OPINION

Multi-disciplinary centres/networks of excellence for endometriosis management and research: a proposal

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Centres/networks of excellence are the only way forward to ensure that women with endometriosis receive consistent, evidence-based care, ensuring excellence, continuity of care, multi-disciplinarity, research, training and cost-effectiveness. Clinical excellence should be achieved by proper training, adherence to evidence-based guidelines, quality management and continuous measurement of patient outcome as a central focus. To ensure continuity of care, the first step is to assign to each patient a central gynaecologist who must have continuously updated knowledge regarding all diagnostic and management options for endometriosis and who must set priorities and realistic expectations together with the woman using a long-term multi-disciplinary treatment plan. Scientific research within and scientific collaboration between centres/networks of excellence will create the critical mass of patients and tissue samples that is needed to make progress. Centres/networks of excellence should be accredited as training centres by professional bodies. They should aim at improving the cost-effectiveness of the management of endometriosis by a reduction in the time to diagnosis, a reduction in the time before individualized specialist care is invoked, a reduction of expensive hit-and-miss treatments and a reduction in expensive fertility treatments, if the disease is under control before fertility is impaired.

Key words: centre/endometriosis/excellence/multi-disciplinary/quality

Excellence

Excellence is defined as ‘1) the state of quality of excelling or being exceptionally good; extreme merit. 2) an action, feature etc., in which a person excels’ (The Collins Concise Dictionary of the English Language, 1988). In this opinion paper, the authors aim to discuss a set of criteria on how the treatment of, and research into, endometriosis can become exceptionally good through the implementation of multi-disciplinary centres and networks of excellence, where those who treat women with endometriosis, and/or conduct research into the disease, excel at what they do.

The challenge of endometriosis

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction; the condition is predominantly found in women of reproductive age, from all ethnic and social groups (Kennedy et al., 2005), although it has been found also in pre-menarcheal girls without an obstructive anomaly of the reproductive tract (Marsh and Laufer, 2005), which contributes to the argument that one presumed aetiology of the disease is not sufficient.

Although evidence has been presented that subtle endometriotic lesions are a normal physiologic condition occurring intermittently in all women (Koninckx et al., 1999), other data suggest that endometriosis is a progressive disease in about 50% of symptomatic women and nonhuman primates with a variable and unpredictable rate of progression (Koninckx et al., 1991; D’Hooghe et al., 1996; D’Hooghe and Hill, 2006). Endometriosis can also be asymptomatic but is often associated with pain and reduced fertility and possible symptoms include dysmenorrhea, pelvic pain (cyclical and non-cyclical), dyspareunia, lower abdominal and/or back pain, infertility or sub-fertility, dyschezia, dysuria, loin pain and chronic fatigue. Bladder- and bowel-associated symptoms are typically cyclical, and endometriosis can also be associated with significant gastrointestinal symptoms: pain, nausea, vomiting, early satiety, bloating and distension, and altered bowel habits. Furthermore, a cross-sectional survey from 1998 suggested that hypothyroidism, fibromyalgia, chronic fatigue syndrome, autoimmune diseases, allergies and asthma are all significantly

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more common in women with endometriosis than in women in the general US population (Sinaii et al., 2002).

Defining endometriosis into a ‘disease’, ‘illness’ and/or a ‘physiological phenomenon’ with a known cause (or known triggers/mechanisms) has thus far eluded many scientists. Consequently, endometriosis remains a considerable challenge for those who attempt to understand the symptoms and signs of endometriosis that vary according to the location and severity of the disease/illness, as well as the impact on the general physical, mental and social well-being of a woman.

Why the need for centres and networks of excellence?
The challenge of endometriosis accentuates the need to look at it as a persistent and/or chronic disease/illness, at least in a subset of highly symptomatic women, as their symptoms may continue despite seemingly adequate medical and/or surgical treatment. This may affect their quality of life because of debilitating pain, the emotional impact of sub-fertility, anger and frustration about disease recurrence, and uncertainty about the future regarding repeated surgeries and/or long-term hit-and-miss medical therapies and their associated side-effects (Hummelshoj, 2004).

This was highlighted in the recently published European Society for Human Reproduction and Embryology (ESHRE) Guideline on the Diagnosis and Management of Endometriosis, which emphasized the complexity of the management of advanced endometriosis and the necessity to refer to centres with the necessary expertise to offer all available treatments in a multi-disciplinary context (Kennedy et al., 2005).

The authors of this paper therefore propose that networks and centres of excellence within a multi-disciplinary context is the only way forward to ensure that women with persistent/chronic endometriosis receive consistent, evidence-based and cost-efficient care within a framework which is able to provide excellence, continuity of care, a multi-disciplinary approach, research, training and cost effectiveness.

Excellence
In clinical excellence, those who excel practice according to guidelines of evidence-based medicine and according to quality management with the patient as their central focus. This mantra becomes the aim when establishing centres, networks or regions of excellence within the discipline of endometriosis. In a clinical context, and in reality, this would constitute centrally co-ordinated care for patients with endometriosis within a multi-disciplinary centre or network of accredited practitioners, who each specialize in a specific discipline, which constitutes a significant part of an overall solution and treatment plan for each patient to manage their individual symptomatic profile.

Having mentioned ‘guidelines’ and ‘evidence-based medicine’, it is important, however, to recognize the danger in only accepting data from randomized, controlled trials, as was highlighted at the recent World Congress on Endometriosis, and to continuously assess improvement of the illness and/or quality of life in individual patients, rather than focus on disease resolution alone (Hummelshoj et al., 2006).

Continuity of care
With persistent and/or chronic diseases, continuity of care becomes the only stabilizing factor for the patient who needs ongoing treatment(s). The first step is therefore to assign a central gynaecologist to the woman who seeks care for her endometriosis symptoms through a centre of excellence. Together, they will map out the appropriate clinical pathway depending on the woman’s symptoms, expectations, needs/wants, age etc. This central, or primary, gynaecologist must have continuously updated knowledge regarding all diagnostic and management options for symptomatic women with endometriosis. She/he must set priorities together with the woman to provide her with the entire range of therapies and/or a combination of these.

Regardless of where the woman is in her treatment cycle, the primary gynaecologist becomes her continued point of reference. She/he is the one who works with the woman to co-ordinate and individualize her long-term treatment plan, depending on which symptoms need to be managed at any given time.

A multi-disciplinary approach
With persistent and/or chronic diseases, an integrated approach involving a multi-disciplinary team is not just needed but essential (Martin and Ling, 1999; Metzger, 2002). Thus, the third component of a centre/network of excellence is for the primary gynaecologist to work together with a therapeutic network, which can consist of

(i) gynaecologists with a sub-speciality certificate in reproductive endocrinology and infertility;
(ii) a multi-disciplinary surgical team led by a surgically experienced gynaecologist working together for complex cases with urologists, gastrointestinal surgeons and/or general surgeons;
(iii) pain specialists;
(iv) nurses;
(v) physiotherapists;
(vi) counsellors;
(vii) psychologists/psychiatrists;
(viii) nutritionists/dieticians;
(ix) patient support organizations;
(x) non-traditional practitioners.

These practitioners, with their different sets of skills, may all play an important role in providing a holistic solution to an individual’s needs, and if all these cogs in this treatment and management wheel are well linked, the likelihood of positive, long-term results become greater (see Figure 1).

Research
With persistent and/or chronic diseases, clinical and basic research must be prioritized to increase the understanding of this disease and to improve diagnostic accuracy and therapeutic effectiveness. The fourth component therefore encompasses research, which should be an integral part of any centre/network of excellence.

Clinical studies should be based on computerized, electronic patient files allowing labelling of all the associated symptoms of the patient as well as the presence/absence of endometriotic
lesions. Clinical research should be aimed at continuously measuring clinical outcome data for all symptoms associated with endometriosis, as well as recurrence of disease and/or symptoms, and any complications associated with medical/surgical management. Furthermore, it may be possible to study quality of life issues using reliable and valid questionnaires to gain a better understanding of how to ultimately treat women with endometriosis.

Incorporating research into a centre of excellence will allow not only for more widespread patient participation in clinical and/or basic research trials but also for much needed multi-centre collaboration. This enables the creation of the critical mass necessary for any meaningful research, where having a sufficient number of tissues and/or body fluids, obtained as a part of diagnostic or therapeutic surgery in patients with and without endometriosis (and with fully documented clinical information), is imperative. Clinical and basic research should enable an improved understanding of the pathogenesis, spontaneous evolution and recurrence risk of endometriosis (D’Hooghe and Debrock, 2003).

Training
As discussed above, the management of endometriosis, especially the more severe/advanced forms, requires a multi-disciplinary approach. Thus, training for gynaecologists who wish to specialize in the management of endometriosis should be provided by a centre/network of excellence in endometriosis. The format for this training can be based on existing formats for sub-speciality training in reproductive medicine, gynaecologic oncology or fetal–maternal medicine, as has been done by the European Board and College of Obstetrics and Gynecology (www.ebcog.org) and by the American Board of Obstetrics and Gynecology (www.abog.org). However, the advanced training in endometriosis management should not be considered as a new sub-speciality training but rather as additional postgraduate training that can be offered to board-certified general gynaecologists or to sub-specialists in reproductive medicine. This education should contain theoretical and practical training in the diagnosis, medical and surgical management of endometriosis, and outcome assessment after treatment.

The aim of this training would be to improve the care of patients in collaboration with other care providers. After completion of training, the clinician should have better knowledge, practice, teaching, research and audit skills; should be able to co-ordinate and promote collaboration in the clinical management of endometriosis and to provide leadership in endometriosis research. More specifically, they should have the necessary medical and surgical skills for optimal management of women with endometriosis, including those with extensive disease. Therefore, a team approach is essential.

Figure 1. The centre/network of excellence in endometriosis (a framework for long term multi-disciplinary patient management).
Training should be regulated by a relevant professional body to provide sufficient expertise, using peer-reviewed, regularly updated guidelines and protocols published by national or international professional bodies. The training should last at least 18 months, be carried out within a multi-disciplinary centre, as outlined above, and include

(i) general gynaecologic and reproductive surgery, including multi-disciplinary surgical management of deeply infiltrating endometriosis affecting bowel and bladder;
(ii) sub-fertility and reproductive endocrinology, including all aspects of assisted reproduction technology;
(iii) diagnostic methods;
(iv) histopathology of endometriosis;
(v) counselling;
(vi) participation in and contribution to the teaching of other health care professionals.

Participation in audit and clinical or basic research is essential, and the trainee should make a significant contribution to at least one research project resulting in a co-authorship of a scientific paper in an international peer-reviewed medical journal during his/her training programme.

Training should be structured throughout with clearly defined targets to be met after specified intervals. An educational plan should be drawn up in consultation with the trainee at the beginning of each attachment and progress should be monitored regularly using a log book containing all clinical and research activities of the trainee.

Centre/network commitments

To provide post-graduate training for a practitioner to specialize in the management of endometriosis, a centre must

(i) provide a service for the referral and transfer of patients with endometriosis who would benefit from the facilities, expertise and experience offered by the centre/network of excellence;
(ii) have established close collaboration with related disciplines to provide a high degree of teamwork and resources for the investigation and management of such patients;
(iii) have established close collaboration with other specialists within and outside of the centre, including major regional roles in continuing postgraduate education and training, research advice and co-ordination, and audit;
(iv) have an adequate workload providing a full range of experience in the management of endometriosis. Alternatively, two or more centres may collaborate in providing a programme with all the required experience;
(v) have a director who will co-ordinate the training programme, accept the main responsibility for its supervision and be actively involved; when more than one centre provides the programme, there must be a supervisor at each centre, with one designated as having overall responsibility. Directors and supervisors should be consultants with special experience in the management of endometriosis;
(vi) have adequate medical staffing to enable the trainee to be engaged in his/her sub-speciality field on a full-time basis;
(vii) have adequate library, laboratory and other resources available to support clinical work, training and research;
(viii) provide the resources for a research programme related to the sub-speciality.

Cost effectiveness

Persistent and/or chronic diseases come with a price, although what that cost is to the individual, and to society, is very difficult to calculate. Diagnostic and surgical procedures, drugs, fertility treatments and involvement of health care professionals all factor in when a woman presents with and/or is treated for symptoms suggestive of endometriosis. However, it is not sufficient to just look at the cost of all of these treatments but also to evaluate the impact of the disease on her life and ability to work because of either hit-and-miss treatments or inadequate management of her symptoms.

A 2005 survey on pain and quality of life, carried out by the Endometriosis All Party Parliamentary Group (EAPPG) in the UK, indicated that 78% of symptomatic women with endometriosis (n = 7025) lose a mean of 5.3 days of work a month because of their symptoms (Hummelshoj et al., 2006), with a potential cost of days lost at work of €30 billion across Europe alone. In the USA, indirect costs due to time off work as a result of chronic pelvic pain (CPP), where 87% may have had endometriosis, has been estimated at US$555.3 million a year (Mathias et al., 1996). This is before taking into account the cost of drugs, surgery, infertility treatments etc., which for CPP in the UK alone is estimated at £158 million a year, with indirect costs of £24 million (Stones and Selfe, 2000). Furthermore, endometriosis has been identified as a risk factor for poor outcome at follow up in a UK hospital-based series of women referred with CPP (Selfe et al., 1998).

The vast majority of diagnostic laparoscopies are carried out to investigate pelvic pain and sub-fertility, in which endometriosis is often implicated, at a likely annual cost in the UK alone of over £46 million (Pearson and Pickersgill, 2004). If we then bear in mind that not all laparoscopies are accurate, that we do not know how often endometriosis is missed if/when it looks atypical and that many surgeons, because of inadequate resources or skills, do not treat the disease at the time of the diagnostic procedure, this cost would be significantly higher. When, on top of that, the average diagnostic delay is over 8 years with 65% of women with endometriosis initially being misdiagnosed and almost 50% having to see five doctors or more before correct diagnosis (Hummelshoj et al., 2006), this cost is bound to increase further, both for the healthcare system and the woman herself (a) in cost of drugs and (b) if she is unable to work because of inadequate management of her symptoms, as suggested by the EAPPG data mentioned above.

Early referral to a centre of expertise, which is skilled in the effective diagnosis and management of endometriosis, is therefore bound to have a profound impact on the reduction of health care (and individual) costs by

(i) reducing the time to diagnosis and the time wasted to see numerous health care professionals;
(ii) subsequently reducing the time before individualized specialist care is invoked;
(iii) subsequently reducing expensive hit-and-miss treatments;
(iv) subsequently reducing expensive fertility treatments if the disease is under control before fertility is impaired.

These costs alone would justify centralized care, but in addition, early and effective management of endometriosis symptoms
may significantly reduce days lost to education and/or work because of the disease.

Turning ideas into practice: What constitutes a multi-disciplinary centre/network of excellence?

Ideally, from both a logistics and practical point of view, the location should be in an academic centre of gynaecology and obstetrics, which in addition to its clinical expertise, should also have the mission, the ability and the resources to conduct ongoing research into the origin, evolution, diagnosis, treatment and prevention of endometriosis, as outlined above, along with access to all the other disciplines within the therapeutic network (see Figure 1). This would facilitate easy referral as well as inter-disciplinary communication and thus seamless, integrated patient management.

However, ‘utopia’ is one thing and reality another. Whilst the primary gynaecologist may very well be situated within an academic setting, it is unlikely that it is possible to gather the entire network’s expertise underneath one roof. A viable solution would be to create a ‘multi-disciplinary network of excellence’ – a virtual centre – where specialists work in different places but where (a) a central, shared electronic file for each patient is maintained and updated at every consultation carried out within the centre/network to ensure that every practitioner is kept continuously up to date with her latest treatments and corresponding results, regardless of who carried out the last treatment and (b) where regular and formal interdisciplinary discussions regarding patient management are conducted.

Practitioner commitment and accreditation

All practitioners participating in a centre/network of excellence need to commit to an accredited level of expertise in line with the peer-reviewed standards of the recognized professional organizations to which they belong. They must ensure that their continued medical education is not only ongoing but that they are completely up to date with the current literature on endometriosis including evidence-based clinical guidelines and that their clinical management is based on these.

Acknowledging that disease recurrence is probable in endometriosis, all practitioners must recognize that each and every one of them have specific and complementary expertise and skills and, based on this, refer to the most suitable person within the network to ensure that the woman receives the best possible treatment and support at any given time.

A commitment to an agreed ‘service level agreement’ could include

(i) participation in regular multi-disciplinary case discussions of complex cases (at least every 6–8 weeks);
(ii) commitment to continuing medical education;
(iii) commitment to high-quality clinical and basic research with publications in international peer-reviewed journals;
(iv) commitment to training of practitioners in all appropriate disciplines in the management of endometriosis;
(v) commitment to adhere to recognized quality management systems, i.e. ISO 9001:2000, as well as to published, peer-reviewed, evidence-based guidelines when managing endometriosis.

Regulation and indication

Whereas it may be relatively easy to agree on training standards and accreditation, an open question remains as to who identifies these centres/networks of excellence, how they become accredited and who provides ongoing regulation.

The authors suggest that, in an ideal world, this would be done at an international level in collaboration with the World Endometriosis Society and the special interest groups on endometriosis within ESHRE and the American Society for Reproductive Medicine (ASRM). In a realistic world, however, indication, accreditation and regulation needs to be provided at national level, adhering to national standards. This, however, must be done in true collaboration between national departments of health and national societies for obstetrics and gynaecology, with input from peers who specialize in the treatment of endometriosis.

Taking centres/networks of excellence one step further ...

Well-established centres/networks of excellence provide the perfect setting for creating international coalitions that specialize in the management of, and research into, endometriosis. They are the only way to acquire sufficient numbers of patients for large randomized trials and to create large banks of tissue samples linked to well-defined clinical data.

With sufficient recognition, these could be ‘supervised’ by the Special Interest Groups for Endometriosis in international professional organizations such as ESHRE, the ASRM and the World Endometriosis Society. These networks would also provide the perfect platforms for generating international funding (European Union, National Institutes of Health etc.) for much needed basic research and would provide substantial credibility when raising awareness for endometriosis at a political and legislative level.

References


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