

**The Impact of Surgically Diagnosed Symptomatic Endometriosis on
Women's Social Lives**

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Abstract

Endometriosis is a women's health condition affecting 1 in 10 women of reproductive age and is associated with negative physical and psychological symptoms. Endometriosis occurs where presence of endometrial-like tissue is located in places outside of the uterus, causing an inflammatory response. This study utilised a concurrent mixed method approach to address two research aims. The first aim was to investigate the impact of surgically diagnosed symptomatic endometriosis on women's social lives, specifically, family and friend relationships, work, education, attendance at social events, leisure activities and general household tasks. The second aim intended to compare clinical characteristics of the study population to normative adult populations. Participants (18-55 years; $N = 970$) completed an online survey containing demographic and open-ended questions and three short-form measures; the Depression, Anxiety, Stress Scale (DASS-21), Short-Form Endometriosis Health Profile (EHP-5) and World Health Organisation Quality of Life Scale (WHOQoL-BREF). Qualitative analysis detected negative impacts on women's social lives with few positive impacts. Quantitative analyses established a significant result ($p < 0.01$) in all subscale mean scores excluding two EHP-5 subscales, indicating that the study population is significantly different to normative adult populations demonstrating higher levels of psychological distress, lower health status and reduced quality of life.

Declaration

This thesis contains no material which has been accepted for the award of any other degree of diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made. I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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Introduction

1.1 Overview

Endometriosis is a chronic and progressive women's health condition affecting 1 in 15 women of reproductive age with new research suggesting this number could be as high as 1 in 10 (Gilmour et al, 2008; Kennedy et al, 2005; AIHW, 2019). The aetiology of endometriosis remains unknown but occurs when presence of endometrial-like tissue is located in places outside of the uterus (AIHW, 2019). Endometriosis responds to women's monthly fluctuations and triggers an inflammatory response which causes bleeding into the surrounding tissue (Gilmour et al, 2008; Kennedy et al, 2005). Endometriosis is associated with various negative physical and psychological symptoms, most commonly, chronic pain, chronic pelvic pain (CPP), dysmenorrhoea (painful periods), heavy menstrual bleeding, dyspareunia (painful intercourse), infertility and consequently mental health issues such as depression and anxiety (Culley et al., 2013). Laparoscopic surgery remains the 'gold standard' for diagnosis of endometriosis and allows for surgical confirmation of the disease (Kennedy et al, 2005). It is known that treatment of endometriosis is best conducted through a multidisciplinary and individualised approach, most commonly utilising laparoscopic ablation, extraction or therapeutic hormonal medication to reduce women's menstruation (Kennedy et al, 2005; Gilmour et al, 2008).

While endometriosis is one of the most common diseases affecting Australian women, it has long been subject to under-recognition, resulting in a significant diagnostic delay of approximately 7 years between symptom onset and surgical diagnosis (Cox et al, 2003; Endometriosis Australia, 2018; Nnhoam et al, 2011). Post-diagnosis, many women report health care providers to lack knowledge, therefore, limiting the provision of adequate support, care and information (Young et al, 2015). In July 2018, the Australian Government introduced a National Action Plan for Endometriosis whereby the Minister for Health, Honourable Greg

Hunt issued an apology on behalf of the Australian Parliament and medical system for the historic failures that endometriosis sufferers have endured (Australian Government, 2018). The plan aims to improve the quality of life for Australian women with endometriosis by contributing an additional \$1 million funding to the existing \$2.5 million Medical Research Future Fund. Endometriosis is reported to cost Australians more than \$7.7 billion in healthcare, absenteeism, lost social and economic participation (Australian Government, 2018). The plan also aims to provide greater awareness and education to health professionals highlighting the psychological, social and economic effects on women by improving access to services that are appropriate, available and accessible (Australian Government, 2018). While funding and research is necessary, historical lack of recognition and aetiology for many women has resulted in lack of validation of symptoms and a delay in targeted treatment (Rush, 2018). While funding is a step in the right direction, chronic lack of recognition and public knowledge highlighting endometriosis is likely attributable to the negative overall endometriosis experience shared by many women.

1.2 Social Lives

Strong evidence exists to suggest that social integration is fundamental to overall human health, specifically mental health (Seeman, 1996). Social life is known to encompass the various ways in which humans interact with one another within society including family and friend relationships, work, education, attendance at social events, leisure activities and general household tasks. It has been estimated that between 19 to 48 percent of women with endometriosis experience negative impacts on their social lives (Culley et al, 2013). However, another study reported that all women with symptomatic endometriosis experienced negative impacts upon their social life (Jones et al, 2004b). Evidently, the social experience varies between each individual's network of social relationships and women with a relative lack of

social interaction are associated with an increased risk for poorer health outcomes such as increased pain and psychological distress (Seeman, 1996).

Existing literature has highlighted a number of negative social experiences shared by women with symptomatic endometriosis (Denny, 2004). Reduced social participation in women with endometriosis was found to be a result of debilitating pain symptoms, the need to be nearby a lavatory and fear of symptom onset in public which left many women feeling depressed and moody (Gilmour et al, 2008; Jones et al, 2004b). Many women report issues with mobility, poor sleep and appetite all impacting upon their daily activities, with many suggesting they were unable to complete them altogether (Jones et al, 2004b). These symptoms play a crucial role in the engagement of women in daily activities including bathing, eating, drinking, walking, standing, sitting, and various household activities such as cooking, shopping and cleaning (Jones et al, 2004b). For some women, caring for their children or pets also proved problematic (Jones et al, 2004b). Women have notably expressed their need to change or cancel plans, miss out on events and for some, lack a social life at all due to their endometriosis (Young et al, 2015). Some women reported that their social lives became non-existent, attendance at social events diminished and in some cases was the cause of family and relationship break-down (Jones et al, 2004b). Feelings of social isolation have been reported among many women (Jones et al, 2004b). Three reasons have been attributed to experiences of social isolation; lack of understanding from others, fear that others thought they were 'moaning' and the link of endometriosis to menstruation suggesting they were not 'coping' as well as other women do (Jones et al, 2004b). Another qualitative study identified social isolation as a key theme but attributed this to the lack of understanding about endometriosis' natural history leading toward resigned behaviour in women and eventual social isolation (Mellado et al, 2015). In contrast, one study identified a small number of women to experience

positive social experiences resulting from their endometriosis reporting that family and friends were a good form of social support and they were 'lucky' to have them (Denny, 2004).

Additional negative social experiences for many women with endometriosis is that of intrusion or 'disruption' to their work and education (Denny, 2004; Gilmour et al, 2008). Women reportedly lose 7.41 hours of work time per week when symptoms are at their worst (Fourquet et al, 2011). Notably, women experiencing pain were required to take sick leave, were unable to perform their job in full capacities and claimed to have limitations on their employment opportunities (Denny, 2004). Echoing this finding, menstruation pain along with bowel and bladder irregularities, common symptoms of endometriosis, also made it difficult for women to function at work (Gilmour et al, 2008). With regards to education, experiences of pain and fatigue were seen to be key indicators of poor grades, inability to study and withdrawal from education (Gilmour et al, 2008). Many women have reportedly been unable to maintain full-time employment due to exceeding leave or un-supportive workplace environments which has been attributed to a lack of understanding from fellow colleagues or employers claiming their endometriosis was 'trivialised' and they were made to feel as if they needed to 'justify' themselves (Denny, 2004; Gilmour et al, 2008). Disclosure of diagnoses and symptoms was often withheld from employers, notably male employers or male dominated work environments due to the personal and gender-specific nature of endometriosis and endometriosis symptoms (Gilmour et al, 2008; Jones et al, 2004b). It appears women are also withdrawn from disclosure to employers in fear of negative repercussions such as pressure to take leave or discontinue work (Gilmour et al, 2008). In contrast to above findings, a minority of women reported experiences with supportive employers who were sympathetic and catered to their individual needs by providing social support and flexibility in hours and work arrangements (Denny, 2004). Another study found women to show signs of perseverance in their desire to 'carry on' or 'work around' their symptoms to avoid taking sick leave (Mortimer,

2002). It has also been proposed that a combination of these disruptions to work and education often resulted in feelings of guilt for many women (Jones et al, 2004b).

Evidently, endometriosis is known to impact on all facets of a woman's life and whilst an existing body of bio-medical and psychological literature highlights women's experiences with endometriosis, few have explored in-depth the impact symptomatic endometriosis has on women's social lives (Denny, 2004; Young et al, 2015). Existing qualitative literature on this topic has historically been limited to small sample sizes ranging from 15 to 29 participants and has been suggested to lack depth, rigour and robustness, as to the real lived experiences of women with endometriosis (Denny & Khan, 2006; Denny, 2004; Mellado et al, 2015). A systematic review conducted in 2015 by Young and colleagues found the experiences of women with endometriosis to inform an array of vital research but identified a gap in the literature highlighting the impact of reduced social participation in women with endometriosis (Young et al, 2015). This discovery formed the basis of the rationale of the first research aim.

1.3 Psychological Health, Health Status and Quality of Life

Pain in women with endometriosis is known to be the main predicting factor of increased psychological distress, lowered health status and reduced quality of life (QoL) in various aspects (Jones et al, 2004b; Huntington & Gilmour, 2005; Eriksen et al, 2007; Rush et al, 2018; Gao et al, 2006; Sepulcri et al, 2009). QoL is a multi-dimensional concept that encompasses the general well-being of people in society specific to their physical, psychological and social welfare (Colwell et al, 1997).

A qualitative study found all women with symptomatic endometriosis to report a negative impact on all areas of QoL including physical functioning, role performance, energy and vitality, social functioning, intercourse and emotional well-being (Jones et al, 2004b). Evidently, endometriosis is also known to impact on women's family and friends, work, education and social lives (Young et al, 2015; Jones et al, 2004b; Huntington & Gilmour,

2005). The effect of endometriosis on women's physical health is known to be substantial with QoL scores found to be similar or below those reported in women with cancer and HIV (Nnoaham et al, 2011; Rush, 2018). Existing research has associated a reduced QoL in women with endometriosis with uncertainty and unpredictability of the disease, poor treatment, reduction in everyday activities, issues surrounding fertility, work, education, poor mental health and wellbeing, poor psycho-social functioning and most commonly, pain (Culley et al, 2013). While endometriosis associated pain and infertility can negatively affect physical, psychological and social functioning, the QoL of women with endometriosis appears to be substantially dependent upon a number of other domains listed above (Jones et al, 2004b).

In addition to reduced QoL, a number of quantitative studies have indicated that women with endometriosis are subject to increased psychological distress. Findings suggest that 63.5 percent of women with endometriosis suffer with major anxiety and 32.7 percent suffer with severe depression while other studies suggest between 75 to 86 percent of women with endometriosis experience feelings of depression or anxiety some or most of the time (Sepulcri et al, 2009; Lemaire, 2004; Lorencatto et al, 2006). A comparative study attributed psychological distress in women with endometriosis to infertility, indicated by increased mental disorders and psychiatric help seeking behaviours found in infertile women compared with fertile women (Roth et al, 2001).

Research has suggested that women with endometriosis experience a significantly impaired QoL in all dimensions (Gao et al, 2006). Previously, quantitative studies have utilised an array of self-report measures to compare QoL between normative adult populations and endometriosis populations whereby findings indicate significantly impaired QoL in women with endometriosis (De Graaff et al, 2013; Aubry et al, 2017; Simoens et al, 2012; Nnoaham et al, 2011). A literature review conducted in 2013 by Culley and colleagues suggested that future QoL research take a concurrent mixed method approach utilising endometriosis-specific

measures such as the Endometriosis Health Profile-5 (EHP-5) to draw on the combined strengths of qualitative and quantitative research (Culley et al, 2013). This suggestion formed the basis of the rationale for the second research aim.

1.4 The Current Study

Evidently, existing literature has suggested that women with symptomatic endometriosis experience an array of negative impacts on their social lives, reduced QoL in various aspects and increased psychological distress (Culley et al, 2013; Eriksen et al, 2008; Huntington & Gilmour, 2005; Jones et al, 2004b). As discussed, the current study will consider recommendations from previous research to address the gap in the current literature. The first aim of this study was adopted from a gap discovered through a systematic review by Young and colleagues (Young et al, 2015). A qualitative approach was adopted to investigate the impact of surgically diagnosed symptomatic endometriosis on women's social lives, specifically, family and friend relationships, work, education, attendance at social events, leisure activities and general household tasks. The second aim of this study was adopted from a literature review by Culley and colleagues suggesting the use of a concurrent mixed method approach to assess QoL utilising endometriosis-specific measures. Therefore, a quantitative approach was adopted to compare clinical characteristics of the study population to a normative adult population on three short-form measures.

Methodology

2.1 Theoretical Framework and Study Design

Given the literature gap and restrictive sample sizes in existing literature, a concurrent mixed method approach was adopted to promote an in-depth understanding and yield rich data by drawing on the combined strengths of qualitative and quantitative research (Green & Thorogood, 2009).

Qualitative research concerns the subjective world and the ways in which humans interpret and make sense of their own reality (Denny & Khan, 2006). Therefore, the first aim of this study was to use inductive content analysis to examine in-depth the lived social experience of women with surgically diagnosed symptomatic endometriosis with particular reference to their relationships with family and friends, attendance and engagement at social events, impact on work and/ or education and engagement in leisure activities and household tasks. While the current study is informed by theories of women's experience with endometriosis, the intent was to understand in-depth their lived social experiences without assigning data to pre-determined theories. The use of an inductive approach allows for theories to emerge on their own without the need for verification of existing theories (Zhang et al, 2005). Through an inductive category development approach, the data were tentatively categorised before being step by step deduced to quantify responses (Mayring, 2000). Reoccurring themes taking the form of a single word, complete answer or direct quotation were detected and coded into positive and negative impacts. Once all responses had been coded in this way, themes of similar or identical content were merged and reduced until a succinct number of categories was established (Mayring, 2000). It should be noted that the inherent flexibility of this approach is particularly suited to studies exploring sensitive issues such as women's health issues (Dickson-Swift et al, 2008).

The second aim of this study was to compare clinical characteristics of the population to a normative adult population on three short-form measures; the Depression, Anxiety and Stress Scale-21 (DASS-21), Endometriosis Health Profile-5 (EHP-5) and the World Health Organisation Quality of Life-BREF (WHOQoL-BREF). In order to determine whether the sample mean of the study population was statistically different from a normative adult population, One Sample t Tests were conducted.

The use of a concurrent mixed method approach allowed for quantitative research to identify the impact of endometriosis on women's lives in specific areas while qualitative exploration allowed for deeper understandings through the examination of women's individualised lived experience (Denny & Khan 2006; Young et al, 2015; Denny, 2004).

2.2 Participants

A cross-sectional sampling framework was adopted. In order to be eligible, women were required to be over the age of 18, have a surgical diagnosis of symptomatic endometriosis and reside within Australia. Rationale for the criterion is as follows; firstly, it is known that the majority of women with an endometriosis diagnosis are of reproductive age (AIHW, 2019). Additionally, it is assumed that women without symptomatic endometriosis would not experience disruption to their social participation. Finally, according to Endometriosis Australia, endometriosis can currently only be diagnosed via laparoscopic surgery (Endometriosis Australia, 2019).

Due to time constraints and data saturation, qualitative data were collected for 970 participants but only analysed for the first 200 participants, meaning that further inclusion had not yielded any additional information. Quantitative data was collected and analysed for a total of 970 participants.

2.3 Measures

Once the two research aims were formulated, the survey responses were screened for unnecessary text and paraphrased into better understood common language. From the 200 participants, responses to seven individual open-ended questions were analysed, totaling 1,400 statements. A fellow independent student researcher extracted themes from 10 (5 percent) of survey responses before final result interpretation was arrived at through quantitative steps of analysis. This process improved consistency and reliability of the content analysis process through inter-rater reliability (Mayring, 2000). The presentation of the qualitative data tables

was adopted from the layout of a content analysis study conducted by Vogel and colleagues (Vogel et al, 2018).

Two areas of demographic information were gathered; demographic and clinical characteristics of participants. General demographics included age, age of symptom onset and diagnosis, marital status, sexuality, number of children, Aboriginal or Torres Strait Islander, country of birth, employment status, leave status and education type. Clinical characteristics of participants consisted of results on three short-form measures; DASS-21, EHP-5 and WHOQoL-BREF.

Initially the online survey was distributed via the student researchers' personal social media accounts including Facebook and Instagram. Through the use of tags and hashtags, a snowball sample was generated. A poster (Appendix A) was displayed within three women's health clinics in Adelaide, South Australia; Aware Women's Health, O and G and Women's Health Specialists. The ABC Riverland Radio contacted the student researcher to request and arrange an interview for their morning segment to discuss why the study was chosen, what reaction the study had received thus far and encourage listeners to participate. Endometriosis Australia shared the online survey via their Facebook and Instagram page along with a social media advertisement adapted from the poster (Appendix B). The post from Endometriosis Australia generated an overwhelming response from women and consequently, the survey was closed one week later, earlier than originally anticipated. All incomplete responses to the survey were excluded upon commencement of data analysis.

At the conclusion of the survey, participants were provided the option to leave their General Practitioner (GP) and personal details should they wish for their results on all three short-form measures (DASS-21, EHP-5 and WHOQoL-BREF) to be sent to their GP for further assessment with an attached cover letter (Appendix C). Additionally, participants were

provided the option to record their email address should they choose to receive a summary of key findings at the conclusion of the study.

2.31 Depression Anxiety Stress Scale-21 (DASS-21; Lovibond & Lovibond, 1995)

The Depression Anxiety Stress Scale-21 (DASS-21) is a short form 21-item self-report instrument designed to measure the three related negative emotional states; 'Depression', 'Anxiety' and 'Stress' (Lovibond & Lovibond, 1995). Each item is rated along a four-point Likert scale from 0 ('Never - Did not apply to me at all') to 3 ('Almost always - Applied to me very much or most of the time') in response to questions such as 'I found it hard to wind down'. Higher scores indicate higher levels of psychological distress in any or multiple of the three negative emotional states. Scores are multiplied by two to calculate the final score for each subscale, enabling comparison with normative data and clinical severity ratings (Lovibond & Lovibond, 1995). The total of these subscale scores gives a General Psychological Distress (GPD) score. The DASS-21 is known to be psychometrically sound with good reliability and validity (Oei et al, 2013).

2.32 Short-Form Endometriosis Health Profile-5 (EHP-5; Jones et al, 2004a)

The short form Endometriosis Health Profile (EHP-5) is an endometriosis-specific health-related quality of life (HRQoL) patient self-report questionnaire, used to measure the wide range of effects that endometriosis can have on women's lives. The EHP-5 is a two-part questionnaire consisting of a 5-item core regarding 'Pain', 'Control and powerlessness', 'Emotions', 'Social support', 'Self-image', and a 6-item modular regarding 'Work life', 'Relation with children', 'Sexual intercourse', 'Medical profession', 'Treatment' and 'Infertility' (Jones et al, 2001a). Participants were asked questions followed from the statement, 'During the last 4 weeks, how often, because of your endometriosis have you' such as 'Been unable to go to social events because of the pain?' or 'Felt as though your symptoms are ruling your life'. Participant response options include 'Never', 'Rarely', 'Sometimes',

'Often' or 'Always'. Each scale is then standardised on a scale of 0-100, where 0 indicates the best health status through to 100 indicating the worst health status. Scores for each scale are calculated from the total of the raw scores of each item divided by the maximum possible raw score of all the items in the scale, multiplied by 100 (Jones et al, 2001a). The EHP-5 derived from the long-form Endometriosis Health Profile-30 (EHP-30) is shorter and could fulfil a role in the evaluation of HRQoL in everyday clinical practice, demonstrates very high internal consistency and allows for a single overall QoL score to measure how endometriosis impairs daily life (Bourdel et al, 2019). The EHP-5 is known to have a 95 percent confidence interval within the scales along with significant correlations ($p < 0.01$) (Jones, et al, 2004a).

2.33 World Health Organisation Quality of Life-BREF (WHOQoL-BREF; The WHOQoL Group, 1995)

The World Health Organisation Quality of Life-BREF (WHOQoL-BREF) is a short form version of the WHOQoL comprising of 26 questions extracted from the original instrument. The questionnaire was developed to provide a short form QoL assessment for more practical use cross-culturally and measures four broad domains; 'Physical Health', 'Psychological Health', 'Social Relationships' and 'Environment' (WHO, 1996). Participants are asked how they feel about their QoL, health or other areas. Questions follow the statement; 'The following questions ask about how much have you experienced certain things in the last two weeks' such as 'To what extent do you feel that physical pain prevents you from doing what you need to do?'. Participant responses include 'Not at all', 'A little', 'A moderate amount', 'Very much', or 'An extreme amount'. Domain raw scores are calculated to transformed scores between 0-100 and scaled in a positive direction whereby higher scores denote a higher quality of life and lower scores denote a lower quality of life. The WHOQoL-BREF is known to have excellent psychometric properties indicating strong reliability and validity and an overall sound cross-cultural validity (Skevington et al, 2004).

2.34 Open-ended survey questions

Seven open-ended questions were posed to participants in order to gain a deeper understanding of the impact of symptomatic endometriosis on women's social lives. Careful consideration was given to the phrasing of questions so as to omit more in-depth responses. Questions were framed to participants as 'How has your experience with endometriosis impacted on...' your overall life, family and friend relationships, work and education, attendance at social events and engagement in leisure activities and general household tasks. Participants were encouraged to discuss the open-ended questions with as much detail as possible but also able to be open and free to write as much as they wished. Participants were also assured that any information provided would not be personally identifiable within the final thesis.

2.4 Procedure

The research study was approved by The University of Adelaide Human Research Ethics Committee (HREC) (Approval number: H-2019-097) (Appendix D). To minimise participant burden, the survey was disseminated online via SurveyMonkey at a time and place convenient to the participant (Appendix E) (SurveyMonkey Inc., 1999). Research was conducted over a five-week period, spanning 12 June 2019 to 18 July 2019.

At the outset of the survey, participants were provided a participant information sheet outlining the intent of the research and information about confidentiality and anonymity (Appendix C). While potential risks associated with the online survey were not anticipated, it was acknowledged that the nature of questions surrounding women's experience with endometriosis may cause distress. For this reason, participants were provided contact details for Lifeline, the psychosocial support agency and directed to the Endometriosis Australia support website. Contact details of the student researcher, supervisor and HREC were provided

to participants should they have any questions, concerns or complaints regarding the project. Completion and submission of the survey implied informed consent.

2.5 Analysis

Open-ended survey responses were analysed using the inductive content analysis procedure as outlined by Mayring in 2000 (Mayring, 2000). An inductive approach was used given the limited prior investigation into the impact of endometriosis on women's social participation. It is suggested that well-performed qualitative analysis develops categories to describe and explain social phenomena derived from systematically gathered data (Pope et al, 2000).

Participant results on all three measures; WHOQoL-BREF, EHP-5 and DASS-21 were analysed using SPSS (IBM SPSS Statistics Version 25 – Release 25.0.0.1). Cronbach's Alpha was calculated to test the level of internal consistency. Results of the DASS-21, EHP-5 and WHOQoL-BREF were scored accordingly and used to describe the data sample. One Sample t Tests were calculated in order to determine whether the sample mean of the study population was statistically different from normative adult populations on all three measures.

Results

3.1 Demographic Characteristics of Participants

Demographic characteristics of participants are outlined in Table 1. Of the 970 women, participants were aged between 18 and 55 with a mean age of 29 and standard deviation of 7.28. Most women received a surgical diagnosis between the ages of 18-24 while majority reported onset of symptoms below the age of 18. The largest group of women described a diagnostic delay of nine or more years. Majority of women were married or in a relationship and heterosexual. Most women did not have children. Of the 970 participants, 25 women were Aboriginal and three were Torres Strait Islander. The vast majority of women were born in Australia with others born in countries such as New Zealand, England, South Africa, United States of America and Scotland other countries. Most women were employed full-time

followed by those who were employed part-time, casually and finally, unemployed. A small number of women were on leave or undertaking other paid or unpaid work. Of the women on leave, most were on maternity leave, others were on sick leave, unpaid leave, annual leave or receiving workers compensation. A number of participants were attending some form of education institution including University, Technical and Further Education (TAFE) or other institutions.

Table 1.

Demographic characteristics of participants (N = 970)

Demographic Characteristic	M (SD)	N (%) of Participants	
Age	29 (\pm 7.28)		
Age of symptom onset Age of surgical diagnosis			
Under 18		705 (73%)	96 (10%)
18-24		169 (17%)	442 (46%)
25-34		82 (8%)	344 (35%)
35-44		13 (1%)	82 (8%)
45-54		1 (0%)	6 (1%)
Years between onset & diagnosis			
0-2		221 (23%)	
3-4		134 (14%)	
5-6		145 (15%)	
7-8		111 (11%)	
9+		350 (36%)	
Marital Status			
Married		343 (35%)	
In a relationship		414 (43%)	
Divorced		10 (1%)	
Separate but not divorced		11 (1%)	
Single		192 (20%)	
Sexuality			
Heterosexual		848 (87%)	
Bisexual		93 (10%)	
Homosexual		8 (1%)	
Other		10 (1%)	
Prefer not to say		11 (1%)	
Number of children			
0		706 (73%)	
1		115 (12%)	

2	112 (12%)
3	25 (3%)
4	11 (1%)
5+	1 (0%)
Aboriginal and Torres Strait Islander (*N = 28)	
Aboriginal	25 (3%)
Torres Strait Islander	3 (0%)
Country of birth	
Australia	881 (91%)
New Zealand	24 (2%)
England	23 (2%)
South Africa	8 (1%)
United States of America	6 (1%)
Scotland	5 (1%)
Other	23 (2%)
Employment status	
Full-time employment	416 (43%)
Part-time employment	195 (20%)
Casual employment	166 (17%)
Unemployed	124 (13%)
On leave	55 (6%)
Other work (paid or unpaid)	14 (1%)
Leave status (*N = 55)	
Maternity leave	30 (3%)
Sick leave	19 (2%)
Unpaid leave	3 (0%)
Annual leave	2 (0%)
Worker's compensation	1 (0%)
Education type (*N = 317)	
University	238 (25%)
Technical & Further Education (TAFE)	69 (7%)
Other	10 (1%)

Note.

* = Number of participants differs from 970 total

3.2 Aim 1: Investigate the impact surgically diagnosed symptomatic endometriosis has on women's social lives

The following tables provide a code, theme, direct quote example from a randomly selected participant and the number and percentage of participants who endorsed each theme.

200 responses to seven individual open-ended questions were analysed, totaling 1,400

statements. Throughout analysis of qualitative data, a total of 43 themes were generated. These themes were categorised into one of the following seven categories whereby 'P' indicates positive and 'N' signifies negative impacts on women's lives. The first category addressed the overall impact of endometriosis on women's lives (Table 2). The second category regarded the impact on social interaction with friends (Table 3). The third category focused on social interaction with family (Table 4). The fourth category concerned the impact on women's work and/ or education (Table 5). The fifth category considered the impact on women's social engagement and/ or attendance at social events (Table 6). Finally, category six concentrated on women's engagement in leisure activities (Table 7) and category seven examined their engagement in household tasks (Table 8). For ease of presentation, themes endorsed by 15 percent or more participants were included. Themes endorsed by 14 percent of participants and less are included in Appendices G through to M.

3.21 Overall impact

Among the 1,400 statements within seven categories, the most prevalent theme identified was the negative experience of physical symptoms such as pain, fatigue, heavy bleeding, infertility and weight gain, on women's overall lives (theme N1.OI). Psychological symptoms such as anxiety, depression, and mood swings were addressed by a significant number of women (theme N2.OI). 38 percent of women alluded to limitations placed upon their overall lives with regards to their abilities and functions (theme N3.OI). Many women expressed a negative impact on their work and/ or education suggesting they were unable to work or study, required a significant amount of sick leave or were subject to workplace harassment (theme N4.OI). Two themes referred to problematic relationships and relationship break-down (theme N5.OI) and issues with intimacy, libido and sexual intercourse (theme N6.OI). A number of women also voiced concern highlighting fear of infertility with a number claiming they experienced infertility or sub-fertility (theme N7.OI). Women also maintained

their endometriosis accompanied a number of social implications (theme N8.OI) with some suggesting they experienced a loss of personal identity whereby they became unrecognisable (theme N9.OI).

Table 2.

Content analysis of overall impact (N = 200)

Code	Theme	Direct Quote Example	N (%) of Participants
N1.OI	Physical symptoms	“Life is harder when you're in pain 90% of the time”	137 (69%)
N2.OI	Psychological symptoms	“It has severely impacted my mental health and resulted in anxiety and ongoing therapy”	88 (44%)
N3.OI	Limitations put on life and overall abilities and functions	“Endo has held me hostage within my own life”	75 (38%)
N4.OI	Negative impact on work and/ or education	“I reduced down to work casually and often need time off without pay”	67 (34%)
N5.OI	Problematic relationships and relationship breakdown	“My fiancée left me because I was sick all the time”	45 (23%)
N6.OI	Problems with intimacy, libido and sexual intercourse	“Sex would result in bleeding and cramping for days after”	42 (21%)
N7.OI	Infertility, sub-fertility and fear of infertility	“The fear of not being able to have children is always on my mind”	40 (20%)
N8.OI	Social implications	“Due to constant pain, I hardly socialise and feel isolated most of the time”	37 (19%)
N9.OI	Loss of personal identity	“Endo has deemed me unrecognisable”	32 (16%)

Note.

P= Positive impact

N= Negative impact

3.22 Social interaction with friends

Within the category concerning social interaction with friends, the most common theme expressed by women was a lack of understanding from family and friends (theme N1.FR), however, a number of women referred to positive support and understanding (theme P1.FR). A significant number of women suggested they were unable to interact socially due to an array

of negative physical symptoms (theme N2.FR). Some women reported loss of friendships (theme N3.FR). Many women revealed the need to cancel or rescheduling of plans or the need to leave events early (theme N4.FR). Some women also conveyed experiences of complete social withdrawal or feelings of isolation (theme N5.FR).

Table 3.

Content analysis of impact on social interaction with friends (N = 200)

Code	Theme	Direct Quote Example	N (%) of Participants
P1.FR	Understanding and support from friends	"My friends have been very supportive and understanding"	45 (23%)
N1.FR	Lack of understanding and support from friends	"I feel disconnected from them as I don't think they understand"	74 (37%)
N2.FR	Inability to attend due to physical symptoms	"Things like irregular bleeding, recovery times and bloating affect my social interaction"	58 (29%)
N3.FR	Loss of friendships	"I have lost friends because of it"	57 (29%)
N4.FR	Cancelling of plans prior or last minute and leaving early	"I've cancelled so many plans with friends due to being sick"	45 (23%)
N5.FR	Social withdrawal and isolation	"I feel isolated and alone"	38 (19%)

Note.

P= Positive impact

N= Negative impact

3.23 Social interaction with family

The majority of respondents expressed either support and understanding from family (theme P1.FA) or lack thereof (theme N1.FA). Many women also reported a tendency to withdraw or distance themselves from family relationships (theme N2.FA). A number of women suggested endometriosis had caused them to miss out on time shared with family and attendance at family functions (theme N3.FA).

Table 4.*Content analysis of impact on social interaction with family (N = 200)*

Code	Theme	Direct Quote Example	N (%) of Participants
P1.FA	Understanding and support from family	“They have been with me every step of the way and have provided me with essential support throughout the whole journey”	67 (34%)
N1.FA	Lack of understanding and support from family	“I’ve felt more isolated and detached from my family as they don’t really understand what I’m going through”	69 (35%)
N2.FA	Withdrawal and distancing from family relationships	“I have withdrawn a lot from my family”	48 (24%)
N3.FA	Missing out on family time and functions	“I can’t enjoy simple things like watching my little brothers play football”	41 (21%)

Note.

P= Positive impact

N= Negative impact

3.24 Work and education

A significant number of women expressed support and understanding from their workplace and/ or education institution (theme P1.WE) compared with a smaller number who lacked support and understanding (theme N3.WE). A number of women expressed that their endometriosis symptoms negatively impacted on their work and/ or education, claiming issues with pain, concentration, ‘brain fog’ and fatigue (theme N1.WE). A significant number of respondents referred to their use of sick leave, some suggesting they required leave without pay (theme N2.WE). Some women referred to a reduction in hours at their work and/ or education institution with some suggesting they changed from full-time to part-time (theme N4.WE). A concerning number of women claimed they had been subject to workplace harassment in the form of bullying or unfair dismissal (theme N5.WE). Some women also voiced concerns for fear of repercussions if they disclosed their endometriosis diagnosis to

their employer (theme N6.WE) while other women claimed they were unemployed due to their endometriosis (theme N7.WE).

Table 5.

Content analysis of impact on work and/ or education (N = 200)

Code	Theme	Direct Quote Example	N (%) of Participants
P1.WE	Understanding and support from employer, workplace and/ or education institution	“My boss is a fabulous woman who fully supports me”	99 (50%)
N1.WE	Physical symptoms impacting upon work and/ or education	“I find it difficult to concentrate... and am always exhausted from afternoon classes”	83 (42%)
N2.WE	Exhausting sick leave and unpaid leave	“I constantly use all my sick leave and have to take unpaid leave”	82 (41%)
N3.WE	Lack of understanding and support from employer, workplace and/ or education institution	“Nobody is understanding of endo. They think it's just an excuse”	57 (29%)
N4.WE	Reduction of work and/ or education hours (e.g. full-time to part-time)	“I've had to go part-time and I hate it”	39 (20%)
N5.WE	Workplace harassment, bullying and unfair dismissal	“I had one employer tell me that due to my health, I am on the bottom of the merit list and unlikely to have my contract renewed”	34 (17%)
N6.WE	Fear for repercussions of disclosure to employer	“I haven't told them as I feel I won't get hours”	34 (17%)
N7.WE	Unemployment due to endometriosis	“I can't work and have not worked for 12 years... because I was always in pain”	34 (17%)

Note.

P= Positive impact

N= Negative impact

3.25 Attendance and engagement in social events

A majority of women claimed they did not attend social events at all (theme N1.SE) with many claiming their attendance at social events was restricted by their endometriosis symptoms (theme N2.SE). Some women expressed their need to cancel or reschedule plans (theme N3.SE) with many voicing concerns for their fear of or sadness surrounding missing

out on social events such as birthdays and weddings due to their endometriosis (theme N4.SE). Some women said they tended to leave or want to leave social events early (theme N5.SE). Another common theme among women was the need for symptom management at social events such as medications, access to bathrooms or wheat bags (theme N6.SE).

Table 6.

Content analysis of impact on attendance and engagement in social events (N= 200)

Code	Theme	Direct Quote Example	N (%) of Participants
P1.SE	Perseverance to attend social events	"I always power through"	36 (18%)
N1.SE	Don't attend social events	"I don't attend social gatherings at all"	136 (68%)
N2.SE	Attendance and engagement is restricted by physical symptoms	"If I'm in pain I'm much more emotional and end up crying in the corner with a friend"	64 (32%)
N3.SE	Cancelling of plans prior or last minute	"I frequently have to cancel events, including my own 21 st birthday"	36 (18%)
N4.SE	Missing out and fear of missing out on social events	"I often miss out on events due to pain and heavy bleeding"	33 (17%)
N5.SE	Leave and/ or want to leave events early	"I will often have to leave early from symptoms"	33 (17%)
N6.SE	Requirement of symptom management at social events	"I generally take as many pain killers as I can safely, pop on a heat pack and head off in comfortable clothes"	29 (15%)

Note.

P= Positive impact

N= Negative impact

3.26 Engagement in leisure activities

An overwhelming majority of women referred to an inability to engage in any leisure activities due to their endometriosis physical symptoms (theme N1.LA). Some women acknowledged the benefits of physical activity for symptom relief and management (theme P1.LA). A small number of women expressed their inability to engage in team sports due to their symptoms letting the team down (theme N2.LA).

Table 7.*Content analysis of impact on engagement in leisure activities (N = 200)*

Code	Theme	Direct Quote Example	N (%) of Participants
P1.LA	Acknowledgement of importance of physical activity for symptom relief	"I use gym as my escape and therapy for my mental health"	45 (23%)
N1.LA	Inability to engage in leisure activities due to physical symptoms	"I have had to stop due to fatigue and pain"	171 (86%)
N2.LA	Inability to engage in team sports	"I can't participate in a team sport in fear of being unreliable and letting people down"	33 (17%)

Note.

P= Positive impact

N= Negative impact

3.27 Engagement in household tasks

The majority of respondents alluded to a physical inability to complete household tasks due to their endometriosis physical symptoms (theme N1.HT). A number of women spoke of their learned patience, acceptance and adaptability toward their household tasks (theme P1.HT) and others claimed to received help and support from family and friends for these tasks (theme P2.HT). Some women reported their engagement in household tasks was dependent on good and bad days (theme N2.HT). Another theme included the psychological restrictions on women's engagement in household tasks whereby they felt depressed or lacked motivation (theme N3.HT). Some women also expressed concern for the impact on their household such as the lack of maintenance and being untidy due to their inability to engage in tasks (theme N4.HT).

Table 8.*Content analysis of impact on engagement in household tasks (N = 200)*

Code	Theme	Direct Quote Example	N (%) of Participants
P1.HT	Patience, acceptance and adaptation toward inability to complete household tasks	"I've learned to work smarter, not harder"	51 (26%)

P2.HT	Support and help from family and friends	"I rely heavily on my partner to assist with household duties when I'm unwell"	29 (15%)
N1.HT	Physical inability to complete household tasks	"Fatigue and pain prevents me from being able to clean"	118 (59%)
N2.HT	Dependent on good days and bad days	"Depends on how my body and mind are coping"	35 (18%)
N3.HT	Mental inability to complete household days	"I have depression and lack motivation to do things"	32 (16%)
N4.HT	Negative impact upon household due to inability to complete household tasks	"The house is always a mess because I spend most of my time sleeping"	32 (16%)

Note.

P= Positive impact

N= Negative impact

3.3 Aim 2: Compare clinical characteristics of participants to normative adult populations on three short-form measures

Clinical characteristics were calculated for participants and compared with normative adult populations, outlined in Table 2. Results of the DASS-21, EHP-5 and WHOQoL-BREF were scored accordingly and used to describe the data sample. A Cronbach's Alpha level of .890 for this study indicates a high level of internal consistency among all three measures administered (Bonnett & Wright, 2015).

Participants reported elevated levels of depression, anxiety and stress as measured by the DASS-21. Mean scores of the participants resulted significantly higher than that of normative sample scores obtained from a general adult population. The mean total score of participants on the DASS-21 was 44.84 in comparison to 8.3 in the normative adult population (Crawford et al, 2011). The highest score among the participants was seen in the anxiety subscale with a mean of 15.48 compared with 1.74 in the normative adult population (Crawford et al, 2011).

The EHP-5 results were analysed alongside the scores of a comparable endometriosis population on the EHP-30. The comparable population were based in the UK and had surgically confirmed endometriosis and at diagnosis were symptomatic (Jones et al, 2001b).

The EHP-5 has demonstrated strong construct validity which was assessed by correlating scores between the EHP-30 and EHP-5. Results suggested high correlations for all comparisons (-0.41 to -0.73) (Jones et al, 2001b). It is therefore assumed that the EHP-5 should replicate scores obtained using the long form version of the EHP. Participants scored similar to the normative endometriosis population in a number of subscales whereby higher scores denoted a lower health status (Jones et al, 2001b). Interestingly, significantly higher scores, indicating a lower health status in the participants were found in the subscales 'Social support', 'Self-image', 'Intercourse', 'Medical profession' and 'Treatment'.

Results for the study population also indicated lower overall QoL in all four domains; Physical Health, Psychological Health, Social Relationships and Environment when compared to normative adult populations (Hawthorne et al, 2006). The lowest QoL of participants was depicted in the physical health domain with a mean score of 44.15 compared to the normative adult population of 73.5 (Hawthorne et al, 2006).

Table 9.

Clinical characteristics of participants and normative adult populations (N = 970)

Measure	Subscale	Normative <i>M</i>	Participant <i>M</i>	SD	Scale Range
DASS-21	Depression	2.57	17.4	11.81	0-42
	Anxiety	1.74	15.48	10.1	0-42
	Stress	3.99	11.96	6.33	0-24
EHP-5	Pain	52.5	53.09	23.84	0-100
	Control and powerlessness	67.5	66.93	24.33	0-100
	Emotion and well-being	50.6	63.4	28.99	0-100
	Social support	48.2	78.32	22.54	0-100
	Self-image	48.1	71.72	25.95	0-100
	Work	43.4	55.79	26.07	0-100
	Relationship with children	58.8	48.35	30.77	0-100
	Intercourse	35.2	73.68	29.31	0-100
	Medical profession	29.8	52.67	32.93	0-100
	Treatment	51.1	73.52	26	0-100
	Infertility	63.7	74.25	30.17	0-100

WHOQoL- BREF	Physical Health	73.5	44.15	19.45	0-94
	Psychological Health	73.6	45.15	18.34	0-94
	Social Relationships	71.5	48.12	22.12	0-100
	Environment	75.1	61.16	18.52	0-100

Note.

Measure abbreviations:

DASS-21: Depression, Anxiety and Stress Scale – Short Form

EHP-5: Endometriosis Health Profile – Short Form

WHOQoL-BREF: World Health Organisation Quality of Life – Short Form

Normative scores:

DASS-21: Normative sample scores from an Australian general adult population (Crawford et al, 2011)

EHP-5: Normative sample scores from an Endometriosis population (Jones et al, 2001a)

WHOQoL-BREF: Normative sample scores from an Australian general adult population (Hawthorne et al, 2006).

Interpretation:

DASS-21: Higher scores denote higher Depression, Anxiety and Stress

EHP-5: Higher scores denote lower health status

WHOQoL-BREF: Higher scores denote higher Quality of Life

Table 3 presents descriptive statistics of One Sample t Tests for women's results on all clinical subscales compared to normative adult populations. Statistically significant results were found in all subscale mean scores excluding two subscales; 'Pain' and 'Control and powerlessness' in the EHP-5. This finding allows for the conclusion that the sample mean is not equal to the normative adult populations. Therefore, the study population mean scores on all DASS-21, WHOQoL-BREF and majority EHP-5 subscales are significantly different than average scores of normative adult populations. The same conclusion cannot be drawn for the two EHP-5 subscales 'Pain' and 'Control and powerlessness' which did not result in statistical significance. This finding indicates that the study population mean scores were not significantly different from normative adult populations in the two subscales listed above.

Table 10.

Test of statistical difference between participants and normative adult population scores (N = 970)

Measure	Subscale	T-Test	Df	P-value	Mean Difference
DASS-21	Depression	39.088	969	.000	14.832

	Anxiety	42.372	969	.000	13.740
	Stress	39.215	969	.000	7.970
EHP-5	Pain	.774	969	.439	.593
	Control and powerlessness	-.726	969	.468	-.567
	Emotion and well-being	13.752	969	.000	12.802
	Social support	41.621	969	.000	30.125
	Self-image	28.352	969	.000	23.627
	Work	14.378	913	.000	12.399
	Relationship with children	-6.064	318	.000	-10.446
	Intercourse	38.764	871	.000	38.481
	Medical profession	20.639	883	.000	22.858
	Treatment	26.282	928	.000	22.420
	Infertility	10.112	835	.000	10.552
WHOQoL	Physical Health	-46.985	969	.000	-29.348
-BREF	Psychological Health	-48.581	969	.000	-28.446
	Social Relationships	-32.497	969	.000	-23.084
	Environment	-23.440	969	.000	-13.937

Note. Measure abbreviations:

DASS-21: Depression, Anxiety and Stress Scale – Short Form

EHP-5: Endometriosis Health Profile – Short Form

WHOQoL-BREF: World Health Organisation Quality of Life – Short Form

Normative scores:

DASS-21: Normative sample scores from an Australian general adult population (Crawford et al, 2011)

EHP-5: Normative sample scores from an Endometriosis population (Jones et al, 2001a)

WHOQoL-BREF: Normative sample scores from an Australian general adult population (Hawthorne et al, 2006).

Discussion

4.1 Overview

This study employed a concurrent mixed method approach to address the critical gaps in the literature regarding an in-depth understanding of women's social lives and the clinical characteristics of women with surgically diagnosed symptomatic endometriosis.

Qualitative analysis was used to address the first aim of the study; the impact of endometriosis on women's social lives with particular reference to their relationships with family and friends, attendance and engagement at social events, impact on work, education and engagement in leisure activities and household tasks. As previously indicated, the rationale

for this aim was based on the suggestion from a systematic review by Young and colleagues who found a significant gap in literature highlighting the impact of reduced social participation in women with endometriosis (Young et al, 2015). Previous studies are limited to small sample sizes and have demonstrated a lack of depth, rigour and robustness, as to the real lived experiences of women with endometriosis (Denny & Khan, 2006).

As suggested in a literature review by Culley and colleagues, the current study used a concurrent mixed method approach to assess QoL utilising an endometriosis-specific measure, the EHP-5. Quantitative analysis was employed to address the second aim of the study; comparing clinical characteristics of the participants to general adult populations on three short-form measures; the DASS-21, EHP-5 and WHOQoL-BREF. Statistical analysis was conducted to compare clinical characteristics of the population to a general adult population. These tests calculated a statistically significant result in all subscale mean scores excluding two of the EHP-5 subscales; 'Pain' and 'Control and powerlessness'. Statistical results allowed for the conclusion that normative population means were significantly different to the population mean on all three measures.

Unmistakably, women with symptomatic endometriosis face a number of challenges. Initially, research indicates that most women with endometriosis are subject to a significant diagnostic delay of approximately 7 years between symptom onset and surgical diagnosis (Cox et al, 2003; Endometriosis Australia, 2018; Nnhoam et al, 2011). The current study found 73 percent of participants reported symptom onset under the age of 18 with 36 percent of women reporting a diagnostic delay of nine or more years. Studies suggest that such a significant delay in diagnosis leads many women to feelings of frustration and isolation (Jones et al, 2004b). Women experience a combination of negative physical symptoms such as CPP, dysmenorrhoea, heavy menstrual bleeding, dyspareunia and infertility (Culley et al., 2013). Women in the current study claimed that their lives were subject to limits in their overall

abilities and functions with one woman stating endometriosis was holding her “hostage” (theme N3.OI). A number of women also claimed to have lost their personal identity with endometriosis deeming them unrecognisable (theme N9.OI). As previously suggested, women with a relative lack of social interaction are known to be associated with an increased risk for poorer health outcomes (Seeman, 1996). Therefore, combining these challenges with a widespread lack of understanding and recognition for endometriosis appears to be a stepping stone to an array of physical, psychological and social issues for many women with endometriosis.

Many women raised concerns about the impact endometriosis had on their relationships with family and friends and in particular, expressed a lack of understanding and support. As discussed, the ways in which humans interact with others is central to overall human health (Seeman, 1996). While not previously explored, a number of key themes identified relationships with family, friends and partners as ongoing challenges for women with endometriosis. Women suggested that endometriosis encompassed a range of social implications in their overall lives (theme N8.OI) and made reference to a lack of support and understanding from family (theme N1.FA) and friends (theme N1.FR) stating they experienced feelings of disconnect and detachment. A number of women also alluded to loss of friendships claiming this to be caused by their endometriosis (theme N3.RF). This lack of support and understanding may explain the tendency of women to withdraw or distance themselves from family relationships (theme N2.FA) or experience total withdrawal and isolation from social interactions with friends (theme N5.FR).

Consequently, feelings of social isolation are known to be experienced by women with symptomatic endometriosis, which has been attributed to a general lack understanding about endometriosis (Mellado et al, 2015). This knowledge ties in with findings by Jones and colleagues whereby women expressed a lack of understanding from others encompassing a fear

that they were complaining or not coping as well with menstruation as other women do (Jones et al, 2004b). A majority of women stated that they often had to cancel or leave events early due to their endometriosis symptoms while others stated that they simply did not attend social events or gatherings at all (theme N4.FR; theme N3.SE; theme N5.SE; theme N1.SE). Previous literature found women needing to frequently cancel or change plans due to their endometriosis and subsequently miss out on social events (Young et al, 2015). As formerly suggested, many women in the current study reported missing out on important events such as birthdays, weddings and even general time spent with family as a result of endometriosis symptoms (theme N3.FA; theme N4.SE).

The diminishing social lives of many women with endometriosis has previously been ascribed as the cause of family and relationship break-down (Jones et al, 2004b). In addition to a diminishing social life, 21 percent of women in the current study reported problems with intimacy, libido and sexual intercourse due to dyspareunia (theme N6.OI) alongside 20 percent of women who suffered infertility or were fearful of infertility (theme N7.OI). An earlier study found women's long term relationships to suffer due to feelings of not being a 'complete woman' due to their infertility (Jones et al, 2004b). It is possible therefore, to assume that a combination of factors listed above could contribute to the high prevalence of problematic relationships and relationship and marriage breakdown seen in respondents, one of which claimed her fiancé left her due to her endometriosis (theme N5.OI).

In addition to friend and family relationships, 38 percent of women in this study claimed endometriosis had negatively impacted upon their work and/ or education through an array of challenges (theme N4.OI). Previous literature suggested that many women were subject to unsupportive workplace environments attributable to a lack of understanding from employers and fellow colleagues (Denny, 2004; Gilmour et al, 2008). Contrary to this finding, the current study found more women (50%) to express feelings of support and understanding

from their employer, workplace and/ or education institution compared with less women (29%) who expressed a lack of support and understanding. Previous studies also found that women were unable to maintain full-time positions due to their endometriosis symptoms or un-supportive workplaces and/ or education institutions (Gilmour et al, 2008). The current study found a number of women reported negative experiences of workplace harassment, bullying and unfair dismissal (theme N5.WE) and many were unable to maintain full-time employment and consequently reduced hours or changed to part-time or casual employment (theme N4.WE) (Denny, 2004, Gilmour et al, 2008). A staggering 17 percent of women said they were unemployed due to their endometriosis (theme N7.WE). Complementary to previous findings, a number of women did not disclose their endometriosis diagnoses to their employer due to fear of repercussions (theme N6.WE) (Gilmour et al, 2008). Literature suggests that women feel embarrassed and less likely to discuss their endometriosis with employers and colleagues given it has long been associated with emotional states such as hysteria (Gilmour et al, 2008; Jones et al, 2004b). Not noted in previous studies was the finding that many women experienced financial strain due to the exhaustion of their sick leave and requirement to take unpaid leave (theme N2.WE).

Evidently, women with symptomatic endometriosis experience severe social consequences, mostly stemming from a lack of understanding and consequently, lack of support from their friends, family and in some cases, employers, workplace and education institution. One study attributed the lack of understanding in these domains to the absence of aetiology and information on endometriosis' natural history (Mellado et al, 2015). Another study found women to experience significant positive differences in attitudes with people who had an understanding of the disease (Gilmour et al, 2008). As acknowledged in the apology issued on behalf of the Australian Parliament and medical system for the historic failures that sufferers of endometriosis endured, the general lack of knowledge in society about

endometriosis has severe social implications for many women. This truly highlights the importance of an increase in awareness surrounding the disease not only among health care professionals but also within the wider community (Australian Government, 2018). Increased awareness of endometriosis within society would allow for better support for women who currently experience a lack understanding from family and friends, are unable to engage or attend social events, experience workplace or education issues and hopefully reduce the breakdown of friend and family relationships and in extreme cases, social isolation.

Previous studies exploring mental health in women with endometriosis detected a high prevalence of psychological distress, particularly depression and anxiety, comparable to that of women with HIV (Sepulcri et al, 2009; Lemaire, 2004; Lorencatto et al, 2006; Rush 2018). The current study found DASS-21 scores to be significantly higher than the normative adult population presented in Table 10, indicating a degree of psychological distress in all capacities (Crawford et al, 2011). DASS-21 mean scores for women in the current study indicated ranges of moderate depression (17.4), severe anxiety (15.48) and normal stress (11.96), all significantly elevated compared to the normative adult population. The challenge of psychological distress such as depression and anxiety, impacting on women's social lives was also detected as a reoccurring theme within qualitative analysis. Women reported psychological endometriosis symptoms as having an overall impact on their lives with one woman stating she required ongoing therapy (theme N2.OI). Psychological symptoms were also noted as a negative impact on women's ability to engage or complete household tasks which also corresponded with a lack of motivation (theme N3.HT). Quantitative findings in this study replicated those discovered in previous research while qualitative expression of psychological distress appeared confounding. Knowledge of the extent of psychological distress present in women with endometriosis demonstrates a need for consideration of psychological intervention as part of a multidisciplinary approach for women.

Pain is known to be the key predicting factor of reduced QoL and increased psychological distress in women with endometriosis (Jones et al, 2004b; Huntington & Gilmour, 2005; Eriksen et al, 2007; Rush et al, 2018; Gao et al, 2006; Sepulcri et al, 2009). QoL is known to encompass dimensions including general wellbeing, mental health and psycho-social functioning (Culley et al, 2013). WHOQoL-BREF scores within the current study indicated that women with symptomatic endometriosis experienced lower QoL in all four subscales; Physical Health, Psychological Health, Social Relationships and Environment when compared to a normative adult population (Hawthorne et al, 2006). These findings correspond with existing literature suggesting that women with endometriosis are known to experience deficits in particular facets of QoL (Nnoaham et al, 2011). In addition to WHOQoL-BREF findings, physical symptoms, most commonly, pain also presented as a key challenge and reoccurring theme for women among qualitative analysis. Among the 1,400 statements, the most frequently occurring theme concerned the impact of physical symptoms on women's social lives occurring in 69 percent of women within the overall impact category (theme N1.OI), 29 percent in the social interaction with friends category (theme N2.FR), 42 percent in the work and education category (theme N1.WE), 32 percent in the social events category (theme N2.SE), 86 percent in the leisure activity category (theme N1.LA) and 59 percent in the household tasks category (theme N1.HT). Previous research suggested that physical symptoms are significant predictors of reduced social participation and increased psychological distress in women with endometriosis (Gilmour et al, 2008; Jones et al, 2004b). Evidently, the impact of physical symptoms frequented in several categories indicating the large effect it has on women's social lives but also on QoL in multiple domains. As described as a key aim of the National Action Plan for Endometriosis, funding to improve QoL for Australian women is of utmost importance (Australian Government 2018). Knowledge of the QoL deficits within women with endometriosis allows for the increase in health professional

understandings of how the disease affects a patients QoL with an aim to improve and provide more subjective meaning to health care for all women.

In addition to increased psychological distress and reduced QoL, women in the current study were also seen to have a lower health status when compared to a normative endometriosis population. Particularly unforeseen was the finding that statistical analyses calculated statistically significant results in all EHP-5 subscale mean scores excluding 'Pain' and 'Control and powerlessness'. This finding indicated that the mean scores of the normative endometriosis population on the long-form EHP-30 differed significantly to the participants short-form EHP-5 scores. Given that higher scores in the EHP-5 and EHP-30 denote a lower health status, previous studies using the EHP-30 reported mean subscale scores ranging from 40 to 52 (Pain), 42 to 50 (Emotion and well-being), 39 to 48 (Social support) and 32 to 43 (Work) (Jones et al, 2001a; Khong et al, 2010). The scores obtained on the EHP-5 within the current study were significantly higher indicating a lower health status; 53.09 (Pain), 63.4 (Emotion and well-being), 78.32 (Social support), 55.79 (Work). Perhaps most relevant to this study is the difference in mean scores on the 'Social support' subscale indicating endometriosis had a significant impact on women's social support network in the current study compared with previous endometriosis populations (Jones et al, 2001a). Considering the criterion validity that lies between the EHP-30 and EHP-5, it was assumed that the scores would be replicable between the two and differences would not be detected. It is not known why such a significant difference was found within this study; however it could possibly be attributed to the 18 year gap between data collection in the two studies (Jones et al, 2001a). Nonetheless, EHP-5 findings clearly highlight and provide evidence of the negative impact symptomatic endometriosis has on women's health status in all facets.

Consistent with wider literature, this study found symptomatic endometriosis to have significant negative impacts on women's social lives, psychological health, QoL and health

status. Despite these overarching findings, a number of positive themes emerged throughout the qualitative content analysis process. Among existing literature, only one study made reference to women's positive social experience with endometriosis reporting that family and friends were a good form of social support (Denny, 2004). Positive experiences within the current were shared by women reporting that their family and friends had been very understanding and provided essential support throughout their endometriosis journey whether it be through encouraging them to be social, help with household tasks or just lend supportive and advice (theme P1.FR; theme P1.FA; theme P2.HT). A number of women shared experiences of supportive employers, workplaces and education institutions in response to their endometriosis with support as a central theme (theme P1.WE). Some women exhibited perseverance to attend social events such as birthdays, weddings or general functions despite their negative endometriosis symptoms such as pain and fatigue (theme P1.SE). Perseverance in these women was categorised as a positive theme due to their ability to take control of their social lives despite adversity. Additionally, a number of women acknowledged that physical activity was important for symptom relief – both physical and psychological (theme P1.LA). Despite having symptomatic endometriosis, one woman stated that attending a gym was her form of escape from endometriosis and was used as her therapy. The final positive theme detected was that of the patience, acceptance and adaptation of women's limitations within the household tasks category (theme P1.HT). While many women reported mainly negative experiences in this category, a number of women allowed themselves to be freed of the pressures to keep a tidy home. The emergence of positive themes within the study come in light of the overwhelming negative endometriosis social experience. Knowledge of the positive endometriosis experiences in women's social lives has the potential to help women maintain a positive outlook. It provides an opportunity to build on the positive experiences

shared by fellow sufferers; seeking supportive peers, perseverance, patience, acceptance, adaptation, taking control and engaging in physical activity.

4.2 Strengths

As discussed, previous qualitative research in this area of endometriosis has been subject to minimal sample sizes ranging from 15 to 29 participants, thus, restricting findings from being representative and generalisable to a wider population (Denny & Khan, 2006, Denny, 2004; Mellado et al, 2015). The current study utilised psychometrically robust measures among a sample of 970 participants, potentially increasing the generalisability of the study.

In addition to sample size, survey completion in this study was conducted entirely online, minimising participant burden and inconvenience regarding response times. While participants were guaranteed complete anonymity and confidentiality, they were also provided the option to leave their email to receive a summary sheet of key research findings and also to leave their GP details to have their test results on all three measures forwarded to their GP for further investigation.

4.3 Limitations

One limitation of this research was the absence of EHP-5 mean scores from a normative endometriosis population to use in comparison to the current study population. Normative EHP-5 scores were replaced with scores on the long-form measure, EHP-30. Despite this limitation, the EHP-5 and EHP-30 demonstrate strong construct validity (Jones et al, 2001a).

Another limitation was detected in the recruitment process whereby participants self-elected to participate in the study and were recruited mainly through social media. The population sample therefore may be subject to selection bias in the lack of consideration for women with endometriosis who do not use or have access to social media.

In addition, time restrictions and data saturation allowed for only 200 participant open-ended responses to be analysed despite collection of 970. Whilst it is believed this sample was still representative of the population, utilising all participant data may have increased generalisability.

4.4 Recommendations for Future Research

This study did not decipher between participants varying stages of endometriosis. It is thought that the various stages of endometriosis, stage 1, minimal to stage 4, severe, could possibly encompass differing experiences and symptoms for women and therefore a possibility for diverse research findings. It is suggested that future researchers take this concept into consideration.

Moreover, some researchers have suggested that a number of age-related endometriosis differences exist whereby the experience for adolescents and teens is distinct from an adult population (Gilmour et al, 2008; Culley et al, 2013; Cox et al, 2003). Research suggests that endometriosis is more common in teenagers than once thought, causing concern for implications on their future social lives as well as education and work opportunities (Gilmour et al, 2008). While the current study restricted participants to be aged 18 and above, future research is needed to assess the social impact of endometriosis specifically on adolescents and teens.

Throughout the research process, it became apparent that a number of transgender and non-binary people also suffer with symptomatic endometriosis. The current study was limited to women with surgically diagnosed symptomatic endometriosis, however, knowledge and awareness of the social experience of transgender and non-binary people is of importance for future researchers.

4.5 Implications

It is hoped that this study will add to the growing literature in this field and provides an in-depth examination into the impact surgically diagnosed symptomatic endometriosis has on women's social lives. In addition, this study aims to promote increased widespread understandings of endometriosis to lower psychological distress and health status and increase women's QoL.

Evidently, women's social lives have important implications for the clinical management of their endometriosis and should be contemplated alongside their multidisciplinary and individualised management when assessing their future support needs. Health care providers should consider women's social needs as an integral aspect to the evaluation, development and implementation of future interventions toward increasing women's QoL.

4.6 Conclusions

Surgically diagnosed symptomatic endometriosis was found to have many negative impacts and few positive impacts on women's social lives with significant psychological effects. Qualitative analysis allowed for deeper understandings of the lived endometriosis experience for women. Findings indicated that endometriosis has significant impacts on women's relationships with family and friends, attendance and engagement at social events, impact on work, education and engagement in leisure activities and household tasks. Quantitative analysis indicated that the clinical characteristics of the study population differ significantly to normative adult populations demonstrating higher levels of psychological distress, lower health status and reduced quality of life in women with surgically diagnosed symptomatic endometriosis.

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Appendix B.

Social media advertisement



The advertisement is a pink rectangular graphic with white text. At the top center is the University of Adelaide crest, with the text 'THE UNIVERSITY of ADELAIDE' below it. To the right of the crest is the text 'HREC Approval Number: H-2019-097'. The main headline is in large, bold, pink font: 'Do you have surgically diagnosed symptomatic endometriosis?'. Below this is a sub-headline in pink: 'Are you over the age of 18 and currently residing in Australia?'. The project title is in bold black: 'Project title: The Impact of Symptomatic Endometriosis on Women's Social Participation'. The text continues with: 'Endometriosis currently affects 1 in 10 Australian women of reproductive age'. 'Most common symptoms of endometriosis include chronic pelvic pain (CPP), painful periods, painful intercourse, infertility and mental health problems such as depression and anxiety'. 'For many women, these symptoms can take a toll on their social lives whether it be relationships with friends and family, attendance at social events, impact on work and/or education and engagement in leisurely activities'. 'Taking part in the 25 minute survey is entirely confidential and anonymous unless agreeable by you. The survey consists of multiple choice and short-answer questions that will tell us a little about you and your experience with endometriosis'. 'This thesis will form the basis for the degree of Bachelor of Psychological Science (Honours)'. 'Please direct any queries or concerns to the Student Researcher, Melody Mastrangelo'. There is a black redaction box below this text. At the bottom, it says 'For further information or to participate head to the link' followed by another black redaction box.


HREC Approval Number: H-2019-097
THE UNIVERSITY
of ADELAIDE

Do you have surgically diagnosed symptomatic endometriosis?

Are you over the age of 18 and currently residing in Australia?

Project title: The Impact of Symptomatic Endometriosis on Women's Social Participation

Endometriosis currently affects **1 in 10** Australian women of reproductive age

Most common **symptoms** of endometriosis include chronic pelvic pain (CPP), painful periods, painful intercourse, infertility and mental health problems such as depression and anxiety

For many women, these symptoms can take a toll on their **social lives** whether it be relationships with friends and family, attendance at social events, impact on work and/or education and engagement in leisurely activities

Taking part in the **25 minute** survey is entirely **confidential** and **anonymous** unless agreeable by you. The survey consists of **multiple choice** and **short-answer questions** that will tell us a little about you and your experience with endometriosis

This thesis will form the basis for the degree of Bachelor of Psychological Science (Honours)

Please direct any queries or concerns to the Student Researcher, Melody Mastrangelo

For further information or to participate head to the link 

Appendix D.

HREC approval

████████████████████

████ June 2019

Professor Deborah Turnbull
Psychology

Dear Professor Turnbull

ETHICS APPROVAL No: ██████████

PROJECT TITLE: The impact of symptomatic endometriosis on women's social participation

The ethics application for the above project has been reviewed by the Human Research Ethics Committee and is deemed to meet the requirements of the *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*.

You are authorised to commence your research on: 12/06/2019

The ethics expiry date for this project is: 30/06/2022

NAMED INVESTIGATORS:

Chief Investigator:	Professor Deborah Turnbull
Student - Undergraduate Bachelors Honours:	Miss Melody Georgia Mastrangelo

CONDITIONS OF APPROVAL: Thank you for your considered responses to the matters raised. The revised application provided on 05/06/19 and amended documentation provided on 12/06/19 has been approved.

Ethics approval is granted for three years and is subject to satisfactory annual reporting. The form titled Annual Report on Project Status is to be used when reporting annual progress and project completion and can be downloaded at <http://www.adelaide.edu.au/research-services/oreci/human/reporting/>. Prior to expiry, ethics approval may be extended for a further period.

Participants in the study are to be given a copy of the information sheet and the signed consent form to retain. It is also a condition of approval that you immediately report anything which might warrant review of ethical approval including:

- serious or unexpected adverse effects on participants,
- previously unforeseen events which might affect continued ethical acceptability of the project,
- proposed changes to the protocol or project investigators; and
- the project is discontinued before the expected date of completion.

Yours sincerely,

Dr Tiffany Gill
Acting Chair

The University of Adelaide



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CRICOS Provider Number 00123M

Appendix E.

Survey exported from SurveyMonkey

Social Participation in Women with Symptomatic Endometriosis Screening Questions

* 1. Are you over the age of 18?

Yes

No

* 2. Do you have a surgical diagnosis of endometriosis?

Yes

No

* 3. Does your endometriosis cause symptoms of any kind?

Yes

No

* 4. Do you currently reside within Australia?

Yes

No

* 7. The following questions ask about **how much** you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
(F1.4) To what extent do you feel that physical pain prevents you from doing what you need to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F11.3) How much do you need any medical treatment to function in your daily life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F24.2) How much do you enjoy life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F24.2) To what extent do you feel your life to be meaningful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 8. The following questions ask about **how much** you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	Extremely
(F5.3) How well are you able to concentrate?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F16.1) How safe do you feel in your daily life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
(F22.1) How healthy is your physical environment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	၅ နှစ်အောက်	၅ နှစ် - ၁၀ နှစ်	၁၀ နှစ် - ၁၅ နှစ်	၁၅ နှစ် - ၂၀ နှစ်	၂၀ နှစ်အထက်
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<p>အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p> <p>• အိမ်ထောင်ရေး</p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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* 12. The following question refers to **how often** you have felt or experienced certain things in the last two weeks.












	Never	Seldom	Quite often	Very often	Always
(F8.1) How often do you have negative feelings such as blue mood, despair, anxiety, depression?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>










































የሚከተሉትን ጉዳዮች ለሚገኙት ስኬት ደረጃዎች ለመለየት ይጠቀሙ።

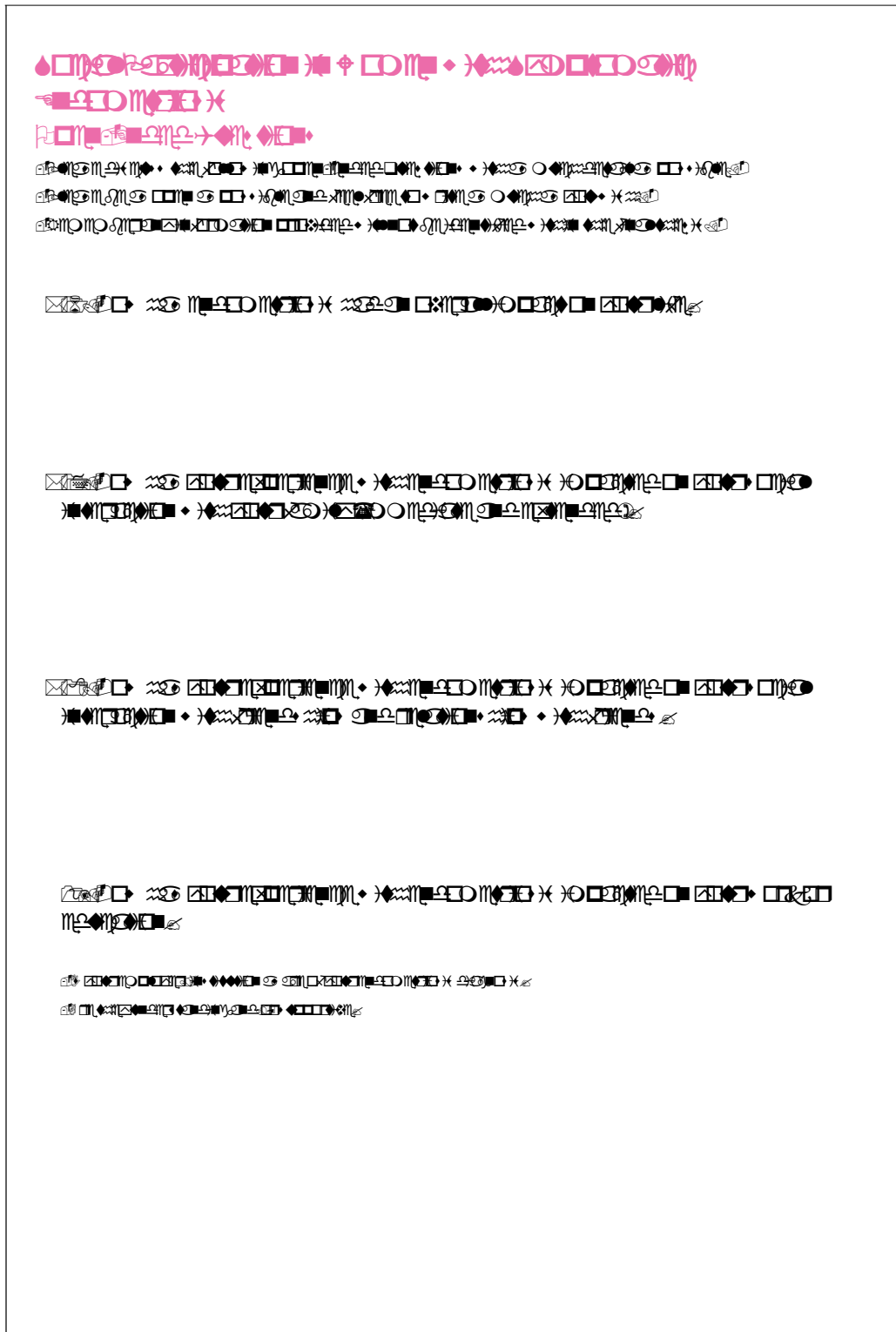
የሚከተሉትን ጉዳዮች ለመለየት ይጠቀሙ።

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የሚከተሉትን ጉዳዮች ለመለየት ይጠቀሙ።	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>  සමස්තයෙන්ම ඔබ සමූහයේ සාමාජිකයන්ගේ චර්යාවන් වෙත </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>  ඔබ සමූහයේ සාමාජිකයන් ඔබ සමූහයේ සාමාජිකයන් </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>  ඔබ සමූහයේ සාමාජිකයන් ඔබ සමූහයේ සාමාජිකයන් ඔබ සමූහයේ සාමාජිකයන් ඔබ සමූහයේ සාමාජිකයන් </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>  ඔබ සමූහයේ සාමාජිකයන් ඔබ සමූහයේ සාමාජිකයන් </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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<p>  ඔබ සමූහයේ සාමාජිකයන් ඔබ සමූහයේ සාමාජිකයන් </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>  ♦   </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>    ♦ ♦      </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>  ♦   </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>  ♦  ♦  </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>    </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>   ♦ ♦  </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>  ♦    </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>         </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>    </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>  ♦   </p>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



* 20. How has your experience with endometriosis impacted upon your attendance and engagement at social events (e.g. gatherings, parties, lunches, etc.)?

* 21. How has your experience with endometriosis impacted on your engagement in leisure activities (e.g. netball, hiking, swimming, etc.)?

* 22. How has your experience with endometriosis impacted your engagement in household tasks (e.g. cleaning, gardening, grocery shopping, etc.)?

Social Participation in Women with Symptomatic Endometriosis

Questions about you

* 23. What is your age (in years)?

* 24. What is your present marital status?

Married

Widowed

Single

Divorced

In a relationship

Separated but not divorced

Other (please specify)

* 25. What is your sexuality?

Heterosexual

Homosexual

Bisexual

Prefer not to say

Other (please specify)

* 26. Who do you currently reside with in your household?

* 27. Are you of Aboriginal or Torres Strait Islander origin?

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander

* 28. In which country were you born?

- Australia
- England
- New Zealand
- India
- Other (please specify)
- Italy
- Vietnam
- Philippines

* 29. Are you currently attending a school or any other education institution?

- No
- Yes, full-time student
- Yes, part-time student

* 30. What type of education institution are you attending?

- University or other higher education institution
- Technical or further education institution (including TAFE Colleges)
- N/A
- Other education institution (please specify)

* 35. Do you have a job of any kind?

- | | |
|---|---|
| <input type="radio"/> Yes, casually employed | <input type="radio"/> Yes, unpaid work in a family business |
| <input type="radio"/> Yes, employed part-time | <input type="radio"/> Yes, other unpaid work |
| <input type="radio"/> Yes, employed full-time | <input type="radio"/> No, do not have a job |
| <input type="radio"/> Yes, but currently on leave (please specify - e.g. annual leave, long-service leave, maternity leave, carers leave, etc.) | |

* 36. Approximately how many hours of paid work do you do per week?

- | | |
|---------------------------------------|--|
| <input type="radio"/> N/A | <input type="radio"/> 16-25 hours |
| <input type="radio"/> 5 hours or less | <input type="radio"/> 26-35 hours |
| <input type="radio"/> 5-10 hours | <input type="radio"/> 36 or more hours |
| <input type="radio"/> 11-15 hours | |

* 37. Approximately how many hours do you sleep each night?

- 4 hours or less
- 5-6 hours
- 7-8 hours
- 9+ hours

* 38. Approximately how many hours do you spend with your friends and/or family per week (e.g. gatherings, parties, lunches)

- | | |
|--------------------------------------|---------------------------------|
| <input type="radio"/> 0 hours | <input type="radio"/> 4-6 hours |
| <input type="radio"/> 1 hour or less | <input type="radio"/> 7-9 hours |
| <input type="radio"/> 1-3 hours | <input type="radio"/> 10+ hours |

* 39. Approximately how many hours do you spend at social events per week (e.g. gatherings, parties, lunches, etc.)

- | | |
|--------------------------------------|---------------------------------|
| <input type="radio"/> 0 hours | <input type="radio"/> 4-6 hours |
| <input type="radio"/> 1 hour or less | <input type="radio"/> 7-9 hours |
| <input type="radio"/> 1-3 hours | <input type="radio"/> 10+ hours |

* 40. Approximately how many hours do you engage in leisurely activities per week? (e.g. netball, hiking, swimming, etc.)

- | | |
|--------------------------------------|---------------------------------|
| <input type="radio"/> 0 hours | <input type="radio"/> 4-6 hours |
| <input type="radio"/> 1 hour or less | <input type="radio"/> 7-9 hours |
| <input type="radio"/> 1-3 hours | <input type="radio"/> 10+ hours |

* 41. Approximately how many hours do you spend doing general household tasks per week? (e.g. cleaning, gardening, cooking, grocery shopping, etc.)

- | | |
|--------------------------------------|---------------------------------|
| <input type="radio"/> 0 hours | <input type="radio"/> 4-6 hours |
| <input type="radio"/> 1 hour or less | <input type="radio"/> 7-9 hours |
| <input type="radio"/> 1-3 hours | <input type="radio"/> 10+ hours |

Social Participation in Women with Symptomatic Endometriosis

Questions about your experience with endometriosis

* 42. What symptoms do you have as a result of your endometriosis? (physical or psychological)

* 43. What treatments or surgeries have you undergone for treatment of your endometriosis (you may select more than one option)?

- Ablation laparoscopic surgery
- Extraction laparoscopic surgery
- Hysterectomy
- Hormonal contraceptives
- Other (please specify)

* 44. How many laparoscopic surgeries have you undergone for your endometriosis since diagnosis?

- None
- 1
- 2
- 3
- 4
- 5+

* 45. At what age did your onset of endometriosis symptoms occur?

- | | |
|--------------------------------|-----------------------------|
| <input type="radio"/> Under 18 | <input type="radio"/> 45-54 |
| <input type="radio"/> 18-24 | <input type="radio"/> 55-64 |
| <input type="radio"/> 25-34 | <input type="radio"/> 65+ |
| <input type="radio"/> 35-44 | |

* 46. At what age did you receive a surgical diagnosis of endometriosis?

- | | |
|--------------------------------|-----------------------------|
| <input type="radio"/> Under 18 | <input type="radio"/> 45-54 |
| <input type="radio"/> 18-24 | <input type="radio"/> 55-64 |
| <input type="radio"/> 25-34 | <input type="radio"/> 65+ |
| <input type="radio"/> 35-44 | |

* 47. From the onset of endometriosis symptoms, how long did it take to receive a surgical diagnosis of endometriosis?

- | | |
|-------------------------------|---------------------------------|
| <input type="radio"/> 0-1year | <input type="radio"/> 6 years |
| <input type="radio"/> 2 years | <input type="radio"/> 7 years |
| <input type="radio"/> 3 years | <input type="radio"/> 8 years |
| <input type="radio"/> 4 years | <input type="radio"/> 9 years |
| <input type="radio"/> 5 years | <input type="radio"/> 10+ years |

50. OPTIONAL: Participant email address

Email Address

Appendix F.

Participant information sheet

**PARTICIPANT INFORMATION SHEET**

PROJECT TITLE: The impact of symptomatic endometriosis on women's social participation

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: [REDACTED]

PRINCIPAL INVESTIGATOR: Professor Deborah Turnbull

STUDENT RESEARCHER: Melody Georgia Mastrangelo

STUDENT'S DEGREE: Bachelor of Psychological Science - Honours

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This project will examine endometriosis; a chronic condition that affects 1 in 10 women of reproductive age. Endometriosis can only be discovered through laparoscopic surgery which for many women, results in a significant delay in diagnosis. Symptoms of endometriosis can include chronic pain, infertility and mental health issues such as depression and anxiety. A considerable amount of research into women's experiences with endometriosis has focused on physical and mental health. The social impact of endometriosis however, has been very much overlooked and therefore left unexplored. The aim of this study is to gain an insight and understanding of the social experience for women with symptomatic endometriosis with regards to family and friend relationships, work and education, attendance at social events, leisure activities and general household tasks.

Who is undertaking the project?

This project is being conducted by Melody Mastrangelo. This research will form the basis for the degree of Bachelor of Psychological Science (Honours) at The University of Adelaide under the supervision of Professor Deborah Turnbull.

Why am I being invited to participate?

You are eligible to participate in this project if you:

- Are over 18 years of age
- Have a surgical diagnosis of endometriosis
- Have symptoms associated with your endometriosis
- Currently reside within Australia

What am I being invited to do?

You are being invited to complete an online survey consisting of 115 questions (multiple choice, short answer and open-ended). The survey comprises of seven sections;

1. Screening questions regarding your eligibility to participate
2. The World Health Organisation Quality of Life (WHOQoL-BREF) used to assess quality of life
3. Short-Form Endometriosis Health Profile (EHP-5) used to measure the wide range of effects that endometriosis can have on women's lives
4. Depression Anxiety Stress Scale (DASS) used to measure the three related emotional states of depression, anxiety and tension/stress
5. 6 open-ended questions asking about your overall experience of endometriosis with specific regard to the effect on your family and friend relationships, work and education, attendance at social events, leisure activities and general household tasks

6. Questions about you
7. Questions about your experience with endometriosis

How much time will my involvement in the project take?

It is estimated that involvement in the online survey will take approximately 25 minutes. The online survey can be completed in your own time at your own convenience.

Are there any risks associated with participating in this project?

Foreseeable risks for participation in this online survey are minimal. The researcher has taken into consideration the fact that living with endometriosis itself can be very distressing. Possible areas of burden include inconvenience and emotional distress. Inconvenience may be experienced by time taken to complete the online survey (approximately 25 minutes). Psychological harm may be experienced by potential feelings of distress surrounding disclosure of sensitive information about your experience with endometriosis.

If you do experience any feelings of distress, please do not hesitate to contact your GP for a referral to a Mental Health Service provider. You can also contact Lifeline Australia on 13 11 14 for 24-hour crisis support and suicide prevention or visit the following Endometriosis Australia Support Group page to find the nearest support group to you (<https://www.endometriosisaustralia.org/support-groups>).

What are the potential benefits of the research project?

The potential benefit of this study (which is by no means assured) is the potential contribution to this area of endometriosis research. Another potential benefit is information regarding access to the Endometriosis Australia Support Groups website for access to endometriosis specific support services within your State/Territory. Additionally, the option to have test results forwarded to your GP. Finally, a summary of key research findings can be sent to you at completion of the project.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you choose to participate, you can withdraw from the study at any point up until submission of the online survey.

What will happen to my information?

Confidentiality and privacy: Participation in this study is completely confidential and anonymous unless agreeable by you. Identifiable information will not be gathered at any point of this study unless agreed to by you. The researcher will take utmost care to ensure that direct quotes sourced from the survey will only be used if entirely non-identifiable. At conclusion of the survey, you will have the option to leave your name and address and the name and address of your GP to have their test results forwarded your GP. You will also be given the option to leave your email address should you be interested in the outcome of the research in order to be forwarded a summary of key research findings at completion of the project.

Storage: Data gathered from the online survey will be stored within the SurveyMonkey portal. All associated data will be stored on the Student (S) Drive, a secure password protected site only accessible by the research student and Supervisor. Data will be stored for a minimum of five years.

Publishing: The main use of this research is to form the basis for the degree of Bachelor of Psychological Science (Honours) thesis. All information and results from this project will be reported within the thesis. Should this project be of a publishable standard, it will be made publicly accessible in the form of a publication or journal article. As discussed, participation in this study maintains complete confidentiality and anonymity.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

Who do I contact if I have questions, concerns a complaint about the project?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number [REDACTED]). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (Updated 2018).

If you have questions or problems associated with your participation in the project, or wish to raise a concern or complaint about the project, you can contact the Student Researcher (Melody) on:

[REDACTED]

OR the Principal Investigator (Professor Deborah Turnbull) on:

[REDACTED]

If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

If you have read the participation information sheet and wish to participate within this study, please click 'NEXT' to begin the online survey. Completion and submission of the online survey implies full consent.

Yours sincerely,

Melody Mastrangelo
Student Researcher

Professor Deborah Turnbull
Principal Investigator

Appendix G.*Content analysis of overall impact (N = 200)*

Code	Theme	Direct Quote Example	N (%) of Participants
P1.OI	Self-kindness, positive affirmations and empowerment	"Endo has made me the woman I am"	12 (6%)
N10.OI	Loss of family and friend relationships	"My friends and family don't understand what I'm going through"	28 (14%)
N11.OI	Negative surgery experience/ impact	"My symptoms are back after less than 18 months and I am genuinely terrified"	25 (13%)
N12.OI	Financial strain	"I have to spend so much money on treatments and medications"	26 (13%)
N13.OI	Reliance on medication	"It has me bed ridden and on very strong painkillers daily"	22 (11%)
N14.OI	Desire for better widespread understandings	"I try and educate anyone and everyone"	20 (10%)
N15.OI	Problems with medical system	"The medical system has failed me"	20 (10%)
N16.OI	Concern for impact on own children	"I feel like a bad mother"	19 (10%)
N17.OI	Unpredictability of endometriosis and symptoms	"Some days you have no pain and on others you can't even move"	14 (7%)

Note.

P= Positive impact

N= Negative impact

Appendix H.*Content analysis of impact on social interaction with friends (N = 200)*

Code	Theme	Direct Quote Example	N (%) of Participants
P2.FR	Positive social experience	"Some friendships have gotten stronger"	11 (6%)
P3.FR	Newfound friendships and connections through endometriosis	"I talk a lot on Endo focused Facebook pages where women are going through similar struggles"	8 (4%)
P4.FR	Supportive partner	"My partner is amazing... he makes sure I get out every now and again"	6 (3%)
N7.FR	Fear of pain onset	"Sometimes there is a fear of pain so I just avoid it"	19 (10%)
N8.FR	Social anxiety	"I have developed social anxiety"	16 (8%)
N9.FR	Emotions with friend and family pregnancy/ies	"I have cried after finding out that a friend is pregnant"	11 (6%)

N10.FR	Missing out on events and special occasions	"I often miss out on events due to pain"	8 (4%)
N11.FR	Negative body image	"I feel uncomfortable in social settings when it comes to the way I look"	6 (3%)

Note.

P= Positive impact

N= Negative impact

Appendix I.

Content analysis of impact on social interaction with family (N = 200)

Code	Theme	Direct Quote Example	N (%) of Participants
P2.FA	The strengthening and bringing together of family	"In some ways it has brought us closer"	11 (6%)
N4.FA	Strain placed upon relationships	"I really hated myself because I wasn't happy but also because I couldn't keep my husband happy"	22 (11%)
N5.FA	Fear of feelings of being a burden on family	"I feel like a constant burden on my family"	20 (10%)
N6.FA	Feelings of guilt for family	"I often experience feelings of guilt because my husband has to pick up my slack"	14 (7%)
N7.FA	Endometriosis is hereditary	"My mum experienced endometriosis when she was my age and has been my biggest cheerleader"	11 (6%)

Note.

P= Positive impact

N= Negative impact

Appendix J.

Content analysis of impact on work and/ or education (N = 200)

Code	Theme	Direct Quote Example	N (%) of Participants
P2.WE	Perseverance to attend work and/ or education institution	"If I don't work, I don't get paid so I just push through the pain"	18 (9%)
N8.WE	Pain management at work	"I am able to perform while under the effect of high dose pain relief"	23 (12%)

N9.WE	Awkwardness with male employer and/ or workplace	“It is awkward because my management is made up of males... they don't understand or know how to support me in the work place”	16 (8%)
N10.WE	Financial strain and instability	“My sick leave always runs out... then I have to use leave without pay... that puts a lot of pressure on me”	16 (8%)

Note.

P= Positive impact

N= Negative impact

Appendix K.

Content analysis of impact on attendance and engagement in social events (N= 200)

Code	Theme	Direct Quote Example	N (%) of Participants
N7.SE	Social anxiety and fear of social events	“Sometimes I've had to leave early due to my anxiety”	27 (14%)
N8.SE	Fear of unpredictable symptoms	“I get anxious about having a 'flare-up' and not being able to leave or access things that would help soothe the pain”	25 (13%)
N9.SE	'Flare-up' due to alcohol and food consumption	“I don't ever consume alcohol or any unusual or new food that might set off cramping”	21 (11%)

Note.

P= Positive impact

N= Negative impact

Appendix L.

Content analysis of impact on engagement in leisure activities (N = 200)

Code	Theme	Direct Quote Example	N (%) of Participants
P1.LA	Adaptability of physical activity depending on pain and/ or period	“I just make adjustments on days where I am in pain”	23 (12%)
P2.LA	Perseverance to engage in leisure activities	“It's made sport harder but it feels good when I push through”	26 (13%)
N4.LA	Inability to engage in leisure activities due to psychological health	“Often too fatigued to engage in leisure activities, especially while I have my period”	23 (12%)

N5.LA	Lack of motivation to engage in leisure activities	"I have lost motivation to continue trying"	20 (10%)
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Note.

P= Positive impact

N= Negative impact

Appendix M.

Content analysis of impact on engagement in household tasks (N = 200)

Code	Theme	Direct Quote Example	N (%) of Participants
P3.HT	Outsourcing of household tasks (e.g. cleaner, gardener and online grocery shopping)	"I order online, hire a gardener and cleaner for things I cannot do"	17 (9%)

Note.

P= Positive impact

N= Negative impact