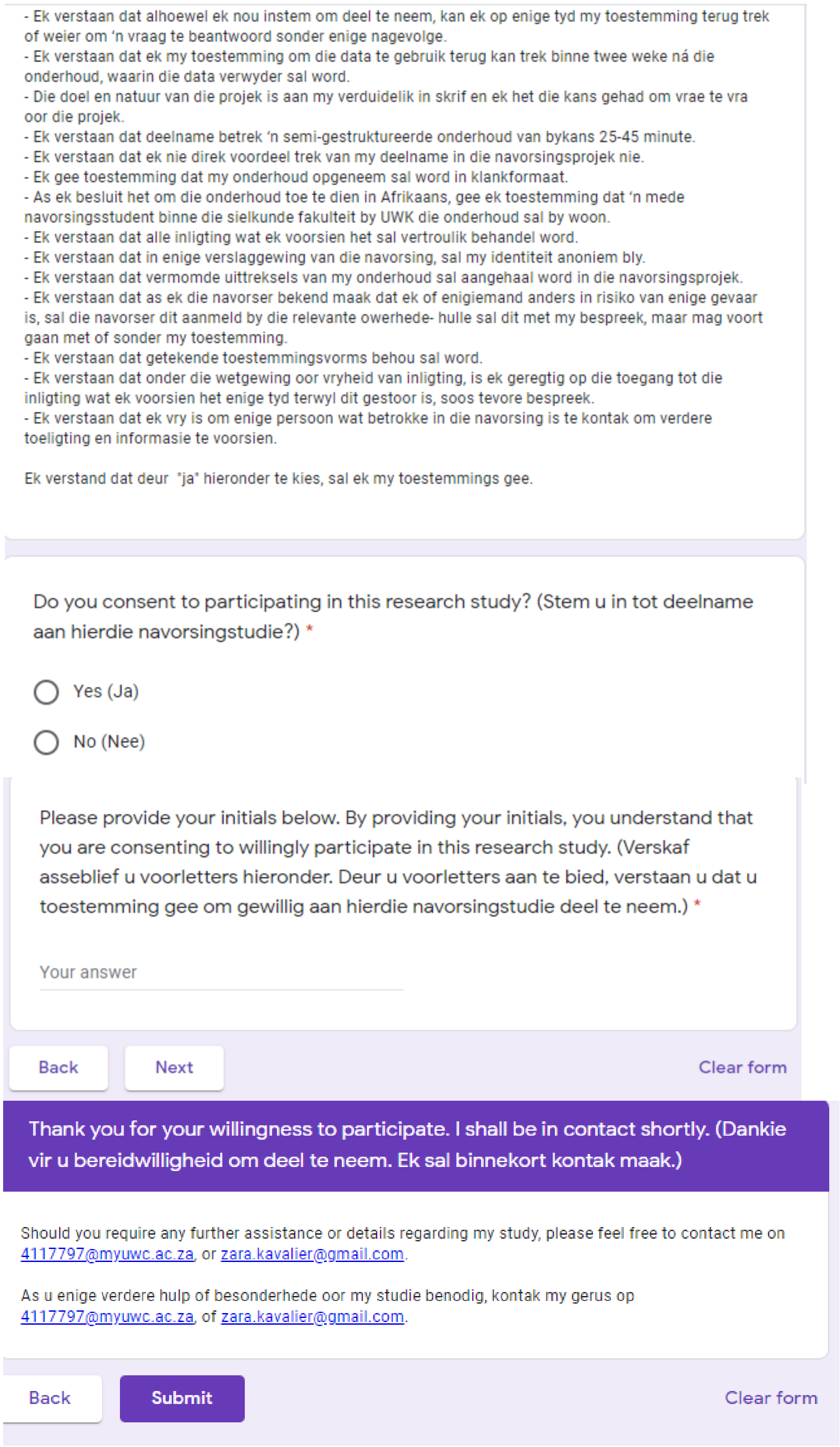
ENGLISH:

- I voluntarily agree to participate in this research study.
- I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind.
- I understand that I can withdraw permission to use data from my interview within two weeks after the interview, in which case the material will be deleted.
- I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.
- I understand that participation involves a semi-structured interview that lasts around 25-45 minutes long.
- I understand that I will not benefit directly from participating in this research.
- I agree to my interview being audio-recorded.
- Should I decide to have the interview conducted in Afrikaans, I agree to a fellow research student within the faculty of psychology at UWC to conduct the interview with me.
- I understand that all information I provide for this study will be treated confidentially.
- I understand that in any report on the results of this research my identity will remain anonymous.
- I understand that disguised extracts from my interview may be quoted in the research study
- I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.
- I understand that signed consent forms will be retained.
- I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.
- I understand that I am free to contact any of the people involved in the research to seek further clarification and information.

I understand that by choosing "yes" below, I am giving my consent.

AFRIKAANS:

- Ek stem vrywillig saam om in hierdie navorsingsprojek deel te neem.
- Ek verstaan dat alhoewel ek nou instem om deel te neem, kan ek op enige tyd my toestemming terug trek



- Ek verstaan dat alhoewel ek nou instem om deel te neem, kan ek op enige tyd my toestemming terug trek of weier om 'n vraag te beantwoord sonder enige nagevolge.
- Ek verstaan dat ek my toestemming om die data te gebruik terug kan trek binne twee weke ná die onderhoud, waarin die data verwyder sal word.
- Die doel en natuur van die projek is aan my verduidelik in skrif en ek het die kans gehad om vrae te vra oor die projek.
- Ek verstaan dat deelname betrek 'n semi-gestruktureerde onderhoud van bykans 25-45 minute.
- Ek verstaan dat ek nie direk voordeel trek van my deelname in die navorsingsprojek nie.
- Ek gee toestemming dat my onderhoud opgeneem sal word in klankformaat.
- As ek besluit het om die onderhoud toe te dien in Afrikaans, gee ek toestemming dat 'n mede navorsingsstudent binne die sielkunde fakulteit by UWK die onderhoud sal by woon.
- Ek verstaan dat alle inligting wat ek voorsien het sal vertroulik behandel word.
- Ek verstaan dat in enige verslaggewing van die navorsing, sal my identiteit anoniem bly.
- Ek verstaan dat vermomde uittreksels van my onderhoud sal aangehaal word in die navorsingsprojek.
- Ek verstaan dat as ek die navorser bekend maak dat ek of enigiemand anders in risiko van enige gevaar is, sal die navorser dit aanmeld by die relevante owerhede- hulle sal dit met my bespreek, maar mag voort gaan met of sonder my toestemming.
- Ek verstaan dat getekende toestemmingsvorms behou sal word.
- Ek verstaan dat onder die wetgewing oor vryheid van inligting, is ek geregtig op die toegang tot die inligting wat ek voorsien het enige tyd terwyl dit gestoor is, soos tevore bespreek.
- Ek verstaan dat ek vry is om enige persoon wat betrokke in die navorsing is te kontak om verdere toeligting en informasie te voorsien.

Ek verstand dat deur "ja" hieronder te kies, sal ek my toestemmings gee.

Do you consent to participating in this research study? (Stem u in tot deelname aan hierdie navorsingstudie?) *

○ Yes (Ja)

○ No (Nee)

Please provide your initials below. By providing your initials, you understand that you are consenting to willingly participate in this research study. (Verskaf asseblief u voorletters hieronder. Deur u voorletters aan te bied, verstaan u dat u toestemming gee om gewillig aan hierdie navorsingstudie deel te neem.) *

Your answer

Thank you for your willingness to participate. I shall be in contact shortly. (Dankie vir u bereidwilligheid om deel te neem. Ek sal binnekort kontak maak.)

Should you require any further assistance or details regarding my study, please feel free to contact me on 4117797@myuwc.ac.za, or zara.kavalier@gmail.com.

As u enige verdere hulp of besonderhede oor my studie benodig, kontak my gerus op 4117797@myuwc.ac.za, of zara.kavalier@gmail.com.

Appendix F: Information Sheet (English)

UNIVERSITY *of the* WESTERN CAPE

DEPARTMENT OF PSYCHOLOGY
Private Bag X 17, Bellville 7535, South Africa, Telephone: (021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

Project Title: The lived experiences of young women with endometriosis in South Africa: An exploration of chronic pain with regards to physical, psychological and social wellbeing.

What is this study about?

This is a research project being conducted by Zara Kavalieratos, a research psychology master's student at the University of the Western Cape. I am inviting you to participate in this research project because you are of female sex, between the ages of 25-35 years old and have a medical diagnosis of endometriosis. The purpose of this research project is to explore the lived experiences of young women with endometriosis in South Africa.

What will I be asked to do if I agree to participate?

You will be asked to participate in a semi-structured interview, which should not take longer than 25-45 minutes.

Would my participation in this study be kept confidential?

I undertake to protect your identity and the nature of your contribution. To ensure your anonymity, I will request you express your interest to participate in the research study by signing up via a google forms link provided on Facebook as to not disclose your identity to other group members.

To ensure your confidentiality, no person shall be given access to the interview recordings, nor the interview transcripts except to be used during the research analysis process.

If I write a report or article about this research project, your identity will be protected.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. I will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention. Beneficial referrals include: Lifeline Sexual Health Line (086 132 2322); The South African Depression and Anxiety Group (080 021 2223).

What are the benefits of this research?

This research is not designed to help you personally, but the results may help me learn more about the subjective lived experiences of endometriosis in young women in South Africa, and thus, contribute to existing literature on the topic.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Zara Kavalieratos within the department of psychology at the University of the Western Cape. If you have any questions about the research study itself, please contact either myself, Zara Kavalieratos on email (4117797@myuwc.ac.za) or via phone (072 511 9962); or my supervisor Prof. Michelle Andipatin (mandipatin@uwc.ac.za).

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Research Supervisors:

Prof. Michelle Andipatin - mandipatin@uwc.ac.za

Tel: +27 76 428 3703

Head of Department of Psychology:

Prof. Anita Padmanabhanunni - apadmana@uwc.ac.za

Tel: +27 (0)21 959 2842

Dean of the Faculty of Community and Health Sciences:

Prof. Anthea Rhoda - arhoda@uwc.ac.za

Tel: +27 (0)21 959 3261

Biomedical Research Ethics Council:

Anusha Marimutu - +27 (0)31 260 4769

Nondumiso Mngadi - +27 (0)31 260 2486

Pravini Pillay - +27 (0)31 260 8323

Email: BMREC@ukzn.ac.za

Appendix G: Inligtingsblad (Afrikaans)

UNIVERSITY *of the* WESTERN CAPE

DEPARTMENT OF PSYCHOLOGY
Private Bag X 17, Bellville 7535, South Africa, Telephone: (021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

Projek Titel: Die geleefde evaring van jong vrouens met endometriosise in Suid-Afrika: ‘n Verkenning van kroniese pyn in verband met fisies, sielkundig, en sosiale welstand.

Waaroor gaan die navorsing?

Die navorsingsprojek word uitgevoer deur Zara Kavalieratos, ‘n meesters student in navorsings sielkunde by die Universiteit van die Wes-Kaap. Ek nooi u om deel te neem aan die navorsingsproject want u is deel van die vroulike geslag, tussen die ouderdom van 25-35 jaar, en het ‘n mediese diagnose van endometriose. Die doel van hierdie navorsingsprojek is om die geleefde ervaringe van jong vrouens met endometriose in Suid-Afrika te verken.

Wat sal ek gevra word as ek deel neem?

U sal gevra word om deel te neem in ‘n semi-gestruktureerde onderhoud, wat nie langer as 25-45 minute van u tyd sal neem nie.

Sal my deelname vertroulik gehou word?

Ek onderneem om u se identitied te beskerm en die aard van u bydae. Om u anonimiteit te verseker, sal ek versoek dat u opteken deur Google vorms as u belang stel om deel te neem in die navorsings projek. Dit sal versker dat u anoniem bly en u identiteit sal nie geopenbaar word aan ander groep lede nie.

Om vertroulikheid te verseker, sal niemand toegang gegee word aan die onderhoud opnames, of die onderhoud trankripsie nie, behalwe wanneer dit gebruik word gedurende die navorsings analise proses.

As ek ‘n verslag of artikel oor hierdie navorsings projek doen, sal u identiteit ook anoniem bly.

Wat is die nagevolge van hieride navorsing?

Alle menslike interaksies en praat oor self en ander dra sekere nagevolge. Ek sal nogtans sulke nagevolge probeer verminder en dadelik optree om u te help as u enige ongemak ervaar, gedurende die proses van u deelname in hierdie navorsings projek. Waar nodig, sal ‘n gepaste verwysing gegee word na ‘n geskikte professioneel vir enige verdere hulp of ingryping.

Voordelige verwysings sluit in, Lifeline Seksuele Gesondheids Lyn (086 132 2322); The Suid-Afrikaanse Depressie en Angs Groep (080 021 2223).

Wat is die voordele van hierdie navorsing?

Die navorsing is nie ontwerp om u persoonlike te help nie, maar die resultate mag my help om meer te leer oor hierdie subjektiewe geleefde evaring van endometriose op jong vrouens in Suid-Afrika, en hierdeer dra dit ook by die bestaande literatuur oor hierdie onderwerp.

Moet ek deel wees van hierdie navorsing en mag ek enige tyd ophou deel neem?

U deelname aan hierdie navorsings projek is heeltemal vrywilig. U mag kies om glad nie deel te neem nie. As u kies om deel te neem aan hierdie navorsing, mag u enige tyd ophou met u deelname. As u besluit om nie verder deel te neem in hierdie navorsing nie, sal u nie gepenaliseer of enige voordele verloor nie.

Wat as ek vrae het?

Hierdie navorsing word uitgevoer deur Zara Kavalieratos by die departement van sielkunde by die Universiteit van die Wes-Kaap. As u enige vrae het oor die navorsings projek, kontak asseblief vir my, Zara Kavalieratos op die volgende e-pos adres (4117797@myuwc.ac.za) of u kan my kontak op die volgende nommer (072 511 9962). U kan ook my toesighouer Prof. Michelle Andipatin (mandipatin@uwc.ac.za) kontak.

As u enige vrae het oor hierdie navorsing en u regte as n navorsings deelnemer or as u enige probleme wil rapporteer wat u ervaar het verwant aan die studie, kontak asseblief:

Research Supervisors:

Prof. Michelle Andipatin - mandipatin@uwc.ac.za

Tel: +27 76 428 3703

Head of Department of Psychology:

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Appendix H: Consent form (English)

UNIVERSITY *of the* WESTERN CAPE

DEPARTMENT OF PSYCHOLOGY
Private Bag X 17, Bellville 7535, South Africa, Telephone: (021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

CONSENT FORM

Project Title:

- I voluntarily agree to participate in this research study.
- I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind.
- I understand that I can withdraw permission to use data from my interview within two weeks after the interview, in which case the material will be deleted.
- I have had the purpose and nature of the study explained to me in writing and I have had the opportunity to ask questions about the study.
- I understand that participation involves a semi-structured interview that lasts around 25-45 minutes long.
- I understand that I will not benefit directly from participating in this research.
- I agree to my interview being audio-recorded.
- Should I decide to have the interview conducted in Afrikaans, I agree to a fellow research student within the faculty of psychology at UWC to conduct the interview with me.
- I understand that all information I provide for this study will be treated confidentially.
- I understand that in any report on the results of this research my identity will remain anonymous.
- I understand that disguised extracts from my interview may be quoted in the research study
- I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.
- I understand that signed consent forms will be retained.

- I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.
- I understand that I am free to contact any of the people involved in the research to seek further clarification and information.

Appendix I: Toestemmingsvorm (Afrikaans)

UNIVERSITEIT *van die* WESKAAPLAND

DEPARTEMENT VAN SIELKUNDE
Private Bag X 17, Bellville 7535, South Africa, Telephone:
(021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

TOESTEMMINGSVORM

Projek Titel:

- Ek stem vrywillig saam om in hierdie navorsingsprojek deel te neem.
- Ek verstaan dat alhoewel ek nou instem om deel te neem, kan ek op enige tyd my toestemming terug trek of weier om ‘n vraag te beantwoord sonder enige nagevolge.
- Ek verstaan dat ek my toestemming om die data te gebruik terug kan trek binne twee weke ná die onderhoud, waarin die data verwyder sal word.
- Die doel en natuur van die projek is aan my verduidelik in skrif en ek het die kans gehad om vrae te vra oor die projek.
- Ek verstaan dat deelname betrek ‘n semi-gestruktureerde onderhoud van bykans 25-45 minute.
- Ek verstaan dat ek nie direk voordeel trek van my deelname in die navorsingsprojek nie.
- Ek gee toestemming dat my onderhoud opgeneem sal word in klankformaat.
- As ek besluit het om die onderhoud toe te dien in Afrikaans, gee ek toestemming dat ‘n mede navorsingsstudent binne die sielkunde fakulteit by UWK die onderhoud sal by woon.
- Ek verstaan dat alle inligting wat ek voorsien het sal vertroulik behandel word.
- Ek verstaan dat in enige verslaggewing van die navorsing, sal my identiteit anoniem bly.
- Ek verstaan dat vermomde uittreksels van my onderhoud sal aangehaal word in die navorsingsprojek.
- Ek verstaan dat as ek die navorser bekend maak dat ek of enigiemand anders in risiko van enige gevaar is, sal die navorser dit aanmeld by die relevante owerhede- hulle sal dit met my bespreek, maar mag voort gaan met of sonder my toestemming.

- Ek verstaan dat getekende toestemmingsvorms behou sal word.
- Ek verstaan dat onder die wetgewing oor vryheid van inligting, is ek geregtig op die toegang tot die inligting wat ek voorsien het enige tyd terwyl dit gestoor is, soos tevore bespreek.
- Ek verstaan dat ek vry is om enige persoon wat betrokke in die navorsing is te kontak om verdere toeligting en informasie te voorsien.