

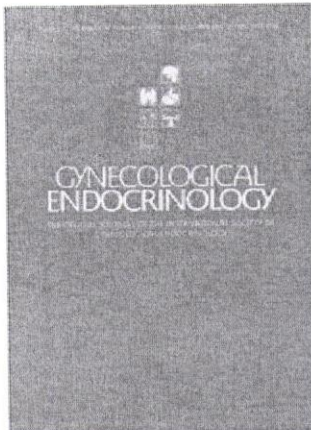
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ORIGINAL PAPER

Impact of endometriosis on quality of life: A pilot study

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Abstract

Endometriosis affects 6–10% of women in reproductive age, 35–50% of whom experience pain, infertility or both. Mild cases are managed medically but surgery provides relief to women in pain. However, symptoms recur in 75% of cases within 2 years. We investigated the impact of endometriosis on quality of life among 65 women aged 18–60 years working at a city supermarket in Giessen, Germany. Of the 65 women, 12 had undergone surgeries, 22 had dysmenorrhoea, 24 dyspareunia and 3 were infertile. Of the 22 women with dysmenorrhoea, 10 had difficulties performing gardening, housework, sports and leisure activities. Five of these 10 women experienced social isolation, 6 professional setbacks; 6 declined efficiency at work and 3 had taken time off work. Of the 24 women with dyspareunia, 7 experienced minimal, 12 light and 5 moderate to strong pain. Only 16 of these 24 women discussed the problem with their partners. This study demonstrates that pain is a major cause of physical, psycho-social, emotional and professional or work related impairment among women with endometriosis. Because endometriosis is likely to impose emotional and financial burdens, we suggest that future studies should be extended to include interviews with family members.

Keywords: Endometriosis, dysmenorrhoea, dyspareunia, pelvic pain, quality of life

Introduction

Endometriosis is an oestrogen-dependent chronic gynecological disorder associated with pelvic pain and infertility. It is characterized by the presence of uterine endometrial tissue outside the normal location; usually in the pelvic peritoneum but may also occur in ovaries, retro-vaginal septum and rarely in the pericardium, pleura and occasionally in the brain [1]. Prevalence is estimated at 6–10% in the general female population with a frequency of 35–50% in women with pain, infertility or both [2–4]. Severe cases can result in extensive pelvic adhesions and distortion of pelvic anatomy and result in infertility. Pain symptoms include dysmenorrhoea, chronic non-menstrual pain, pelvic pain and dyspareunia. Pelvic disease is diagnosed by laparoscopic assessment followed with histological confirmation of viable endometrial glands and stromal tissue on pelvic peritoneum. Mild cases are treated medically using contraceptive steroids, progestagens, agonists of

gonadotropin releasing hormone (GnRH), androgens and non-steroidal anti-inflammatory agents [5–8]. Because of undesirable side effects, treatments aiming to lower circulating concentrations of estradiol (contraceptive steroids, progestagens and GnRH agonists) are useful for limited periods prompting change or use of additional medication. Surgery provides relief to women in pain but symptoms recur in 75% of cases within 2 years [9–11] and in about 10% of women even after hysterectomy and bilateral salpingo-oophorectomy [12]. More than 50% of women with endometriosis suffer deep dyspareunia during their entire sex lives [13]. This is thought to result from stimulation of pain fibers by traction of scarred inelastic tissue [14], or probably due to pressure on endometriotic nodules embedded in fibrotic tissue. Dyspareunia in rectal or lower sacrococcygeal areas is thought to involve recto-vaginal or utero-sacral ligaments [15]. Whether or not the intensity of pain is associated with neural invasion by endometriotic lesions is unclear [16]. A number of reports have

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associated dyspareunia with negative attitudes toward sex, anxiety and avoidance of intercourse [17,18]. Thus, women with dyspareunia have lower sexual desire, arousal, frequency of intercourse and experience fewer orgasms [19]. Additional reports have indicated that sexual life is severely impaired in women with deep dyspareunia and that women with endometriosis of uterosacral ligaments (USLE) have most severe impairment of sexual function characterized by higher intensity of pain and less satisfying orgasms [13]. Endometriosis imposes heavy tolls on general well being, personal relations, demanding time off work and high costs associated with hospitalization, surgery and chemotherapy. These are often confounded with increased risks to ovarian cancer and auto-immune disorders [20]. We investigated the impact of endometriosis on quality of life among 65 women aged 18–60 years working at a city supermarket in Giessen, Germany.

Study design and method of data collection

Setting: Tertiary Referral Clinic at the Department of Obstetric and Gynecology, Justus Liebig University of Giessen, Germany. **Study design and subjects:** A qualitative study involving 65 female employees (aged 18–60) working at a city supermarket in Giessen, Germany. **Method:** We developed a questionnaire comprising 51 questions to explore patient's clinical histories, symptoms related to and impact of endometriosis on quality of life. **Target:** Physical and emotional well-being, social function, work-based and/or professional performance, participation in sexual intercourse and relation with partner. Questionnaires were administered to consented patients during in-depth interviews conducted on a one-to-one basis. Data were analyzed qualitatively. This study was approved by the Committee for Human Research at Justus Liebig University Giessen, and conducted in accordance with the Helsinki declaration for research on human subjects.

Results

Of the 65 women, 12 (18.46%) had undergone surgical operations for pelvic pain and 2 (3%) received medical treatment for endometriosis. Twenty-two of 65 women (33.8%) had dysmenorrhoea; 6 of them (27%) starting with their first menstruation. Twenty-four of 65 women (36.9%) had dyspareunia, 7 (10.8%) and 11 (17%) histories of ovarian cysts, and myomas, respectively. Twelve of 65 (18.5%) women suffered combined dysmenorrhoea and dyspareunia. Three of 65 women (4.6%) aged 26, 27 and 49, respectively, were infertile (Figure 1 and Table I). One of the three infertile women (aged 27) had undergone surgical operations

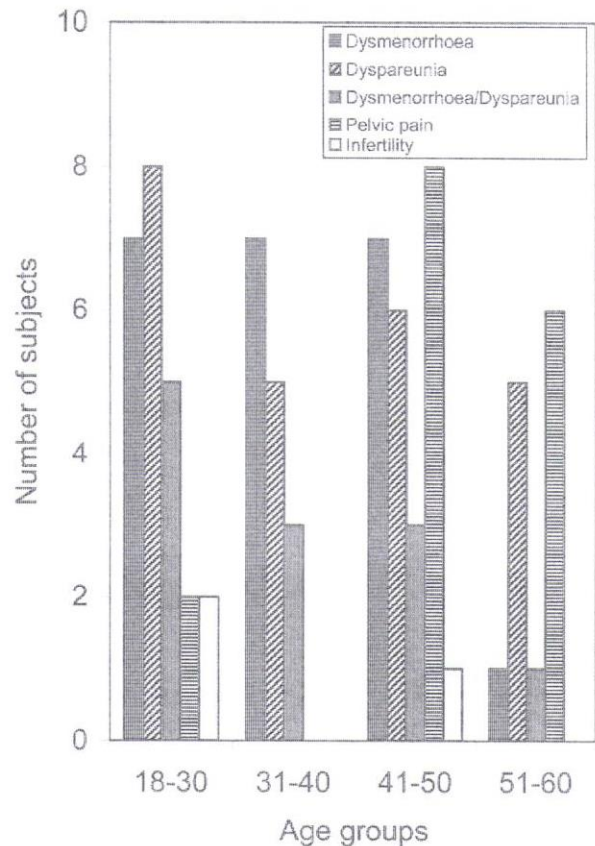


Figure 1. Incidence of endometriosis symptoms by age groups.

for pelvic pain and had neither dysmenorrhoea nor dyspareunia; the other (aged 26) had no surgical history for pelvic pain but had deep dyspareunia. The third infertile woman (aged 49) had dysmenorrhoea and deep dyspareunia. Of the 22 patients with dysmenorrhoea, 6 (27%) reported that pain started before; 16 (72.7%) at the onset of menstruation. Eighteen of these 22 women (81.8%) had taken medication with no long-term benefits. Of the 24 women with dyspareunia, 7 (29%) experienced minimal pain; 12 (50%) light, and 5 (21%) moderate to strong pain. Two of these 24 women (8%) felt pain at the entry to vagina, 13 (54%) deep in vagina and 5 (21%) in pelvis. Four women reported pelvic pain during intercourse. These four cases together with the 12 that already had undergone surgeries for pelvic pain constitute 16 of 65 (24.6%). Figure 2 presents the distribution of symptoms among the 65 women in this study. Because of endometriosis, 30 of the 65 women (46%) had attempted not to conceive using condoms, intra-uterine devices, contraceptive pills and hormone release systems.

Impact of endometriosis on quality of life

Of the 22 women with dysmenorrhoea, 10 (45.5%) had impaired ability to do gardening, house work,

Table I. Distribution of subjects to clinical histories.

Age groups	Dysmenorrhoea	Dyspareunia	Surgery for pelvic pain	Pelvic pain during intercourse	Infertility	Ovarian cyst and/or myoma	Medical treatments for endometriosis	Medication for dysmenorrhoea	Alternative therapies
18-30	7	8	1	1	2	0	0	4	1
31-40	7	5	0	0	0	6	1	6	0
41-50	7	6	7	1	1	9	1	7	2
51-60	1	5	4	2	0	3	0	1	1
Total	22	24	12	4	3	18	2	18	4

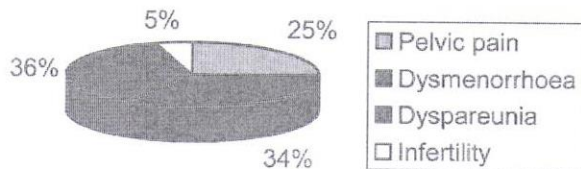


Figure 2. Distribution of symptoms in the study group.

sports and leisure activities. Of these 10 women, 6 (60%) had experienced professional set-backs, 6 (60%) a decline in efficiency at work, 5 (50%) social isolation and 3 (30%) had taken time off work to stay at home or in bed because of dysmenorrhoeal pain. Figure 3 shows the impact of endometriosis on aspects of life among subjects with only dysmenorrhoea. Only 16 of the 24 women with dyspareunia (67%) discussed their pain with their partners; 1 reported that the pain had affected her relationship with her partner. The information provided in this study demonstrate that endometriosis affects negatively personal and emotional well being, psycho-social, recreational, professional or work related activities as well as family lives.

Discussion

Because endometriosis affects quality of life in a complex multidimensional manner, adopting a qualitative methodology to conduct in-depth interviews into subjective experiences of patients is necessary. The observation in this study that 10 of 10 (100%) women with only dysmenorrhoeal symptoms reported impaired abilities to participate in gardening, house-work, sports and leisure activities demonstrates that pain is as a major cause of physical, emotional, as well as psycho-social and professional or work-related impairment among women with endometriosis. Equally, the fact that 6 of these 10 women (60%) experienced professional setbacks and a decline in efficiency at work, respectively, and that 5 of these 10 women (50%) experienced social isolation re-enforces the multi-dimensional impact of endometriosis. The observation in this study that only 16 of 24 women with dyspareunia (67%) discussed their pain with their partners suggests tendencies to

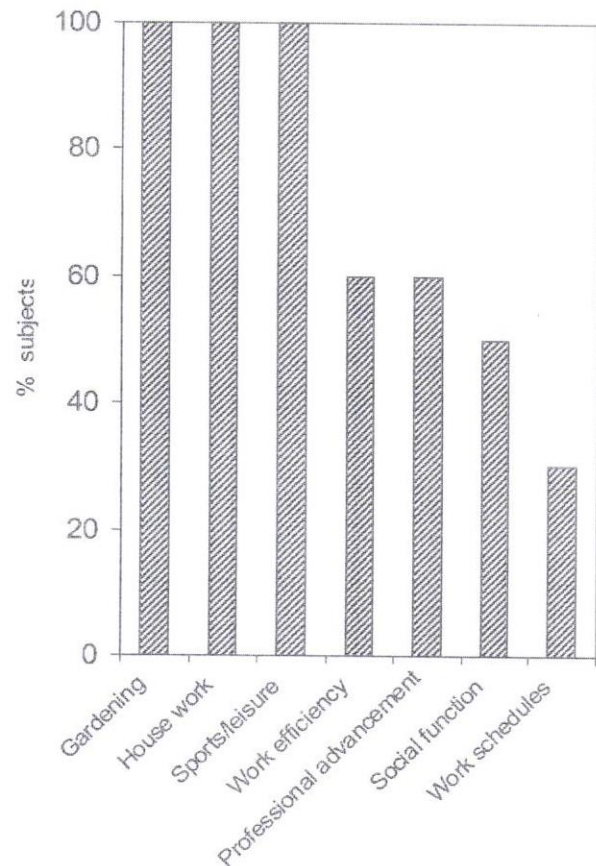


Figure 3. Impairment of selected functions by dysmenorrhoea.

stigmatization and self-pity. That such feelings, if not openly discussed and managed promptly, can lead to depression and family break-ups cannot be overstated. In fact, one woman indicated that the relationship with her partner had deteriorated because of endometriosis. These observations provide evidence of the debilitating impact of endometriosis and agree to a large extent with previous reports that endometriosis impacts negatively on quality of life among the affected women. In a study involving 24 women with laparoscopic confirmation of endometriosis, it was reported that employment and infertility were of particular concern for these women [21]. Physical appearance, lack of control and power-

lessness, social isolation and concerns that their daughters might develop endometriosis were other areas of concern. Elsewhere, a randomized double-blind study on 48 women with verified endometriosis; 18 of whom dropped before the end of study, demonstrated that treatment with nafarelin led to significant reduction in sleep disturbance, anxiety; improved emotional balance, paid work life and other psychosocial parameters [22]. Additional reports indicated that laparoscopic excision of endometriosis led to improvement on quality of sex life in 68 women with deep dyspareunia [23]. Subjects reported increased variety in sex life, frequency of intercourse, more satisfying orgasms, relaxation during and being more relaxed and fulfilled after sex. These observations together with the data presented in this study confirm that endometriosis does indeed affect quality of life in affected women and that both surgery and medical treatment provide pain relief albeit temporarily. On the basis of our findings, the literature reviewed in the text herein and the fact that endometriosis is likely to affect patients' families emotionally and financially, we suggest that future studies be extended to include if appropriate, interviews to patients' families on a case-by-case basis.

Conclusion

Despite the recent advances in medical sciences, endometriosis continues to impact negatively the lives of affected women. Results of this study identify pain as a major cause of physical, psycho-social, professional or work related and emotional impairment among women with endometriosis. The observation in this study that only 16 of 24 (67%) of women discussed dyspareunia associated pain with their partners and elsewhere that symptoms recur in about 75% of cases within 2 years of surgical excision and in about 10% of women even after hysterectomy and bilateral salpingo-oophorectomy demonstrate that prospects for long-term treatment are still lacking. Equally disturbing is the fact that long-term use of oral contraceptives, androgenic agents, progestin and GnRH analogues in the management of endometriosis is limited by undesirable side effects. That the subjects of this study were female employees of a City supermarket exposes the unquantified economic impact due to reduced performance at work, slackened career advancement and time offs to stay at home or in bed. Because endometriosis is likely to impose emotional and financial burdens to patients' families, we suggest that future studies should if appropriate, be extended to include interviews with family members on a case-by-case basis.

Declaration of interest: The authors report no conflict of interest.

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