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EDITORIAL

Quality of life for women with endometriosis: premenopausal and postmenopausal perspectives

Tevfik Yoldemir 

ASSOCIATE EDITOR

Endometriosis affects 6–10% of reproductive-aged women, of whom almost 25% are in their forties and as many as 5% are postmenopausal^{1–3}. In women of reproductive age the most typical endometriosis-related symptoms are menstrual-related pelvic pain and dyspareunia; however, non-menstrual pelvic pain and dyspareunia predominate in older women. Symptoms of endometriosis may severely affect quality of life, causing difficulties in daily activities and social life, altering general health and personal relationships. Pain may significantly impair physical, mental, and social well-being and infertility may cause psychological stress, low self-esteem, and depression.

The fact that there are nine instruments commonly used to assess quality of life in endometriosis sufferers points to the difficulties in accurately assessing the impact of this condition^{4,5}. Those commonly used include the Short Form 36 (SF-36), a questionnaire used for general quality of life comprising 36 items in eight domains; the Short Form Health Survey version 2 (SF-36v2), which is similar to the first version but with changes made to the wording of questions and response categories; the Short Form 12 (SF-12), which is an abbreviated version of the SF-36; and the World Health Organization Quality of Life Assessment-bref (WHOQOL-bref), a brief questionnaire comprising 26 items, again intended for general health use. The Duke Health Profile, the EuroQOL-5 dimension instrument (EQ-5D), and the World Endometriosis Research Foundation's Global Study of Women's Health instrument (WERF-GSWH) are also commonly used questionnaires used to assess general and health-related well-being. The Endometriosis Health Profile (EHP-30) consists of 30 questions with five subscales for pain, control/powerlessness, emotional well-being, social support, and self image. A shorter version, EHP-5, is somewhat more practical and suitable for both clinical practice and research.

Correctly, quality of life is usually associated with symptomatology rather than a specific disease diagnosis⁴ and, in the case of endometriosis, there is commonly a lack of correlation between stage of disease and severity of symptoms, perhaps because symptoms are linked to complex sensory and neural mechanisms related to depth of endometriotic implants rather than the extent of disease.

Women with endometriosis have a higher rate of comorbid pain syndromes than chronic pain sufferers and may be prone to depression, anxiety, and chronic fatigue. Peripheral

sensitization and central sensitization are also common in endometriosis⁵.

Quality of life in endometriosis is positively affected by age and negatively affected by the number of symptoms. Younger women with endometriosis generally report worse quality of life than patients over 40 years of age. This might be due to the development of more effective coping mechanisms by older women, by younger women having more severe disease, by attenuation of disease in older women, by changing hormone levels with age, or by a combination of these factors^{4,6}.

Women of advanced age are reported to suffer more depressive symptoms than younger women. Employed women and those who exercise regularly are also significantly less likely to be impacted by endometriosis.

Medical treatments for endometriosis have some positive effects on quality of life, with little to separate the different options. Gonadotropin releasing hormone analog therapy for more than 6 months improves health-related quality of life, particularly with regard to pain control. The addition of add-back hormone therapy further improves self-image and emotions⁵.

Subcutaneous injection of depot medroxyprogesterone acetate improves health-related quality of life during treatment and benefits may persist through 18-month follow-up. Six months of therapy seems to be the minimum duration, with quite similar results seen for various oral progestogen therapies, including dienogest, cyproterone acetate, and medroxyprogesterone acetate, all improving health-related quality of life, the psychiatric profile, and sexual function. Similarly, 6 months of therapy with a combined oral contraceptive improves pain as well as psycho-emotional status and sexual function which may persist for 12 months after discontinuation. The postoperative levonorgestrel intrauterine system for 12 months improves both physical and mental health for women with moderate to severe pain related to endometriosis⁵.

Almost two-thirds of older women with endometriosis use coping strategies such as physical exercise, rest, yoga, specific diets, massage, acupuncture, warm baths, or heating pads to handle their pain. Adaptive or constructive coping mechanisms have a positive impact on quality of life, whereas negative techniques, such as dissociation or self-medication, can reduce quality of life⁶.

Surgical excision of endometriosis improves dyspareunia. The quality of sex life does not improve as fast, probably because repeated experiences of pain and loss of pleasure create a cognitive scheme of negative expectations that disturb sexuality⁷. Importantly, the long-term improvement in quality of life is dependent on full surgical clearance of endometriosis, which reduces the risk of recurrence of symptoms and repeat surgery.

Surgically or medically induced menopause relieves endometriosis-related symptoms, but can simultaneously trigger troublesome menopausal vasomotor symptoms, vaginal dryness, sleep and mood disturbances, and painful intercourse. These are especially prevalent and severe in women with a sudden onset of the hypoestrogenic state. The Menopause-specific Quality of Life (MENQOL) Questionnaire is the most frequently used tool to assess health-related quality of life in the immediate postmenopausal period. The MENQOL improves upon several instruments used to assess the impact of menopausal symptoms on quality of life, including the Kupperman Index and the General Well-Being Scale. The MENQOL is a self-administered specific instrument covering 29 climacteric symptoms or complaints with four domains – vasomotor, psychosocial, physical, and sexual.

Few studies have investigated the use of hormone therapy in postmenopausal women with a history of endometriosis. There are two specific concerns in these women. First, there is the possibility that exogenous estrogen will reactivate growth of endometriotic deposits and cause symptom recurrence. Second, there is a concern that estrogen might promote malignant transformation of residual endometriotic tissue⁸. The decision whether or not to prescribe hormone therapy in women with a history of endometriosis should take into account risk factors, such as residual disease after surgery and obesity, which causes increased aromatase activity in peripheral tissues resulting in higher systemic estrogen levels. Postmenopausal women must be actively counseled about the limitations of the current data regarding the risk of disease recurrence or malignant transformation⁸. Although the use of combined hormone therapy instead of an estrogen-only formulation is suggested to minimize the risk of recurrence of endometriosis, there are still risks with combined estrogen–progestin hormone therapy and alternative therapies such as tibolone and tissue-selective estrogen complexes might be considered⁸.

Clearly, we still have much to do to find the most effective medical treatment for endometriosis and to refine surgical techniques to improve long-term outcomes and quality of life. Unfortunately, measuring health-related quality of life in endometriosis patients has so far been less than satisfactory. Too often, there is heterogeneity of study design, patients' demographics, disease severity, and data presentation. Sample calculations are rarely done, whilst corrections

for possible confounders and determinants with the highest prognostic value are rarely described⁵.

Perimenopausal and postmenopausal endometriosis is a serious condition, more common than once thought and perhaps with more serious long-term consequences. There can be no doubt that this condition adversely affects the quality of life of those afflicted and, equally, no doubt that better tools are needed for measuring and managing quality of life for these women.

Of clinical importance, a holistic approach to management should include advice on physical fitness, psychological well-being, and social environment as well as thoughtful evidence-based advice on treatment, relief of symptoms, and improvement in quality of life.

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