'My Devil Womb': Patients' perspectives on, and understanding of, endometriosis: An observational cross-sectional study

Nadine Chilton[1], Sarah van Oudtshoorn[1], Jennifer Pontré[1], Krishnan Karthigasu[1], and Bernadette McElhinney[1]

[1]King Edward Memorial Hospital for Women Perth

January 30, 2024

Abstract

Objective: To gain insight into patients' understanding of endometriosis, utilised sources of information on endometriosis, and perceptions of available treatment options. Design: Observational cross-sectional study. Setting: Data were collected from an outpatient specialist endometriosis clinic within a tertiary hospital. Participants: New patients referred with symptoms suggestive of endometriosis. Methods: A paper based questionnaire was completed by new patients on their first presentation to the clinic. Main outcome measures: Patient understanding of symptoms and causes of endometriosis, types and expectations of treatment, and sources of information utilised by patients in researching endometriosis. Results: Approximately half of all included patients were unsure of the aetiology of endometriosis. Patients who relied on information from specialist gynaecologists were more optimistic about the outcome of surgical treatment, while those who relied on general practitioners were more optimistic about the outcome of medical treatment, when compared to those who sought information from online sources. Conclusions: Endometriosis is a chronic and debilitating condition, yet there is limited data available regarding both the sources of information that patients' access, and their perceptions of the disease. Given the high proportion of patients in our study who lacked knowledge of endometriosis, and the negative correlation between the use of social media for information and perception of treatment, there is a clear need for improved access to evidence-based resources for patient education. Funding: None received Keywords: Endometriosis, laparoscopy, social media, patient education

Title: 'My Devil Womb': Patients' perspectives on, and understanding of, endometriosis: An observational cross-sectional study

Short Running Title: Patients' Perspectives on Endometriosis

Word count abstract: 231

Word count main text: 2473

Table count: Two

Keywords: Endometriosis, laparoscopy, social media, patient education

Abstract:

Objective: To gain insight into patients' understanding of endometriosis, utilised sources of information on endometriosis, and perceptions of available treatment options.

Design: Observational cross-sectional study.

Setting: Data were collected from an outpatient specialist endometriosis clinic within a tertiary hospital.

Participants: New patients referred with symptoms suggestive of endometriosis.

Methods: A paper based questionnaire was completed by new patients on their first presentation to the clinic.

Main outcome measures: Patient understanding of symptoms and causes of endometriosis, types and expectations of treatment, and sources of information utilised by patients in researching endometriosis.

Results: Approximately half of all included patients were unsure of the aetiology of endometriosis. Patients who relied on information from specialist gynaecologists were more optimistic about the outcome of surgical treatment, while those who relied on general practitioners were more optimistic about the outcome of medical treatment, when compared to those who sought information from online sources.

Conclusions: Endometriosis is a chronic and debilitating condition, yet there is limited data available regarding both the sources of information that patients' access, and their perceptions of the disease. Given the high proportion of patients in our study who lacked knowledge of endometriosis, and the negative correlation between the use of social media for information and perception of treatment, there is a clear need for improved access to evidence-based resources for patient education.

Main Text:

Introduction

Endometriosis is a chronic, inflammatory condition affecting 10% of the reproductive age group[1-3]. Endometriosis can be associated with debilitating symptoms including pain and subfertility[3-5]. The aetiology of endometriosis remains unclear and is probably multifactorial, involving hormonal, immunological and environmental factors[6]. Endometriosis is 'incurable', therefore numerous medical and surgical treatment options, aimed at suppression of symptoms and prevention of disease progression, exist ranging from hormonal therapies to laparoscopic excision or ablation[4, 5, 7, 8]. An average delay of 10 years between onset of symptoms and formal diagnosis has been reported. Whilst many disease related factors are known to contribute to this issue[9], a lack of patient awareness of endometriosis is known to play a major role, as does accessibility of high quality patient information[4, 10]. Unsurprisingly, patients who lack information experience higher levels of emotional distress when diagnosed with endometriosis[2]. This, in turn, contributes to delays in diagnosis as patients may be unaware of the significance of their symptoms.

Recently, the impact of endometriosis on patients' lives has been recognised. The National Action Plan for Endometriosis, which was launched in Australia in 2018[11], formally acknowledged its burden as a chronic condition. One of the first priorities is to increase awareness and education in Australia, for both patients and health professionals, in an effort to reduce delays to diagnosis. In an era where unauthorised information is widely available online[12], there is a lack of data demonstrating which sources are regularly utilised by patients to obtain such information and the authenticity of the different sources. In addition, there is minimal understanding regarding what knowledge patients have in relation to the various treatment options available, and a lack of insight into how patients perceive these treatments.

The objective of this pilot study was threefold: to ascertain what patients understand about endometriosis, where they obtain their information from and to gain an understanding of perceptions of treatment options for endometriosis.

Materials and methods

An observational cross-sectional pilot study was conducted over a 12-month period from October 2017 to October 2018 inclusive, in an outpatient endometriosis clinic within a tertiary hospital. Patients presenting for their first appointment, with symptoms suggestive of endometriosis and over 18 years of age, were invited to complete a paper questionnaire on arrival by the clinic nurse. An information sheet was provided outlining the purpose of the study. Participation was voluntary, consent was implied if the patient agreed to complete a

questionnaire and all questionnaires were de-identified. Fifty-six patients agreed to participate and completed questionnaires (one questionnaire was incomplete and excluded from analysis). The questionnaire covered five main areas: patient demographics (age, ethnicity, primary language, family history of endometriosis, parity and mode of delivery, use of contraception and type), menstrual cycle, current symptoms of endometriosis, understanding of endometriosis, previous treatments and expectations of treatment. Ethical approval was sought and granted on the 15th of August 2017 from the Women and Newborn Health Service Governance, Evidence, Knowledge and Outcome Ethics Committee (GEKO reference 15884). No funding was received for this study, and the authors have no conflicts of interest to declare.

Patients were asked to rate their understanding of endometriosis. Reply options included nil, poor, average, good and excellent. Patients were asked if they were satisfied with their current level of knowledge (*'yes/no'* response).

To assess the sources of information utilised to obtain knowledge, eighteen options were provided, namely: friends, family members, word of mouth, general practitioner, specialist obstetrician/gynaecologist, other medical staff, internet searches, Facebook, Twitter, internet blogs, podcasts, internet chat rooms/forums, support groups, brochures, television, newspaper articles, magazines and radio. Patients were asked to tick the options that applied to them and to rank the three most important sources (with '1' the most important and '3' the least important).

Patients were asked what they believed were the causes of endometriosis, their symptoms of endometriosis, what treatment options they knew were available and which treatment options they believed to be the best for endometriosis. In addition, a free text box was provided. Finally, patient expectations of treatment were assessed. Patients were asked if they thought that their treatment would bring about 'no change' or 'an improvement/deterioration' of their pain symptoms, reproductive potential and quality of life (QOL) with regard to surgical and medical treatment.

Demographic and descriptive statistics were initially computed in Excel. Frequencies and percentages were calculated for categorical variables including: age group, pain, fertility, satisfaction with knowledge, previous treatment, sources of information and expectations of treatment. For some categorical data, grouping of responses was required as numbers in individual groups were too small for analysis ('no change' and 'worsening' were grouped together). The mean, range and standard deviation were calculated for continuous variables such as severity of pain, number of pain days per month and life impact severity rating. Statistical analyses were performed in SPSS v22. Chi-Squared tests were utilised to analyse categorical variables and continuous variables were analysed using independent t-tests. Specifically, Chi-square analyses between satisfaction of knowledge and history of previous treatment (medical or surgical) were performed. Independent t-test analyses were performed between life impact severity rating and the number of days per month pain was experienced, against satisfaction with current knowledge of endometriosis.

Results

Fifty-five patients completed questionnaires for this study. Mean patient age was 33 years (range 18 to 52 years). The majority of respondents were of Caucasian (66%) followed by Asian (12%), then African (5%) descent. Six patients (10%) did not identify with an ethnic group.

More than half of the patients reported their main symptom as pain (56%); 7% reported subfertility as their main issue. Thirty-three percent of patients were unsure whether the predominant issue was pain or subfertility. Only 54% of patients reported that they had regular cycles (n=29). The average severity of pain score was 8.5 (range 3-10; n=51). The average number of days per month that they reported experiencing pain was 13.6 (range 2-31 days). The average self rated life impact severity from their symptoms was 6.9 (range 1-10).

More patients had previously undergone surgical rather than medical treatment; 60% of patients had undergone previous surgery for endometriosis compared to only 27% who reported prior utilisation of medical treatment.

Patients' understanding of endometriosis

More than half of patients (53%), were satisfied with their current level of knowledge of endometriosis. Almost half of the patient cohort was unsure of the potential causes of endometriosis (n=25; 46%). Twelve percent (n=7) felt that it was due to 'hormones', 5% (n=3) retrograde menstruation and another 5% stated endometrial metaplasia as a cause. Sixteen percent (n=9) attributed genetics as a causal factor. Several patient responses were unexpected with respect to the cause of endometriosis. Some of the more notable responses included *"my devil womb", "it's the blood from menstruation that doesn't come out", "bad blood",* and *"stress in the body"* .

There was no association between history of prior treatment for endometriosis and current satisfaction with knowledge. Again, there was no association between severity of disease, as rated by patients, and satisfaction with knowledge.

Sources utilised by patients in self-education about endometriosis

The use of internet search engines and gynaecologists were the two most relied upon sources of information on endometriosis (Table 1). The least utilised sources of information included books, journals, magazines and newspapers.

Expectations of treatment

A large proportion of patients expected that medical treatment would improve their symptoms, with 54% expecting an improvement in fertility, 78% expecting an improvement in pain, and 78% expecting an improvement in QOL (Table 1). Greater expectations were placed on the outcome of surgical treatment, with almost 90% of patients expecting an improvement in symptoms and quality of life following surgery. A majority (64%) expected an improvement in fertility (Table 1).

Discussion

Main findings

This pilot study has highlighted that patients with endometriosis experience significant symptoms. The average pain score for patients was 8.5/10 for 13.6 days per month, with an impact score of 6.9. This is a significant pain score for almost 2 weeks per month. Considering the burden that endometriosis places on society, and the overall prevalence, this equates to a significant number of patients who are affected by this condition. The severity of the symptoms experienced by the patients, and the treatment they undergo, does not have a correlation with their level of knowledge. Almost half of patients were unsure of the causes of endometriosis.

It would appear that patients rely heavily on Internet search engines and gynaecologists for their information. Patients' level of optimism regarding treatment options was influenced by their sources of information. Patients were more optimistic about medical treatment and surgical treatment if information was sought from general practitioners and gynaecologists respectively, compared to online sources. This would indicate that imparting accurate, relevant information is more beneficial. Patients' expectations of medical treatment were compared with the sources of information they utilised for self-education. We found a statistically significant negative association between reliance on Facebook for information and expectations of medical treatment with regard to symptom control (Table 2). A statistically significant positive association, however, was found between a reliance on the GP for information and a high expectation of medical treatment for relief of pain (Table 2). In other words, patients who relied on GPs for information expected their symptoms and pain to improve on medical treatment. Similarly, there was a statistically significant positive association between surgical treatment and reliance on gynaecologists for information with regard to symptoms and quality of life, but a negative association if information was sought from other clinic staff (Table 2).

Surprisingly over half of patients in this study thought that medical treatment would improve their fertility. In reality, most medical treatments preclude pregnancy. This would suggest that patients are not properly informed. A body of evidence supports the positive benefits of surgery with regard to fertility. Sixty-four

per cent of patients thought that surgery would be beneficial with regard to fertility. The effect of surgery on fertility depends on the severity of the disease. Oocyte quality will have a significant impact as well. Two RCT's compared laparoscopic excision of mild and minimal endometriosis with diagnostic laparoscopy alone [13, 14]. Whilst one group reported a positive effect [13], the other group found no positive benefit.

Ninety per cent of patients expected an improvement in their pain after surgery despite 60% of these patients having undergone previous surgery. Although comprehensive data is lacking, in a systemic review, the number of patients who did not experience a decrease in pain after surgery for endometriosis was 11.8% [15].

Strengths and limitations

The main limitation of our study is the small sample size and random assignment of patients. As this study was initially designed as a pilot study, patients were not systematically invited to participate and therefore patients who met the inclusion criteria may have been missed. We did not collate numbers of patients who declined to participate on initial invitation, which would have allowed us to analyse the proportion of patients whom responded, in the context of the total number of patients that were eligible for participation.

Interpretation

Endometriosis can cause significant sequelae for patients, including chronic pelvic pain and subfertility. If not recognised in a timely manner, patients can transition from experiencing cyclical dysmenorrhoea to chronic pelvic pain.

Although laparoscopic assessment of the pelvis is regarded as the 'Gold Standard' of care, it should not always be offered as the first line of management. Medical options are generally worth trialling in patients not desiring fertility with normal imaging. Historically, length of time to diagnosis tends to be unacceptably long and treatments may vary significantly between specialists. The National Action Plan for Endometriosis has been instigated to address this delay and streamline treatment options.

In the current era of digital technology, patients have the option of resorting to online resources for medical information. While these resources provide a more personal experience of various chronic diseases and present information that is easily consumed[16], their use can be hazardous as there is no regulation of the content of the information that patients have access to with regards to accuracy and appropriateness. Furthermore, there is a tendency for patients to report negative experiences more readily on social media.

Although many studies exist reporting on endometriosis and its treatment options, there is a paucity of data investigating patient awareness and understanding of endometriosis and available sources of information. Surprisingly, in this study, one third of patients were unable to differentiate between pain or subfertility as their primary concern. Twice as many patients had undergone surgery as opposed to medical treatment at initial presentation to the clinic. Despite universal access to the Internet and online medical forums, nearly 50% of patients had not built a clear picture of the potential causes of endometriosis. Interestingly 60% of patients had previously undergone surgical treatment, presumably by a specialist gynaecologist, yet were unaware of the aetiology of endometriosis. Prior treatment and severity of symptoms had no impact on degree of patient satisfaction with respect to knowledge regarding the condition. There were two major sources of information, namely gynaecologists and internet search engines. Patients were overall more positive that their symptoms would improve following medical treatment, and less certain that their fertility would. Patient expectations placed on surgical treatments were higher. Those patients who relied on their GP for information, rather than Facebook, had more optimistic beliefs regarding the value of medical treatment.

Sixty per cent of patients had undergone previous surgery yet, overall, 88.7% expected a significant improvement in pain, and 94.3% expected an improvement in quality of life. Thus, even those patients with recurrence of pain after previous surgery for endometriosis expected a high rate of success of repeat surgery. The results were not as high for medical treatment.

Conclusion

In Australia, the recently released National Action Plan for Endometriosis is welcomed yet well overdue. It is the first ever blueprint seeking to improve not only public awareness, but also the understanding and more timely diagnosis and treatment of an often misunderstood and debilitating condition affecting only women. The plan was developed with the help of medical specialists, endometriosis advocacy groups, patients with endometriosis and their families, clinicians, researchers and parliamentarians. The plan outlines a comprehensive 5-year plan, which signals a significant step in the right direction.

Our data indicates that a majority of patients lack accurate information regarding their diagnosis. Whilst specialist gynaecologists and GPs are a trusted source of information, there is evidence to suggest that social media, due to its convenient accessibility, is another prominent source of information, despite its potential for lack of scientific rigor. Given the impact of endometriosis as a chronic condition, it is in the interest of health professionals involved in its management, to provide accurate information on the condition. Treatment options should be evidence-based and widely accessible to the population as a whole. There is an increasing need for rigorous scientific data to guide management and research into endometriosis should be promoted widely.

Disclosure of interests:

The authors for this article have no conflicts of interest to declare.

Contribution to authorship

SVO designed and disseminated the questionnaire and applied for ethics approval. NC collated the questionnaires, performed the statistical analyses and wrote the initial manuscript. All authors were involved in the editing and production of the final manuscript.

Ethics approval

Ethical approval was sought and granted on the 15[th]August 2017 from the WNHS GEKO Ethic Committee (GEKO reference 15884).

Table list:

Table 1: Sources of information utilised and expectations of medical and surgical treatment for women with suspected endometriosis

Table 2: Association between sources of information and expectations of medical and surgical treatment for women with suspected endometriosis

References

1. Shadbolt, N.A., M.A. Parker, and L.A. Orthia, *Communicating endometriosis with young women to decrease diagnosis time.* Health Promotion Journal of Australia, 2013. **24** : p. 151-154.

2. Lemaire, G.S., *More than just menstrual cramps: Symptoms and Uncertainty among women with endometriosis.* JOGNN, 2004. **33** : p. 71-79.

3. Moradi, M., et al., *Impact of endometriosis on women's lives: a qualitative study.* BMC Women's Health, 2014. **14** : p. 123-135.

4. Bush, D., et al., *Endometriosis education in schools: A New Zealand model examining the impact of an education program in schools in early recognition of symptoms suggesting endometriosis.* Aust NZJ Obstet Gynaecol, 2017. **57** : p. 452-457.

5. Young, K., J. Fisher, and M. Kirkman, *Clinicians' perceptions of women's experiences of endometriosis and of psychosocial care for endometriosis.* Aust NZJ Obstet Gynaecol, 2017. **57** : p. 87-92.

6. Vercellini, P., et al., *Endometriosis: pathogenesis and treatment.* Nature Reviews Endocrinology, 2014. **10** : p. 261-275.

7. Abbott, J., et al., *Laparoscopic excision of endometriosis: A randomized, placebo-controlled trial.* Fertility and Sterility 2004.**82** (4): p. 878-884.

8. Guidice, L.C., *Endometriosis.* The New England Journal of Medicine, 2010. **362** : p. 2389-2398.

9. Ballard, K., K. Lowton, and J. Wright, *What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis.* Fertility and Sterility, 2006. **86** (5): p. 1296-1301.

10. Shah, D.K., et al., *Public perceptions of endometriosis: perspectives from both genders.* Acta Obstetricia et Gynaecologia, 2010.**89** : p. 646-650.

11. Australian Government Department of Health, *National Action Plan for Endometriosis.* 2018.

12. Hirsh, M., et al., *Googling endomtriosis: a systemic review of information available on the internet.* American Journal of Obstetrics and Gynaecology, 201. **216** (5): p. 451-458.

13. Marcoux, S., et al., *Laparoscopic surgery in infertile women with minimal or mild endometriosis.* The New England Journal of Medicine, 1997. **337** (4): p. 217-222.

14. Gruppo Italiano per lo Studio dell'Endometriosi, *Ablation of lesions or no treatment in minimal-mild endometriosis in infertile women: a randomized trial.* Human Reproduction, 1999. **14** (5): p. 1332-1334.

15. Singh, S.S., et al., *Surgical Outcomes in Patients with Endometriosis: A systemic Review.* Journal of Obstetrics and Gynaecology, 2020. **42** (7): p. 881-888.

16. Lupton, D. and S. Maslen, *How women use digital technologies for health: Qualitative interview and focus group study.* Journal of Medical Internet Research, 2019. **21** (1).

Hosted file

Table 1.docx available at https://authorea.com/users/726133/articles/708834--my-devil-womb-patients-perspectives-on-and-understanding-of-endometriosis-an-observational-cross-sectional-study

Hosted file

TABLE 2- Association between sources of information and expectations of medical and surgical treatment available at https://authorea.com/users/726133/articles/708834--my-devil-womb-patients-perspectives-on-and-understanding-of-endometriosis-an-observational-cross-sectional-study