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Impact of Coping Strategies on Quality of Life of Adolescents and Young Women with Endometriosis

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Abstract

PURPOSE: Endometriosis is a hormone-dependent, inflammatory, painful condition affecting 1 in 10 women during their reproductive years. The symptoms of endometriosis—dysmenorrhea, dyspareunia, infertility—negatively impact the quality of life (QoL) of the affected women. Few studies have been conducted on mental health and QoL impact in a younger endometriosis patient population (adolescents and young women). This study quantitative, cross-sectional study was designed to address this gap by ascertaining whether coping strategies may impact the QoL of this patient population.

METHODS: After consent, participants (n=24) completed a sociodemographic questionnaire, Beck Anxiety Inventory (BAI), Beck Depression Inventory II (BDI-II), Coping Strategies Inventory (CSI), Endometriosis Health Patient-5 (EHP-5), and Visual Analogue Scale (VAS).

RESULTS: Participants reported the use of both positive and maladaptive strategies to deal with the symptomatology, which were associated with QoL levels and mental health status. Associations between QoL and maladaptive coping strategies (*e.g.*, autocriticism, social withdrawal) were uncovered. Cognitive restructuring was identified as an adaptive coping strategy that impacts QoL positively.

CONCLUSIONS: These results provide additional evidence showing that endometriosis symptoms substantially affect the psychological well-being of young patients and identify opportunities for interventions (*e.g.*, cognitive behavioral, rational/emotive therapy) to implement coping styles leading to improved QoL.

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DECLARATION OF INTERESTS

The authors declare no conflicts of interest.

Keywords

Endometriosis; Adolescents; Young adults; Quality of life; Pelvic Pain; Coping; Depression; Anxiety

INTRODUCTION

Endometriosis is a gynecological disease that causes, dysmenorrhea, chronic pelvic pain, dyspareunia, and often infertility to 1 in 10 adolescents and women of reproductive age (1, 2). Endometriosis is a very common women's health problem affecting an estimated 176 million women and teens affected (3), occurring in adolescents and girls as young as 8 years of age. In addition, there have been documented cases of endometriosis occurring prior to menarche (4–6). Many women with endometriosis report that their symptoms begin during their adolescent years although are not diagnosed with endometriosis by laparoscopy until years later (7). Endometriosis symptoms, primarily the chronic, severe pelvic pain that is often refractory to available therapies, impacts all biopsychosocial aspects of the patients' lives (8–10). There is ample qualitative and quantitative evidence that the symptoms of endometriosis represent a great source of stress and cause substantial negative impact on psychological parameters and quality of life (QoL) for the adult patient (9–17).

It has been proposed that psychological and emotional distress resulting from endometriosis symptoms (e.g., chronic pelvic pain (CPP) and infertility) may influence the perception of pain in these patients, who also present high rates of somatization, anxiety and depression (18). There is evidence that pelvic pain is the main driver of depressive symptoms; however, it is also possible that the presence of a mental health condition increases the perception of pain (19, 20). Because the personal experience of pelvic pain impacts emotional functioning, and high levels of anxiety and depression can magnify the pain severity, it is important to better understand their interplay if we are to offer these patients real solutions.

For young women and adolescents with endometriosis, who are going through many physical, hormonal and emotional changes related to their development, this crucial time of their lives can be negatively impacted by being diagnosed with a chronic, enigmatic, and painful illness such as endometriosis (21, 22). The physical and psychological impact of symptoms, often severe and unpredictable, at a time in life when self-esteem, social involvement, school attendance, and performance are critical for this patient population, can lead to the development of serious emotional issues and cause long-term effects in their psychological well-being (23). Increased emotional vulnerability leads to difficulties to cope with the illness, causing increased frustration, anger, and depression as patients experience a lack of understanding of their condition (12, 13). For young women and adolescents, this is complicated by the facts that the diagnostic process can be prolonged over several years and there are fewer options of medical treatments, and by preoccupations about the long-term impact on their studies and professional development, personal relationships, and future fertility (7, 24).

Coping strategies can be categorized as either ineffective (maladaptive) or effective (adaptive) in managing stressful life events. Maladaptive coping strategies may lead to

deleterious effects such as emotional distress, whereas adaptive strategies usually result in successful resolution and appropriate management of the situation (25). In the particular case of dealing with symptoms of a chronic and painful disease it has been shown that the adaptive coping strategy known as ‘problem-focused’ can be correlated with quality of life and symptom presentation (26). Individuals are more successful at coping when they deal effectively with life changes and stressful situations (27). This presents the opportunity for helping patients cope well with symptoms by providing the right tools to deal with the stress related to complex diagnoses. Having a good knowledge base and understanding of their disease is most important for patients to regain some control of their health; more patient control is associated to improved health outcomes (28). There is evidence that emotional strength and positive adaptation attitudes produce benefits in psychosocial aspects of adult women living with chronic conditions, including changing old beliefs about pain, increased self-esteem and improvements in QoL (29); however, the symptoms and experiences that are relevant to an adolescent and young adult population could be different to those of adults (30, 31). The psychosocial impact of endometriosis symptoms in young women is not fully understood since few studies have examined the possible association of coping strategies, mental health and QoL on a young female population affected by painful symptoms (8, 32).

Thus, in order to address this gap in knowledge we aimed to ascertain the commonly used strategies used by teens and young adult women to cope with endometriosis symptoms, and to assess whether coping strategies may impact the QoL of this patient population through a quantitative, cross-sectional study.

METHODS

Study subjects

Potential participants, adolescents/young women 13 to 25 years old with surgical diagnosis who participated in the “EndoTeens” initiative, an educational/focus group program organized by the patient support organization (the “Fundación Puertorriqueña de Pacientes con Endometriosis, Inc. or ENDOPR”) were invited to participate in this study. The EndoTeens initiative consisted of a year-long program of lectures and workshops on topics relevant to adolescents and young women. Participants also completed questionnaires on mental health, physical health and general wellbeing. In addition, a recruitment flyer and information about the study was sent through the ENDOPR mail listing, web page (www.endometriosispr.com), and social media (Facebook group: “Endometriosis Puerto Rico”). Participants signed a consent form and/or an assent form (if younger than 21, the legal adult age in Puerto Rico). For those considered minors, a consent form signed by their parents. Out of 30 individuals who consented for participation and received the survey packet, a total of 24 completed the questionnaires, for a 80% response rate. Questionnaires were completed either in person during these educational activities or by mail. All completed questionnaires were coded with an ID# assigned to each subject to protect their identity. This study was conducted after protocol approval by the Ponce Health Sciences University Institutional Review Board (IRB (Protocol number 120412-IF).

Instruments

Sociodemographic/clinical history—A general health survey was administered to obtain socio-demographic data, as well as clinical (e.g., symptoms, medications), gynecological, risk factors, and contact information.

Beck Anxiety Inventory (BAI)—The Beck Anxiety Inventory (BAI) is a multiple-choice self-report inventory that measures the severity of an anxiety in adults and adolescents (33). It consists of 21 items that are rated on a scale from 0 to 3. Each item is descriptive of subjective, somatic, or panic-related symptoms of anxiety. Each of the items on the BAI is a simple description of a symptom of anxiety in one of its four expressed aspects: subjective (e.g., “unable to relax”), neurophysiologic (e.g., “numbness or tingling”), autonomic (e.g., “feeling hot”) or panic-related (e.g., “fear of losing control”). Each symptom item has four possible answer choices: Not at All = 0; Mildly = 1; Moderately = 2; Severely = 3. The clinician assigns the following values to each response: Not at All = 0; Mildly = 1; Moderately = 2, and; Severely = 3. The values for each item are summed yielding an overall or total score for all 21 symptoms that can range between 0 and 63 points. A total score of 0 – 7 is interpreted as a “Minimal” level of anxiety; 8 – 15 as “Mild”; 16 – 25 as “Moderate”, and; 26 – 63 as “Severe”. The **BAI** internal consistency (Cronbach’s alpha) ranges from .92 to .94 for adults and test-retest (one week interval) reliability are .75. The BAI has also been shown to possess acceptable reliability and convergent and discriminate validity for both 14–18 year and inpatients and outpatients population.

Beck Depression Inventory II (BDI-II)—The BDI-II (34) consists of 21 items rated on a 4 point rating from 0 to 3 to assess the severity of depression in adults and adolescents. A total score is obtained by summing the ratings given by the test taker on all items. Interpretation is based on the total score that can range from 0–63. Scores in the 0–9, 10–16, 17–29 and 30–63 indicate depression levels that are ‘Minimal’, ‘Mild’, ‘Moderate’, or ‘Severe’, respectively. The BDI-II has demonstrated excellent test-retest reliability, high internal consistency and moderate to high convergent validity(35). Alpha reliability coefficients range from .79 to .90.

Coping Strategies Inventory (CSI)—The CSI assesses the ability to cope with stress and difficulties (36, 37). The scale contains 40 items with a 5-point Likert response format and the level of measurement is ordinal. The CSI has a hierarchical structure made up of eight primary strategies (Problem solving, Cognitive restructuring, Social support, Express emotions, Problem avoidance, Wishful thinking, Social withdrawal and Self-criticism), four secondary and two tertiary ones. Secondary scales come from the empiric grouping of the primary ones; tertiary scales arising from the empiric grouping of the secondary ones. The alpha coefficients of the CSI are between 0.63 and 0.89(36).

Endometriosis Health Patient-5 (EHP-5)—The EHP-5 is a validated instrument to measure domains of endometriosis-related QoL: illness, independent living, and physical ability, psychological state and social interaction (38, 39). This questionnaire consists of 2 questions that assess whether and how much symptoms of endometriosis interfere with work and daily activities during the past 4 weeks. However, for this study we focused in the first

session (questions 1a through 1f) to assess QoL. The impact of endometriosis in activity impairments, mood and appearance changes, perception that others do not understand and feelings that pain control's one's life were assessed. Items were scored from 0–4 (Likert Format) with higher scores (3–4) indicative of worse health related QoL or high impact.

Visual Analogue Scale (VAS)—The Visual Analogue Scale (VAS) measures a characteristic or attitude that is believed to range across a continuum of values and cannot easily be directly measured (40). It is commonly used to estimate the amount of pain felt, with scores that range across a continuum from no pain (0) to an extreme amount of pain, the worst imaginable pain (10). The VAS is a valid and reliable measure of chronic pain intensity in general that has been previously used specifically for endometriosis pain (41, 42).

Statistical Analyses

Data collected was entered into Excel and analyzed using the Statistical Package for Social Sciences (SPSS v.20). The main statistical analyses performed included descriptive statistics for each variable (frequency distribution, measures of central tendency and measures of variability). Pearson product-moment correlation coefficient was conducted to investigate the relationship between Impact of Endometriosis, Pain, Anxiety, Depression, Coping Strategies, and QoL using SPSS Version 20 for testing whether two variables are linearly related in some population. Each variable in this study was correlated with each of the other values, which allowed the researchers to see which pairs have a positive or negative correlation. A statistically significant correlation was indicated by a probability value of less than 0.05.

RESULTS

All study protocols and materials were approved by the PHSU IRB Committee. All study participants read and signed an assent form or an informed consent form prior to answering the questionnaires.

Patient characteristics

Of the 30 participants consented, 24 completed the questionnaires. No reminders were sent, and no incentives were given for completing the questionnaires. In the 24 questionnaire packets received there was no missing data. Table 1 summarizes the demographic characteristics of the study participants (N=24). All participants were considered adolescents (32.5%) or young women (62.5%). Half of the participants were married and 71% were already enrolled in college (undergraduate or graduate level). All but one participant had health insurance. Most of the participants did not exercise (66.7%) and the majority (95.8%) were non-smokers.

All the participants suffered pelvic pain, with the majority (75%) reporting always having dysmenorrhea (Table 2). More than half (58%) indicated that they suffered pain during or after intercourse. Almost all (92%) reported that pain affected their daily life. All participants reported other medical conditions including ovarian cysts, chronic pelvic pain

and migraines. The majority (71%) reported that the age at onset of symptoms of endometriosis was between 13 and 17 years old. The VAS scores indicate that all the participants suffered from pelvic pain, with the overwhelming majority (n=19; 79%) reporting severe menstrual pain of 7–10.

Impact of the endometriosis symptoms on QoL

Endometriosis-related QoL was measured using the EHP-5 as described previously (10, 43). All but one young woman with endometriosis report difficulty walking and feeling that pain controlled her life. Half of the participants indicated that endometriosis symptoms substantially interfere with tasks performed at work and school and causes mood changes. Overall, these results show that endometriosis symptoms exert a negative impact on their emotions and well-being, specifically in domains related to performance at work/study, perception that pain controls life, mood changes, feeling of others not understanding) in approximately half of the patients in the study (Table 3).

Levels of Anxiety and Depression Measured by BAI and BDI-II

Most participants reported at least mild anxiety (>79%) and depression (>54%). Almost half (45.8%) had moderate-severe levels of anxiety, and a third (33.4%) had moderate-severe levels of depression.

Correlations between psychological wellbeing, pain and endometriosis-related QoL

QoL scores measured by EHP-5 were positively correlated with anxiety, depression, but not with pain levels (measured by VAS) (Table 4). Depression and anxiety scores were also significantly correlated.

Correlations between coping strategies and endometriosis-related QoL

We observed significant correlations between low QoL scores and coping strategies including Autocriticism (positive), Emotion expression (negative), Social support (negative), Cognitive restructuring (negative), and Social withdraw (negative). Across the board, Autocriticism was the coping strategy more strongly associated with substantial and negative impact on most of the QoL domains assessed (Table 5). In addition, Social Withdraw scores correlated with impact on work/school performance, mood and physical changes, and feelings of being misunderstood. Cognitive Restructuring was correlated with Work/study impact, Physical deficiencies, Activity impairment, and Mood changes. Significant negative correlations were observed also between Express Emotion and Work/study impairments. Correlations between Social support and QoL scores were also observed (negative for impact on work/study and positive for severe incapacitating pain).

DISCUSSION

The main aims of this study were i) to explore if endometriosis symptoms impact health related QoL and psychological wellbeing of a population of adolescents and young adult women diagnosed with this condition, and ii) to test the hypothesis that low QoL scores and poor psychological health could be associated with coping mechanisms. The results of this study support our hypothesis: subjects reported high levels of depression and anxiety, which

appeared to directly affect their QoL, as shown previously in adult patient populations, and the use of maladaptive coping strategies were correlated with poor QoL scores. To our knowledge, few studies have been conducted in younger women with endometriosis to assess impact of coping on QoL. Epidemiological surveys have shown that young patients with a chronic illness are at a significantly greater risk than healthy peers to develop behavioral and emotional problems (44). Given the lack of effective therapies for endometriosis and the high likelihood that symptoms will become chronic and progressively debilitating if left untreated, it is imperative that patients are coached on the use of adaptive coping strategies to limit the impact on their emotional distress and mental health status promptly after symptom onset.

Most of the participants in this study reported severe menstrual pain and many reported high rates of anxiety and depression and poor QoL that could be ascribed to their dealing with symptoms of this chronic condition. Most of them reported that pain controls their life; interferes with job/studies, and limits physical activities. Many reported severe mood changes and appearance changes because of their condition, which is significant since these factors also affect negatively their self-esteem. Most felt misunderstood by others and blamed poor performance at work or school to endometriosis symptoms. These findings are in accord to previous studies showing that patients with endometriosis feel lack of support from others, lose the ability to perform at work, and have limitations in day-to-day activities, reducing their QoL (3, 9, 10, 15). Also, there is ample evidence showing that women with endometriosis score high in measures of depression and anxiety (12, 45, 46). These two symptoms are emotional manifestations commonly observed in patients with chronic pelvic pain, the key symptom of endometriosis (47, 48), which may have a range of negative effects both on the personal and social levels, and on reduced QoL (11, 19). More studies addressing the correlation between the diagnosis of endometriosis and psychopathological comorbidities are needed in order to accumulate evidence that can inform patient care (20). Future studies should be well designed to prevent confounding by disease staging, symptoms experienced (pain, infertility), use of hormone therapy, among others variables(18).

We also assessed the coping strategies commonly used by young women with endometriosis and observed that those who use adaptive coping strategies have higher QoL scores, which supports our hypothesis. Coping represents behavioral and cognitive efforts to deal with stressful encounters by employing either problem-solving and emotion-focused strategies (49, 50). Whether one uses predominantly one strategy over another is determined by individual differences in preferred coping styles and/or perceived controllability of the stressful event: work-related or family-related problems induce problem-focused coping mechanisms, while physical health problems may activate emotion-focused coping strategies (51). We were also interested to know if there were significant correlations between coping strategies including Autocriticism, Expression of emotions, Social support, Cognitive restructuring, and Social withdraw, and QoL scores. Across the board, Autocriticism was the coping strategy more strongly associated with substantial and negative impact on QoL. Specifically, those with high scores in Autocriticism reported poor performance at work or school, being more prone to mood changes, and were most likely to report feeling misunderstood and experiencing physical changes. Also, poor cognitive restructuring,

critical for the development of adaptive coping when presented with stressful events, was correlated with physical limitations, activity impairment, and mood changes. Interestingly, Social support was positively associated with severity of pain; this may indicate that the support system (family, friends, and spouses) is in place in those severe cases. In sum, individuals scoring high in maladaptive coping skills such as Autocriticism and Social withdrawal were more prone to suffer mood and physical changes, are most likely to report feeling of being misunderstood.

The present study presents several limitations, including a relatively small sample size; however, this is a patient population that has been shown before to have low response rates to invitations to participate in research (even referred to as a “hard to survey” population) (52). Also, this study was conducted in Puerto Rico, and all participants were Hispanics; thus, results might be influenced by the unique cultural, health care access, and type of support available for the participants and not necessarily generalizable to other young women in other areas of the world where there are, for instance, centers of excellence (specialized centers for endometriosis care). It is important to note that while this study uncovered coping strategies and traits impacting QoL in this particular population of young women with endometriosis, the data presented here does not imply that these characteristics would put someone at risk for a diagnosis of endometriosis. Importantly, the correlations observed may not be specific to endometriosis but rather represent mental health and coping manifestations of all girls/young women with any severe chronic pain condition (53, 54). Despite the small sample size, this study provides additional evidence showing that endometriosis symptoms substantially affect the overall wellbeing of a young patient population and identifies opportunities for psychological interventions such as behavioral cognitive and rational-emotive therapy to restructure coping styles and receive psychosocial support leading to improved QoL in this patient population.

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Table 1 –

Demographics

Variable	Frequency	Percent
Age		
13–19yrs	9	37.5
20–25yrs	15	62.5
Marital Status		
Married	12	50.0
Single	11	45.8
Cohabitate	1	4.2
Education Level		
High School	7	29.2
Technical Degree	7	29.2
Bachelor's Degree	8	33.3
Master's Degree	1	4.2
Doctoral Degree	1	4.2
Medical Plan		
Private Health Insurance	12	50.0
Public Health Insurance	11	45.8
Do not have Health Insurance	1	4.2
Do You Exercise?		
Yes	8	33.3
No	16	66.7
Do You Smoke?		
Yes	1	4.2
No	23	95.8

Table 2.

Gynecologic characteristics and endometriosis symptoms

Variable	Frequency	Percent
Dysmenorrhea		
Almost Always	6	25.0
Always	18	75.0
Pain is Incapacitating		
Yes	22	91.7
No	2	8.3
Menstrual Cycle		
Regular	15	62.5
Irregular	9	37.5
Dyspareunia		
Never	1	4.2
Almost Never	2	8.3
Almost Always	8	33.3
Always	6	25.0
Do not apply	7	29.2
Other Medical Conditions		
Chronic Pelvic Pain	2	8.3
Cysts	1	4.2
Migraine	3	12.5
More than one condition	18	75.0
Years Diagnosed		
Less than one year	8	33.3
1 to 3	8	33.3
4 to 7	6	25.0
8–10	2	8.3
Onset of Symptoms (yrs)		
7–12	5	20.8
13–17	17	70.8
18–22	1	4.2
23–25	1	4.2
Family History		
None	21	87.5
Sister	1	4.2
Cousin	2	8.3
Medical Treatment		
Yes	23	95.8
No	1	4.2

Table 3.

QoL of endometriosis patients measured by EHP-5

Activities Affected	Never (0) n (%)	Low (1–3) n (%)	High (3–4) n (%)
Work and/or Study	3 (12.5%)	9 (37.5%)	12 (50.0%)
Walking	1 (4.2%)	13 (54.2%)	10 (41.7%)
The Pain Controls Your Life	1 (4.2%)	12 (50.0%)	11 (45.8%)
Mood Changes	2 (8.3%)	10 (41.7%)	12 (50.0%)
Others Do Not Understand You	5 (20.8%)	8 (33.3%)	11 (45.8%)
Physical Changes	7 (29.2%)	8 (33.3%)	9 (37.5%)

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Table 4

Correlation Matrix between Impact of Endometriosis, Pain, Anxiety, and Depression

Variable	1	2	3	4
1. Impact of Endometriosis	1			
2. VAS	.334	1		
3. Anxiety	.546 ^{**}	.166	1	
4. Depression	.701 ^{**}	.322	.812 ^{**}	1

Note.

*
p<.05**
p<.01.

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Table 5.

Correlation matrix between Coping Strategies and Endometriosis related Quality of Life

Variable	Work and study	Can't walk because of the severity of the pain	Activity Impairment	Mood changes	No one understands	Physical Changes
Problem Solving	.198	-.231	-.298	-.068	.089	.274
Auto-criticism	.511*	.089	.521**	.441*	.477*	.433*
Express Emotion	-.410*	-.304	-.276	-.292	-.236	-.163
Wishful Thinking	.049	.170	.010	.076	.045	.065
Social Support	-.411*	.550**	-.248	-.174	-.146	-.250
Cognitive Restructuring	-.570**	-.471*	-.497*	-.411*	-.218	-.352
Problem Avoidance	-.241	-.336	-.359	-.222	-.211	-.161
Social Withdraw	.466*	-.014	.386	.467*	.449*	.424*

Note.

*
p<.05**
p<.01.

Women with endometriosis had significant correlations between low QoL scores and coping strategies including auto-criticism, expression of emotions, social support, cognitive restructuring, and social withdraw.