

# **Endometriosis**

# Diagnosis, treatment and patient experiences

A systematic review and assessment of medical, economic, social and ethical aspects

SBU ASSESSMENTS | ASSESSMENT OF METHODS IN HEALTH CARE AND SOCIAL SERVICES

MAY 2018 | WWW.SBU.SE/277E

#### **Conclusions**

- ▶ GnRH-agonist and gestagen treatment seem to have similar pain-relieving effect, but GnRH-agonists decrease bone density.
- Postoperative treatment with gestagen and monophasic contraceptives seem to have similar pain relieving effect in women with chronic pelvic pain and dyspareunia. Hormonal intrauterine contraceptive devices may reduce dysmenorrhea in comparison to no treatment.
- ▶ Vaginal ultrasound has a clinical value in the diagnosis of endometrioma, and before operating for deep endometriosis. This applies to the identification of the spread of disease in women with well-established clinical suspicion of endometriosis. Vaginal ultrasound is inexpensive, easily accessible, has no contraindications and requires no preparation. Healthcare professionals conducting ultrasound examinations need to be experienced.
- During fertility treatment, the ultralong pretreatment with GnRH-agonist has a higher chance of resulting in pregnancy for women with endometriosis, compared to the short pretreatment.
- Women with endometriosis symptom experience that they are treated with ignorance about endometriosis in the non-specialised care. They experience delays in both their diagnosis and treatment, and feel that healthcare professionals do not take their problems seriously. In addition, it appears that increased expertise and improved attitudes among health care professionals could improve the life situation of women with endometriosis.
- Despite the large number of identified studies, there is a general lack of scientific evidence for most treatments. Future research should be more standardized regarding the length of treatment, follow up and evaluating the



outcome/pain. More research is needed in the important areas of diagnostics, and evaluation of surgical treatment effect.

## **Background**

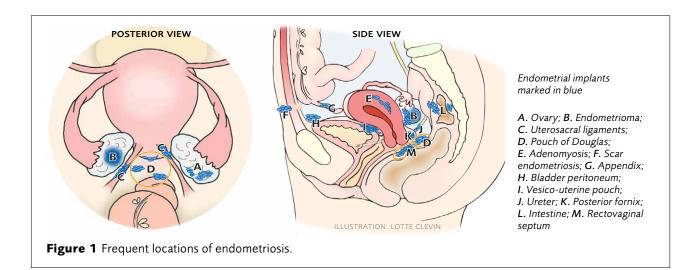
Endometriosis is a chronic disease where the uterine mucosa (endometrium) grows outside the uterus. Women with endometriosis may be without symptoms or they may experience pain of varying degree. The most common types of pain are dysmenorrhea, dyspareunia and chronic pelvic pain. Endometriosis can also reduce fertility. The disease can affect quality of life, reduce the woman's ability to cope with work or study, and effect social relationships. It is estimated that around 10% of women of reproductive age have endometriosis. It takes five to seven years from the onset of symptoms until a diagnosis is set. There is currently no cure, but several treatments can relieve the symptoms.

#### Aim

The aim of this systematic review was to evaluate the scientific evidence with regards to diagnostic performance of different imaging methods for the diagnosis of endometriosis and to assess the ability of different treatments to reduce pain or improve fertility. In addition, qualitative studies regarding women's experiences with endometriosis health care were evaluated.

## Method

Prospective peer-reviewed studies were included if they evaluated the ability of any imaging method to aid in the diagnosis of women presenting with clinical



symptoms of endometriosis compared to surgical diagnosis, with or without the use of biopsies. Studies evaluating the effect of treatments should be prospective controlled studies that focus on women with diagnosed endometriosis. Due to advancements in both imaging technology and surgical techniques, studies addressing these questions needed to be published in 2000 or later. Qualitative methodology was used to assess women's experience of endometriosis health care. Only studies with low or moderate risk of bias were included in the systematic review. The reliability of the scientific evidence was assessed using GRADE, or GRADE-CERQual for METASynthesis of qualitative data. The literature search was performed in November 2017.

#### Result

A total of 44 diagnostic studies, 181 treatment studies and 9 studies concerning women's experiences of the endometriosis health care were included in this systematic review.

# **Scientific uncertainties**

This systematic review demonstrates that the scientific evidence is insufficient to answer many clinically relevant questions regarding diagnosis and treatment of endometriosis.

The included studies were most often carried out at specialist clinics, with a selected population and specialized staff; therefore, the results may not be transferable to public health care or the general public. Importantly, we do not have evidence to guide the treatment of pain when hormone treatments are ineffective. These patients are currently being treated with strong, potentially addictive, analgesics.

This report identifies many scientific uncertainties. This is in part due to study heterogeneity, that is, the

inconsistent definitions of endometriosis in diagnostic studies, variations in the length of treatment or follow-up, and inconsistent evaluation and reporting of outcomes (dysmenorrhea, dyspareunia and pelvic pain) that make it difficult to reliably assess the body of evidence. In addition, it is difficult to ethically or practically assess some methods or focus on certain populations, for instance, the evaluation of surgical interventions, or diagnostic methods where the reference method is surgery.

# Project group

## Experts

- · Carina Berterö, Professor, Linköping University
- Greta Edelstam, Associate Professor, Senior Consultant, Danderyd Hospital
- Jens Jørgen Kjer, Senior Consultant, Copenhagen
- Anna-Sofia Melin, Consultant, Capio Globen Gynecology Clinic and Huddinge Youth Guidance
- Annica Rhodin, Senior Consultant, Uppsala University Hospital
- Lil Valentin, Professor, Senior Consultant, Lund University

### SBU

Jenny Odeberg (Project Manager), Agneta Brolund, Martin Eriksson, Sara Fundell, Susanne Gustafsson, Therese Kedebring, Naama Kenan Modén, Hanna Olofsson, Agneta Pettersson and Karin Rydin

#### Scientific reviewers

Mats Brännström, Axel Forman and Maria Nyström

SBU Assessments no 277, 2018 www.sbu.se/en • registrator@sbu.se English Proofreading: Rebecca Silverstein, SBU Graphic Design: Elin Rye-Danjelsen, SBU