

Impact of Endometriosis on Work Productivity and Quality of Life: a Survey from Italy

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Abstract: *Endometriosis, usually called as "cancer of the career-woman", is being recognized as a "social disease" for its prevalence and its debilitating impact on young women, leading to a high socio-economic burden of the disease. This study was performed from January 2011 to January 2013 at the Department of Gynecological, Obstetrics and Urological Sciences (Sapienza University of Rome, Sant' Andrea Hospital) in order to assess the impact of endometriosis-related symptoms on work productivity and health-related quality of life (HRQoL). Anonymous questionnaires were administered individually to a total of 254 women with surgically diagnosed endometriosis. The questionnaires consisted of three sections: Patient Health Survey (SF-12), the Endometriosis Health Profile (EHP-5), and the Work Productivity and Activity Impairment Survey (WPAI). Our results confirm that endometriosis has a significant impact on work productivity and HRQoL of affected women, leading to high economic burden and huge costs to society. Therefore it is time to make serious investments in researchers, in order to achieve a precocious diagnosis of the disease and to improve the treatment of this debilitating condition.*

Key words: Endometriosis, work productivity, quality of life, pelvic pain, women, costs

1. Introduction

Endometriosis is an estrogen-dependent chronic inflammatory disease (Giudice, 2010) which affects 6-10% of women in reproductive age (Zhao et al, 1998). It has been estimated that 176 million women worldwide suffer from this disease (Adamson et al, 2010). It affects women at the most productive period of their lives, particularly in terms of work. Endometriosis can be associated with dysmenorrhea, dyspareunia, chronic pelvic pain, abnormal bleeding and infertility (Simoens et al, 2007). Specifically, endometriosis-associated pain is the major cause of physical, psycho-social, emotional and work related impairment among these women (Oehmke F et al, 2009). Therefore endometriosis can be considered a debilitating disease which has a detrimental effect on the health-related quality of life (HRQoL) in a large number of patients, as reported by several studies (Mathias et al, 1996; Bodner et al, 1997; Gao et al, 2006; Bianconi et al, 2007).

HRQoL is a multidimensional, dynamic concept that encompasses physical,

Psychological and social aspects associated with a disease or its treatment (Guyatt et al, 1993). Generic instruments most commonly used to assess HRQoL include the Patient Health Survey SF-36, its abbreviated form SF-12, EQ-5D (used to measure utilities). Another generic instrument created to evaluate the impact of a disease on productivity loss and daily life activities is the Work Productivity and Activity Impairment Questionnaire (WPAI), validated for use in many diseases but not in endometriosis (Reilly et al, 2004). The only validated disease-specific HRQoL scales for endometriosis are the Endometriosis Health Profile EHP-30 and its shorter version, EHP-5 (Jones et al, 2001; Jones et al, 2004).

The objective of the present study was to quantify the impact of endometriosis-related symptoms on physical, mental health status, sexuality and work-related aspects (absenteeism, presenteeism, work productivity, and activity impairment) on a sample of 254 patients basing on anonymous questionnaires.

2. Material and methods

This cross-sectional study was performed from January 2011 to January 2013 at the Department of Gynecological, Obstetrics and Urological Sciences ("Sapienza" University of Rome, Sant' Andrea Hospital). Throughout the period of analysis, clinical information from patients with surgically diagnosed endometriosis (n=254) has been obtaining. The ethics committee approved the protocols and questionnaires used in this study. The questionnaires were filled out during the outpatient medical examinations. Anonymous questionnaires have been used to quantify the impact of endometriosis on work productivity and health-related quality of life (HRQoL). The questionnaires consist of questions from the Work Productivity and Activity Impairment Questionnaire (WPAI), the Endometriosis Health Profile (EHP-5), and the Patient Health Survey (SF-12).

2.1 Questionnaires

We administered the three questionnaires WPAI, EHP-5 and SF-12 during the outpatient medical examinations. The WPAI questionnaire contains 6 questions and it is a validated instrument to measure impairments in work and activities. The impact on work is measured using a scale from 0 (no effect on work) to 100 (completely prevented working), obtaining information regarding the number of missed work hours, the total number of working hours and perceived work productivity. The WPAI is calculated using four types of score: work time missed, work productivity, impairment at work and activity impairments. These scores are expressed in percentages: higher percentages stand for a greater impairment and less productivity at work (Fourquet et al, 2011). The EHP-5 contains 11 questions that evaluate the influence of endometriosis-related symptoms on work and daily life. Many items are measured: 5 items including pain, control and inability, mood, lack of social support, appearance changes, from the core

questionnaire and 6 items from the modular questionnaire including work, impact on sexual life, maternity, treatment efficacy, relationship with children and physicians (the modular questionnaire may not be applicable to every woman with endometriosis). The impact on health aspects is measured using a scale from 0 (best possible health status) to 100 (worst possible health status) (Goshtasebi et al, 2011). The SF-12 questionnaire contains 10 questions that evaluate 8 concepts commonly represented in health surveys: limitations in role functioning due to emotional and physical health, general health, pain, mental health, vitality, social and physical functioning during the past month (Fourquet et al, 1996; Fourquet et al. 1998). It provides a comprehensive and efficient way to measure general health from patient's point of view. Most patients can complete the questionnaire in few minutes. The SF-12 is scored using two summary scores: Mental Component Summary (MCS-12) and Physical Component Summary (PCS-12). The PCS-12 and the MCS-12 scores have a range of 0 to 100 and have a mean score of 50 and a standard deviation of 10. Scores greater than 50, represent above average health status, while scores of ≤ 40 represent significant disability (Fourquet et al, 2008).

3. Results

From the total of 254 patients, 222 completed the questionnaire with a response rate of 87.4%. The patients recruited had the following socio-demographic characteristics: the mean age of population was 37.9 ± 6.5 ; regarding citizenship, 91.9% of patients was Italian; regarding marital status, 98 were unmarried (44.1%), 114 married (51.4%) and 10 separate (4.5%). All women participants were workers: 197 were employees and 25 were freelance professionals. 44.1% of women reported problems in sexual intercourses with own partner and a mean assumption of analgesics drugs per month of 3.8 ± 4.5 . As regards menstrual cycle characteristics, intensity of dysmenorrhea was reported 7.8 ± 2.3 , intensity of chronic pelvic

pain 5.2 ± 3.1 , intensity of dyspareunia 4.1 ± 3.3 .

3.1 WPAI results

Participants were employed for a mean of 36.4 ± 12 hours. The majority of women were employees (88.7%) whereas only 11.3% were freelance professionals. Almost all of them (96.4%) were employed at the time of the interview. The mean time missed from work because of problems related to endometriosis was 2.3 ± 5.3 hours during the last 7 days, on the other hand the mean time missed from work because of any other reason (e.g. vacation, holidays) was 0.5 ± 1.5 hours during the last 7 days. During the past seven days the patients reported actually to work a mean of 33.8 ± 12.4 hours. Only 36 (16.2%) of women declared that endometriosis did not affect their daily life activities. 73 (32.9%) patients reported that the disease minimally (on scale 1-3) interfered, 98 (44.1%) reported that the disease moderately (on scale 4-6) interfered and 15 (6.8%) reported that the disease extremely interfered (on scale 7-10). Based on similar scale less than 26 women (12%) reported no impact of endometriosis on work productivity, 52 (23.4%) declared minimally, 78 (35.1%) moderately, 66 (29.7%) extremely.

3.2 SF-12 results

The majority of patients revealed an overall good general health status (14.4% considered it "excellent", 21.6% "very good" and 36.9% "good"). Endometriosis-related symptoms interfered with moderate daily activities and with extreme physical activity (climbing several flights of stairs) in 59.5% and 54.9% of cases, respectively. In the last month, 67.6% and 53.2% of women were limited in the kind of work or in other regular daily activities and accomplished less than would have liked because of physical health problems. Emotional problems limited 55% of patients in work and led 49.5% of them to accomplish less than they would have liked. Pain due to endometriosis interfered with

normal work in 79.3% of cases; 12.6% of them declared that it compromised both housework and work outside home extremely or quite a bit. Table I shows the four questions about how the patients feel and how things have been with them during the last 4 weeks.

3.3 EHP-5 results

Table II shows the response frequencies for the EHP-5 core questionnaire. It demonstrates that 55% of women perceived difficulty walking due to pain, 59.5% reported that pain controlled their life, 49.5% had mood swings, 35.1% complained that no one understood their feelings, 50.9% felt that their appearance has been affected by endometriosis.

4. Discussion

This study on Italian women with endometriosis confirms the evidence reported by surveys conducted in other countries, demonstrating that endometriosis has a negative impact on work productivity and health-related quality of life (HRQoL) of affected women. Nowadays this issue is of growing interest in a society where increased health care costs and limited resources are of increasing concern. For this reason in recent years, the studies quantifying the costs of endometriosis (Gao et al, 2006; Nnoaham et al, 2011; Simoens et al, 2012) and the impact of the disease on health, work productivity, and daily life activities have increased (Damario et al, 1995; Oehmke F et al, 2009; Fourquet et al, 2010; Reilly et al, 2008; Reilly et al, 2010).

As regards the first aspect, in order to extrapolate the total annual societal burden of endometriosis, a recent multi-centre study was conducted by Simoens et. al in 10 countries. The authors, using a theoretical model, reported that the average annual total cost per woman affected by endometriosis was €9579 (95% confidence interval €8559-€10599) and costs of productivity loss of €6298 per woman were double the health care costs of €3113 per woman, showing that the

economic burden of endometriosis arises predominantly from productivity loss. They also extrapolated the total annual societal costs for endometriosis in Italy, which was € 9.3 billion (Simoens et al, 2012)

Regarding the impact of the disease on HRQoL, Jia et al. recently reviewed all the available literature on the subject and the authors concluded that HRQoL is impaired in such women, and medical or surgical treatment to alleviate pain could partially restore this impairment (Jia et al, 2012).

In the present study HRQoL was assessed through generic (SF-12, WPAI) and specific (EHP-5) instruments.

Although requiring a structural and linguistic revision, also the Italian version of EHP-30 appeared to be more appropriate than generic tools to assess the quality of life of Italian women suffering for endometriosis (Maiorana et al, 2012). In the present study we used EHP-5 because is an easier procedure administered to patients.

The mean hours missed at work by women because of problems related to endometriosis resulted $2,3 \pm 5,3$ hours during the last 7 days. Our results were lower than the ones calculated in two recent studies. In one study, work productivity loss was 10.8 hours/week and in the other one, on average, patients lost approximately 1 day of work a week (Forquet et al, 2011; Nnoham et al, 2011). Moreover, the majority of our patients declared that endometriosis had a negative impact on their daily life activities (32,9% minimally and 44,1% moderately) and on their work productivity (respectively 35,1% moderately and 29,7% extremely). In addition to the costs for the society due to work productivity loss, endometriosis has a high economic burden on individual patient, which has to pay continuously for all drugs and exams necessary for the disease.

Although endometriosis is not a life-threatening disease, this study confirmed that it can substantially affect women's work productivity and HRQL. Thus, endometriosis can be both physically and emotionally debilitating. Physically, endometriosis pain

can impair work and daily activities. Psychologically, the disease can lead to depression, anxiety and feelings of low self-esteem, which in turn lead to impairment in work productivity and HRQoL (Lemaire, 2004).

5. Conclusions

Endometriosis generally affects women during the most productive years of their lives, when they should be finishing education, starting a career and probably have a family. Although endometriosis is known to have relevant impact on different aspects of patients' daily lives, the disease often remains misdiagnosed. Consequently, the burden of endometriosis on women and society remains under-estimated. For these women to have their productivity impaired, their quality of life compromised and their chances for starting a family reduced, is something society can no longer afford to ignore. Therefore it is time to make serious investment in preventing this debilitating condition in the next generation of women improving the collective level of awareness of endometriosis, its detection, and its treatment.

Table I. Impact of endometriosis-related symptoms on the general well-being during the last 4 weeks.

| | Always N (%) | Almost always N (%) | Most of the time N (%) | Some of the time N (%) | Almost never N (%) | Never N (%) |
|--|-----------------|---------------------------|------------------------------|------------------------------|--------------------------|----------------|
| Have you felt calm and peaceful | 56 (25.2) | 60 (27) | 54 (24.3) | 40 (18) | 6 (2.7) | 6 (2.7) |
| Did you have a lot of energy | 62 (27.9) | 88 (39.6) | 50 (22.5) | 9 (4.1) | 7 (3.1) | 6 (2.7) |
| Have you felt downhearted and depressed | 4 (1.8) | 8 (3.6) | 44 (19.8) | 54 (24.3) | 50 (22.5) | 62 (27.9) |
| How much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)? | 22 (9.9) | 24 (10.8) | / | 60 (27) | 48 (21.6) | 68 (30.6) |

Table II. Core questionnaire of Endometriosis Health Profile (EHP-5)

| | Never N (%) | Rarely N (%) | Sometimes N (%) | Often N (%) | Always N (%) |
|--|----------------|-----------------|--------------------|----------------|-----------------|
| Difficulty walking because of the pain | 100 (45) | 48 (21.6) | 18 (8.1) | 8 (3.6) | 48 (21.6) |
| Control of life and powerlessness | 90 (40.5) | 34 (15.3) | 48 (21.6) | 36 (16.2) | 14 (6.3) |
| Mood swings | 112 (50.5) | 54 (24.3) | 44 (19.8) | 8 (3.6) | 4 (1.8) |
| Perception of lack of social support | 144 (64.9) | 50 (22.5) | 18 (8.1) | 8 (3.6) | 2 (0.9) |
| Influence on self-image | 109 (49.1) | 65 (29.3) | 34 (15.3) | 11 (5) | 3 (1.4) |

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