Age-Related Differences in Quality of Life in Swedish Women with Endometriosis

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Abstract

Objective: The purpose of this observational study was to evaluate the impact of endometriosis on quality of life (QoL) in different age groups of Swedish women with endometriosis. Recruitment occurred through the Endometriosis Association (Sweden) (n=400) and five gynecology departments of five Swedish hospitals (n=400). All voluntary female members of the patient organization and patients attending specialist clinics due to endometriosis (n=800) were invited by sending them a questionnaire. An age- and gender-matched sample of the general Swedish population was used as a control group when analyzing SF-36 data.

Methods: A postal questionnaire (including SF-36) was distributed to 800 women. The questionnaire was evaluated by using descriptive statistics, and SF-36 was evaluated according to standard methods.

Results: Of the 449 (56%) self-administered questionnaires returned, 431 (96%) contained evaluable answers. Women with endometriosis have significantly lower SF-36 scores than the general female Swedish population, and the score depends on the women’s age. Younger women experience more symptoms and have a lower QoL score compared with women in the older age group.

Conclusion: Women with endometriosis have significantly lower QoL than the general female Swedish population and it depends on the women’s age, where younger women express more symptoms and have a lower QoL compared with women in the older age group. Our results highlight that more healthcare resources should be focused on younger women with endometriosis.

Introduction

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus. The lesions cause inflammation, which is associated with pain and other symptoms such as subfertility. The disease is most common in women of fertile age, with an estimated prevalence between 3.5% and 10% in the general female population and as high as 50% in women with infertility. Retrospective studies report a diagnosis of endometriosis in 25%–38% of adolescents with chronic pelvic pain.

Common symptoms in women with endometriosis include dysmenorrhea, lower abdominal pain, and deep dyspareunia. There are several reports concerning heredity, and the relative risk of having endometriosis has been reported to be elevated in first-degree relatives. Many women accept their pelvic pain, dysmenorrhea, and dyspareunia as part of their lives, acknowledging that their grandmothers, mothers, and sisters have had the same problems. Despite a decrease in quality of life (QoL), they may have difficulties in distinguishing what should be considered as “normal” and “abnormal.” It is also well known that women with endometriosis experience a delay in diagnosis ranging from 3 to 11 years. A delay in diagnosis may be a result of lack of more substantial symptoms and self-treatment of dysmenorrhea and other types of pain with oral contraceptives (OCs) and painkillers.

Women with symptomatic endometriosis have a decreased QoL and negative adjustments in their academic careers, work careers, and social lives. Endometriosis has also been the subject of several studies regarding cost, burden of illness, and QoL. These studies have been performed among women attending tertiary hospitals, or specialized endometriosis centers, which implies a more severe disease. Also, in addition to diagnosis based on laparoscopy, these women are probably subject to more extensive treatment, both medical and surgical. The response rates in many of these studies have been low, which increases the risk of selection bias.

Study Aim and Objective

The impact of endometriosis in different age groups regarding QoL has not been studied in a Swedish population. This study aims at investigating the age-related impact of endometriosis on QoL.

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Materials and Methods

Study design

A retrospective, self-administered patient questionnaire-based study regarding healthcare resources, burden of illness, and QoL was performed in Sweden in 2010. Following two focus-group meetings with members of the Endometriosis Association (Sweden) in 2009, the protocol and questionnaire were developed. Information collected was based on 53 questions (1–12 months retrospective or questions such as “have you ever” and “are you presently”) divided in six categories and included the following: (1) physical and psychological symptom description (8 questions), (2) doctors’ appointments (15 questions, 12 months recall), (3) medical treatment and coping strategies (5 questions, 12 months recall), (4) work/education patterns (10 questions, 1–3 months recall), (5) relationships, including fertility (12 questions, present to 12 months recall), and (6) demographics (3 questions). Lay terms were used for all medical conditions for better comprehension. In addition, SF-36 version 1 (36 questions) was used as a standardized measure of QoL. Questionnaires were sent to all members of the Endometriosis Association (Sweden) \( n = 400 \), to randomly selected women attending gynecological clinics at three medium-sized hospitals in northern, middle, and southern Sweden (Östersunds sjukhus, Höglandssjukhuset Eksjö, Hallands sjukhus Kungsbacka, respectively), one large clinic in Stockholm (Karolinska University Hospital, Huddinge), and one endometriosis specialist clinic at the National Endometriosis Centre (Akademiska University Hospital, Uppsala). Random selection of patients attending clinics was achieved by following a list of numbers developed by an external part (Statisticon AB). The questionnaires were anonymous.

Ethics approval

The study was approved by the Ethics Review Board (Uppsala, Sweden) (Dnr 2010/216). A response to the questionnaire was regarded as implicit consent to participate in the study.

Population

We included all members of the patient organization in 2010 \( n = 400 \), where the vast majority (96.8%) of cases were diagnosed by a gynecologist. We also randomized patients with surgically verified endometriosis attending clinics during 2007–2010 \( n = 400 \). For description of symptoms, a brief medical history, including data on disease symptoms, care-seeking events, and use of medication, was obtained through the questionnaire. The study group was divided into three predefined age groups (<30, 30–39, and ≥40 years), as well as by origin of the respondents (patient association or clinics), and analyzed separately.

SF-36 Health Survey

The SF-36 questionnaire is a generic QoL questionnaire used to assess two major aspects of health: physical and mental health. It comprises 36 items within 8 multi-item scales (general health/change in health, physical function, physical role function, emotional role function, pain, energy/vitality, social function, and mental health). Each category covers two different dimensions (physical, psychological).

For each of the categories, a subscale score can be calculated; the total score ranges from 0 to 100, and dimensional scores over the entire profile can be computed. Higher scores indicate better QoL. SF-36 version 1 (4 weeks retrospective) was used as a self-administered Swedish version (licensed from Quality Metric, Inc.). The SF-36 data were analyzed according to standard procedures, with results presented on a scale of 0–100. An age- and gender-matched random sample \( n = 1192 \) from the Swedish SF-36 normative database population \( n = 8930 \) was used as reference group, where three age- and gender-matched controls were selected for each patient in the study when analyzing SF-36.

Statistical methods

In general, all data were evaluated according to type, that is, descriptive statistics for continuous variables and frequency tables for categorical data. For SF-36 scores presented in graphs, means are presented along with 95% confidence intervals and a \( p \)-value of <0.05 was considered statistically significant. The reference population (age- and gender-matched Swedish female population) has only aggregated data. Therefore, in comparisons involving the reference population, confidence intervals were compared instead of hypothesis testing levels and nonoverlapping confidence intervals were considered to represent a significant difference. The confidence intervals for the aggregated data of the reference population are narrower since the number of women included was three times higher than the study population. For comparisons within study data, \( p \)-values presented are from independent sample \( t \)-tests. One-way analysis of variance was carried out for comparison of several groups, complemented with \( p \)-values from Tukey’s HSD (honestly significant difference) test for pair-wise comparisons. The full analysis set (FAS) was defined as the set of all subjects who returned the questionnaire. Owing to the character of the study, this was defined as the intention to treat population. The FAS was the primary analysis set, and all analyses presented were performed on this set.

Results

Response rate

Out of the 800 self-administered questionnaires distributed (including SF-36), 449 (56%) were returned and 431 (96%) contained evaluable answers. Of the evaluable questionnaires, 232 (54%) were from the Swedish Endometriosis Association and 199 (46%) from the five participating clinics.

Description of symptoms

In general, younger women reported more symptoms or endometriosis-related problems compared with women in the older age groups (Fig. 1). More than half (56.6%) of all the women reported that they had had endometriosis symptoms for more than 10 years (Table 1). Early doctors’ consultation was more common in younger groups. The mean age at first visit to a doctor because of symptoms of endometriosis was 24.2 years. The great majority (75.9%) was diagnosed at 20–39 years of age (median 29.3 years) (Table 1). Some of the most commonly reported symptoms or findings were dysmenorrhea (40.6%), ovarian endometriomas (66.4%), pain during defecation (59.6%), and pain when standing up (55.2%). Pain when
FIG. 1. Symptom description. Fourteen possible answers regarding symptoms and signs of endometriosis are symbolized as bars on the x-axis. Missing data: n = 14.

<table>
<thead>
<tr>
<th>Parameters</th>
<th>PA, n = 232 (53.8%)</th>
<th>Uppsala, n = 62 (14.4%)</th>
<th>Huddinge, n = 47 (10.9%)</th>
<th>Östersund, n = 26 (6.0%)</th>
<th>Kungsbacka, n = 35 (8.1%)</th>
<th>Eksjö, n = 29 (6.7%)</th>
<th>Total, n = 431</th>
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<tr>
<td>Age (mean, years)</td>
<td>36.4</td>
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<td>37.5</td>
<td>36.7</td>
<td>37.6</td>
<td>37.6</td>
<td>36.7</td>
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<td>Age at first doctor’s visit (mean)</td>
<td>22.5</td>
<td>26.0</td>
<td>27.1</td>
<td>26.3</td>
<td>26.8</td>
<td>24.7</td>
<td>24.2</td>
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<td>Age at diagnosis (mean)</td>
<td>28.6</td>
<td>29.5</td>
<td>31.8</td>
<td>29.7</td>
<td>32.0</td>
<td>27.8</td>
<td>29.3</td>
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<td>How long have you had symptoms?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>&lt;6 months</td>
<td>2 (0.9%)</td>
<td>1 (1.6%)</td>
<td>—</td>
<td>3 (11.5%)</td>
<td>—</td>
<td>2 (6.9%)</td>
<td>6 (1.4%)</td>
</tr>
<tr>
<td>6–12 months</td>
<td>1 (0.4%)</td>
<td>3 (4.8%)</td>
<td>3 (6.4%)</td>
<td>1 (3.8%)</td>
<td>—</td>
<td>2 (6.9%)</td>
<td>10 (2.3%)</td>
</tr>
<tr>
<td>1–2 years</td>
<td>2 (0.9%)</td>
<td>2 (3.2%)</td>
<td>1 (2.1%)</td>
<td>1 (3.8%)</td>
<td>1 (2.9%)</td>
<td>4 (13.8%)</td>
<td>11 (2.6%)</td>
</tr>
<tr>
<td>2–5 years</td>
<td>29 (12.5%)</td>
<td>14 (22.6%)</td>
<td>7 (14.9%)</td>
<td>5 (19.2%)</td>
<td>2 (5.7%)</td>
<td>5 (17.2%)</td>
<td>62 (14.4%)</td>
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<tr>
<td>5–10 years</td>
<td>47 (20.3%)</td>
<td>9 (14.5%)</td>
<td>11 (23.4%)</td>
<td>4 (15.4%)</td>
<td>8 (22.9%)</td>
<td>4 (13.8%)</td>
<td>83 (19.3%)</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>146 (62.9%)</td>
<td>31 (50.0%)</td>
<td>20 (42.6%)</td>
<td>11 (42.3%)</td>
<td>24 (68.6%)</td>
<td>12 (41.4%)</td>
<td>244 (56.6%)</td>
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<td></td>
<td></td>
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<td>Single</td>
<td>38 (16.4%)</td>
<td>11 (17.7%)</td>
<td>12 (25.5%)</td>
<td>3 (11.5%)</td>
<td>5 (14.3%)</td>
<td>3 (10.3%)</td>
<td>72 (16.7%)</td>
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<td>Married/in relationship</td>
<td>170 (73.3%)</td>
<td>41 (66.1%)</td>
<td>27 (57.4%)</td>
<td>16 (61.5%)</td>
<td>29 (82.9%)</td>
<td>22 (75.9%)</td>
<td>305 (70.8%)</td>
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<td>Living apart</td>
<td>14 (6.0%)</td>
<td>5 (8.1%)</td>
<td>2 (4.3%)</td>
<td>5 (19.2%)</td>
<td>—</td>
<td>4 (13.8%)</td>
<td>30 (7.0%)</td>
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<tr>
<td>Divorced or separated</td>
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<td>3 (4.8%)</td>
<td>2 (4.3%)</td>
<td>1 (3.8%)</td>
<td>—</td>
<td>—</td>
<td>11 (2.6%)</td>
</tr>
<tr>
<td>Widow</td>
<td>—</td>
<td>—</td>
<td>1 (2.1%)</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>1 (0.2%)</td>
</tr>
<tr>
<td>Education, n (%)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Primary school</td>
<td>10 (4.3%)</td>
<td>3 (4.8%)</td>
<td>2 (4.3%)</td>
<td>2 (7.7%)</td>
<td>1 (2.9%)</td>
<td>2 (6.9%)</td>
<td>20 (4.6%)</td>
</tr>
<tr>
<td>High school</td>
<td>57 (24.6%)</td>
<td>23 (37.1%)</td>
<td>12 (25.5%)</td>
<td>9 (34.6%)</td>
<td>12 (34.3%)</td>
<td>10 (34.5%)</td>
<td>123 (28.5%)</td>
</tr>
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<td>Residential college</td>
<td>4 (1.7%)</td>
<td>1 (1.6%)</td>
<td>3 (6.4%)</td>
<td>2 (7.7%)</td>
<td>2 (5.7%)</td>
<td>2 (6.9%)</td>
<td>14 (3.2%)</td>
</tr>
<tr>
<td>Vocational education</td>
<td>42 (18.1%)</td>
<td>6 (9.7%)</td>
<td>7 (14.9%)</td>
<td>2 (7.7%)</td>
<td>5 (14.3%)</td>
<td>6 (20.7%)</td>
<td>68 (15.8%)</td>
</tr>
<tr>
<td>University</td>
<td>116 (50.0%)</td>
<td>29 (46.8%)</td>
<td>19 (40.4%)</td>
<td>10 (38.5%)</td>
<td>15 (42.9%)</td>
<td>9 (31.0%)</td>
<td>198 (45.9%)</td>
</tr>
<tr>
<td>Full-time activity, n (%)</td>
<td>118 (50.9%)</td>
<td>32 (51.6%)</td>
<td>22 (46.8%)</td>
<td>11 (42.3%)</td>
<td>18 (51.4%)</td>
<td>11 (37.9%)</td>
<td>212 (49.2%)</td>
</tr>
</tbody>
</table>

aHighest level; bStudies, employment or similar.
PA, Patient Association (Endometriosis Association, Sweden).
standing up was especially frequently reported (78.5%) in the youngest age group (<30 years) but dysmenorrhea, pain not related to the menstrual cycle, and bladder-related pain were also more commonly reported by the youngest in this study population (Fig. 1).

Demographics

The demographics of individual study centers and the total study group are shown in Table 1. The mean age was 36.7 years (range 16–67 years) within the whole study population and it was similar across sites. The majority (77.8%) of women in the three age groups (<30, 30–39, ≥40 years) were married or in a relationship. A large proportion (45.9%) reported graduation from college or university, with the highest rate of academic graduates in the patient association (50%) and the lowest in Eksjö (31%). Almost half of the study population was full-time employees (49.2%). However, despite the fact that almost half of the study population was full-time employees, one fifth (20.4%) had at some point of their life either lost or quit a job because of their endometriosis-associated problems (Fig. 2). Many had chosen a different career (17.4%) or had reduced their working hours (24.6%) because of endometriosis. Almost 17% reported having refrained from promotion or further education (23.2%) as a result of the disease. Alterations in main daily occupation were commonly reported by all age groups. Women in the youngest age group reported, for example, being students more often (22.6% vs. 4.8% and 1.4%, respectively) and had refrained from or quit their education more often (34.4% vs. 21.0% and 19.4%) due to their endometriosis compared with the older age groups. Furthermore, the youngest women more frequently reported having lost or quit a job (26.9% vs. 17.2% and 21.5%) due to the disease compared with the older women.

Quality of life

The women in this study population reported significantly lower SF-36 scores than the general population, especially as regards the subscales Vitality (VT) (36.6 vs. 66.7), Role Physical (RP) (48.3 vs. 86.0), and General Health (GH) (49.5 vs. 77.9), while the score for Physical Functioning (PF) was closer to normal (79.9 vs. 90.8) (Fig. 3a). Members of the patient association also reported significantly lower General Health compared with reports from women attending clinics (44.9 vs. 54.9). In addition, there were significantly lower scores in the age group of <30 years compared with the age group of 40 and above within the study population in RP ($p = 0.01716$), SF ($p = 0.004337$), RE ($p = 0.014436$), and MH ($p = 0.035019$) (Fig. 3b). QoL was positively affected by age and negatively affected by the number of symptoms. Further analysis of the self-administered questionnaire showed that women in this situation were also severely affected in their everyday lives, as regards both physical as well as psychological limitations. More than half of the study participants (63%) reported effects on their general well-being due to endometriosis-related symptoms during the previous month. Furthermore, many expressed feelings of low energy, depressed mood, and severe impairments in social life.

Sexual relationships

Many of the women (42.7%) reported through the self-administered questionnaire as having avoided sexual relationships at some time because of their endometriosis. Presently, 37.6% of women <30 years of age avoided sexual

FIG. 2. Adaptation of main daily activity (e.g., studies or work) because of symptoms of endometriosis. Missing data: $n = 14$. 
relations due to their endometriosis compared with 26.9% and 26.4% in women above 30 years, respectively. Furthermore, avoidance of sexual relationships was mainly because of pain (55.7%). Pain during and after intercourse was reported most commonly by the youngest (68.8% vs. 58.6 and 44.4%, respectively), and the most commonly reported pain in all age groups was specified as deep dyspareunia (44.1%). Women in the younger age groups also had trouble talking about endometriosis with their relatives, friends, and partners and many felt alone. Approximately, half of the study group (45.5%) had at some point tried to get pregnant but not succeeded. The number of women (n=77) having met with a fertility specialist within the last 12 months was highest in the age group 30–39 years (29.6%).

Coping strategies

In addition to medical treatment, almost 81% in the youngest age group reported that they used coping strategies to handle their pain, while 65.6% and 60.4%, respectively, of women in the older age groups reported the use of coping mechanisms. Commonly used strategies were physical exercise, rest, yoga, specific diets, therapy, massage, acupuncture, warm baths, or heating pads. Women in this population often added above-mentioned strategies to their lives, but it could also be that they had to remove certain methods to cope with the disease.

Emotional consequences of endometriosis

Feelings of guilt and frustration at not being able to participate and contribute fully in normal daily activities (41.1%) or in social events with friends and family (33.9%) were common, the latter mostly affecting women in the youngest age group. The study population expressed frustration (43.6%) with their disease and felt as if it was controlling their lives (45.0%). These feelings were most pronounced in the age group of 30–39 years. More than a third (34.1%) often or always felt guilt or frustration at not being able to have intercourse. The women in this study also expressed frustration as well as disappointment regarding bad encounters with the healthcare system and personnel. Almost 40% felt that the healthcare system was unable to help them with their disease.

Discussion

This study was aimed at assessing the impact of endometriosis on different aspects of QoL in different age groups of a Swedish endometriosis population. By using SF-36, we showed that women with endometriosis suffer severely decreased QoL compared with an age- and gender-matched general population. In addition, we also considered the origin of the women, depending if they were responding to questionnaires from clinics or the patient association, when analyzing the results. As described earlier, endometriosis principally affects bodily pain and psychological and social functioning. These domains of QoL are usually associated with measures of disease activity. We have shown significant differences in QoL within our study population with regard to women’s age, a factor attributable to disease activity, as well as in regard to the origin of the respondent. Plausible explanations for women in the patient association to have a tendency of lower QoL compared to women recruited from clinics could be that they have experienced bad encounters in the healthcare sector, which may be a reason to join a support group. It could also be that they might not be satisfied with their treatment and have less faith in coping with the disease, therefore joining an association to find support outside of the healthcare sector. Reduced QoL was more pronounced in younger women compared with the older age groups, which
definitely goes against what is seen in a general population where QoL usually decreases with age.\textsuperscript{2,3} We see the same pattern in our reference population with decreasing QoL in older women (data not shown). These differences are important to recognize when prioritizing care of these patients and also when discussing health economic aspects. Furthermore, the incidence of endometriosis is believed to increase because of changes in women’s physiology and lifestyle, such as the decreasing age at menarche\textsuperscript{24} and the tendency to have children later.\textsuperscript{25} These lifestyle changes may increase the number of times a woman menstruates and thus increase the incidence of endometriosis.\textsuperscript{26}

There was a tendency that younger women experienced more symptoms, which could reflect a correlation between the activity of the disease and, for example, more worries regarding fertility and problems conceiving. More women (35%) in the youngest age group had noticed symptoms of endometriosis early in life and had also sought help before the age of 20 compared with women in older age groups (19%). This could be explained by the fact that young respondents had a more recent time of recall compared with the older respondents (recall bias). In addition, by definition, they could not have been diagnosed later in life. There is evidence that women who have an earlier onset of endometriosis experience more severe symptoms.\textsuperscript{27} Thus, the probability of seeking healthcare should increase with more severe disease symptoms, higher educational level, and age. Older women also have a higher probability of being diagnosed by chance, for example, when having other examinations or when undergoing surgery. One could speculate that women in the older age group have a different approach to pain compared with younger women. With increasing age, endometriosis patients are more likely to have undergone stronger medical or more radical surgical treatment. Older women may have relatively often undergone surgery, including hysterectomy and ovariectomy, which may result in a decline or elimination of symptoms and thus better QoL. Older women have also had time to develop strategies to handle problems caused by endometriosis.

Nonsteroidal anti-inflammatory drugs and OCs are prescribed for adolescent patients with chronic pelvic pain. If pain is refractory, endometriosis is diagnosed in 50%-70% of these patients.\textsuperscript{28} These results suggest that endometriosis is the most common diagnosis in women with chronic pelvic pain or lower abdominal pain in young women (premenarcheal and perimenarcheal girls). The American Endometriosis Association’s 1998 registry of 4000 adult women with endometriosis reported that two thirds of those responding to the survey experienced pelvic pain before 20 years of age and almost one fifth between age 15 and 19.\textsuperscript{29}

Despite the fact that all the women in this study had been treated for their endometriosis and had been in contact with the healthcare system on a regular basis, many of them were disappointed with the support they received. This was more apparent in younger women. There are thus reasons to improve the care of these patients, not only medically and surgically but also in a broader perspective. Treatment should be individualized and extend to, for example, disciplines such as pain specialists, psychologists, physiotherapists, sexologists, and social workers.

We observed high levels of coping strategies (i.e., nonmedical methods to handle endometriosis in an everyday life) throughout the whole group, but highest among the youngest women. Adaptive or constructive coping mechanisms will probably reduce pain or stress connected to the disease and have a positive impact on QoL. Negative techniques or noncoping, such as dissociation or self-medication, can add to the pain and stresses related to the disease, worsen physical or psychological symptoms, and reduce QoL.\textsuperscript{30,31}

Many reported as having refrained from academic or work opportunities. If one has to refrain from taking opportunities in personal or professional development, it may reduce QoL, increase feelings of frustration and disappointment, and perhaps lead to lower self-esteem. Nevertheless, the causality of this relationship remains uncertain. It can be assumed that work affected by endometriosis-associated symptoms results in a lower QoL. On the contrary, a lower QoL might affect work. In addition to the effect endometriosis may have on women’s professional lives, a negative impact on their personal lives was described in depth. Having a partner or friend to rely on may be factors with a strong positive effect on the mental component of QoL. Unfortunately, the avoidance of sexual relationships was common among women as shown in this study. Planning of intimate situations that might lead to intercourse was commonly carried out so that pain could be handled some time later, for example, at weekends, so as to not affect studies or work. A nonspontaneous sex life would decrease QoL and increase feelings of distress and disappointment for both the women and their partners. Women also expressed feelings of guilt toward their partners, and, as reported by the women, partners expressed feelings of guilt toward the women because of the imposition of physical and psychological pain.

Our data confirm the negative influence of endometriosis on education, work, and social well-being as has been addressed earlier\textsuperscript{19} and add to the knowledge on age differences related to QoL within an endometriosis population.

Despite the fact that women were approached by mail rather than during an outpatient contact, one of the major strengths of the study is that we achieved a relatively high evaluable response rate of 54%. This may be a result of the fact that this is a single-country study with a patient association well connected with their members and specialist clinics that are relatively easy to access. The subsample of women who participated in the study may have been highly motivated to answer the questions, possibly because they were more symptomatic than the nonresponders. Therefore, we must also recognize that those not responding may have opinions different from those reported here. In addition, there are no published data on reduced diagnostic delay in Sweden compared with other countries. Another strength is that we present findings in a large group of Swedish women at different ages and from different sources (patient association and clinics), which increase the generalizability of the data. Respondents were also derived from rural and urban districts to include individuals treated at different levels in the healthcare system up to specialized tertiary centers. It must, however, be recognized that almost 70% of respondents had a prescription of endometriosis-specific treatment during the last 12 months. This may influence symptoms as well as well-being and QoL. As a consequence, there might be an overestimation of the SF-36 scores for women with endometriosis, and thus, an underestimation of the difference between women with endometriosis and the control group.
In regard to limitations of the study, the design used does not permit analysis of any causal inference. Longitudinal studies would allow the confirmation of some causal assumptions derived by the described associations. Another limitation includes selection bias. Both women from the patient organization as well as women from clinics may be regarded as selected groups. In an attempt to reduce selection bias, we invited all members from the patient organization and sent out invitations to a randomized number of patients attending the clinics. Another limitation is one that is general for most questionnaire-based studies and may give a certain bias to the results. Women responding to this questionnaire appeared to have a higher academic qualification, that is, graduated from college/university (45.9%), compared with an age- and gender-matched population (28%). This is a common feature to all types of respondents of questionnaires and not specifically as regards our study population or a population with endometriosis in general. As a consequence of this, they may not be a representative of a general endometriosis population, and this is thus a selection bias to consider. Another limitation is that although the questionnaire used presumed that all reports were due to endometriosis and almost all women recruited from the patient association reported having endometriosis diagnosed by a doctor (96.8%), this could, however, not be confirmed since there was no possibility to trace the respondents and check patient files. Hence, there might have been a few respondents without endometriosis in this material, and the reports given may be influenced by other factors than endometriosis. In contrast, all women recruited from clinics had a surgically confirmed endometriosis. In view of analyzing SF-36, there may be limitations using generic measures of physical functioning and role limitations, as they may be more applicable in assessing a broad array of health-related QoL issues, whereas disease-specific measures of physical functioning and role limitations can be more useful in evaluating clinical management and limitations associated with specific disease conditions. However, as the disease-specific EHP 30 was not available in a validated Swedish version at the time of the study, we decided SF-36 was the most reliable questionnaire available. The selection of the control group from the normal population was assessed as more scientifically accurate than the general population was assessed as more scientifically accurate. The alternative would have been a surgically confirmed endometriosis population. It is, thus, likely that there are women with endometriosis also in the control group, which most likely would lead to smaller rather than larger effect sizes.

Conclusion

Women with endometriosis have significantly lower QoL than the general female Swedish population. Younger women express more symptoms and have a lower QoL compared with women in the older age group. Our results highlight that more healthcare resources should be focused on younger women with endometriosis. This includes awareness among school nurses and youth clinics for earlier diagnosis of the disease, and thus, earlier initiation of appropriate endometriosis and pain treatment. Younger women would benefit from repeated counseling with an endometriosis specialist or nurse and also therapy conversation with a welfare officer or psychologist, since they often have no established strategies to manage their symptoms, like older women usually have.

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Author Disclosure Statement

L.L., P.B., and M.E. are employees of Bayer AB. M.O. has been a temporary consultant for Bayer AB, giving lectures and being a participant of advisory boards.

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