Psychological Wellbeing Among South African Women with Endometriosis: A Quantitative Study

Raeesah Ismail

Faculty of Humanities

School of Human and Community Development

Department of Psychology

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Student Number: 2341220

Supervisor: Dr Shawn Rogers

Declaration

I, Raeesah Ismail, declare that this research project is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university.

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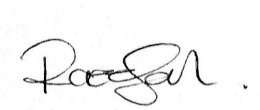
Signature: 

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Abstract

Endometriosis is a chronic illness that significantly impacts the physical, emotional, and psychological wellbeing (PW) of women. Despite its prevalence, the psychological toll of endometriosis remains under-researched, particularly in South Africa, where healthcare disparities and limited resources exacerbate challenges. The aim of this study addresses a critical gap in exploring the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in support groups and perceived medical support), and demographics (age and socioeconomic impact and access) on the experiences of PW in a sample of South African women diagnosed with endometriosis. Using a cross-sectional, correlational design, the study analysed 248 South African women aged 18–55 diagnosed with endometriosis. Participants were recruited via social media, support groups, and university students, employing non-probability sampling. Data was collected using the Ryff Psychological Wellbeing Scale, the Stellenbosch Endometriosis Quality of Life Scale (SEQOL), the Endometriosis Impact Questionnaire (EIQ), and a contextual questionnaire. Descriptive and inferential statistics, including Pearson correlations and regression analyses, were conducted. The simple regression results revealed that perceived medical support, EIQ Social Impact, SEQOL Support, socioeconomic status contextual burden, SEQOL Income, EIQ Employment & Financial and Education impact, and EIQ Psychological Impact and SEQOL PW were all significantly negative predictors of PW. However, delayed diagnosis, age, and support group participation were not found to be significant predictors. Additionally, the overall multiple regression model was significant ($F_{(9, 238)} = 8.81$, $p < .001$) and accounted for approximately 25.0% of the variance in PW with socioeconomic contextual burden emerging as the only significant predictor of PW ($p = .028$). Socioeconomic Impact and Access factors accounted for the largest variance in PW, showing the role of healthcare access and financial strain. The two psychological factor measures also emerged as a key area affecting overall PW. The results emphasise the need for endometriosis awareness, integrating mental health support into treatment plans and addressing systemic barriers to healthcare. This research provides a foundation for future studies to leverage in studying South African women with endometriosis.

Keywords: age, delayed diagnosis, endometriosis, psychological wellbeing, psychosocial support, socioeconomic impact and access, South Africa

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This thesis holds a special place in my heart, as it reflects not only my academic pursuits but also a cause that resonates deeply with me. I have poured my heart and tears into this work, hoping to bring awareness to the experiences and struggles of women living with endometriosis.

Finally, I dedicate this thesis to all the resilient women who bravely navigate the journey of endometriosis. Your strength, courage, and determination inspire me, and I hope that this work contributes in some small way to the understanding, advocacy, and care you deserve.

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Abbreviations

Chronic Illness	CI
Endometriosis Impact Questionnaire	EIQ
Exploratory Factor Analysis	EFA
Healthcare Practitioners	HCP
Health-Related Quality of Life	HRQoL
Human Research Ethics Committee	HREC
Low-to-middle-income countries	LMICs
Participant Information Sheet	PIS
Perceived Medical Support	PMS
Prefrontal Cortex	PFC
Psychological Wellbeing	PW
Ryff's Psychological Wellbeing	RPW
Stellenbosch Endometriosis Quality of Life	SEQOL
Socioeconomic Impact and Access	SEIA
Socioeconomic Status	SES
South Africa	SA
Support Group	SG
Quality of Life	QoL
Western, Educated, Industrialised, Rich, and Democratic	WEIRD

Chapter 1: Introduction and Literature Review

Introduction

Contextualisation

Endometriosis is a prevalent Chronic Illness (CI) (Ellis et al., 2022) characterised by the presence of endometrial-like tissue outside the uterus which often leads to debilitating pain and various health challenges (Liang et al., 2018; Zondervan et al., 2020). Despite its prevalence, the psychological toll of endometriosis has long been underestimated in research and by Healthcare Practitioners (HCP) (Grundström et al., 2017). Within the South African context, disparities in healthcare access, psychosocial factors, and demographic constraints shape the experiences of those living with endometriosis. The journey to diagnosis and the aftercare for many South Africans is often influenced by significant factors that impact PW from accessibility points (Agarwal et al., 2019; Moradi et al., 2014), psychosocial wellbeing (Rempert et al., 2024; Sims et al., 2021), and age (Moradi et al., 2014; Schwab et al., 2022). The scarcity of research addressing the PW of endometriosis highlights the need for this research to explore the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in support groups and perceived medical support), and demographics (age and socioeconomic impact and access) on the experiences of PW in a sample of South African women diagnosed with endometriosis.

Rationale

Understanding the impact of endometriosis on PW is essential for validating the experiences of affected individuals and addressing the prevailing narratives of neglect within healthcare systems. This research aims to uncover the psychological repercussions of living with endometriosis and advocate for greater awareness and support, ultimately contributing to more effective care in South Africa (SA). Endometriosis affects individuals physically in ways such as chronic pelvic pain, dysmenorrhea, dyspareunia, and infertility, and can affect organs beyond the reproductive system (McPherson & Bhattacharya, 2021; NHS, 2022) including the lungs and bowel (Nezhat et al., 2012, Nezhat et al., 2018), bladder (Kristensen et al., 2014), and the brain (Elefante et al., 2022) all of which have its own consequences. This demonstrates that despite its link to the menstrual cycle, endometriosis can manifest independent of menstruation (Edmonds, 2022). Considering the widespread impact of endometriosis, understanding its psychological effects becomes pertinent.

Given the scarcity of research and the increasing recognition of its significance, this study enriches the understanding of South African women's experiences with endometriosis and provides insights to

inform interventions and improve healthcare practices. Through rigorous research methods, this study addresses a critical gap in the literature, as research historically focuses on biological factors or qualitative explorations of Quality of Life (QoL), often neglecting the psychological dimension. Consequently, this thesis conceptualises PW as a crucial component of QoL. QoL and PW are both constructs that are significantly affected by the disease and share many similarities. These two constructs are closely related and often overlap but have distinct emphases and measurements. QoL is a broader construct that encompasses various aspects of an individual's life (Theofilou, 2013) - including PW - while PW specifically refers to mental health - a specific aspect of QoL (Dhanabhakyam & Sarath, 2023). Therefore, PW is a fundamental component of QoL as both constructs contribute significantly to an individual's overall sense of wellbeing.

Furthermore, existing research predominantly centres on common mental health issues such as depression and anxiety related to endometriosis (Pope et al., 2015). While these are important areas of inquiry, there is a pressing need to explore a broader range of psychological outcomes. For far too long, women with endometriosis have been told that their pain is normal and that their concerns are unfounded since endometriosis often cannot be detected non-invasively (Pettersson & Berterö, 2020). This dismissive attitude not only exacerbates PW negatively but also perpetuates a cycle of disbelief and neglect within healthcare systems (Culley et al., 2013; Moradi et al., 2014; Pettersson & Berterö, 2020) and subsequently, the research done. By shedding light on the psychological experiences associated with endometriosis, this research seeks to advocate for awareness and provide a better understanding of this conditions multifaceted impact.

Literature Review

History of Endometriosis

Initial insight into endometriosis was gained through experimental animal studies (Colette & Donnez, 2012). Nonetheless, it was neglected for decades, despite its status as a disease associated with reproductive age (De Graaff et al., 2015; Fuldeore et al., 2015). Over the past decade, there was a notable increase in literature addressing endometriosis, with over 75% of endometriosis-related papers during this period, as reported by Malvezzi et al., (2020) using data from Web of Science. This surge of information enhanced HCP understanding of endometriosis and contributed to improved diagnostic accuracy and awareness of available treatment options among both HCP and the layperson (Malvezzi et al., 2020). However, this assertion holds little significance without understanding the nature of endometriosis as a CI. Therefore, a CI is a complex long-term health condition that typically has no cure, requires ongoing medical management, and persists for a significant period of an individual's life (Whitehead et al., 2017). The development of endometriosis over time is unclear but research suggests that different stages of lesions appear at various stages of life ranging from Stage 1 being minimal to

Stage 4 being the most severe of cases (Holt & Weiss, 2000). However, there is no conclusive evidence supporting a specific progressive pattern for it (Holt & Weiss, 2000). Studies showed that lesions can progress, regress, or remain static (Evers, 2013) with no clear correlation between lesion stage and symptom severity or recurrence. Current classification systems have not proven effective in predicting risk factors or prognosis although there are many hypotheses (Holt & Weiss, 2000; Johnson et al., 2016).

Endometriosis: A Modern Understanding

Endometriosis is characterised by the presence of endometrial-like tissue outside the uterus, forming lesions that respond to hormonal fluctuations during the menstrual cycle (Liang et al., 2018; Zondervan et al., 2020) resulting in inflammation, pain, and the formation of scar tissue (Edmonds, 2022). It is primarily diagnosed through laparoscopic surgery - the current diagnostic gold standard (Zondervan et al., 2020), although advancements in medical imaging and biomarker research are developing (Bauşic et al., 2022; Hsu et al., 2010; Leonardi et al., 2022). These advancements are novel; however, the aim is to reduce the diagnostic delay and alleviate the cost burden. Treatment traditionally consists of pain management, hormonal therapy, and surgical removal of lesions (Ellis et al., 2022). Thus, endometriosis is increasingly being recognised as a complex inflammatory disease that impacts the entire body, requiring an integrated approach for management (Edmonds, 2022; Ellis et al., 2022; Taylor, 2019). Viewing endometrioses solely as a gynaecological issue overlooks its systemic nature and inflammatory origins, rooted in immune dysfunction rather than solely estrogen-related causes (Agarwal et al., 2019; Edmonds, 2022; Taylor, 2019). For this study, there are factors that are linked to PW related to endometriosis. These include delayed diagnosis, Support Group (SG) participation, perceived medical support (PMS), age and Socioeconomic Impact and Access (SEIA).

Prevalence of Endometriosis

As reported in a worldwide epidemiological study, it was estimated that endometriosis affects 10-11% of women in the pre-menopausal population (Bulletti et al., 2010; Ellis et al., 2022). Mecha et al. (2022) discussed the varied prevalence rates of endometriosis across Africa because of the lack of consensus and unconfirmed rates due to conflicting findings. There is no specific data on the extent of endometriosis in SA, reflecting the lack of research. Unfortunately, in SA, the last published prevalence rate in an academic article was from Allen and Wiswedel (1989) where they found a lower prevalence among the black population (2%) compared to the white population (7%) whereas in Nigeria, Fawole et al. (2015) reported a high prevalence of 48,1% as also covered in a review by Labinjo, T. (2020). These differences were attributed to factors such as demographics, access to healthcare and diagnostic delays (Kyama et al., 2007; Mecha et al., 2022). The accuracy of current knowledge about endometriosis in Africa is questioned due to the requirement of surgical visualisation, asymptomatic cases, and limited up-to-date research. Moreover, existing knowledge is biased towards those with access to healthcare

(Shafrir et al., 2018), posing a significant concern for South Africans. Interestingly, endometriosis has been found in males in incredibly rare cases and these cases have been well documented (Jabr & Mani, 2014; Pinkert et al., 1979; Rei et al., 2018; Simsek et al., 2012).

Psychological Wellbeing

Endometriosis poses multifaceted challenges to PW. Firstly, the aetiology of the disease can worsen psychological distress, as individuals grapple with the uncertainty surrounding their condition (Chaman-Ara et al., 2017). Moreover, the delayed diagnostic process adds additional psychological strain (Dunselman et al., 2014) where even after diagnosis, the absence of definitive treatment compounded the psychological burden (Chaman-Ara et al., 2017). The symptoms associated with endometriosis impact daily functioning and diminished overall QoL, psychosocial health, and PW (Chaman-Ara et al., 2017). Furthermore, the economic stressors of endometriosis exacerbate psychological distress and impose substantial financial burdens on patients, their families, and society (Fourquet et al., 2010). What is particularly concerning is that the impact is mostly felt by women of childbearing age, whose reduced productivity due to illness results in unemployment, further exacerbating PW (Fourquet et al., 2010). The findings from De Graaff et al. (2013) and Giuliani et al. (2016) demonstrate the adverse impact of endometriosis on PW, as evidenced by lower psychological scores among affected individuals compared to control groups. Most psychological research on endometriosis predominantly focused on measuring QoL and using qualitative approaches to explore patients' experiences. While these approaches offer valuable insights, there is a need for more independent quantitative research of PW in this population.

Adopting a broader perspective on PW can provide a deeper understanding of the psychological challenges faced by individuals with endometriosis. The definition of wellbeing from the Oxford English Dictionary offers a broad understanding of the term, emphasising aspects of being healthy and happy, as well as good physical and psychological states. PW is integral to happiness, as noted by Diener & Biswas-Diener (2008). It is also a component of mental health, encompassing various affective and behavioural aspects as emphasised by Warr (2007). According to Cooke et al. (2016) during the late 1940s, multiple conceptualisations of wellbeing emerged and were broadly categorised into four approaches namely, hedonic, eudemonic, QoL, and wellness perspectives. The hedonic approaches focus on pleasure and happiness (Ryan & Deci, 2001), often measured through subjective wellbeing, which includes life satisfaction, absence of negative affect, and presence of positive affect (Cooke et al., 2016). Alternatively, eudemonic approaches emphasise fulfilling one's potential and functioning at an optimal level (Lent, 2004), as seen in Ryff's PW model. QoL perspectives consider wellbeing more holistically, encompassing physical, psychological, and social aspects of functioning (Theofilou, 2013). Finally, wellness approaches offer broader and less defined conceptualisations of wellbeing, emphasising a holistic lifestyle (Roscoe, 2009). Despite their theoretical distinctions, these approaches

share a common interest in understanding optimal human functioning and the positive dimensions of human experience, contributing to an excess of constructs.

As stated above, PW is conceptualised as a critical component of QoL, defined through Carol Ryff's multidimensional model (1989), which emphasises eudemonic wellbeing. According to Ryff and Keyes (1995), PW encompasses six components: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth. This comprehensive framework underscores that true happiness comes from living meaningfully and realising one's potential (Ryff, 2014; Ryff & Singer, 2008). Keyes (2007) highlights the role of mental health in promoting flourishing, reinforcing that Ryff's components like purpose in life and autonomy being crucial for overall wellbeing. The impact of PW on QoL is especially relevant in the context of chronic conditions as PW is also major element of Health-Related Quality of Life (HRQoL) (Mergal et al., 2019; Topp et al., 2015; Van Niekerk et al., 2022). For example, Lee et al. (2024) found that PW mediated the relationship between self-management and QoL in hypertension patients, while León et al. (2020) demonstrated that psychosocial determinants are essential for enhancing QoL. Studies showed that individuals with higher PW experienced better QoL, even amid chronic health challenges, as seen in research on breast cancer patients (Abu-Helalah et al., 2022). Furthermore, the presence of social support is a vital mediator as it was found that strong social networks enhanced both PW and overall QoL (Taziki et al., 2021). This thesis, therefore, seeks to expand on these insights, using Ryff's framework as the working definition of PW and to explore the multifaceted impact of endometriosis on South African women's PW.

The COVID-19 pandemic acts as a significant extraneous variable that profoundly affected PW globally, including in SA. Studies described it as a global psychiatric crisis marked by heightened anxiety, depression, and psychological distress (Hossain et al., 2020; Le & Nguyen, 2020). Kim et al. (2020) highlighted that the South African lockdown worsened pre-existing mental health disparities, increasing depressive symptoms and stress among vulnerable populations. Duby et al. (2022) reported that economic hardship, strained family dynamics, and domestic violence compounded these issues for South African women and adolescents. Nguse and Wassenaar (2021) emphasised the struggle of the under-resourced South African mental health system to manage this psychological toll. Women experienced disproportionate economic and social burdens, leading to higher stress and reduced wellbeing (Parry & Gordon, 2020), while Akbas et al. (2021) found that heightened health anxiety and social isolation exacerbated their distress. Holm-Hadulla et al. (2022) observed that South African students experienced higher COVID-19-related fear, impacting wellbeing, and Kalseth et al. (2023) linked reduced social contact to loneliness and lower life satisfaction.

Although this study did not directly measure the impact of the COVID-19 pandemic, its timing and context likely influenced the PW of individuals that participated in this study. As discussed above, the

pandemic exacerbated stressors such as healthcare access, financial strain, and social isolation which are tied to the experiences of women managing endometriosis. While COVID-19 specific variables were not measured, it controlled for this extraneous variable (within the limitations of this paper) by restricting the analysis to data collected post-COVID-19. This decision was made to minimise the influence of the pandemic which emerged as a global crisis in early 2020 introducing a range of stressors discussed above. The study also accounted for broader socioeconomic and psychosocial factors which were intertwined with pandemic-related stressors as noted above. This approached demonstrates the deliberate methodological choices made to address the challenges posed by the pandemic and better ensures that the results provide data without the undue influence of the pandemic. The inclusion of this discussion contextualises the findings within the broader societal challenges posed post-pandemic showing its potential to amplify existing disparities and stressors faced by women with endometriosis in SA.

Factors That Affect Psychological Wellbeing

This section of the literature review will critically engage, review, and discuss the identified factors that affect the PW of South African women with endometriosis.

Delayed Diagnosis

The diagnostic journey for endometriosis has many challenges with laparoscopic surgery as the gold standard for diagnosis due to its difficult nature to diagnosis (Dunselman et al., 2014). Despite symptoms often arising in adolescence, a timely diagnosis remains elusive with individuals typically consulting an average of seven physicians before receiving a diagnosis (Nnoaham et al., 2011). This paired with the average diagnosis duration time being 4 to 11 years significantly demonstrates that it is a strong variable that affects PW (Agarwal et al., 2019; Moradi et al., 2014). The complexity of symptoms, the normalisation of menstrual pain, and the high comorbidity rates make getting an accurate diagnosis tedious. As it stands, surgery is somewhat reserved for individuals on the severe end of the symptom spectrum (this is deduced based on symptom burden) but that the threshold for referral varies based on practitioner awareness, economic barriers, and geographical accessibility to specialised care (Zondervan et al., 2020).

Shortages of endometriosis specialists and the lack of knowledge of this specialisation in both the medical and lay population further exacerbate delays in diagnosis resulting in misdiagnosis, prolonged pain, uncertainty, diminished QoL and PW, and impaired fertility (Abd El-Kader et al., 2019; Ballard et al., 2006; Della Corte et al., 2020; Moradi et al., 2014; Nnoaham et al., 2011). It can then be deduced that diagnostic delays stem primarily from lack of knowledge and accessibility. Recognising this stresses the importance of addressing the impact of diagnostic delays since tackling the challenges in diagnosing endometriosis is out of this papers scope. The diagnostic journey for many women with

endometriosis is often marked by frustration and uncertainty as symptoms are frequently dismissed or attributed to other conditions. The psychological toll of delayed diagnosis could not be overstated with individuals experiencing psychological implications such as feelings of isolation, psychiatric comorbidities, anxiety, and depression (Chen et al., 2016; Laganà et al., 2015; Laganà et al., 2017; Low et al., 1993; Sullivan-Myers et al., 2021). Recognising the negative impact of delayed diagnosis emphasises the urgent need to address these barriers for timely recognition and treatment of endometriosis.

Pope et al. (2015) found that longer delays were associated with increased stress, anxiety, and depression, as women endure prolonged pain and uncertainty about their health. This was compounded by the normalisation of symptoms, where both patients and healthcare providers may dismiss severe symptoms as typical menstrual discomfort, leading to further delays in seeking appropriate care (Ballard et al., 2006). The years leading up to a diagnosis were often marked by recurrent pain and psychological distress, which could severely affect daily functioning and overall wellbeing (Blass et al., 2022). Furthermore, the emotional burden of living with undiagnosed endometriosis led to feelings of isolation and frustration, as women may feel misunderstood or unsupported by their social circles (Culley et al., 2013). The psychological impact of delayed diagnosis extends to social relationships. Women with endometriosis often report difficulties in intimate relationships and social interactions due to their symptoms, which could be exacerbated by the lack of a timely diagnosis. This can lead to feelings of inadequacy and decreased self-esteem, as highlighted by Azevedo et al. (2023), who noted that the pain and infertility associated with endometriosis can result in significant social and psychological losses.

Some literature suggests that the experience of navigating a delayed diagnosis might have fostered resilience in certain women. Manderson et al. (2008) found that women who actively sought answers and engaged in self-advocacy during their diagnostic journey often developed stronger coping strategies, which could mitigate some of the psychological impacts. This suggests that while the delay itself is challenging, the process may lead to personal growth and empowerment for some individuals. Interestingly, Pereira et al. (2021) indicated that after receiving a diagnosis, the psychological impact of the disease stabilised as women gained a better understanding of their condition and treatment options. This adjustment period could lead to improved mental health outcomes as women began to manage their symptoms more effectively and seek appropriate support. The increasing awareness of endometriosis and its implications also played a role in how women cope with delayed diagnoses. As more women share their experiences and advocate for better healthcare practices, the stigma surrounding endometriosis may diminish, potentially leading to improved psychological outcomes even in the face of delays (Culley et al., 2013). The relationship between delayed diagnosis and PW in women with endometriosis was predominantly negative, with significant evidence linking delays to increased psychological distress, reduced QoL, and social strain. However, there were instances where the

experience of navigating a delayed diagnosis could lead to resilience and empowerment. Overall, the need for timely diagnosis and effective management of endometriosis is crucial for minimising psychological harm and improving the overall wellbeing of affected women.

Psychosocial factors

Qualitative and quantitative research have consistently highlighted the negative effects of endometriosis on psychosocial wellbeing (Rempert et al., 2024; Sims et al., 2021). These effects include heightened emotional and psychological distress, poor quality of sleep, decreased QoL, and elevated levels of depression and anxiety (Rempert et al., 2024; Sims et al., 2021).

Perceived Medical Support.

PMS is a pivotal factor influencing the PW of women with chronic conditions such as endometriosis, as it directly impacts how individuals navigate healthcare systems and manage their condition (Mick et al., 2024). It is known that reliable social support is a predictor for resilience (Schwab et al., 2022) but that medical social support has unique implications for endometriosis management. Sullivan-Myers et al. (2021) demonstrated that social support is strongly associated with psychological distress compared to medical or demographic factors, suggesting a complex relationship between support systems and mental health outcomes. Grundström et al. (2017) explored women's experiences of encounters with HCP related to endometriosis revealing a dual nature of these encounters characterised by both destructive and constructive elements. It was found that women often faced elements of ignorance, disbelief, and feelings, of invisibility when seeking care, yet some encounters were affirming leading to increased self-esteem and understanding (Grundström et al., 2017). These findings highlight the varying dynamics faced in healthcare interactions. Additionally, the study emphasised the need for HCP to educate themselves and improve their responsiveness to the unique challenges faced by this population (Grundström et al., 2017). Meta-analysis research has highlighted the systemic issues in healthcare interactions where themes such as trivialisation of women's symptoms, insufficient knowledge among HCP, and the normalisation of menstrual pain prevails (Pettersson and Berterö, 2020). This compiled meta-synthesis of qualitative studies on how women with endometriosis perceive healthcare encounters show that these factors not only prolong the diagnostic process but also deepen psychological distress as women feel dismissed or invalidated in their healthcare journey (Culley et al., 2013; Moradi et al., 2014; Petersson & Berterö, 2020).

In response to these challenges, some women turn to self-education or alternative treatment methods as a form of empowerment, particularly when dissatisfaction with traditional medical care persists (Cox et al., 2003). This self-directed approach shows the compensatory strategies women adopt to mitigate

the emotional and physical toll of inadequate medical support (Cox et al., 2003; Culley et al., 2013; Moradi et al., 2014). The findings above echo the previous studies that indicated inadequate understanding and trivialisation of women's issues can significantly impact PW. Due to a lack of awareness or normalisation of menstrual pain, women might have dismissed their symptoms as being a normal part of menstruation. Moreover, this lack of knowledge and awareness from both parties can prolong the diagnostic process and subsequently, exacerbate PW. Findings from previous qualitative research on difficulties with HCP such as the mental experiences, diagnostic delay, and the normalisation of symptoms as part of womanhood was a shared experience amongst women with endometriosis (Culley et al., 2013; Moradi et al., 2014; Riazi et al., 2014; Seear, 2009a). In the South African context, where healthcare disparities are pronounced, it becomes important to understand how PMS predicts PW. For women navigating a fragmented healthcare system, limited access to knowledgeable HCP may amplify the PW of endometriosis.

Support Groups.

Social support plays a critical role in shaping PW among women with endometriosis. However, a significant proportion of women with this CI report challenges in accessing adequate support (Cox et al., 2003; Markovic et al., 2008). Many experience feelings of isolation (Calvi et al. 2023; Cole et al., 2020; Peterson et al., 2023), disruptions to their social functioning (De Graaff et al., 2013; Olliges et al., 2021; Peterson et al., 2023), and difficulty in disclosing their condition (Gilmour et al., 2008; Shoebotham & Coulson, 2016). Connecting with others who understand their struggles could be beneficial but finding such support can be challenging with the debilitating pain and lack of awareness. These findings are pertinent to this study's focus on the associative and predictive relationships between psychosocial support and PW, specifically support group participation. The internet has emerged as a significant resource for women seeking support, particularly in contexts where awareness and accessibility remain limited. Shoebotham and Coulson (2016) explored therapeutic affordances perceived by women using online SG for endometriosis. Results revealed four therapeutic affordances offered by online SGs: the impact of understanding and empowerment, the acquisition of knowledge, sharing experiences, and self-presentation (Shoebotham & Coulson, 2016). Similarly, Sims et al. (2021) highlighted the role of SGs in reducing endometriosis-related stigma which contributes to psychosocial wellbeing and diagnostic delay.

According to the research, loneliness is a shared experience in this population (Calvi et al. 2023; Cole et al., 2020). Both these studies found that (1) women faced identity discrepancies and struggled to conform to societal expectations; (2) engaged in self-silencing as they felt like a burden; and (3) endometriosis affected their ability to fulfil social roles and maintain relationships. These studies demonstrated the psychological implications of endometriosis, suggesting that individuals who lack

adequate social support might have experienced lower PW. These themes showed the importance of social support in mitigating the negative impact of endometriosis as those who lack such support may face greater challenges in coping with the psychological toll of endometriosis (Cox et al., 2003; Markovic et al., 2008). Likewise with the perceived HCP support, both forms of support highlight the importance of empathy and listening. These aspects echo the therapeutic affordances results found by Shoebotham and Coulson (2016). Furthermore, it aligns with the results from Peterson et al., (2023) whereby physical pain and societal misconceptions prevent many women from seeking support, leaving them vulnerable to isolation.

Social support is important for women with endometriosis, offering emotional validation, understanding, and practical assistance in coping with the challenges of the condition. Moreover, endometriosis-specific SG offer a unique platform for sharing experiences, knowledge, and fostering solidarity and empowerment. These groups offer a safe space for discussing sensitive topics without fear of judgement or endometriosis-related stigma (Kocas et al., 2023; Sims et al., 2021). Culley et al., (2013) encapsulated the psychosocial impacts. There were (1) diagnostic delays contributing to the uncertainty and affecting women's experiences pre and post diagnosis (Ballard et al., 2006; Cox et al., 2003). (2) The negative impact on QoL and (3) employment and education (Fagervold et al., 2009; Fourquet et al., 2010). (4) Higher mental health rates of depression, anxiety, and emotional distress compared to control groups or the general population (Cox et al., 2003; Low et al., 1993; Sims et al., 2021; Sullivan-Myers et al., 2021). Finally, (5) the experience of medical treatment was often marked problematic probing women to turn to alternative forms of management (Cox et al., 2003; Seear, 2009b). These findings all align with the study's exploration of how SG participation predicts PW in that it contributes to the knowledge created on understanding how psychosocial factors shape PW.

Demographic factors

Age.

The relationship between age and PW in women with endometriosis highlights nuanced differences across the lifespan, emphasising the multifaceted role of age as a potential predictor of PW. Younger women often report heightened psychological distress compared to older counterparts, influenced by factors such as symptom burden, developmental challenges, and life-stage disruptions (Schwab et al., 2022). Schwab et al. (2022) identified that women aged 25 and older tended to exhibit higher levels of PW, suggesting that age might have served as a protective factor. This was potentially due to the development of more advanced coping strategies and emotional resilience as women age (Schwab et al., 2022). Conversely, younger women (24 and under) frequently faced elevated levels of anxiety and depression, which were attributed to their relatively limited coping mechanisms, societal stigma, and stressors associated with early adulthood, such as fertility concerns and career development (Moradi et

al., 2014; Schwab et al., 2022). Younger women's vulnerability was further evident in the interplay between symptom severity and HRQoL. Moradi et al. (2014) provided a nuanced analysis by categorising age into three distinct groups: 16–24 years, 25–34 years, and 35 years and older whereby each group demonstrated unique psychosocial, and QoL challenges related to endometriosis.

The youngest group prioritised educational and social aspects of their lives, yet they experienced significant disruptions due to severe symptoms and delayed diagnosis (Moradi et al, 2014). Lövkvist et al. (2016) and Facchin et al. (2017) reinforced these findings, noting that younger women often bore a higher symptom burden, which amplified psychological distress. Moreover, this heightened symptom burden affected emotional wellbeing and created additional challenges, such as fertility concerns and the stigma associated with endometriosis (Missmer et al, 2021). Soteriou and Epiphaniou (2022) added that these factors converged to reduce HRQoL, with younger women reporting greater psychological and social impacts compared to older women. This aligned with the above, suggesting that younger women might have been more vulnerable to the psychological ramifications of endometriosis (Lövkvist et al., 2016; Soteriou & Epiphaniou, 2022). In contrast, older women demonstrated greater psychological resilience, attributed to life experience and established coping mechanisms (Chen et al., 2021; Van Niekerk et al., 2022). Moradi et al. (2014) observed that women aged 35 and above often focused on financial impacts and long-term management, reflecting a shift in priorities and coping strategies. Furthermore, age appeared to correlate positively with knowledge about the condition, suggesting a potential trajectory of self-education and adaptation over time (Marki, 2019; Van Niekerk et al., 2022). However, despite potential adaptation, younger women continued to face greater challenges in PW, social support, and HRQoL whereas older women reported higher HRQoL scores (Soliman et al., 2017 as cited in Missmer et al., 2021; Van Niekerk et al., 2022).

Moreover, Chen et al. (2021) found that older women undergoing surgery for endometriosis often had different management protocols that considered their age and reproductive desires, which might have contributed to improved psychological outcomes. These cumulative findings suggested that while younger women struggled with immediate disruptions, older women had the time to develop strategies to navigate the chronic nature of the condition, although they might have still faced persistent stress and financial burdens (Van Niekerk et al., 2022). The stigma associated with endometriosis added another layer to this multifaceted relationship (Culley et al., 2013; Kocas et al., 2023; Sims et al., 2021). Younger women were more susceptible to the psychological consequences of stigma, particularly societal pressures related to fertility and femininity, which further exacerbated their distress (Soteriou & Epiphaniou, 2022; Tragantzopoulou, 2024). This stigma intersected with developmental challenges, compounding the psychological burden faced by younger women. In contrast, older women tended to exhibit greater resilience and emotional stability, benefiting from more established coping mechanisms and a broader perspective on managing chronic conditions (Chen et al., 2021). These differences in

psychological outcomes across the lifespan highlighted the dynamic and layered role of age in shaping PW.

Neurobiological findings provided additional insight into these age-related differences. Li et al., (2022) found that local cortical connectivity in the right orbitofrontal cortex, a region within the prefrontal cortex (PFC), was positively correlated with PW. Within the same region, Kong et al., (2015) reported that structural variations in the dorsolateral PFC were associated with social wellbeing and psychological resilience. This suggested that as women age and their PFC matures, they might have developed better emotional regulation and coping mechanisms, which could have enhanced their psychological resilience against the distress associated with endometriosis (Kong et al., 2015; Li et al., 2022). Additionally, psychological stress could lead to oxidative stress in the PFC, which might have impaired cognitive functions and emotional regulation (Li et al., 2013). This hinted that this sample, could have been at a greater risk for psychological distress due to the dual burden of chronic pain and the developmental stage of their PFC that was reflected through the younger age cohort. Facchin et al. (2017) emphasised the importance of addressing the neurobiological and psychological interplay in managing endometriosis, particularly for younger women. Research, including Facchin et al. (2017) and Li et al. (2022), underscored the vulnerability of younger women to psychological distress during this developmental period.

While some studies suggested a positive correlation between age and depression among individuals with endometriosis, indicating potential shifts in mental health challenges over the lifespan (Barneveld et al., 2022; Facchin et al., 2017), other investigations revealed complexities in how age intersected with the experience of the disease such as social interactions and feelings of isolation (Missmer et al., 2021). The findings from Moradi et al. (2014) suggested distress related to endometriosis was a universal experience, that the specific factors contributing to reduced wellbeing changed over time. The cumulative evidence underscored the dynamic relationship between age and PW, where age could not be looked at in isolation within their sample, instead with other factors that influenced it. While age-related differences in PW were evident in the literature, the role of contending factors across age groups warrant further investigation.

Socioeconomic Impact and Access.

In this study, SEIA is defined as a multidimensional construct encompassing income, employment, education, and healthcare access, reflecting the complex and dynamic ways these factors interact to shape individuals' QoL and PW. SEIA moves beyond static indicators of socioeconomic status (SES) to account for the lived experiences and systemic challenges faced by individuals managing chronic health conditions like endometriosis. Access to treatment for endometriosis in SA is characterised by disparities between private and public healthcare sectors including facing higher healthcare costs which

are deeply intertwined with SEIA dimensions (Gordon et al., 2020; Soliman et al., 2018). While individuals with private medical aid may have access to more comprehensive care options, including specialised gynaecological services and surgical procedures, those reliant on public healthcare are faced with endless challenges in receiving care. Public healthcare facilities experience resource constraints (Maphumulo & Bhengu, 2019) leading to long waiting lists for gynaecological consultations and interventions. Moreover, both these sectors pose a degree of inaccessibility due to the cost or time required - which often reflect an individual's SEIA profile. On the one hand, private healthcare services pose a significant financial burden for many leaving individuals still not being able to afford services, thus limiting their access within their private aid and searching for assistance in the public sector. On the other hand, these hurdles further burden the public sector and impacts what is offered and to whom. This systemic interplay exacerbates inequities, limiting access to timely and effective care for women with endometriosis (Soliman et al., 2018).

It is clear that the economic burden of endometriosis related to healthcare access and medical care is exorbitant (Armour et al., 2019; Soliman et al., 2018) but may be particularly pronounced in SA where a significant proportion of the population face socioeconomic challenges in both the middle- and lower-income classes (Gordon et al., 2020). SEIA dimensions provide a critical lens for understanding how these disparities manifest. The costs associated with a diagnosis, treatment, and lifelong management can and does place considerable strain on individuals and their families, especially those with limited resources and the healthcare system (Armour et al., 2019; Gordon et al., 2020). High out-of-pocket expenses for specialist consultations, diagnostic intervention, and medication may force individuals to forego necessary healthcare services or delay seeking treatment (Armour et al., 2019). These choices amplify the severity of symptoms, hinder timely interventions, and compromise psychological and overall wellbeing. Educational disruptions and employment-related impacts further compound SEIA challenges, creating long-term socioeconomic repercussions that disproportionately affect vulnerable populations (Soliman et al., 2018). By adopting SEIA as a framework, this study emphasises the interconnectedness of financial, educational, employment, and healthcare access challenges. The construct underscores how these dimensions collectively shape the lived experiences of women with endometriosis, providing a comprehensive perspective on the multifaceted burdens they endure. This holistic approach is critical for understanding the systemic barriers and individual sacrifices that influence psychological and overall wellbeing in this population.

Ryff's Psychological Wellbeing Theoretical Framework

Carol Ryff's PW (RPW) framework has six core characteristics that encapsulate an individual's overall PW (Ryff, 1989; 1995; Ryff & Keyes, 1995). (a) Autonomy refers to the capacity for self-determination while (b) environmental mastery reflects the ability to manage and adapt to life's

challenges effectively. (c) Personal growth signifies the continuous development and realisation of one's potential, while (d) positive relations with others denote the presence of meaningful and satisfying social connections. (e) Purpose in life pertains to having clear goals and a sense of direction, and (f) self-acceptance involves the acknowledgement and appreciation of one's strengths and weaknesses. Therefore, PW refers to a multidimensional construct encompassing various aspects of an individual's psychological functioning and fulfilment (Ryff, 1995). The framework and corresponding scale provided a structured framework for assessing these dimensions and allowed the researchers to quantitatively evaluate the individual's PW. The development of the RPW framework was guided by two perspectives on positive functioning. The first, rooted in Bradburn's work from 1969 (as cited in Ryff & Keyes, 1995), initially separated positive and negative affect defining happiness as the balance between. The second, emphasised life satisfaction as the primary indicator of wellbeing, viewing it as a cognitive component (Ryff & Keyes, 1995). However, PW, as conceptualised by Ryff (1989), extended beyond mere absence of illness to encompass a holistic framework suggesting that PW is determined by both external and internal factors.

In being applied to this research, these dimensions offer a comprehensive lens to assess this samples PW profile. For example, prolonged diagnostic delays and limited treatment access may undermine autonomy and environmental mastery, leading to feelings of hopelessness and reduced control over one's health. Socioeconomic disparities may also affect access to resources that facilitate personal growth and environmental mastery, potentially exacerbating psychological distress. Support factors are integral to understanding PW in women with endometriosis. Within this framework, positive relations with others and perceived support from the medical community directly influence wellbeing. Being part of a SG may foster positive relations, providing instrumental assistance thereby enhancing self-acceptance and purpose in life. PMS, on the other hand, may contribute to feelings related to the autonomy and environmental mastery dimensions. Lastly, age may interact with these variables as older women might have different outlooks and needs compared to their younger counterparts, potentially influencing all dimensions of PW outlined in Ryff's framework.

Ryff's multidimensional model of PW was selected for this study due to its comprehensive and theoretically grounded structure, which aligns closely with the multifaceted challenges faced by individuals living with chronic illnesses like endometriosis. Unlike hedonic models of PW that emphasise happiness and life satisfaction (e.g., Diener's Subjective Wellbeing framework), Ryff's eudaimonic approach captures aspects of human functioning through the sub-dimensions that are particularly salient when studying populations navigating long-term health conditions. This granularity makes it well-suited for exploring how psychosocial and socioeconomic variables uniquely relate to PW in the context of endometriosis. The literature reviewed has illustrated that endometriosis is a

complex, chronic condition with far reaching consequences that extend beyond physical health to significantly impact PW (Ellis et al., 2022; Liang et al., 2018; Zondervan et al., 2020).

Central themes have emerged around diagnostic delay (Agarwal et al., 2019; Moradi et al., 2014), inconsistent PMS (Grundström et al., 2017; Mick et al., 2024), insufficient SG participation (Culley et al., 2013; Shoebotham & Coulson, 2016), age as a potential PW protector (Moradi et al., 2014; Schwab et al., 2022), and SEIA inequalities (Armour et al., 2019; Soliman et al., 2018). These factors intersect to shape how women understand, experience, and manage endometriosis, particularly within under-resourced and under-researched contexts such as SA. Despite growing international recognition of endometriosis as a systemic disease with biopsychosocial ramifications, South African women continue to face diagnostic uncertainty, medical invalidation, and socioeconomic hardship. Moreover, PW, although central to QoL, remains underexplored as an independent construct in local quantitative research. The integration of Ryff's multidimensional model of PW provides a theoretically grounded lens to assess how psychosocial and structural factors shape women's subjective PW (Ryff, 1989; 1995; Ryff & Keyes, 1995). Together, these gaps justify the current study, which seeks to contribute a data-driven understanding of the PW of South African women with endometriosis.

Research Aim

The aim of this study was to explore the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in support groups and perceived medical support), and demographics (age and socioeconomic impact and access) on the experiences of psychological wellbeing in a sample of South African women diagnosed with endometriosis.

Research Questions

Descriptive Research Question: What are the average levels of psychological wellbeing, delayed diagnosis, participation in support groups, perceived medical support, and age and socioeconomic status?

Main Research Question: What are the associative and predictive relationships between delayed diagnosis, psychosocial factors, and demographic factors on the psychological wellbeing of South African women diagnosed with endometriosis?

Hypothesis

To address the aims of the study, the following hypotheses were formulated based on evidence compiled in the literature review regarding delayed diagnosis, psychosocial, and demographic factors that contribute to the PW of South African women diagnosed with endometriosis.

Descriptive research question

Hypothesis 1: South African women with endometriosis will report low to moderate levels of psychological wellbeing, as measured by the Ryff Psychological Wellbeing Scale.

Hypothesis 2: The average duration of delayed diagnosis will fall within the range of four to 11 years.

Hypothesis 3: Participants will report low levels of perceived medical support whereas women that participate in support groups will report higher psychological wellbeing levels.

Hypothesis 4: Age will have high levels of variability with the inclusion criteria including women aged 18 to 55.

Hypothesis 5: Participants will report moderate to high levels of socioeconomic impact and access strain.

Main research question

Hypothesis: At least one of the predictor variables will be a significant predictor of psychological wellbeing.

Sub-Research Question 1

Hypothesis: A significant negative relationship will be associated between delayed diagnosis and psychological wellbeing.

Sub-Research Question 2:

Hypothesis: A significant negative relationship will be associated between lower perceived medical support and lower psychological wellbeing.

Hypothesis: A significant positive relationship will be associated between higher support group participation and higher psychological wellbeing.

Sub-Research Question 3:

Hypothesis: A significant relationship will be negatively associated between higher socioeconomic impact and access and psychological wellbeing.

Hypothesis: A significant relationship will be positively associated between age and psychological wellbeing, with older participants reporting higher psychological wellbeing than younger participants.

The methods and materials used to investigate the above research questions follow in Chapter 2.

Chapter 2: Method Section

Introduction

This chapter will outline the research process in the investigation of the PW of South African women diagnosed with endometriosis.

Research Design

The study investigated the relationships between the listed factors that influence PW in women with endometriosis using three instruments (see Instrument section). This was carried out quantitatively with a non-experimental correlational, cross-sectional between-subjects design in the post-positivist paradigm (Krauss, 2006; Park et al., 2020; Reio, 2016). The decision to adopt a non-experimental design was grounded in considerations of feasibility, duration, and available resources. Non-experimental designs offer advantages such as ease of implementation, cost and time efficiency, and its utility for descriptive purposes (Reio, 2016). Moreover, the ability for there to be repeated measures and replication allowed for trends to be identified over time (Reio, 2016). Although causality cannot be inferred within this research design, this design is well suited to identify patterns of associative and predictive relationships between the variables (Field, 2013). In alignment with the paradigm, the researcher maintained distance from the data collection process and interpreted the findings with reference to theory and contextual influences, while acknowledging the limits of generalisability (Krauss, 2006; Park et al., 2020).

Sample and Sampling Strategy

This study aimed to get 100 participants. The sample consisted of N = 248 South African adults assigned female at birth with medically diagnosed endometriosis by a doctor through non-probability sampling using convenience, purposive, and snowball techniques. The sample had to meet the following inclusion criteria: South African adults assigned female at birth, diagnosed with endometriosis by a doctor, aged between 18 and 55, the ability to complete questionnaires in English, and be willing to participate in an online study. Exclusion criteria included being a minor – below 18 years old and if individuals were unable to comprehend and respond to questions in English. The sample was enlisted from South African SGs, students from the University of the Witwatersrand, and social media platforms (LinkedIn, Facebook, Instagram, and WhatsApp). This approach ensured diversity and representativity in capturing insights into the experiences of those seeking care for endometriosis, particularly considering the financial barriers associated with endometriosis medical treatment. Moreover, including SG members and students ensured a varied demographic representation and increased the accessibility of potential participants. The decision to include women across adulthood acknowledged the lifelong impact of endometriosis which was based on the understanding that endometriosis is a CI that continues

to impact individuals throughout their lives, even beyond menopause. Therefore, the study had a better opportunity that captured a comprehensive range of experiences on living with endometriosis.

Both convenience and purposive sampling have advantages that met the needs of this study such as being commonly used in clinical research (Acharya et al., 2013; Stratton, 2021). Convenience sampling was suitable for recruiting participants from the University student population as it involved accessibility and availability. Since the researcher requested access to the university email chain, this sampling method allowed for quick and convenient recruitment (Acharya et al., 2013; Etikan et al., 2015). Purposive sampling proved useful for recruiting participants from all platforms given it involved selecting the sample purposively (Etikan et al., 2015) and then asking the participants to refer others from their social networks enabling the snowballing approach (Woodley & Lockard, 2016). Snowballing proved effective for the purpose of overcoming the possibility of low participation because it relied on referrals from initial participants to expand the sample size. By combing these sampling strategies, the researcher was able to maximise recruitment efficiency and access to a diverse sample of participants that represented SA far better.

The final sample consisted of 248 South African adults assigned female at birth, all of whom reported a medical diagnosis of endometriosis, either through laparoscopy (77.0%) or verbal confirmation (23.0%). Participants ranged in age from 18 to 54 years (M = 32.85), with most reporting symptom onset between the ages of 12 and 16. The sample was diverse in race and geographic location, though the majority identified as White (40.7%), resided in Gauteng (51.2%), and spoke English as a home language (60.1%). Most participants were employed (62.5%), and the majority self-identified as middle class (71.4%). Nearly one-third of the sample reported no formal education qualification (32.3%). In terms of marital status, 48.4% were married, 46.0% were single, and 3.2% were divorced. A notable portion of the sample (25%) reported at least one comorbid physical or mental health condition. Regarding mental healthcare, the majority of participants (84.7%) had not received professional psychological support, and 43.6% reported no participation in endometriosis-specific support groups.

Instruments

The following self-report instruments were used in the assessment of the relationship between the factors and PW in women with endometriosis. Only specified subsets of the SEQOL and the EIQ were used. Additionally, the Ryff's PW Scale and a Contextual Questionnaire were administered.

Contextual Questionnaire (Appendix A)

The contextual questionnaire allowed the researcher to determine the characteristics of the sample and information from participants that met the inclusion criteria. It was designed to provide a comprehensive overview of participant contextual factors that might have influenced their PW. It

covered nine items pertaining to demographic factors such as age and home language with various response formats – mostly tick-boxes. For delayed diagnosis, three items measured the age of symptom presentation and how long it took to get diagnosed (both in years) and the last item questioned how the diagnosis was given (laparoscopically or verbally diagnosed from HCP). Support Group items involved six contextual questions with various response formats including three items using a Likert type scale with 1 = not at all to 5 = extremely (scoring 3-15 with higher scores indicating better psychosocial support), tick-boxes, and open-ended questions. The PMS section consisted of five items with Likert type scale response format ranging from 1 = not at all to 5 = extremely with higher scores indicating higher negative perception encounters with HCP. Medical encounter item one required reverse scoring. The resource accessibility section (SES) used a Likert scale response format for seven items that assessed participants perceptions of financial burden and barriers to accessing healthcare resources related to endometriosis. Scores ranged from 1 = not at all to 5 = extremely with a possible range of 7 to 35. This section required reverse scoring for items four and six. Higher total scores indicated greater financial strain and barriers to accessing healthcare resources, while lower scores suggest fewer challenges in this regard. The estimated time to complete this instrument was four to six minutes.

Endometriosis Impact Questionnaire (Appendix B)

The EIQ is a self-report questionnaire that measures multidimensional impacts of endometriosis with a long-term view (Moradi et al., 2014, 2019). It asks women how endometriosis has affected their lives over the three recall periods ranging from ‘last 12 months’, ‘1 to 5 years ago’ and ‘more than 5 years ago’. The categorical response format for these items uses a Likert type scale from 0 = not at all to 4 = very much and includes 9 = not applicable. Each item contributes equally, and higher scores indicate a greater impact of endometriosis on their lives indicating lower PW. The instrument has 63 items divided into six dimensions: (1) physical-psychosocial - 33 items (consisting of physical – 13 items, psychological- 16 items, and social impact – 4 items); (2) fertility - 3 items; (3) sexual - 7 items; (4) employment - 11 items; (5) educational - 6 items; and (6) lifestyle - 3 items.

According to Moradi et al. (2019) the estimated time to complete the test was 4 to 30 minutes however, the entire instrument was not used for this study. Instead, the following dimensions included were from dimension 1 the psychological impact (16 items) directly relating to PW and the psychosocial impact (4 items), from dimension 4 the employment and financial impact (11 items), the educational (6 items) and lifestyle (3 items) impact from dimensions 5 and 6 respectively for the SEIA factor, which came to a total of 40 items. The internal consistency reliability for this entire instrument is good with 0.98 Cronbach alpha with the physical-psychosocial dimension having the highest Cronbach alpha for all three recall periods (Moradi et al., 2019). This instrument is both reliable and validated with good

face validity and content validity (inter rater agreements of 0.84 for experts and 0.93 for patients) (Moradi et al., 2019).

Only the first recall period was used in this study to minimise the impact of COVID-19 as an extraneous variable as discussed in Chapter 1. COVID-19 emerged as a global crisis in early 2020 introducing a range of stressors, disruptions in healthcare, and substantial changes in daily living. Specifically, the second recall period, would have been heavily affected by the pandemic which persisted until approximately 2 years ago. During this time, healthcare accessibility, psychological stressors, and the overall impact on individuals' lives were significantly different from pre-pandemic conditions making it challenging to isolate the effects of endometriosis experiences from pandemic-related influences. Moreover, the third recall period, aligned directly with the timeline of the pandemics onset further affecting meaningful results. Consequently, using these two recall periods introduced a confounding variable that could not be controlled for thereby compromising the validity of the findings. Therefore, the decision to use only the first recall period ensured greater consistency and reliability in the data collected and minimised the influence of an uncontrollable global event. Arguably, life may look different for individual's post-pandemic, however the event itself has been eliminated.

Stellenbosch Endometriosis Quality of Life (Appendix C)

The SEQOL is a newly developed measure that was constructed and validated in SA for patients with endometriosis (Roomaney & Kagee, 2017, 2018). This instrument is good for assessing HRQoL in women with endometriosis and can be useful to doctors and patients to track their QoL (Roomaney & Kagee, 2018). Additionally, the instrument is beneficial for researchers to use to increase research in endometriosis, particularly in SA (Roomaney & Kagee, 2018). The instrument consists of 64 items with eight clusters to assess HRQoL (Roomaney & Kagee, 2018). It has a Likert response format, and items are scored: 1 = 'not at all' to 5 = 'very much'; with higher scores indicating a poorer HRQoL. This measure has good reliability with correlation coefficients ranging from 0.72 to 0.88 with the Cronbach Alpha being 0.92 (Roomaney & Kagee, 2018). The PW subscale has good construct validity being strongly correlated with the Endometriosis Health Profile – 30, the only validated HRQoL instrument for women with endometriosis (Roomaney & Kagee, 2018). For purposes of test fatigue and research specificity, only a portion of the instrument was used. The following clusters were included, which resulted in four scores that were summed together: PW (7 items), vitality (3 items), income (4 items), and support (3 items) a total of 17 items as these relate to the factors being studied for PW.

Ryff's PW Scale (Appendix D)

This 18-item instrument (Ryff & Keyes, 1995) is a shorter version of the original 120 item instrument that measures six dimensions of PW in six subscales. The instrument requires 3-5 minutes to complete, requiring a reading level of 6th or 8th grade, and is appropriate for adults. The response format ranged

from 1 = ‘strongly agree’ to 7 = ‘strongly disagree’. Therefore, the total score ranges from 18-108 with higher scores indicating higher levels of PW. The subscales are autonomy; environmental mastery; personal growth; positive relations with others; the purpose in life; and self-acceptance (Ryff & Keyes, 1995). Items Q1-Q3, Q8-Q9, Q11-Q13, and Q17-Q18 were reverse-scored using the formula: [(Number of scale points) + 1) - (Respondent’s answer)]. To calculate subscale scores for each participant, sum respondents’ answers to each subscale’s items was followed. This instrument version has three of the original 20 items to assess each dimension and has correlation coefficients ranging from 0.70 to 0.89 with their corresponding subscales from the original instrument (Ryff & Keyes, 1995). Using the brief version proved appropriate for this study as it reduced test fatigue while still measuring the dimensions reliably.

Data Collection Procedure

The researcher sought and received ethical clearance from the University of the Witwatersrand's Human Research Ethics Committee to conduct the research (HREC Non-Medical, see Appendix E). Once this was granted, the researcher approached the University Registrar to seek permission to invite registered students to participate in the study (see Appendix F). The students were invited through email that contained an electronic invite with a link to the questionnaire with the Participant Information Sheet (PIS; see Appendix G) attached. Furthermore, the researcher requested permission from the administrators of the various online South African SGs to post an invite with the link to the questionnaire (see Appendix H). The administrators were also given the option to post the invite themselves. Additionally, a poster was created using the same information from the PIS in a condensed version to fit for social media circulation by the researcher and supervisor, as well as by means of snowball sampling by individuals and participants (see Appendix I). Included in the poster was a QR code that individuals could scan to take directly to the questionnaire link, anonymously. Alternatively, the researcher’s email was included if individuals preferred to get the link directly through email.

The questionnaire was loaded on an online platform named RedCap. Participants were required to answer questions pertaining to the inclusion criteria and consent box and if this was violated, the stop-system ended the questionnaire. The time it took to complete the questionnaire was estimated to take between 15 to 25 minutes and the link was active for four weeks. Upon completion of the questionnaire, the participants submitted their responses and were not required to confirm it. An anonymous tick-box at the end of the PIS specified agreement to the conditions and that completion and submission was regarded as informed consent to participate in the study. Once the data collection ended, the collected data was transferred to an Excel spreadsheet where it is stored on a password protected laptop and on the University of the Witwatersrand OneDrive with the participants IP addresses destroyed. Due to the nature of an online questionnaire, participants were not required to include any identifying information.

Therefore, participant answers could not be linked to them, ensuring anonymity. After entering the data into Excel, it was transferred to IBM SPSS Statistics for data analysis.

Data Analysis

The data was coded and entered into an Excel spreadsheet before being transferred to IBM SPSS Statistics version 29 for statistical analyses (IBM Corporation, 2024). The data analysis proceeded in five phases: (1) variable preparation and operationalisation; (2) data cleaning and handling of missing data through mean substitution; (3) conducted reliability analyses; (4) descriptive statistics were used to generate the demographic and contextual characteristics of the sample using means, standard deviations, and frequencies (Field, 2013); and (5) inferential analyses including Pearsons correlations, simple regression, and then multiple regression. The study examined PW using the Ryff PW Scale as the outcome variable. Although not initially posed as a formal research question, the SEQOL Psychological Wellbeing subscale and the EIQ Psychological Impact subscale were included in the analysis plan as exploratory predictors. Preliminary descriptive and correlational analyses revealed strong and theoretically meaningful associations with the primary outcome. Given their conceptual alignment with the study's focus on PW, and their empirical significance, an additional research question was formulated to assess their unique predictive contributions. Therefore, the study's variables were organised into five groups: demographics/contextual factors, psychosocial factors, SEIA, psychological variables, and PW. Table 2.1 presents an overview of the variables used in analysis, their roles, sources, scoring details, and directionality.

Descriptive statistics (means, standard deviations, frequencies, and percentages) were calculated for all predictor and outcome variables, as well as demographic characteristics. While Ryff and colleagues have not published universal cut-offs for "low," "moderate," or "high" levels of PW, researchers often classify responses based on quartiles when analysing sample distributions. Following this approach, the current study divided participants into three categories based on quartiles and crosstabulation was done to validate the quartile classification before frequencies were run. For the primary outcome, participants were categorised into three groups using quartiles:

- **Low wellbeing** = ≤ 25th percentile
- **Moderate wellbeing** = 26th to 74th percentile
- **High wellbeing** = ≥ 75th percentile

Pearson's product-moment correlation coefficients (r) were calculated to examine the strength and direction of bivariate relationships. The sign of r indicated the direction (positive/negative) of the association. Cutoffs were interpreted as follows:

- **Small** (r = .10–.29),

- **Moderate** (r = .30–.49),
- **Large** (r ≥ .50)

Table 2.1

Overview of 13 variables

Cluster	Variable	Role	Source / Items	Scoring Detail	Directionality
Contextual Factors	Time to Diagnosis	IV	Contextual Questionnaire (1 item specific)	Number of years	Higher = longer delay
Psychosocial Factors	Perceived Medical Support	IV	5 items, Contextual Questionnaire	5-point Likert (1–5)	Higher = negative perceptions of HCP
	Support Group Participation	IV	6 items, Contextual Questionnaire	5-point Likert (1–5)	Higher = better psychosocial support
	SEQOL Support	IV	3 items, SEQOL	5-point Likert (1–5)	Higher = less support/poorer HRQoL
	EIQ Social Impact	IV	4 items, EIQ	5-point Likert (0–4)	Higher = more negative social impact
Contextual/Demo -graphic Factors	Age	IV	Contextual Questionnaire (1 item)	Reported in years	Higher = older
	SEQOL Income	IV	4 items, SEQOL	5-point Likert (1–5)	Higher = greater income strain//poorer HRQoL
	EIQ Employment/Fina ncial Impact	IV	11 items, EIQ	5-point Likert (0–4)	Higher = greater socioeconomic impact
	EIQ Educational Impact	IV	6 items, EIQ	5-point Likert (0–4)	Higher = greater educational impact
	SES Contextual Score	IV	7 items, Contextual Questionnaire	5-point Likert (1–5)	Higher = greater SES related strain
Psychological Variables	SEQOL Psychological Wellbeing	IV	7 items, SEQOL	5-point Likert (1–5)	Higher = greater psychological distress/poorer HRQoL
	EIQ Psychological Impact	IV	16 items, EIQ	5-point Likert (0–4)	Higher = greater psychological impact
Psychological Wellbeing	Ryff PW Total	DV	18 items, Ryff PW Scale	7-point Likert (1–7)	Higher = higher PW

Following the correlation analysis, a series of simple linear regressions were conducted to evaluate the predictive strength and direction of each significant predictor variable on PW, as measured by the Ryff total score. This approach allowed for the identification of key contributors without the influence of overlapping variance. It was particularly useful for exploring the unique effect of conceptually distinct predictors, especially in a study employing a diverse set of psychosocial and demographic

variables. Each simple regression included one predictor variable and the Ryff PW total as the outcome. The slope coefficient (*B*), coefficient of determination (R^2), and significance levels (*p*) were reported and interpreted. It was then decided to run a multiple linear regression model that included all variables that were significantly associated with PW. It was then decided to run a multiple linear regression to evaluate the combined explanatory power and relative importance of all significant predictors within a single model, although the extent of this should be done in a follow-up research report. Predictors were entered in the following blocks:

- **Block 1:** Psychosocial factors (perceived medical support, SEQOL support, EIQ social impact)
- **Block 2:** Demographic and SEIA variables (contextual SES, EIQ financial/employment/education impacts, SEQOL income)
- **Block 3 (Exploratory):** Psychological variables (EIQ and SEQOL psychological subscales)

All regression assumptions were tested:

- Outcome variable measured on a continuous scale (confirmed by interval – Likert type scale).
- 2 or more predictors are measured on a continuous scale (confirmed by interval – Likert type scale).
- Independence of observations (residuals) (confirmed by interval – Likert type scale).
- Linearity and homoscedasticity: Confirmed via scatterplots of residuals.
- Multicollinearity: All variables showed VIF < 10 and tolerance > .2.
- No significant outliers.
- Normality of residuals: Evaluated using histograms.

Reliability Analyses

Before presenting the main results, preliminary analyses were conducted to ensure the reliability and validity of the instruments used, especially for the instruments where only certain subscales were used (the SEQOL and EIQ dimensions).

Normality Testing

Normality was assessed using both statistical tests (Kolmogorov–Smirnov and Shapiro–Wilk) and descriptive indicators of skewness and kurtosis. A non-significant p-value ($p > .05$) was interpreted as evidence of normality, while skewness and kurtosis values within ±3 were considered robust and acceptable for this parametric analysis (Kline, 2016). Graphical methods, including histograms and Q-Q plots were too analysed. All analyses were conducted using an alpha level of $p < .05$ to determine statistical significance (see Appendix J).

Ethical Consideration

The researcher received ethical clearance from the University of the Witwatersrand's HREC (Non-Medical Protocol Number: MAPSYC-24-03). Upon receiving clearance, permission was sought from the administrators of selected online South African SGs and the University Registrar using access request letters. Participants were not required to submit any personal information, enabling anonymity. An anonymous tick-box at the end of the PIS specified informed consent and that completion and submission of the questionnaire indicated consent given. From the poster, participants could obtain the link through the QR code or the researcher's email. By following the latter, the researcher was aware of the individual's email address, however this was self-corrected through deleting their emails and through no personal identifiers being asked in the questionnaire. Additionally, it could not be assumed that individuals who emailed completed the questionnaire. Participants were provided with detailed information about the study's purpose, procedures, and their rights as participants (American Psychological Association, 2017). These included the right to withdraw from the study without consequence prior to submitting their responses (i.e. voluntary participatory nature) and the confidentiality of their responses. Results are only accessible to the researcher and supervisor with permission requested to be shared with others for verification, analytic and/or publication purposes.

The data is stored on a password protected laptop and on the University of the Witwatersrand OneDrive with the participants IP addresses being destroyed. The sample was deemed as low risk as the questionnaire was completely anonymous and did not involve invasive topics beyond those related to the participant's condition. However, there were safeguards implemented through front-end referrals indicated on the PIS. Choosing to participate (or not) did not create any advantage or disadvantage to the participant and they had the right to omit/ not omit questions during the study. There were no risks or direct benefits from participation. However, should participants wish to know the findings from this study or contact the researcher, the details were included on the PIS for a brief summary instead of individual feedback. There was another tick-box requesting permission to store the data permanently in electronic form and to use this for future research and/or teaching purposes that formed part of the consent. Should it not be ticked, that participants results were destroyed. The results from the study will be published on the Wits E-Theses and Dissertations and possible publications may arise in future. Lastly, the researcher adhered to ethical guidelines/regulations throughout the research process and participants were referred to the HREC (Non-Medical) for any ethical queries.

Chapter 3: Results

Introduction

The aim of this study was to explore the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in SGs and PMS), and demographics (age and SEIA) on the experiences of PW in a sample of South African women diagnosed with endometriosis. This chapter presents the results of the study, organised to address each research question systematically. First, the chapter will present descriptive statistics to provide an overview of the key variables. This will be followed by a series of correlational analyses addressing the study's sub-questions and the regression analyses to examine the predictive relationships among the variables. All analyses were conducted using an alpha level of $p < .05$ to determine statistical significance.

The study (N = 248) encountered challenges related to missing data whereby mean substitution was employed to address minimal missing data, primarily found in the EIQ measurement, with relatively few instances of missing data in other areas which were left. This approach ensured that the analysis remained comprehensive and robust. For each analytical approach, the assumptions of the statistical tests were assessed. These assumptions will be briefly discussed to provide context for the results and to justify the use of parametric analyses where appropriate. The assessment of normality in this study utilised statistical tests and graphical methods to align with each statistical measurement. While the Kolmogorov-Smirnov and Shapiro-Wilk tests indicated slight deviations from normality across several variables ($p < .001$), these tests can be overly sensitive with larger sample sizes, such as the one used in this research ($N = 248$; see Appendix J) (Field, 2018). In contrast, the skewness and kurtosis values for the variables were within acceptable ranges (-3 and 3), and the histograms and Q-Q plots showed distributions that were approximately normal. Given the visual evidence of approximate normality and the robustness of parametric tests to slight deviations from normality, the decision was made to proceed with parametric analyses.

Reliability Analyses

Reliability tests were performed on the SEQOL and EIQ dimensions to confirm internal consistency (see Appendix K). The total used SEQOL subscales demonstrated high internal consistency ($\alpha = .93$), indicating excellent reliability across the 17 items. The total used EIQ scales, consisting of 40 items, also demonstrated excellent internal consistency ($\alpha = .95$), both supporting the stability and consistency of the subscale items. Additionally, the following reliability analyses were conducted to evaluate the internal consistencies of all scales and subscales used in the study. All subscales demonstrated acceptable to excellent reliability with the exception of the Ryff PW subscales which were interpreted as lower (Fields, 2018).

Table 3.2

Reliability Analyses

Instrument/Scale	Number of items	Cronbach Alpha
Psychosocial Factors (predictors)		
Perceived Medical Support	5	.867
SEQOL Support	3	.814
EIQ Social Impact	4	.843
SEIA factors (predictors)		
SEQOL Income	4	.831
EIQ Employment/Financial Impact	11	.919
EIQ Educational Impact	6	.870
SES Contextual	7	.837
Psychological variables (predictors)		
EIQ Psychological Impact	16	.906
SEQOL Psychological Wellbeing	7	.876
Ryff PW (outcome)		
Ryff PW Total	18	.783
Ryff subscales		
Autonomy	3	.637
Environmental mastery	3	.572
Personal Growth	3	.560
Positive Relations	3	.478
Purpose in Life	3	.331
Self-acceptance	3	.578

Contextual Descriptive Results

Table 3.3 (see Appendix L) describes the demographics of the sample. Ethnicity varied with the predominant ethnicity identifying as White (40.7%), second as Coloured (25.8%), and Indian (16.9%) and Black (16.1%) being close, and the remainder falling under other. Geographical provincial distribution captured that the largest proportion of participants resided in Gauteng (51.2%), followed by the Western Cape (22.2%) and then Kwa-Zulu Natal (10.5%). Employment status revealed that 62.5% were employed, 22.6% were unemployed, and 11.7% identified as entrepreneurs. Majority of the participants were married (48.4%), while 46.0% were single, and 3.2% were divorced. In this study, 25% ($N = 62$) of the participants indicated having comorbid conditions. The results on symptom onset revealed that the majority of participants reported experiencing initial menstrual-related symptoms between the ages of 12 and 16. Participants were also asked to classify their perceived social class, with the majority (71.4) identified as middle class as seen in Figure 1.

Figure 1

Perceptions of Socioeconomic Status Distribution

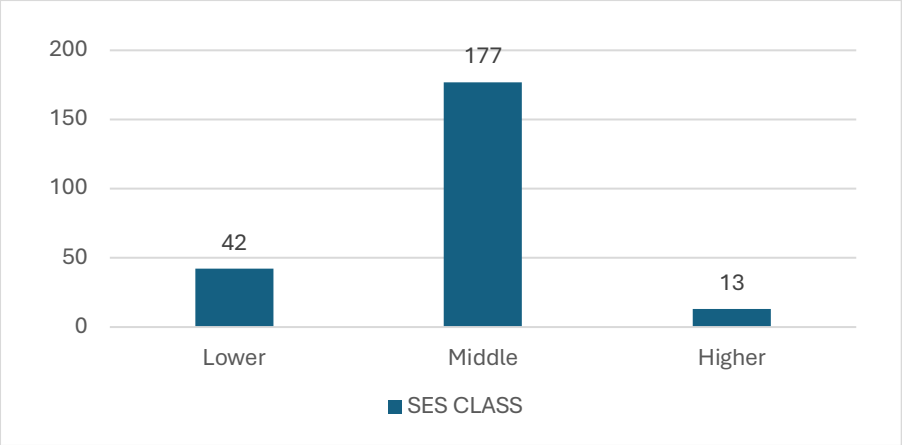

Figure 1: Perceptions of Socioeconomic Status Distribution

The results showed that the majority of participants (32.3%, N = 80) reported having no formal education qualifications, followed by 31.9% (N = 79) who attained tertiary education. Participants who completed secondary education accounted for 2.0% (N = 5), although it can safely be assumed that all participants that hold tertiary education have a secondary education, and this confusion was a result of a vague item from the instrument. Participants were primarily diagnosed through laparoscopic surgery, with 191 participants (77.0%), while 57 participants (23.0%) were diagnosed verbally (see Appendix O). Figure 2 represents SG participation where a notable 43.6% (N = 108) did not indicate participation in any SGs. The majority of participants (84.7%, N = 210) reported not receiving professional psychological help, while 14.5% (N = 36) indicated that they do receive such support (see Appendix P).

Figure 2

Support Group Participation Distribution

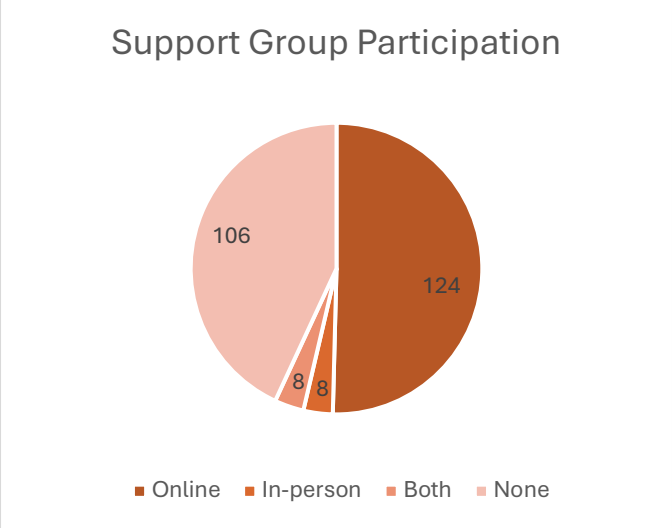

Figure 2: Support Group Participation Distribution

Descriptive Research Question Results

The first research question addresses the average descriptive levels of key variables, including PW, delayed diagnosis, SG participation, PMS, age, and SEIA, in a sample of South African women diagnosed with endometriosis found in Table 3.4.

Table 3.4

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation	Variance
Ryff PW total	248	76,00	50,00	126,00	86,1452	16,19251	262,197
Time it took to get diagnosed	248	34	0	34	8,85	7,213	52,025
Perceived Medical Support	243	20,00	5,00	25,00	16,5885	5,79856	33,623
Support Group Participation	248	6,00	1,00	7,00	4,4516	1,65363	2,734
SES Contextual Questionnaire	229	27,00	8,00	35,00	22,8122	6,47022	41,864
SEQOL Income	182	16,00	4,00	20,00	8,4615	4,72634	22,338
EIQ Employment 1st	248	44,0	,0	44,0	18,874	11,0703	122,551
EIQ Education 1st	248	24,0	,0	24,0	9,127	5,6140	31,517
Age	248	36	18	54	32,85	7,574	57,358
EIQ Psychological Impact 1st	248	60,0	4,0	64,0	47,626	12,6021	158,812
SEQOL PW	243	26,00	9,00	35,00	27,2634	6,97372	48,633

While Ryff and colleagues have not published universal score cut-offs, the current study divided participants into low (25th percentile and below), moderate (25th–75th percentile), and high categories (75th percentile and above). The RPW scores in this sample ranged from 50 to 126 (M = 86.15, SD = 16.19). The quartiles were defined as follows: scores from 50 to 75 were classified as low PW, scores from 76 to 97 were classified as moderate PW, and scores from 98 to 126 were classified as high PW. Based on this classification:

- 26.6% (N = 66) of participants were classified as having **low** PW.
- 49.2% (N = 122) of participants fell into the **moderate** PW category.
- 24.2% (N = 60) of participants were classified as having **high** PW.

These results demonstrate that nearly half of the sample reported moderate levels of PW, with approximately one-quarter each reporting low and high levels. Further analyses were conducted on the subscale results (see Appendix Q). The descriptive analysis for the six subscales: autonomy (M = 16.06; SD = 4.12), environmental mastery (M = 11.79; SD = 3.89), personal growth (M = 16.73; SD = 3.44), positive relations (M = 13.57; SD = 3.94), purpose in life (M = 14.75; SD = 4.04), and self-acceptance (M = 13.23; SD = 4.27). The time to receive an endometriosis diagnosis averages 8.85 years (SD = 7.21). The mean score for SG engagement is 4.45 (SD = 1.65), indicating that on average participants report moderate levels of involvement in SGs. Participants' perceptions of medical encounters (M = 16.59; SD = 5.80), show that experiences with HCP are generally negative, given that higher scores reflect poorer perceptions of medical support.

The SEQOL Income dimension yielded a mean of 8.461 (SD = 4.726), indicating moderate financial strain within the sample. The EIQ Total Employment Impact dimension, which measured the financial and work-related consequences of endometriosis, had a mean of 18.374 (SD = 11.070), highlighting significant variability in employment impacts. The EIQ Total Educational Impact dimension had a mean of 9.127 (SD = 5.614), reflecting moderate disruptions to education. Lastly, the total SES score, representing a composite measure of socioeconomic dimensions, had a mean of 22.812 (SD = 6.470), indicating a wide range of socioeconomic profiles within the sample. These statistics underscore the multidimensional nature of SEIA and its potential influence on PW in this population. The sample's average age is 32.85 years (SD = 7.57), indicating a broad age range that captures young to middle-aged adults. The first age group of younger women (18-24 years) comprised a total of 36 participants, representing 14.4% of the sample. Women in early adulthood (25–29 years) represented a substantial portion of the sample with 56 participants, made up 22.4% of the sample. Women in their 30s (30–39 years) represented the largest age group with 112 respondents, accounting for 44.9% of the sample. Finally, older women (40 years +) included 44 participants in this age bracket, making up 17.6% of the sample. These descriptive results provide a foundational understanding of the sample's descriptive characteristics and highlight areas of significant variability, which are crucial for examining the relationships and potential predictors of PW in this population.

Correlations and Regressions

The following presents the Pearson's correlational results (see table 3.5) from the sub-research questions presented in Chapter 1. For each significant association, a regression analysis was conducted, and then a multiple regression analysis.

Table 3.5

Correlations

		Ryff PW	Time it took	SG Participation	PMS	EIQ Social Impact	SEQOL Support	Age	SES	SEQOL Income	EIQ Employment & Financial Impact	EIQ Educational Impact	EIQ Psychological Impact	SEQOL PW
Ryff PW	Pearson Correlation	1	-,089	,035	-,263*	-,397*	-,181*	,075	-,343*	-,330*	-,385*	-,341*	-,400*	-,294*
	Sig. (2-tailed)		,160	,585	<,001	<,001	,005	,237	<,001	<,001	<,001	<,001	<,001	<,001
	N	248	248	248	243	248	243	248	229	182	248	248	248	243

*. Correlation is significant at the 0.05 level (2-tailed).

Results: Sub-Research Question 1

For the first research question that addresses the relationship between delayed diagnosis and PW in women with endometriosis, the correlational analysis results revealed a non-significant negative correlation (r = -.089; p = .160) indicating no statistically significant relationship between delayed diagnosis and PW in this sample. This suggests that the length of time taken to diagnose endometriosis does not have a significant impact on the overall PW of women in this sample.

Results: Sub-Research Question 2

To address the research question on the relationship between psychosocial factors and PW in women with endometriosis, the Pearson correlational analyses revealed mixed results for each variable. The correlation between PW and SG participation was not significant (r = .035; p = .585). However, for PMS the results indicated that there was a significant negative weak correlation between PW and PMS from HCP (r = -.263; p < .001). This suggests that more negative experiences with HCP were associated with lower PW. To examine this relationship further, a simple linear regression was conducted and was found to be statistically significant F (1, 246) = 18.019, p < .001, R^2 = .068 indicating that PMS explains approximately 6.8% of PW (B = −.737, SE = .174, β = −.261, t = −4.245). This suggests that for every one unit increase in PMS, PW increases by -.737. The regression coefficients are presented in Table 3.6, and the model summary is presented in Table 3.7.

Table 3.6

Regression coefficients

Model	Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
	B	Std. Error	Beta			Lower Bound	Upper Bound
1 (Constant)	98,371	3,047		32,284	<,001	92,370	104,373
PMS	-,737	,174	-,261	-4,245	<,001	-1,079	-,395

a. Dependent Variable: Ryff PW

Table 3.7

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,261[a]	,068	,064	15,66191	,068	18,019	1	246	<,001

a. Predictors: (Constant), PMS

b. Dependent Variable: Ryff PW

The Pearson's results indicated a significant moderate negative correlation (r = -.397; p < .001) suggesting that higher EIQ Social Impact scores (indicating greater negative social effects because higher scores on the EIQ indicate a greater impact of endometriosis) were associated with lower PW. A simple linear regression was conducted and found to be statistically significant [F (1,246) = 46.072, p < .001, R^2 = .158] indicating that EIQ Social Impact explains approximately 15.8% of the variance in PW (B = −1.416'; SE .209; β = −.397, t = −6.783). This suggests that for every one unit increase in EIQ Social Impact, PW decreases by 1.416 units. The regression coefficients are presented in Table 3.8, and the model summary is presented in Table 3.9.

Table 3.8

Regression coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	100,088	2,261		44,260	<,001	95,634	104,542
	EIQ Social Impact	-1,416	,209	-,397	-6,788	<,001	-1,827	-1,005

a. Dependent Variable: Ryff PW

Table 3.9

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,397[a]	,158	,154	14,89080	,158	46,072	1	246	<,001

a. Predictors: (Constant), EIQ Social Impact

b. Dependent Variable: Ryff PW

The relationship between Ryff PW and SEQOL support yielded a statistically significant weak negative correlation between PW and social support, (r = -.181; p = .005). Higher SEQOL scores indicate poorer HRQoL while higher Ryff scores reflect greater PW. This suggests that poorer HRQoL Social Support are associated with lower levels of PW in the sample of women diagnosed with endometriosis. The simple linear regression yielded a significant model [F (1, 246) = 8.171, p = .005, R^2 = .032, indicating that SEQOL Support explained approximately 3.2% of the variance in PW (B = -.831; SE = .291; β = -.179, t = -2.859). This suggests that for every one-unit increase in SEQOL Support, PW decreases by 0.831 units. The regression coefficients are presented in Table 3.10, and the model summary is presented in Table 3.11.

Table 3.10

Regression coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	95,674	3,484		27,460	<,001	88,811	102,536
	SEQOL Support	-,831	,291	-,179	-2,859	,005	-1,403	-,258

a. Dependent Variable: Ryff PW

Table 3.11

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,179[a]	,032	,028	15,96245	,032	8,171	1	246	,005

a. Predictors: (Constant), SEQOL Support

b. Dependent Variable: Ryff PW

Results: Sub-Research Question 3

To address the research question on the relationship between demographic factors and PW in women with endometriosis, the Pearson correlational analyses revealed mixed results. Firstly, the correlation between Ryff PW and age was not found to be statistically significant (r = .075; p = .237). However, a significant moderate negative correlation was found between Ryff PW and SES (r = -.343; p < .001). Higher SES scores, reflecting greater financial strain and barriers to healthcare access are associated with lower PW with a significant regression model summary [$F(1, 246) = 30.668$; $p < .001$; $R^2 = .111$] indicating that SES explains approximately 11.1% of the variance in PW ($B = -.867$, $SE = .157$, $\beta = -.333$, $t = -5.538$) suggesting that for every one-unit increase in SES, PW decreases by .867. The regression coefficients (Table 3.12) and the model summary (Table 3.13) are presented below.

Table 3.12

Regression coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	105,929	3,702		28,613	<,001	98,637	113,221
	SES	-,867	,157	-,333	-5,538	<,001	-1,176	-,559

a. Predictors: (Constant), SES

b. Dependent Variable: Ryff PW

Table 3.13

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,333[a]	,111	,107	15,29971	,111	30,668	1	246	<,001

a. Dependent Variable: Ryff PW

Ryff PW was significantly negatively moderately correlated with SEQOL Income (r = -.330; p < .001), indicating that higher income levels are associated with lower PW. The simple linear regression [F (1, 246) = 22.412, $p < .001$, $R^2 = .083$], indicated that SEQOL Income explains approximately 8.3% of the variance in PW (B = -1.156, SE = .244, β = -.289, t = -4.734). This suggests that for every one unit increase in SEQOL Income (indicating greater financial strain), PW decreases by 1.156 units. The regression coefficients (Table 3.14) and the model summary (Table 3.15) is presented below.

Table 3.14

Regression coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	95,931	2,290		41,885	<,001	91,420	100,442
	SEQOL Income	-1,156	,244	-,289	-4,734	<,001	-1,638	-,675

a. Dependent Variable: Ryff PW

Table 3.15

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,289[a]	,083	,080	15,53323	,083	22,412	1	246	<,001

a. Predictors: (Constant), SEQOL Income

b. Dependent Variable: Ryff PW

A significant moderate negative correlation was found between Ryff PW and EIQ Employment & Financial Impact (r = -.385; $p < .001$) indicating that higher employment & financial impact levels are associated with lower PW. The regression model [F (1,246) = 42.926, $p < .001$, $R^2 = .149$] found that this impact explains approximately 14.9% of the variance in PW ($B = -.564$, $SE = .086$, $\beta = -.385$, $t = -6.552$). Therefore, for every one unit increase in EIQ Employment Impact & Financial, PW decreases by 0.564 units. Additionally, between Ryff PW and EIQ Educational Impact there was a statistically moderate significant negative correlation (r = -.341; $p < .001$), indicating that higher educational impact is also associated with lower PW and the regression model [$F(1, 246) = 32.442$, $p < .001$, $R^2 = .117$] indicated that educational impact explains approximately 11.7% of the variance in PW (B = -.985, SE = .173, β = -.341, t = -5.696). This suggests that for every one unit increase in EIQ Educational Impact, PW decreases by .985 units. The regression coefficients can be found in Table 3.16 and 3.18, and the model summaries in Table 3.17 and 3.19, respectively.

Table 3.16

Regression coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	96,786	1,882		51,429	<,001	93,080	100,493
	EIQ Employment & Financial Impact	-,564	,086	-,385	-6,552	<,001	-,733	-,394

a. Dependent Variable: Ryff PW

Table 3.17

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,385[a]	,149	,145	14,97165	,149	42,926	1	246	<,001

a. Predictors: (Constant), EIQ Employment and Financial Impact

b. Dependent Variable: Ryff PW

Table 3.18

Regression coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	95,131	1,851		51,389	<,001	91,485	98,778
	EIQ Educational Impact	-,985	,173	-,341	-5,696	<,001	-1,325	-,644

a. Dependent Variable: Ryff PW

Table 3.19

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,341[a]	,117	,113	15,25089	,117	32,442	1	246	<,001

a. Predictors: (Constant), EIQ Educational Impact

b. Dependent Variable: Ryff PW

Psychological Wellbeing/Impact Correlations

Pearson correlations revealed a statistically significant moderate negative correlation (r = -.400; $p <$ .001) between Ryff PW and EIQ Psychological Impact, suggesting that greater psychological impact is linked to lower PW. The regression analysis [F (1, 246) = 46.810, $p < .001$, $R^2 = .160$], indicated that EIQ Psychological Impact explains approximately 16.0% of the variance in PW (B = -0.514; SE = .075; β -0.400, t = -6.842). This suggests that for every one-unit increase in EIQ Psychological Impact, PW decreases by 0.514 units. Likewise, the relationship between Ryff PW and SEQOL PW indicated a statistically significant weak negative correlation (r = -.294; $p < .001$), implying that higher psychological impact is associated with reduced PW. The regression analysis [F (1, 246) = 23.127, $p <$ .001, $R^2 = .086$], indicating that SEQOL Psychological Support explains approximately 8.6% of the variance in PW (B = -0.688; SE = .143; β = -0.293; t = -4.809). This suggests that for every one unit increase in SEQOL Psychological Support, PW decreases by 0.638 units. The regression coefficients are presented in Table 3.20 and 3.22, respectively, and the model summaries is presented in Table 3.21 and 3.23, respectively.

Table 3.20

Regression coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	110,613	3,699		29,905	<,001	103,328	117,898
	EIQ Psychological Impact	-,514	,075	-,400	-6,842	<,001	-,662	-,366

a. Dependent Variable: Ryff PW

Table 3.21

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,400[a]	,160	,156	14,87201	,160	46,810	1	246	<,001

a. Predictors: (Constant), EIQ Psychological Impact

b. Dependent Variable: Ryff PW

Table 3.22

Regression Coefficients

Model		Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95,0% Confidence Interval for B	
		B	Std. Error	Beta			Lower Bound	Upper Bound
1	(Constant)	104,893	4,021		26,086	<,001	96,973	112,813
	SEQOL PW	-,688	,143	-,293	-4,809	<,001	-,969	-,406

a. Dependent Variable: Ryff PW

Table 3.23

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	,293[a]	,086	,082	15,51259	,086	23,127	1	246	<,001

a. Predictors: (Constant), SEQOL PW

b. Dependent Variable: Ryff PW

Linear Multiple Regression

A standard multiple regression was conducted to examine the extent to which psychosocial factors (PMS, EIQ Social, SEQOL Support), SEIA factors (SES Contextual, SEQOL Income, EIQ Employment/Financial, and Education), psychological variables (EIQ Psychological Impact and SEQOL PW) predicted PW in South African women diagnosed with endometriosis. Preliminary analyses indicated no violations of the assumptions of linearity, independence of errors, homoscedasticity, unusual points, and normality of residuals (see Appendix R).

The overall regression model was statistically significant, $F(9, 238) = 8.81$, $p < .001$, and accounted for approximately 25.0% of the variance in PW, $R^2 = .250$, Adjusted $R^2 = .222$. Table 3.22 and Table 3.23 presents the regression coefficients, respectively. Among the predictors, only SES Contextual ($B = -0.392$, $\beta = -0.150$, $p = .028$) made a statistically significant contribution to the model. The other predictors did not significantly predict PW (all $p > .05$). The regression coefficients (Table 3.24) and the model summary (Table 3.25) is presented below.

Table 3.24

Regression coefficients

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	115.186	4.867		23.665	<.001		
	PMS	-.224	.180	-.079	-1.246	.214	.774	1.292
	EIQ Social Impact	-.356	.333	-.100	-1.069	.286	.361	2.769
	SEQOL Support	.648	.364	.140	1.780	.076	.511	1.957
	SES Contextual	-.392	.177	-.150	-2.215	.028	.684	1.462
	SEQOL Income	-.189	.325	-.047	-.580	.562	.478	2.094
	EIQ Employment Impact	-.102	.139	-.070	-.732	.465	.348	2.876
	EIQ Educational Impact	-.364	.209	-.126	-1.742	.083	.600	1.668
	EIQ Psychological Impact	-.206	.120	-.161	-1.720	.087	.362	2.766
	SEQOL PW	-.133	.206	-.057	-.647	.519	.408	2.449

a. Dependent Variable: Ryff PW

Table 3.25

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.500[a]	.250	.222	14.28676	.250	8.810	9	238	<.001	.334

a. Predictors: (Constant), SEQOL PW, EIQ Education, PMS, SES Contextual, SEQOL Income, EIQ Social, SEQOL Support, EIQ Psychological Impact, EIQ Employment

b. Dependent Variable: Ryff PW

Conclusion

In this chapter, the results of the statistical analyses were provided to address the research questions presented in Chapter 1. Descriptive data analyses provided an overview of the data, while inferential statistics showed the statistical relationships between the variables, answering the research questions with the addition of the SEQOL and EIQ psychological subscales, and the significant multiple regression model which yielded one significant predictor being SES Contextual.

Chapter 4: Discussion

Introduction

The primary aim of this study was to explore the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in SGs and PMS), and demographic factors (age and SEIA) on the PW in South African women diagnosed with endometriosis. This investigation was guided by the overarching objective of understanding how these variables collectively and individually impact the PW of women facing the chronic and often debilitating effects of endometriosis. As outlined above, this study specifically aimed to: (1) describe the average levels of PW, delayed diagnosis, psychosocial factors, and key demographic factors within the sample; (2) examine the correlational relationships between delayed diagnosis, psychosocial factors, and demographic variables with PW; and (3) investigate if and how these predictors influence PW through simple and multiple regression analyses.

Significant and non-significant findings revealed various relationships between the predictors and PW. The first research question sought to describe the sample characteristics, including levels of PW, delayed diagnosis, psychosocial and demographic variables. Descriptive statistics revealed that participants had an average Ryff PW total score, reflecting moderate levels of PW. Not surprising, the average time it took for this sample to get a diagnosis was approximately 8.85 years, indicating significant delays in receiving a formal diagnosis for endometriosis. When it came to the psychosocial factors, the results revealed varying scores of these factors relationship to PW. Significant negative correlations, varying from weak to moderate strength sizes for social impact, support, and PMS were found to be predictors for PW. However, this was not the case for SG participation as results varied. A notable portion of participants indicated involvement in either online, in-person, or both types of SGs, whereas half of the sample did not participate in any SGs.

The final research question addressed the role of demographic factors, including SEIA and age of which age was not significantly correlated to PW. The results showed that the four dimensions of SEIA (contextual SES, SEQOL Income, EIQ Employment and Financial Impact, and EIQ Educational Impact) were significantly moderate sized predictors of PW in this sample. In the significant multiple regression model, only SES contextual burden emerged as a significant independent predictor of PW, highlighting the prominent role of structural disadvantage in shaping mental health outcomes among women with endometriosis in this sample. In the subsequent sections, these findings will be discussed in relation to existing theoretical and empirical literature and will be systematically done in the order of the research questions presented in Chapter 1. Additionally, the chapter will further explore the study's practical contributions, provide directions for future research and acknowledge the limitations of the study that may have biased the results.

Demographics Characteristics

The demographic characteristics of the sample provide a critical lens for understanding the findings of this study, particularly within the context of SA's stark socioeconomic and healthcare disparities. The sample consisted of 248 South African adults assigned female at birth, all medically diagnosed with endometriosis. The predominance of English-speaking participants reflects the study's reliance on English survey instruments, potentially excluding non-English speakers who could provide culturally and linguistically diverse perspectives on endometriosis. This linguistic bias aligns with the urban concentration of participants, as English is a dominant language in urban centres (Alexander, 2024) and among SGs and academic networks, further reflecting SA's urban-rural divide in access to healthcare and research opportunities. The age distribution of participants, ranging from 18 to 55 years, highlighting key trends in the diagnostic trajectory of endometriosis. The relatively small proportion of younger women (ages 18–24) suggests delayed symptom recognition and diagnosis in adolescence. The clustering of participants age groups aligns with the typical diagnostic timeline, particularly the two middle groups, showing the chronic nature of the condition and the extended delay in receiving a diagnosis. While delayed diagnosis did not emerge as a significant predictor of PW in this study, the persistent challenges associated with diagnostic delays remain a notable concern, particularly in a healthcare system marked by inequities.

Geographically, most participants resided in Gauteng, Western Cape, and KwaZulu-Natal, provinces with better healthcare infrastructure and access to specialists. However, rural provinces like Northern Cape and Limpopo were underrepresented, likely due to limited access to digital platforms used for recruitment and reach. This urban bias reflects systemic disparities in healthcare access and digital literacy, which may hinder participation from women in less-resourced areas. The overrepresentation of English and Afrikaans speakers, alongside the underrepresentation of isiZulu speakers, further highlights these disparities, as isiZulu is the most commonly spoken language in Gauteng yet was scarcely represented in the sample (Alexander, 2024). Ethnic diversity within the sample revealed an overrepresentation of certain groups, deviating from SA’s broader population demographics, which predominantly comprise Black individuals (81.7%) (Statistics SA, 2024). This imbalance may influence the findings, as ethnic groups in SA experience varying degrees of healthcare access, stigma, and economic resources that shape endometriosis management. The concentration of participants in higher SEIA groups or urban centres may further reflect disparities in digital access and recruitment methods, biasing the sample toward those with greater resources and technological proficiency.

The education and employment data further contextualize the socioeconomic landscape of participants. The relatively high proportion of tertiary-educated participants (31.9%) contrasts with national statistics, where only 13.1% of females have tertiary qualifications (Statistics SA, 2024). This

disparity may reflect the sample's urban and middle-class concentration, highlighting intersections between education, healthcare access, and the economic burden of managing a CI. However, the substantial proportion of participants with no formal education or incomplete schooling (32.3%) underscores broader systemic inequalities in accessing quality education and healthcare resources. Employment data revealed that 62.5% of participants were employed, with a smaller percentage identifying as entrepreneurs or unemployed. While employed participants may have better access to private healthcare, they may also face significant workplace challenges in managing endometriosis, such as stigma and reduced productivity. The middle-class predominance in this sample emphasises the economic precarity of this group, as individuals often experience financial strain while navigating private healthcare options for a lifelong condition like endometriosis. The findings reflect a population navigating systemic inequities in healthcare, education, and employment, compounded by regional and linguistic barriers. These contextual factors must be carefully considered when interpreting the results, recognising the broader systemic challenges that shape the lived experiences of women with endometriosis in SA.

Descriptive Results

The reliance on verbal diagnoses (23%) rather than laparoscopic confirmation reflects systemic barriers in accessing specialised healthcare, particularly in under-resourced settings. Additionally, the underutilisation of SGs (42.7% of participants did not engage) and the lack of professional psychological support (84.7%) point to a critical gap in mental health resources and community support for this population. These trends emphasise either unawareness of these resources, accessibility, or societal stigma surrounding mental health and SG participation. The results also reveal that while delayed diagnosis (8.85 years on average) and age were not significantly correlated with PW, other factors—such as the quality of support and ongoing symptom severity—may play a more prominent role in shaping outcomes. The prevalence of comorbidities (25%) adds further complexity to disease management, suggesting that many women face intersecting health burdens that exacerbate psychological distress. The results on symptom onset aligns with the critical developmental years of adolescence, a period marked by significant physiological and psychological changes. Interestingly, despite this early symptom presentation, the mean age of the sample was considerably higher (33 years old), possibly reflecting a prolonged period before diagnosis. These contextual findings highlight systemic inequities in accessing care, limited awareness of resources, and the persistent challenges of managing endometriosis in the South African context.

Delayed Diagnosis

The narrative surrounding delayed diagnosis of endometriosis consistently documents it as a significant contributor to PW often exacerbating prolonged suffering. Previous research has shown that

women can wait between 4 to 11 years for a diagnosis, consulting multiple HCP during this time (Agarwal et al., 2019; Dunselman et al., 2014; Nnoaham et al., 2011). These diagnostic delays have profound implications as discussed in Chapter 1. Research highlights how years of unrelieved pain, uncertainty, and frequent miss diagnoses contribute to anxiety, depression, social isolation, and diminished QoL (Chen et al., 2016; Laganà et al., 2015; Moradi et al., 2014). The emotional burden of delayed diagnosis can also impact relationships and self-esteem, with women often feeling unsupported and misunderstood in both medical and social contexts (Azevedo et al., 2023; Culley et al., 2013). Pope et al. (2015) further elucidates this connection, demonstrating that women who experience longer diagnostic delays report significantly higher levels of psychological distress, including increased stress, anxiety, and depression. This is often due to years of enduring unvalidated pain and a lack of clarity about their condition. Given these well-documented consequences, one might expect a clear, negative relationship between the time taken to receive a diagnosis and PW.

Given these established associations, a strong relationship between delayed diagnosis and PW was anticipated. However, the results of this study did not reveal such despite the average time to diagnosis being 8.85 years which is consistent with previous literature on diagnostic delays. This result challenges the assumption about a direct and universal negative impact of diagnostic delay on PW. This lack of significant correlation suggests that PW in women with endometriosis may be influenced by additional, and perhaps more salient, factors than the duration of undiagnosed symptoms alone. An essential factor that may explain these unexpected findings is the study's inclusion criteria, which required participants to have already received a medical diagnosis of endometriosis. This aspect implies that the sample consisted of individuals who have successfully navigated the diagnostic journey, which may have shifted their psychological outlook. Pereira et al. (2021) suggests that receiving a diagnosis can bring a sense of validation and relief inducing a psychological stabilisation post-diagnosis. Additionally, the literature emphasises that the psychological toll of endometriosis is not solely tied to diagnostic delays but also to the broader experience of living with a CI (Chen et al., 2016; Blass et al., 2022). For women in this study, having a confirmed diagnosis might have facilitated access to management, coping strategies, SGs, and medical interventions and the development of resilience (Manderson et al., 2008; Pope et al., 2015) aligning with the moderate levels of PW reported.

Moreover, societal changes and increasing awareness of endometriosis have fostered stronger community support and advocacy, which could have positively influenced the sample in this study (Culley et al., 2013) as reflected by half of the sample participating in SGs and the mean age being 33 years old. As more women share their stories and demand better healthcare, the stigma and isolation associated with endometriosis are gradually making waves for the better, creating an environment where women feel more supported and understood (Kocas et al., 2023; Sims et al., 2021). While the literature on stigma surrounding endometriosis is limited, it is recognised as a serious contributor to PW in

endometriosis patients (Kocas et al., 2023; Sims et al., 2021) where the increasing visibility of endometriosis in public discourse may also have provided women with access to resources and information that softened the psychological impact of the delay. While these potential protective factors are critical to consider, the call for earlier and more efficient diagnosis remains urgent. The psychological consequences of diagnostic delays are undeniable for many women, particularly those who lack access to adequate support systems or who experience severe and debilitating symptoms. The results suggest that interventions aimed at enhancing PW should not only focus on reducing diagnostic delays but also consider empowering women through education, advocacy, and robust support networks.

Psychosocial Support and Psychological Wellbeing

Support Groups

The present study examined the relationship between three dimensions of social support and PW in women with endometriosis. The SG participation domain measured the extent of participants' involvement in SGs. This is strengthened by the SEQOL support subscale that evaluated the availability and effectiveness of social support systems and the EIQ social impact dimension that examined the broader social implications of endometriosis. Results revealed varied impacts: SG participation showed no significant correlation with PW, while SEQOL Support had a weak negative correlation and EIQ Social Impact demonstrated a moderate negative correlation. These results align partially with the literature but also present nuanced deviations. Studies such as Sims et al. (2021) and Shoebotham and Coulson (2016) emphasise the emotional and practical benefits of SGs, including empowerment, validation, and the opportunity to connect with others who share similar experiences. However, the lack of significance in SG participation's relationship with PW in this study suggests that mere involvement in SGs may not automatically translate to improved PW. Factors like group quality, awareness of groups, cohesion, or even the stigma of participation may mediate these effects. SEQOL Support, which measures general social support, negatively correlated with PW, contrasting with broader literature that often highlights the protective effects of social support on mental health (Sullivan-Myers et al., 2021). This counterintuitive result might reflect the burden of relying on or maintaining support systems while managing a chronic condition. Finally, the EIQ Social Impact dimension’s moderate negative correlation shows the profound social repercussions of endometriosis, echoing findings by De Graaff et al. (2013) and Olliges et al. (2021), who reported significant social and mental health impairments linked to the disease.

The South African context provides a critical backdrop for interpreting these results. Similar to findings in other resource-constrained settings, women in this study reported moderate to high levels of negative social impact. This resonates with literature emphasising the dual burden of CI and systemic inequities in healthcare access, where fragmented systems often leave patients to rely heavily on

informal or online SGs (Cox et al., 2003; Seear, 2009b). The moderate correlation observed between EIQ Social Impact and PW aligns with the broader literature on the detrimental psychological consequences (Cox et al., 2003; Shoebotham & Coulson, 2016) of societal stigma and invisibility of individuals with endometriosis (De Graaff et al., 2013; Kocas et al. 2023; Sims et al., 2021). In contrast, studies from high-income countries often report more positive outcomes associated with SG participation. For example, Shoebotham and Coulson (2016) found that online SGs significantly enhanced participants' empowerment and knowledge acquisition, mitigating some psychological impacts. Systemic inequities in South African healthcare compound the challenges women face in accessing effective support systems. Unlike high-income settings with specialised clinics and awareness programs, South African women often rely on fragmented healthcare networks and informal support, as noted by Seear (2009b). This systemic disparity likely influences the negative social impact captured by the EIQ dimension.

The lack of significant results for SG participation challenges the assumptions about the uniform benefit of SGs and warrants further thought about the conflicting findings from the other social support measurements that were significant (Culley et al., 2013; Kocas et al., 2023; Sims et al., 2021). With only half of the sample reporting participation in SGs, the results may reflect a selection bias, where those engaging in SGs might already be experiencing heightened distress, seeking validation and understanding. This limited participation raises questions about whether the support offered in these settings meets the broader needs of women with endometriosis or that these women are not aware that there are accessible support groups – these questions all highlight the potential for group dynamics to either alleviate or exacerbate psychological strain. Similarly, while SEQOL Support showed a significant relationship, studies in universal healthcare contexts report that robust social support systems typically enhance PW (Cox et al., 2003; Markovic et al., 2008). This relationship may reflect the dual-edged nature of general social support. While support can provide validation and practical assistance, it may also become a source of stress if perceived as insufficient, overly demanding, or the heavy nature of the topics in such spaces such as infertility and symptomology.

Perceived Medical Support

The present study’s findings reveal a significant negative relationship between PMS and PW, contributing to the broader literature on healthcare interactions' impact on mental health outcomes for women with endometriosis. Unlike qualitative findings, which emphasise the lived, dual nature of medical encounters as both affirming and dismissive (Grundström et al., 2017; Pettersson & Berterö, 2020), this study quantifies that relationship, demonstrating a weak but measurable negative effect of poor PMS on PW. The high mean PMS score in this sample reflects predominantly negative healthcare experiences, consistent with the frequent themes of invisibility, trivialisation, and invalidation found in

prior studies as discussed in Chapter 1. Yet, the weak correlation challenges expectations of PMS being a dominant predictor of PW, as seen in high-income contexts, where systemic healthcare supports might buffer such experiences. This nuance aligns with Schwab et al. (2022) and Sullivan-Myers et al. (2021), who argue that social dynamics, more than medical interactions, play a critical role in shaping PW.

In resource-constrained settings like SA, the structural barriers to healthcare, including limited specialist access and stigmatised perceptions of women's health, make healthcare interactions particularly salient for PW. Findings such as those by Grundström et al. (2017) resonate in this context, where dismissive attitudes from HCP often exacerbate the negative impact on women's mental health. The challenges of navigating fragmented healthcare systems, compounded by cultural norms that normalise menstrual pain, mirror findings by Seear (2009a), who emphasised how these systemic inadequacies disproportionately affect women in low-to-middle-income countries (LMICs). Contrastingly, in high-income settings such as Sweden and Australia, Grundström et al. (2017) and Pettersson and Berterö (2020) noted that while women occasionally reported dismissive healthcare encounters, the availability of specialised clinics and endometriosis awareness programs moderated these negative experiences. This divergence underscores the disproportionate role of PMS in LMICs, where women often rely on self-education and alternative therapies (Cox et al., 2003).

Therefore, the results point to a complex dynamic where poor PMS, while impactful, do not singularly define PW outcomes. Instead, broader systemic factors such as financial constraints, symptom burden, and societal stigma appear to play more significant roles in shaping PW. The finding that PMS explains only 6.8% of PW variance aligns with Schwab et al. (2022), who highlight the multifactorial nature of resilience and distress in women with endometriosis. The observed relationship also shows the potential for incremental improvements in HCP interactions to yield meaningful benefits for PW. As Grundström et al. (2017) and Pettersson and Berterö (2020) emphasise, even marginal increases in empathy and patient-centred care can validate women's experiences and improve their PW. This study's quantitative findings offer measurable insight into the impact of PMS on PW, complementing qualitative literature that provides a deeper understanding of the lived experiences underlying these dynamics. For example, Grundström et al. (2017) detail how dismissive encounters often lead to frustration and invisibility, which aligns with the high mean and relational PMS scores reported here. Simultaneously, qualitative findings suggest a dual dynamic: while poor PMS exacerbates distress, it can also motivate women to pursue self-advocacy and alternative coping mechanisms (Cox et al., 2003). This interplay may explain the weak correlation observed, as some participants could have buffered the psychological impact of poor medical encounters through resilience-building behaviours.

Disparities between public and private healthcare, as well as cultural stigmas around menstruation, likely amplify the psychological burden of poor PMS. As noted by Seear (2009a), these factors delay

diagnosis and contribute to dismissive HCP interactions, compounding distress. Yet, the qualitative literature also highlights opportunities for systemic improvements, with Pettersson and Berterö (2020) emphasising that even small changes in HCP empathy and knowledge can significantly alleviate PW, even in resource-constrained settings. The quantitative results challenge qualitative assumptions that overwhelmingly negative HCP interactions dominate psychological outcomes, instead pointing to the need for a more integrated approach that considers systemic, cultural, and individual resilience factors. Integrating these perspectives, it becomes clear that while PMS is a significant factor, its influence is mediated by a web of systemic and cultural dynamics. Simultaneously, the systemic inadequacies and cultural stigmas specific to SA underscore the heightened vulnerability to negative medical encounters, reinforcing the urgency of patient-centred interventions.

Demographics

Age

While the current study did not find a statistically significant relationship between age and PW, this result contributes a critical perspective to the existing body of literature. Much of the previous research such as Moradi et al. (2014) and Schwab et al. (2022) has emphasised age as a significant predictor of PW, identifying challenges faced by younger and older women. Based on those studies, younger women (16–24 years) often experienced heightened psychological distress, primarily due to life-stage disruptions, stigma, and symptom burden. Conversely, older women (35+ years) demonstrate greater psychological resilience, attributed to advanced coping mechanisms, life experience, and the long-term adaptation to chronic illness. However, some studies have suggested that age-related differences in PW may be less pronounced when systemic factors such as healthcare inequalities, stigma, symptom chronicity, and delayed diagnosis exert a pervasive psychological toll across all age groups (Grundström et al., 2017; Lövkvist et al., 2016; Missmer et al., 2021; Seear 2009a).

The divergence from these results in this study may reflect contextual differences specific to SA or the unique characteristics of the sample, such as the broad age distribution and the majority falling between 24–40 years. These results suggest that age-related differences in PW may be less pronounced in settings where systemic challenges overshadow individual-level differences. In resource-constrained settings like SA, the lack of a significant correlation between age and PW could reflect the pervasive psychological toll of living with endometriosis, irrespective of age. Instead, the shared experience of navigating a fragmented healthcare system and cultural stigmas surrounding reproductive health likely contributed to a levelling effect in PW outcomes. These shared stressors likely impose a universal psychological burden as highlighted in studies that document mental strain associated with delayed diagnosis, inadequate medical support, and the normalisation of symptoms as part of womanhood

(Culley et al., 2013; Riazi et al., 2014). This levelling effect may explain the absence of statistically significant results in in PW observed in this study.

The sample's age distribution, with most participants (67.3%) aged between 25–39 may also have contributed to these results. This cohort likely shares overlapping life-stage challenges, such as balancing work and family demands which could mitigate observable age-related variability in PW. Furthermore, the younger women (14.4%) and older women (17.6%) may have limited the statistical power to detect age-related differences, particularly given the distinct psychosocial challenges faced by these groups as noted by Moradi et al. (2014). Neurodevelopmental factors also provide a compelling lens for interpreting these findings. The PFC, responsible for emotional regulation and decision-making, continues to mature into the mid-20s as discussed in Chapter 1. Younger women in the sample may have been more vulnerable to psychological distress due to ongoing PFC development. Conversely, the predominance of participants aged 24–40 suggests a sample that has largely reached neurodevelopmental maturity, potentially mitigating age-related variability in PW.

Younger women in this sample may have had access to buffering mechanisms, such as digital resources or peer support, as suggested by Shoebotham and Coulson (2016), while older women may have faced long-term systemic challenges, creating a uniform psychological burden across the sample. In contrast, studies conducted in high-income settings, such as Sweden (Lövkvist et al., 2016) and Australia (Chen et al., 2021), report significant age-related differences in PW. These studies suggest that younger women face compounded challenges, including higher symptom burden and limited coping mechanisms, while older women benefit from greater access to specialised care and robust social support systems. The deviation in results demonstrates the influence of contextual factors. In SA, the lack of endometriosis awareness may contribute to a shared experience of lowered PW that minimises the impact of age. These contextual disparities highlight the importance of interpreting age-related findings within the broader sociocultural and systemic framework in which the study is conducted.

Qualitative insights from the literature review offer a more nuanced understanding of how age shapes psychological outcomes. Studies such as Culley et al. (2013) and Soteriou and Epiphaniou (2022) highlight the distinct challenges faced by different age groups. Younger women often grapple with disrupted life trajectories and stigma, while older women face long-term financial and emotional burdens. These narratives suggest that age-related differences in PW might manifest more prominently in specific domains, such as autonomy or environmental mastery, as outlined in Ryff's PW framework. The pervasive SEIA disparities and healthcare inequities likely intersect with age to shape PW. Both younger and older women in this sample may face financial barriers to accessing care and maintaining it, while older women have possibly navigated these systemic challenges longer. The findings challenge the dominant narrative in the literature that age is a definitive predictor of PW in women with

endometriosis. Instead, they highlight the need for a more nuanced understanding of how age interacts with other factors as noted in fewer studies.

Socioeconomic Impact and Access

SEIA was assessed through four measures: (1) a contextual SES questionnaire that addressed financial burden, healthcare access, and financial sacrifices made in this sample; (2) the SEQOL income dimension, which reflected the individuals ability to earn; (3) the EIQ employment and financial impact dimension, which captured the employment-related consequences of endometriosis; and (4) the Educational Impact dimension captured disruptions to academic attainment, which are critical for future employment and income potential, linking directly to long-term SEIA implications. The current study found a moderate negative relationship between SEIA and PW, indicating that as the scores of the SEIA factors increases, PW decreases as higher SEIA scores reflect greater impact and accessibility burden. This finding is consistent with existing literature that emphasises the financial, educational, and employment-related burdens of managing endometriosis (Cox et al., 2003; Seear, 2009b). The significant variance in PW explained by SEIA dimensions reflects how income, employment, and educational challenges converge to shape psychological outcomes. Studies like Grundström et al. (2017) have documented the systemic inequities that restrict healthcare access for women with endometriosis, exacerbating financial strain and emotional distress. Similarly, Pettersson and Berterö (2020) highlight how the costs of diagnostic procedures, medical consultations, and treatments compound economic challenges, often forcing individuals to delay or forego care. The significant relationship observed in this study aligns with such narratives, emphasising that SEIA burdens amplify psychological distress by limiting access to timely and effective interventions. However, while the findings corroborate these systemic patterns, they also reflect the unique interplay of SEIA factors within a South African context, where disparities between public and private healthcare exacerbate the challenges identified in global studies.

In settings with systemic inequities similar to those in SA, such as other LMICs, the financial and emotional toll of endometriosis mirrors the patterns observed in this study. Studies like Seear (2009b) have emphasised the role of healthcare barriers in shaping psychological outcomes, suggesting that the inability to afford or access specialised care leads to prolonged suffering and diminished PW. The results here align with such findings, demonstrating that income-related constraints significantly contribute to lower PW. Similarly, the employment-related impacts observed in this study reflect broader patterns of workplace absenteeism, reduced productivity, and stigma, which are common in contexts with limited social and institutional support (Missmer et al, 2021; Sims et al., 2021; Soteriou & Epiphaniou, 2022; Tragantzopoulou, 2024). Women with endometriosis often struggle to maintain stable employment due to chronic pain and fatigue, which compounds financial strain and emotional distress (Seear, 2009b).

Contrastingly, studies conducted in high-resource settings, such as Pettersson and Berterö (2020), report attenuated SEIA effects due to systemic supports like universal healthcare and workplace accommodations. While financial and employment challenges are still present in these settings, the availability of specialised care and social safety nets reduces their psychological effects.

The divergence highlights the contextual specificity of SEIA burdens, suggesting that the significant relationships observed in this study are amplified by the South African healthcare landscape. Each SEIA dimension demonstrated a moderate negative relationship with PW, reflecting the interconnectedness of these factors in shaping psychological outcomes. Higher SEQOL income scores, indicating greater financial strain, were significantly associated with lower PW. This result aligns with narratives from the literature, which highlight how the high costs of diagnostic and treatment interventions force many women to delay or forego care, exacerbating symptoms and psychological distress (Cox et al., 2003; Shoebotham & Coulson, 2016). Educational disruptions emerged as a critical SEIA dimension, with significant implications for PW. Women who experienced academic interruptions due to endometriosis reported lower PW, reflecting the long-term socioeconomic consequences of reduced educational attainment (Cox et al., 2003). This dimension highlights how early disruptions to education can limit future employment opportunities and income potential, creating a cycle of socioeconomic disadvantage that exacerbates psychological distress. The relationships observed between SEIA dimensions and PW suggest that the burdens of managing endometriosis are deeply systemic, reflecting the cumulative impact of financial, employment, and educational challenges on PW.

The quantitative results from this study align with qualitative insights from the literature, offering a comprehensive perspective on the interplay between SEIA and PW. Studies like Grundström et al. (2017) and Shoebotham and Coulson (2016) emphasise the lived experiences of women navigating financial and systemic barriers, highlighting the emotional toll of limited healthcare access and societal stigma. The significant correlations observed in this study provide empirical support for these narratives, demonstrating that SEIA burdens are not only pervasive but also measurable predictors of psychological outcomes. For example, Cox et al. (2003) describe how women's financial sacrifices and employment struggles contribute to feelings of helplessness and reduced autonomy, aligning with the significant effects of SEIA dimensions on PW in this study. Similarly, Seear (2009b) highlights how delayed diagnoses and high out-of-pocket expenses exacerbate psychological distress, reflecting the broader systemic challenges captured by the SEQOL income and EIQ employment dimensions. By integrating these quantitative and qualitative perspectives, this discussion underscores the need for holistic interventions that address both systemic barriers and individual coping mechanisms.

General Discussion on the Psychological Wellbeing

As discussed in the Chapter 3, a new research question emerged for levels of PW whereby the SEQOL PW and the EIQ subscales were assessed relationally. The SEQOL PW Subscale measured aspects of psychological distress and resilience specific to individuals with endometriosis. Similarly, the EIQ Psychological Impact subscale assessed the emotional and psychological effects of endometriosis over time. Both functioned as predictors of PW, offering insight into how the psychological burden of endometriosis contributed to overall PW. This section will begin by discussing the overall PW of this sample as assessed by RPW instrument in relation to the theorist's framework. Thereafter, a brief discussion on the descriptive subscale results as it was not part of the main research question. To conclude this section, the associative and predictive relationship of the abovementioned EIQ and SEQOL subscales on PW will be discussed.

Discussion: Psychological Wellbeing

The results of this study revealed a wide range of PW scores from the 18-item RPW instrument, with participants categorised into low (26.6%), moderate (49.2%), and high levels of PW (24.2%). This distribution highlights considerable variability in the psychological functioning of South African women with endometriosis, emphasising the multidimensional nature of PW as conceptualised by Ryff and Keyes (1995). The Ryff framework posits that PW is shaped by both internal and external factors, and the six dimensions collectively capture how individuals adapt to challenges, find purpose, and develop meaningful relationships (Ryff & Keyes, 1995; Ryff, 2014).

The relatively high proportion of participants in the moderate category may reflect a baseline of psychological resilience among South African women with endometriosis. Women in this category may demonstrate moderate autonomy and personal growth, enabling them to navigate the challenges of managing a CI within a context of systemic constraints. However, the notable proportion of participants in the low PW category suggests significant psychological distress and challenges in achieving key dimensions like environmental mastery and self-acceptance. Women with low PW scores may struggle with autonomy, feeling disempowered in their ability to make decisions about their health due to financial, cultural, or systemic barriers, as highlighted in the literature (Chaman-Ara et al., 2017). Similarly, their environmental mastery, may be compromised by PMS and physical symptoms of endometriosis, which disrupt daily functioning and exacerbate psychological distress. The SEIA associated with endometriosis in this sample, likely further undermines this dimension of PW, as previously emphasised by Fourquet et al. (2010) and echoed in this study's findings. Participants classified as having high PW likely benefit most from protective factors such as effective coping strategies, strong support networks, and better access to healthcare resources. These individuals may have better experiences as related to the dimensions, especially in autonomy and persona growth,

enabling them to cultivate resilience despite the challenges of living with endometriosis. The importance of social support in enhancing PW is well-documented in Chapter 1, and it is possible that participants in the high PW group have leveraged online SGs or interpersonal networks to mitigate the psychological burden of their condition.

The variability in PW levels aligns with the multidimensional nature of Ryff's framework, which posits that wellbeing is not a singular construct but rather an interplay of distinct yet interconnected dimensions (Ryff, 1989, 1995). The distribution observed in this study may reflect how systemic barriers, SEIA disparities, and individual resilience interact to shape PW among South African women with endometriosis. The findings of De Graaff et al. (2013) and Giuliani et al. (2016), which demonstrated lower psychological scores among women with endometriosis compared to controls, are particularly relevant here. The high proportion of participants with moderate or low PW suggests that the chronic nature of the disease, coupled with limited access to effective treatments, may suppress optimal PW. It is also critical to consider that the absence of universal cut-offs for "low," "moderate," and "high" PW scores necessitated the use of quartile-based classifications in this study. While this method provided a practical framework for interpreting the data, it might have oversimplified the nuances of individual experiences. For example, participants classified as having moderate PW may exhibit strengths in certain dimensions (e.g., personal growth or purpose in life) while simultaneously struggling with others (e.g., environmental mastery or autonomy). For this reason, as discussed in Chapter 3, analyses of this were conducted to better understand the specific challenges faced by this population.

The high levels of variability observed in this study echo findings from previous research that identified significant psychological distress among women with endometriosis (Chaman-Ara et al., 2017). However, the present study's results deviate somewhat from studies like De Graaff et al. (2013) and Giuliani et al. (2016), which suggested uniformly low PW levels in women with endometriosis. This discrepancy may be attributed to the cultural, social, and economic context of SA, where structural inequalities and healthcare access challenges intersect to create diverse experiences of PW. Additionally, the strong reliance on online SGs observed in this study may have contributed to higher scores in dimensions like positive relations and self-acceptance for some participants. The COVID-19 pandemic undoubtedly posed significant challenges to PW that may still be present that were mostly out of the researchers control, as highlighted in the literature, with increased anxiety, depression, and distress reported globally and in SA.

In the context of this study, the moderate levels of PW observed in the sample may reflect the compounded effects of the pandemic alongside the pre-existing burdens of living with endometriosis. The pandemic's restrictions on movement, social interaction, and healthcare access likely exacerbated

the psychological toll for women in this sample, particularly given the chronic and often debilitating nature of endometriosis. Reduced access to medical care during lockdowns, a critical issue noted by Nguse and Wassenaar (2021), may have intensified participants' experiences of delayed diagnoses and insufficient treatment, potentially undermining environmental mastery, a dimension in which this sample demonstrated the lowest scores. Moreover, the economic hardships documented during the pandemic, as described by Duby et al. (2022) and Parry and Gordon (2020), may have further contributed to the strain on environmental master, autonomy and purpose in life for participants, particularly those affected negatively by SEIA factors. These financial constraints likely intersected with the already high costs of managing endometriosis, impacting participants' ability to access care and maintain a sense of agency over their condition. This could explain the variability in the PW scores, with some individuals potentially more resilient to pandemic-related stressors, while others experienced pronounced difficulties.

Additionally, the pandemic's role in increasing isolation, as highlighted by Akbas et al. (2021) and Kalseth et al. (2023), may have disrupted participants' positive relations with others. Social isolation during lockdowns likely their positive relations with others resulting in diminished opportunities for support from family, friends, and SGs, which are essential for buffering the psychological impacts of chronic illness. This aligns with the low-moderate scores observed in this dimension, indicating that while some participants may have maintained meaningful relationships, others likely struggled to connect amid the constraints of the pandemic and post-pandemic world. While the moderate levels of PW in this sample may suggest a degree of resilience, the findings should be interpreted cautiously, as the pandemic may have masked more pronounced patterns of psychological distress or exacerbated disparities within the sample. Future research should account for the unique psychological burdens introduced by the pandemic, particularly for women managing chronic conditions, to better understand how these external stressors interact with the psychological dimensions outlined in Ryff's framework as well as resilience.

Discussion: Ryff Subscales

The results for the six subscales of RPW framework provide a detailed understanding of the multidimensional aspects of PW in this sample. Participants generally scored higher in autonomy and personal growth, reflecting strengths in self-determination and the capacity for continued development. This aligns with the literature on psychological resilience and adaptive coping methods (Manderson et al., 2008; Marki, 2019; Schwab et al., 2022; Van Niekerk et al., 2022). However, environmental mastery emerged as a notable area of vulnerability with the lowest scores aligning with the literature, which emphasises the condition's disruptive impact on daily functioning and QoL (Chaman-Ara et al., 2017). This dimension captures the ability to manage and adapt to life’s challenges, which may be hindered by

the multifaceted burden of endometriosis. These findings align with Ryff's conceptualisation that environmental mastery is often compromised in the context of chronic health conditions, where external stressors significantly limit individuals' perceived control over their environment. Positive relations with others and self-acceptance demonstrated moderate scores, reflecting variability in participants' social connections and their ability to acknowledge and appreciate their strengths and limitations. Lower scores in these dimensions may reflect the psychological toll of living with a stigmatised and invisible illness, which often leads to social isolation and reduced self-worth, as noted in the literature (Sims et al., 2021; Soteriou & Epiphaniou, 2022; Tragantzopoulou, 2024). These findings show the importance of social (Schwab et al., 2022) and medical support (Grundström et al., 2017; Pettersson & Berterö, 2020) systems in fostering self-acceptance and meaningful interpersonal relationships (Sullivan-Myers et al., 2021).

Interestingly, purpose in life showed moderate levels across the sample, suggesting that participants generally maintain a sense of direction and goals, although some may struggle due to the psychological and physical toll of endometriosis, as highlighted in the literature (Fourquet et al., 2010). This is particularly relevant in the context of delayed diagnosis (Pope et al., 2015) and self-educating (Cox et al., 2003) about endometriosis, which may exacerbate feelings of uncertainty but using education as a tool for autonomy, environmental mastery, and purpose (Manderson et al., 2008; Moradi et al., 2014; Pereira et al., 2021). Ryff emphasises that purpose in life is foundational to eudaimonic wellbeing, and its variability in this sample highlights the nuanced ways chronic conditions impact individuals' ability to set and pursue meaningful goals (Ryff & Keyes, 1995; Ryff, 2014; Ryff & Singer, 2008). Overall, the subscale results reveal a complex psychological profile in this sample, with certain strengths, such as personal growth and autonomy, coexisting with challenges in environmental mastery and self-acceptance. These findings provide a critical lens for understanding the interplay between external barriers and internal resilience, emphasising the need for comprehensive interventions that address both the systemic and psychological dimensions of wellbeing in women with endometriosis.

Discussion: EIQ and SEQOL Subscales

The results highlight significant relationships between PW, as measured by RPW framework, and the psychological dimensions captured by the SEQOL PW and EIQ Psychological Impact subscales. These relationships reveal the influence of endometriosis-specific psychological experiences on general PW, providing insight into how the chronic burden of endometriosis shapes PW. The EIQ Psychological Impact subscale exhibited a moderate negative correlation with RPW variable, indicating that individuals experiencing greater psychological distress related to endometriosis reported lower levels of PW. The regression analysis further demonstrated that the EIQ Psychological Impact subscale explained 16% of the variance in PW. This relationship emphasises the multidimensional burden of

endometriosis, wherein psychological impact stemming from chronic pain, uncertainty, and social stigma significantly compromises PW. These findings align with existing literature, including studies by Chaman-Ara et al. (2017) and Giuliani et al. (2016), which emphasise the detrimental effects of CI-related psychological strain on mental health and QoL. The SEQOL PW subscale also exhibited a significant, although weaker, negative correlation with Ryff PW and the regression analysis indicated that this subscale accounted for 8.6% of the variance in PW. This also reflects the interplay between endometriosis-specific psychological experiences and general wellbeing.

Although the SEQOL PW relationship is weaker compared to the EIQ Psychological Impact, the significant association suggests that these dimensions captured by the SEQOL and EIQ subscales also contribute to overall PW. The weaker correlation may reflect the broader scope of the SEQOL PW subscale, which incorporates both resilience factors and psychological challenges, compared to the more narrowly focused EIQ Psychological Impact subscale. The significant relationships observed in this study reinforce the importance of integrating psychological care into the management of endometriosis. Furthermore, the COVID-19 pandemic likely amplified these challenges (Akbas et al., 2021; Hossain et al., 2020; Le & Nguyen, 2020; Parry & Gordon, 2020), as highlighted in the literature review and the general PW discussion section above. These contextual factors underscore the need for systemic changes to address the multifaceted burden of endometriosis on PW. The results align with Ryff's framework, illustrating how CI disrupts core dimensions of PW. These findings highlight the urgent need for comprehensive, multidisciplinary approaches to care that address both the physical and psychological dimensions of endometriosis.

Discussion: Multiple Regression

A standard multiple regression analysis was conducted to identify the unique predictors of PW among South African women diagnosed with endometriosis. The overall model was statistically significant, accounting for 25.0% of the variance in PW. However, when controlling for all predictors simultaneously, only SES contextual, one of the factors within SEIA, emerged as a significant independent predictor of PW, while psychosocial factors, the remainder three SEIA variables, and psychological variables were not statistically significant. This result suggests that although several variables (except delayed diagnosis, age, and SG participation), were individually associated with PW in the simple regression analyses, their independent predictive power diminished once SES was controlled. This is consistent with previous research highlighting the pervasive impact of structural socioeconomic factors on health outcomes (Gordon et al., 2020; Soliman et al., 2018), and aligns with evidence that broader socioeconomic context profoundly shapes individuals' access to healthcare, coping resources, and overall quality of life. It is however, an interesting result for the health-related landscape of South African women with endometriosis.

The diminishing of associations between the predictors and PW in the multiple regression model may indicate that the benefits of perceived support and psychological resilience are constrained by the material realities of socioeconomic disadvantage. Although access to SGs and healthcare has been shown to positively influence PW among women with endometriosis (Shoebotham & Coulson, 2016; Sims et al., 2021; Culley et al., 2013), these resources may be less accessible or less effective for women facing greater socioeconomic barriers. Similarly, while endometriosis is associated with significant psychological burden, including depression, anxiety, and emotional distress (Rempert et al., 2024; Sullivan-Myers et al., 2021), the ability to manage these challenges effectively may depend heavily on one's socioeconomic position.

It is important to consider the sample characteristics when interpreting these results. The majority of participants identified as middle class and were recruited primarily through online platforms and SGs, suggesting a sample with relatively greater access to healthcare resources, education, and social support than the broader South African population. Despite this, SES still emerged as the only significant independent predictor of PW, highlighting the influence of socioeconomic disparities even within comparatively advantaged groups. It is possible that the effects of socioeconomic disadvantage on PW may be even more pronounced among women from lower socioeconomic backgrounds who were underrepresented in this sample. Future research should seek to include more socioeconomically and geographically diverse samples to fully capture the systemic barriers faced by women managing endometriosis in SA.

The results that SES emerged as the only significant independent predictor of PW must be understood within the broader socioeconomic and healthcare context of SA. Chronic conditions such as endometriosis require access to timely diagnosis, ongoing specialist care, and psychosocial support — resources that are inequitably distributed in SA's highly stratified healthcare system (Gordon et al., 2020; Soliman et al., 2018). This pattern is consistent with Ryff's multidimensional model of PW, as socioeconomic disadvantage is likely to undermine key dimensions such as autonomy, environmental mastery, and personal growth (Ryff, 1989; Ryff & Keyes, 1995). While international research has highlighted the important role of psychosocial support in mitigating the psychological burden of endometriosis (Shoebotham & Coulson, 2016; Sims et al., 2021), the dominance of SES in the current study suggests that in resource-limited contexts, broader structural inequalities may override the buffering effects of social support. These results highlight the urgent need for healthcare policies and interventions in South Africa to address not only clinical care pathways but also the systemic barriers that undermine PW in this population.

Chapter 5: Conclusions

Practical Implications

The findings of this study show the importance of considering SEIA factors when evaluating the PW of women with endometriosis in SA. The most consistent predictor of PW across analyses was the socioeconomic contextual index (SES contextual score part of SEIA), which significantly predicted lower PW in the multiple regression model. This supports the growing call for policy and healthcare reform that acknowledges the financial and structural challenges patients face when seeking care for chronic illnesses like endometriosis. While most psychosocial factors showed significant associations with PW in bivariate analyses, they were not robust predictors in the multivariate model. This suggests that while supportive healthcare experiences may matter, broader socioeconomic barriers could exert a more consistent influence on women's psychological outcomes and subsequently their psychosocial experiences. These findings advocate, cautiously, for the inclusion of social determinants of health in treatment planning, policy advocacy, and patient education strategies.

The practical implication here is not to assume causality or recommend specific interventions, but rather to encourage further exploration of how economic access, healthcare navigation, and perceived systemic support intersect to shape the PW of this sample. These results also invite healthcare providers to consider the indirect psychological toll that socioeconomic stressors may impose on individuals managing endometriosis, even when physical symptoms are addressed. Collaborative efforts between medical institutions and community organisations can improve the QoL for women with endometriosis. This research also supports educational initiatives to raise awareness, reduce stigma, and provide essential knowledge to others about the psychological impacts of endometriosis. By uniting academic and professional communities, resources can be allocated to expand local knowledge and foster interdisciplinary collaboration among psychologists, doctors, nutritionists, educators, and community stakeholders. Leveraging these findings alongside existing knowledge, is critical.

Future Directions

The results of this study are modest and as a master's level investigation into the PW of South African women with endometriosis, it has inherent confinements that the researcher is aware of. However, the future directions for this topic are vast given the scarcity of research in this field. Concerted effort has been made to propose practical avenues for future directions to the steadily growing discourse in this area.

Theoretical Directions

Future research could delve into integrating psychological theories such as incorporating resource stress, culture, and spirituality into the biopsychosocial model; stress and coping models; or developing

an overall wellbeing framework specific to CI relative to South African findings to understand the complex interplay between endometriosis, mental health, and QoL. This could also involve exploring how cognitive and emotional processes, such as rumination, resilience, and emotional regulation, influence the PW of women with endometriosis. The potential cognitive impact of chronic pain associated with endometriosis, exploring how it may influence executive functioning also warrants investigation. Additionally, there is an opportunity to develop comprehensive cognitive or case profiles of South African women with endometriosis, capturing the diverse and individualised nature of the condition. Such profiles would facilitate the creation of personalised interventions and support systems. This could be coupled with using the DSM-5 psychological cluster within the Somatic Symptom and Related Disorders called the illness anxiety disorder and investigating the aetiology of endometriosis through exposure to adversity and/or trauma. Future research should test the mediating or moderating role of SES on psychosocial and psychological predictors of PW, to better understand the mechanisms driving outcomes in women with endometriosis.

Methodological Directions

In the field of psychology, there is a need for culturally sensitive and validated psychometric tools to assess PW in the South African context. Future studies could work on validating or adapting existing psychological measures to ensure cultural relevance and accuracy. Employing experimental designs to test these instruments in this sample could provide evidence for effective strategies to improve PW in women with endometriosis. Future psychological research could use techniques such as structural equation modelling to understand the complex, multivariate relationships between PW, psychosocial factors, and demographic variables. This would allow for a more comprehensive understanding of the predictors and mediators of PW. Longitudinal studies should be conducted to explore temporal and causal relationships between predictors and PW, and future samples should include more diverse socioeconomic and geographic backgrounds. Qualitative research approaches should also be incorporated to capture the lived experiences of women managing endometriosis across different contexts.

Applied Directions in Psychology

Given that multiple SEIA factors were significantly associated with PW in bivariate analyses and SES contextual in multivariate analysis, there is scope for community-level psychological services to be paired with medical care such as SGs facilitated by trained psychologists or peer leaders, as pioneered through the endometriosis SG under the South African Depression and Anxiety Group. These interventions could be implemented at both group and individual levels. Psychoeducational interventions could be piloted to test whether increasing awareness of support options or addressing social support quality leads to improvements in PW. Importantly, the study's cross-sectional design

limits the certainty with which interventions can be prescribed. However, the patterns observed do offer a starting point for exploring psychological assessments and interventions that are embedded within socioeconomic realities, particularly for those navigating care within South Africa's public health system.

This study addresses a critical gap in local knowledge on endometriosis where research on this condition is limited. Currently, as of 2024, there are three published studies on non-medical aspects of endometriosis in SA, specifically on QoL (Roomaney & Kagee, 2016b), fatigue management (Sibande & Roomaney, 2022) and coping strategies (Roomaney & Kagee, 2016a), and this current study on PW. As one of the few studies focused on this population, it offers a foundational framework for future work. Future research could replicate and extend findings from non-Western, Educated, Industrialised, Rich, and Democratic (WEIRD) contexts, focusing on culturally specific nuances and well-documented associations between endometriosis, anxiety, and depression (Laganà et al., 2017; Pope et al., 2015). By prioritising culturally relevant, context-specific research, future studies can expand the understanding of endometriosis and its psychological impact. This research emphasises the importance of applying psychological principles to enhance the QoL and PW of women with endometriosis, paving the way for meaningful real-world change.

Limitations

Theoretical Limitations

The main theoretical limitation is its reliance on Ryff's (short version) Western framework, which may not fully capture the complexity of endometriosis-related PW in local context. Theories predominantly developed within WEIRD contexts may not adequately reflect the unique factors affecting South African women with endometriosis and the general South African population. While the study did account for some salient features such as healthcare accessibility and socioeconomic factors, it did not account for cultural, religious, spirituality, and stigma related factors. Additionally, the study does not account for potential intersectional influences, such as COVID-19, romantic partners, peers, familial support, fertility, and sexual and reproductive aspects which could provide a more comprehensive understanding of how endometriosis impacts PW but were all out of this papers scope.

Methodological Limitations

The research methodology has limitations that must be acknowledged. First, the use of non-probability sampling methods, introduces potential sampling bias limiting the representativity of the sample. While these methods were practical for recruiting participants, they resulted in an overrepresentation of urban, English-speaking (inclusion criteria) women, potentially excluding those from under-resourced areas. The sample may not adequately represent all South African women with

endometriosis, as it is likely biased towards individuals with greater access to digital platforms or stronger engagement with endometriosis support networks. This introduces selection bias and affects the external validity of the results. The study's cross-sectional design does not allow for the establishment of causal relationships between the predictors and PW and merely shows the associations that were identified. Furthermore, it does not capture temporal variations in PW, which could change with fluctuating pain levels or varying access to support over time. Another key limitation arises from the reliance on self-report instruments, which are subject to biases such as social desirability and recall inaccuracies. Participants may overreport or underreport their PW, potentially compromising the reliability and validity of the data.

Additionally, there are psychometric limitations associated with the selected dimensions of the instruments used. While using specific subscales of an instrument may influence the reliability and validity of the results, it is crucial to note that this study has no intention of using the instruments for diagnostic purposes. Reliability analyses were run to counter this limitation as far as possible. While RPW is a validated tool, its brief version might miss nuanced aspects of PW specific to women with endometriosis. The study faced minimal challenges related to missing data, which introduced limitations that could affect the validity and reliability of the findings. Specifically, some missing data were addressed using mean substitution, while in other cases, left blank. These approaches, although commonly used, come with inherent drawbacks despite it being used carefully on a small scale of missingness. Using mean substitution to replace missing data can lead to biased estimates and reduced variability in the dataset (Field, 2018).

It was possible that the university and social media samples would skew the data to a younger demographic where the SG sample could possibly be the median between the younger and older demographic. While all three strategies have appealing advantages, there are also limitations with each having bias potential and limited generalisability power given the non-probabilistic nature of them (Acharya et al., 2013; Stratton, 2021; Woodley & Lockard, 2016). Additionally, snowballing relies on the cooperation and the social networks of the participants which may result in underrepresentation or overrepresentation of the sample as it depends on the characteristics of the initial participants and their social networks (Woodley & Lockard, 2016).

Applied Limitations

While the proposed future directions are grounded in realistic and evidence-based recommendations, their application relies on the assumption that this study, along with other local research, will be carefully considered and utilised by relevant stakeholders. However, the implementation of these recommendations may be constrained by cultural, resource, and systemic limitations unique to SA. Similarly, integrating holistic assessment tools into routine healthcare settings would require systemic

changes that may be difficult to achieve within the current limitations of SA's healthcare system. Additionally, training HCP to recognise and address the psychological impacts of endometriosis necessitates substantial resources, institutional commitment, and buy-in from HCP. These factors may hinder the translation of research findings into practice, particularly in a context marked by disparities in resource allocation and service provision. While this research offers a critical foundation for advancing care for women with endometriosis, its practical application will require concerted efforts from policymakers, healthcare institutions, and community organisations to overcome these barriers.

The main limitation of this study, being correlational in nature, for the application to PW is the inability to establish causal relationships. In the context of PW, this limitation means that while the study may identify significant associations between delayed diagnosis, psychosocial factors, demographic variables, and PW, it cannot determine whether these factors directly cause changes in PW. The study does not provide direct evidence to inform intervention efficacy making it challenging to translate the results into actionable, evidence-based intervention strategies without further experimental or longitudinal research. Consequently, while the study can inform hypotheses and highlight areas of concern, it may not provide the definitive guidance needed for evidence-based psychological interventions or policy changes. It is for these reasons that the future directions section is so broad and optimistic in nature because there is widespread potential for experimental and non-experimental growth. Again, this study has the ability to be used a stepping stone for propelling research in the area at larger scales.

Conclusion

This study, while constrained by the scope and resources of a master's-level, correlational research project, has made a meaningful contribution to addressing the substantial gap in the South African knowledge base on endometriosis. It explored the associative and predictive relationships between PW, delayed diagnosis, PMS, participation in SGs, age, and SEIA among South African women with endometriosis. The results revealed moderate PW across the sample, with variability reflecting diverse experiences. Predictors of PW were identified, and included the psychosocial factors of PMS, EIQ Social Support, SEQOL Support, and SEIA dimensions: SES contextual items, EIQ Employment & Financial Impact and Education, all of which were significantly negatively associated with PW. Additionally, the study found that the lack of significant associations with delayed diagnosis, participation in SGs, and age may indicate that other factors such as symptom severity or access to social support play a more prominent role in shaping PW outcomes. While simple regressions revealed multiple significant associations between predictors and PW, only one variable, socioeconomic contextual burden, remained a significant predictor in the multiple regression model. This demonstrates

the dominant and potentially mediating role of structural socioeconomic realities in shaping psychological outcomes.

The correlational design, while limiting causal interpretations, highlights areas for further exploration. This work has emphasised the need for longitudinal and experimental research to establish causal pathways and refine the understanding of these relationships. Moreover, the study demonstrates the importance of contextualising endometriosis-related PW within systemic barriers. Beyond theoretical contributions, this research offers actionable insights for healthcare, clinical practice, and community-based involvements. Ultimately, it stresses the importance for raising awareness, reduce stigma, and address barriers to care. In addition to its applied implications, this research provides a platform for interdisciplinary collaboration and to expand these findings in SA and other non-WEIRD contexts, exploring culturally specific determinants of PW and QoL in women with endometriosis. The development of comprehensive cognitive and psychological profiles and culturally informed frameworks for interventions would advance research and practice, fostering a more nuanced understanding of the condition.

This study represents an important starting point for addressing the underexplored PW dimensions of demographic and psychosocial factors of endometriosis in SA. By summarising the main findings and proposing practical and theoretical applications, it lays the groundwork for future researchers to build upon, ultimately contributing to a more equitable, informed, and supportive healthcare environment. This thesis stresses the importance of addressing the long-overlooked psychological effects of endometriosis within the South African context, where disparities in healthcare access and psychosocial support compound the challenges faced by affected women. By focusing on PW as a central component of QoL, this research highlighted the multifaceted impact of endometriosis and addresses a critical gap in the literature. This study not only validates the lived experiences of women but also advocates for greater awareness and tailored interventions, contributing to a more holistic understanding of this debilitating condition.

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Appendices

Appendix A - Contextual Questionnaire

To be completed by the participant.

Criteria for inclusion

Age:18 - 55

Sex - Female

Diagnosed endometriosis,

South African,

Can complete a questionnaire in English,

Willingness to participate.

Criteria for exclusion

Age < 18,

Unable to comprehend and respond to questions.

Instructions: Answer all questions to the best of your ability.

1. Age in Years: _____

2. Home Language:

Afrikaans ☐

English ☐

Ndebele ☐

Sepedi ☐

Sotho ☐

Swazi ☐

South African sign language ☐

Tswana ☐

Tsonga ☐

Venda ☐

Other ‘ ☐

Xhosa ☐

Zulu ☐

3. Ethnicity:

Black ☐

Coloured ☐

Indian ☐

White ☐

Other ☐

4. Province That You Reside In:

Eastern Cape ☐

Free State ☐

Gauteng ☐

Kwa-Zulu Natal ☐

Limpopo ☐

Mpumalanga ☐

North-West ☐

Northern Cape ☐

Western Cape ☐

5. Level of Education (years of schooling):

☐ Secondary tuition

☐ Tertiary tuition

☐ None

☐ Prefer not to say

6. Employment Status:

Employed ☐

Unemployed ☐

Entrepreneur ☐

7. Marital Status:

☐ Married

☐ Single

☐ Divorced

☐ Prefer not to say

9. Which Class Do You Consider Yourself in:

Lower income class ☐

Middle income class ☐

Higher income class ☐

Delayed diagnosis items:

9. At what age did you first present with symptoms (in years): _____

10. How long did it take for you to get diagnosed (in years): _____

11. How were you diagnosed with endometriosis?

☐ **Laparoscopically**

☐ **Verbal diagnosed from health practitioner**

Support group items:

12. Are you in an endometriosis support group:

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

13. Are you in any support group that assists with your psychological wellbeing:

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

14. Does participating in a support group improve your psychological wellbeing:

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely

- 9: Not applicable

15. Is the support group you are in online or in-person:

☐ Online

☐ In-person

☐ Both

☐ Not Applicable

16. Are you receiving professional mental health support for your endometriosis:

☐ Yes

☐ No

17. Do you have other comorbidities (illnesses), if yes kindly list them: _____

Scoring for Likert scale:

3-15 with higher scores indicating better psychosocial support

9 should be captured as 0

Medical encounters items:

Instructions: Please rate the following items on the scale that you believe represents you best.

18. Do you feel like you were listened to and taken seriously by the various healthcare practitioners you have seen:

Response options:

- 1: Not at all

- 2: Slightly

- 3: Moderately

- 4: Very much

- 5: Extremely

- 9: Not applicable

19. Felt doctor(s) seen are not doing anything for you?

Response options:

- 1: Not at all

- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

20. Felt doctor(s) think it is all in your mind?

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

21. Felt frustrated at doctor(s) lack of knowledge about endometriosis?

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

22. Felt like you are wasting the doctor(s) time?

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much

- 5: Extremely

- 9: Not applicable

Scoring

5-25 with higher scores indicating higher negative perception encounters with HCP

9 should be captured as 0

Item 1 to be reverse scored

Socioeconomic Status Questionnaire

Instructions: Please rate the following items on the scale that you believe represents you best.

1. To what extent do you find the cost of treatment for your condition to be a financial burden?

Response options:

- 1: Not at all

- 2: Slightly

- 3: Moderately

- 4: Very much

- 5: Extremely

- 9: Not applicable

2. To what degree have financial concerns hindered your ability to seek necessary healthcare?

Response options:

- 1: Not at all

- 2: Slightly

- 3: Moderately

- 4: Very much

- 5: Extremely

- 9: Not applicable

3. How often do you feel compelled to choose between paying for healthcare and other essential expenses, such as food or rent?

Response options:

- 1: Not at all

- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

4. How confident are you in your ability to afford the medication prescribed for your condition?

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

5. How frequently have you needed to delay or skip doses of medication due to concerns about cost?

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much
- 5: Extremely
- 9: Not applicable

6. To what extent does your medical aid coverage alleviate financial strain related to healthcare expenses?

Response options:

- 1: Not at all
- 2: Slightly
- 3: Moderately
- 4: Very much

- 5: Completely

- 9: Not applicable

7. How often have you resorted to borrowing money or taking out a loan to cover healthcare expenses?

Response options:

- 1: Not at all

- 2: Slightly

- 3: Moderately

- 4: Very much

- 5: Extremely

- 9: Not applicable

Scoring:

Sum the responses for all seven questions to obtain a total score, with a possible range of 7 to 35.

9 should be captured as 0.

Items 4 and 6 to be reverse scored

Score Interpretation:

Higher total scores indicate greater financial strain and barriers to accessing healthcare resources, while lower scores suggest fewer challenges in this regard.

Appendix B - Endometriosis Impact Questionnaire

Endometriosis Impact Questionnaire (63-item EIQ)

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Maryam Moradi, Melissa Parker, Anne Sneddon, Violeta Lopez, David Ellwood

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- The questions in the EIQ have been developed based on 10 focus group discussions with 35 women with endometriosis. EIQ aims to measure the long term impact of endometriosis on different aspects of women's lives.
- Your valuable participation will contribute towards better understanding of the impact of endometriosis on women's lives and to better meet the needs of women with this condition.
- Please be assured that all responses are strictly confidential. Only combined data from all the questionnaires will be reported.
- Completing this questionnaire is voluntary. By completing the questionnaire you are indicating your consent to participate in the study.
- There are no right or wrong answers to any of the questions, so please respond according to your feelings and experiences about how endometriosis has affected your life.
- This questionnaire takes about 15(± 6) minutes to complete.
- If you have any questions about the questionnaire or the study please contact Maryam Moradi by email maryam.moradi.fu@gmail.com.
- Once you have completed the questionnaire please return it to us in the envelope provided.

We appreciate you filling out all dimensions to help us complete this important study.

Instructions: We ask you to complete the EIQ questionnaire by placing in every box the number which best describes how much endometriosis has affected your life over three time periods (last 12 months, 1 to 5 years ago and more than 5 years ago).

0 = Not at all
1 = A little
2 = Somewhat
3 = Quite a lot
4 = Very much
9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is about the effect of endometriosis on working and you did not work in that time period)

Example:

Because of My Endometriosis:	**Last 12 months**	**1 to 5 years ago**	**More than 5 years ago**
Q1. I had severe period pain.	**1**	**3**	**4**
Q2. I found it difficult to care for my child.	**0**	**4**	**9**

This woman's answer for question 2 shows she did not have any children more than 5 years ago (9), then she had a baby 3 years ago and "Because of her endometriosis" she found it difficult "Very much" (4) to care for her child, but during the last 12 months she has not had this problem at all (0). Some dimensions of the EIQ may not relevant to you, so you could skip to the next dimension.

I have read the instructions and I am ready to begin. ☐ Yes

Dimension 1. Psychological Impact of Endometriosis (Questions marked * are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all
1 = A little
2 = Somewhat
3 = Quite a lot
4 = Very much
9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not related to you)

Because of My Endometriosis:		**Last 12 months**	**1 to 5 years ago**	**More than 5 years ago**
Q14.*	I felt depressed.			
Q15.*	I felt uncertain because of the unpredictable nature of endometriosis and its symptoms.			
Q16.*	I felt uncertain about the effectiveness of my treatment/s.			
Q17.*	I experienced mood swings (due to my symptoms/pain or treatment side effect).			
Q18.*	I felt nobody understands how I feel.			
Q19.*	I felt less self-confident.			
Q20.*	I was unhappy about my appearance (e.g. due to weight gain, surgery scar/s).			
Q21.*	I felt my identity has been disrupted as a woman, partner, mother etc.			
Q22.*	I felt embarrassed (e.g. symptoms at work place, school, explaining to employers, colleagues or teachers).			
Q23.*	I felt jealous (e.g. of others who have no pain or have had children or pain free sex).			
Q24.*	I felt worried that my symptoms will get worse.			
Q25.*	I was worried about the effect of endometriosis on my future plans.			
Q26.*	I felt annoyed about the amount of painkillers I have had to take.			
Q27.*	I had feelings of defeat or hopelessness (e.g. not being able to deal with this disease anymore).			
Q28.*	I was concerned about overuse or accidental of pain killers.			
Q29.*	I was not able to control my life as I would like.			

Dimension 1. Social Impact of Endometriosis (Questions marked * are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all
1 = A little
2 = Somewhat
3 = Quite a lot
4 = Very much
9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not relevant to you)

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q30.* I reduced participation in social events like attending parties or going out with my friends.	☐	☐	☐
Q31.* I decreased my leisure activities (like hobbies or going on holidays).	☐	☐	☐
Q32.* I had problems with my relationships with other people (e.g. because of my mood swings or pain).	☐	☐	☐
Q33.* I felt isolated.	☐	☐	☐

Dimension 4. Employment and Financial Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all
1 = A little
2 = Somewhat
3 = Quite a lot
4 = Very much
9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or did not study in that time period)

If all the following questions about "Employment" are not relevant to you (never worked or did not have endometriosis when you were working) please tick the box, **answer only Question 54** and go to the next dimension. ☐

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q44. I had difficulty pursuing my preferred career.			
Q45. I experienced limitations in what I can do at work.			
Q46. I reduced my working hours.			
Q47. I took time off work.			
Q48. I experienced difficulty concentrating or focusing on my work.			
Q49. I think that I missed out on job promotions.			
Q50. I was afraid of losing my job.			
Q51. I had to change or give up my job.			
Q52. I had a reduction in my income.			
Q53. I felt that I was unable to reach my career goals.			
Q54. I experienced financial hardship (due to the cost of diagnosis or treatment medications, surgery, infertility or lost job opportunities).			

Dimension 5. Educational Impact of Endometriosis

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all
1 = A little
2 = Somewhat
3 = Quite a lot
4 = Very much
9 =Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or did not study in that time period)

If all the following questions about "Educational Impact" are not relevant to you (did not have endometriosis when you were at school/university) please tick the box and go to the next dimension. ☐

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q55. I took time off school/studies.	☐	☐	☐
Q56. I experienced difficulty concentrating or focusing on my studies.	☐	☐	☐
Q57. I did not complete my study requirements on time.	☐	☐	☐
Q58. I missed school/university exams.	☐	☐	☐
Q59. I needed more time to complete schooling/studies (e.g. extensions, re-enrolment).	☐	☐	☐
Q60. I felt that I was unable to reach my education goals.	☐	☐	☐

Dimension 6. Lifestyle Impact of Endometriosis (Questions marked * are mandatory)

Please complete questions by placing in every box the number which best describes how much endometriosis has affected your life. Please remember to put a number in all three columns.

0 = Not at all
1 = A little
2 = Somewhat
3 = Quite a lot
4 = Very much
9 = Not applicable, was not relevant to you during that time period (e.g. did not have endometriosis in that time period or question is not relevant to you)

Because of My Endometriosis:

	Last 12 months	1 to 5 years ago	More than 5 years ago
Q61.* I consumed alcohol to help me cope (e.g. with my symptoms or feelings).	☐	☐	☐
Q62.* I smoked cigarettes (tobacco) to help me cope (e.g. with my symptoms or feelings).	☐	☐	☐
Q63.* I used other illicit substances or drugs to help me cope (e.g. with my symptoms or feelings).	☐	☐	☐

Appendix C - Stellenbosch Endometriosis Quality Of Life

The Stellenbosch Endometriosis Quality of Life (SEQOL)

Description

The SEQOL is used to measure health-related quality of life in women with endometriosis. The questionnaire consists of 35 questions that cluster into 8 dimensions.

The SEQOL was developed as a Doctoral thesis and is the property of the University of Stellenbosch. Permission to make the measure available in the public domain has been granted by Innovus on behalf of the university. The measure may be referenced as follows:

Roomaney, R., Kagee, A., & Stellenbosch University. Faculty of Arts Social Sciences. Dept. of Psychology. (2017). The construction and validation of a health-related quality of life measure for women with endometriosis. Stellenbosch: Stellenbosch University.

Instructions

Below is a list of statements that other women with endometriosis have said affects their quality of life (QOL). Please indicate if these statements relate to your experience of the impact of endometriosis on your QOL.

Please circle or mark one number per line to indicate your response as it applies to the past 8 weeks. Calculate a score for each set of questions by adding the numbers that you circled. You can score the measure at different times (e.g. monthly) to monitor changes in quality of life.

Because of my endometriosis....

Psychological well-being

	Not at all	A little bit	Some what	Quite a bit	Very much
1. I was worried that my condition would get worse	1	2	3	4	5
2. I felt helpless	1	2	3	4	5
3. I felt like I am the only person with endometriosis	1	2	3	4	5
4. I was concerned about living with endometriosis for the rest of my life	1	2	3	4	5
5. I struggled to cope	1	2	3	4	5
6. I was unsure about how to manage my pain	1	2	3	4	5
7. I felt anxious about not knowing how to deal with my endometriosis	1	2	3	4	5
TOTAL					

Vitality

	Not at all	A little bit	Some what	Quite a bit	Very much
8. I experience pain all the time	1	2	3	4	5
9. My symptoms affected my day-to-day living	1	2	3	4	5
10. I had to stay in bed	1	2	3	4	5
TOTAL					

Income

	Not at all	A little bit	Some what	Quite a bit	Very much
11. I resigned/quit schooling because of my illness	1	2	3	4	5
12. I missed school/work because of my illness	1	2	3	4	5
13. I was forced to take unpaid leave because of my illness	1	2	3	4	5
14. My illness limited my ability to earn an income	1	2	3	4	5
TOTAL					

Support

	Not at all	A little bit	Some what	Quite a bit	Very much
33. I needed guidelines on how to manage my endometriosis	1	2	3	4	5
34. I needed more support	1	2	3	4	5
35. I felt the need to speak to other women with endometriosis	1	2	3	4	5
TOTAL					

Appendix D - Ryff's Psychological Wellbeing Scale

Psychological Wellbeing (18 items)

This survey accompanies a measure in the SPARQTools.org Measuring Mobility toolkit, which provides practitioners curated instruments for assessing mobility from poverty and tools for selecting the most appropriate measures for their programs.

Age: Adult

Duration: 3-5 minutes

Reading Level: 6th to 8th grade

Number of items: 18

Answer Format: 1 = strongly agree; 2 = somewhat agree; 3 = a little agree; 4 = neither agree or disagree; 5 = a little disagree; 6 = somewhat disagree; 7 = strongly disagree.

Scoring:

The Autonomy subscale items are Q15,Q17, Q18. The Environmental Mastery subscale items are Q4, Q8, Q9. The Personal Growth subscale items are Q11, Q12, Q14. The Positive Relations with Others subscale items are Q6, Q13, Q16. The Purpose in Life subscale items are Q3, Q7, Q10. The Self-Acceptance subscale items are Q1, Q2, and Q5.

Q1, Q2, Q3, Q8, Q9, Q11, Q12, Q13, Q17, and Q18 should be reverse-scored. Reverse-scored items are worded in the opposite direction of what the scale is measuring. The formula for reverse-scoring an item is: ((Number of scale points) + 1) - (Respondent's answer). For example, Q1 is a 7-point scale. If a respondent answered 3 on Q1, you would re-code their answer as: (7 + 1) - 3 = 5. In other words, you would enter a 5 for this respondents' answer to Q1. To calculate subscale scores for each participant, sum respondents' answers to each subscale's items. Higher scores mean higher levels of psychological well-being.

Sources:

Ryff, C. D., Almeida, D. M., Ayanian, J. S., Carr, D. S., Cleary, P. D., Coe, C., Williams, D. (2010). National Survey of Midlife Development in the United States (MIDUS II), 2004-2006: Documentation of psychosocial constructs and composite variables in MIDUS II Project 1. Ann Arbor, MI: Inter-university Consortium for Political and Social Research.

Ryff, C. D., & Keyes, C. L. M. (1995). The structure of psychological well-being revisited. Journal of Personality and Social Psychology, 69(4), 719–727.

Instructions: Circle one response below each statement to indicate how much you agree or disagree.

1. "I like most parts of my personality."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

2. "When I look at the story of my life, I am pleased with how things have turned out so far."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

3. "Some people wander aimlessly through life, but I am not one of them."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

4. "The demands of everyday life often get me down."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

5. "In many ways I feel disappointed about my achievements in life."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

6. "Maintaining close relationships has been difficult and frustrating for me."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

7. "I live life one day at a time and don't really think about the future."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

8. “In general, I feel I am in charge of the situation in which I live.”

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

9. “I am good at managing the responsibilities of daily life.”

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

10. “I sometimes feel as if I've done all there is to do in life.”

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

11. “For me, life has been a continuous process of learning, changing, and growth.”

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

12. “I think it is important to have new experiences that challenge how I think about myself and the world.”

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

13. “People would describe me as a giving person, willing to share my time with others.”

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

14. "I gave up trying to make big improvements or changes in my life a long time ago"

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

15. "I tend to be influenced by people with strong opinions"

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

16. "I have not experienced many warm and trusting relationships with others."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

17. "I have confidence in my own opinions, even if they are different from the way most other people think."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

18. "I judge myself by what I think is important, not by the values of what others think is important."

Strongly agree	Somewhat agree	A little agree	Neither agree nor disagree	A little disagree	Somewhat disagree	Strongly disagree

Appendix E – Ethics Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE
CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: MAPSYC-24-03**
PROJECT TITLE:	"Psychological Wellbeing among South African Women with Endometriosis: A Quantitative Study ".
INVESTIGATOR	Ismail Raeesah
SCHOOL/DEPARTMENT OF INVESTIGATOR	SHCD/Psychology
DATE CONSIDERED	10 June 2024
DECISION OF THE COMMITTEE	Approved unconditionally
RISK LEVEL	Low Risk
EXPIRY DATE	31 December 2026

ISSUE DATE OF CERTIFICATE 08 July 2024 **CHAIRPERSON** Aline Ferreira Correia
(Prof. Aline Ferreira Correia)

cc: Dr Shawn Rogers (Supervisor)

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved, I/we undertake to submit an amendment of the protocol to the Committee.

R.Ismail
Signature

09 / 07 / 2024
Date

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix F – Access Request Letter for Registrar

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG | SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

Access Request Letter

Dear Ms Potgieter,

My name is Raeesah Ismail, and I am a student currently completing my Master's in Research Psychology at the University of the Witwatersrand. As part of the requirements for my degree, I am conducting research. My research aim is to explore the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in support groups and perceived medical support), and demographics (age and socioeconomic status) on the experiences of psychological wellbeing in a sample of South African women diagnosed with endometriosis. I will be using data obtained from volunteers who are South African adults assigned female at birth, diagnosed with endometriosis by a doctor, aged between 18 and 55, the ability to complete questionnaires in English, and be willing to participate in an online study.

I am writing to please request permission to invite registered students to volunteer to participate in my study. This will entail circulating an email of which the students will be invited through an e-mail that will contain an invite with a link to the Participant Information Sheet along with the questionnaire which will be attached. Additionally, a poster will be attached using the same information from the Participant Information Sheet but slightly condensed to fit for social media usage where it will be circulated by the researcher and supervisor as well as for individuals and potential participants to circulate.

Participating in the study will require the participant to access and complete an online questionnaire at a convenient time for them. The questionnaire should take approximately 15-25 minutes to complete, and they will be asked to do this within three weeks of receiving the invitation. Participation is completely voluntary, and participants will not be advantaged or disadvantaged in any way, whether they choose to complete the questionnaires or not. They will be asked for informed consent to participate in the study at the end of the Participant Information Sheet and submission of the completed questionnaire will be regarded as consent to participate in the study. If they access the questionnaire, they will be able to choose to stop answering the questionnaire at any point before submitting their answers.

No individual identifying information, such as name or identity number, will be asked for and participants will therefore be completely anonymous. Their responses will remain strictly confidential, and their anonymity is guaranteed as no individually identifying information will be recorded in the dataset. There are no direct benefits for participating in the study. In the event that participants are concerned by any of the questions asked in the questionnaires and/or if they would like to discuss any of these further, they can contact: The South African Depression and Anxiety Group (SADAG) free 24-hour toll-free call line and query about endometriosis specific support groups:

- On 0800 567 567 or 0800 21 22 23 or 0800 12 13 14 available every day of the year, Chat with a SADAG Counsellor live via WhatsApp on 076 882 2775 from 8am to 5pm.

Participants will be able to obtain feedback for the study in the form of a summary of the general results by requesting this from the researcher; individual feedback will not be possible as the data is anonymous. You are welcome to contact me if you would like to receive this feedback as well. Data from the questionnaires will be stored securely in the form of a fully anonymised spreadsheet on password-protected computers. With permission, I and my supervisor will store the responses permanently in anonymous, electronic form to possibly use for future research projects and/or for teaching purposes. Findings from this study will be reported in a research report on the Wits E-Theses and Dissertations submitted to the University of the Witwatersrand and may be reported in academic journals and/or at conferences as well. The fully anonymised dataset may also be

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provided to other researchers or academics for verification purposes. The fully anonymized dataset may also be provided to other researchers or academics for verification and analytic purposes.

This research will help to better understand the psychological wellbeing of women with endometriosis. If you would like to be informed of the final research findings (a summary) please contact me on 2341220@students.wits.ac.za

Should you have questions or concerns about the study you may contact me or my supervisor, Dr Shawn Rogers on shawn.rogers@wits.ac.za

Ethical queries can also be directed to: The University of the Witwatersrand Human Research Ethics Committee (non-medical): 011-717-1408; email hrecnon-medical@wits.ac.za

I would be very grateful if you would please consider my request to use the email repository to invite all students to participate in the study. If you are willing to allow this, please can you provide me with permission for this in writing? The permission letter should be on your department's letterhead, signed and dated, and should specifically refer to myself by name and the title of my study. For convenience, a template that can be used for this letter is provided below.

Thank you for considering request,

Sincerely,

Raeesah Ismail

Researcher: Raeesah Ismail; cell: 0792017977; email: 2341220@students.wits.ac.za

Supervisor: Dr Shawn Rogers on shawn.rogers@wits.ac.za

Template For Permission

[Organisation/department letterhead to be added]

Date:

Dear to whom it may concern,

Re: Permission to invite participation in a research study at **[name of organization/ department to be inserted]**.

I, _____ [name and job role/ position to be inserted], as an authorised representative of [name of organisation to be inserted], do hereby give permission for **[insert name and student number of**

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PSYCHOLOGY

researcher] to approach **[insert group of people]** in order to invite them to participate in their research study on a voluntary basis as per the conditions set out in the access request letter provided to me.

Specifically, permission is granted to **[insert name of the researcher]** to **[insert specific actions needed e.g. to send an electronic invitation with online link and participant information sheet for the study to a suitable representative in the organisation to circulate to people in order to invite them to consider participating in the study on a voluntary basis]**.

[Signature and contact details of representative to be inserted]

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Appendix G – Participant Information Sheet

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

PARTICIPANT INFORMATION SHEET

Ethics clearance reference number: **MAPSYC-24-03**

2024

Dear Prospective Participant,

My name is Raeesah Ismail, and I am a student currently pursuing research with my supervisor, Dr Shawn Rogers, towards a Master's in Research Psychology at the University of the Witwatersrand. We are inviting you to participate in a study that will explore the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in support groups and perceived medical support), and demographics (age and socioeconomic status) on the experiences of psychological wellbeing in a sample of South African women diagnosed with endometriosis. I will be using data obtained from volunteers who are South African adults assigned female at birth, diagnosed with endometriosis by a doctor, aged between 18 and 55, the ability to complete questionnaires in English, and be willing to participate in an online study. If you meet these criteria, I would like to ask you to please consider participating in my study. Participating will require you to access and complete an online questionnaire at a convenient time for you. These questionnaires should take approximately 15-25 minutes to complete, and you are asked to do this within three weeks of receiving this invitation.

Can I Withdraw from This Study Even After Having Agreed to Participate?

Participating in this study is voluntary and you are under no obligation to consent to participate. You will be asked for informed consent to participate in the study at the end of this participant information sheet and submission of the completed questionnaire will be regarded as consent to participate in the study. If you access the questionnaire, you can choose to stop answering the questionnaire at any point before submitting your answers. However, it will not be possible to withdraw once you have submitted the questionnaire. No individual identifying information, such as your name or identity number, will be asked for and you will therefore be completely anonymous. Your responses will remain strictly confidential, and your anonymity is guaranteed as no individually identifying information will be recorded in the dataset and your IP address will be deleted. Results will only be accessible to me and my supervisor with permission requested to be shared with others for verification, analytic and/or publication purposes.

What Are the Potential Benefits of Taking Part in This Study?

Choosing to take part (or not) will not create any advantage or disadvantage to you and you have the right to omit/ not omit questions during the study by clicking the 'not applicable to me'. There will be no risks or direct benefits from participation. However, should you wish to know the findings from this study, my details will appear below for a summary of the results as individual feedback will not be possible as the data is anonymous.

How Will the Researcher(s) Protect the Security of Data?

Data from the questionnaires will be stored securely in the form of a fully anonymized spreadsheet on password-protected computers. With your permission, I and my supervisor would like to store your responses permanently in anonymous, electronic form to possibly use for future research projects and/or for teaching purposes. Findings from this study will be reported in a research report on the Wits E-Theses and Dissertations submitted to the University of the Witwatersrand and may be reported in academic journals and/or at conferences as well. The fully anonymized dataset may also be provided to other researchers or academics for verification and analytic purposes.

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SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

In the event that you are concerned by any of the questions asked in the questionnaires you can contact:

The South African Depression and Anxiety Group (SADAG) free 24-hour toll-free call line and query about endometriosis specific support groups:

- On 0800 567 567 or 0800 21 22 23 or 0800 12 13 14 available every day of the year, Chat with a SADAG Counsellor live via WhatsApp on 076 882 2775 from 8am to 5pm.

Has The Study Received Ethics Approval?

This study has received written approval from the University of the Witwatersrand's Human Research Ethics Committee (Non-Medical). I would like to humbly request that you circulate the invitation to participate questionnaire link for others who meet the inclusion criteria to potentially participate. A shorter invitation poster for this is attached to this link and can be used to circulate the research.

How Will I Be Informed of The Findings/Results of The Research?

This research will help to better understand the psychological wellbeing of women with endometriosis. If you would like to be informed of the final research findings (a summary) please contact Raeesah Ismail on 2341220@students.wits.ac.za

Should you have questions or concerns about the study you may contact me or my supervisor, Dr Shawn Rogers on shawn.rogers@wits.ac.za

Ethical queries can also be directed to: The University of the Witwatersrand Human Research Ethics Committee (non-medical): 011-717-1408; email hrecnon-medical@wits.ac.za

Thank you for considering participating in my research,

Sincerely,

Raeesah

Researcher: Raeesah Ismail; cell: 0792017977; email: 2341220@students.wits.ac.za

Supervisor: Dr Shawn Rogers on shawn.rogers@wits.ac.za

I have read the details of this study and consent to participate in the study on a voluntary basis. I also understand that I may withdraw at any point up to submission of the questionnaire.

YES	NO

I have read the details of this study and consent to my results being shared with others for verification, analytic and/or publication purposes.

YES	NO

Appendix H – Access Request Letter for Support Group Administrators

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SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

Access Request Letter

Dear Administrator,

My name is Raeesah Ismail, and I am a student currently completing my Master's in Research Psychology at the University of the Witwatersrand. As part of the requirements for my degree, I am conducting research. My research aim is to explore the associative and predictive relationships between delayed diagnosis, psychosocial factors (participation in support groups and perceived medical support), and demographics (age and socioeconomic status) on the experiences of psychological wellbeing in a sample of South African women diagnosed with endometriosis. I will be using data obtained from volunteers who are South African adults assigned female at birth, diagnosed with endometriosis by a doctor, aged between 18 and 55, the ability to complete questionnaires in English, and be willing to participate in an online study.

I am writing to please request permission to invite your support group members to volunteer to participate in my study. This will entail posting an invite along with a link to the Participation Information Sheet that will include the questionnaire which will be attached. Additionally, a poster will be attached using the same information from the Participant Information Sheet but slightly condensed to fit for social media usage where it will be circulated by the researcher and supervisor as well as for individuals and potential participants to circulate. Participating in the study will require the participant to access and complete an online questionnaire at a convenient time for them. The questionnaire should take approximately 15-25 minutes to complete, and they will be asked to do this within three weeks of receiving the invitation.

Participation is completely voluntary, and participants will not be advantaged or disadvantaged in any way, whether they choose to complete the questionnaires or not. They will be asked for informed consent to participate in the study at the end of the Participant Information Sheet and submission of the completed questionnaire will be regarded as consent to participate in the study. If they access the questionnaire, they will be able to choose to stop answering the questionnaire at any point before submitting their answers.

No individual identifying information, such as name or identity number, will be asked for and participants will therefore be completely anonymous. Their responses will remain strictly confidential, and their anonymity is guaranteed as no individual identifying information will be recorded in the dataset. There are no direct benefits for participating in the study. In the event that participants are concerned by any of the questions asked in the questionnaires and/or if they would like to discuss any of these further, they can contact: The South African Depression and Anxiety Group (SADAG) free 24-hour toll-free call line and query about endometriosis specific support groups:

- On 0800 567 567 or 0800 21 22 23 or 0800 12 13 14 available every day of the year, Chat with a SADAG Counsellor live via WhatsApp on 076 882 2775 from 8am to 5pm.

Participants will be able to obtain feedback for the study in the form of a summary of the general results by requesting this from the researcher; individual feedback will not be possible as the data is anonymous. You are welcome to contact me if you would like to receive this feedback as well. Data from the questionnaires will be stored securely in the form of a fully anonymised spreadsheet on password-protected computers. With permission, I and my supervisor will store the responses permanently in anonymous, electronic form to possibly use for future research projects and/or for teaching purposes. Findings from this study will be reported in a research report on the Wits E-Theses and Dissertations submitted to the University of the Witwatersrand and may be reported in academic journals and/or at conferences as well. The fully anonymised dataset may also be

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provided to other researchers or academics for verification purposes. The fully anonymized dataset may also be provided to other researchers or academics for verification and analytic purposes.

This research will help to better understand the psychological wellbeing of women with endometriosis. If you would like to be informed of the final research findings (a summary) please contact me on 2341220@students.wits.ac.za

Should you have questions or concerns about the study you may contact me or my supervisor, Dr Shawn Rogers on shawn.rogers@wits.ac.za

Ethical queries can also be directed to: The University of the Witwatersrand Human Research Ethics Committee (non-medical): 011-717-1408; email hrecnon-medical@wits.ac.za

I would be very grateful if you would please consider my request to use the email repository to invite all students and staff to participate in the study. If you are willing to allow this, please can you provide me with permission for this in writing? The permission letter should be on your department's letterhead, signed and dated, and should specifically refer to myself by name and the title of my study. For convenience, a template that can be used for this letter is provided below.

Thank you for considering participating in my research,

Sincerely,

Raeesah

Researcher: Raeesah Ismail; cell: 0792017977; email: 2341220@students.wits.ac.za

Supervisor: Dr Shawn Rogers on shawn.rogers@wits.ac.za

Template For Permission

[Organisation/department letterhead to be added]

Date:

Dear to whom it may concern,

Re: Permission to invite participation in a research study at **[name of organisation/ department to be inserted].**

I, _____ [name and job role/ position to be inserted], as an authorised representative of [name of organisation to be inserted], do hereby give permission for **[insert name and student number of researcher]** to approach **[insert group of people]** in order to invite them to participate in their research study on a voluntary basis as per the conditions set out in the access request letter provided to me.

Specifically, permission is granted to **[insert name of the researcher]** to **[insert specific actions needed e.g. to send an electronic invitation with online link and participant information sheet for the study to a suitable**

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representative in the organisation to circulate to people in order to invite them to consider participating in the study on a voluntary basis].

[Signature and contact details of representative to be inserted]

Appendix I – Social Media Poster

Appendix J – Normality Statistics

Table 3.1

Normality Statistics

Variable	Skewness	Kurtosis
PW		
Ryff PW total (OUTCOME)	.164	-.696
SEQOL PW (PREDICTOR)	-.902	-.217
EIQ Psychological Impact (PREDICTOR)	-.935	.523
Delayed Diagnosis		
Time it took to get diagnosed (PREDICTOR)	1.316	1.715
Psychosocial Factors		
Support Group Participation *(PREDICTOR)*	-.286	-.909
SEQOL Support *(PREDICTOR)*	-.601	-.847
EIQ Social Impact *(PREDICTOR)*	-.370	-.839
Medical Encounters *(PREDICTOR)*	-.510	-.827
Demographic Factors		
Socioeconomic Items (PREDICTOR)	-.484	-.532
Age (PREDICTOR)	.438	-.291
EIQ Employment and Financial Impact (PREDICTOR)	.430	-.403
EIQ Educational Impact (PREDICTOR)	.628	.400
SEQOL Income (PREDICTOR)	1.112	.207

*$p < .05$

Appendix K – Reliability Statistics

SEQOL Reliability

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
,926	,928	17

EIQ Reliability

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
,946	,945	40

Appendix L – Demographic Statistics

Table 3.1

Demographic Statistics

Variable	N	Percent (%)
Home Language		
Afrikaans	53	21.4%
English	149	60.1%
Ndebele	1	.4%
Sepedi	7	2.8%
Sotho	8	3.2%
Tswana	8	3.2%
Tsonga	3	1.2%
Other	8	3.2%
Xhosa	11	4.4%
Ethnicity		
Black	40	16.1%
Coloured	64	25.8%
Indian	42	16.9%
White	101	40.7%
Other	1	.4%
Province		
Eastern Cape	9	3.6%
Free State	6	2.4%
Gauteng	127	51.2%
Kwa-Zulu Natal	26	10.5%
Limpopo	4	1.6%
Mpumalanga	13	5.2%
North-West	7	2.8%
Northern Cape	1	.4%
Western Cape	55	22.2%

Level of Education		
Secondary	5	%
Tertiary	79	%
None	80	%
Prefer not to say	74	29.8%
Employment Status		
Employed	155	62.5%
Unemployed	56	22.6%
Entrepreneur	29	11.7%
Marital Status		
Married	120	48.4%
Single	114	46.0%
Divorced	8	3.2%
Social Class		
Lower income class	42	16.9%
Middle income class	177	71.4%
Higher income class	13	5.2%

Appendix M – Comorbid conditions

Comorbid conditions

	N	%
	62	25,0%
ADD , Anxiety and Depression	1	0,4%
adenmayosis	1	0,4%
adenomyosis	1	0,4%
Adenomyosis	3	1,2%
Adenomyosis, IBS	1	0,4%
ADHD, Depression	1	0,4%
adneomyosis, bipolar, adhd	1	0,4%
aneamia	1	0,4%
Anemia and low blood pressure	1	0,4%
Anemia, low BP and suspected IBS	1	0,4%
anxiety	1	0,4%
Anxiety, Depression, Poly Cystic Ovarian Syndrome, and Adenomyosis	1	0,4%
APS, Low blood pressure, Cholesterol	1	0,4%
arthritis, migraine	1	0,4%
asma	1	0,4%
Asmath, IBS	1	0,4%
asthma	1	0,4%
Asthma	7	2,8%
asthma , hypothyroidism, hypertension	1	0,4%
Asthma, Rheumatoid Arthritis	1	0,4%
asthma, adenomyosis, Hiatal Hernia, GERD, IBS, Depression	1	0,4%
Asthma, chronic sinusitis	1	0,4%
Asthma, gluten and dairy intolerance	1	0,4%
Asthma. Pelvic Pain	1	0,4%
Bronchitis	1	0,4%
Chronic Migraines, Fatty Liver	1	0,4%
chronic pain	1	0,4%

Chronic pain	1	0,4%
Chronic pelvic pain , irritable bowel syndrome	1	0,4%
depression	3	1,2%
Depression	2	0,8%
depression, anxiety	1	0,4%
Depression, Anxiety, ADHD	1	0,4%
Depression, Anxiety, Hypothyroidism, High blood pressure, Cholesterol	1	0,4%
depression,asthma	1	0,4%
Ehlers Danlos Syndrome, Depression, Anxiety, OCD	1	0,4%
Endometriosis of bladder, bowel, uterus , Adenomyosis , IBS , EoE, anxiety , redundant colon , gerd	1	0,4%
Epilepsy and bipolar disorder	1	0,4%
Epilepsy and Depression	1	0,4%
factor v leiden	1	0,4%
Fertility issues	1	0,4%
Fibroids	1	0,4%
fibroids, fibromyalgia, costochondritis	1	0,4%
Fibromialgia	1	0,4%
Fibromyalgia	2	0,8%
GAD, IBS, PTSD	1	0,4%
GAE	1	0,4%
Gastritis & Schizoaffective Disorder	1	0,4%
Graves Disease	1	0,4%
hernia, Barlow syndrome, depression and anxiety	1	0,4%
High bp	1	0,4%
high BP, headaches, diarrhea, constant abdominal pain	1	0,4%
High Cholesterol	1	0,4%
hyperlipidemia	1	0,4%
Hypertension	8	3,2%
hypertension, diabetes, arthritis	1	0,4%
Hypertension, high cholesterol	1	0,4%
Hypertension, irregular heart rhythm	1	0,4%
Hypo thyroid, insomnia, water retention, panic attacks	1	0,4%

Hypothyriodism	1	0,4%
hypothyroidism	2	0,8%
Hypothyroidism	2	0,8%
hypothyroidism, psoriatic arthritis, spondylitis	1	0,4%
IBS	3	1,2%
idiopathic intercranial hypertension	1	0,4%
If I had symptoms I was not aware of it and I was diagnosed within 6 months after discovering a mass on a sonar machine and lots of testing afterwards and then the operation	1	0,4%
Insulin resistance	2	0,8%
Interstitial Cystitis	1	0,4%
migraine	1	0,4%
migraines	1	0,4%
Migraines	1	0,4%
n/a	1	0,4%
N/A	1	0,4%
Na	1	0,4%
Nerve damage, colitis	1	0,4%
Nil	1	0,4%
no	12	4,8%
No	27	10,9%
No.	1	0,4%
none	2	0,8%
None	5	2,0%
Not applicable	1	0,4%
Not exactly a comorbidity, but severe anxiety	1	0,4%
OCOS, Fibroids	1	0,4%
Ovarian Cysts	1	0,4%
pcons	1	0,4%
pcos	2	0,8%
Pcos	1	0,4%
PCOS	7	2,8%
PCOS and depression	1	0,4%
PCOS, Depression	1	0,4%

PCOS, IBS	1	0,4%
Pcos, thyroid	1	0,4%
PCOS,Highblood,Cholesterol insulin resistant	1	0,4%
Pcos. Surgery in 2022 I had Endometriosis, adhesions, Fibroid on uterus and Gallbladder removed	1	0,4%
Pelvic Congestion Syndrome	1	0,4%
peptic ulcer	1	0,4%
prolactinoma	1	0,4%
Rheumatic Heart Disease, Rheumatoid Arthritis, Hypotension	1	0,4%
Rheumatoid arthritis	1	0,4%
Rheumatoid arthritis and Asthma	1	0,4%
Serve Migraine and IBS	1	0,4%
severe anaemia (due to blood loss during menses-endo bleeding related))	1	0,4%
SPD	1	0,4%
spinal nerve pain, anxiety, gluten intolerance	1	0,4%
stomach ulcer	1	0,4%
Stomach ulcers	1	0,4%
Thyroid & high blood pressure	1	0,4%
under active thyroid	1	0,4%
Uterine Abnormality	1	0,4%
weight gain, stomach/digestive issues, infertility	1	0,4%
yes, i am in peri menopause as a result of huge endometriotomas on both of my ovaries	1	0,4%
yes, SLE, Adenomyosis, EOE	1	0,4%

Appendix N – Symptom Presentation Onset

Symptom Presentation Onset

	N	%
1	1	0,4%
5	1	0,4%
8	1	0,4%
9	4	1,6%
10	3	1,2%
11	6	2,4%
12	11	4,4%
13	24	9,7%
14	28	11,3%
15	30	12,1%
16	28	11,3%
17	19	7,7%
18	9	3,6%
19	12	4,8%
20	14	5,6%
21	4	1,6%
22	2	0,8%
23	1	0,4%
24	4	1,6%

25	13	5,2%
26	3	1,2%
27	3	1,2%
28	9	3,6%
29	1	0,4%
30	2	0,8%
31	1	0,4%
32	3	1,2%
33	3	1,2%
34	3	1,2%
35	1	0,4%
38	2	0,8%
40	1	0,4%
42	1	0,4%

Appendix O - Diagnosis Method

Diagnosis Method

	N	%
Laparoscopic	191	77,0%
Verbal	57	23,0%

Appendix P – Receiving professional psychological help

Receiving professional psychological help

	N	%
No	210	84,7%
Yes	36	14,5%
Missing System	1	0,4%

Appendix Q – Ryff Psychological wellbeing subscale Results

Ryff Psychological Wellbeing Subscale Descriptives

	N	Range	Minimum	Maximum	Mean	Std. Deviation	Variance
Ryff Autonomy	248	18,00	3,00	21,00	16,0605	4,11578	16,940
Ryff environmental Mastery	248	18,00	3,00	21,00	11,7944	3,89462	15,168
Ryff Personal Growth	248	15,00	6,00	21,00	16,7339	3,43973	11,832
Ryff Positive Relations	248	18,00	3,00	21,00	13,5726	3,93813	15,509
Ryff Life Purpose	248	18,00	3,00	21,00	14,7540	4,03527	16,283
Ryff Self-Acceptance	248	18,00	3,00	21,00	13,2298	4,26543	18,194
Valid N (listwise)	248						

Appendix R: Multiple Regression Assumptions

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	16184.249	9	1798.250	8.810	<.001[b]
	Residual	48578.525	238	204.111		
	Total	64762.774	247			

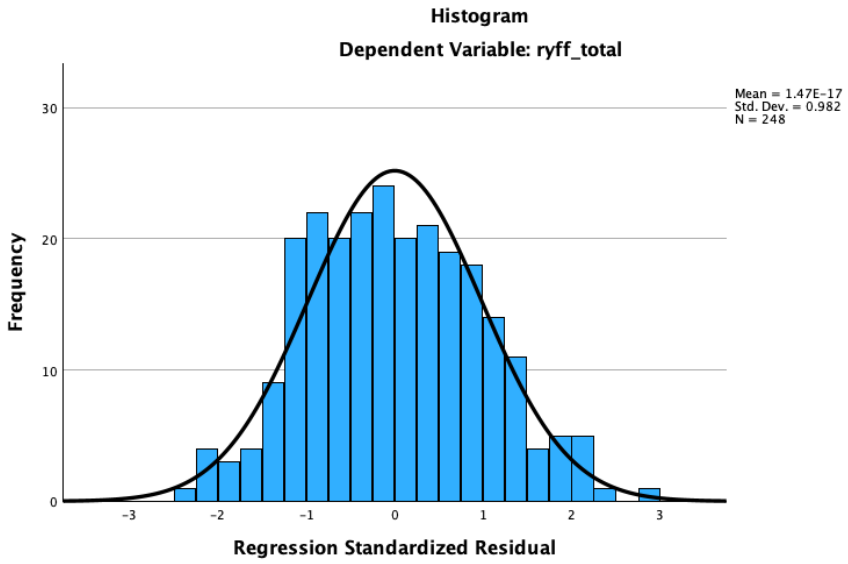
a. Dependent Variable: Ryff PW

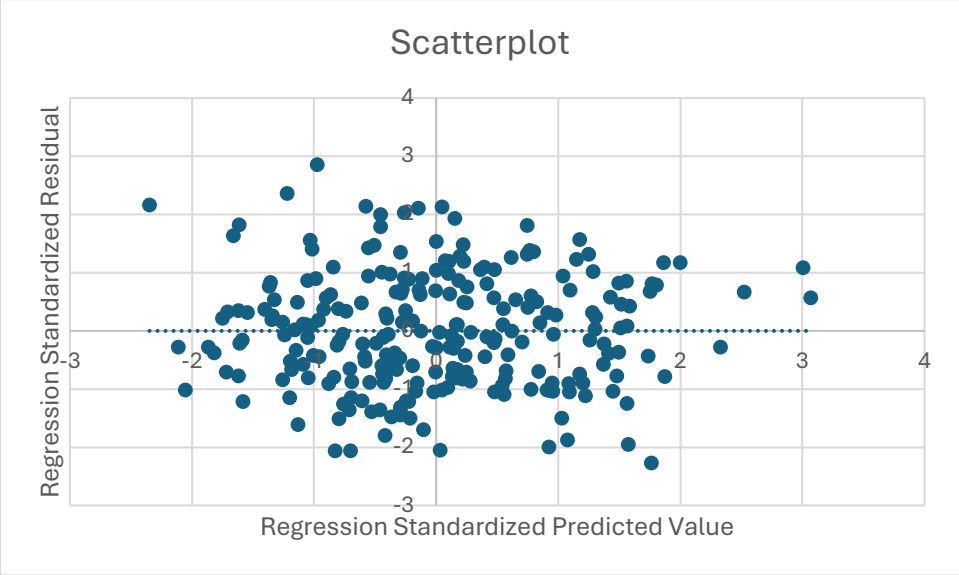
b. Predictors: (Constant), SEQOL PW, EIQ Education, PMS, SES Contextual, SEQOL Income, EIQ Social, SEQOL Support, EIQ Psychological Impact, EIQ Employment

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	67.1403	110.9972	86.1452	8.09464	248
Std. Predicted Value	-2.348	3.070	.000	1.000	248
Std Error of Predicted Value	1.274	4.728	2.793	.657	248
Adjusted Predicted Value	65.5153	110.4554	86.1337	8.13055	248
Residual	-32.42377	40.74534	.00000	14.02406	248
Std. Residual	-2.269	2.852	.000	.982	248
Stud. Residual	-2.353	2.909	.000	1.002	248
Deleted Residual	-34.85184	42.38297	.01143	14.61557	248
Stud. Deleted Residual	-2.376	2.956	.001	1.005	248
Mahal. Distance	.969	26.053	8.964	4.632	248
Cook's Distance	.000	.042	.004	.006	248
Centred Leverage Value	.004	.105	.036	.019	248

a. Dependent Variable: Ryff PW




Scatterplot
Regression Standardized Residual
Regression Standardized Predicted Value
4
3
2
1
0
-1
-2
-3
-3
-2
-1
0
1
2
3
4