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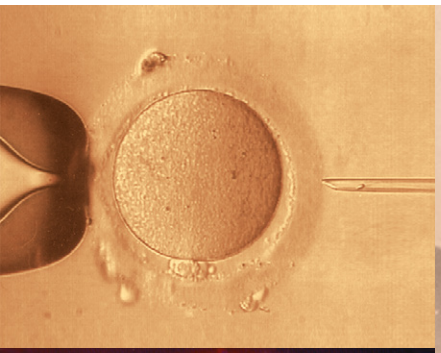

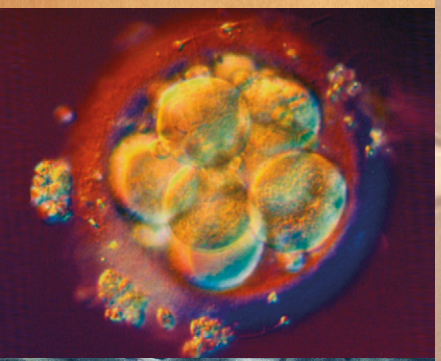

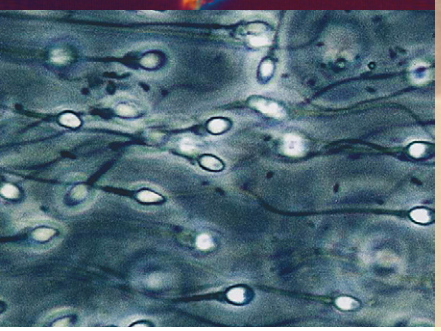

Pattern of Endometriosis Care in German-speaking Countries: the QS ENDO Project

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Pattern of Endometriosis Care in German-speaking Countries: the QS ENDO Project

M. Zalewski[1]*, F. Zeppernick[1]*, M. M. Wölfler[1,2], E. Janschek[3], J. Keckstein[3], M. Sillem[4], K.-W. Schweppe[5], I. Meinhold-Heerlein[1]; for the QS Endo committee members of the Stiftung Endometrioseforschung (SEF)

Das Qualitätssicherungsprogramm QS ENDO wurde initiiert, um die Versorgungsrealität für Endometriose in der DACH-Region (Deutschland, Österreich, Schweiz) zu erfassen.

Die erste Phase (QS ENDO Real) wird einen Überblick über die aktuelle Versorgung von Endometriosepatientinnen erbringen. In der zweiten Phase (QS ENDO Pilot) werden die tatsächlichen Behandlungen an Endometriosezentren der Stufe II und III innerhalb eines einmonatigen Zeitraumes abgefragt. In Phase III (QS ENDO Study) wird diese Abfrage auf alle behandelnden Kliniken in der DACH-Region ausgeweitet.

Das QS ENDO-Projekt wird als erstes Programm dieser Art ein umfassendes Verständnis der tatsächlichen Versorgungsrealität liefern. Dies soll dabei helfen, Qualitätsindikatoren für die Diagnostik und Therapie der Endometriose zu generieren.

Schlüsselwörter: Endometrioseversorgung, Qualitätssicherung, Qualitätsindikatoren

The implementation of a quality assurance program in endometriosis QS ENDO was initiated to evaluate the actual pattern of endometriosis care in German-speaking countries.

After the first phase (QS ENDO Real) which will yield an overview of the current endometriosis care, phase II (QS ENDO Pilot) will be retrieving the actual care of the patients during a 1-month period in all high-level certified endometriosis centers. In phase III (QS ENDO Study), a representative, comprehensive analysis of care across all treating facilities of the German-speaking countries is planned.

The QS ENDO project will be the first program of its kind to acquire a profound understanding of the pattern and quality of endometriosis care, which will help to generate quality indicators for diagnosis and treatment. **J Reproduktionsmed Endokrinol_Online 2017; 14 (6): 311–2.**

Key words: Endometriosis care, quality assurance, quality indicators

Introduction

Endometriosis is a common disorder affecting approximately 10–15% of reproductive-age women [1]. It is characterized by the presence of endometrial-like tissue outside the uterine cavity. Typical symptoms include dysmenorrhea, pelvic pain and subfertility.

The symptoms and treatment-related effects of endometriosis often affect young, active women during their economically productive lives, which – the medical challenges aside – causes a substantial financial burden on the health-care system [2, 3]. One of the main reasons for the high impact on patients' quality of life (QoL) is the long delay in diagnosis. Patients often experience a lag time of up to 10 years between the onset of symptoms and diagnosis [4, 5]. The effects of dealing with debilitating pain combined with the emotional impact of sub-fertility further complicate the patient's situation.

It seems obvious that more research is needed to determine physician and patient factors that influence diagnostic and treatment decisions in endometriosis.

The positive changes obtained by benchmarking in the treatment of ovarian cancer was one of the major drivers motivating the bid to repeat that success story in this, one of the main medical challenges facing young women during their productive lives [6]. Work on ovarian cancer demonstrated that the creation of a quality assurance program **(QS OVAR)** resulted in overall improvement in the quality of care of patients with ovarian cancer. While adherence to treatment guidelines varied markedly early in the study [7], rates of staging and treatment according to guidelines improved over time with continued participation in the program. The QS OVAR program also demonstrated that the structure and size of the hospital did not have a significant impact on survival. The only transparent treatment facility characteristic that significantly impacted the prognosis of ovarian cancer was participation in clinical studies [6]. One study on ovarian cancer found that the likelihood of a patient receiving a recommended therapy grew when providers received training [8].

QS ENDO Project

Standardized quality indicators for treatment of endometriosis have yet to be established. This lack of standards represents a hurdle to improving the quality of treatment, and it is one which ought to be overcome. In view of the success of the QS OVAR program, we hope that the implementation of a quality assurance program in endometriosis (QS ENDO) will help to raise the standard of endometriosis care in German-speaking countries and gain better adherence to treatment guidelines. Furthermore, we hope that the program will have positive effects in terms of shortening the lag time between the onset of symptoms and diagnosis, reducing non-beneficial surgical interventions and improving patient satisfaction or QoL.

The QS ENDO program is to proceed in four phases: QS ENDO Real, QS ENDO Pilot, QS ENDO Study and QS ENDO

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Follow up. The four phases shall be implemented in stages over course of the coming decade.

The aim of Phase I **(QS ENDO Real)** is to obtain a comprehensive overview of current availability and quality of care of patients with endometriosis in German-speaking countries.

During Phase II **(QS ENDO Pilot)**, centers already certified as high-level endometriosis specialist centers (Levels II and III) by the Stiftung Endometrioseforschung (SEF) will be asked to provide detailed records of all patients diagnosed and treated within a 1-month period. Each of the approximately 60 centers should report on an average of 10 consecutive patients.

During Phase III **(QS ENDO Study),** all gynecologic treatment facilities in the German-speaking countries (the so-called DACH region) will be asked to report on a sample of patients during a specific treatment period. This will enable a representative, comprehensive analysis of care across the region. The number of patients whose care each facility will be asked to track as part of the study will be matched to the facility's size and structure based on the results of Phase I.

Phase IV **(QS ENDO Follow-up)** is intended to follow up on care and outcomes for patients documented during Phases II and III in order to generate valid data on the efficacy of treatment.

The purpose of Phase I (QS ENDO Real) is to evaluate the pattern and quality of endometriosis care in the European countries in which the predominate everyday language is German, or in other words, in the so-called DACH countries of Germany (D), Austria (A) and Switzerland (CH).

All gynecology departments in the DACH region will be contacted via regular mail and asked to provide a description of the current quality of care of endometriosis patients. A two-page questionnaire will be supplied to facilitate reporting. The parameters of the questionnaire were developed by a panel of 25 experts during a 3-day workshop on quality management in endometriosis treatment which took place at the Weissensee Conference of the scientific board of the Stiftung Endometrioseforschung (SEF) in Austria in 2016. The goal is a response rate of at least 10–20%.

In general, the questionnaire includes several structural as well as content-related questions:

- Apart from the size and structure of the treatment facility, information about human resource management as well as providers' level of education and training are surveyed.
- The questionnaire asks a responding physician to estimate the number of patient contacts as well as the number and type of surgical interventions which take place and
- another set of questions focuses on the assessment of certain symptoms and diagnostic steps, e.g., the evaluation of dysmenorrhea or the use of transvaginal ultrasound for an effective and efficient patient work-up.

To our knowledge, the QS ENDO project will be the first effort spanning the DACH region to acquire a profound understanding of the pattern and quality of endometriosis care, which will help to generate quality indicators for treatment.

A strength of the concept of QS ENDO Real is that it provides a pen-to-paper response setting, creating a low threshold for respondents to be willing to participate; but the very same feature might also be seen as a weaknesses in that respondents may overestimate or underestimate some data.

Finally, we would add that the potential bias caused by respondents approximating numbers of patients during Phase I will be corrected during Phases II and III. In those phases (QS ENDO Pilot and Study), information will be gathered about actual diagnostics and treatments performed in consecutive patients based on real patient data rather than on estimates.

As the questionnaires for Phase I were distributed in 2016, we expect to be able to publish the results of QS ENDO Real by the end of 2017.

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Conflict of Interest

The authors have no conflict of interest to disclose.

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