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REVIEW PAPER

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ENDOMETRIOSIS – THE CHALLENGE FOR OCCUPATIONAL LIFE OF DIAGNOSED WOMEN: A REVIEW OF QUANTITATIVE STUDIES

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Abstract

The aim of the article was to summarize the results offered in the research on occupational functioning of women with endometriosis. We followed PRISMA guidelines. Database search was done in November 2017 using EBSCO. In the review were included the articles clearly referring to the relationships between endometriosis and work or any aspect of work (e.g., work productivity, work ability, absenteeism). Eight papers were included in the final review. Seven studies were cross-sectional, 1 retrospective. The majority of researchers used standardized research measures, such as *Work Ability Index*, *Work Productivity and Activity Impairment Questionnaire* or *Health Related Productivity Questionnaire*. Only in 2 studies the reference group was considered, one of them consisted of healthy women. The results clearly indicate that endometriosis is a disease that causes major disturbance in occupational functioning of the suffering women. In the future the researchers should search for individual and organizational correlates of the improvement of occupational functioning in this group of patients. The methodology of the existing studies has been evaluated and the methodological cues for future research has been given. Med Pr 2018;69(6):663–671

Key words: pain, quality of work life, sickness absence, work ability, women's health, chronic disease

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INTRODUCTION

Endometriosis is an estrogen-related disorder of a still unknown etiology and it is reported to affect 10% of women of reproductive age [1]. The core pathology of this disease is the presence of endometrium cells outside the uterus. Ectopic endometrial cells spread and form endometriosis foci mainly in the organs of pelvic (ovaries, uterosacral ligaments and intestines) but also outside the pelvis. These ectopic cells are affected by cyclic hormonal fluctuations similarly to endometrial cells in the uterus – they proliferate and slough off but are not expelled from the body during menstruation. This process causes chronic inflammation in the area of endometriosis foci, as well as pain, adhesions and anatomic distortion in pelvic.

There is a considerable delay in the diagnosis of endometriosis [2–5]. Frequently do women seek advice from numerous doctors before anyone recognizes the symptoms correctly. The symptoms are commonly neglected or ignored by women themselves as well as their relatives or doctors. Sometimes even severe menstrual pain is considered as normal. Moreover, because some of the symptoms are considered embarrassing (e.g., painful sexual intercourses or defecation) the suffering women refrain from consulting their discomfort with a doctor, which defers the accurate diagnosis.

The endometriosis treatment usually includes hormone therapy and surgery interventions. Yet, despite a great pharmacology and medical technology development, current therapies are still not fully effective and the disease tends to recur.

Living with endometriosis

Symptoms of endometriosis adversely affect patients' everyday lives, thus, the life of a woman suffering from endometriosis could be described as "shaped by pain" [6]. The pain accompanies periods (*dysmenorrhea*), sexual

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intercourses (*dyspareunia*), defecation (*dyschezia*), and urination (*dysuria*) [7]. Patients often complain about nausea [8–10] and chronic fatigue [11,12]. Importantly, women with endometriosis report high levels of stress [13], depressive symptoms and anxiety [14].

Endometriosis is found to be one of the leading causes of infertility [15]. This, in turn, leads to subsequent psychological consequences that affect mental health of women with endometriosis more than those with other gynaecological problems [16]. Women suffering from endometriosis experience crises in their relationships and also their partners' quality of life is affected by the illness [17]. Depending on the stage of the illness and the severity of pain, social functioning of women with endometriosis is significantly impaired as well [12,18].

Social costs of endometriosis

Due to its social costs, it is postulated to consider endometriosis as a social disease [19]. The costs result mainly from the diagnostic delay, ineffective treatment, high index of hospital admissions, surgery procedures and concomitant health problems (infertility, mental health problems). Endometriosis affects women of productive age, hence it influences women's occupational functioning.

In 2006, the World Endometriosis Research Foundation (WERF) [20] initiated the EndoCost Study to assess the direct and indirect costs of the disease born by society (including costs of productivity loss) and by the diagnosed women themselves. Data was collected in 12 medical centers from 10 countries (N = 909). The average annual total cost was calculated to over EUR 9000 per woman and the costs of productivity loss (approx. EUR 6000 per woman) were twice as high as healthcare costs (surgeries, monitoring tests, hospitalizations and physicians visits). The data showed that economic burden associated with endometriosis was similar to the one tied to other serious chronic diseases such as diabetes, Crohn's disease or rheumatoid arthritis [21].

Rationale and the aim of the article

The purpose of our review was to find research and summarize what is already known on the impact of endometriosis on the occupational functioning of women since such summary has not been done yet.

METHODS

Selection of articles – eligibility criteria and search

Conducting the review search and analysis, we followed the PRISMA guidelines. To find relevant papers, we searched the following databases using the EBSCO: MEDLINE Complete, OAIster, MasterFILE Premier and JSTOR Journals with no limits as regards the earliest date of publication. The search was performed in November 2017. Exact duplicates were automatically excluded from the results. We searched only for articles written in English and published in peer-reviewed journals.

First, we used the following keywords: "endometriosis" and "work;" "endometriosis" and "occupation*" (asterisk was used for retrieving variations of a searched word) in the title; "endometriosis" in the title and "work" in the abstract or keywords.

RESULTS

Study selection

Forty-four records met the primary criteria and were screened for eligibility for further analysis. We excluded: qualitative studies (N = 4), a review (N = 1), unpublished PhD thesis (N = 1), articles in which "work" did not refer to paid work (N = 6), articles in which "work" occurred in the abstract but was only a part of the introduction (N = 8), papers considering the influence of work on the risk of endometriosis (N = 4), articles in which researchers studied the influence of different therapies, on, e.g., functioning at work (N = 5), articles in which the main topic was not endometriosis but endometriosis-related symptoms (N = 2) and articles focused on estimating costs of endometriosis (N = 3). Next, 3 out of the 11 remaining papers were excluded due to their significant methodological shortcomings. Eventually, a total of 8 papers were included in the final review. The stages of study selection are presented in the flow diagram (Figure 1).

Characteristics of selected studies

Data collection

In the reviewed studies, women were identified in patients' registers and invited to the study by post or e-mail [8,10,16,22,23] or they were recruited from hospital wards [9,24,25].

Study samples

With the exception of Nnoaham et al. study [24] that was conducted in 16 clinics in 10 European countries, North and South America and Asia, all the other studies referred to local societies: central America [10,16], Denmark [8], Italy [25], Norway [9] and USA [23]. The smallest study group included 78 women [9] and the largest – 1318 [23].

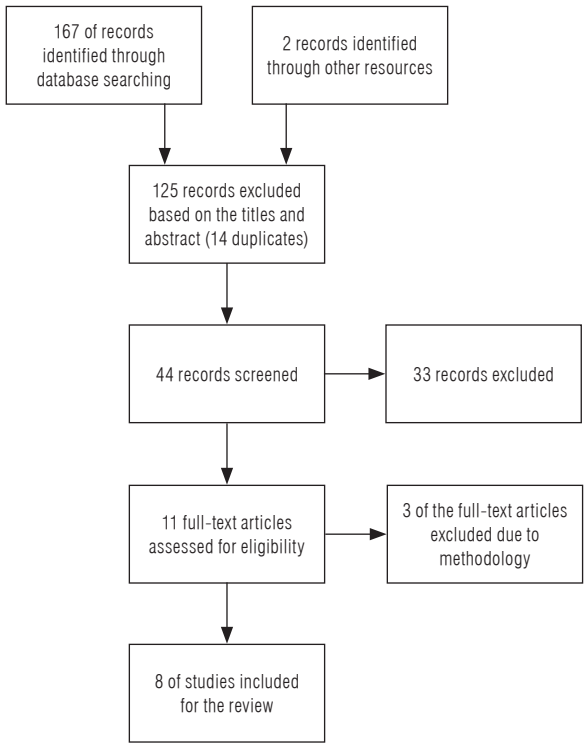

Figure 1. Flow diagram showing the process of studies selection for the review

The diagnosis of endometriosis was the inclusion criterion in all studies, but the accepted basis of the diagnosis varied between the reviewed studies (Table 1).

Study designs

All the reviewed studies were cross-sectional, only one was a 15-year-long retrospective study [9]. Two studies included control groups – 1 consisted of women from the general population [8], the other – of symptomatic (pelvic pain and subfertility) women without endometriosis and women to be sterilized [24].

Measures

Most authors used standardized tools to measure work-related variables: *Work Productivity and Activity Impairment Questionnaire* [16,24,25], a short version of *Work Ability Index* [8], *Global Study of Women's Health Questionnaire* [24], work-related module of the *Endometriosis Health Profile* [8] or *Health-Related Productivity Questionnaire* [23]. Two teams of researchers developed their own surveys [9,16].

Research areas

Having analyzed the content of the selected papers, we distinguished the following research areas:

- impact of endometriosis-induced pain on occupational functioning,
- deterioration of work ability, work performance and quality of work caused by endometriosis,
- productivity loss caused by endometriosis-related symptoms.

The summary of the studies included in the review is presented in the Table 1.

The impact of endometriosis-induced pain on occupational functioning

Two publications by Fourquet et al. [10,16] depict the situation of women suffering from endometriosis in South America. At least 66% of the studied women experienced pain-related difficulties in work, 43% identified these difficulties as severe [10]. For 60% of them (N = 64) the pain was the reason for missed working days [16].

In a study by Caserta et al. [25], nearly 30% of the studied women considered the impact of endometriosis on work as extreme, 35% as moderate and 23% as minimal. Only 12% of them reported no impact of endometriosis on their work. The percentage of women who experienced extreme negative influence of endometriosis on work was even higher in Fourquet's study – 43% [10]. In a study by De Graaf et al. [22] 51% of the participants reported that endometriosis negatively affected their work.

Hansen et al. [8] showed the range of pain intensity and pain-related consequences at work in the case of women with diagnosed endometriosis in comparison to a reference group of the general female population.

Women with endometriosis took sick leaves due to their pain significantly more often than healthy women from the reference group. Up to 59% of the respondents felt the endometriosis pain impaired their work efficiency. In the case of 53% it decreased concentration, 30% felt guilty taking a day off because of the pain, and 31% felt worried because of their inability to work due to the pain. The wide range of difficulties included: stomachache related or unrelated to menstruation, pain at urination and defecation, irregular bleeding, constipation or diarrhea. The studied women also reported to have experienced nausea, vomiting, headache, fatigue and lack of energy, pain while standing, sitting and walking.

The study of Hansen et al. [8] also revealed mental consequences of the suffering, directly related to work. Women experienced a sense of guilt and embarrassment and they worried about worse functioning at work.

Table 1. Methodology of the reviewed studies on occupational functioning of women with endometriosis

References	Keywords	Work-related measured variables	Study design	Method of data collection	Participants	Diagnostic delay measured	Standardized questionnaires to measure work-related variables	Limitations
Fagervold et al. 2009 [9] Norway	work ability, quality of work life	absenteeism, changes in work due to endometriosis	retrospective descriptive (15 years follow-up)	hospitals	N = 78 (age: unknown) women discharged from hospital with the ICD-9 diagnosis and/or histological verified endometriosis control group: no	no	no	small sample, recall and reporting errors
Fourquet et al. 2010 [10] South America	work performance	limitations in work activity, decrease in quality of work, career consequences	cross sectional quantitative study	questionnaires distributed via mail and e-mail	N = 107 (age: M±SD = 34.5±6.6 years old) self-reported surgically diagnosed women control group: no	yes (M±SD = 8.9±7.9)	no	results representative for the women with severe endometriosis, sample consisted of well-educated women (small differences in the level of education of women), recall and reporting errors
Nnoaham et al. 2011 [24] multinational	work productivity	absenteeism, presenteeism, overall productivity loss	multicenter cross-sectional study with prospective recruitment	16 hospitals, 10 countries	N = 745 (age: M±SD = 32.5±6.2 years old (18–45 years old)) premenopausal women scheduled for laparoscopy without previous surgical diagnosis of endometriosis control group: yes, symptomatic control women without endometriosis (N = 587) and sterilization control women without endometriosis (N = 86)	yes (M±SD = 6.7±6.3)	WPAI:GH	variables were measured in the weeks leading to the scheduled surgery, results may be affected by this fact and the symptoms themselves
Fourquet et al. 2011 [10] South America	work productivity	absenteeism, presenteeism, work productivity, decrease in quality of work, career consequences	cross sectional quantitative study	questionnaires distributed via mail and e-mail	N = 193 (age: M = 33.2 years old (18–52 years old)) self-reported surgically diagnosed women control group: no	measured but not reported	WPAI	no data on severity of disease
Hansen et al. 2013 [8] Denmark	work ability, quality of work life	absenteeism, work ability, implications for work life	cross sectional study (even though the authors considered it a cohort study)	electronic questionnaire distributed online	N = 610 (age: < 19 years old, > 50 years old) women with endometriosis diagnosed by laparoscopy or/and magnetic resonance (MR) control group: yes, healthy women (N = 751)	yes, percentages	EHP-30, WAI short	recall bias, no validation of endometriosis in medical records, respondents selected on the basis of their availability and interest
Caserta et al. 2013 [25] Italy	work productivity	work productivity	cross-sectional	questionnaires distributed in hospital during outpatient medical examination	N = 222 (age: M±SD = 37.9±6.5 years old) women with surgically diagnosed endometriosis control group: no	no	WPAI	not mentioned

De Graaf et al. 2013 [22] multinational	not related to work	negative effect on endometriosis work	cross-sectional	questionnaires distributed via mail to participants after positive answer to the invitation	N = 931 (age: M±SD = 36.1±6.8 years old (14–67 years old)) women with laparoscopic and/or histological diagnosis of endometriosis control group: no	yes years of patient delay*: M±SD = 2.1±4 (0–32) doctor delay**: M±SD = 3.4±5.3 (0–38) total delay: M±SD = 5.5±6.6 (0–38)	GSWH	possible over representation of women with moderate and severe endometriosis, low response rate to the mail invitation (29%)
Soliman et al. 2017 [23] USA	work productivity	absenteeism, presenteeism, overall productivity loss	cross-sectional	web based survey	N = 1 318 (age: M±SD = 34.6±0.3 years old (18–49 years old)) women with symptomatic endometriosis, currently being treated or having hysterectomy control group: no	no	HRPQ	participation of women who had access to the internet only, recall bias, the type of treatment was not controlled

* Patient delay – interval between onset of symptoms to first visit.
** Doctor delay – interval between first doctor visit and diagnosis.
WPAI:GH – *Work Productivity and Activity Impairment: General Health V2.2*, WPAI – *Work Productivity and Activity Impairment*, EHP-30 – *Endometriosis Health Questionnaire 30*, WAI – *Work Ability Index*, GSWH – *Global Study of Women's Health Questionnaire*, HRPQ – *Health Related Productivity Questionnaire*.

They accomplished less than desired because of the pain and they felt they could have been able to work longer and more efficiently if they had not felt the pain. Additionally, their ambitions would have been higher if they had been more concentrated, but it was the pain that hindered their concentration.

Deterioration of work ability, work performance and quality of work caused by endometriosis

Fagervold et al. [9] conducted a retrospective study illustrating 15-year-long experience of the life with endometriosis. The results showed significant negative correlations between the number of the endometriosis symptoms in the past (pain, dysmenorrhea, pain at ovulation, dyspareunia, pain at defecation, constant pelvic pain, menorrhagia, irregular menstrual cycles, urinary symptoms, flatulence/constipation, fatigue) and later course of patients' education and work. Nearly a half of the respondents who participated in the follow-up study (49%) experienced negative influence of endometriosis on their work ability. Five percent of the studied women decreased their working hours (from full-time to part-time) due to their disease and another 3% changed their place of employment. One woman (1%) became unable to work.

The study by De Graaf et al. [22] showed that among women who reported negative impact of endometriosis on their work, 11% lost their jobs and 7% changed their jobs.

In a study by Fourquet et al. [16], 84% of women reported decrease in the quality of their work due to endometriosis and its symptoms made 20% of the studied women temporarily disabled. Furthermore, 66% of the respondents reported that the work-related activities they could perform were limited [10].

Hansen et al. [8] revealed that the number of sick days, disturbances due to symptoms and work ability differed significantly between women suffering from endometriosis and healthy women. Poor work ability was reported by 14% of the women with endometriosis vs. 8% of healthy women from the reference group. Excellent work ability was declared only by 12% of the suffering women in contrast to 38% of the women from the reference group. Decreased work ability was predicted by fatigue, lack of energy, pain frequency, higher daily level of pain, the higher number of sick days and feeling depressed at work. That study also showed the relationship between work ability and the diagnostic delay. Almost a half of the women who had been diagnosed within 2 years from the occurrence of the first symptoms (48%) assessed their ability to work as excellent and only 16% found it poor. Among women who were diagnosed within 7–8 years from the first symptoms, these percentages equaled 5% and 24%, respectively.

Fourquet et al. calculated that a substantial number of women believed that their symptoms extremely affected their work productivity (N = 44, 48%) [10] and 84% of the studied women reported a decrease in the quality of their work due to endometriosis and its symptoms [16]. Many women reported that they accomplished less than expected – 64% of them attributed it to physical limitations, 63% to emotional problems resulting from the experienced symptoms. Most respondents (66%) felt that because of the endometriosis the range of work-related activities they could perform was limited [10]. Almost 40% of the studied women faced professional consequences – their professional development was inhibited due to high rates of absenteeism and/or low performance (N = 15), they were not promoted (N = 8), did not receive merit or excellence bonuses (N = 3), missed professional seminars (N = 2), lost clients (N = 1), were "totally incapacitated" (N = 3), dismissed or they quit the job (N = 3) [16].

In the study of Nnoaham et al. [24] the productivity loss was higher among women with endometriosis than in the case of the symptomatic control group without endometriosis (11±12.2% vs. 8±10.2% of productivity loss).

Productivity loss caused by endometriosis-related symptoms

The reviewed studies referred to productivity loss as measured by absenteeism (missed working time) and presenteeism (reduced work effectiveness due to coming to work despite experiencing health problems and symptoms).

Long sick leaves were more common among women with endometriosis than among women of general population [8]. Over 20% of the suffering women and 8% of the healthy women reported sick leaves lasting 25–100 days. Sick leaves lasting 100–365 days were taken by 6% of the suffering and 3% of the healthy women [8].

In the paper by Fagervold et al. [9], 44% women took 0.9±1.7 sick leaves due to endometriosis-related symptoms per month on average.

Fourquet et al. [16] showed that due to inability to perform physical activities, the suffering women missed 3 working days a month on average (±3.7), which yields over a month of absence a year. The authors also calculated the days of absence due to treatment, operation and rehabilitation to 19 days a year (±19.3). It occurred that the absence of women with endometriosis

was longer than among people suffering from headaches, arthritis or backache. At the same time, 69% of the respondents admitted that they continued working despite the experienced pain.

In the other study of Fourquet et al. [10] the authors calculated that the average length of absence equaled less than 1 working day a week (7±9 h), which means nearly 20% of the whole average working week. In contrast, the average number of missing working hours due to other reasons (e.g., holidays) equaled 4 h (±10 h).

A study by Nnoaham et al. [24] showed significantly higher presenteeism (coming to work despite being ill) among women with endometriosis than in the case of the symptomatic control group without endometriosis (6±7.9 h/week vs. 5±6.7 h/week).

Caserta et al. [25] showed that average absence due to endometriosis equaled 2±5.3 h within the week preceding the study. The number of hours worked within the 7 days preceding the study amounted to 34±12.4 on average (in a 40-h working week).

Soliman et al. [23] calculated that women lost 1.1 work h/week and 6.6 days/year on average because of absenteeism; and 5.3 work h/week and 31.8 days per year due to unproductive days at work (presenteeism).

Based on the results, it may be concluded that the absence due to endometriosis amounted to approx. 1 working day a week on average.

CONCLUSIONS

Summary of the evidence

The presented review shows that the research directly referring to the impact of endometriosis on work is surprisingly scarce, given the negative consequences of endometriosis on occupational functioning and their financial costs. The previous research on the impact of endometriosis on professional life of the suffering women lacks the established methodology and the differences in the design of these studies make it difficult to compare the findings. At the moment, there are too few studies to do a meta-analysis. Despite little empirical material so far, we believe the existing studies provide valuable conclusions and cues for researchers willing to undertake that issue in the future studies.

To summarize, Hansen's et al. study [8] indicated pain and diagnostic delay as predictors of poor ability to work and sense of guilt as a mental consequence of inability to work. These authors also recognized long-term consequences of the diagnostic delay – 1 in 4 women who assessed their work ability as poor got their diagnosis 7–8 years after the occurrence of the first symptoms. Long diagnostic delay makes the disease develop and produce more symptoms and more irreversible changes. Thus, we believe that the diagnostic delay should become an issue of quantitative studies to determine the contribution of patients' behavior ("biting the bullet" attitude, self-treatment with easily accessible painkillers, postponing the decision to see the doctor, etc.) and the contribution of the attitude of doctors (ignoring patients' symptoms, postponing the diagnostic procedures possibly due to economic reasons).

Alarmingly, Fourquet et al. [16] recognized little awareness of endometriosis – 65% of the studied patients had never heard of the disease before the surgery and had never suspected that they had had endometriosis. The awareness of endometriosis, both among patients and their families, is crucial to avoid many phenomena related to this disease, e.g., the diagnostic delay, but also to improve social life of the suffering women. For many women describing the pain and proving its onerousness is difficult. This makes other people unaware of their suffering. Greater social awareness of endometriosis would help these women to be more open and feel more comfortable to talk about the disease and its symptoms. Thus, others would have more understanding for the suffering women, be less ignorant or less willing to suspect that they simulate or exaggerate their pain. Feeling more compassion from other people, women would be more courageous to participate in social life despite their symptoms.

The reviewed studies also draw attention to some methodological difficulties in studying the relationships between endometriosis (or any other chronic disease) and its impact on professional life. First, Nnoaham et al. [24] noted that work productivity loss and other variables related to occupational functioning were measured shortly before the operation (weeks before), which could significantly influence the responses. Moreover, the declared number of days of absence at work might have resulted from the perceived symptoms at that moment of the study. The fact that women were waiting for the operation might suggest severe stages of the disease, which could significantly confound the measuring outcomes. On the other hand, this situation might have caused these women to suffer less, because they had already received the diagnosis and expected a relief after the operation.

We believe that research on mental consequences of living with endometriosis needs to consider the specificity of the situation and life circumstances of

women at the moment of the study (e.g., exacerbation of symptoms, waiting for the operation, or infertility treatment).

A reliable estimation of work absence or costs of treatment of endometriosis poses another methodological challenge. Such variables as sick leaves, the date of diagnosis, the number and types of medical procedures, money spent on medications are burdened with a recall bias. Thus, the researchers should attempt to have the access to medical records.

The time since diagnosis has been included only in 1 of the reviewed studies [22]. Since diagnostic delay plays a critical role in the progression of the disease, time that has passed since the occurrence of the first symptoms and the date of diagnosis should be controlled in the studies on endometriosis. On the one hand, the longer one lives with the diagnosis of chronic disease, the longer they live with the burden of the disease. On the other hand, it is the time given to adapt to the disease and its consequences. We consider the influence of years of living with endometriosis on mental health and social functioning as a field for further scientific exploration.

Considering the previous studies on women suffering from endometriosis, we believe that further research in this group of patients should also focus on predictors of adaptive functioning or post-traumatic growth. We believe that post-traumatic growth in this group of patients is possible and finding any possible positive consequences of living with this difficult disease would be beneficial.

Limitations

The above review has also its limitations. We searched only for papers written in English. Probably, some local researchers also undertake the issue of the impact endometriosis on occupational functioning but the results might not be published in English or in peer-reviewed journals. Moreover, the inclusion criteria used in this systematic review were relatively strict – we were looking specifically for papers describing quantitative studies on the impact of endometriosis at paid work. Probably, other papers (for instance based on qualitative studies) could also enhance the discussion on the issue.

Summary

We recommend further studies on the impact of endometriosis on occupational functioning. Yet, we believe researchers should no longer ask whether endometriosis has an adverse impact on the work life of the suffering women because it has already been unambiguously confirmed. More urgently, they should search for individual and organizational correlates of the optimal occupational functioning despite the illness. Especially, studies on the attitude and awareness of the people surrounding women with endometriosis constitute an important future research direction.

Indicating the range of productivity loss or work absence in this group and its relation to economic costs for national budgets is another important issue because nothing is that persuasive as money. Unlike in some other countries [23], such calculations have not been done in Poland yet. We believe that the arguments based on exact figures would be the most convincing for stakeholders (politicians, insurers, healthcare professionals and employers) to undertake preventive and corrective measures such as improving the diagnostic processes or increasing the social awareness of the endometriosis.

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