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Endometriosis centers of expertise in the Netherlands: Development toward regional networks of multidisciplinary care

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1 | INTRODUCTION

Endometriosis is a common and complex disease that is difficult to diagnose and treat.^{1,2}

Centralization of care in expertise centers can contribute to a multidisciplinary approach to both diagnosing and treating endometriosis. However, until June 2020, no criteria for endometriosis expertise centers in the Netherlands were established.

The aim of centralization of endometriosis care is to improve treatment for women with endometriosis by shortening the delay in diagnosis and reducing morbidity, leading to an improvement of their quality of life. This aim is in accordance with the advices of the European Society of Human Reproduction and Embryology (ESHRE), the World Endometriosis Society (WES), and the National Institute for Health and Care Excellence (NICE). Centralization of

surgery has already proved to be successful in other disciplines in terms of improving clinical outcome.^{3,4} A retrospective multicenter study in France shows a correlation between surgical experience and postoperative complications in the treatment of deep infiltrating endometriosis.⁵

Already in 2006, D'Hooghe and Hummelshoj discussed in their opinion paper how the treatment of and research into endometriosis could be improved by the implementation of multidisciplinary centers and networks of excellence.⁶ In 2011, the WES formulated two consensus statements clarifying the importance of endometriosis expertise centers.⁷ WES initiated a consensus workshop regarding centralization of care in 2017, where the following advices were formulated: the centralization of endometriosis care is necessary, with a specific focus on surgery, fertility, pain, and psychosocial guidance, seeking adequate support and the proper mode in each local context (WES, personal communication).

In a number of European countries such as Denmark (2001), Germany (2005), and France (2017), expertise centers to centralize endometriosis care have been implemented (Table 1).⁸⁻¹⁰

Abbreviations: ESHRE, European Society of Human Reproduction and Embryology; NICE, National Institute for Health and Care Excellence; NVOG, Nederlandse Vereniging voor Obstetrie en Gynaecologie (Dutch Society for Obstetrics and Gynecology); WES, World Endometriosis Society

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TABLE 1 Criteria for endometriosis expertise centers in different European countries

Endometriosis expertise centers in different countries			
Denmark ⁸		Specialist centers	
		Treatment of advanced endometriosis	
Germany ⁹	Level 1 Basic endometriosis care: diagnostics and medical treatment	Level 2 Medical and surgical treatment	Level 3 <ul style="list-style-type: none"> • Offering complete endometriosis care, including highly specialized endometriosis surgery for deep infiltrating endometriosis • Teaching residents in pathophysiology and endocrinology • Offering special training courses for medical and surgical treatment • Participating in or conducting scientific studies
France ¹⁰		Centers of expertise	
		Responsibility for <ul style="list-style-type: none"> • Organizing geographical coverage: directory members, contacting users and government bodies, circulating procedures, protocols, and guidelines, developing epidemiological data collection system, organizing monthly meetings • Offering complete tertiary care: coverage of all diagnostic and therapeutic resources for managing endometriosis • Communication and education between doctors and patients, involvement in university and postgraduate education and training for professionals, promotion of the best practice • Research and evaluation: organizing prospective database for patients undergoing surgery for complex endometriosis, operating clinical audit activities, collecting annual caseload data, and participating in research 	
The Netherlands		Level 1 <ul style="list-style-type: none"> • Clinical aspects • Professional aspects • Organizational aspects 	Level 2 <ul style="list-style-type: none"> • Clinical aspects • Professional aspects • Organizational aspects • Educational aspects • Research aspects

2 | METHODOLOGY

A Special Interest Group (SIG) of gynecologists involved in care for women with endometriosis, embedded in the Dutch Society for Obstetrics and Gynecology (Nederlandse Vereniging voor Obstetrie en Gynaecologie, NVOG), was founded in 2009. Members of the SIG aimed to organize endometriosis care in expertise centers and develop criteria for centralization of care.

In 2016, a nationwide cross-sectional questionnaire study was conducted among all hospitals in the Netherlands ($n = 85$) to assess the current Dutch situation and evaluate the Dutch gynecologists' opinion regarding the centralization of endometriosis care. From each hospital, one gynecologist responsible for endometriosis care was asked to respond. A total of 67 gynecologists responded (response rate 79%). Ninety-three percentage of the respondents discussed their difficult cases with medical specialists in other hospitals, and 82% referred women with endometriosis to another hospital for

advice concerning diagnostics or treatment, for multidisciplinary treatment, or for reasons of endometriosis-associated subfertility. In total, 85% of the respondents thought that endometriosis care should be centralized, whereas 24% stated that complex cases should be treated only in an expertise center.¹¹ These numbers show the support for endometriosis expertise centers among Dutch gynecologists.

In 2016, the board of the NVOG SIG Endometriosis wrote a proposal for criteria for endometriosis expertise centers, based on available literature, examples from other countries, and the results from the questionnaire conducted in 2016. This quality standard was reviewed by all 75 members of the SIG and the members of the Dutch patient association, Endometriose Stichting (ES).

In 2017, NVOG members involved in benign gynecology or reproductive medicine were asked to comment on the proposal for the quality standard. Subsequently, the document was, according to the NVOG's quality regulation, sent to the NVOG's committee for quality and to the NVOG committee of professional interests in 2018.

TABLE 2 Dutch criteria for endometriosis expertise centers

Dutch criteria for level 1 endometriosis expertise centers	
1. Clinical aspects	<p>Laparoscopic treatment of peritoneal and ovarian endometriosis:</p> <ul style="list-style-type: none"> • Adhesiolysis • Diathermic, plasma- or laser ablation of peritoneal and superficial endometriosis • Cystectomy with minimal damage to the ovarian cortex <p>Excision by laparotomy of small nodules in the abdominal wall (<3 cm, none or limited infiltration in the underlying fascia)</p> <p>Surgery is provided by gynecologists having an affinity with (minimal invasive) endometriosis surgery, shown by education and experience</p> <p>Surgery can take place in a level 1 center if a high degree of certainty has been obtained that no deep endometriosis is present</p> <p>Fertility treatment: at least Intra Uterine Insemination (IUI) is offered; In Vitro Fertilization (IVF) may be referred to another hospital</p>
2. Professional aspects	<p>At least one of the gynecologists involved in endometriosis care is a member of the NVOG Special Interest Group Endometriosis</p> <p>At least one of the gynecologists involved in endometriosis care has participated in postacademic training in the field of endometriosis</p>
3. Organizational aspects	At least two times participation in a year in regional meetings with level 2 endometriosis expertise center
Additional criteria for level 2 endometriosis expertise centers	
1. Clinical aspects	<p>Multidisciplinary approach with a team that consists of at least a gastrointestinal surgeon, a urologist, and a radiologist. Preferably also present in the team are a gastrointestinal specialist, a pain specialist, a pelvic physiotherapist, a psychologist, and a specialized nurse</p> <p>Laparoscopic multidisciplinary surgical treatment of deep endometriosis</p> <p>Fertility treatment: all treatment options are offered. IVF may also be offered in a satellite setting (ovarian stimulation in the clinic, but ovum pick-up at the IVF center) or transport setting (ovarian stimulation and ovum pick-up in the clinic and transport of collected oocytes to the IVF center)</p>
2. Professional aspects	<p>A minimum of at least 50 new patients per hospital per year</p> <p>At least 50 endometriosis surgeries per hospital per year, of which at least 20 deep endometriosis surgeries</p> <p>The gynecologist performing the surgical procedures has had a learning curve consisting of at least 50 deep endometriosis surgeries per surgeon</p>
3. Organizational aspects	<p>Registration of the number of new patients, the number of surgeries and the number and character of complications is recorded in a standard format developed by the special interest group for the purpose of the annual report</p> <p>The patient satisfaction is listed by questionnaires</p> <p>Regional collaboration between level 1 centers and the level 2 center: regional meeting at least two times a year</p>
4. Educational aspects	An internship on endometriosis is offered for registrars in gynecology
5. Research aspects	Participation in research (self-initiated or in collaboration with another center)

Note: Quantitative criteria are indicated in the table. Where no numbers are indicated, there are no quantitative criteria.

After review, the quality standard was approved by the board of the NVOG in early 2020. Then, the quality standard was sent for the final agreement to the NVOG members. Comments of individual members could be answered without adaptation of the text. Finally, the document was authorized by the members of the NVOG, and the quality standard was ready to be implemented in daily practice in June 2020.

No ethical approval was necessary in this process.

3 | ORGANIZATIONAL STRUCTURE

For optimizing care, different levels of expertise centers are needed to reach regional collaboration. Therefore two levels of

centers of expertise are developed: level 1 and level 2 centers (Table 2). In regional networks, a level 2 center is surrounded by at least two level 1 centers to increase the involvement of professionals and to make all centers accessible to all women suffering from endometriosis.

4 | ASSESSMENT

A hospital intending to become registered as an expertise center can apply at the NVOG. The NVOG's review committee for quality will monitor whether the center meets the criteria described above. All centers will be listed on the website of the NVOG to ensure

transparency. These data will also be shared with the ES in order to provide information to women.

5 | IMPLEMENTATION

After implementing care in level 1 and level 2 centers within regions of the Netherlands, the quality of care for women who have been treated in these centers will be evaluated every 5 years by the NVOG's review committee for quality. This is an already established NVOG quality control system, and its task it is to audit the quality of gynecologic care of all Dutch hospitals once every 5 years. Endometriosis expertise centers will be audited in this system, and the criteria for level 1 and level 2 centers will be checked. In level 1 centers, patient numbers will be registered, as well as numbers of surgical procedures, patient satisfaction as measured by means of questionnaires, and morbidity and complication rates after surgery. Moreover, membership of the NVOG Special Interest Group Endometriosis and postgraduate education of the professionals working in the expertise centers will be checked. For level 2 centers, these items will be checked, as well as proof of organization of regional meetings, evaluation of the internship by the registrars, and scientific output of the professionals working in the level 2 centers. In the coming years, we hope to present data about the implementation of expertise centers. To date, there are no such data available from other countries after implementation.

6 | DISCUSSION

In this paper, we have described the process of developing criteria for centralization of care for women with endometriosis in the Netherlands. In the regional collaboration system with the different levels of expertise, attention has been paid not only to the organization of surgical care but also to the organization of pain management, fertility care, scientific research, and education. This is in accordance with, for example, the German situation. In Germany, the organization of care in three levels of expertise proves to function adequately.⁹ Because of the smaller number of inhabitants in the Netherlands and the smaller distances between hospitals, it is expected that two levels of expertise will be sufficient to effectively organize care in regional networks. The level 2 and 3 centers in Germany are similar to the level 1 and 2 centers in the Netherlands. The basic endometriosis care, provided in level 1 centers in Germany, is provided by general practitioners and nonspecialized gynecologists in the Netherlands. Because the Netherlands is a relatively small but densely populated country, collaboration in regional networks instead of a competitive approach is crucial to improve and optimize care.

7 | CONCLUSION

It has been a long-lasting but carefully considered process to develop the quality standard with criteria for endometriosis centers of

expertise in The Netherlands. Substantial attention has been paid to creating a broad consensus among members of the patient association, as well as gynecologists.

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AUTHOR CONTRIBUTIONS

Conceptualization: Laura de Kok, Annemiek Nap.

Methodology: Laura de Kok, Annemiek Nap, Jacques Maas, Paul van Kesteren, Nehalennia van Hanegem, Ellen Klinkert, Velja Mijatovic, Johann Rhemrev, Harold Verhoeve.

Project Administration: Laura de Kok, Annemiek Nap, Jacques Maas, Paul van Kesteren.

Writing - Original Draft: Laura de Kok, Annemiek Nap, Jacques Maas, Paul van Kesteren.

Writing - Review and Editing: Laura de Kok, Annemiek Nap, Jacques Maas, Paul van Kesteren, Nehalennia van Hanegem, Ellen Klinkert, Velja Mijatovic, Johann Rhemrev, Harold Verhoeve.

All authors have read and approved the final version of the manuscript.

Laura de Kok had full access to all of the data in this study and has taken complete responsibility for the integrity of the data and the accuracy of the data analysis.

TRANSPARENCY STATEMENT

Laura de Kok affirms that this manuscript is an honest, accurate, and transparent account of the study being reported with no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

CONFLICT OF INTERESTS

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The authors confirm that the data supporting the findings of this study are available within the article.

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