

## “Centers of excellence in endometriosis surgery” or “centers of excellence in endometriosis”

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**Abstract** Centers of excellent endometriosis surgery could improve the care of women with endometriosis, especially if combined with control of the quality of the surgery performed, e.g., through systematic taping of entire interventions. Centers of excellence in endometriosis without emphasis on providing excellent surgery seem of little value and could do more harm than good.

**Keywords** Endometriosis · Center of excellence · Surgery · Deep endometriosis · Videoregistration · Quality control

It is amazing how little progress has been made over the last two decades in understanding the pathophysiology of endometriosis and of the associated pain or infertility. Fundamental questions that existed more than 15 years ago remain unanswered. First, whether subtle lesions are a “natural condition occurring intermittently in most women” or whether we should consider them active and important endometriosis lesions continues to be debated [1]. Secondly,

there still is no explanation why severe lesions develop in some women only. Medical treatment has not made much progress. We have known for more than 30 years that endometriotic lesions are hormone responsive, that they become inactive or less active after menopause, and that they can decidualize during pregnancy. It is, thus, not surprising that during medical therapy with ovarian suppression, or oral contraceptives or progestagen, only therapy endometriotic lesions become less inactive; they, however, do not disappear. Medical treatments do not enhance fertility [2]. Although widely accepted as a treatment of endometriosis-associated pain, we recently suggested [3] that the evidence of effectiveness of medical therapy upon endometriosis-associated pain should be considered with caution. Indeed, none of the trials we reviewed fulfilled the randomized controlled trial (RCT) criteria of sufficient blinding of the clinician and/or the patient; full blinding indeed is practically impossible to achieve for hormonal drugs abolishing the menstrual cycle. Moreover, dysmenorrhea disappears by definition in all women when menstruation is abolished, thus, always reducing total pain scores; in addition, the absence of dysmenorrhea will have important carry-over effects decreasing the rating of all other pain symptoms. Finally, an important placebo effect exists for all pain symptoms; even for very severe deep endometriosis-associated pain [3] (women that had 13 to 15/15 on a Biberoglu–Behrman scale), an overall 30% placebo effect exists. In half of the women, the placebo effect even reduces pain rating by 80%.

New dogmas, such as the delay in diagnosis [4] and centers of excellence [5] have been introduced. The delay in diagnosis in endometriosis is important and seems well established. It is questionable, however, whether the political use is not slightly inappropriate [6] since a delay in diagnosis probably is not specific for endometriosis and since the same

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delay can probably be found for all nonlife-threatening diseases causing chronic pain such as, e.g., interstitial cystitis. The delay in diagnosis varies with the expertise and the education of the physician. We indeed only recognize what we know. This has been demonstrated many years ago for the laparoscopic recognition of subtle endometriosis; it also explains the apparently “increasing” incidence of the diagnosis of deep endometriosis in comparison with the period before 1990 when this was a rare diagnosis. Recognition of a disease also varies with the special interests of the physician whether this is endometriosis or early cancer or anything else. This diagnostic delay of endometriosis obviously causes suffering and impairs a woman’s quality of life. This, however, holds true for most other chronic pain syndromes. For endometriosis, it is fortunate that there is no evidence that this delay in diagnosis impairs treatment outcome nor that endometriosis becomes worse during this period. Centers of excellence have become “fashionable” in many areas of medicine as infertility and oncology. Centers of excellence in endometriosis [5] have been suggested in order to reduce the delay in diagnosis and improve quality of treatment. Many of the arguments used to justify such centers of excellence sound—possibly unconsciously—as lobbying for personal interests, while lacking evidence that the suggested goals will indeed be achieved. Indeed, it is doubtful whether the existence of centers of excellence will accelerate diagnosis since endometriosis patients normally will be referred after the diagnosis has been made. In contrast with oncology and infertility with a straightforward referral basis, the referral of endometriosis patients is much less clear since the pain symptoms of endometriosis are much less specific. To accelerate diagnosis centers for chronic pelvic pain might be more useful than centers of excellence in endometriosis. In addition, whether centers of excellence improve treatment outcome is not that obvious. Infertility diagnosis and treatment have over the last decades largely been centralized in in vitro fertilization (IVF) centers at least partially as a consequence either of restrictive regulation of the number of IVF centers or as a consequence of organizational and industrial imperatives stimulating larger units. Simultaneously, we witnessed a decrease of the focus on fertility surgery and possibly a decrease in its quality [7]. It is unclear whether the emphasis on IVF while often disregarding surgery [8] has been an advantage for infertility patients.

If we want to improve the care of women with endometriosis, we should decrease the diagnostic delay and improve treatment. In order to decrease the delay in diagnosis of endometriosis in women with pelvic pain, we need centers (of excellence) for chronic pelvic pain. Since medical treatment today only reduces pain while never curing the disease, surgical treatment of endometriosis remains the first and most important treatment. The surgical treatment of severe endometriosis has been proven to be so effective that randomized

controlled trials comparing surgery with expectant management for larger cystic ovarian endometriosis and for deep endometriosis would be considered unethical in women with severe pain. For typical superficial lesions, RCT’s have proven efficacy [9]. Since, in addition, severe endometriosis surgery has been recognized as requiring skill and expertise, it might be preferable to have *centers of excellence in endometriosis surgery* or *centers of excellent endometriosis surgery*. Those reporting on surgery, furthermore, published low recurrence rates of less than 10% and less than 5% for cystic and deep endometriosis.

Ideally, endometriosis surgery should combine the diagnostic laparoscopy with surgery if required and should be performed by a surgeon trained not only in the recognition of endometriosis but also in other causes of pelvic pain. Moreover, those performing endometriosis surgery should have the expertise and the technical skills to perform the more advanced surgical interventions when necessary. Centers of excellence in endometriosis surgery could be a major step forward in achieving this. Today, unfortunately, women often need a second intervention since the surgery could not be performed during the diagnostic laparoscopy. This, however, is considered a minor problem which is difficult to solve. What is worse is incomplete surgery since it seems—although never formally proven and unethical to prove—that the first surgery is the most important one and that inadequate or incomplete surgery will make subsequent surgery more difficult impairing outcome. Too often women still undergo a hysterectomy leaving the deep endometriosis nodule untouched. Bowel resections for deep endometriosis are performed liberally notwithstanding frequent and serious long-term consequences of low rectum resections [10]. Some of these bowel resections are even performed for little endometriosis outside the bowel and occasionally in women without endometriosis as demonstrated later by pathology. Centers of excellence in endometriosis surgery might help to raise the standard of care. Since, beside the circumstances, the most important variable in the outcome of surgery is the surgeon, we strongly suggest that some kind of quality control of surgery be implemented. This can be done by a regular audit of the results and complications and even better by systematic taping of entire interventions [11]. To become recognized as a center of excellence in endometriosis surgery, we, therefore, strongly suggest that a strict quality control, preferably by systematic taping, should become a key criterion.

In conclusion, centers of excellence in endometriosis surgery could improve the care of women with endometriosis, especially if combined with control of the quality of the surgery performed, e.g., through systematic taping of entire interventions. Centers of excellence in endometriosis without emphasis on providing excellent surgery seem of little value and could do more harm than good [5].

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