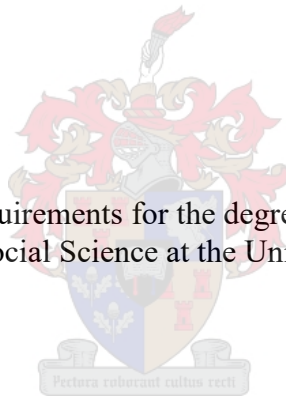


Exploring fatigue among women who live with endometriosis in South Africa

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Thesis presented in fulfilment of the requirements for the degree of Masters of Arts (Psychology) in the
Faculty of Arts and Social Science at the University of Stellenbosch



Supervisor: Dr Rizwana Roomaney

March 2020

DECLARATION

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Endometriosis is an incapacitating gynecological disease affecting approximately 10-15% of females of reproductive age. The symptoms of endometriosis negatively affect women's mental, emotional and physical well-being. Common symptoms reported in numerous studies include chronic pain, inflammation, dyspareunia and heavy menstrual bleeding. Fatigue has been identified as a commonly reported secondary symptom. However, there is limited research on the impact that endometriosis-related fatigue has on women living with endometriosis and the management strategies these women use to alleviate fatigue and mitigate the negative impact of fatigue. Fatigue can have a negative impact on the patient's quality of life. This thesis presents data collected from 25 South African women who were diagnosed with endometriosis and reported experiencing endometriosis-related fatigue. The data captured their understanding and subjective experiences of fatigue, how it affected them on a daily basis and how they manage it. I collected the data using semi-structured interviews and recruited participants using social media and at a public tertiary hospital. I recorded the interviews and transcribed them, with the help of other transcribers. I employed a thematic analysis to analyze my data and found three major themes namely; (1) Fatigue-a constant companion, (2) The impact of fatigue, and (3) Fatigue management strategies. In the current study, women reported that fatigue was disabling at home, in the workplace and in social spaces. The results highlight a relationship between occupational stress, daily stress, nutrition and lifestyle, feelings of depression, endometriosis and fatigue. The findings demonstrate a lack of fatigue management strategies, advice and treatment from health practitioners. Therefore, the data shows a need for an intervention that will help endometriosis patients manage endometriosis-related fatigue. Additionally, the findings highlight the importance of health practitioners' support for women with endometriosis.

Keywords: Endometriosis, fatigue, fatigue management strategies, endometriosis-related fatigue, thematic analysis

ABSTRACT IN SWATI

I endometriosis sifo lesigcilatako, sebantfu labasikati, lesiphatsa incenye lesuka ku 10% kuya ku 15% webantfu labasikati labasesigabeni sekutfole bantfwana. Timphawu talesifo tiyabahlukubeta bomake emtimbeni, emoyeni nasengondvweni. Timphawu letijwayelekile tifaka ekhatsi buhlungu lobungapheli, kuvuvuka, kopha kakhulu nabaye esikhatsini. Kudzinwa nako kubikiwe njenge luphawu lolubahluphako emva kwaleti letibaliwe ngenhla. Luncane lucwaningo lolwentiwe mayelana nekudzinwa kwebantfu labanalesifo, ekutsi bakhona njani kutsita. Kudzinwa lokubangwa ngulesifo kuyayiphathamisa imphilo yalona lophatsekile. Lolucwaningo lolu lubukete bantfu labasikati labangema shumi lamabili nesihlanu (25) balana Eningizimu ne Africa, labatfolakele banalesifo. Laba labakhulunyisiwe nabo babikile kutsi bayadzinwa noma bayakhatsala emtimbeni ngenca yalesifo. Lolucwaningo lubukete kuvisisa kwabo, netimphawu lababhekane nato bona, nekutsi ke bakhona njani kuchubeka baphile nato. Bantfu ngibatfole ngekusebentisa tingoni te social media nesibhedlela lesifundzisako. Tingcoco tetfu ngatitfwebula ngase ngisitwa ngulabanye kutsi ngitibhale phansi. Ngasebetisa luhlelwa lwekubuketa lokutsiwa yi thematic analysis kuchaza kabanti lolwati lebesengilutfolile. Natfole kutsi kunetingoni letintsatfu letibalulekile kulolucwaningo (1) Kukhatsala lohlala uhamba nako, (2) tingcinamba letiletfa ngulokudzinwa, (3). Taba tekuchubeka nemphilo nekudzinwa. Kulolucwaningo lwami, bantfu bebabika kutsi lokukhatsala emtimbeni kubaphatsa kabi ekhaya, emsebentini nasetindzaweni tekutijabulisa. Loku kwakhombisa budlelwane phakatsi kwe stress, indlela yekudla nemphilo Kanye nekutiva uphansi emoyeni, kudzinwa kanye nalesifo I endometriosis. Lolwati lengilutfolile lukhombise kutsi batfu bete tindlela leticacile letibasita kutsi bakhone kuphila nalokudzinwa lokubangwa ngulesifo. Futsi lolwati lukhombe sidzingo sekutsi kube netaba letentiwako letitawukhona kusita bantfu labanalesifo kutsi bakhona kuchubeka nemphilo

banaletimphawu. Kwekugcina kutsi, lolucwaningo lukhombe kutsi kuyadzingeka kutsi labasebenta kutemphilo babasekele bomake labagula ngulesifo I endometriosis

Keywords: Endometriosis, fatigue, fatigue management strategies, endometriosis-related fatigue, thematic analysis

OPSOMMING

Endometriose is 'n onbevoegde ginekologiese siekte wat ongeveer 10-15% van die vrouens van die voortplantingsouderdom aantast. Die simptome van endometriose beïnvloed vroue se geestelike, emosionele en liggaamlike welstand negatief. Algemene simptome wat in talle studies gerapporteer is, sluit in chroniese pyn, ontsteking, dyspareunie en swaar menstruele bloeding. Moegheid is geïdentifiseer as 'n sekondêre simptome wat algemeen gerapporteer word. Daar is egter beperkte navorsing oor die impak wat endometriose-verwante moegheid het op vroue wat met endometriose leef, en die bestuurstrategieë wat hierdie vroue gebruik om moegheid te verlig en die negatiewe impak van moegheid te verminder. Moegheid kan 'n negatiewe invloed hê op die kwaliteit van die pasiënt. In hierdie tesis word gegewens versamel van 25 Suid-Afrikaanse vroue wat ten tyde van die studie met endometriose gediagnoseer is en volgens endometriose-verwante moegheid ervaar is. Die gegewens het hul begrip en subjektiewe ervarings van moegheid vasgevang, hoe dit hulle daaglik beïnvloed het en hoe hulle dit hanteer. Ek het die data met semi-gestruktureerde onderhoude versamel en die deelnemers op sosiale media en in 'n openbare tersiêre hospitaal gewerf. Ek het die onderhoude opgeneem en getranskribeer, met die hulp van ander transkribeer. Ek het 'n tematiese analise gebruik om my data te ontleed en het drie hooftemas gevind, naamlik; (1) Moegheid - 'n konstante metgesel, (2) die impak van moegheid, en (3) moegheidsbestuurstrategieë. In die huidige studie het vroue gerapporteer dat moegheid tuis, in die werkplek en in sosiale ruimtes gestremd was. Die resultate beklemtoon 'n verband tussen beroepstres, daaglikse stres, voeding en lewenstyl, gevoelens van depressie, endometriose en moegheid. Die bevindings toon 'n gebrek aan strategieë vir die bestuur van moegheid, advies en behandeling van gesondheidspraktisyns. Daarom toon die data 'n behoefte aan 'n intervensie wat endometriose-pasiënte sal help om endometriose-verwante

moegheid te bestuur. Die bevindings beklemtoon ook die belangrikheid van ondersteuning van gesondheidspraktisyns vir vroue met endometriose.

Sleutelwoorde: Endometriose, moegheid, strategieë vir moegheidshantering, endometriose-
verwante moegheid, tematiese analise

ACKNOWLEDGEMENTS

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Bomngwenyama! Amaningi anginawo zihlobo zam, inhliziyi yam igcwele ukubonga kuphela. Ningithwele, nangenza ngaba yimbali eqhakazayo ezizweni, ngabonakala! Kukho konke, ngibonga umdali ongibusise ngani, makanenzele kahle aze abusise futhi agcwalise lapho nithathe khona.

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DEDICATION

This thesis is dedicated to:

- My late grandmother Mofumahali “ma Sesi” Moipone Margaret Mokoena-Sibande.

Mokoena oa ha Molibeli, Koenanyana koena li e hloile, Li e sirile ka seriti metsing,

Koena e hlapa maliboho e a nyolosa!

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Chapter 1

INTRODUCTION

1.1. Background

Endometriosis is an incapacitating chronic, gynecological disease that affects patients mentally, emotionally and physically (Culley et al., 2013; De Graaff et al., 2013; Gilmour, Huntington & Wilson, 2008; Moradi, Parker, Sneddon, Lopez, & Ellwood, 2014). Denny and Mann (2007) report that approximately 15% of females of reproductive age have endometriosis. Endometriosis is described as the presence of endometrial-like tissue found outside the uterus, causing inflammation, pelvic pain and contributes to infertility (Kennedy et al., 2005; Zegers-Hochschild et al., 2017). This tissue can grow on the bladder, fallopian tubes and in extreme cases, the brain and lungs (Greene et al., 2016; Huntington & Gilmour, 2005; Lorencatto et al., 2006).

The primary symptoms of endometriosis are pain during and after sexual intercourse, painful menstruation, chronic pelvic pain (CPP), infertility and pain during passing of stools (Kennedy et al., 2005; Mao & Anastasi, 2010). The secondary symptoms of endometriosis are fatigue, lethargy, heavy menstrual bleeding, constipation and abdominal bleeding (Mao & Anastasi, 2010). The combination of these symptoms contributes negatively to the daily lives of women suffering from endometriosis (Bernuit et al., 2011; Cavaggioni et al., 2014; Eriksen et al., 2008; Gilmour et al., 2008; Marques, Bahamondes, Aldrighi, & Petta, 2004; Petrelluzzi, Garcia, Petta, Grassi-Kassisse, & Spardari-Bratfisch, 2008; Pope, Sharma, Sharma, & Mazmanian, 2015; Roomaney & Kagee, 2016; Roomaney & Kagee, 2018; Tripoli et al., 2011).

Approximately 70% of women with endometriosis suffer from CPP (Nnoaham et al., 2011). Even though pain is universally known as a substantial symptom of endometriosis, a study conducted by Ballweg (2004) reported that other symptoms such as fatigue, abdominal bleeding, gastrointestinal problems and allergic diseases were also reported by most women with endometriosis. Furthermore, patients with endometriosis reported that CPP and fatigue interfered with their daily activities (Jones, Jenkinson, & Kennedy, 2004). Endometriosis is also associated with persistent fatigue, symptoms of depression, insomnia and chronic pain (Huntington & Gilmour, 2005; Lorencatto, Petta, Jose Navarro, Bahamondes, & Matos, 2006). As seen in the studies referenced above, fatigue seems to be a secondary symptom of endometriosis that has not been the focus of many endometriosis studies.

1.2. Impact of endometriosis on women's lives

According to Moradi et al. (2014), endometriosis has a negative impact on women's daily lives and affects different domains including the social and the psychological. In a critical review, Culley and colleagues (2013) reviewed research on the psychological and social impact of endometriosis on the lives of women with endometriosis and give a comprehensive understanding of the women's experience of endometriosis. The common themes that emerged from the 39 studies (16 qualitative and 23 quantitative) included uncertainty of quality of life and daily activities, pain, diagnostic delays, emotional and mental health well-being, planning to have children, intimate relationships, self-management and medical management; work, education and many others.

Previous research highlights that pain limited women's social lives. Women in these studies mentioned that they were not able to attend social events or take part in strenuous activity

due to pain (Culley et al., 2013; Jones et al., 2004; Gilmour et al., 2008). According to Mellado et al. (2016) women with endometriosis identified chronic pain as one of the major influences of social isolation. This meant that women's social circles were limited to their friends and family. This was partly because they did not share their endometriosis experience with others and preferred to manage it on their own.

In the study by Moradi and colleagues (2014), women reported that pain, mood swings, anger and stress brought by endometriosis negatively impacted their relationships. Women also reported dyspareunia (painful sexual intercourse) to be a common symptom that affected their marital/sexual relationships, leading to breakups or divorces (Cox, Henderson, Andersen, Cagliarini, & Ski, 2003; Denny, 2004; Denny & Mann, 2007; Huntington & Gilmour, 2005). Moradi et al. (2014) further state that the experience of pain hindered sexual intercourse, which resulted in a lowered self-esteem and a negative impact on relationships. Moreover, Moradi et al. (2014) states that the endometriosis experience made women to lose life opportunities, lack self-confidence and also have regrets.

Many studies highlight the impact of endometriosis on women's capability to work (Culley et al., 2013; Gilmour et al., 2008; Moradi et al., 2014, Nnoaham et al., 2011). Studies indicate that endometriosis resulted in women losing their jobs, resigning and even stopping their studies (Gilmour et al., 2008; Roomaney & Kagee, 2018). This had consequences for these patients because their professional and personal development and their ability to make a living was greatly affected. Moreover, research has shown that endometriosis results in massive losses to the economy due to absenteeism and loss of productivity (Simoens, Hummelshoj, & D'Hoogte, 2007).

1.3. Fatigue

According to Berger et al. (2015), Braley and Chervin (2010), Perl, Quigley and Hevey (2014), Power, Bradley, French, Wall and Hawker (2008) fatigue is an incapacitating symptom of chronic illnesses such as osteoarthritis, cancer and multiple sclerosis. By definition, fatigue is a persistent, individual feeling of exhaustion or tiredness (Tack, 1990; Pigeon, Sateia, & Ferguson, 2003). In some qualitative studies, women with endometriosis mentioned feeling fatigued even though the studies were not solely focused on exploring or understanding fatigue (Gilmour et al., 2008; Hansen, Kesmodel, Baldursson, Schultz, & Forman, 2013; Moradi et al., 2014). Despite the impact that fatigue has on women with endometriosis, at the time of this study, only one quantitative study explored fatigue among women with endometriosis (Ramin-Wright et al., 2018). Ramin-Wright and colleagues (2018) compared the prevalence of fatigue among females with endometriosis (n=560) to those who did not have endometriosis (n=560). The participants were recruited from private practices and hospitals in Germany and Austria between 2010 and 2016.

Ramin-Wright et al. (2018) found that persistent fatigue was experienced by many females with endometriosis. In their study 50.7% of females with endometriosis reported experiencing fatigue and 22.4% of females without endometriosis reported experiencing fatigue. Moreover, persistent fatigue in females with endometriosis was linked to occupational stress, symptoms of depression, insomnia, pain and a high body mass index (BMI). In this study, participants who experienced pain reported to be highly affected by fatigue. Furthermore, there was a strong association between persistent fatigue and frequent insomnia, which were commonly experienced by females with endometriosis. There was no association between age, disease stage, time of first diagnosis and fatigue (Ramin-Wright et al., 2018). The results in the

study by Ramin-Wright and colleagues (2018) emphasized that fatigue is a prevalent and overlooked symptom in women with endometriosis.

Therefore, this study seeks to understand the experiences and descriptions of fatigue among women with endometriosis. Furthermore, this study is a sub-study of a larger project that aims to develop a psychosocial intervention to manage persistent fatigue among women with endometriosis. To develop this intervention, an understanding of the experience of persistent fatigue and an exploration of how women with endometriosis manage their fatigue is required.

1.4. Rationale

There are approximately 176 million women worldwide living with endometriosis (Adamson, Kennedy, & Hummelshoj, 2010). Fatigue is an overlooked secondary symptom of endometriosis that affects many women suffering with endometriosis. Furthermore, fatigue can cause distress, which can affect the quality of life and the daily functioning of patients living with endometriosis. Literature has shown fatigue to be present in chronic illnesses such as multiple sclerosis, osteoarthritis and cancer (Cella, Lai, Chang, Peterman, & Slavin, 2002; Flinn & Stube, 2009; Franssen, Bultmann, Kant, & van Amelsvoort, 2003; Pollard, Choy, Gonzalez, Khoshaba, & Scott, 2006; Power et al., 2008; Spichiger, Rieder, Muller-Frohlich, & Kesselring, 2012; Tench, McCurdie, White, & D'Cruz, 2000). Only a few studies report on fatigue as a symptom of endometriosis. Kangas, Bovbjerg and Montgomery, (2008) and van Kessel et al. (2008) show that psychosocial (cognitive behaviour therapy-based) interventions have been successful in decreasing fatigue in patients with multiple sclerosis and cancer. To date, no interventions have been developed to reduce fatigue in patients with endometriosis. This study is

the first part of a project that seeks to develop an intervention to help women with endometriosis manage fatigue.

1.5. Research aim and objectives

The aim of this study is to understand how women with endometriosis describe, experience and manage persistent fatigue. The objectives are as follows:

1. To understand fatigue in women with endometriosis.
2. To explore the factors that women with endometriosis regard as triggers of fatigue.
3. To gain a descriptive understanding of what maintains fatigue among patients with endometriosis.
4. To understand how women with endometriosis manage their fatigue.

1.6. Thesis outline

Chapter 1 provided an introduction to the concepts of endometriosis and fatigue. This chapter contained the objectives, aims of the study and, the structure of this thesis.

Chapter 2 consists of the literature review. The chapter reviews the previous research on endometriosis, fatigue and endometriosis-associated fatigue. The chapter also contains the theoretical framework that was referred to in the study.

Chapter 3 contains the methodology used in this study. Including the research design, recruitment procedure, data collection procedure, data analysis and ethical considerations.

Chapter 4 consists of the findings of the thematic analysis. Each theme is described and supported with the inclusion of quotations.

Chapter 5 contains the discussion of the findings based on the aims and objectives outlined in chapter one and the literature review in chapter two.

Chapter 6 provides the conclusion of this research study, recommendations for future studies and for health care professionals. The chapter also presents the limitations of this study

Chapter 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1. Introduction

In the following chapter, I will be reviewing literature on fatigue, endometriosis and chronic illnesses. I will start by discussing the diagnosis, treatment/management of endometriosis and describe the impact of endometriosis on the lives of individuals living with it. I will then seek to explore fatigue in other chronic illnesses. I will conclude this chapter by describing the theoretical framework that I used in this study.

2.1.1. Diagnosis, treatment and endometriosis management

Endometriosis is not diagnosed using medical imagery (i.e. ultrasounds) and there are no biomarkers to diagnose the disease (Mao & Anastasi, 2010; Vodolazkaia et al., 2010). Endometriosis is diagnosed by inspecting the pelvis using a Laparoscope (an instrument resembling a telescope), which is inserted into the abdomen through a small incision. This process is called a laparoscopy and is considered the gold standard for diagnosis (Denny, 2004b; Farquhar, 2007). The laparoscopy is usually followed by a histological examination of the excised tissue to confirm the diagnosis (Dunselman et al., 2014). Since the diagnosis relies upon surgery it can be challenging for patients to obtain a diagnosis, especially in resource-constrained settings. This is also reflected in this current study.

2.1.2. Diagnostic delay

Many studies demonstrate that there is a delay in diagnosing endometriosis. Diagnostic delay is defined as the time from onset of symptoms until diagnosis (Ballard,

Lowton, & Wright, 2006; Cox et al., 2003; Denny, 2004a; Denny, 2004b, Markovic, Manderson, & Warren, 2008). This diagnostic delay has been quantified in several studies. The average period between diagnosis and the onset of symptoms was 10.7 years in Italy, 10.4 years in Austria and Germany, and 11.7 years in the United States of America (Hadfield, Mardon, Barlow, & Kennedy, 1996; Hudelist et al., 2012; Nnoaham et al., 2011). The diagnostic period is slightly lower in the Netherlands (7.4 years), Brazil (7 years) and the United Kingdom (7.9 years) (Arruda, Petta, Abrao, & Benneti-Pinto, 2003; Hadfield et al., 1996; Staal, van der Zanden, & Nap, 2016). These statistics show that women often live with the symptoms of endometriosis for years before being diagnosed.

The need for a laparoscopic diagnosis is partly to blame for this delay. Women with endometriosis mainly attribute the diagnostic delay to their symptoms being normalized and downplayed by family members and doctors (Cox et al., 2003; Denny, 2004b). According to Markovic and colleagues (2008) the delay in diagnosing endometriosis comes from both doctors and patients. The reasons for the delay at the patient level are that women do not seek medical assistance because it is difficult to differentiate between pathological and normal symptoms (Ballard et al., 2006). Furthermore, patients themselves, friends and family are often oblivious of what endometriosis is (Denny, 2007; Forquet et al., 2010). The view that menstrual abnormalities are normal and the ideology that menstrual pain should be endured also influences the delay (Cox et al., 2003b; Denny, 2004b; Ballard et al., 2006). Another factor contributing to the delay in diagnosis, is that women use hormone medications such as contraceptives, which suppress symptoms of endometriosis. This further discourages them not to seek medical assistance.

Lastly, diagnosis is delayed because doctors use techniques like sonograms to examine pain. These techniques are not as efficient as the laparoscopy in diagnosing endometriosis (Ballard et al., 2006). At the doctor level, women reported that medical practitioners trivialized, normalized and dismissed their symptoms, which made patients feel that they were ignored, and they were not believed. Most times, women reported being misdiagnosed (Denny, 2004b; Jones et al., 2004; Huntington & Gilmour, 2005; Denny & Mann, 2007). According to Cox et al. (2003), Denny (2004b), Denny and Mann (2007) and Jones et al. (2004), medical practitioners were said to lack awareness, knowledge and sympathy. These practitioners showed attitudes that maintained myths about endometriosis.

Markovic and colleagues (2008) gave four reasons as to why women decided to seek medical assistance. Patients sought medical assistance when their daily functioning was disrupted, when they experienced problems with falling pregnant, when their families or close friends encouraged them to do so and when they experienced dyspareunia and pain in relation to their menstrual cycle. The topic of menstruation is a taboo in many communities and discussing it can result in stigmatization. Therefore, because of this stigma, women conceal menstrual abnormalities, and this further results in the delay in diagnosing endometriosis (Seear, 2009).

2.1.3. Treatment and management

Endometriosis cannot be cured but treatment is aimed at alleviating symptoms (Donnez, 2012). Treatment choices include mild analgesic, non-steroidal anti-inflammatory medication, gonadotrophin-releasing hormone analogues, synthetic androgens and surgical interventions (Brown & Farquhar, 2015; Flower, Liu, Chen, Lewith, & Little, 2009; Young,

Fisher, & Kirkman, 2016). Specialist surgery for endometriosis also produced positive outcomes (Brown & Farquhar, 2015).

Oral contraceptives (aimed at stopping the process of ovulation/ subdue the menstrual cycle) and non-steroidal anti-inflammatory (for pain relief) are usually the first medication that patients with endometriosis use (Laufner, Sanfilippo, & Rose, 2003). An alternative to these is the use of gonadotrophin-releasing hormone analogues that yield menopause-like symptoms and Danazol for symptom relief. However, the use of Danazol produces side effects such as weight gain, hot flushes, muscle cramps and acne (Zurlo & Frank, 1990). They are used for no more than six months continuously.

Surgical interventions include hysterectomy, conservation and definitive surgery. Conservation surgery includes the removal of adhesions, cysts and endometrial tissue (European Society of Human Reproduction and Embryology [ESHRE], 2007). Hysterectomy involves the removal of the uterus, cervix and one of the ovaries is reserved for the maintenance of essential hormones (Prentice, 2001; Sutton, 2001). Lastly, definitive surgery includes removing the cervix, uterus, both the ovaries and fallopian tubes. The aim of surgical interventions is to get rid of adhesions and endometrial tissue for women to be relieved of pelvic pain (Abbott, Hawe, Clayton, & Garry, 2003; Low, Edelman, Sutton, 1993; Jackson & Telner, 2006). Definitive and hysterectomy options are usually considered when the vital organs of the patient are at risk, which can further affect quality of life. Treatment does not guarantee that there will not be any recurrence of endometriosis (ESHRE, 2007).

Different therapeutic alternatives for pregnancy as well as endometriosis indicate comparable and limited results (Kodaman, 2015; Leeners, Damaso, Ochsenein-Kolble, & Farquhar, 2018). According to Vercellini et al. (2013), Vercellini et al. (2012) and Koga,

Takamura, Fijii and Osuga (2015), surgery has a positive impact on infertility, pain and dyspareunia as well as on the quality of life for a patient with endometriosis. However, in approximately 10% to 55% of cases, the symptoms of endometriosis reoccur (Vercillini et al., 2009; Shakiba, Bena, McGill, Minger, & Falcone, 2008). Medication such as hormonal treatments are not always successful in reducing disease symptoms, meaning that women find themselves dealing with chronic symptoms for a prolonged time (Koga et al., 2015).

2.1.4. The relationship between doctor and patient

The chronic nature of endometriosis results in patients having prolonged engagement with medical professionals (Hirsh, Ladipo, Bhal, & Shaw, 2001; Jones et al., 2004). A study among 202 women diagnosed with endometriosis in South Africa found that the feelings about the medical profession was a significant predictor of symptoms of depression (Roomaney, Kagee, & Heylen, 2019). This highlights the importance of sufficient/ satisfactory support.

Bertakis and colleagues (1998) emphasize that patient satisfaction with medical assistance is pivotal and necessary since it has a strong impact on quality of life. Moreover, patient satisfaction decreases complaints and the number of women seeking for second opinions, with the potential of cutting costs (Chow, Mayer, Darzi, & Athanasiou, 2009). Lukas and colleagues (2018) conducted a study among 498 women with endometriosis and found that 45.4% of participants were not satisfied with the medical support they received. Participants commonly reported that they did not receive enough information about endometriosis and the treatment options available to them. Therefore, in order to achieve patient satisfaction with medical support, health practitioners must provide enough information on endometriosis and how they can manage it (Lukas et al., 2018).

Due to the limitations of medical interventions for endometriosis, women have developed various coping strategies to manage endometriosis. Coping strategies include lifestyle modifications (i.e. dietary changes), self-management techniques (e.g. planning) and alternative or Chinese medicine (Flower et al., 2009; Huntington & Gilmour, 2005; Markovic et al., 2008; Roomaney & Kagee, 2016). With little support from medical professionals, patients reported that they took charge of their illness and learned ways of managing it. In a study conducted by Cox et al. (2003) women reported that they advocated to be in control of their endometriosis treatment/management plan. This is further translated into being in control of their lives.

2.1.5. Impact of endometriosis on women's lives

Qualitative studies show that the symptoms of endometriosis have a negative impact on all spheres of patients' lives such as their ability to work, start a family, relationships, physical functioning, social functioning, sexual functioning, womanhood, psychological well-being and education (Buster, 2013; Carvalho et al., 2013; Culley et al., 2013; Mellado et al, 2016; Moradi et al., 2014). Chronic pelvic pain appears to be the most significant feature of endometriosis. Numerous studies have reported that pain had a negative impact on the quality of life of women with endometriosis (Bernuit et al., 2011; Gilmour et al., 2008; Marques et al., 2004; Petrelluzzi et al., 2008; Roomaney & Kagee, 2016; Pope et al., 2015; Tripoli et al., 2011). Therefore, healthcare practitioners should not only focus on the biomedical aspects of endometriosis but on how it affects their lives holistically (Altam & Wolczyk, 2010). In the following sections I describe the impact of endometriosis on several domains in women's lives.

2.1.5.1. Physical functioning

The physiological impact of endometriosis is related to symptoms, bodily changes and the side effects from the treatment (Moradi et al., 2014). Women reported pain to be a primary symptom that limits their day-to-day physical activities, such walking, lying down or standing, self-care, participating in sport, driving and etc. (Moradi et al., 2014; Roomaney & Kagee, 2018). Additionally, low energy and fatigue were also reported to be among the physical impacts that limit women with endometriosis (Moradi et al., 2014). Moradi and colleagues (2014) found that women were not satisfied with their body image because some gained weight, others were unhappy about the scarring from surgery and the paleness from heavy bleeding.

2.1.5.2. Inability to work

Many women report the negative impact that endometriosis has on their ability to be effective in the workplace and at school (Culley et al., 2013; De Graaf et al., 2013; Forquet, Báez, Figueria, Iriarte, & Flores, 2011; Gilmour et al., 2008, Moradi et al., 2014; Nnoaham et al., 2011). Due to decreased work efficiency, women with endometriosis lose an average of more than 10 hours each week in the workplace (Nnoaham et al., 2011). Endometriosis can prevent women from performing their daily roles and activities. Women with endometriosis reported that the illness prohibited them from performing certain daily roles at home, such as being a mother and performing chores around the house. Hansen et al. (2013) conducted a study aimed at investigating the link between symptoms of endometriosis and the ability of Danish women with endometriosis to work at their optimal best. The study included 1361 participants who completed an electronic survey (based on endometriosis health profile 30-questionnaire and work ability index). Hansen et al. (2013) found that decreased work

performance was associated with feeling depressed at work, higher level of pain on a daily basis, increased number of sick days, lack of energy and fatigue.

Women with endometriosis stated that symptoms, such as pain, made it difficult or impossible for them to be productive in the workplace, resulting in them constantly taking sick leave (Denny, 2004a). Gilmour et al. (2008) interviewed eighteen women with endometriosis in New Zealand and found that women with endometriosis did not reveal their illness to co-workers and employers because they feared losing their jobs. Gilmour et al. (2008) also found that endometriosis had a negative impact on the academic performance of women. This sometimes prompted some women to leave school. The inability to work or be productive at work may impede on the career and personal development of these women. In addition, Roomaney and Kagee (2018) conducted a study among 25 South African women, using face to face interviews to collect the data. It is quite pivotal to emphasize that this study was conducted in a country where wealth and health inequalities still exist (Benatar, 2013). Due to the historical past of South Africa, racial and economic class inequalities are still quite evident in the healthcare system. According to Benatar (2013) 84 % of South Africans make use of the public health care facility because they cannot afford private health care facilities, which is personalized. Roomaney and Kagee (2018) found that women with endometriosis in South Africa reported that they were breadwinners. This made it difficult for them to stay away from work because their jobs were pivotal for survival. Therefore, they experienced added pressure because they were forced to work.

2.1.5.3. Social functioning

Endometriosis has a negative effect on the interpersonal sphere of patients with endometriosis (Culley et al., 2013). Women in qualitative studies reported that the

endometriosis-related pain limited their social participation, leading to isolation (Cox et al., 2003; Mellado et al., 2016; Roomaney & Kagee, 2018). Participants reported that they were often unable to attend and participate in social events (Cox et al., 2003), resulting in their social networks becoming smaller because they were unwilling to disclose their disease to others and preferred dealing with the effects of endometriosis on their own (Jones et al., 2004). Some women with endometriosis consulted online support groups (Shoebotham & Coulson, 2016). Web-based interviews with 69 women with endometriosis revealed that there were many concerns with online support groups such as misunderstandings between members that may lead to arguments, accuracy of information, being too reliant on the group and confidentiality among group members. However, females also mentioned that online support groups were helpful because it allowed them to share their experiences with endometriosis and acquire more knowledge about the illness from others who were experiencing the same symptoms (Shoebotham & Coulson, 2016).

2.1.5.4. Sex and intimate relationships

Dyspareunia refers to painful sexual intercourse and is a primary symptom of endometriosis (Jarzabek-Bielecka, Radomski, & Pawlaczyk, 2010). Several qualitative studies show that sexual pain related to endometriosis negatively impacts women's self-esteem and the quality of the relationships that they have with their intimate partners (Cox et al., 2003; Denny, 2004; Denny & Mann, 2007; Huntington & Gilmour, 2005). In the study by Roomaney & Kagee (2018), South African women with endometriosis reported that their avoidance of sexual intercourse with partners resulted in relationship break-up, divorce and infidelity.

Quantitative studies indicate a relationship between sexual dysfunction and psychological distress in women with endometriosis (De Graaf, Van Lankveld, Smits, Van Beek, & Dunselman, 2016; Donato et al., 2014; Fritzer et al., 2013; Melis et al., 2015). Fritzer and colleagues (2013) conducted a study in Australia which aimed to assess the impact and the prevalence of sexual distress, sexual dysfunction and interpersonal relationships among women with endometriosis. The data was collected from 125 women with the use of questionnaires. Fritzer et al. (2013) found significant correlations between pain intensity during sex and sexual dysfunction, feelings of guilt toward partner, less sex per month and feeling less feminine. Some of these findings show the possibility of an interaction between pelvic pain and psychological distress.

De Graaf et al. (2016) conducted a quantitative study that sought to understand the extent to which endometriosis and mental and physical symptoms were associated with the perceived level of sexual functioning in women and their male partners. The study had an experimental group (n= 83 women with endometriosis; n=74 partners) and a control group (n=40 women with no endometriosis; n=26 partners). De Graaf et al. (2016) found that women with endometriosis reported significantly more frequent pain during sexual intercourse than women without endometriosis (53% versus 15%, $p = .001$). Furthermore, depressive symptoms and dyspareunia were negative predictors of sexual functioning. Interestingly, sexual functioning between male partners of women with and without endometriosis were comparable.

2.1.5.5. *Fertility*

Literature highlights the association between endometriosis and infertility (Carvalho et al., 2013; Fourquet et al., 2010). Approximately 47% of women with fertility problems have

endometriosis (Denn & Mann, 2007). Various factors contribute to fertility issues in patients with endometriosis. These are factors such as the environment, genetics and mechanical issues (Macer & Taylor, 2012). Not being able to have children has a negative impact on women who experience it. Women with fertility problems reported feeling stressed in their intimate relationships (Jones et al., 2004). Markovic et al. (2008) found that infertility was a worry for women with endometriosis, even when they were not planning to conceive in the immediate future. A diagnosis of endometriosis has been reported to put pressure on couples to try to start a family earlier than planned (Culley et al., 2013).

2.1.5.6. *Endometriosis and mental health*

Pope et al. (2015) and Chen et al. (2016) state that endometriosis affects mental health because it is linked to anxiety and symptoms of depression. Previous literature suggested predictors that potentially affected symptoms of depression and anxiety such as the status of one's intimate relationship, age, pelvic pain, infertility and treatment variables (De Graaf et al., 2013; De Sepulcri & do Amal, 2009; Fachhin et al., 2017; Huntington & Gilmour, 2005; Jones et al., 2004). In many studies endometriosis patients report having symptoms of depression (De Sepulcri & do Amal, 2009; Eriksen et al., 2008; Lagana et al., 2015; Lorencatto et al., 2006; Souza et al., 2011; Whelan, 2007). There have been numerous studies exploring the topic of mental health in particular, symptoms of depression and anxiety among women with endometriosis and interventions to assist these women. The following paragraphs will report on various studies that explored mental health among women with endometriosis.

Roomaney and colleagues (2019) assessed biopsychosocial predictors of symptoms of depression among women with endometriosis in South Africa. They administered various

measures, including the endometriosis health profile, Beck depression inventory, Stellenbosch endometriosis quality of life menstrual characteristics subscale and Short form health survey Physical functioning subscale to 202 women who were diagnosed with endometriosis. They found that participants had high levels of depressive symptoms and 43.1% of participants in their study reported to have moderate to severe symptoms of depression. Furthermore, they compared their results with those from the South African Stress and Health study and found that women with endometriosis reported greater levels of distress than the general population. It was also interesting to note that physical functioning was the strongest predictor of depressive symptoms. Lagana et al. (2015) also reported that women with endometriosis present with more symptoms of depression than the general population. In their study they found that out of 166 women with endometriosis, 134 participants presented with symptoms of depression (Lagana et al., 2015).

A study by Facchin et al. (2017) identified factors that affected the mental well-being of women with endometriosis. The sample consisted of 210 women diagnosed with endometriosis. Participants completed several self-report measures, such as Ruminative response scale and the Hospital anxiety and depression scale. Facchin and colleagues found that pain severity had a negative impact on the psychological health of women with endometriosis. Strong evidence on the relationship between pain and poor mental health outcomes was provided by Cox et al. (2015), Kumar et al. (2010), Facchin et al. (2015) and Pope et al. (2015). Moreover, Facchin et al. (2017) found that there was an important link between psychological health, which is symptoms of depression in this case, and individual differences among women with endometriosis. According to Facchin et al. (2017), women with increased self-efficacy and self-esteem seemed less distressed. Facchin and colleagues

emphasized the importance of multidisciplinary treatments that are customized to address the individual needs of women with endometriosis. Nagyova et al. (2015) and Juth et al. (2008) also add that evaluating and improving self-efficacy and self-esteem among women with endometriosis needs to be prioritized and seen as key factors in psychological treatment.

Lorencatto et al. (2006) conducted a study to compare the prevalence of symptoms of depression among women diagnosed with endometriosis and experience pain and women without pain. Out of 100 (50 pain free and 50 with pain) women, 86% of women with pain were depressed and 38% of women without pain were depressed. Eriksen et al. (2008) compared mental health differences between endometriosis patients (n=43) with pain and without pain (n=20). They found that there were no variations in the levels of symptoms of depression and anxiety.

2.1.6. Fatigue and chronic diseases

Highleyman (2001) described fatigue as lack of energy or exhaustion, tiredness that is unusual and prolonged which decreases the ability to sustain power or force output, particularly over time. Fatigue can be sporadic or continuous, it may also take time to advance, and may become worse over time (Sharpe & Wilk, 2002). Lee, Lentz, Taylor, Mitchell and Woods (1994) describe fatigue as tiredness that cannot be alleviated by a full night sleep. Greenberg (2002) reported an association between fatigue and psychological distress, with increased stress being associated with increased psychological distress. This makes sense when considering the adjustments that individuals need to make to accommodate fatigue in daily activities. Moreover, Clarke (2002) state that there might be stigma attached to fatigue and the experience of fatigue.

Fatigue is a common and challenging symptom of some chronic diseases, like multiple sclerosis, rheumatoid disorders, stroke, symptoms of depression and cancer (Cella et al., 2002; Flinn & Stube, 2009; Franssen et al., 2003; Pollard et al., 2006; Spichiger et al., 2012; Tench et al., 2000). Fatigue is an incapacitating symptom that negatively affects the patients' quality of life and self-care activities (Spichiger et al., 2012). In many studies, patients with chronic illnesses describe fatigue as an unpleasant, unfamiliar sense of exhaustion or tiredness with spiritual, cognitive, physical, affective dimensions that appear in various patterns resulting in stress and frustration (Flinn & Stube, 2010; Nikolaus, Bode, Taal, van de Laar, 2010; Power et al., 2008).

Overman, Kool, Da Silva and Geenen (2016) conducted a quantitative study that reported on the prevalence of severe fatigue among patients with rheumatic diseases. The data were collected using online questionnaires 6120 (88% female; mean age: 47). The patients in this study encompassed approximately 30 various rheumatic diseases. Overman and colleagues (2016) found that 41%-57% participants who had a single inflammatory rheumatic disease such as rheumatoid arthritis, scleroderma and many others, presented with severe fatigue. Severe fatigue was least prevalent in osteoarthritis patients (35%) and highly prevalent in fibromyalgia patients (82%). Moreover, Overman et al. (2016) found an association between multiple rheumatic diseases, fibromyalgia, language, younger age and lower education. In summary, more than 50% of patients with rheumatic diseases experienced severe fatigue.

A qualitative study by Corbett, Groarke, Walsh and McGuire (2016) explored the experience of cancer-related fatigue among cancer patients in post treatment. The study collected data using focus groups with 18 participants. Corbett et al. (2016) found that

participants were worried that their symptoms were not accepted in society, and this was because the general population did not understand fatigue. Many patients reported that they often felt like people around them did not understand their new reality, which resulted in them feeling isolated. In this study, fatigue was ascribed to heightened stress during cancer. Patients in this study also felt that they were not prepared enough for the experience of persistent fatigue post-cancer and this left them frustrated, confused and isolated. Lastly, these patients reported that they used active coping strategies to manage their fatigue. They mentioned using strategies such as taking naps, exercise and reserving energy.

According to Bower (2008) at least 30 % of cancer survivors present with persistent fatigue post-diagnosis. Fatigue is an untreated symptom which negatively affects functioning, socioeconomic consequences and quality of life (Hjollund, Andersen, & Bech, 2007; Minton et al., 2013). According El-Shami et al. (2015) this recurring negative impact of persistent fatigue delays patients to return to normal functioning. Scott, Lasch, Barsevick and Piault-Louise (2011) state that because fatigue is invisible, society may discredit or trivialize the patients fatigue experience. Furthermore, patients with cancer-related fatigue mentioned that they experienced a lot of misunderstanding or lack of knowledge from health practitioners, friends and family (Rosman, 2009).

According to Ingles, Eskes and Phillips (1999), post-stroke fatigue has been conceptualized as having numerous factors such as physical fatigue, social fatigue and cognitive fatigue. It may vary from one individual to another. One study explored the occupational impact of fatigue on post-stroke survivors (Flinn & Stube, 2010). The data were collected using focus groups with 19 post-stroke survivors. Participants reported that they felt unprepared for the experience of fatigue and that it was a challenge for them to adapt to the

incapacitating impact of fatigue, especially with regards to roles and daily activities (Flinn & Stube, 2010). These daily roles and activities included sleeping, social participation, returning to work, reading and driving. Furthermore, participants mentioned that exercise like water aerobics, walking and the use of assistive technology helped them in reducing fatigue. Lastly, participants said that there was a difference in fatigue experience prior stroke and post stroke (Flinn & Stube, 2010).

2.1.7. The experience of fatigue and the impact it has on the lives of patients with chronic illnesses

Studies indicate that the way in which patients with fatigue view or respond to their fatigue plays a pivotal role in fatigue-management (Wilson, Whitehead, & Burrell, 2011). It is evident that to some extent, the fatigue experience is generic across illnesses (Flinn & Stube, 2010; Nikolaus et al., 2010; Power et al., 2008; Spichiger et al., 2012). There are fascinating differences in how individuals of different chronic illnesses experience fatigue. For example, in illnesses such as asthma, where the fatigue is episodic or is short-lived, individuals know that the fatigue will end after the episode and manage their fatigue accordingly (Ream & Richardson, 1997). However, patients with illnesses such as chronic fatigue syndrome and fibromyalgia deal with fatigue that is chronic and persistent. These patients realize that fatigue is part of their daily life, which makes them to push through and do what is important to them (Schaefer, 1997). It is important to note that some chronic illnesses and their features are usually invisible, such as fatigue and endometriosis. Health practitioners tend to normalize the experience of fatigue (Spichiger et al., 2012). In addition, some patients tend to endure the fatigue because they think it is part of the disease and a result of the treatment for their chronic disease (Tsai, Lin, Chao, & Lin, 2010).

Nikolaus et al. (2010) conducted a study that aimed at exploring the fatigue experience of rheumatoid arthritis patients. They used in-depth structured interviews to ask 31 (8 males and 23 Females; between 32-83 years) participants about their subjective experience of fatigue. Nikolaus et al. (2010) mention that participants reported different types of fatigue. Firstly, participants mentioned that there was a difference between physical and mental fatigue. Secondly, they mentioned that there was fatigue brought by physical activity or poor sleep and lastly, there was fatigue which was combined with pain. Females reported being unable to work and sometimes being too fatigued in the workplace, finding it difficult to support or assist others, cancelling appointment and invitations to meetings or social events, being stressed from fatigue and being unable to do chores. Furthermore, females in this study also reported that they managed their fatigue by planning their activities and made sure to prioritize the important tasks (Nikolaus et al., 2010). Moreover, younger females reported feeling more fatigued than older females. This difference was attributed by the multiple daily roles that young females had than older females. This study shows that fatigue can negatively affect individuals in several domains such as physical functioning, mental well-being and social functioning (Nikolaus et al., 2010).

Qualitative studies reiterate the importance that people with rheumatoid arthritis ascribe to fatigue (Carr et al., 2003; Ahlem et al., 2004). Many factors affect rheumatoid arthritis fatigue such as illness perceptions, psychosocial factors, poor social support and health beliefs (Huyser et al., 1998; Reijmsma et al., 1998). Fatigue in rheumatoid arthritis is strongly associated to symptoms of depression and pain (Wolfe, Hawley, & Wilson, 1996; Rupp et al., 2004; Tack, 1990; Fifield, Tennen, Reisine, & McQuillan, 1998; Wolfe & Michuad, 2004; Suurmeijer et al., 2001; Fifield et al., 2001; Jump, Fifield, Tennen, Reisine,

& Guiliano, 2004). It is because of this relationship that the term fibromyalgic rheumatoid arthritis came about. This term describes a subgroup of patients with increased levels of pain, fatigue and symptoms of depression (Wolfe & Michaud, 2004).

Patients report having challenges in performing daily tasks like driving, reading, child-care and spending quality time with friends and family (Flinn & Stube, 2010; Nikolaus et al., 2010). Patients also reported sleep disturbances and regularly skipping work or school resulting in poor job productivity or job loss, which may have financial implications (Nikolaus et al., 2010). According to the study by Barroso (2001), participants reported that they had to leave their jobs or decrease their work commitments. In one research study, participants reported that they had a challenge in meeting role-expectations. Fatigue had a negative impact on the role of being a mother, wife, employee and girlfriend (Barroso, 2001).

Many patients (cancer patients, fibromyalgia patients, post-stroke patients and hemopoietic stem cell transplantation patients) have shared their frustrations about the unpredictable nature of fatigue and decreased capability to think distinctly which had an impact on numerous areas of their lives (Barsevick, Whitmer, & Walker, 2001; Flinn & Stube, 2010; Schaefer, 1995; So & Tai, 2005; Spichiger et al., 2012). Even though patients face challenges in their daily lives because of fatigue, they continue to search for ways to manage it (Barsevick et al., 2001; Schaefer, 1995; So & Tai, 2005; Spichiger et al., 2012).

2.1.8. Endometriosis and fatigue

Research focusing solely on fatigue among women with endometriosis is limited. Few qualitative studies only mentioned fatigue as part of the experience of endometriosis (Ballweg, 2004; Huntington & Gilmour, 2005; Jones et al., 2004; Lorençatto et al., 2006; Moradi et al., 2014; Petrelluzzi et al., 2008; Roomaney, 2017). Only one recently published

study has focused on fatigue among the endometriosis population. This study reported on the prevalence of fatigue in a sample of women with endometriosis (Ramin-Wright et al., 2018). I will now discuss the relationship between endometriosis and fatigue and describe research relating to this.

Lemaire (2004) collected data from 298 women attending an Endometriosis Association conference in the United States and found that fatigue was one of the top three symptoms reported by participants. In a study conducted by Sinai, Clearly, Ballweg, Nieman and Stratton (2002), the Endometriosis Association conducted a cross-sectional survey of 3680 females who were surgically diagnosed with endometriosis. Sinai et al. (2002) reported that 99% of these participants had pain and 41% reported infertility. Similarly, Ramin-Wright and colleagues (2018) found that women with endometriosis reported significantly more fatigue than the control group. However, there was no association between fatigue and age.

Chronic exposure to increased stress can lead to adrenal fatigue and this could be one of the many explanations of the relationship between endometriosis and fatigue (Ramin-Wright et al., 2018). Fatigue is not only associated with stress, but it is also strongly associated with pain, symptoms of depression, insomnia and occupational stress (Ramin-Wright et al., 2018). Additionally, a high body mass index (BMI) was linked to frequent fatigue, however, symptoms of depression and pain were reported to be factors that had a great influence on fatigue. Furthermore, studies by Hansen et al. (2013) and van Aken et al. (2018) highlight that women with endometriosis often suffer from stress.

Patients with endometriosis have mentioned experiencing fatigue in numerous studies (Ballweg, 2004; Huntington & Gilmour, 2005; Jones et al., 2004; Lorençatto et al., 2006; Moradi et al., 2014; Petreluzzi et al., 2008; Ramin-Wright et al., 2018). For example, a study

with 7000 women with endometriosis found that approximately 85% of participants reported experiencing fatigue, with fatigue being the second and most common symptom reported by women, after menstrual pain (Ballweg, 2004). However, these studies only looked at the impact of endometriosis and not specifically fatigue as done in the current study. Gilmour et al. (2008) and Jones et al. (2004) found that most women stated that pain, fatigue and their preoccupation with pain limited their social relations. In the study by Gilmour et al. (2008), women reported that they stopped playing sports, attending social events and walking due to chronic pain. Participants in the study by Jones et al. (2004) also reported that endometriosis, specifically pain, made them stop or avoid attending events. These females also mentioned that pain prohibited them from starting new activities.

While there is currently no explanation for endometriosis-associated fatigue, literature states that fatigue may be related to pain in women with endometriosis (Ramin-Wright et al., 2018). Studies have explored the relationship between disease stage and fatigue, but findings are inconclusive. Ramin-Wright and colleagues (2018) did not find a significant association between fatigue and endometriosis stage but this finding is not in agreement to what Ashrafi, Sadatmahalleh, Akhoond and Talebi (2016) found. According to Ashrafi et al. (2016) there is a significant relationship between disease stage and the symptoms of endometriosis. In summary, persistent fatigue is said to be one of the most disabling symptoms of endometriosis, yet it is still unacknowledged and not discussed (Riaz et al., 2015). The following paragraphs are mostly informed by qualitative studies relating to fatigue in other chronic illnesses.

2.1.9. Managing fatigue

Even though fatigue can be debilitating, patients manage fatigue using social support systems, making practical changes and cognitive adjustments (Tsai et al., 2010). Patients consider fatigue as a feature of living with chronic diseases such as cancer, fibromyalgia and rheumatoid arthritis (Schaefer, 1997; Spichiger et al., 2012). Individuals living with chronic diseases employ fatigue coping strategies such as planning, reducing and pacing their daily tasks, nutrition modification (changing one's diet to eating non-inflammatory and wholesome food), taking planned naps, exercising in moderation and keeping in mind not to exert the body. This was to decrease the discomfort that came with fatigue (Barsevick et al., 2001; Schaefer, 1995; So & Tai, 2005; Spichiger et al., 2012; Stuifbergen & Rogers, 1997). One useful strategy, known as pacing, refers to patients deciding which period of the day is best for them to do activities valuable to them (Barsevick et al., 2001; So & Tai, 2005; Tsai et al., 2010).

Social support can help patients in managing fatigue (Jump et al., 2005; Tsai et al., 2010). Social support refers to the social assets that people see to be accessible or that are given to them by non-professionals with regards to both formal care groups and casual helping relationships (Gottlieb & Bergen, 2010). It can be family, friends and health practitioners educating themselves about fatigue so that they are able to best help the patient (Piredda et al., 2007; Ream, Browne, Glaus, Knipping, & Frei, 2003; Tsai et al., 2010). Family and friends can help the patients with fatigue by assisting with household chores for the patient to conserve energy for other day-to-day tasks that they value the most, such as self-care, childcare or their careers (Piredda et al., 2007; Ream et al., 2003). In a study

conducted among 15 breast cancer patients in Taiwan, patients reported that strong social support resulted in them feeling less fatigued (Tsai et al., 2010).

Several studies reported that individuals who experienced fatigue hesitated to report fatigue to a healthcare practitioner (Bersewick et al., 2001; Gledhill, 2005; Passik et al., 2002; Potter, 2004; Wu & McSweeney, 2007). Patients may hold a belief that fatigue is a normal part of an illness and this belief can limit patients as they may not be aware of options available to them to manage their fatigue (Bersewick et al., 2001; Gledhill, 2005; Passik et al., 2002; Potter, 2004; Tsai et al., 2010; Wu & McSweeney, 2007). This further becomes a challenge for physicians to develop interventions that will assist patients to manage fatigue because they do not know how patients experience and describe fatigue (Piredda et al., 2007; Ream et al., 2003). Since patients assume that fatigue is part of having an illness, they may find methods to cope with fatigue.

2.2. Theoretical framework

2.2.1. Energy envelope theory

King, Jason, Frakenberg and Jordon (1997) developed the energy envelop theory, which explains fatigue using energy levels. According to this theory, individuals are able to pace activity in relation to their available energy supply. According to King et al. (1997) individuals are encouraged to stay within the envelope. This is a range of energy expenditure where an individual should neither over exert nor under exert; but maintain an optimal level of activity.

The theory postulates that if an individual's expended energy levels are within the envelope of the available energy levels, they will be able to sustain psychological and

physical functioning, while decreasing severity and frequency of fatigue (Jason et al. 2013). Once an individual has found balance, it is possible to steadily increase activity without compromising function (King et al., 1997; Pesek, Jason, & Taylor, 2000).

There are two components in this model, namely perceived energy (amount of energy available) and expended energy (energy that an individual uses) (Pesek et al., 2000). The energy envelope theory focuses on trying to find a balance between total avoidance of activity and high levels of daily activity. An example of this is the buddy volunteer program by Shlaes and Jason (1996). Chronic fatigue syndrome (CFS) patients were provided with a buddy to assist them with daily chores and this allowed patients to do tasks that did not deplete their energy. This program was meant to assist and not take away all the tasks that patients needed to do. Maintenance of energy levels can make it possible for individuals with fatigue to expand their energy envelope. This means that their perceived energy can increase over time. This affords patients the opportunity to take part in higher levels of physical activity (Friedberg & Krupp, 1994). Therefore, overexerting oneself and going outside the energy envelope can lower quality of life and increase the level of fatigue (Jason et al., 1999).

A four-month volunteer caregiving program was developed to help patients with chronic fatigue syndrome (CFS) to manage their fatigue (Shlaes & Jason, 1996). This program entailed a volunteer who was community member and a mentor, an individual with CFS. The role of a volunteer was to assist patients with CFS with daily chores on a regular basis by visiting patient's homes. The role of the mentor was to provide emotional and informational support to the patients. There were 12 participants (6 control group; 6 experimental group). The experimental group received a volunteer to assist them with daily

chores while the control group did not. When the program ended, the experimental group showed a decrease in fatigue severity and the control group had a significant increase in fatigue severity. These findings implied that if CFS patients would avoid overexerting themselves, they can avoid relapses and setbacks. Furthermore, this could increase their tolerance. Moreover, CFS patients must not be compelled to either decrease or increase activity levels but practice conserving energy and moderate activity.

Chapter 3

RESEARCH DESIGN AND METHODOLOGY

3.1. Introduction

In this chapter, I outline the research methodology used in this study. This includes the research design, participant recruitment, data collection, data analysis using thematic analysis, trustworthiness of the study, my reflections on the research process and ethical considerations.

3.2. Research design

The overall aim of the broader project is to develop a psychosocial intervention that will assist women with endometriosis to manage persistent fatigue. The aim of my study is to understand fatigue among women with endometriosis and the findings from my study will in part, inform the intervention. The current study is an exploratory study that used a qualitative research design to obtain an in depth understanding and comprehensive description of how women with endometriosis experienced persistent fatigue. The qualitative approach that I used in this study examined the words spoken by the participants and not the measurement of variables as used in a quantitative approach (Bless, Higson-Smith, & Sithole, 2013). I collected data by conducting face to face interviews with women who were diagnosed with endometriosis and who reported that they experienced fatigue that impaired their daily functioning.

3.3. Participants

3.3.1. Inclusion Criteria

Women who met the following criteria were requested to participate:

1. 18 years and above
2. Diagnosed with endometriosis (diagnosed by a gynecologist)
3. Experience fatigue that impaired daily functioning (affecting their ability to perform day to day activities)
4. Had a good comprehension of English or Afrikaans to be able to participate

3.3.2. Exclusion Criteria

Women with endometriosis who did not experience fatigue that impaired daily functioning.

3.3.3. Participant recruitment

I used convenience sampling to recruit participants for this study in two different settings. Convenience sampling is a non-probability sampling method where a sample in a target population is selected because they are easily accessible, willing to participate, can be available at a stipulated time and geographical location for the purpose or the aim of the study (Dornyei, 2007). The convenience sampling method is used in qualitative studies (Dornyei, 2007). First, I recruited participants online. I used a flyer to recruit participants for this study (please see appendix A). This flyer was posted on two local endometriosis support groups, namely Endometriosis Support South Africa (ESSA) and the Foundation for Endometriosis Awareness, Advocacy and Support South Africa (FEAAS). I posted the flyer in both these groups after obtaining permission from the group administrators. Women then

contacted me or my supervisor via email, indicating their interest in the study. I responded via email or phone call and informed them about the study and what was required of participants. I asked them a few questions regarding their fatigue and endometriosis. If they met the criteria of the study, I asked them for consent to be interviewed at a time and place that would be comfortable and convenient for them. When I met with the participants, I discussed the consent form and explained the nature of the study, the ethical issues and aims of the study.

I also visited the Tygerberg Hospital endometriosis clinic on Thursdays to recruit participants. The doctors and the nurses introduced me to the potential participants and also mentioned the study to the patients. If the patients showed interest in the study, I asked them a few questions to determine if they met the study's inclusion criteria. If they agreed to participate, the interview took place in a private room at the clinic. Some participants were interested in the study but were not able to stay for an interview. When this happened, I gave patients the flyer with my contact details, and they called me to set up an interview appointment at a time and place that was convenient for them.

3.4. Data collection

I used face to face, individual, semi-structured interviews to collect data for this study. I proposed to conduct 30 interviews with women with endometriosis who experienced fatigue. However, I reached data saturation after the 20th interview. Data saturation occurs when the researcher does not get new information or concepts from the data (Bless et al., 2013). To make sure that there was no new information that would emerge from the data, I continued with the interviews until I had a sample of 25 participants. According to Lasch et

al. (2010) the data that comes from qualitative interviews embody the investigated experience and not the sample. Therefore, the 25 interviews certainly represent the experience of fatigue among women with endometriosis.

Interviews were conducted at several private locations such as participants' workplaces (meeting boardrooms), in their homes, in one of the private rooms in the psychology department at Stellenbosch University and in a private room at the Tygerberg hospital endometriosis clinic. Semi-structured interviewing is a qualitative data collection technique where the interviewer asks a series of scheduled open-ended questions or themes. Participants are asked the same questions, but the interviewer becomes flexible in how the questions are asked (Given, 2008). Additionally, semi-structured interviews provide a platform for the participants to bring in new themes that were not covered by the interviewer (Bless et al., 2013). According to DiCicco-Bloom and Crabtree (2006), semi-structured interviews are a commonly employed format of qualitative interview.

All the participants received a copy of the consent form. I explained the aims of the study in depth and their rights as participants. I gave them an opportunity to ask any questions that they had. Furthermore, I asked if they were still comfortable taking part in the study and when they agreed, they signed the consent form. The consent form had contact details of my supervisor and I. At the end of the interview, I reminded them that they could contact us should they experience distress triggered by the interview (my supervisor and I had prepared psychological/ counselling services, in the case that participants needed them) or should they need more information. I used an interview schedule (the interview schedule arose from the engagement with the literature) to guide the conversation I had with the participants (please see appendix B). I started the interview by asking participants the first question on the

schedule which is: “Can you please describe your energy levels on a typical day?” The next eight questions on the interview schedule looked at the management of fatigue, impact of fatigue and defining fatigue when you have endometriosis. The interview schedule was the same with all the 25 participants, but they were not asked in the same way. The way the questions were asked depended on the interview conversation and the small talk that occurred prior the interview. Moreover, I used some probes, close ended, direct, interpreting and follow-up questions (Bless et al., 2013; Kvale, 2007).

I only conducted interviews in English and my supervisor conducted Afrikaans interviews, with me present. The language depended on the preference of the participant. I met with my supervisor on a regular basis to discuss the interviews and themes emerging. We spoke about how to also ask questions that will give us rich descriptions that would paint a picture of participants’ experiences of fatigue. These discussions made me to constantly scrutinize my interviewing skills and ask the interview questions better, in a way that made the participants share everything they felt comfortable sharing about fatigue.

Participants provided written permission to audio-record the interviews. The interviews ranged from 30 minutes to one hour and 16 minutes. At the end of each interview, as per requirement of the Health Research Ethics Committee (HREC) at Stellenbosch University, all the participants received R100 gift voucher as a token of gratitude for being part of the study. Most participants indicated that they were happy to participate in the interview because for some, it was the first time openly talking about the impact of endometriosis and fatigue on their lives after being diagnosed with endometriosis. They also reported how great it was to actually talk to someone who understood and did not think they are lazy. I transcribed all the English interviews and asked a researcher to transcribe and translate the

Afrikaans interviews. The researcher signed a confidentiality agreement and was paid for the work.

3.5. Data analysis

I checked all transcriptions for accuracy and completeness. I did this by listening to the interviews while reading the transcribed versions. This allowed me to immerse and familiarize myself with the data. I entered the transcribed interviews into Atlas Ti version 8, a qualitative management tool. I used the thematic analysis to analyze all the interviews and I followed Braun and Clarkes (2006) guidelines to identify and analyze themes found in the data (Braun & Clarke, 2006). I used Braun and Clarke (2006) guidelines to analyze the data in the following manner:

I familiarized myself with the content of the data by listening to the interviews I recorded, reading the transcribed interviews and the mini notes I had generated when I discussed the interviews with my supervisor. In this way I was able to immerse myself in the data. After immersing myself in the data and being familiar with the data, I was able to generate initial codes.

I used the first 6 interviews to generate a primary codebook. These interviews initially generated 404 codes. My supervisor kept track of the development of these codes, we spoke about them and agreed to keep and change the names of some of the codes. After 20 interviews, I reached data saturation and there were no new codes emerging. I stopped data collection at 25 interviews and generated a total of 696 codes.

I looked at similar codes in the data and I grouped them to form themes. Each of the themes had consistent codes and pertinent quotations were closely examined with the help of

my supervisor. This ensured that the data extracted and the codes for each theme formed a comprehensible pattern and brought meaning to the theme. Each of the themes developed for this study, were an accurate representation of the whole data set. Moreover, these themes reflected what fatigue is and how it is experienced among women with endometriosis in South Africa.

3.6. Trustworthiness

For this study, I made use of a few methods to enrich the trustworthiness in the data analysis and collection (Babbie & Mouton, 2001). Firstly, my supervisor trained me in conducting interviews to make sure that I was skilled enough to collect the data. Throughout the data collection process, I met with my supervisor every week to discuss how the interviews went. She gave me feedback and suggestions on how to improve on my interviewing skills and asking the right questions. During these meetings, I made notes that were used during the interviews and the data analysis phase. This was to ensure that the analysis represented what the interviews captured. Throughout the coding process, my supervisor checked the codes, discussed them with me and gave me feedback.

3.7. Ethical considerations

This project received ethical approval from the Health Research Ethics Committee (HREC) at Stellenbosch University (N17/10/099) (please refer to Appendix D) and permission to recruit participants from Tygerberg hospital from the Western Cape Department of Health (please refer to Appendix E). Permission from the WCDOH was not required for recruiting participants from NPO's. The Facebook groups and the Western Cape Department of Health was approached only after the HREC approved the study.

Since I had transcribers, they were required to sign a confidentiality agreement. When I met the potential participants, I informed them about their right to decline being a participant in this study. I also informed them that the study was independent from the clinic and would not have an impact on their treatment. I assured them that everything we discussed was confidential and that their identity would be kept anonymous.

Before each interview, the participants and I read and discussed the consent form. We discussed their rights regarding the research study and that they are permitted to end the interview at any time. I mentioned to them that they had the right to not answer any questions that made them feel uneasy. All the patients signed the consent form as part of agreeing to take part in the study and agreed to be audio recorded while they were interviewed (please refer to appendix C). All the files containing patient's personal information and consent forms were carefully stored in a locked cupboard in my supervisor's office. Furthermore, I used pseudonyms to ensure their anonymity. Data will be stored for five years after completion of study and then be destroyed.

3.8. Reflexivity

Before I started my data collection, my supervisor and I went to the hospital to meet the doctors who work with endometriosis patients. We discussed the study and how we were going to approach participants. This was an opportunity to meet the other doctors, nurses and one endometriosis patient in the hospital. I also got to familiarize myself with the building too. I worked alongside the doctor who introduced me to prospective participants after having identified diagnosed endometriosis patients. I would then tell them what the study was, what the aims of the study were and ask questions to check if they met the criteria to be

part of the study. I asked them if they had enough time to speak to me after their appointment with the doctor and if they were interested to be part of the study. For those patients who were unable to meet me after their appointment, we exchanged contact details to schedule a meeting time. For patients who were interested and were able to meet me after their doctor's appointment, the doctor would bring them to me.

I got to the clinic quite early and this gave me time to organize a private room with the nurses for all the interviews for that day, making sure that I had water, snacks and some tissues should the participants need anything. This was done to create a warm and inviting space for the participants to be comfortable. My time spent at the hospital, having conversations with the nurses and student doctors made me realize the importance of language in health care, especially for illnesses like endometriosis. There were times when I had to be translator to assist a doctor who did not understand isiXhosa and a patient who also did not understand English. This could be one of the many barriers that women or anyone face in accessing basic health care.

I was very worried as to how the patients were going to perceive me because I am a young female wanting to ask about private matters or matters not many talk about. Moreover, I was worried I did not know anything about endometriosis before this study and I thought this would affect how I interacted with participants. After I was done with my literature review, I got acquainted with endometriosis and the concepts around it. This made me not only to be confident to approach participants but to be able to present endometriosis awareness talks around in schools and churches. All of the participants in this study were very welcoming and so willing to talk about their endometriosis journey and fatigue experience. The training that I got from my supervisor prior data collection actually helped

me to put a lot of things into perspective. The check-ins every week with my supervisor also helped in making sure that the interview process was not overwhelming. When I analyzed my data, I made sure not to impose what I already knew about endometriosis on the data I got. I made sure that the data spoke for itself. My supervisor checked my coding, the development of my themes and how I discussed the themes to make sure I was objective.

I cannot begin to imagine how women with endometriosis deal with the limitations that they faced because of this illness and its symptoms. I learnt so much about positivity, self-love and genuine happiness from the participants. As a researcher, I have learnt so much from this experience; from interviewing skills to observing the sheer strength that women possess.

Chapter 4

FINDINGS

4.1. Introduction

In this chapter, I describe the demographic characteristics of participants in this study and report the findings. I will report on the themes that I created during the data analysis process. I will start with the first theme, namely fatigue- a constant companion, which reveals how participants described and understood their fatigue. I will then describe the impact that fatigue had on participants' lives and conclude the chapter by describing the fatigue management strategies that participants reported using.

4.2. Description of participants

The participants in this study consisted of 25 women diagnosed with endometriosis. Participants' ages ranged from 22 to 45 years (mean age = 35 years). Most of the women were single (n = 10), did not have children (n = 13), completed tertiary education (n=13), employed fulltime (n=18) and spoke Afrikaans as their home-language (n=12).

I collected some information about participants' health. The majority of participants were diagnosed with stage 4 endometriosis (n= 12), were diagnosed with endometriosis more than three years prior to the interview (n=13) and were not using any form of treatment for endometriosis (n=12). No participants reported using any form of fertility treatment at the time of the interview. Participants did not report having any other medical conditions associated with fatigue, except for one, who reported that she was diagnosed with depression.

Table 4-1

Demographic information of participants

| Description | Number |
|--|---------------|
| <i>Age</i> | |
| Range | 22-45 |
| Mean | 35 |
| <i>Relationship status</i> | |
| Single | 10 |
| Married | 13 |
| Separated | 1 |
| Divorced | 1 |
| <i>Living situation</i> | |
| Live alone | 2 |
| Live with other adult(s), no children | 10 |
| Live with other adult(s) and children | 10 |
| Live with children only | 3 |
| <i>Home language</i> | |
| Setswana | 2 |
| IsiXhosa | 2 |
| English | 8 |
| Afrikaans | 12 |
| IsiZulu | 1 |
| <i>Highest level of education</i> | |

| | |
|--|----|
| Started high school but did not complete | 1 |
| Completed grade 12 | 6 |
| Completed tertiary | 13 |
| Started tertiary but did not graduate | 5 |
| <hr/> <i>Number of children</i> | |
| 0 | 13 |
| 1 | 8 |
| 2 | 1 |
| 3 | 2 |
| <hr/> <i>Employment status</i> | |
| Student | 1 |
| Unemployed | 5 |
| Employed (Part time) | 1 |
| Employed (Full time) | 18 |
| <hr/> <i>Income (Household income per year)</i> | |
| Does not know | 2 |
| Less than R5000 | 1 |
| R5001-R20 000 | 4 |
| R20 001-R80 000 | 5 |
| R80 001-R110 000 | 1 |
| R110 001-R200 000 | 1 |
| R200 001-R300 000 | 5 |
| R300 001 and above | 5 |
| <hr/> | |

| | |
|------------------------------------|----|
| <i>Time since diagnosis</i> | |
| Less than 6 months ago | 2 |
| 1 year ago | 7 |
| Between 1 and 3 years ago | 3 |
| More than 3 years ago | 13 |
| <i>Disease stage</i> | |
| Does not know | 7 |
| Stage 1 | |
| Stage 2 | 2 |
| Stage 3 | 3 |
| Stage 4 | 12 |
| Unsure | 1 |
| <i>Treatment</i> | |
| None | 11 |
| Oral contraceptives | 10 |
| Mirena | 1 |
| Injection | 1 |
| Chinese reflexology | 1 |
| Fertility treatment | 0 |

4.2.1. Fatigue - a constant companion

Participants in this study found it difficult to define or describe fatigue. They emphasized that fatigue was not tiredness caused by overworking oneself (i.e. over-exertion), but rather a

constant exhaustion that occurred even when they were not doing anything. Participants repeatedly expressed the persistent nature of this exhaustion. Nomcebo, a 42 year old single mother, described fatigue as follows:

People need to understand that there's a difference between fatigue and random tiredness. Fatigue is there, it stays, you can mask it but it's constant. It's not just, "I'm tired today." It's there, so you need to manage it all the time.

Most participants in this study referred to fatigue as a confinement, which affected multiple spheres of their lives. Participants also mentioned that they felt that their constant low levels of energy limited them from engaging in activities that they enjoyed. Women in this study reiterated that their fatigue made them feel confined because they had no control of the fatigue and the impact that it had on their bodies. Nomfundo, a young mother of 26 years, described the impact of fatigue as follows:

So, you just sit at home whole day, even if you just think about walking, you're tired already. So, that's just my daily prison.

Even though all participants reported feeling fatigue and were diagnosed with endometriosis, very few thought that the two were related. Participants attributed their fatigue to a number of factors such as having too many chores, long working hours, endometriosis treatment and menstruation, which they reported might have left them tired and drained. Participants also attributed their fatigue to age, weight gain and inactivity. In attempts to define fatigue, participants stated that fatigue consisted of two components namely, the physical and the mental. I will now describe these two components.

4.2.1.1. Fatigue rooted in the body

Participants reported that part of fatigue was rooted in their bodies. They described fatigue as a persistent feeling of discomfort and lack of energy, which caused them distress and had a negative impact on their bodies. 43 year old Nomvula, diagnosed with endometriosis four years prior the interview, described physical aspects of her fatigue as follows:

I don't know the only way I can describe the type of fatigue I experience it's... it feels you know you have this elephant sitting on your chest, and it just pressing you down all the time so you feel weigh down your body feels heavy.

Most participants described fatigue as energy depletion, which they experienced for most of the day. Participants reported that they felt drained from the moment they woke up in the morning to the moment they went to bed. In addition to feeling drained for most of the day, participants highlighted that they could not do anything to increase their energy levels. Some participants described fatigue as death or lifelessness because they could not alleviate it. This further had a psychological impact on them because of the ultimate feeling of powerlessness. Nokuthula, a 41 year old mother of two children, described fatigue in the following account:

Totally draining. Draining... and again it's about the person that you are, if you're strong willed and all of that, it goes against everything that you are. So, you have that internal fight with yourself as well. You can do this, why are you allowing this to get you down. As a matter of fact, you are drained and my status would always be that I'm drained, because it feels like all of the life has been sucked out of you. And there's nothing you can do about it, absolutely nothing.

Women in this study described fatigue as a symptom that varied. They mentioned that fatigue was persistent but varied in intensity. They mentioned that they had some days when they were able to go through the day with less challenges and days when fatigue greatly interfered with their daily functioning. On a scale of 1 -10, participants predicted their energy levels to be between 3 and 5 on bad days and 6-9 on good days. Nomvula elaborated more on her description of fatigue:

So there are days when I feel really, really exhausted, struggle to get through the day can't wait to get to bed at night, and there are days when I am kind of ok, when the fatigue is not that bad, it doesn't interfere hmm with my day to day activities.

Most women in this study associated fatigue to pain in their attempt to describe fatigue. Some participants reiterated that fatigue was a mental and physical impairment caused by lack of energy. Some participants described fatigue as the influence of stress, which left the body feeling too exhausted, further contributing to restlessness. For some women in this study, fatigue was the feeling of exhaustion amidst efforts or attempts to boost energy even without performing any strenuous tasks.

4.2.1.2. *Fatigue rooted in the mind*

Women in this study also described fatigue as an illness/feeling/symptom that occurs in the mind. Many participants described fatigue as a tiredness of the mind or brain. They referred to fatigue as constant pain or suffering. According to participants, this mental tiredness made their bodies tired which influenced their physical and social functioning. Participants further stated that they believed that fatigue was when the body and brain were not in sync. Many participants attributed their fatigue to their inability to allow their bodies to

rest because they felt that they could not switch their minds off. Nonceba, a young wife, elaborated on fatigue as a mental component:

Fatigue for me is this race in your head so if the head and the body is not in sync at the same level... so, like I said to you, I can't sleep my body is tired, but the head is still racing. So, until my head and my body is not in sync, I'm not gonna sleep. Until my head and my body is not fully in sync, I'm not gonna function at work, I'm not gonna. So, I'm trying to look for that balance to sync it, but I don't know how and where and how and what.

Many participants likened fatigue with distress. They reported that fatigue was constantly present and was a representation of darkness for the most part of their day. Participants also mentioned that fatigue meant suffering and isolation. Nomuzi commented as follows:

It reminds me of a day when it's just so gloomy outside, it's... you just wanna be in bed all day and then it doesn't rain but it... you get that sense of it's gonna rain and then you just wanna be in bed. So, when I think of fatigue or my fatigue, I think grey and the weather. So, that is how I... if I were to paint it would be mostly grey.

Participants described fatigue as an internal fight between the body and mind. The fight was either to not do any tasks or to convince themselves to engage in daily activities, namely self-care, chores, going to work, attending events etc. According to the women, this internal battle between the body and mind needed great mental strength, which also contributed to increased fatigue. Furthermore, women mentioned that their fatigue was sometimes dependent on how they felt. For example, they reported that they felt more fatigued when they felt sad as compared to when they felt happy or excited.

4.2.2. Impact of fatigue

The descriptions of fatigue above begin to paint a picture of what living with fatigue is like. Participants reported that fatigue affected their lives in several domains. In the sections below, I will describe the impact of fatigue on participants' emotions, interpersonal relationships, sex lives, family, social interactions and work.

4.2.2.1. Emotional impact of fatigue

Participants reported feeling a myriad of emotions due to their fatigue. Emotions such as frustration, sadness, feeling overwhelmed, angry and defeated. The most common emotion reported by women was frustration. Many women in this study said that they felt frustrated because they could not function normally or did not have the energy that they previously had, which participants associated with old age. Nothende, a 41 year old wife, expressed her frustration as follows:

The frustrating part is like if you see people enjoying themselves, you sit and you feel like an old person man like, "I'm gonna die next week or I'm gonna die this week." It's like something's blocking you, you just wanna stay inside away from everything. You just feel isolated man, you see? That's how you feel.

Most women in this study reported experiencing feeling sad. Women stated that they isolated themselves from others because they were too tired to participate in social activities. Most participants felt that their bodies kept them bounded to their homes, which left them feeling trapped. Participants reported that fatigue limited them in engaging with their hobbies, which left them feeling unhappy, discouraged and despondent for most of the day. Noluthando, a 24 year old female, made the following comment about the emotional impact of fatigue:

My biggest hobby, biggest passion, and then suddenly you don't have the energy to do that anymore and now you kind of captured, you know in your home which becomes a prison and you just feel like kind of all depressed, I think. Yah. It makes me feel depressed, hmm miserable, to be honest...ja that is the effect that it has at the end of the day, you feel depressed and you feel like you been you overwhelmed by the four walls you know, it's like you searching for that breaking out point, where you can just be like yes this is the exit I can go now and you look for it, but you don't seem to find it, basically.

For most women in this study, being unable to do any chores, spend time with loved ones, engage in self-care activities and work regularly, overwhelmed them with emotion. Participants reported that they felt sad, angry, betrayed by their bodies and even defeated. Participants reported that these emotions persisted for long periods. Nolwazi, a student, described her experience as follows:

Ja, at least I can work for now but that became frustrating too, like I remember at a certain point all I did was like cry. Ja, I remember it so well. All I did was like cry for two days and I had to go home eventually 'cause I was like, "I can't do this anymore, I can't do this anymore." 'Cause I just like... I can't do anything, I can't cook for myself, I can't... I remember I couldn't even get to the bathroom at a certain point last year. So, it's really... it's tormenting.

Some participants reported that they questioned why they could not do tasks or be part of social activities like their peers. This raised existential questions for some participants, while some stated that their illness experience made them question God. Participants reported that they made sense of their fatigue by attributing it to God and believing that there was a greater purpose to their fatigue. This belief meant that participants

sought divine intervention as part of coping with fatigue. Women reported that they felt somewhat angry and withdrawn from their colleagues and friends, which also made it a challenge for them to make meaningful contributions in their communities, at work and at home. Nomalungelo, a 28 year old commented as follows:

It makes me feel sad, 'cause then you now sit with a, "Lord, why me?" Type of stuff, 'cause everybody's young, everybody's doing what they're supposed to and so.

4.2.2.2. *Intimate relationships*

For this study, intimate relationships are defined as interpersonal relationships that involve emotional and sexual intimacy. These can either be heterosexual or homosexual relationships.

Participants reported loss of normal physical functioning, which had a negative impact on their intimate relationships. Additionally, women mentioned that they stopped doing certain activities that they would usually do with their partners. These activities included going out for dates, engaging in sports as a couple, attending family events and meeting up with friends due to their fatigue. Participants said that being unable to do these activities with their partners, put strain on their relationships. Furthermore, participants emphasized that they felt sorry for their partners because their partners often had to compromise to accommodate their fatigue. Women in this study mentioned that they sometimes tried doing tasks with their partners, but it meant that participants had to ignore their fatigue because they wanted to make their partners happy. Some participants pointed out that they had to mask their fatigue and others made their partners aware of the effort it took to ignore the fatigue and take part in some activities with their partners. Many women in this study reported that fatigue caused several limitations on their relationships because they were unable to do what "usual" couples would do. The impact of

fatigue on intimate relationships was notable, with many participants reporting fights, break ups, separations and divorce. Noluthando commented as follows:

but now we don't do much together anymore because the thing is, I don't feel like it, cause I'm tired, I don't have the energy to go hiking or whatever I mean, and sometimes it put a strain like on the relationship itself you know it creates unnecessary you know like arguments, but she understands, it's just like I get so frustrated because she understands I would I want you to not understand, you know? Hmm, but a lot of the times I just suck it up and do it, you know and say ok, ja, no let's go, even though I'm dying inside, because in the end of the day you want your partner to be happy in the relationship as well, it's about compromising because I mean she's been compromising a lot because of my state of health so I mean sometime just like nope, suck it up let's go.

Participants reported that fatigue not only affected them personally but also affected their partners. Women who were interviewed stated that their partners complained about their constant state of exhaustion, which caused issues for the relationship, especially when it came to sexual intimacy. Participants reported that they had fears of losing their partners because they were unable to spend some quality time with them. These women reported that they were preoccupied by the fatigue and the effects it had on their lives and bodies. Some participants reported that they sometimes preferred being alone than being in a space where their energy was needed. Some women stated that they felt overwhelmed by being in intimate relationships because it required effort and interaction, which in their case, would tire them even more. Nogolide commented as follows:

I just decided, "Listen, do I really want to... do you really want to lose your marriage and lose your husband because you are just focused on how you're feeling mentally and

physically all the time?” Tired... And he used to say, “You’re always tired, you’re always tired.” And he would complain because eight o’ clock I want to go sleep, I’m too tired. I would be scared of him coming from work because he would want attention and I wouldn’t be able to give it to him.

Some women reported that their partners were also forced to stay home with them quite often. Many reported that they felt that their partners did not mind staying home with them, however, participants felt that it eliminated the adventure and spontaneity in their relationships. Nokusola said the following:

You know, so now he doesn’t want to go anywhere anymore, because he knows I’m not gonna go with. So most, we are literally stuck at home most of the time, I promise you, we are at home most of the time. Sometimes he would go you know, take a break and go to one his friends.

Participants reported that they planned their sexual lives around fatigue, which also eliminated the spontaneity around sexual intercourse. This had an impact on their sexual intimacy with their spouses or partners. The women in this study further stated that they only had sex when they had enough energy and time. Nombuyiselo, a 27 year old wife shared her experience:

Ja and I think even being intimate with my husband it like takes... I always said I don’t want to be one of those people who say, “Okay Monday night’s sex night.” Or whatever, you know? But at this point in time it gets to a point in time it gets to a point where you kind of have to go, “Okay, let’s make sure that we both have energy and we both have time.” And whatever, because otherwise you just don’t get to do it, it’s not a spontaneous thing really

One major symptom of endometriosis that participants reported was dyspareunia, which, in conjunction with fatigue, had a major impact on their sex lives. The participants in this study reported that it was difficult for them to have sex because of low energy levels and their body refused to take part in any activity/task. These women were preoccupied by the feeling of fatigue to a point where their body image became an issue, finding it difficult to engage in sexual intercourse. Most women in this study spoke about the difficulty of having to deal with a sexually unsatisfied husband or partner. Participants also highlighted the frustration of being tired, young and sexually inactive; and how these factors played a major role in their intimate relationships.

Participants reported that although their energy was too low for sex, and they went for longer periods without intercourse, their partners or spouses often understood. Despite this understanding, women in this study reported that they felt they did not fulfill their duties as wives or partners. Participants stated that fatigue got in the way of them spending quality time with their spouses or partners and more than anything, to be sexually intimate with them. This put so much pressure on them and strained the relationship. Nomatyala, a young, married woman commented on the impact of fatigue on her marriage as follows:

And I think now, now that I'm married especially if I can go into personal details, when you're married and you trying to make time for each other, especially in bed it gets to that point where some nights you just can't and from that side it can't be understood. So that is quite hectic. It's hard, it's tough, it's frustrating and like you say, you wanna be the best wife, you wanna be there for him when he needs me but it's difficult. 'cause as much as I try and force myself there's some nights I just... I cannot. I just... I have to sleep. It adds pressure and without you knowing it affects other aspects.

4.2.2.3. Family

Fatigue affected participants' interactions with family members. Most mothers in this study reported that fatigue limited interaction with their children because their energy levels were always low. Activities such as assisting with homework, going out and caring for their children were negatively impacted by their low energy levels. Some mothers reported having to prioritize work due to limited energy, which made it a challenge to spend quality time with their children. They prioritized work because they were breadwinners at home and their income was necessary for the wellbeing of the family. Participants said that this made them feel like they were bad mothers to their children. The women in this study shared how emotionally taxing it was that they struggled to bond with their children. These women reported that they felt guilty that their children would grow up not having made memories with them. Some mothers reported missing out on the most important milestones in their children's development. A few mothers felt like they were irresponsible human beings because they thought fatigue made them a bit selfish, since fatigue required that they focused on themselves more. Nomonde shared her experience as follows:

As a mother I feel bad, because of I am unable to do a lot of things with her. I am unable to go out and play with her, I'm unable to take her to the movies, or to take her to the park, or wherever, because I don't have that strength or the energy. So, my child is not, I cannot do a lot of things with her, which affects me in a way, because of now it means she needs to spend more time with her daddy, you know part of me feels like I'm an irresponsible mother, maybe, she will always have a preference to her daddy. Her growing up, is she gonna have a lot of memories with her daddy than with me, sharing a lot of bond with her

daddy than with me, when she grow up is she gonna look at me like the mother who was unable to do things because of she was always tired, you know that guilt, in me, as a mother.

Most participants shared how difficult it was to deal with the feeling of not being able to engage in activities with their families. Women in this study stated that because their fatigue was persistent, they would go for longer periods having not done any activities or tasks for the family and with them too, which further became a daily pattern.

Participants emphasized that many of their family members did not understand fatigue and that this misunderstanding caused a lot of harm. Many participants shared their experience of being perceived as lazy because they were always tired. Participants also reported that they had to ignore comments regarding their fatigue, even though it hurt them. Considering that participants did not know much about their fatigue, they were unable to explain it to family members. Nonceba commented as follows:

When I went for surgery my mom-in-law phoned me, that time we were just dating, my mom-in-law phoned me and said to me that I shouldn't be lazy, I should get out of bed and be active and I shouldn't feel sorry for myself.

Participants reported that there was an internalized cultural expectation for them to nurture and take care of their families. When they failed to do so adequately, others perceived them as lazy and their lack of energy was not taken into consideration. The internalized cultural expectation also resulted in personal feelings of failure when they were unable to perform tasks relating to their families and homes. Nolusindiso made the following comment about her internalized expectations:

Oh, I always say to myself, I now feel so, but I have to do I'm a mother, I have to I have to help my children, I have to do everything in the house, it is expected from me as a woman, and I say sometimes tell myself to stop being lazy.

4.2.2.4. Social

According to participants, endometriosis-related fatigue made a substantial impact on their social interactions. Participants reported that they tried meeting up with friends because they felt obligated to do so, but that they did not have enough energy to maintain these social interactions. Some participants mentioned that they felt exhausted when they met up with friends and needed time to recover. A few participants reported that they felt depleted after social interaction (going out either to eat and catch up or party) and needed rest or sleep for a few days to recover.

Most participants in this study reported that they only went out when it was necessary. Some participants mentioned that their energy was never enough to last them for the whole night while they were out with friends or family. They found themselves having to excuse themselves earlier than normal and this would sometimes be a problem to either the participants or others. Some participants reported that they preferred being around friends in the comfort of their own home or a space where they would go to sleep if they needed to. This was highly problematic for younger participants in the study who could not grapple with the notion of being young and unable to do what other young people did. Nomuzi, a 24 year old student shared her experience of fatigue and how she managed it as follows:

You know, the worst. You know, when you're at a party, ne (hey)? You know young people go out a lot. So, when I'm at a party or when I'm with friends and then 10 o'clock, 11 o'clock I want to go home 'cause I'm tired man. And everyone at that time it's like peak of

the night and then I'm sitting here so tired and I just wanna go sleep. So, that's why I've come to a point where I don't go out a lot. If I do hang out with friends I prefer to do it at home or at a place where I know I can just duck in and go sleep.

Many women in this study reported that they were outgoing before they had fatigue. Moreover, these participants mentioned that fatigue changed them because they isolated themselves from others and social activities.

Participants mentioned how fatigue made them cancel plans that they made with others. Participants reported that they did not have control over their bodies, especially when they felt fatigued. Women in this study reported that they found themselves having to come up with lies good enough to excuse them from plans or even meeting up with people. Most participants also reported that it was challenging to advise people on how to support them because they also did not know how to manage their own fatigue. This is what Nolwazi had to say about planning her life around fatigue:

Then I have to like cancel the plans then I must type the message and I'm thinking, "Should I say I'm having a flare up? Should I not say it?" so, it's always like those types of things that you have to like always configure different lies for people to understand that you just genuinely cannot do whatever it is that you wanna do. So, it's ja, I'd say it's isolating. Like, people will try and be there, but they really can't be there 'cause it's also difficult to tell someone how to be there when you yourself don't know how to sort of manage the situation.

4.2.2.5. Work/professional interactions

All the participants that were employed at the time of interview reported that they were always late for work. This was because they found it difficult to wake up or get out of

bed resulting in them often being late for work and thereby negatively affecting their work lives/productivity. Some participants reported that they struggled with male employers because they assumed that their employers would not understand endometriosis and the resulting fatigue and therefore did not explain to them why they were late. However, some women in this study mentioned that they did not feel apologetic for having fatigue, which made them report late for work. They reiterated that the struggles they faced due to fatigue were not the same as the challenges that their colleagues faced on a daily basis. A few participants reported that some employers and colleagues understood their endometriosis and fatigue. Nonetheless, this understanding did not make the work environment better for some women in this study.

Many women in this study stated that they were forced to stay away from work on days when they felt severely fatigued and often lied or made excuses to their employers about their absenteeism. Participants reported that it was difficult to ask their employers for leave when they felt fatigued. Women reported that they were often unproductive when they felt fatigued. However, women felt compelled to stay at work, even when they were unproductive. Participants pushed through their fatigue, as colleagues were often unaware of their fatigue. Participants reported that sometimes fatigue affected their concentration. This was frustrating for them because they needed to meet certain work deadlines. Women in this study reported that they had to keep up with the pressure of the work environment and this resulted in energy depletion. Moreover, women highlighted the difficulty of not having the luxury of working less hours in the workplace because it would result in salary reduction. Nomvula commented as follows:

Haven't at all. I mean it's difficult to even ask for days hmm, when you feel so tired you feel like I just cannot get out of bed and I cannot do it! I just want to stay here and sleep, forever, and then you'll remember but how, or you ask yourself how do I tell my boss I'm not coming in today because I'm tired, I mean there's absolutely no way in hell they going to say no it's fine take the day off stay at home. There's no flexibility for me to working reduced hours unless I'm gonna to take a pay-cut obviously.

Women worked hard to earn money to maintain their homes and support their families and therefore did not have the option to quit or work less. Some participants reported that they were concerned about losing their jobs. They highlighted that since they were always fatigued, they feared or were preoccupied with messing things up or not doing their job as expected. Noluthando expressed her fear of losing her job as follows:

hmm because the thing is, I have anxiety as well, so it all goes in together you know because you're so tired and my anxiety climbs and climbs because you so scared you will screw up at work or something.

Noluvuyo also expressed her fear of losing her job due to fatigue as follows:

At one point I thought I was going to lose my job because I'm always tired and until I brought leaflets. To a certain extent my ... the principal understood because she also had, so she understood. So I thought okay there I had someone, it's not that I had but I mean, she understood to a certain extent what I'm going through. So, as long as she understood, I thought, "Okay, now I'm safe." She cannot just tell me I must take my bags and leave, you know?

Some participants reported that they resigned from work because of their fatigue. Other women reported that they often took leave from work. Nomfundo shared the following:

Yes, and it's been three years, so I had to somehow get... I left my job because I had to stay out of work, I went to doctors three times a month, and I stayed home for seven days after that visit to the doctor. And then I just decided, listen I have no benefit to the company. So, I'll just resign and stay at home because I talked to my husband he said, "No, it's fine. Just stay at home because now you're feeling like you're depending on people, getting money from people without bringing something to work." So, they were fine with it, I resigned and stayed at home.

Some participants reported that their fatigue affected their interactions with fellow colleagues. Participants mentioned that they conserved their energy for important matters at work and avoided small talk with colleagues in an attempt to do so. This negatively influenced their collegial relationships as they were unable to bond with their colleagues. 40 year old Nomthandazo shared her work experience as follows:

So it does affect your interaction with your colleagues as well cause honestly speaking you can't come in the morning super tired and you have to do your work and you have to entertain, it's not a matter of entertaining but that's how it is at work, you need to talk to people, ja. So, you just like ok, can you just talk to me about work? (laugh) If it's not, you just don't wanna strain yourself that much ja.

Many participants stated that they felt isolated when colleagues planned activities (work and social) without them (participants) because they (participants) seemed uninterested. Participants reported that they felt as though they were all alone in dealing with

fatigue in the workplace. Some women in this study reported that they preferred not sharing their fatigue experience with their colleagues because they felt that they were not going to understand, while some participants shared their fatigue experience with their colleagues. For the participants that shared their experience with their colleagues, they received support from colleagues when they needed it. Support such as helping them with a few work tasks when they were unable to push through, some reported that their colleagues were more empathetic and some mentioned that their colleagues were able to adapt some work events to try and accommodate them (participants). More than anything, participants expressed great joy when employers and colleagues understood that they were not lazy but rather that they were ill. This validation was important to them.

4.3. Fatigue management strategies

I will now describe the strategies that participants reported to be using to manage their fatigue. These are clustered into two broad categories, namely cognitive and practical strategies. I will also discuss the importance of maintenance in alleviating fatigue. I will begin by discussing participants' reflections on the individualized nature of fatigue management strategies.

4.3.1. Fatigue-management strategies are individualized.

Participants reported that they used individual fatigue-management strategies. They highlighted that what worked for one woman did not work for the other. It is also important to note that women in study mentioned that they sought for fatigue management advice from friends, family, and other endometriosis sufferers from support groups. Fatigue is not commonly considered a symptom of endometriosis and doctors do not ask patients about

fatigue. Therefore, doctors do not offer women any management strategies to alleviate their fatigue. This is why women in this study further mentioned that they were open to trying alternative remedies and strategies in the quest of increasing their energy levels. Many participants reported that they did not know what to do to manage fatigue because most of their strategies either did not work or were unsustainable. Nolwandle commented on the individualized nature of fatigue management strategies:

No. no one knows what to do, no one. You see, everyone has their own theory on how to manage fatigue, everyone has their remedies and you try, you try remedies. You're willing to listen because you want this fatigue to go away.

Participants reported that they went through numerous trials and errors to find what worked for them individually. Moreover, these participants emphasized that all these strategies required them to listen or be aware of the changes that happened in their bodies. Considerable time was spent on finding an effective and sustainable fatigue management strategy. Nomvula said the following regarding finding a management strategy:

What I found, hmm, in my support network of women that I speak to, is that what works for me is not necessarily going to work for you, so it's different for everybody. So, I might find that hmm taking a multivitamin work, vitamin B is going to work great for me it's going to help me with my energy levels, hmm, but it might not work for you. So, I would say that you need to try and find what works for you, it's gonna be a case of trial and error.

Some participants pointed out that they knew that fatigue was somewhat related to the endometriosis, which limited these participants from seeking advice for the fatigue as it was illness related. Most women in this study did not ask for fatigue management advice from their practitioners. These participants also stated that their practitioners did not ask or speak

about endometriosis-related fatigue. Only a few participants, who were aware of the fatigue and tried numerous other strategies, reported seeking advice for fatigue from their practitioners. Only a few practitioners gave fatigue advice. However, women reported that this advice was nothing that they had not tried before and that the strategies offered by practitioners were not individualized management strategies. The advice from practitioners was therefore often dismissed.

Furthermore, participants reported that health care practitioners did not prioritize fatigue management/advice. Many women in this study stated that their health care practitioners normalized their fatigue experience and did not offer individualized fatigue management strategies. When they did, the management strategies were often not sustainable or effective. Although some participants did not seek or prioritize fatigue advice, a few participants reported that they got fatigue advice from various people, namely friends, family members who understood endometriosis, dieticians, other endometriosis patients, online endometriosis support groups and pastors. Nomonde mentioned that she got advice from a support group:

No, except that group where they saying exercise and you do, which at some places I do exercises, some says do yoga, someone says do squats, someone says you know all these kinds of things, but not on a professional level of how to deal with fatigue.

Nomcebo received fatigue advice from friend:

That's why now, my other friend taught me, "You know what? Take a nap during the day. It helps." And it really does help, take a nap but my friends understand me by now, so if I wanna go out I'll go out, if I don't wanna go out, I'm not gonna go out, I'll just stay at home.

Some participants took the advice and reported that it worked for them and for some, the advice did not work even after trying it. Most women in this study did not prioritize the fatigue advice because they did not follow the advice through. This was because some women gave up on finding a sustainable management strategy and for some women, the advice was something they have tried before. Nombuso commented on the fatigue advice she got as follows:

So, a lot of the treatments that I've been offered for normal women to help energy absolutely work. I don't follow through.

4.3.2. Cognitive strategies

I will now discuss the cognitive strategies that women used to manage fatigue. For this study, cognitive strategies are defined as mental thoughts or approaches used to manage fatigue. The cognitive strategies that will be described include pushing through, planning and pacing.

4.3.2.1. Pushing through

Pushing through is when an individual forces themselves mentally and physically to continue performing tasks despite very low energy levels. Participants reported that they pushed through their fatigue to get most things done. This strategy was commonly used by participants that were employed at the time of the study. Not only was this strategy used by employed participants, but the unemployed women in this study also used the strategy of pushing through in their homes. Many of these participants reported that they struggled to sleep and attributed this to their bodies being overworked as a result of pushing through their fatigue. Some women reported that they used activity monitors that were able to track their

sleep and found that their bodies did not rest well at night, leaving them with insufficient energy the next morning. Participants who did not have activity monitors reported similar sentiments. Many women reported that when work became overwhelming, they took a break by taking a walk, locking themselves in a bathroom or finding a room for some quiet moment. Participants did this to reenergize or increase their remaining energy. Most participants reported feeling frequently burnt out.

For most participants who were employed at the time of the interview, the strategy to push through was not by choice. These women reported that they had to push through their fatigue because they had to make money to provide for themselves and their families.

Nombulelo shared the following:

You just sort of force yourself to, because you know you need to go to work to get your money, so you just force yourself through that.

Pushing through often meant that women concealed their fatigue. These participants reported that they had to mask their fatigue from the public so that they were able to get tasks done, especially on bad days (when their energy was lower than usual). Furthermore, these women reported that pushing through became a norm since they were struggling with fatigue for a long period of time. This meant that they would have to use more energy than they had on a daily basis. Nombuso shared the following about her experience of concealing her fatigue from others:

because I had to force it, sorry, that was a total, total ..., but it's something that affects me every day, and I can't say how. So again, you also have to hide your fatigue, but after so many years it's not a conscious thing anymore.

As stated above, pushing through for these women became a norm, an everyday strategy that required little thought. The participants in this study emphasized that they forced themselves to work or be busy because non-activity also increased their fatigue. Moreover, participants stated that despite the latter, the day ended in them being completely depleted and eventually having to rest.

4.3.2.2. *Planning and pacing*

Many participants stated the importance of energy conservation. Two strategies that were highlighted by participants were task management (planning) and balancing activity and rest (pacing). This was important because it ensured that all the tasks that participants valued were prioritized. These women reported that they had to make sure that those around them understood the dynamics of fatigue and the management thereof. They mentioned that they had means of trying to balance rest and tasks so that they reserved energy. For example, some participants reported that they would usually take a nap after work, as a means of increasing energy levels for cooking or other chores later on. For some participants, cooking enough for two or three days helped them reserve energy for other tasks that needed their attention. Nomcebo commented as follows regarding planning around her fatigue:

I've also learnt to manage my cooking. I try to do a lot of cooking over the weekend then during the week its easy foods, it's like warming up and you know easy foods. And when I cook, I try to cook for two days because I don't know if I'm gonna feel like cooking the next day or you know?

Participants, who experienced fatigue for longer periods, reported that they used pacing and planning as a fatigue management strategy. These participants stated that they had to make sure they balanced rest and performing certain activities. Participants also mentioned

that it was important for them to choose which tasks they used their energy on and how they used their energy. For example, women in this study reported making decisions on which events to attend and having to cancel ones that were not a priority. According to these women, this gave them control of their energy and to some extent, their lives. Women reported that they made sure that they used their energy wisely. Nomvula commented as follows:

I think it's given me a more of a sense of control so to speak. I feel a bit more in control of.... I don't know, my fatigue levels if I can call it that because, like I said if I have to go to both events, then I know that I'm gonna... So, I know that I have to choose either or, so it so because I have that awareness or that choice that I know I can make it that sort of helped.

Participants reported that they prioritized resting more than doing tasks like house chores, attending events and etc. Their energy was mostly used for the tasks that they were compelled to do, such as going to work. Even though most of the participants' energy was mostly used for work, some women reported using the remaining energy for tasks that were not much of a priority to them but were equally as important to them and their families. Participants mentioned tasks such as household chores, visiting family members and hobbies.

Participants reported that fatigue controlled their daily activities and how they went about performing these activities. Since they did not have control over their fatigue, they reported that they planned tasks around fatigue, which had a great impact on how they lived their lives. Most participants mentioned that all the planning they did also revolved around sleeping or being inactive. Nokusola commented as follows:

It [fatigue] controls my life, ja, that ja, at the moment it controls my life, because I literally plan my whole life around resting because I'm tired constantly. I'll like plan ok this is the time I get home, that's is how much time it's gonna take me to cook, then I'm thinking ok then I'll put my clothes ready for tomorrow for work, then I'll take a bath but by the time I'm done cooking, I'm not lis to put clothes ready, then I just take a bath quick-quick because then I'm thinking you know if I get into bed now, I'll probably have 8 or 9 hours of sleep. That's how I plan my day.

More than planning almost everything around fatigue, women in this study mentioned that the planning not only affected them personally but affected the people around them too. Participants reported that they had to embrace fatigue first, for them to find management strategies that decreased their fatigue. They emphasized that they advocated for themselves and their plans in places of employment, school, home and etc. Women in this study reported that because they spent most of their time at work, they had to also make work plans that catered for their fatigue. It is also important to note that not every participant in this study had the luxury to make their employer understand their endometriosis related fatigue and ask for reasonable accommodation for example flexible working hours.

Participants reported that they planned well in advance, which made room for improvising when it was necessary. Women in this study associated stress and fatigue. Therefore, these women mentioned that planning assisted them in decreasing stress, which meant that their fatigue also decreased. Noxolo shared the following about planning in advance to cater for her fatigue:

so at least like if I plan stuff, I like planning long before the time so by the time it gets there I just want to see and then I must do this this and that, then. It lessens the stress, so it doesn't tire me out as much.

4.3.3. Practical strategies

For the purpose of this study, practical strategies will be defined as physical or pragmatic approaches used to manage fatigue. All participants spoke about using practical strategies in managing fatigue. For these participants, most of these strategies were interdependent on one another. The practical strategies highlighted in this section are, exercise, keeping busy, sleep, supplements, energy drinks and the link between food and fatigue.

4.3.3.1. Exercise

Women in this study reported that exercise helped them to manage their fatigue. They mentioned that being consistent with light exercise helped boost their energy levels. Participants reported experiencing more energy after they had exercised than when they did not exercise at all. Participants emphasized that exercise did not have to be strenuous for it to be effective, and stated that, even a short session of 10 -30 minutes of exercise was sufficient to decrease fatigue. Nogolide exercised much more than the other participants and said the following about exercise:

I run almost every day like say 4ks or 5ks every day and I cycle and I also do some like, you know, normal exercises a bit of crunches and all that stuff I do every day. But it really helps, it just boosts your energy levels it helps you too with the tiredness because I was

tired all the time and now, I have more energy. I sleep like five hours for the most for the day and I feel rested because I'm always busy. I'm always doing something.

As stated, participants were aware that exercise was beneficial to some extent. Participants reported that knowing what exercises to do, how much of these exercises one needs to do also mattered the most in managing fatigue. They reported that being in control of their exercise routine guaranteed them an increase in energy. Nolwandle mentioned the following regarding exercise as one of the fatigue management strategy she used:

Exercise... exercise does make a difference. I must say, it's a little difference but even that needs you to control how you do it and control what you do when, and how much of it you do. Like, there's certain thing that works for your body, there's certain things that don't work.

However, it was a struggle for women to exercise. Participants reported that endometriosis got in their way of managing fatigue with exercise. They stated that some of the exercises that they did, triggered endometriosis and pain from other surgical procedures that they had in the past. Women in this study reported that they knew the significance and the benefits of exercise in the management of fatigue. However, some participants reported that they felt exhausted to even go to gym or do some exercises. Nontobeko shared the following:

I do not know how to handle it. I think just, exercise is very important, and it is something I must do, but I feel so tired.

Despite the benefits of physical exercise for fatigue, participants in this study reported that they did not have time to go to the gym or do some physical exercises. Some mentioned that they finished working late, some said that they had many things that needed their

attention and for some, they just did not have the energy after doing certain tasks.

Participants who used exercise as a management strategy also reported that their fatigue increased when they did not exercise.

However, exercise was not an effective fatigue management strategy for all participants. Some participants reported that exercise left them feeling exhausted. Furthermore, these women mentioned that they did not experience any energy shift.

4.3.3.2. *Keeping busy*

One important strategy that was mentioned by these participants was keeping busy. The participants who were interviewed for this study reported that keeping busy made them less fatigued than being inactive. They stated that the more you keep busy, the less pain you feel and the less fatigued you feel. Participants also reported that keeping busy contributed to feeling rested and it provided them with more energy to do more tasks. Nogoide, a 41 year old mother commented as follows regarding keeping busy and the impact it had on her energy levels:

I saw that because I had a job where I was busy all the time, I was walking all the time, a lot, climbing steps and doing whatever and doing it every day, working hard, it made me feel less tired. I could come home at night and still cook. I still had the strength to cook, I could do washing, and I could do everything because I'm less tired because I'm busy all the time. So, then I realised that keeping busy helps me because I'm more healthy, I feel much better with myself I don't feel so sad anymore because I'm not tired anymore and then I started thinking

4.3.3.3. *Sleep*

Participants reported that they managed fatigue by sleeping. They further stated that because they slept more, they felt that they were not able to get things done. Women in this study reported feeling tired even after sleeping for several hours. Some participants reported that they preferred laying down or relaxing than sleeping in the afternoons. This was because sleeping during the day made it difficult for them to sleep at night. Nonkululeko commented as follows:

It will probably be, go lie down. I don't want to sleep during the day, especially late in the afternoon because then I can't sleep at night. I would be dead tired at night, and I won't be able to sleep. I'm awake sometimes till five o'clock in the morning.

As stated, participants reported that they chose sleeping when their fatigue was excessive, while some tried to avoid sleeping by taking walks or keeping busy. Some participants mentioned that at times, their energy was depleted to the extent at which they were compelled to sleep. Nolwazi said the following:

But I mean most of the time my body just gives in and I just sleep. That's what I do most of these days, I just sleep."

Participants reported that sometimes they were not able to manage the fatigue because it got too much. They mentioned that exercise and other forms of fatigue management were not effective. They therefore opted to sleep, as they thought that sleep was the best fatigue management strategy that would prevent burnout. Women in this study reported that sleep helped them to cope with fatigue. They stated that sleep gave them energy to perform other tasks.

4.3.3.4. *Supplements*

Women in this study reported using various supplements to boost their energy levels. They mentioned using Vitamin B, Magnesium, Calci-mag, Berocca and many others. Some participants preferred using multivitamins, but overall, participants reported that using supplements helped them with sleep.

For some participants, supplements were used as a support in addition to the other fatigue management strategies that they frequently used. These women reported that a combined approach worked better than just having a single fatigue management strategy. Nombulelo said the following:

but I think like during the day I, for me I, I'm quite an active person, so I still manage to, get to gym every day and do my training for triathlons and stuff but, I do need the support of supplements.

Participants reported that supplements assisted them to get through the day. Furthermore, they pointed out that vitamins did not alleviate the fatigue, but it gave them enough energy to do necessary tasks. Participants reported that they used vitamins for most days to cope with the fatigue. These women were aware that dependence on these vitamins was not ideal, but it was one of the strategies that seemed to increase their energy levels. This enabled them to complete important tasks for each day. Nonceba commented as follows:

Ja, all the vitamins I can get. The Omegas, Vitamin D I'm trying to get, I have I think Berocca almost every day, morning and afternoon. I'm not supposed to, but I do. Just to complete what I need to complete for the day.

Some participants mentioned that they were unable to face the day without taking vitamins. They reported that these vitamins helped them to push through the day. However,

participants also stated that these vitamins did not alleviate the fatigue, but only helped them to some extent. Women in this study reported that these supplements also acted as a placebo. Despite not seeing the change in their fatigue, participants continued taking these vitamins because in their minds, they believed that these supplements worked for them. Nonceba also shared the following:

I don't think I can do without them. I'd probably be dead, probably passed out on the couch by nine o'clock, ten o'clock. They keep me going. But they help a little bit. I think in the mind it's like, "Oh I took something, now I got to just move."

Women in the study reported that for them, these supplements did not work at all and that they preferred sleeping when they felt that their energy was low. Nomthandazo commented as follows:

"I just like I said, ok, I do try some supplements at times, but they do not work. They have it or not. So, I tell people, hmm, if I feel like I do not have that much energy, I'll just go and lie down. I prefer to lie down."

4.3.3.5. Drinks for energy

Most participants reported that they drank coffee to increase their energy levels. These women further reported that the increase in energy levels was not sustainable. Therefore, women in this study worked towards reducing their coffee intake. Nomcebo shared her experience of coffee:

I try to limit my coffee intake to one or two cups a day not more than that, because it will give you a spike but then it will just leave you hanging somewhere."

Some participants reported that on days where fatigue did not entirely impair their functioning, coffee or an energy drink helped them push through the day. Some of the

participants mentioned trying tea to boost their energy levels to avoid the knock-on effect that coffee had. However, women in this study reported that they depended on coffee for alertness because the teas they tried were ineffective.

Participants also highlighted that most of the drinks they took for energy were not sustainable. However, they mentioned that they depended on these energy drinks to take them through the day. Participants mentioned that they were not able to push through the day if they did not have an energy drink. Nolwandle commented as follows:

If I don't drink them then I can't... you can't live on energy drinks obviously. There was a time when I was on energy drinks all the time, every single day.

4.3.3.6. Food

Participants reported that there was a link between diet and fatigue. They mentioned that a clean diet (eating whole foods in their natural state and avoiding processed foods) was necessary for an individual with endometriosis. Women in this study reported that there were specific foods such as processed meats, fast foods, soft drinks, dairy, gluten and fried foods; that triggered endometriosis and fatigue that had to be avoided. Furthermore, these participants reported putting an effort on their diet. Nomalungelo stated the following regarding diet:

But I am trying I started like I said now with the... and the water and the more vegetables and green stuff. Change of diet, also with the endo they said that the type of food that we're eating is also like a trigger so I am trying to do well.

As Nomalungelo mentioned that nutrition was important. Many women in this study reiterated that they changed their diet or were trying to find a sustainable and cost-effective diet for themselves. This change was reported to have helped with keeping energy levels

high. Participants reported that certain foods made them feel tired. Nomatyala commented as follows:

I've tried to change my diet. That has helped slightly, I can feel the difference, I find if I eat a lot of carbs and sugar, I'm definitely more tired than when I wouldn't.

Some participants mentioned that more than the change of diet, eating clean and how the food was cooked was important. Many participants reported that they ate food to boost and maintain high energy levels where possible. These women mentioned that they planned their meals by cooking more food to last them for more days. This was done with the intention to reserve energy or cater for days when they did not have energy to cook.

Nomcebo, a 42 year old mother, said the following:

I've also learnt to manage my cooking. I try to do a lot of cooking over the weekend then during the week its easy foods, it's like warming up and you know easy foods. And when I cook, I try to cook for two days because I don't know if I'm gonna feel like cooking the next day or you know? And I try to put in a lot of legumes in my food like lentils, anything that's going to sustain your energy.

For some women in this study, it was difficult to stick to a clean and healthy diet because they were not entirely in control of the food they ate.

4.3.4. The maintenance of fatigue management strategies

Women in this study reported that most of the management strategies that they used, were ineffective. Participants mentioned the reasons why these strategies were ineffective for them. Participants highlighted two important points about fatigue management strategies. First, they noted that fatigue management strategies were only effective for a short period of time. Many reported that when they started using a strategy it worked initially but seemed to

stop working after some time. Participants also noted that perhaps more consistency was needed in implementing fatigue management strategies. Some reported that their inconsistency with the application of these strategies may have played a role in these strategies not working. Nonkululeko shared her fatigue management strategy below:

I've tried to use multivitamins, I've had it for a while and then it will take maybe up to two weeks for it to start working and it works for a while and then after that I just don't feel the difference anymore.

Most participants reported that some fatigue management strategies (exercise, supplements and energy drinks) that they tried were impractical, expensive and non-sustainable. These participants recognized that fatigue might be something that they will have to deal with forever, and this influenced the kind of management strategies they decided on or explored. Participants highlighted this in light of having to deal with endometriosis. Participants reiterated on the link between fatigue and endometriosis. They also reported that it was impossible to manage fatigue and ignore endometriosis. Therefore, women in this study reported that they tried finding management strategies for endometriosis, for example going on an endo diet, which in some way, the benefits thereof, decreased their fatigue. However, as participants reported, having a management strategy and consistently applying it were separate issues, partly due to financial considerations. Participants expressed that the management of both fatigue and endometriosis frustrated them because it seemed like a rollercoaster ride

4.4. Chapter summary

In this chapter, I described the participants in the study and reported on their experiences of fatigue. I reported on how participants described fatigue as a constant companion and the effect that fatigue had on their lives and daily functioning. I reported the fatigue management strategies that women reported using and concluded the findings by mentioning the maintenance and importance of consistency in using these fatigue-management strategies.

Chapter 5

DISCUSSION

5.1. Introduction

The purpose of this study was to explore fatigue and understand the subjective experiences of fatigue among women with endometriosis. Furthermore, the study aimed to explore on the impact of fatigue on women's lives and how women describe and manage fatigue on a daily basis. It was also important to find out what women with endometriosis thought triggered their fatigue. Chapter 5 provides a detailed, structured and analyzed discussion of the results presented in chapter 4. The results will be discussed in light of the existing literature and the theoretical framework presented in chapter 2. The following paragraphs will discuss three major themes from the findings in chapter 4. Themes that will be discussed include the descriptions and understanding of fatigue, impact of fatigue and fatigue management strategies.

5.2. Descriptions and understanding of fatigue

Literature reports that fatigue is a common symptom of chronic and acute illnesses such as cancer, rheumatoid arthritis, osteoarthritis, HIV and multiple sclerosis (Barosso, 2001; Flinn & Stube, 2010; Nikolaus et al., 2010; Scott et al., 2011; Stuifbergen et al., 2001). However, there is still misunderstandings and confusion surrounding the definition of fatigue and its use. In general, it was difficult for women in this study to describe or define fatigue. All participants were unable to clearly articulate their experience of fatigue. It is important to note that fatigue is not a feature that is only exclusive to women with endometriosis. Patients

with other chronic illnesses also found it difficult to describe their fatigue (Flinn & Stube, 2010; Kralik et al., 2005; Nikolaus et al., 2010; Power et al., 2008; Scott et al., 2011).

In this study women with endometriosis defined fatigue as a persistent or continuous exhaustion, even in the absence of activity. According to these participants, fatigue did not have a clear cause. Fatigue was also defined as a lack of energy or energy depletion. This definition or description was in line with other qualitative findings. For example, post-stroke patients reported that they struggled to describe and define the fatigue that they experienced (Flinn & Stube, 2010). Moreover, post-stroke patients defined fatigue by using the boundaries imposed by fatigue. Kralik et al. (2005) studied women's experiences of fatigue in chronic illnesses and they found that the participants reported that fatigue was different from tiredness. The latter was the same finding that cancer patients reported (Scott et al., 2011). With cancer patients, the fatigue experience was described as a tiredness that was more intense after diagnosis or treatment (Scott et al., 2011). Women in this study used different terms to describe their fatigue experience. They used words such as exhausted, drained, depleted, death, prison, discomfort, internal fight, lack of energy and heavy chest. These descriptions were similar to those found in other studies. In Kralik et al. (2005) women described fatigue using words like overwhelming, drained and feeling wiped out. Osteoarthritis patients in Power et al.'s study (2008) used words like tired, exhausted, weakness, loss of energy and worn out to describe their fatigue.

In attempts to define fatigue, women in this study mentioned that fatigue comprised of two components namely; the mental and physical. Women reported that fatigue was a persistent feeling of discomfort that lasted for longer periods and this had a negative impact on their bodies. Furthermore, fatigue meant that the body was not in sync with the mind. This

simply means that a tired mind is a tired body. Women in this study reiterated that fatigue was when their bodies were not able to rest because their minds could not switch off. A few qualitative studies highlight the above. For example, post-stroke patients reported that there were three types of fatigue; physical, social and cognitive fatigue (Flinn & Stube, 2010). Osteoarthritis patients report two types of fatigue; the mental (persistent, affecting your thinking and not being able to focus) and physical (short lived and linked to pains and aches) fatigue (Power et al., 2008). Furthermore, osteoarthritis patients mentioned that the experience of mental fatigue was worse than physical fatigue.

I also found that fatigue varied in intensity and duration among participants. This means that there were days when fatigue was intense and limited most of the daily functioning among participants and there were other days when fatigue was bearable with not much limitations to daily functioning. A similar finding was also reported by the women with endometriosis in the study by Moradi et al. (2014), however, they found that pain varied as they did not explore fatigue. Also, in line with the definition of persistent fatigue, women in this study reported that sleep did not alleviate their fatigue. This finding is supported by Kralik et al. (2005) and Power et al. (2008). Their participants reported that sleeping or getting enough rest did not decrease fatigue.

In defining or describing fatigue, females in this study referred to an association between pain and fatigue. Participants reported that if an individual experiences pain, they were highly likely to feel fatigued. This is a similar finding that is found in a number of chronic illness studies. Ramin-Wright and colleagues (2018) evaluated the prevalence of fatigue among females with endometriosis and those without endometriosis. They reported that there was a significant association between fatigue and pain in females with

endometriosis. The relationship between fatigue and pain was also reported among patients with rheumatoid arthritis (Jump et al., 2004; Fifield et al., 1998; Fifield et al., 2001; Nikolaus et al., 2010; Rupp et al., 2004; Suurmeijer et al., 2001; Tack, 1990; Wolfe et al., 1996; Wolfe & Michaud, 2004), and osteoarthritis (Power et al., 2008; Wolfe et al., 1996; Wolfe & Michaud, 2004).

5.3. Impact of fatigue

Since endometriosis is an invisible disease and fatigue an invisible symptom, it may be easy for health practitioners, family, friends and colleagues to dismiss the experience of both fatigue and endometriosis. Hence, similar to the experience of endometriosis and other chronic illnesses, women in this study reported that health practitioners neglected their fatigue experience. For example, while the patients receiving chemotherapy in the Spichiger et al. (2012) study reported that they were told to expect fatigue at the beginning of their treatment, their experience of fatigue was overlooked by doctors during treatment. In Kralik et al. (2005) participants with chronic illnesses reported that the invisibility of fatigue made it difficult for them to get fatigue assistance from healthcare practitioners, friends and family.

Fatigue is an incapacitating symptom that negatively affects women's quality of life. Participants in the current study reported that fatigue impaired their daily functioning and negatively impacted their mental well-being, relationships (collegial, family, intimate relationships and friendships), work performance and social interactions. Chronic illness patients in other studies have also indicated that fatigue negatively impacted their relationships (Flinn & Stube, 2010; Nikolaus et al., 2010), work performance (Barroso, 2001;

Flinn & Stube, 2010; Nikolaus et al., 2010) and mental health (Greenberg, 2002; Nikolaus et al., 2010).

Patients in this study made a link between fatigue and distress, which may be a possible explanation between fatigue and endometriosis. Most participants stated that they felt distressed because of the limitations brought by fatigue and endometriosis. Participants in other studies reported being distressed because of the illness. For example, Greenberg (2002), who looked at clinical dimensions of fatigue and Lemaire (2004) who assessed the severity, frequency, interference with daily life and symptom distress linked to endometriosis, highlighted that fatigue was linked to distress. Furthermore, post treatment cancer survivors seemed to attribute fatigue with stress during cancer (Corbett et al., 2016) and osteoarthritis patients made an association between fatigue and stress (Power et al., 2008).

Some participants stated that they felt distressed at times because of their endometriosis and their sentiments are supported by a vast body of research that indicates an association between endometriosis and depression (Eriksen et al., 2008; Facchin et al., 2017; Lagana et al., 2015; Lorencatto et al., 2006; Roomaney et al., 2019; Souza et al., 2011; van Aken et al., 2018). Participants in the current study also reported that the more pain they felt, the more fatigued they felt. Therefore, concluded that there was an association between their fatigue and pain. Their assertions indicate that there may be a complex relationship between distress, pain and fatigue. Only a few studies in literature seem to mention this relationship. For example, in evaluating the prevalence of fatigue among women with endometriosis and those without endometriosis, Ramin-Wright and colleagues (2018) found that participants who experienced pain had high levels of fatigue. Moreover, Ramin-Wright et al. (2018) also

mentioned that there was a link between fatigue and stress. Furthermore, osteoarthritis patients in the study by Power and colleagues (2008) also highlighted the similar relationship found in this study.

In the current study, participants associated fatigue with feelings of depression, and stated that the combination of these symptoms affected their social interactions and relationships because they often isolated themselves due to being too tired. Moreover, because of the physical limitations brought by fatigue, women reported feelings of sadness, discouragement and frustration. Various studies among patients with chronic illnesses such as post-stroke, osteoarthritis, rheumatoid arthritis also reported this finding (Flinn & Stube, 2010; Kralik et al., 2005; Nikolaus et al., 2010; Power et al., 2008).

Endometriosis literature highlights the impact of dyspareunia on women's self-esteem and their relationships with their intimate partners (Cox et al., 2003; Denny, 2004; Denny & Mann, 2007; Huntington & Gilmour, 2005; Fritzer et al., 2013). However, none of these studies mention the impact of fatigue on women's self-esteem, body image and their sexual dysfunction. The revelation that some women planned their sexual activity around their energy levels, not only the pain associated with sexual intercourse, is a new finding among women with endometriosis. Moreover, since women in this study reported that they had to plan sexual intercourse around their energy levels, this had a negative impact on their intimate relationships. For some participants, this impact of fatigue on their sex lives led to fights, break-ups and divorce. There are no studies reporting a similar finding. However, Roomaney and Kagee (2018) found that avoidance of sexual intercourse led to relationship break-ups, divorce and infidelity among South African women with endometriosis. De Graaf et al. (2016) found that there was a correlation between depression, dyspareunia and sexual

function among women with endometriosis. However, fatigue was not mentioned as one of the factors affecting participants' sex lives. Another novel finding was that young women in this study were frustrated that they were young and sexually inactive because of the fatigue.

Clark (2002) highlighted the stigma surrounding the experience of fatigue. Participants in this study reported feeling stigmatized due to their fatigue experience. Women struggled with the awareness that other people around them perceived them as lazy and this was because a number of people found it difficult to understand fatigue. Participants in this study were perceived to be lazy because they were always tired and often refrained from performing tasks. Additionally, they were unable to fulfil their roles as mother, wife, colleague, friend or daughter and the same results were found in the study conducted by Barroso (2001). Barroso (2001) interviewed 31 males and females who were HIV positive exploring the characteristics of fatigue among this population. Barroso (2001) found that fatigue interfered with participants in fulfilling their roles.

Some of the participants in this study reported that they were unable to get instrumental support because they did not communicate how they wanted others (family, friends, colleagues and employers) to support/ assist them. This was because participants also struggled with managing their fatigue.

Women's reluctance to share their diagnosis with others may be due to exulansis. Exulansis refers to one's tendency to stop talking about a certain experience because others cannot relate to it. In this case, participants stopped explaining what endometriosis and fatigue was to others, especially in the workplace. Contrary to this current study, participants in the Gilmour et al. (2008) study reported that they did not tell colleagues and employers about endometriosis because they feared losing their jobs. Some women in this study

received support from their colleagues and employers after making them understand endometriosis. But it is also important to note that even when some colleagues and employers understood endometriosis, some women in this study reported that it did not make the experience of fatigue better in the workplace. This is because some participants did not receive any instrumental or social support. Furthermore, this affected collegiate relationships. There was no literature that reported a similar finding.

All participants in this study reported that it was difficult to wake up in the morning. However, the challenge to wake up in the morning was reported to be a major difficulty for those who had to go to their place of work. Participants reported having good days (when their daily functioning was not entirely interfered by fatigue) and bad days (when their daily functioning was interfered by fatigue, making it difficult to get through the day). Women in this study reported that they were either absent from work or pushed through on bad days. Some women reported that they were not able to keep their jobs because they became overwhelmed, some reported that they were unproductive because of their low energy levels and this had financial implications. A similar finding on women with endometriosis is reported in the study by Roomaney and Kagee (2018). They mentioned that some women in their study reported that they were breadwinners. Therefore, they were not able to stay off work because they needed to provide for their families. Some studies mention the occupational impact of fatigue. For example, post-stroke patients reported that it was difficult to adapt to the incapacitating impact of fatigue and this included having to be productive at work (Flinn & Stube, 2010). In another study by Nikolaus et al. (2010), rheumatoid arthritis patients mentioned that they were unable to work, and, at times, patients were too fatigued while in the workplace. Furthermore, rheumatoid arthritis patients reported that they

regularly skipped work, and this resulted in poor job productivity which had financial implications (Nikolaus et al., 2010).

A quantitative study by Ramin-Wright and colleagues (2018) is the one study that currently reports a link between fatigue and occupational stress among women with endometriosis. Other studies on endometriosis stated that women reported that pain made it difficult for them to concentrate at work. This further made them to be unproductive and take more sick leave days. However, these studies do not mention fatigue as a symptom that can affect women with endometriosis in the workplace (Culley et al., 2013; De Graaf et al., 2013; Forquet et al., 2011; Gilmour et al., 2008, Moradi et al., 2014; Nnoaham et al., 2011). Denny (2004a) and Hansen et al. (2013) also reported that their participants stated that feeling depressed, fatigued, in pain and taking sick leave impacted work performance and productivity.

5.4. Fatigue management strategies

Endometriosis is a life-long chronic illness. This means that women in this study had to manage fatigue for as long as they had endometriosis. The findings have shown that women in this study managed fatigue differently depending on the duration of their fatigue experience. Participants who were new to living with endometriosis seemed to be struggling to find effective strategies to manage fatigue than those who have been dealing endometriosis for a long time. It is important to reiterate that participants reported that management strategies are individualized. What worked for one individual did not necessarily work for the other. However, the study shows that women did not know how to manage fatigue because most fatigue management strategies they used, were not entirely effective. Therefore,

participants reported that they struggled or had to deal with or felt fatigued for a long period of time. According to Nikolaus et al. (2013), one of the pivotal predictors of fatigue was negative coping and Ramin-Wright and colleagues (2018) further added that endometriosis-related fatigue might be a consequence of poor disease coping.

Despite the challenges or limitations brought by fatigue, some participants in this study still searched for fatigue management strategies. However, most women gave up trying to find a management strategy because most of the strategies they tried were ineffective or unsustainable. Women who often gave up were those who reported that they were unable to financially afford both endometriosis and fatigue management strategies. This was not the case in other studies among patients with cancer, fibromyalgia, chronic fatigue syndrome and, patients after hemopoietic stem cell transplantation; where patients continued to search for ways to manage fatigue (Barsevick et al., 2001; Schaefer, 1995; So & Tai, 2005; Spichiger et al., 2012). Participants in this study also mentioned that the added financial burden associated with some fatigue management strategies made adherence to these strategies challenging. In a quantitative study by Schmidt et al. (2012), there was a link between fatigue and financial situation. Moreover, 27% of participants with persistent fatigue reported a decline in their financial situations due to the cancer experience. Because there are limited studies on endometriosis-related fatigue, this current study is the only one to be reporting on the financial implications of fatigue management among women with endometriosis.

In this study, women prioritized seeking fatigue management advice when their daily functioning was impaired. However, health practitioners did not give fatigue advice unless the patient asked for it, and when they did, the advice was not individualized or practical for

the patient. Moreover, women in this study also received fatigue advice from family, friends, online support groups and colleagues. In chronic illnesses studies, many patients report either seeking advice from their health practitioners or managing the fatigue on their own by finding fatigue management strategies that will boost their energy levels. For example, Repping-Wuts, Uitterhoeve, van Riel and van Achterberg (2008) highlighted that rheumatoid arthritis patients reported that they did not explicitly ask for fatigue advice from health practitioners, however, they were told that fatigue was part of their illness. Additionally, these patients reported that they found their own management strategy by trial and error, which was the same finding in the current study. In another study with Taiwanese women with breast cancer, women reported that they endured fatigue because they thought it was inevitable since they had cancer. Therefore, they did not talk to their health practitioner or family about it (Tsai et al., 2010).

In this study, women did not report receiving any medication to alleviate or manage fatigue but according to Acciarresi, Bogousslavsky and Paciaroni (2014) psychotherapy and pharmacological treatments are used to treat fatigue in women with chronic illnesses. Ramin-Wright et al. (2018) state that these treatments may help with sleep and depression among women with endometriosis-related fatigue. The current study highlights the importance for health practitioners to be aware of fatigue as a debilitating symptom of endometriosis, to improve on fatigue advice/management/ treatment. Lukas et al. (2018) also mentioned the importance of health practitioners support in assisting women alleviate the symptoms of endometriosis, which in turn, enhances patient's satisfaction.

Social and instrumental support, practical changes and mental adjustments were also some of the alternative methods women in this study used to manage or cope with fatigue.

This is the same as what Tsai and colleagues (2010) found in their study. Participants used alternative coping styles to manage fatigue; such as keeping busy, pushing through, planning, pacing, lifestyle and dietary modifications and exercise. Many participants in this study used a combination of these coping styles to achieve a slight decrease in fatigue. This was a similar finding in some research studies that looked into chronic illnesses and how women managed fatigue (Barsevick et al., 2001; Schaefer, 1995; So & Tai, 2005; Spichiger et al., 2012; Stuifbergen & Rogers, 1997). There are many reasons why women used these coping styles; namely, to conceal fatigue, boost and reserve energy, to maintain control of their lives and lessen being overwhelmed by fatigue. It is important to understand that some of these coping styles (e.g pushing through the fatigue) became normal due to long periods of fatigue experience.

Participants reported that they planned their lives around fatigue, which also affected the people around them too. This made it quite stressful because many people did not understand fatigue, let alone endometriosis. Some participants reported that exercise was beneficial because it helped increase energy levels, but for other participants, it triggered symptoms of endometriosis, mostly pain. Many studies also reported on the benefits of exercise on women with fatigue (Barsevick et al., 2001; Schaefer, 1995; So & Tai, 2005; Spichiger et al., 2012; Stuifbergen & Rogers, 1997).

The current study was also very interesting because it highlighted that keeping busy resulted in feeling less fatigued. This is because keeping busy reduced pain for some women in the study. Some studies highlight that keeping busy was one of the strategies used by patients to manage fatigue. For example, Foltz et al. (1996), Given et al. (2002) and Nail et

al. (1991) reported that cancer patients used self-care behaviors to manage fatigue. These behaviors included exercise and walking, planning, keeping busy and getting more sleep.

This meant that keeping busy meant more energy for women which interestingly made them sleep a little better. However, it is pivotal to point out that sleep did not alleviate fatigue. Lee et al. (1994) also points out that a full night sleep does not alleviate fatigue.

The results indicated that supplements used with other management strategies or coping styles decreased fatigue for some women in this study. Again, as with sleep, supplements did not alleviate fatigue, but it assisted participants to push through especially on days when their energy was very low. Participants reported a link between fatigue and diet. Participants reported that eating clean (whole foods) or healthy, helped in keeping energy levels high. Many participants reported that they ate for energy and some who did not eat clean or healthy, reported that their energy levels would decrease after eating certain foods like pasta, potato chips and bread. The findings of this study are similar to those of previous research studies that mention that modifying diet is a management strategy commonly utilized to decrease fatigue (Wells & Fedric, 2001; Swann, 2008). Again, the link between fatigue and diet is also reported in the study by Tsai and colleagues (2010). The breast cancer patients in Tsai et al. (2010) reported that adjusting their diet, cooking methods and eating small portions decreased fatigue discomfort. Alberg, Ekman, Gaston-Johansson and Mock (2003) further mention that adequate hydration and diet seem to assist in the management of fatigue. These results indicate that it is impossible to manage fatigue and ignore endometriosis/ other symptoms of endometriosis.

Chapter 6

CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

6.1 Conclusions

In this chapter I will give an overview of the current study. This chapter will discuss the limitations of this study and recommendations for future research and healthcare practitioners.

6.1.1 Objectives of this study

6.1.1.1 Understanding fatigue in women with endometriosis

The first objective of this study was to understand the experience of fatigue among women with endometriosis. Using the interview schedule, I was able to create a warm and welcoming interviewing environment that made participants to be comfortable to speak about their experiences of fatigue. For some participants, the interview was the first time they opened up about their endometriosis and fatigue journey in the way that we did.

Chapter five indicates that participants found it hard to describe and define their fatigue. Furthermore, it was difficult for participants to clearly express their fatigue experience. However, participants defined fatigue as a continuous or persistent exhaustion that did not have a clear cause, lasting for longer periods. Women also used a variety of terms to describe what fatigue was. They used words such as drained, depleted, heavy chest, internal fight and many other words mentioned in chapter four and five. Additionally, in trying to further define fatigue, women mentioned that fatigue comprised of two components. These components suggested that fatigue was rooted in the mind and in the body, meaning that fatigue is when one is not able to physically perform certain task because the mind feels exhausted. Moreover, the components

suggested that fatigue could also mean that the body was not in sync with the mind and this meant that if the mind was tired then the body will be tired too.

Participants reported that they had bad and good days of fatigue. On a good day, participants are able to function without much fatigue interference and on a bad day, daily functioning was completely disrupted. Women in this study also highlighted that there was a link between fatigue and pain because the more pain they felt the less energy they had.

Women in this study also mentioned that their fatigue experience was normalized by health practitioners, family and friends. Participants also mentioned that fatigue had a negative impact on their mental health, relationships at home, work, socially and, lastly their work performance. Many participants associated distress with fatigue. Furthermore, participants mentioned that distress was a consequence of limitations that were brought on by fatigue and endometriosis. Participants also reported feelings of depression that further affected their relationships, social interactions because they usually isolated themselves due to exhaustion. Fatigue was also reported as one of the factors affecting sexual intercourse among couples because participants reported that they planned their sexual activity around their energy levels. This greatly impacted their relationships with their partners. Young participants also lamented their frustration at being young and too tired to have sexual intercourse.

Women in this study struggled to deal with the idea that people perceived them as lazy. This was because they either refrained from doing tasks or failed at completing a task due to being too tired. In general, participants reported that they found it difficult to play their roles as mothers, wives, daughters, colleagues and friends. Some participants were reluctant to share their diagnosis because they felt that people were not going to relate to the experience of endometriosis and fatigue. Many participants expressed that it was difficult to wake up and this

difficulty was reported more by employed participants. Furthermore, participants would sometimes miss work or pushed through the fatigue on bad days. Fatigue was overwhelming because the employed participants mentioned that they had to fight fatigue and other endometriosis symptoms to keep their jobs since they needed the money to maintain their families and the financial aspect of their illness.

6.1.1.2 Factors that trigger fatigue

The second objective of this study was to explore the factors that women with endometriosis regard as triggers of fatigue. Patients mentioned a few factors that triggered fatigue. Pushing through was a management strategy that they used to cope with fatigue, but participants also mentioned that pushing through can also increase fatigue levels. This was because participants used more energy than they had. According to the energy envelope theory, the participants' expended energy was not within the envelope of the perceived energy (amount of energy available). This further increased the severity and frequency of fatigue, affecting their daily functioning. Pain and stress were associated with fatigue and participants mentioned that the more stressed and pain they felt, the more they felt fatigued. For some participants, exercise did not decrease fatigue levels, instead they reported to feel more tired after attempting to exercise. Foods like pasta, potatoes, bread and etc. were reported to trigger fatigue or increase fatigue levels.

6.1.1.3 Description of what maintains fatigue in patients with endometriosis

The third objective of this study was to gain a descriptive understanding of what maintains fatigue in patients with endometriosis. A few things that were visible in the findings (chapter four) was that fatigue was a huge challenge among participants who were inconsistent in

their methods, or who only used one strategy instead of multiple strategies mentioned in chapter four. For instance, eating wholesome foods, light exercises or walking, pacing and planning. Another factor that maintains fatigue was the whole ideology of not sharing your diagnosis or making people around you understand your illness and how you want to be assisted so that your fatigue levels decrease. However, it becomes a challenge if one does not know how they can be assisted. Lastly, not prioritizing fatigue advice appeared to be an issue when women in this study were asked if they had ever asked their healthcare practitioner for fatigue advice. Not being able to get fatigue advice from healthcare practitioners can be another factor contributing to the maintenance of fatigue among women with endometriosis.

6.1.1.4 Management of fatigue

The fourth objective of this study was to understand how women with endometriosis manage fatigue. Many participants did not know how to manage their fatigue because most of the strategies they tried were either ineffective or unsustainable. All participants mentioned that the fatigue management strategies they used were individualized and they were all aware that what worked for one person, was not necessarily what would work for the other. Women mentioned that they mostly asked their friends, family and other endometriosis sufferers for fatigue management strategies. Participants also reported that in order for them to find a management strategy, they had to go through a trial and error phase.

Fatigue was seen as part of endometriosis and this limited women in accessing possible fatigue advice from their healthcare practitioners. Participants reported that they only sought for fatigue advice from their healthcare practitioners when fatigue impaired their daily functioning. Due to fatigue limitation and challenges, some participants stopped looking for better fatigue management strategies, however, other participants continued looking for effective strategies.

Women in this study reported that they had to deal with the financial implications of having to manage both fatigue and endometriosis.

Participants mentioned that management strategies were divided into two namely; cognitive (pushing through, planning and pacing) and practical strategies (Exercise, keeping busy, sleep, supplements, energy drinks, and nutritional modifications). These strategies were used in conjunction with each other to conceal, boost and reserve energy. Moreover, these strategies made women feel like they had a little control of their lives which reduced the overwhelming feeling that fatigue brings. It is important to note that women reported that all these fatigue management strategies did not alleviate fatigue but made it a bit easier at times, for them to manage fatigue.

6.2 Limitations of this research study

The first limitation was language. Since most participants were from a province whose dominant languages were English, IsiXhosa and Afrikaans, some participants preferred to be interviewed in Afrikaans. Since I was not able to do so, my supervisor was able to conduct the Afrikaans interviews. We had the transcriptions translated into English, but I feel that as I read some of the translations, meaning was lost, because the English language could not convey the entire message carried by the original text.

The second limitation was the recruitment phase. When I asked the patients about fatigue, some had to think about it because they had never been given an opportunity to speak about fatigue. Some mentioned that they had fatigue and when we sat down for an interview, they told me about fatigue pre surgery which relieved them mostly of pain and fatigue.

The third limitation was the correlation between endometriosis-related fatigue and depression. Some participants in this study mentioned feeling depressed or having feelings of depression because of the fatigue. However, I could not assess this correlation since it was beyond the scope of this study.

A final limitation relates to comorbidity of fatigue and distress. Research indicates that women with endometriosis experience high levels of psychological distress. Lower energy levels are a symptom of distress. Participants may therefore have been experiencing fatigue as part of the symptoms of distress but assessing this was beyond the scope of the thesis.

6.3 Recommendations

6.3.1 Future researchers

I recommend the following research be conducted:

1. Research could be conducted on the prevalence of fatigue among women with endometriosis especially in South Africa, where most of the female population is not aware of what endometriosis is.
2. Future research could investigate the correlates associated with fatigue among women with endometriosis.
3. Future research could investigate the relationship between depressive symptoms and fatigue among women with endometriosis.
4. Future research can also focus on developing interventions to help women with endometriosis-related fatigue manage their fatigue.

6.3.2 Healthcare practitioners

Based on the findings of my study, I would like to make some recommendations for healthcare practitioners working with women with endometriosis. I would like to encourage healthcare providers to learn more about endometriosis-related fatigue and how it negatively affects women living with it. This knowledge will assist healthcare practitioners to develop interventions that assist women with endometriosis-related fatigue how to manage their fatigue.

The findings of this study shows that the fatigue experience among women with endometriosis was normalized by healthcare practitioners, family members, friends and colleagues. Both participants and healthcare practitioners did not prioritize seeking fatigue management advice. This is why I recommend awareness programs focusing on endometriosis-related fatigue. These awareness programs will provide more information about endometriosis-related fatigue to healthcare practitioners, endometriosis patients and the society at large.

Patient empowerment programs should be developed to assist or equip patients with relevant skills to advocate for their treatment. This will also make patients confident in telling their family and friends how to assist them in hopes of reducing/managing fatigue. Lastly, it would be great for healthcare practitioners to prioritize fatigue advice among women with endometriosis. This can be done by including fatigue screening for every checkup or doctor's appointment. I am fully aware that this might be a problem or an issue to implement in public healthcare taking into consideration lack of resources.

6.4 Conclusion

This study shows that fatigue is a symptom of endometriosis that has a negative impact on the lives of women. Moreover, women with endometriosis-related fatigue are not able to

clearly articulate their fatigue experience; which makes it difficult for them to receive instrumental support because they do not know how they can be assisted. Fatigue management strategies have somehow assisted some participants to cope with the burden of fatigue. However, all of the strategies that women reported did not alleviate fatigue. The findings of this study indicate a need for fatigue interventions to be developed to assist women manage endometriosis-related fatigue.

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Appendix A

Do you have endometriosis and feel fatigued?

You are invited to participate in a research study. The study aims to explore chronic fatigue in women with endometriosis.

To be eligible to participate, you need to be above the age of 18, have been diagnosed with endometriosis by a doctor and experience fatigue often.

You will be asked to participate in an interview and will be asked about your experiences of fatigue.

If you are interested in learning more about this study, please contact the researcher on the details provided below.

This study is being conducted under the auspices of the Department of Psychology at Stellenbosch University. Ethical clearance was granted by Stellenbosch University's Health Research Ethics Committee (HREC2) and permission to conduct the study was granted by the Western Cape Department of Health.

Principal investigator**Dr R. Roomaney****[rizwanaroomaney@sun.ac.](mailto:rizwanaroomaney@sun.ac.za)****za****021 808 3973****Co-investigator****Dr M. Loades****[M.E.Loades@bath.ac.](mailto:M.E.Loades@bath.ac.uk)****uk****Student****Ms. Z. Sibande****18319033@sun.ac.za****076 572 1414**

Appendix B

Interview schedule

I am going to ask you a few questions about your endometriosis and fatigue. Please take your time to answer the questions, providing as much or as little information as you feel comfortable sharing. The information that you share will be treated as confidential. If at any time you would like to end this interview you are free to do so.

1. Please describe your energy levels on a typical day
2. Can you tell me about your energy levels during the last few months?

Prompt: has this changed – if so in what ways? What is the most frustrating aspect of these changes? Are there any benefits to these changes?

3. How would you describe your fatigue?

Prompt: have you experienced a fatigue like this before? Is it like any other type of fatigue you have experienced?

4. Can you tell me what you do when you are feeling fatigued?

Prompt: Do you rest more? Do you try to work through this?

5. Has anyone given you any good advice about how to manage your fatigue?

Prompt: Who was it that gave you this advice? What was the advice? Why did you think it would be useful – i.e. did they have experience themselves of managing fatigue or were they professional carers? Did you look up information from the internet? Where did you receive this help or advice – at home/hospital outpatients?

6. Are you able to get help from anyone to manage or cope with your fatigue?

Prompt: Do you have a supportive social network who can help with household tasks/finance/emotional support? Do you have good relationships with your health professionals? What kind of help and support do you get from family and friends?

7. If you had to give some advice to another woman who was experiencing fatigue what would you tell her?

Prompt: Can you think of three things that you find most useful to do when you are feeling fatigued?

8. That is the end of my questions – do you have anything else you would like to add about your fatigue and how it affects you that we have not discussed?

Appendix C

Informed consent form for interviews

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT: The development, implementation and feasibility of a psychosocial intervention for persistent fatigue in patients with endometriosis

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Dr. R. Roomaney

CO-INVESTIGATOR: Dr. M. Loades

STUDENT: Ms. Z. Sibande

ADDRESS: Room 2019, Psychology Department, Wilcox Building, Ryneveld Street, Stellenbosch, 7600

CONTACT NUMBER: 0218083973

You are being invited to participate in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the Principal Investigator any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point until the time of data publication, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

Who may participate in this study?

Any patient that has been diagnosed with endometriosis by a doctor and who experiences a lot of tiredness may participate.

Will you benefit from taking part in this research?

There are no direct benefits associated with participating in this study. However, the successful development of a course for tiredness may be of benefit to patients with endometriosis.

Are there in risks involved in your taking part in this research?

There are no known risks to participating in this study. Should you have any concerns do not hesitate to contact the researcher. Should you feel distressed during the interview, please inform the interviewer who will refer you to a counselling centre. If you feel distressed after the interview then please contact Dr Roomaney on the number given below.

Who will have access to your medical records?

The researcher will not have access to your medical records and will not discuss your case with your doctor.

All information collected will remain confidential, with only the researcher and supervisors having direct access to the data. All persons handling data will be required to sign confidentiality agreements. Any information that may lead to the identification of participants will be removed when reporting the research.

All recorded interviews and transcriptions will be stored on password protected computers with only the principal investigator, co-investigator, student and relevant research assistants having access. Transcriptions will contain pseudonyms (fake names) and all information that can be used to identify participants will be masked. The interviews and transcriptions will be kept for a period of five years after completion of the study and then destroyed. All hard copies of completed consent forms will be kept by the principal investigator in a locked cupboard in her office.

Will you be paid to take part in this study and are there any costs involved?

Participants will receive a Checkers gift voucher to the value of R100 as compensation for their time and inconvenience and R50 to cover travel expenses.

Is there anything else that you should know or do?

- You can contact Rizwana Roomaney at 0218083973 if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled (*insert title of study*).

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2018.

.....
Signature of participant

.....
Signature of witness

Declaration by investigator

I declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*)

Signed at (*place*) on (*date*) 2018.

.....
Signature of investigator

.....
Signature of witness

Appendix D



Health Research Ethics Committee (HREC)

Approval Notice

New Application

19/04/2018

Project ID :1760

HREC Reference #: N17/10/099

Title: The development, implementation and feasibility of a psychosocial intervention for persistent fatigue in patients with endometriosis

Dear Dr. Rizwana Roomaney,

The **New Application** received on 22/01/2018 13:36 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 19/04/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your **Project ID [1760]** on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct

Link and the application should be submitted to the HREC before the year has expired. Please see [Forms and Instructions](#) on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government [website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process](https://www.westerncape.gov.za/general-publication/health-research-approval-process). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. **Ethics** approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: [Forms and Instructions](#) on our HREC website <https://applyethics.sun.ac.za/ProjectView/Index/1760>

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Francis Masiye ,
HREC Coordinator,
Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372

Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:

IRB0005240 (HREC1)·IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The [HREC abides by the ethical norms and principles for research, established by the World Medical Association \(2013\). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health \(2006\). Guidelines for Good](#)

[Practice in the Conduct of Clinical Trials with Human Participants in South Africa \(2nd edition\)](#); as well as the Department of Health

(2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services

Appendix E



TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: Dr GG
Marinus
TELEPHONE: 021 938 5752


Ethics Reference: N17/10/099

TITLE: The development, implementation and feasibility of a psychosocial intervention for persistent fatigue in patients with endometriosis


Dear Dr Rizwana Roomaney

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).



DR GG MARINUS
MANAGER: MEDICAL SERVICES




DR D ERASMUS
CHIEF EXECUTIVE OFFICER
Date: 7 June 2018

Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938-6267 fax: +27 21 938-4890

Private Bag X3, Tygerberg, 7505
www.capegateway.gov.za

Ethics Reference: N17/10/099

TITLE: **The development, implementation and feasibility of a psychosocial intervention for persistent fatigue in patients with endometriosis**

BY _____
An authorized representative of Tygerberg Hospital

NAME Dr DS Erasmus

TITLE CEO

DATE 7 June 2018