endometriosis: a multidisciplinary disease

Paolo Vercellini
special interview
Preface

Dear Colleagues,

We are together with the 26th issue of the Endometriosis and Adenomyosis Society’s bulletin.

The subject of this issue is “Endometriosis as a multidisciplinary disease”. Improving the disease and/or the quality of life of each individual is the most important approach in endometriosis instead of focusing on the disease itself. It can only be achieved with the coordinated performance of all associated disciplines. Abstracts of 6 articles about multidisciplinary approach are included in the bulletin along with articles originating from our country in the second quarter of 2023. In addition, information about our society’s scientific and social activities and its relations with international associations is presented in this issue.

The 15th World Endometriosis Congress (WES-WCE 2023/EDINBURG) was a highly successful congress full of proud results for our association. Our society’s founding president and board member Prof. Dr. Engin Oral was elected to the new WES board. His work for many years both in our country and in the international arena (European Endometriosis League (EEL) - President (2018-2020) and board member) have been crowned with this new duty. In addition, Dr. Fitnat Topbaş Selçuk who is one of the successful members of our core group made us proud by her new appointment to the WES early career board. In the congress, Dr. Fırat Büyüktaş’ article was selected as the study attaining the highest score among the studies from the Middle East and African countries. Prof. Dr. Engin Oral gave a presentation titled “Endometriosis-Adenomyosis”. Additionally, Assoc. Prof. Pınar Bahat was involved in the meeting as a speaker and Dr. Fitnat Topbaş Selçuk as a chairman.

Our society’s other success in the international arena was Prof. Dr. Taner Usta’s, the society’s former president and board member, election as the representative of the pelvic pain of ESGE in FIGO.

Prof. Dr. Taner Usta and Prof. Dr. Ahmet Kale attended the AAGL-ESGE joint meeting GynItaly 2023 IEG in Rome. These two board members together with Dr. Nilufer Akgün, Dr. Merve Didem and Dr. Elif Cansu Gündoğdu who are members of the society’s early career team, participated as instructors in the laparoscopy course in Hamburg.

Prof. Dr. Taner Usta gave a talk on neuropelvology at the University of Bologna on May 8th. He made an online presentation titled “Robotic Surgery in Diaphragm Endometriosis” at the Korea Gynecological Robotic Surgery Congress on May 13th. He gave a speech on “Pelvic Pain” at the Romanian National Endometriosis Congress on June 1st. On June 3rd, he held a presentation titled “Robotic Surgery in Lumbosacral Neuropathy” at RCOG.

On May 19th, Prof. Dr. Moamar al Jafout who is a board member of WES, president of the Asian Endometriosis Association (ASEA), the founder of Emirates Endometriosis League (EMEL) and Jordan Endometriosis Society, gave a webinar talk on "Nerve Fibers in Endometriosis" moderated by Prof. Dr. Ümit İnceboz, the president of our society.
With the contributions of Prof. Dr. Kutay Biberoğlu who is among the founder members of our society and still a member of our advisory board, we are in close collaboration with the Asian Endometriosis Association, and we plan joint projects in the future.

During this period, Endo-Adeno article meetings continued regularly. Dr. Fitnat Topbaş Selçuki and Dr. Fırat Büyüktaşkı gave their presentations under the moderation of Prof. Dr. Kutay Biberoğlu on April 13, 2023. Prof. Dr. Levent Şentürk moderated the presentations held by Dr. Işık Sözen and Dr. Fatih Aktoz on May 17th.

The Endoacademy webinars continued intensely. On April 20th Dr. Karolin Ohanoğlu and Dr. Çağlar Çetin “When surgery for which patient”, on April 27th Dr. Ayşegül Bestel and Dr. Nilüfer Cimşit “Approach and management of postmenopausal endometriosis”, on May 10th Dr. Nilüfer Akgün “Classifications in endometriosis” moderated by Prof. Dr. Turgut Var, and on May 18th Dr. Ayşegül Mut “Fertility preservation in endometriosis cases” moderated by Dr. Yusuf Aytaç Tohma held their presentations, and the topics were discussed in detail. In addition, on May 25th, Dr. Ezgi Darıcı made a presentation sharing her experiences on the education she received in Belgium with the members of our association.

On April 18, 2023, Dr. Nilüfer Akgün gave a presentation on “Raising awareness on endometriosis”, which was a part of our continuous meetings on "It is possible to live with endometriosis" at Ankara Bahçeşehir College.

On May 9, 2023, Prof Dr. Turgut Var gave a seminar on "Awareness and Current Approaches in Endometriosis and Adenomyosis" at Ankara Lokman Hekim University Faculty of Medicine. The 4th and 5th grade students of the medical faculty, obstetricians, gynecologists and other related specialists participated in the meeting.

We have completed the preparations for the meetings planned for the upcoming term, and we invite our colleagues to these meetings. On September 3, 2023, the meeting on “Endometriosis; from diagnosis to management” will be held under the chairmanship of Prof. Dr. Koray Elter and Prof. Dr. Erkan Alataş in Denizli. On September 24, 2023, the symposium on “Multidisciplinary approach to endometriosis and adenomyosis” will be held under the chairmanship of Prof. Dr. Ümit İnceboz and Doç. Dr. Yusuf Aytaç Tohma in Ankara. In addition, the preparations continue for the meeting “Endometriosis and Adenomyosis: Bench to Bedside” that we are planning together with Oxford and Edinburgh Universities on February 2-3, 2024, in Istanbul.

We hope you enjoy reading this bulletin.

On behalf of the board of Endometriosis and Adenomyosis Society

Responsible for the bulletin, Prof. Dr. Turgut Var
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SELECTED ARTICLES


1. Patients’ and relatives’ perspectives on best possible care in the context of developing a multidisciplinary center for endometriosis and adenomyosis: findings from a national survey.

Marianne Omtvedt, Elisabeth Bean, Kirsten Hald, Elisabeth Raasholm Larby, Guri B. Majak and Tina Tellum Omtvedt et al.

Abstract

Background: Endometriosis and adenomyosis are common benign conditions compromising both physical and psychological health, with a negative impact on quality of life. This survey aimed to establish what the users’ perspectives are on best possible care in the context of developing a multidisciplinary center for endometriosis and adenomyosis in Norway.

Methods: An electronic questionnaire was developed in collaboration between the Norwegian Patient’s Endometriosis Society (NPES) and gynecologists with special interest in endometriosis and adenomyosis. The questionnaire was distributed digitally to the members of NPES in May 2021.

Results: 938 participants answered the questionnaire. Better patient information, long term therapeutic plans and integration of their partners into their care were the main concerns. Multidisciplinary care was a key issue for the majority, with (n = 775) 89% stating a need for a consultation with a psychologist, (n = 744) 86% at least one consultation with a nutritionist, (n = 733) 85% a physiotherapist, and (n = 676) 78% needing a sex therapist and (n = 935) 99,7% consider research and (n = 934) 99,8% consider quality
assurance initiated by the endometriosis center to be important. The qualitative analysis of free text answers revealed a great need for updated and easily accessible information, meeting competent health care professionals and being taken seriously/listened to.

Conclusions: This survey shows similar perceptions and a high level of agreement regarding their needs amongst people with endometriosis and/or adenomyosis. This survey supports recommendations by the experts that endometriosis/adenomyosis care should be centralized in specialized, multidisciplinary centers. The results of the present work will be valuable for the future planning and development of a multidisciplinary endometriosis center.

Keywords: Adenomyosis; Centralized endometriosis center; Endometriosis; Multidisciplinary care; Patient-centeredness; Quality of care; Women’s health.


Abstract

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.

3. Rethinking endometriosis care: applying the chronic care model via a multidisciplinary program for the care of women with endometriosis.

Sanjay K Agarwal, Warren G Foster, and Erik J Groessl

Abstract

Endometriosis is a chronic, painful disease without a cure. Due largely to chronic pain, endometriosis can lead to significant physical, mental, relationship, and financial burdens. Within the conventional single provider model of care—in which the patient is primarily taken care of by her physician and complementary strategies based on psychology, nutrition, pain medicine, pelvic physical therapy, and so on may not be readily available in a coordinated manner—most women with endometriosis live with unresolved pain and the consequences of that pain. We therefore propose that there is an urgent need to search for alternative models of care. In the current paper, we discuss our experiences with an model of care in which we adopt a long-term, patient-focused, and multidisciplinary chronic care model for women with endometriosis. Our objective is to improve long-term clinical outcomes for women with endometriosis. For geographical areas and healthcare systems in which it is feasible, we propose consideration of this multidisciplinary model of care as an alternative to the single provider model and
offer guidance for those considering establishment of such a program. We also initiate a conversation about which clinical outcomes pertaining to endometriosis are important and should be tracked to assess the efficacy and value of multidisciplinary and other endometriosis healthcare models.

Keywords: endometriosis, multidisciplinary, chronic care model, multimodal, quality of life, health services

4. Interdisciplinary Teams in Endometriosis Care

Catherine Allaire, Alicia Jean Long, Mohamed A Bedaiwy, Paul J Yong.

Abstract

Endometriosis-associated chronic pelvic pain can at times be a complex problem that is resistant to standard medical and surgical therapies. Multiple comorbidities and central sensitization may be at play and must be recognized with the help of a thorough history and physical examination. If a complex pain problem is identified, most endometriosis expert reviews and guidelines recommend multidisciplinary care. However, there are no specific recommendations about what should be the components of this approach and how that type of team care should be delivered. There is evidence showing the effectiveness of specific interventions such as pain education, physical therapy, psychological therapies, and pharmacotherapies for the treatment of chronic pain. Interdisciplinary team models have been well studied and validated in other chronic pain conditions such as low back pain. The published evidence in support of interdisciplinary teams for endometriosis-associated chronic pain is more limited but appears promising. Based on the available evidence, a model for an interdisciplinary team approach for endometriosis care is outlined.

5. Real-world characteristics of women with endometriosis-related pain entering a multidisciplinary endometriosis program.


Abstract

Background: Women with endometriosis are commonly treated by their sole provider. In this single-provider model of care, women frequently report long diagnostic delays, unresolved pelvic pain, multiple laparoscopic surgeries, sequential consultations with numerous providers, and an overall dissatisfaction with care. The emergence of multidisciplinary endometriosis centers aims to reduce diagnostic delays, improve pain management, and promote patient satisfaction; however, baseline data at the time of presentation to a multidisciplinary center are lacking.

Methods: A real-world, retrospective, single-site, cross-sectional study of women with surgically confirmed and/or clinically diagnosed endometriosis generated baseline data for a planned longitudinal assessment of multidisciplinary care of endometriosis. The primary objective was to determine the proportion of patients experiencing mild, moderate, or severe pain for dysmenorrhea, non-menstrual pelvic pain (NMPP), and dyspareunia at entry into a multidisciplinary endometriosis clinic. Also explored were relationships between pain scores and clinical endpoints obtained from electronic medical records.

Results: More than half (59%) of the study participants (n = 638) reported experiencing pelvic pain for ≥ 5 years. Pain intensity was highest for patients reporting dysmenorrhea, followed by NMPP, and dyspareunia. Significant correlations were observed between total pelvic pain and patient age (r = -0.22, p < 0.001, n = 506) and number of previous healthcare providers (r = 0.16, p = 0.006, n = 292); number of
previous providers and duration of pain \( (r = 0.21, p < 0.0001, n = 279) \); and duration of pain and years since diagnosis \( (r = 0.60, p < 0.001, n = 302) \). Mean pain scores differed significantly by age group for dysmenorrhea \( (p < 0.001) \), NMPP \( (p = 0.005) \), and total pelvic pain \( (p < 0.001) \), but not for dyspareunia \( (p = 0.06) \), with the highest mean pain scores reported among those < 30 years of age.

Conclusion: These real-world data indicate that in the single-provider model of care, unresolved pelvic pain is common among women with endometriosis. Alternative care models, including a multidisciplinary approach, need to be evaluated for improvements in clinical outcomes. These data also highlight the importance of addressing NMPP, which may be particularly troublesome for patients.

Keywords: Endometriosis; Multidisciplinary approach; Pain; Real-word evidence

6. The role of the multidisciplinary team in the management of deep infiltrating endometriosis. Lilian Ugwumadu, Rima Chakrabarti, Elaine Williams-Brown, John Rendle, Ian Swift, Babbin John, Heather Allen-Coward, Emmanuel Ofuasia.

Abstract

The multidisciplinary team (MDT) is considered good practice in the management of chronic conditions and is now a well-established part of clinical care in the NHS. There has been a recent drive to have MDTs in the management of women with severe endometriosis requiring complex surgery as a result of recommendations from the European Society for Human Reproduction and Embryology (ESHRE) and British Society for Gynaecological Endoscopy (BSGE). The multidisciplinary approach to the management of patients with endometriosis leads to better results in patient outcomes; however, there are potentially a number of barriers to its implementation and maintenance. This paper aims to review the potential benefits, disadvantages and barriers of the multidisciplinary team in the management of severe endometriosis.

Keywords: Deep infiltrating endometriosis; Multidisciplinary care; Multidisciplinary meetings; Multidisciplinary team; Rectovaginal endometriosis.
The 15th World Endometriosis Congress (WCE 2023/) EDINBURGH was a productive congress for our association. Our association's founding president and board member Prof. Dr. Engin Oral has been elected to the new WES board of directors. In addition, Dr. Fitnat Topbaş Seçüki, one of the most successful core group members of our association, became another source of pride by becoming a new member of the WES Early Career Board.

At this congress, Dr. Fırat Büyüktaş'ın's article was selected as the highest-scoring study among the studies submitted from the Middle East and African countries.
On April 18th, 2023, Dr. Nilufer Akgun made a presentation titled “Endo’lu yaşamak mümkün” (It is possible to live with Endo) with the aim of raising awareness in endometriosis at Ankara Bahçeşehir College.

Our Endo-Adeno article meetings continued regularly.
Prof. Dr. Turgut Var gave a seminar on “Awareness and Current Approaches in Endometriosis and Adenomyosis” at Ankara Lokman Hekim University Faculty of Medicine.

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Prof. Dr. Taner Usta and Prof. Dr. Ahmet Kale served as instructors in the laparoscopy course in Hamburg with the young team members Dr. Nilufer Akgün, Dr. Merve Didem and Dr. Elif Cansu Gündoğdu.
UPCOMING ACTIVITIES

On September 3, 2023, under the chairmanship of Prof. Dr. Koray Elter and Prof. Dr. Erkan Alataş, a meeting on “Endometriosis: From Diagnosis to Management” will be held in Denizli Pamukkale University.

On September 24, 2023, in Ankara, under the chairmanship of Prof. Dr. Ümit İnceboz and Assoc. Prof. Dr. Yusuf Aytaç Tohma, a symposium named “Multidisciplinary Approach to Endometriosis and Adenomyosis” will be held.

The preparations for the "Endometriosis and Adenomyosis: Bench to Bedside" meeting, which we are planning together with Oxford and Edinburgh Universities on February 2-3, 2024, in Istanbul, continue.
INTERVIEW WITH AN “ENDO SPECIALIST”

Endometriosis and Adenomyosis Society, Turkiye: Could you tell us about how you started your endometriosis journey?

Paolo Vercellini: I was quite impressed by the groundbreaking developments in gynaecological endocrinology during my 4th year at the Medical Faculty of Milano in 1977. I decided to apply for an internship at “Luigi Mangiagalli” one of Milano’s biggest obstetrics and gynecology hospitals. I had the unique chance to meet the chief of the hospital at the time, Professor Giovanni Battista Candiani, and witness his clinical and research works. Endometriosis was one of his fields of interest and he engaged me with one of his friends, Prof. Luigi Fedele who specialized in reproductive surgery. My thesis was about microsurgical techniques in ovarian endometriosis. I followed Prof. Candiani’s and Prof. Fedele’s studies on the pathogenesis and the treatment of endometriosis after I started my residency in OBGYN in 1981. I recall those years with great excitement and joy. I am grateful to my mentors for their passion for teaching their young colleagues how to run clinical studies and the management of this disease which was known very little at the time.

EAS: How is your daily routine?

PC: My routine has changed a lot since 2018 when I became the head of the department of obstetrics and gynecology in the same hospital where I graduated 40 years ago. As a matter of fact, I have never moved. Nowadays, managing a department comes with many organizational duties other than your academic and clinical work. Still, I organize my research program and spare almost half my day for clinical studies.

EAS: What do you think is the hardest thing about endometriosis?

PC: It’s a million-dollar question! I believe the most difficult target would be defining the most effective precautions to avoid the development of disease and curative treatment.

EAS: What do you think is the most important thing for a physician when approaching an endometriosis patient?

PC: The most important thing in a patient-doctor relationship is to listen to your patient with great empathy and make her feel that everything could be solved when you work together. Humanity is much needed in medicine.
**EAS:** What is the most important thing for an endometriosis patient to know?

**PC:** It is very important to enlighten the patient about her situation and the cons and pros of treatment options. This way, patients will be able to make the best decision for their situation and priorities.

**EAS:** What advice would you give for young colleagues who want to specialize in endometriosis?

**PC:** My advice would be to work hard and stay updated. This is the only way to give endometriosis patients the best evidence-based treatment options.

**EAS:** What properties are needed in a doctor who works on endometriosis?

**PC:** A doctor specializing in endometriosis should be able to manage the psychological aspects of this disease, which can turn the patient’s life upside down. Listening carefully, knowing when and how to talk, and reducing the level of anxiety and psychological intensity could be as effective as surgical skills or expensive drugs.

**EAS:** We know that you have a very high H-index when we look at your academic career. What advice would you give to your young colleagues who want to progress in science?

**PC:** Just pursue your passion and remember that H-index is nothing other than the outcome of a satisfying academic career. The goal is to create important data to improve women’s health. If young colleagues want to contribute to science, they should know that being able to help patients is what really matters.

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Interviewer: Hümeýra Demirkıran, M.D.
ARTICLES ON ENDOMETRIOSIS FROM OUR COUNTRY FROM THE LAST 3 MONTHS

CLIMACTERIC  https://doi.org/10.1080/13697137.2023.2190882
REVIEW Evaluation and management of endometriosis T. Yoldemir
Department of Obstetrics and Gynaecology, Marmara University School of Medicine, Istanbul, Turkey
ABSTRACT The initial diagnostic investigations for endometriosis are physical examination and pelvic ultrasound. The pelvic examination should include a speculum examination and vaginal palpation. Mobility, fixation and/or tenderness of the uterus and site-specific tenderness in the pelvis should be evaluated. Transvaginal ultrasound and pelvic magnetic resonance imaging are recommended to evaluate the extent of the endometriosis and to determine whether any urinary tract or bowel procedures might also be required during surgical resection. Quality of life should be assessed by using the Endometriosis Health Profile-30, its short version EHP-5 or the generic quality of life questionnaire SF-36. Management of endometriosis is recommended when it has a functional impact (pain, infertility) or causes organ dysfunction. Many gynecological societies have published different guidelines for the evaluation and management of endometriosis. However, the complexity of this disease together with the different available treatments lead to significant discrepancies between the recommendations. Postmenopausal endometriosis should be considered when a patient has a history of symptoms before menopause including dysmenorrhea, dyspareunia, dyschezia, infertility and chronic pelvic pain. Malignant transformation of endometriosis is estimated to occur in about 0.7–1.6% of women affected by endometriosis. Endometriosis is associated with an increased risk of ovarian cancer, specifically clear cell, endometrioid and low-grade serous types.

ORIGIANL ARTICLE
Rev Assoc Med Bras 2023;69(6):e20221679
Is there an association between endometriosis and thyroid autoimmunity?
Hilal Şerifoğlu1, Sevcan Arzu Arinkan2*, Ozge Pasin3, Fisun Vural1
SUMMARY OBJECTIVE: It has been suggested that non-uterine endometrial implants can express thyroid-stimulating hormone receptors, thus inducing the formation of thyroid-stimulating immunoglobulin. We aimed to compare the autoantibody positivity in patients with and without endometriosis and to determine whether there is a difference in the incidence of thyroid diseases.
METHODS: This prospective observational study was conducted on 102 women who had been operated on for benign gynecological diseases. Cases enrolling in the study were divided into two groups: the study group with endometriosis (n=51) and the control group without endometriosis (n=51). The blood tests for thyroid-stimulating hormone, free thyroxine (fT4), thyroid-stimulating immunoglobulin, and anti-thyroid peroxidase antibody levels were checked.
RESULTS: The mean thyroid-stimulating immunoglobulin level was found to be higher in the endometriosis group than in the control group. However, this difference was not statistically significant. No significant difference was detected between endometriosis and control groups in terms of antithyroid peroxidase antibody and thyroid-stimulating hormone levels. The mean fT4 value (0.97±0.13 ng/dL) of the endometriosis patients was found to be significantly lower than the control group (1.08±0.21 ng/dL) (p=0.002; p<0.05). The mean anti-thyroid peroxidase antibody value of cases with bilateral endometrioma (82.21±252.29 IU/mL) was significantly higher than cases with unilateral endometrioma (15.81±83.13 IU/mL) (p=0.028; p<0.05). There is a positive and significant relationship between the size of endometriosis and anti-thyroid peroxidase antibody values (p=0.011; p<0.05).
CONCLUSION: This study points to an association between endometrioma diameter and anti-thyroid peroxidase antibody values which can be a stepping stone for new studies evaluating this hypothesis further.
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