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ORIGINAL ARTICLE

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# Centres of excellence for the management of advanced endometriosis: where are they and what do they do?

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**Abstract** We examined how advanced endometriosis is managed in the United Kingdom, and what support exists for the development of centres of excellence. A questionnaire was sent to all 1,447 registered consultants in the United Kingdom. Of the 617 who replied some 505 treated endometriosis, representing 267 of the 341 hospitals listed. Of the consultants 157 (31%) felt that they worked in a centre of excellence, representing 94 of the 267 hospitals. There were 169 consultants who treated rectovaginal disease themselves, but only 66 used excisional procedures. Support was expressed by 429 consultants (84.9%) for the development of centres of excellence for the treatment of advanced endometriosis.

**Keywords** Centres of excellence · Endometriosis · Survey

## Introduction

The management of advanced endometriosis poses significant challenges to the clinician. Women are often in considerable pain and have a dramatically impaired quality of life [1]. The surgery to excise disease, which is often close to or involving the rectum, is often technically difficult. In our experience women often need considerable support for their physical and emotional needs as well as assistance with chronic pain management. Because of these challenges the Royal College of Obstetricians and Gynaecologists recommends that "severe cases of endometriosis should be referred to centres of excellence where relevant clinical expertise is available" [2]. On 30 April 2003 the All-Party Parliamentary Group on Endometriosis met for a seminar at the Houses of Parliament, London. It concluded that a network of centres of excellence should be developed in the United Kingdom. Currently there is no formal criterion by which a centre of excellence should be defined, nor precisely what role it should have. To complicate matters further, there is considerable variation in the techniques used to manage advanced and particularly rectovaginal disease, with no consensus or randomised trials to identify the most effective treatment.

The aim of this study was to shed some light on how the most advanced endometriosis is managed in the United Kingdom. We use the example of endometriosis which involves the rectum or pre-rectal fascia (also known as cul de sac or rectovaginal disease) as a benchmark for this, as we feel that it is one of the most technically challenging types of endometriosis to manage. We also aimed to assess the professional support for the development of a network of centres of excellence and to identify what services these centres should offer.

## Methods

A database of the postal address and hospital of all practising consultants in the United Kingdom was obtained from the Royal College of Obstetricians and Gynaecologists. A total of 1,447 consultants were identified from the database, and these received by post a questionnaire which had been approved by the College and the National Endometriosis Society. We received 617 replies. Excluding those who had retired, had moved, or did not practice any gynaecology, we identified 505 consultants who treated patients with endometriosis. These represented 267 (78%) of an identified 341 hospitals in the UK.

The questions asked were in three groups. Firstly, consultants were asked to estimate the number of women with endometriosis whom they treated in the past year, as well as the number with stage III, IV (using the revised American Fertility Society classification) or rectal disease. They were asked whether they saw tertiary referrals, and whether they considered their hospital to be a centre of excellence in the treatment of endometriosis. A definition of a centre of excellence was deliberately not given. Secondly, they were asked about their management of endometriosis which involved the rectum or prerectal fascia. Finally, they were asked whether they felt there should be a network of centres of excellence to manage advanced endometriosis, and what services they should offer. Free text comments were recorded.

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**Table 1** Number of consultants using different methods used to treat endometriosis affecting the rectum or prerectal fascia (one or more options may have been selected where appropriate)

| | Laparoscopy | Laparotomy |
|---|---|---|
| Ablation | 40 (47%) | 19 (16%) |
| Shaving of prerectal fascia | 40 (47%) | 31 (25%) |
| Disc resection of rectal wall | 11 (13%) | 12 (10%) |
| Anterior rectal resection | 8 (9%) | 18 (15%) |
| Combined with colorectal surgeons | 50 (59%) | 99 (81%) |
| Treat all disease except that involving the rectum and refer to colorectal surgeons | 19 (22%) | 22 (18%) |

## Results

The responding consultants reported treating an estimated 22,596 cases of endometriosis in the past year, with a mean of 48.5 cases each. Of these, 4,129 (18.3%) were stage III or IV, and 1,047 (4.6) affecting the rectum.

Of the respondents 157 (31%) felt that they worked in a centre of excellence, representing 94 (35%) of the hospitals identified. When asked how they would manage disease involving the rectum or prerectal fascia, 156 (30.9%) would refer to another hospital, 119 (23.7%) to a colleague, and 53 (10.5%) to general surgeons. In 169 cases (33.4%) the consultants treated rectal or prerectal disease themselves; of these 67 used excisional procedures (shaving the prerectal fascia, disk or segmental rectal resection). Details of the surgical procedures used are listed in Table 1. Medical treatment was used by 128 consultants, including gonadotropin-releasing hormone analogues ($n$=127), danazol ($n$=26), the combined oral contraceptive pill ($n$=44) and progestogens ($n$=38). When asked whether they thought there should be a network of identified tertiary referral centres which have the skills and services to both manage advanced endometriosis and train others in the advanced surgical skills required, 429 (84.9%) replied yes. It was considered appropriate for the following services to be offered: gynaecological ($n$=452), colorectal ($n$=430), pain management ($n$=352), specialist nursing ($n$=347), pain counselling ($n$=316), urological ($n$=284), infertility ($n$=286), research coordinating ($n$=283), psychotherapeutic ($n$=188) and complementary ($n$=160).

## Discussion

The findings of this survey demonstrate a wide variation in the way in which advanced endometriosis is managed by consultants in the United Kingdom, and that one-third of hospitals represented are considered by their consultants to be centres of excellence. In spite of this only 66 (13%) of those treating endometriosis offer excisional surgery for rectal or prerectal disease. If a network of centres is to be established, a formal definition is required. We propose that a centre of excellence would need to have the facilities to offer the complete range of medical and surgical treatments available for women with advanced endometriosis. Treatment should be as radical or as conservative as the woman chooses and should not be limited by the gynaecologist's unfamiliarity with techniques used to treat advanced disease. The centre should be able to offer the complete surgical excision of all visible disease, which in the case of rectovaginal endometriosis may require dissection of the rectovaginal septum and possible rectal surgery. If gynaecologists do not have the confidence or necessary skills to perform perirectal surgery themselves, there should be adequate intraoperative colorectal surgical support, as referring on for a postoperative surgical review would potentially result in additional surgical procedures for patients. A multidisciplinary team is essential to address the various needs of women with advanced disease. Consultant gynaecologists in the United Kingdom feel that a colorectal surgeon is the most important additional member of the team, followed by a pain management team, a specialist nurse, and some access to counselling. The opinion was expressed by 32% that access to complementary therapies should also be incorporated in the service.

Many units in the United Kingdom offer services for women with advanced disease, but the developing a network of centres would be aimed principally at achieving equality of access for patients. A network should be readily accessible for patients, their general practitioners and other gynaecologists, and it should be easy to identify what services individual centres are offering. The Royal College of Obstetricians and Gynaecologists has emphasised the importance of involving patients in the establishment of services [3], and it would be essential to maintain input from individual patients and their support groups during the development of any network. There is evidence that surgical excision of advanced endometriosis improves pain and quality of life [1, 4]. In our own practice, women having excisional surgery show an 86% improvement, with those having a disc or segmental resection of the rectum having significantly better pain scores and quality of life than those having shaving of the prerectal fascia [4]. The method and the extent of resection required is still a matter of debate [5]. In light of this, all centres treating advanced disease should continuously monitor and audit their methods, complications and results.

Reviewing the free text comments highlighted the concerns which some consultants have about centres of excellence causing a reduction in the skills in peripheral units. A more positive way of viewing centres of excellence would be as providing skills to treat the endometriosis which peripheral units may not feel confident in managing themselves. Additionally, they should offer back-up, support and most importantly advanced training

to those wishing to specialise in the surgical treatment of advanced endometriosis and those working in other hospitals. The majority of other comments noted that advanced endometriosis is treated with varying efficacy across the country and encouraged the urgent establishment of a network of centres. With growing pressure from patients and their support groups there now appears to be a political will to develop such centres. This study has also demonstrated that there is also a professional will to do so. Provided that adequate funding is made available, the development of a network of centres for the management of advanced endometriosis has a promising future.

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