Assessing the knowledge of endometriosis diagnostic tools in a large, international lay population: an online survey.

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Abstract

Objective: To assess the general population's knowledge regarding the utility and availability of tools to diagnosis endometriosis, with focus on ultrasound. Design: An international cross-sectional online survey study was performed between August and October 2019. Setting and Population: 5301 respondents, representing 73 countries. Methods: 23 questions survey focused on knowledge of endometriosis diagnosis distributed globally via patient- and community-endometriosis groups using social media. Main outcomes and measures: Descriptive data of the knowledge of diagnostic tools for diagnosing endometriosis, including details about diagnosis using ultrasound. Results: 84.0% of respondents had been previously diagnosed with endometriosis, 71.5% of which were diagnosed at the time of surgery. Ultrasound and MRI were the methods of diagnosis in 6.5% and 1.8%, respectively. 91.8%, 28.8%, and 16.6% of respondents believed surgery, ultrasound and MRI could diagnose endometriosis, respectively (more than one answer allowed). In those diagnosed by surgery, 21.7% knew about ultrasound as a diagnosis method compared to 51.5% knowing in those diagnosed non-surgically ($p<0.001$). 14.7%, 31.1%, and 18.2% stated superficial, ovarian, and deep endometriosis could be diagnosed with ultrasound (32.9% stated they did not know which phenotypes of endometriosis could be diagnosed). 58.4% of respondents do not believe they could access an advanced ultrasound in their region. Conclusions: There are significant gaps in the understanding of diagnosing endometriosis using non-surgical tools in this study population.

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Assessing the knowledge of endometriosis diagnostic tools in a large, international lay population: an online survey.

SHORT TITLE :

General knowledge on diagnosing endometriosis

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Abstract

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An international cross-sectional online survey study was performed between August and October 2019.

Setting and Population:

5301 respondents, representing 73 countries.

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23 questions survey focused on knowledge of endometriosis diagnosis distributed globally via patient- and community-endometriosis groups using social media.

Main outcomes and measures:

Descriptive data of the knowledge of diagnostic tools for diagnosing endometriosis, including details about diagnosis using ultrasound.

Results :

84.0% of respondents had been previously diagnosed with endometriosis, 71.5% of which were diagnosed at the time of surgery. Ultrasound and MRI were the methods of diagnosis in 6.5% and 1.8%, respectively. 91.8%, 28.8%, and 16.6% of respondents believed surgery, ultrasound and MRI could diagnose endometriosis, respectively (more than one answer allowed). In those diagnosed by surgery, 21.7% knew about ultrasound as a diagnosis method compared to 51.5% knowing in those diagnosed non-surgically (p <0.001). 14.7%, 31.1%, and 18.2% stated superficial, ovarian, and deep endometriosis could be diagnosed with ultrasound (32.9% stated they did not know which phenotypes of endometriosis could be diagnosed). 58.4% of respondents do not believe they could access an advanced ultrasound in their region.

Conclusions : There are significant gaps in the understanding of diagnosing endometriosis using non-surgical tools in this study population.

Keywords :

Endometriosis; Pelvic pain; Diagnosis; Ultrasound; Magnetic resonance imaging; Needs assessment; Patient survey; Community involvement; Awareness

TWEETABLE Abstract

International survey (5301 respondents) indicates there is a low knowledge of non-surgical diagnostic tools for endometriosis.

INTRODUCTION

Endometriosis is one the most common gynaecological diseases affecting an estimated 10% of reproductive-age women and those born female-sex worldwide, equivalent to 190 million individuals.[1]Diagnosing endometriosis continues to be a challenge due to a myriad of factors including nonspecific symptoms[2], limitations with non-invasive biomarkers and imaging[3], symptom normalization[4], and lack of awareness on the part of both the public and healthcare providers.[5] These factors have led to a typical lengthy interval of time between symptom onset and diagnosis.[6] Despite the historical and current challenges, non-invasive imaging such as advanced transvaginal ultrasound (TVS) and magnetic resonance imaging (MRI) have demonstrated excellent diagnostic accuracy in visualising ovarian endometriomas (OE), deep endometriosis (DE) and pelvic adhesions such as pouch of Douglas obliteration[7], which could potentially increase the likelihood of an earlier diagnosis and avoid the need for major surgery (surgical diagnosis). Besides the benefit of initiating targeted therapy for endometriosis sooner, focus groups revealed that medical labelling (i.e. being given a diagnosis) would significantly and positively impact employment, relationships, and family planning.[8] The experiences of validation, empowerment, and a sense of control over endometriosis have been described to occur following medical labelling.[8–10]

Whilst the general public has limited to no knowledge of the disease, the knowledge of individuals with endometriosis is thought to be more sizeable and includes an appreciation of the gaps in care that require improvement.[11] There is also a growing tendency for patients to seek expert endometriosis physicians for diagnosis and treatment. The patient voice is increasingly represented in endometriosis research, bridging the gap between healthcare providers and their patients, reaching both with a deeper understanding of where improvements need to be made regarding care and management.[5,12] However, these voices often belong to highly educated and connected individuals or organisations in developed nations. As diagnosing endometriosis remains the gatekeeper to initiating therapy, our study aimed to assess the knowledge level of the lay international population regarding the process and tools used in diagnosing endometriosis.

MATERIAL AND METHODS

The development and reporting of the study were guided by the CHERRIES checklist[13] (Appendix 1).

An anonymous and open international e-survey was distributed from August to October 2019 using SurveyMonkey (San Mateo, California, USA). The primary outcome was the proportion of respondents aware of the utility of various diagnostic tools to diagnose endometriosis. Secondary outcomes attempted to delve deeper into understanding the intricacies of diagnostic tools for various endometriosis disease states and various clinical scenarios, emphasising ultrasound as the typical first-line investigative tool for endometriosis symptomatology.

Original questions were brainstormed and formulated by the research team. These questions were piloted on a group of 10 women in the lay population. Questions were modified according to feedback to improve the interpretability of the questions.

Once ethically approved by the Nepean Blue Mountains Local Health District Human Research Ethics Committee (2019/ETH00444)**,** the survey (Appendix 2) was disseminated via the social media outlets Facebook, Twitter, and Instagram, through collaborations with national and international endometriosis community groups. Reminder posts were sent out one and two months after the initial release of the survey. The target population was a convenience sample; an international and diverse population, encompassing all ethnicities, ages, and genders, was sought to reflect that of the general population. The survey advertisement is depicted in Appendix 3 and includes a recommended short statement for ease of use on social media. Prior to initiating the survey, potential respondents were shown the patient information sheet (Appendix 4). Respondents were told the length of time of the survey, data storage process/policies, security of data, name of the investigator, and purpose of the study. Completion of the survey was voluntary and implied informed

consent. No incentives were offered. Respondents took as much time as they needed to consent to provide information in the survey; however, it was impossible to withdraw consent once the survey was submitted.

The survey consisted of 26 questions over 12 pages, with two to five questions per page. Each respondent had the same order of questions. In multiple choice-type questions, the potential responses were displayed in a semi-structured fashion. When appropriate, questions included an option to answer, "I don't know" or "other (please specify)". Adaptive questioning was used to reduce the number and complexity of questions. No "completeness check" was required before the survey was submitted. Respondents could not review and change their answers (e.g. through a*back* button or a review step that displays a summary of the responses) due to the survey's nature. On page 11 of the survey, respondents were provided with educational information that would have potentially resulted in a difference in their responses to the preceding questions. At the conclusion of the survey, respondents were asked if they learned anything from completing the survey. Multiple responses were turned "off", only allowing the survey to be taken once from the same device.

Once collected, the data was stored on the SurveyMonkey server. View, participation, and completion rate were not sought. Completeness rate, defined as the percentage of survey takers that completed the entire survey, was captured by SurveyMonkey. Completed aspects of surveys which were incomplete (where, for example, users did not answer all questions) were included in the analysis. Timestamps were not used, and no timeframe for completion was used as a cut-off to determine inclusion in the analysis. Descriptive statistics were reported using medians/interquartile ranges (IQR), numbers and percentages, and comparisons were made using chi-square tests. Analyses were performed in SAS v9.4 (Cary, USA) and R (R Core Team, 2019)[14]. The weighting of items or propensity scores have not been used to adjust for a "non-representative sample".

RESULTS

Respondents

A total of 5301 responses were retrieved, representing 73 countries, with a median responder's age of 33 (Q1 27; Q3 39; IQR 11) years. The demographic characteristics are summarised in Table 1. Female-identifying individuals made up the majority of the respondents (98.5%). The distribution of the respondents, by region, is depicted in Figure 1. 84.0% of respondents stated they had been previously diagnosed with endometriosis, 71.5% of which were diagnosed at the time of surgery. Ultrasound and MRI were the methods of diagnosis in 6.5% and 1.8%, respectively. Respondents with post-secondary education have not reported more surgical diagnosis when compared to those without ($p = 0.40$).

Primary outcome

28.8% and 16.6% of respondents believed ultrasound and MRI could diagnose endometriosis, respectively, whilst 91.8% believed that surgery was a diagnostic method (more than one answer was allowed). The proportion who believed that a CT scan or blood test could diagnose endometriosis were 7.2% and 6.1%. respectively. 3.7% chose "I don't know" to answer this question (Figure 2). 71.51% had endometriosis diagnosed via surgery. In those diagnosed by surgery, 21.7% believed ultrasound was a diagnostic method compared to 51.5% in those not diagnosed by surgery ($p < 0.001$).

Secondary outcomes

When explicitly asked which phenotypes of endometriosis could be diagnosed using ultrasound, 14.7%, 31.1%, and 18.2% stated superficial, ovarian, and deep endometriosis could be diagnosed. 32.9% stated they did not know which phenotypes of endometriosis could be diagnosed using ultrasound. 58.4% of respondents do not believe they could access an ultrasound equipped to diagnose endometriosis in their region.

Respondents were asked to choose from a list of possible benefits of an ultrasound diagnosis of endometriosis for a *patient undergoing surgery* . In the opinion of 74.8% of respondents, ultrasound may allow a patient to understand their disease better; 75.9% of them responded that it might inform the patients what may be removed during surgery; 71.7% answered that it could reassure the patients that the team is aware where

the deposits are and can plan the surgery to remove as much as possible; 71.7% responded that it might assist the patients in the decision for or against surgery.

Similarly, respondents were asked to choose from a list of possible benefits of an ultrasound diagnosis of endometriosis for a *surgeon that is planning to perform surgery.* In the opinion of 77.6%, gynaecologists could be better prepared regarding the stage of disease; 78.3% thought it would help the gynaecologist to counsel their patients on the risks and benefits of surgery more comprehensively; 78.6% believed ultrasound might guide a gynaecologist to consult other surgical services; 68.5% responded that would help to anticipate the time to complete the surgery; 72.0% believed that it would help to predict the patient's recovery time; and finally, 65.6% responded it would reduce the need for diagnostic laparoscopy.

From the acquisition of further knowledge perspective, when asked about*what sources for more information on endometriosis* (more than one answer was allowed), the most significant proportion of the respondents (77.8%) responded that the internet was the source for additional information. 68.6% of the surveyed population chose the gynaecologist. The choices for textbooks or literature, social media, and friends and family were 44.8, 42.6%, and 23.5%, respectively. Following the provision of educational material near the end of the survey, we asked if respondents learned anything in the process of completing the survey, to which 54.0% answered, "yes".

DISCUSSION

Main findings

This international, cross-sectional online survey revealed a significant disparity between the present-day evidence for the utility of imaging for endometriosis and a diverse international population's comprehension of this utility. The vast majority of respondents believe surgery is a tool that can diagnose endometriosis and that the non-invasive tools (imaging, blood tests) cannot diagnose endometriosis. Ultrasound could diagnose endometriosis in the opinion of 28.8% of the respondents, and MRI 16.6%. Respondents who had a surgical diagnosis of endometriosis were far less likely to select ultrasound as a diagnostic tool in comparison to those who were diagnosed in a non-surgical fashion. Approximately one-third of respondents were not aware of which phenotype of endometriosis could be diagnosed using ultrasound. However, roughly one in three were aware endometriomas were diagnosable using ultrasound, while one in five and one in seven believed ultrasound could diagnose deep endometriosis and superficial endometriosis, respectively. Access to an advanced TVS in their region was not considered possible for the majority of the respondents.

Interpretation

In a 2016 Cochrane systematic review on non-invasive imaging for endometriosis, it was reported that advanced TVS has a sensitivity of 0.79 (95% CI 0.69-0.89) and a specificity of 0.94 (95% CI 0.88-1.00) in diagnosing deep endometriosis.[15] For deep endometriosis, MRI has sensitivity 0.94 (95% CI 0.90-0.97) and specificity of 0.77 (95% CI 0.44-1.00).[15] This translates to MRI being overall more likely to detect deep endometriosis, but it does so at the expense of a much larger false positive rate. TVS and MRI are equally effective at diagnosing endometriomas.[15] MRI is also considered a reasonable option in some centres, given its performance and cultural considerations, comparable to ultrasound for DE mapping using the IDEA consensus.[7] Despite the studies used in this systematic review being published in 2015 or earlier, knowledge translation to the end-users of imaging tests, our patients, remains limited. Among the survey responders, only just over one-fourth knew about the possibility of diagnosis via advanced TVS and less than one-fifth knew about the utility of MRI, and the majority do not believe that sort of advanced TVS could potentially be offered where they live.

We did not inquire about MRI access as we advocate that ultrasound should be considered the first-line imaging modality.[16] However, the same obstacles exist with MRI where an expert radiologist is essential to ensure the correct protocol and interpretation for endometriosis.[17] We believe the access to endometriosis MRI expertise would match that of advanced TVS.

Online sources are commonly used by people with endometriosis for information about various aspects re-

lated to their condition; however their healthcare providers' knowledge level may also be a relevant factor contributing to the general population knowledge level. In an international survey of gynaecologists, a minority of respondents used advanced TVS or MRI to evaluate patients with suspected endometriosis, and, in some regions, the availability of advanced TVS is potentially as low as 14%.[18] As such, we may suspect that gynaecologists are not teaching their patients, either passively or actively, about advanced techniques to diagnose non-invasively. The reason behind that phenomenon is likely to be multifactorial, relating to system differences such as healthcare funding models (e.g. private versus public), training in gynaecological ultrasound[19], who is performing/interpreting imaging tests (i.e. sonographer versus radiologist versus gynaecologist), and national clinical practice guidelines.

Demographics likely play an important role in the diagnostic process. Bougie *et al* . noted significant differences in the likelihood of an endometriosis diagnosis based on race and ethnicity.[20] Another factor might be education, which is, of course, intimately related to race, ethnicity, and other socioeconomic factors. In our study, the majority of respondents (68.2%) had post-secondary education. We found no difference in the proportion of post-secondary education in those with a surgical diagnosis compared to those without. However, it is possible that the overall high levels of education of the patients may have helped to more effectively navigate complicated healthcare systems and advocate for themselves to reach surgery (for diagnostic or therapeutic purposes) in their care pathway. Even in this highly educated cohort, 54.0% learned something from the content within the survey. With internet resources considered the primary source of information, this demonstrates the potential role of open web-based educational platforms. As this study only investigated country of residence, with a majority of responses from racially and ethnically diverse countries such as Australia, United Kingdom, Canada, and the United States of America, we cannot exactly comment on racial or ethnic differences. However, the diagnostic and care pathway for patients of various racial and ethnic backgrounds warrants study.

The approach to diagnosing endometriosis is changing.[21] While diagnostic laparoscopy is often used, it is used less as a diagnostic procedure and more when surgical treatment is indicated.[22] However, this is problematic because it leaves individuals *undiagnosed* unless they fit surgical indications. Moreover, without using preoperative diagnostic tools, there is a chance a diagnostic laparoscopy with planned treatment may be incomplete or abandoned due to surprisingly advanced disease.[23] Advanced imaging could represent a breakthrough in the former two-step approach of diagnostic and treatment laparoscopies, highly reducing the risks and the cost of care for patients.[24]

It would be essential to consider that, in the opinion of the vast majority of the respondents, the internet and the gynaecologist would be the chosen sources to acquire further knowledge on endometriosis. However, there is evidence that might be significant impairment in the quality and credibility of the internet's information related to endometriosis and other gynaecological conditions.[25–27] We cannot not emphasise enough the importance of continuous education programmes of health care professionals and gynaecologists to increase the availability of recent advancements of diagnostic tools for endometriosis.[28]

Strengths and limitations

This research's strengths involve the considerable sample size and the decision to seek the layperson perspective, building a foundation for knowledge-translation research. There are known limitations of an online survey approach, mostly related to the inclusion criteria of the respondents. As previously shown with the results, there is a risk of bias secondary to the motivation for responding to the survey, where the vast majority of the responses came from individuals already suffering with the disease and with the diagnosis confirmed. In this particular case, this inclusion bias does not impair the conclusions; on the contrary, it reveals even more clearly the hypothesis that the knowledge regarding the diagnostic options for endometriosis is significantly impaired. One would expect the knowledge level of the unaffected general population to be even less. Finally, our recruitment was almost solely via advisory and support groups on social media, and people recruited via this method are likely to have more severe symptoms than those recruited in other settings such as tertiary care. So, it is possible that our respondents may be biased towards a more severe impact of their symptoms on their lives and may not represent the population of people with endometriosis

as a whole.

The respondents' inclusion was also influenced by the language, given that the survey was distributed only in English and primarily English-using social media profiles. Since the survey origin was Australia, there was greater involvement of the local Australian advocacy organisations, yielding a disproportionate response from Australia. Comprehension barriers to participating or adequately responding to the survey could have occurred, particularly because it dealt with medical information and a complex and controversial disease. However, the pilot questionnaire with the integration of feedback should have mitigated this effect.

Conclusion

There is a clear gap in the general knowledge related to the most recent data on the capabilities of non-invasive diagnosis of endometriosis, especially related to the use of advanced ultrasound. In parallel to improving patient understanding of the diagnostic tools, it is essential to similarly increase healthcare providers' education about advanced imaging modalities and how to use them to achieve knowledge-translation goals of wide-spread availability of non-invasive diagnostic tools for endometriosis.

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DISCLOSURES

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Contribution to Authorship

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Conception and design of study:

Leonardi M; Tun-Ismail AN; Robledo K; Armour M; Condous G.

Acquisition of data:

Leonardi M; Tun-Ismail AN; Robledo K; Armour M; Condous G.

Analysis and/or interpretation of data:

Leonardi M; Rocha RM; Tun-Ismail AN; Robledo K; Armour M; Condous G.

Category 2

Drafting the manuscript: Leonardi M; Rocha RM.

Revising the manuscript critically for important intellectual content:

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Category 3

Approval of the version of the manuscript to be published:

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Details of Ethics Approval

This research was ethically approved by the Nepean Blue Mountains Local Health District Human Research Ethics Committee under reference number 2019/ETH00444.

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None

FIGURES/TABLES/APPENDIX CAPTION

Appendix 1: CHERRIES checklist.

Appendix 2: Online survey model.

Appendix 3: Survey Social-Media post

Appendix 4: Participant information sheet

Figure 1: Proportion of respondents by region

Figure 2: Which methods can be used to diagnose endometriosis? Legend: The y axis represents the percentage of responses. Respondents were allowed to choose more than one answer. n - number of respondents; % - percentage; MRI - Magnetic Resonance Imaging. CT - Computerized Tomography.

Table 1: Table 1 Demographic characteristics of respondents, n = 5301 respondents. Legend: IQR – interquartile range; n – number; % - percentage; MRI – magnetic resonance imaging.

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Table 1 Demographic characteristics of respondents, n = 5301 respondents.

Legend: IQR – interquartile range; n – number; % - percentage; MRI – magnetic resonance imaging.

Characteristic	n, %
Gender	
Female	5238, 98.8
Male	50, 1.0
Other	11, 0.2
Prefer not to say	2, 0.1
Currently employed	
Yes	4342, 81.9
No	959, 18.1
Level of education	
High School or less	1686, 31.8
College or more	3615, 68.2
Diagnosis Status	
Diagnosed with endometriosis	4453, 84.0
Method of Diagnosis	
Surgery	3791, 71.5
Ultrasound	345, 6.5
MRI	96, 1.8
Clinical	449, 8,5
Physical Examination	248, 4.7
Other	371, 7.0

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`Figure 1 Proportion of responders by Region.pdf` available at https://authorea.com/users/316231/articles/516353-assessing-the-knowledge-of-endometriosis-diagnostic-tools-in-a-large-international-lay-population-an-online-survey

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`Figure 2 What methods can be used to diagnose endometriosis 20032021.pdf` available at https://authorea.com/users/316231/articles/516353-assessing-the-knowledge-of-endometriosis-diagnostic-tools-in-a-large-international-lay-population-an-online-survey