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Quantification of the Impact of Endometriosis Symptoms on Health Related Quality of Life and Work Productivity

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Abstract

OBJECTIVE—To quantify the impact of endometriosis-related symptoms on physical and mental health status, health-related quality of life (HRQoL), and work-related aspects (absenteeism, presenteeism, work productivity, activity impairment).

DESIGN—Cross-sectional quantitative study.

SETTING—Academic and research institution.

PATIENT(S)—Women (n=193) with self-reported surgically diagnosed endometriosis from the Endometriosis Patient Registry at Ponce School of Medicine and Health Sciences (PSMHS).

INTERVENTION(S)—Patients completed an anonymous questionnaire divided into three sections consisting of questions from the Patient Health Survey (SF-12®), the Endometriosis Health Profile (EHP-5), and the Work Productivity and Activity Impairment Survey (WPAI).

MAIN OUTCOME MEASURE(S)—Impact of endometriosis symptoms on physical and mental health status, health-related quality of life (HRQoL), absenteeism, presenteeism, work productivity and activity impairment was quantified.

RESULTS—Patients had SF-12 scores denoting significant disability in the physical and mental health components. They also reported an average of 7.41 hrs (approximately one working day) of work time loss during the week the symptoms are worse. In addition, WPAI scores show high impact on work-related domains: 13% of average loss in work time (absenteeism), 65% of their work was impaired (presenteeism), 64% loss in efficiency levels (work productivity loss), and 60% of daily activities perturbed (activity impairment).

CONCLUSION—Endometriosis symptoms such as chronic, incapacitating pelvic pain and infertility negatively and substantially impact the physical and mental health status, HRQoL, and productivity at work of patients with endometriosis.

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Conflict of interest:

There is no conflict of interest related to this study.

Keywords

Endometriosis; health-related quality of life; work productivity; pelvic pain; quality of life

Introduction

It is well recognized that endometriosis causes severe and incapacitating painful symptoms including chronic pelvic pain, dysmenorrhea, and dyspareunia (1). Endometriosis is common during the reproductive years, what should be the most productive time of women's lives (2-10). It has been estimated that endometriosis affects 10% of women worldwide, which represents seven million women in the US. In Puerto Rico the estimated prevalence is 2,775 per 100,000 women (11).

The painful, chronic symptoms of endometriosis are known to result in poor quality of life (QoL) in a substantial number of patients (12-15). Impact on health, work productivity, and daily life activities has been already described by qualitative studies (16-20) and costs of productivity loss has been estimated (21). Such studies have also shown that endometriosis symptoms negatively impact patients' social wellbeing, affecting relationships, lowering self-esteem, and leading to a feeling of loss of control (3, 22, 23). In order to quantify this impact, various instruments (e.g., SF-36®, SF-12®, EQ-5D, Duke Health Profile) have been used to measure effects on QoL and health-related QoL (HRQoL) in patients with endometriosis (13, 24). Collectively, these studies concluded that endometriosis substantially and negatively impairs HRQoL in areas of physical, psychological, and social function. To date, the only validated endometriosis-specific HRQoL instruments are EHP-30 and its shorter version, EHP-5 (25-29). The standard application of these valuable instruments will allow for comparisons of endometriosis-related HRQoL across different ethnic groups and geographical regions (30-34).

One important aspect of QoL is work productivity; however, the impact of endometriosis symptoms on this particular area has not been quantified to date using standardized instruments. The Work Productivity and Activity Impairment Questionnaire (WPAI) is a validated instrument that measures the effect of both general and specific symptoms on work productivity and daily tasks (34). Impact of symptoms are measured as hours of missed work (absenteeism), perceived impairment of work tasks (presenteeism), perceived loss in productivity levels (work productivity loss), and impairment of patient's daily life activities (activity impairment). Using WPAI, in combination with EHP5 and SF-12®, we aimed to validate and quantify the negative effects of endometriosis on physical and mental health, HRQoL and productivity at work in patients who are part of an endometriosis patient registry in Puerto Rico.

Materials and Methods

Study Population

This cross-sectional study was performed during May 2008-May 2009. Since 2001, the Endometriosis Research Program (ERP) at PSMHS has been obtaining demographic and clinical information from patients with self-reported surgically diagnosed of endometriosis (n=715) and controls (n=246). The PSMHS Institutional Review Board (IRB) approved the protocols and questionnaires used in this study. The study instrument was sent to patients with surgical confirmation of endometriosis via regular post mail (n=219) using a systematic aleatory sampling technique or via e-mail to all valid addresses registered in our patient database (n=259) using an online survey website (Survey Monkey) for a total of 478

patients. Initials, date of birth, and surgeon's name were used to warrant that participants completed the questionnaire only once.

Study Questionnaires

We condensed the Spanish versions of three questionnaires, SF-12®, EHP-5, and WPAI, into one survey. SF-12®, EHP-5 have been used previously to measure endometriosis-related HRQoL in other populations; to our knowledge, this is the first time WPAI has been applied to an endometriosis patient population. SF-12® provides Patient Reported Outcomes (PRO) data by measuring patient's perceptions of their general health status during the past four weeks in eight dimensions: physical functioning, social functioning, role limitations due to physical problems, role limitation due to emotional problems, mental health, energy and vitality, pain, and general perception of health (35, 36). Questions are subdivided into ten questions that refer to the physical and emotional status during the past month, and whether patients felt that these had interfered with carrying out daily life activities. SF-12® also yields two different global scores: the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The PCS and MCS global scoring system was standardized using a representative sample of the US general population. PCS and MCS scores, calculated according to published methods (www.sf-36.org), have a range of 0-100 (mean=50±10). Thus, SF-12® scores ≥50 represent above average health status and scores of ≤40 have been used as determinant of significant disability (37).

The endometriosis-specific EHP-5 survey was developed and validated in an effort to have a condensed HRQoL instrument that could be used in a time-effective manner during a clinical consult and/or encounters with researchers (29). EHP-5 consists of 11 questions that assess whether and how much symptoms of endometriosis interfere on work and daily activities during the past four weeks. Other aspects of the impact of endometriosis measured are mood and appearance changes, perception that others do not understand, and feelings that pain controls their lives. Also, impact on sexual life, childcare, relationship with doctor, treatment efficacy and maternity are also measured.

WPAI consists of six questions about work experiences and perceptions of productivity levels at work. Impact on work aspects is measured using a scale, from zero (not affected) to 100 (could not work at all) and obtaining information regarding total number of working hours, number of missing working hours due to symptoms, and perceived productivity at work. Patients were instructed to respond these questions according to how they felt during the week of their last menstrual period (when exacerbation of symptoms most commonly occurs) or during the week of the month when symptoms were worse. WPAI yields four types of scores expressed as impairment percentages: Absenteeism (work time missed), Presenteeism (impairment at work/reduced on-the-job effectiveness), Work Productivity (overall work impairment/absenteeism + presenteeism) and Activity Impairments. Higher WPAI percentages indicate greater impairment and less productivity. Scoring was conducted as described in www.reillyassociates.net/WPAI_Scoring.html.

Statistical analyses

Data from the mailed surveys were manually entered into Excel® (Microsoft). Data collected through the online website survey service were automatically entered into Excel. Data was merged and coded for analysis using EpiInfo™ (CDC, Atlanta, GA). Estimation of variables by distribution of frequencies, percentages, and standard deviations were conducted using SPSS v15 (Chicago, IL). Comparisons were performed between patients who reported a high impact of symptoms on EHP-5 domains. P values of less than 0.5 were considered significant.

Results

The questionnaire was completed by 193 women, for a response rate of 40%. Age was determined for 154 women, subtracting the date of birth from the date of completion of the questionnaire. The mean age of the population was 33.2 y/o (median: 34.0; range 18-52). Mean age of patients who answered the regular mail questionnaire was 36.2 y/o (range 22-52), while mean age of those who responded to the electronic questionnaire was 31.9 y/o ($t = 3.65$; 152 df; $p < 0.001$).

SF-12® Health Survey Results

The majority of participants rated their general health status as, at a minimum, “good” ($n = 111/158$; 70%). More than half of the participants reported that moderate ($n = 78/129$, 61%) and extreme ($n = 98/135$; 73%) daily activities had been limited by symptoms. The majority of women reported that work-related activities were affected due to their physical health. Many reported that due to physical limitations (64%) and emotional problems secondary to symptoms (63%) they accomplished less than expected. The majority (66%) also reported that they were limited in the kind of work-related activities they could carry out (Table 1).

Almost all participants reported effects of endometriosis-related symptoms on their general wellbeing during the last month. Only 18% of women reported feeling calm and peaceful often (i.e., most or all of the time), while 27% felt low energy, 35% felt depressed and discouraged, and 38% felt impairments in social life. The SF-12® PCS and MCS scores were 38.4 ± 6.7 and 39.5 ± 6.2 , respectively, indicating substantial disability.

EHP-5 Questionnaire Results

Many participants (43%) reported that pain interfered with work substantially (i.e., quite a bit or extremely) during the last month, and were physically impaired (e.g., had difficulties walking; 41%). Also, they reported substantial impact in their emotional health: 41% perceived that the pain controlled their life, 68% had mood changes, 61% felt that no one understood how they felt, and 48% had a poor concept of their physical appearance. We categorized patients into two groups, based on their perception of the level of impact that painful symptoms had on three EHP-5 domains: work, physical impairment and emotional health. Patients who reported that pain interfered frequently or always with these domains were categorized as “high impact”. Very few patients reported that painful symptoms never interfered with these domains (Table 2).

Two thirds of the participants (64%) reported being childless (i.e., child care was irrelevant). Many patients reported often (frequently or always) feeling depressed when considering the possibility of not having kids (56%), being worried about sexual aspects of personal relationships (38%), and being frustrated about perceived inefficacy of treatments (39%). Very few patients (13%) felt that their physicians minimize their symptoms.

WPAI: Work Productivity and Activity Impairment Survey Results

The majority of the participants were employed for a mean of 24.6 hours (hrs) during the last week (median of 30.0 $SD \pm 15.98$ hrs). Three quarters of respondents ($n = 116/155$; 74.8%) were working when the survey was answered. Subjects were categorized as full-time employees (> 28 hours per week; $n = 64$; 68%) and part-time employees (≤ 27 hours per week; $n = 30$; 31.9%).

When asked “how many hours did you miss from work because of endometriosis?”, 101 participants reported missing work in the past week due to their health problem (mean loss in work time = 7.41 hrs; $SD \pm 8.97$ hrs) during those seven days when symptoms were worse.

They reported a mean loss of 4.31 hrs ($SD \pm 10.0$ hrs) due to other reasons (e.g., vacations, holidays) during the same period.

Patients were asked to rate the impact of endometriosis-related symptoms on productivity loss and daily life using a scale of 0 to 10. Less than 10% reported not being affected by the disease. Of those patients who reported being affected, a substantial proportion perceived that symptoms extremely affected their work productivity (48%; $n=44/92$; median impact) and daily life activities (57% $n=80/140$). Based on this scale, loss of productivity had a median of 6.0 (moderately affected) and daily life activities a median of 7.0 (extremely affected). These data show that for approximately half of the patients with endometriosis in this study there is a substantial impact of endometriosis symptoms in important aspects related to productivity at work and daily life (Table 3).

The effects of endometriosis symptoms on the four domains measured by WPAI were quantified as % median: $13\% \pm 27.6$ (mean: 22) of average loss in work time (absenteeism); $65\% \pm 27.5$ (mean: 60) of their work was impaired (presenteeism); $64\% \pm 35.5$ (mean: 57) of perceived loss in efficiency levels (work productivity loss); and $60\% \pm 36.4$ (mean: 54) of the patients' regular daily activities were disturbed (activity impairment).

Comparison between EHP-5 and WPAI results

Next, patients were categorized as "high impact" vs "low impact" based on three EHP-5 domains: impact at work, physical impairment, and emotional health. EHP-5 results were compared with WPAI results to determine if higher EHP-5 scores would be able to predict a greater impact of symptoms on work. We observed that, indeed, patients categorized as "high impact" had significantly higher WPAI Presenteeism, Work productivity loss and Activity impairment scores indicating greater impairment and less productivity (Table 4).

Discussion

This cross-sectional study on 193 Puerto Rican women with endometriosis supports the evidence gathered by qualitative studies conducted in other populations indicating that endometriosis-related symptoms have a negative impact on QoL, HRQoL, and work productivity. In order to quantify the impact of endometriosis-related symptoms in these important aspects of a person's life, we compiled questions from three validated, standardized questionnaires into one instrument. WPAI and SF-12® have been translated to Spanish and validated previously (38, 39). EHP-5 had not been translated to Spanish, although its questions were derived from SF-36, which has been previously translated to Spanish.

We mailed the questionnaire via regular mail to randomly-selected patients from the PSMHS-ERP patient registry, and to all e-mail addresses registered in our database using an online survey system. This decision was based on previous studies from our group showing that Internet is accessible to only a fraction of patients in our registry. The only significant difference observed between these two groups was age: patients who responded by regular mail were older than those who responded electronically. This simply may indicate the expected pattern of access to and regular use of Internet among age groups. We observed a similar frequency of employed participants among the groups (data not shown).

The SF-12® and SF-36® questionnaires have been previously used to study the impact of symptoms and treatments on QoL of patients with endometriosis mainly in Caucasian populations (5, 12, 40-43). Because we used SF-12®, our results can only be compared to those of only two studies. In both studies, patients with endometriosis scored lower in the physical (PCS) and mental parameters (MCS) as compared to the general population. In this

study, patients had scores that were between those reported previously and less than 40, indicating significant disability. These data suggest that endometriosis negatively impacts HRQoL across populations (37).

The endometriosis-specific surveys EHP-30/EHP-5 have been translated and validated in several populations (25, 30, 31, 44); however, these valuable instruments have not been widely used. A literature search identified only three studies using these instruments (32, 45, 46). In our experience, EHP-5 was easily administered and very useful to obtain important PRO data supporting the impact of symptoms. EHP-5 results further demonstrated that endometriosis symptoms negatively affect many aspects of a substantial proportion of patients' physical and mental health, including sexual relations, treatment expectations, and maternity issues. Among QoL domains most commonly affected were changes in mood, and perceptions that no one understands, which were reported by more than half of respondents. Also, feeling depressed due to the possibility of not being able to conceive was commonly reported as a major distress.

To our knowledge, WPAI has not been used before to quantify the impact of endometriosis symptoms on work aspects. Patients reported a substantial impact of symptoms in both work productivity (moderately affected) and daily life activities (extremely affected). In average, patients lost approximately one day of work time a week, which may be detrimental to their functions at work, to their job-related relationships, and to professional growth. All WPAI domains measured were shown to have high scores, meaning substantial impairment of work-related aspects. Compared to patients with rheumatoid arthritis, patients in this study reported worse WPAI outcomes in all domains measured except for absenteeism (13% vs. 46%) (47). This provides further evidence in support to the previous observation that endometriosis patients make an effort to be present at work despite feeling physically impaired by symptoms (18). Also, except for absenteeism, we observed statistically significant differences between patients reporting high vs low impact on EHP-5 domains in all WPAI dimensions. Moreover, we observed an association between EHP-5 and WPAI results, supporting the use of EHP-5 as a tool to predict work-related problems in these patients. In summary, this quantitative study provides tangible evidence for the negative impact of endometriosis on important aspects related to work and daily life, as shown before qualitatively (18).

This study is limited in that we did not obtain information about disease severity. Rather, we measured the subject's perceptions of disease burden using instruments designed to collect PRO data. It is noteworthy that disease severity defined by the patient does not necessarily correlate with physician-rated severity scores, as shown in other diseases such as ulcerative colitis, in which endoscopy severity scores had limited value in estimating HRQoL (48). Quantifying the negative impact of chronic, painful diseases such as endometriosis using PRO data that documents severity as perceived by the patient is of utmost importance to develop effective treatment plans geared towards helping patients improve their QoL and allow them to be productive members of our society.

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Capsule

This cross-sectional study quantified the impact of endometriosis symptoms on physical and mental health status, HRQoL, and for the first time the effects on work productivity of patients.

Table 1
Impact of endometriosis-related symptoms on work-related activities experienced during the past four weeks (SF-12®)

	Yes N (%)	No N (%)	N
<i>Accomplished less than would have liked, due to physical health problems</i>	99 (63.5)	57 (36.5)	156
<i>Were limited in the kind of work or other activities due to their physical health</i>	102 (66.2)	52 (33.8)	154
<i>Accomplished less than would have liked, due to emotional health</i>	94 (62.7)	60 (37.3)	150
<i>Were limited in the kind of work or other activities due to emotional health</i>	69 (45.4)	83 (54.6)	152

Table 2
Impact of endometriosis-related symptoms on physical and mental health (EHP-5)

	Never N (%)	Low Impact		High Impact	
		Rarely N (%)	Sometimes N (%)	Often N (%)	Always N (%)
<i>Due to endometriosis:</i>					
<i>Pain interferes with work</i>	14 (8.9)	19 (12.1)	57 (36.3)	43 (27.4)	24 (15.3)
<i>Difficulty walking due to pain</i>	23 (14.6)	24 (15.3)	45 (28.7)	40 (25.5)	25 (15.9)
<i>Pain controls life</i>	27 (17.2)	25 (15.9)	41 (26.1)	32 (20.4)	32 (20.4)
<i>Mood changes</i>	4 (2.5)	11 (7.0)	35 (22.3)	59 (37.6)	48 (30.6)
<i>Perceive that no one understands their feelings</i>	12 (7.6)	8 (5.1)	42 (26.8)	46 (29.3)	49 (31.2)
<i>Perceive changes in physical appearance</i>	23 (14.6)	20 (12.7)	38 (24.2)	37 (23.6)	39 (24.8)

Table 3
Impact of endometriosis-related symptoms on productivity loss and daily life activities (WPAD)

Impact of endometriosis symptoms on:	Not Affected (0) n (%)	Lightly Affected (1-3) n (%)	Moderately Affected (4-6) n (%)	Extremely Affected (7-10) n (%)	Mean, Median (±SD)
<i>Loss of productivity</i>	10 (9.8)	22 (21.6)	26 (25.5)	44 (43.1)	5.3, 6.0 (3.1)
<i>Daily life activities</i>	12 (7.9)	15 (9.9)	45 (29.6)	80 (52.6)	5.9, 7.0 (2.9)

Table 4
WPAI Mean Scores Among Groups Classified According to EHP-5 Domains (Disease Impact at Work, Physical Impairment, and Emotional Health)

Domain	EHP-5 Work			EHP-5 Physical Impairment			EHP-5 Emotional Health		
	High Impact n % Mean $\pm$ SD	Low Impact n % Mean $\pm$ SD	p-value	High Impact n % Mean $\pm$ SD	Low Impact n % Mean $\pm$ SD	p-value	High Impact n % Mean $\pm$ SD	Low Impact n % Mean $\pm$ SD	p-value
<i>Absenteeism</i>	26 23.0 $\pm$ 28.8	26 23.0 $\pm$ 31.2	>0.999	25 22.3 $\pm$ 29.0	29 23.2 $\pm$ 30.9	0.908	26 25.7 $\pm$ 30.5	26 20.0 $\pm$ 30.3	0.501
<i>Presenteeism</i>	24 65.4 $\pm$ 25.2	18 47.2 $\pm$ 23.2	0.020	21 64.8 $\pm$ 24.0	21 51.4 $\pm$ 26.0	0.092	21 65.7 $\pm$ 24.4	20 45.0 $\pm$ 25.8	0.014
<i>Work Productivity Loss</i>	38 69.9 $\pm$ 31.9	37 49.2 $\pm$ 34.4	0.009	37 66.8 $\pm$ 34.3	36 51.2 $\pm$ 33.7	0.055	39 71.3 $\pm$ 32.3	32 45.7 $\pm$ 33.7	0.002
<i>Activity Impairment</i>	38 62.4 $\pm$ 29.1	38 39.2 $\pm$ 26.0	<0.001	35 60.0 $\pm$ 46.5	37 46.5 $\pm$ 26.3	0.048	35 63.7 $\pm$ 28.1	35 40.6 $\pm$ 26.5	0.001