Healthcare Consumption and Cost Estimates Concerning Swedish Women with Endometriosis

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Keywords

Endometriosis · Healthcare consumption · Cost estimates · Absenteeism · Presenteeism · Chronic pelvic pain

Abstract

Introduction: Endometriosis is known for its substantial effect on women's wellbeing and quality of life. In order to evaluate disease burden, treatments and health services, assessments of healthcare consumption and cost estimates are necessary. **Objectives:** The aim of this study was to estimate healthcare consumption and annual cost per woman with endometriosis in Sweden and to examine healthcare consumption and costs in different age groups. **Methods:** A questionnaire was distributed to 400 members of the Endometriosis Association and to 400 randomly selected women with surgically confirmed endometriosis. Official statistics were obtained via correspondence, publications, and database searches. **Results:** Analysis of the 431 returned questionnaires showed that women under 30 years utilized more inpatient and outpatient care than older women. The mean annual cost among all women was EUR 8,768/woman. The direct healthcare cost of managing the disease was EUR

4,282, while the indirect cost was EUR 4,486. Absence from work was reported by 32% of the women, while 36% reported reduced time at work because of endometriosis. **Conclusion:** Our results confirm the substantial negative effect of endometriosis upon women's lives and their relatively high healthcare consumption.

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Introduction

Endometriosis, a gynecological disease defined as the presence of ectopic endometrial-like tissue [1], affects approximately 10% of women of reproductive age [2]. The disease is complex and heterogenic, and a combination of immunological, hormonal, genetic, and epigenetic factors may all be involved in the etiology [3]. The symptoms are variable and often nonspecific, which makes diagnosis of the condition challenging. A definitive diagnosis can only be made with a positive histological biopsy sample. For practical and economic reasons, this is not always possible, which could be a factor behind the observed diagnostic delay, especially in primary care [1]. The delay

can be up to 10 years from symptom onset to diagnosis [4–7].

Most endometriosis symptoms involve pain, which affects both quality of life and productivity [4], resulting in a significant financial impact. The direct healthcare costs of managing the disease (inpatient, outpatient, surgical, drug costs etc.) and the indirect costs (loss of productivity at work) are substantial and have been the focus of 3 systematic literature reviews [8–10]. The most recent included 12 studies published between 2000 and 2013 from the USA, Austria, Belgium, Brazil, Canada, Finland, Germany, and Italy. Two of the studies included data from 10 countries. Because of great variation in methodology, healthcare systems, and costs, the direct and indirect cost estimates varied widely. The estimates of direct costs ranged between USD 1,109/woman/year in Canada to USD 12,118/woman/year in the United States. The indirect costs were also highest in the United States, at USD 15,737/woman/year, while the lowest estimate was found in Austria, at USD 3,314 woman/year [10].

Information on healthcare consumption and estimates of costs is important in the work of clarifying disease burden and improving the efficiency of health-service consumption and treatments. In Sweden, no cost estimates are available, as far as we know. Therefore, the aim of this study was to estimate healthcare consumption and annual cost per woman with endometriosis in Sweden and to examine healthcare consumption and costs in different age groups.

Material and Methods

This article is based on material from a large retrospective cross-sectional study performed in Sweden in 2010 [11], in which a self-administered questionnaire was distributed to 400 randomly selected women with surgically confirmed endometriosis. They were attending 3 middle-sized gynecological clinics in Sweden, one large clinic and one endometriosis specialist clinic. The questionnaire was also sent to 400 members of the Endometriosis Association, Sweden. In total, 800 questionnaires were sent out.

The questionnaire was developed after 2 focus-group meetings with members of the Endometriosis Association and was inspired by a validated generic questionnaire, Short Form Health Survey 36 [12] (known as SF-36) and the disease-specific questionnaire Endometriosis Health Profile-30 [13]. It included 53 questions (1–12 months retrospective or questions such as “Have you ever...?” and “Are you presently...?”) divided into 6 categories: (a) physical and psychological symptom description, (b) contacts with physicians/nurses, (c) treatment, (d) work/education patterns, (e) relationships and fertility, and (f) demographics. The questions covered the number of contacts and/or visits to general physicians, gynecologists, fertility specialists, midwives and nurses in primary care, planned hospital visits, visits to an emergency department, surgical

procedures, and days in hospital as a result of endometriosis during the previous 12 months. For questions regarding inability to work, study, or perform everyday tasks because of endometriosis, the time period covered the previous 4 weeks in order to reduce recall bias. If the women did not respond to the questionnaire within 3 weeks, a reminder was sent.

Official statistics were obtained via correspondence, database searches, and publications from The Swedish Association of Pharmaceutical Industries, The National Board of Health and Welfare Statistics Sweden, The Swedish Insurance agency, The Swedish Association of Local Authorities and Regions, and The Swedish eHealth Agency.

Cost Estimates

All costs were originally obtained in connection with financial year 2010, except for drug costs, for which the financial year was 2015, since no database for previous years was available. All costs (in euros) were recalculated to present-day (2019) values, taking the monetary inflation under consideration, unless otherwise specified.

Costs per patient were obtained by multiplying the mean resource used by the cost per unit. Cost per unit was a mean cost computed either from official databases or from pricelists from all Swedish healthcare regions. A patient fee of EUR 8.38 was added to the cost of patient days (varying costs in different regions; EUR 8–10/day).

The mean salary for Swedish women of all ages was used. Since Sweden has a minimum employee benefit, 34% was added to the salary cost. When estimating indirect costs the lost wages method was used [14].

The questionnaire included a self-reported estimation of productivity loss, but only costs derived from absenteeism were included in the results, since short-term self-reported absenteeism seem to correlate well with administrative data [15], while instruments to estimate presenteeism need further validation [16, 17].

Costs arising from drug consumption were calculated by asking which drugs the women had bought in the previous 12 months for the treatment of endometriosis and pain (both prescription and over-the-counter drugs) and the number of times for each type of medication. The pharmaceuticals were then grouped according to the ATC classification system, using the lowest cost for each ATC code.

To estimate the costs of surgical procedures, the women were asked to state the numbers and types of surgery. Using DRG codes 358 and 359 and operation codes for Female genital organs and Digestive system and spleen in the NOMESCO Classification of Surgical Procedures Version 1.16 with any endometriosis ICD-10 code (N80.0–N80.9) in a database containing all reported Swedish cases in 2010, the mean cost of surgery was computed. The cost of hospitalization associated with surgery was extracted, since patient days were counted as a separate cost unit.

Statistical Analyses

Based on previous studies and experiences, we assumed that a sample size of 400 women would be sufficient to provide an estimate of resource subjects. Assuming a 50% response rate, 800 questionnaires were sent out. The 400 recruited participants from the clinics were randomly selected from a larger group of patients by randomization carried out by an external statistician company

Table 1. Demographic and descriptive data on participants subdivided after age group

	<30 years	30–39 years	≥40 years	Total
Age, years, <i>n</i> , mean ± SD	93	186	144	423
Age	25.2±3.1	35.3±2.6	45.9±5.7	36.7±8.7
Age at first visit to a doctor due to endometriosis	18.3±4.5	23.3±7.3	29.8±10.8	24.2±9.3
Age when diagnosed by a doctor	22.5±3.4	28.9±5.2	34.3±8.3	29.3±7.5
Marriage status <i>n</i> (% of answers)	89	183	141	413
Single	23 (26)	25 (14)	24 (17)	72 (17)
Married/cohabitation	52 (58)	148 (81)	99 (70)	299 (72)
Separate living	10 (11)	8 (4)	12 (9)	30 (7)
Divorced/separated	4 (4)	2 (1)	5 (4)	11 (3)
Widow	–	–	1 (0.1)	1 (0.2)
Highest level of education <i>n</i> (% of answers)	93	185	143	421
Primary school	9 (10)	5 (3)	6 (4)	20 (5)
High school	33 (35)	42 (23)	48 (34)	123 (29)
Residential college	5 (5)	4 (2)	5 (3)	14 (3)
Vocational education	16 (17)	32 (17)	19 (13)	67 (16)
University	30 (32)	102 (55)	65 (45)	197 (47)
Main occupation during the previous 4 weeks <i>n</i> (% of answers)	83	163	134	380
Paid employment ≥30 h/week	33 (40)	101 (62)	76 (57)	210 (55)
Paid employment <30 h/week	14 (17)	12 (7)	13 (10)	39 (10)
Student	21 (25)	9 (6)	2 (1)	32 (8)
Managing household tasks	1 (1)	7 (4)	3 (2)	11 (3)
Unemployed	2 (2)	2 (1)	4 (3)	8 (2)
Early retirement or disability pension	2 (2)	3 (2)	16 (12)	21 (6)
Retired	–	–	2 (1)	2 (1)
Other	10 (12)	29 (18)	18 (13)	57 (15)
Duration of endometriosis symptoms <i>n</i> (% of answers)	93	186	144	412
<6 months	2 (2)	1 (1)	3 (2)	6 (1)
6–12 months	5 (5)	3 (2)	2 (1)	10 (2)
1–2 years	2 (2)	7 (4)	2 (1)	11 (3)
2–5 years	24 (26)	24 (13)	14 (10)	62 (15)
5–10 years	26 (28)	36 (19)	20 (14)	82 (20)
>10 years	30 (32)	112 (60)	99 (69)	241 (58)

(Statisticon AB). The study population was divided into 3 pre-defined age groups (<30, 30–39 and ≥40 years).

Variables on continuous scales are described as mean, SD, and range and nominal data as frequency and percentage. In our logistic regression models, the age group 30–39 constituted the reference group. The results of logistic regression are given as ORs with 95% CIs. The level of statistical significance was set at $p < 0.05$.

IBM SPSS Statistics version 20 was used for the analyses. An external statistician conducted logistic regression analyses, using R version 3.2.2. (Statisticon AB).

Results

Out of the 800 self-administered questionnaires distributed, 449 (56%) were returned, and after correcting for doublets, 431 remained. Of the evaluable question-

naires, 199 were from the 5 participating clinics and 232 were from the Endometriosis Association. The vast majority of the women recruited from the Endometriosis Association (96.8%) reported that they had been diagnosed by a gynecologist.

A summary of patient characteristics is shown in Table 1. The mean age of all women was 36.7 years, 24.2 years at the time of the first visit to a doctor because of endometriosis-associated problems, and 29.3 at diagnosis, a delay of 5.1 years. During the past 12 months, 27% reported that they had undergone surgery for endometriosis.

The mean annual consumption of healthcare resources differed between age groups and apart from visits to fertility specialists, younger women utilized more inpatient and outpatient care. Almost half of the women under 30 years old had visited their general

Table 2. Logistic regression with ORs and 95% CIs for the likelihood of having used healthcare resources or receiving pharmaceutical benefit during the previous 12 months. The age group 30–39 years constitutes the reference group

	OR	95% CI	<i>p</i> value
General practitioner, visit, years			
<30	1.69	1.01–2.84	0.047
≥40	1.03	0.65–1.65	0.893
General practitioner, telephone contact, years			
<30	2.36	1.37–4.06	0.002
≥40	0.86	0.50–1.47	0.580
Nurse or midwife, visit, years			
<30	1.70	0.99–2.95	0.056
≥40	0.31	0.16–0.61	0.001
Nurse or midwife, telephone contact, years			
<30	1.85	1.05–3.27	0.035
≥40	0.46	0.24–0.88	0.020
Gynecologist, visit, years			
<30	1.69	0.88–3.25	0.113
≥40	0.61	0.38–1.00	0.051
Gynecologist, telephone contact, years			
<30	1.81	1.07–3.07	0.028
≥40	0.56	0.36–0.88	0.012
Fertility specialist, visit, years			
<30	0.32	0.16–0.65	0.002
≥40	0.16	0.08–0.34	<0.001
Emergency room visit, years			
<30	2.75	1.61–4.68	<0.001
≥40	0.60	0.34–1.06	0.080
Other planned hospital visit, years			
<30	1.44	0.87–2.38	0.160
≥40	0.72	0.46–1.12	0.147
Admission to hospital, years			
<30	1.92	1.14–3.24	0.015
≥40	0.63	0.37–1.06	0.083
Surgery for endometriosis, years			
<30	2.07	1.22–3.53	0.007
≥40	0.83	0.49–1.40	0.483
Pharmaceutical benefit, years			
<30	1.67	1.00–2.81	0.050
≥40	0.64	0.39–1.05	0.079

physician during the previous year (overall range 0–30). A majority had visited gynecologists and/or had had telephone contact. Emergency room visit frequency was high among the young, were almost half having had at least one visit, and 9% having had >3 visits (overall range 0–11). Moreover, 42% had been admitted to hospital and 41% had undergone surgery. Every third woman aged 30–39 years had visited a fertility specialist at some time the previous year, and almost half of women aged 30–39 had ever experienced assisted reproduction.

The higher healthcare consumption in the youngest age group was also reflected in the logistic regression analyses concerning the likelihood of having used healthcare resources or having received pharmaceutical benefit during the previous 12 months. Many of the outcomes showed statistically significant differences (see the ORs in Table 2). Younger women showed higher ORs as regards visiting (OR 1.69, 95% CI 1.01–2.84) and having telephone contact (OR 2.36, 95% CI 1.37–4.06) with general practitioners. They also had more telephone contacts with both nurses/midwives (OR 1.85, 95% CI 1.05–3.27) and gynecologists (OR 1.81, 95% CI 1.07–3.07). However, the higher odds regarding gynecologist visits were not statistically significant. They also had higher odds as regards emergency room visits (OR 2.75, 95% CI 1.61–4.68, admissions to hospital (OR 1.92, 95% CI 1.14–3.24), and surgery (OR 2.07, 95% CI 1.22–3.53).

The oldest women (≥40 years) showed lower odds as regards nurse/midwife visits (OR 0.31, 95% CI 0.16–0.61) and telephone contacts with both nurses/midwives (OR 0.46, 95% CI 0.24–0.88) and gynecologists (OR 0.56, 95% CI 0.36–0.88).

As shown in Table 3, the mean total annual cost was EUR 8,768/woman. Reduced work productivity accounted for a substantial part of the cost, as 32% of the women reported absence from work because of endometriosis, and 36% reported reduced time at the workplace because of the condition. Major direct cost drivers were hospitalization (EUR 1,438/woman/year), surgery (EUR 749/woman/year), and visits to gynecologists (EUR 591/woman/year). Loss of productivity was estimated to cost EUR 4,486/woman/year (Table 3).

Costs related to visits to fertility specialists were highest among women aged 30–39. All other costs were highest in the youngest age group. Women aged 30–39 showed the lowest total cost (EUR 7,702/woman/year; Table 3). Figure 1 demonstrates the distribution of direct, indirect, and pharmaceutical costs divided into the 3 age groups and the whole study population.

Discussion

The results showed that both healthcare consumption and cost estimates were highest in the youngest age group. They visited an emergency department more than once a year because of endometriosis-related symptoms, at an age where most people rarely need emergency care. Assuming a 3–5% prevalence of symptomatic endometrio-

Table 3. Mean cost per woman per year in each age group and in the whole study population

	Under 30 years	30–39 years	Over 40 years	All ages
Direct costs, EUR				
Visits to gynecologist	932	574	410	591
Visits to fertility specialist	72	305	58	172
Visits to emergency room	350	180	79	183
Other planned hospital visits	455	250	239	288
Visits to general practitioner	259	164	153	179
Visits to nurse or midwife	65	40	15	36
Telephone contact with general practitioner	184	70	97	102
Telephone contact with gynecologist	465	264	177	275
Telephone contact with nurse or midwife	132	89	36	79
Cost of inpatient care-based patient days	2,022	1,358	1,227	1,438
Pharmaceuticals, and so on	18	14	9	13
Pharmaceuticals, prescription	78	44	15	41
Pharmaceuticals, benefit	193	141	101	136
Surgery	1,203	658	635	749
Indirect costs, EUR				
Loss of productivity	6,172	3,553	4,773	4,486
Total, EUR	12,601	7,702	8,025	8,768

sis in women of fertile age (15–50 years), our data suggest that 39,000–65,000 emergency department visits could be related to endometriosis annually in Sweden.

There are several possible reasons why younger women with endometriosis showed higher healthcare consumption than older women. First, younger women might not have developed strategies to manage their symptoms on their own to the same extent as women with a longer disease experience. Second, younger women are probably more likely to find information on the internet where they might be encouraged to seek care. It might also be that younger women do not accept pain symptoms as a normal state and they become active care seekers.

The high healthcare consumption among the young is concordant with the results of another Swedish study based on data from the same questionnaire as described herein, where young women with endometriosis experienced more symptoms and had a lower quality of life compared with older women [11].

Women of 30–39 years of age stood out in 2 areas. They had the lowest mean level of absence from work and were the most likely to have paid visits to fertility specialists. The latter observation was expected, since in Sweden, women in the other age groups often have a lower wish to conceive. However, we were surprised to find the lowest mean level of sick leave in this age group. The results might be affected by a high rate of pregnancies, childbirth, and periods of breast-feeding and parental leave in

Fig. 1. Donut chart: inner to outer circle representing women of <30 years, 30–39 years, ≥40 years, and the whole study population, respectively.

the 30–39-year age group, leading to less sick leave, as the women may already be absent for other reasons. Another possible explanation may be that women in this age group are at a stage of their professional careers where they are more unwilling to be on sick leave.

Diagnostic delay was found to be around 5 years. This was measured as doctor's delay, from the first visit to a doctor because of presumed endometriosis-related symptoms until being diagnosed with endometriosis. Diagnostic delays also generate additional costs, as women with endometriosis utilize more healthcare than controls, both before and after diagnosis [18]. By improving diagnostics and raising awareness of the condition, both among women and physicians, recognition and diagnostic delay could be reduced, perhaps letting women come to terms with their sickness at an earlier stage and start developing coping mechanisms. This might increase productivity and result in better quality of life.

The high costs of endometriosis care are well in line with what previously has been shown, where reduced work productivity and direct in-patient costs, including surgery, are identified as the major cost drivers [10]. Women in the youngest age group generated over 60% higher costs compared with the older women. Because of the chronic nature of the disease, one would expect that the symptoms, and therefore the cost, would progress with age. A possible explanation for our results is that the older women might have developed coping mechanisms over time that could decrease the impact of the symptoms. This has also been suggested earlier [19, 20].

Many women in the study had undergone assisted reproduction. The need for assisted reproduction among endometriosis patients is well known, as infertility affects 30–50% of all women with endometriosis. They are also at higher risk of decreased ovarian reserve, as a result of the disease pathophysiologic mechanisms [21].

The direct cost EUR 4,282 can be compared with data published by the Swedish Association of Local Authorities and Regions, wherein they reported an annual healthcare direct cost of EUR 1,951 for an average female Swede. Our total annual cost of EUR 8,768/woman can also be compared with other recent Swedish studies reporting annual costs in other benign persistent conditions: annual total cost of migraine was EUR 10,790 (EUR rate 2013) per patient [22], annual total cost of Irritable bowel syndrome with predominant constipation was EUR 12,873 (EUR rate 2019) per patient [23], and mean total cost of low back pain was EUR 2,753 (EUR rate 2016) per episode [24].

The indirect cost of reduced work productivity contributed less to the total cost compared with what others have shown, 46–59 vs. 66% [25] and 78% [26]. In contrast, Prast et al. [27] estimated a figure of only 27% of total cost due to loss of productivity. These differences might arise from methodological differences as well as different social security systems. Costs arising from presenteeism are excluded from our results, which is likely to have led to underestimation of the total cost, and is a limitation of the study. Furthermore, we did not include indirect cost like transportation and so on, which also may result in an underestimation of the cost.

To obtain healthcare consumption and cost estimates not only from women with the most severe symptoms, we included women with surgically verified disease as well as women from the Endometriosis Association who have self-reported endometriosis. This can be considered both as a strength, since they are more likely to represent the less severe endometriosis patients not having had a need of surgery, and a weakness, considering the risk of including women without endometriosis. This constrains us from making any comparisons between the groups. Another limitation is that the inclusion of women from the Endometriosis Association might have resulted in a selected group of individuals more driven and interested in their own health, which in turn might affect the results. Also, we did not study the relation of severity and duration of endometriosis to costs, which may have provided an interesting dimension to the results.

The response rate (56%) may seem low, but since we sent out 800 questionnaires, we had a lot of answers even with the relatively low rate. A response rate >50% is generally considered acceptable [28]. A reminder was sent to participants who did not answer the first questionnaire.

Among our responders, there was a high amount of women with a university degree, which is not representative of the total Swedish population. Because of differences in healthcare systems and socioeconomic variance, the cost estimates may be of limited generalizability.

In conclusion, we as well as others have shown that women with endometriosis show a high level of healthcare consumption, leading to high direct costs. We have now, for the first time, shown that women under 30 years of age with endometriosis consume more healthcare resources, thus leading to higher costs per year compared with women over 30 years.

Increased awareness of endometriosis among healthcare professionals as well as the general population is of public interest, as awareness may prevent diagnostic de-

lays and thereby not only lead to decreased costs but also to an improvement the quality of life for a large group of women in their prime years. Since a majority of women with endometriosis experience symptom relief with relatively cheap drugs, such as over-the-counter analgesics and hormones, and the current recommendation is to suppress symptoms even without a definite diagnosis, increased awareness could also diminish costs by reducing surgical procedures. Furthermore, clinic should probably strive toward working in multiprofessional teams around the most complicated cases. This could strengthen the bio-psycho-social caring aspects of this chronic disease, which may lead to less healthcare consumption and costs.

Future studies could focus on women's experiences of the quality of endometriosis healthcare and on what aspects of endometriosis care may be most cost-effective to improve in relation to experiences, personal suffering, and economic burden.

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Statement of Ethics

The study was approved by the Ethics Review Board in Uppsala, Sweden (Dnr 2010/216), which ensures that it complies with the guidelines for human studies and was conducted in accordance with the World Medical Association Declaration of Helsinki.

Disclosure Statement

A larger study, on which this paper is based, was carried out in association with Bayer Healthcare 2009–2010. Bayer has legal rights to the questionnaire and data used in this paper. Lena Lövkvist was employed by Bayer at the time of the study.

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Author Contributions

H.G. and G.H.S. contributed equally to this work. G.H.S., L.L., and M.O. designed the study and collected data. All authors conducted the analyses and discussed results and conclusions. H.G. was the leading writer of the manuscript, but all authors contributed in the writing. The final version was approved by all authors.

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