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Living with endometriosis: the role of the Internet in supporting the diagnosis and treatment process

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Abstract

Those living with endometriosis turn to online resources for information and support. Despite an abundance of information, delays in diagnosis and perpetuation of untruths remain.

This study aims to assess and evaluate the role of the Internet in the diagnosis, treatment options and support of people living with endometriosis.

The results of this mixed-methods study show that people are very active information seekers with the majority favoring national endometriosis websites and their associated Facebook accounts. There is a positive attitude towards information and sharing experiences online, but women trust official endometriosis organizations more than other resources on the Internet.

Keywords: Endometriosis, Internet, Online Information, Support

Introduction

Endometriosis affects approximately 200 million people worldwide from a variety of ethnicities and socio-economic backgrounds (Endometriosis Foundation of America, 2020). Endometriosis is a chronic and debilitating condition characterized by the presence of endometrial glands, which induce a chronic, inflammatory reaction (Kennedy et al., 2005). The exact prevalence of endometriosis is unknown but estimates range from 2 to 10% within the general female population but up to 50% in infertile women (Meuleman et al., 2009; Parasar et al., 2017). Notwithstanding its prevalence, endometriosis remains a relatively unknown condition in the public eye, the symptoms are not readily identifiable and treatment options elude those who are not directly affected (Shah et al., 2010). Many of those living with endometriosis suffer from the symptoms for several years before being diagnosed (Nnoaham et al., 2011). This culminates in unnecessary suffering, exacerbation of the disease and an overall reduction in quality of life. Delays in diagnosis and misdiagnosis are the result of multiple factors, including stigma around menstruation, painful sex and gynecological issues and the societal normalization of women’s pain (Arruda et al., 2003), even from a very young age (Yeo & Chu, 2017). This is compounded by many healthcare providers' unfamiliarity with the condition and confusion over what is best practice for the management of the disease (Van Der Zanden et al., 2019). The effects of the condition on the quality of life of those affected range from chronic debilitating pain and fatigue (Culley et al., 2013), to infertility, depression and feelings of inadequacy (Facchin et al., 2015), loss of social interaction (Gallagher *et al*. 2018), disrupted education and working lives (Hudson *et al*. 2016; Marinho et al., 2018) disabling bowel symptoms, dysfunctional urination and painful sex (Simoens et al., 2012). Endometriosis also imposes economic and societal costs, such as healthcare costs, employment related costs and childcare maintenance (Armour et al., 2019), similar to those of other chronic conditions such as rheumatoid arthritis, type 2 diabetes and Crohn’s disease (Simoens et al., 2012).

The Internet is an accessible source of health information for sufferers of endometriosis and for patients in general (Kwan, Shaw & Murnane, 2019). In 2018, “What is endometriosis?” was the third most trending health-related question on Google (Welch, 2018). 70% of adults regularly browse the Internet for explanations or information surrounding medical conditions (Kaicker et al., 2010). There are more than 400,000 Google searches on endometriosis per month in the United States alone (Hirsch et al., 2017). A considerable amount of online searching is dedicated to the issue of infertility linked to endometriosis, with more distressed patients reporting higher rates of searching (Davidson, 2005; Brochu et al., 2019). Indeed, women who have endometriosis frequently report high levels of anxiety and depression (Laganà et al., 2017).

Online health resources on complex conditions such as endometriosis often report conflicting information due to infrequent updates and lack of currency, which contribute to patients’ confusion and anxiety (Dean, 2011). The American National Institutes of Health (NIH) recommends that health information be written at a level understandable by sixth-grade students. However, such information, in addition to not being met in many instances (Hutchinson, Baird & Garg, 2016), poses a challenge in regard to establishing its accuracy, reliability and trustworthiness (Chen et al., 2018; Lovett et al., 2019).

Unregulated, ungoverned and medically unsound information, which is not subject to the normal supervisory framework seen within the scientific community, could adversely influence patients' comprehension, compliance to therapy and medical decision-making, leading to poor outcomes (Berkman et al., 2011; Armstrong-Heimsoth et al., 2017; Parker & Ratzan, 2019).

In their systematic study of five popular Internet search engines including Google and Yahoo, Hirsch et al. (2017) screened 750 web pages containing information related to endometriosis. Over 33% of the web pages did not cite authorship and approximately 50% did not reference nor report the sources of information used to generate the content. A study by Lovett et al. (2019) sought to evaluate online information on dysmenorrhea (a central feature of endometriosis) and used the same four metrics as Hirsch and colleagues: readability, credibility, quality and usability. The researchers studied three popular search engines, Google, Yahoo and Bing, and screened 60 web pages. Of these, 25 were assessed with well-established tools (e.g. Flesch-Kincaid Reading Ease tool, which assesses the readability and understandability of English text, and DISCERN, which evaluates the quality of written information on treatment choices for a health problem). These websites were deemed to be written at the reading level of tenth-grade students. Only 60% of the websites were HON (Health On The Net) certified and even then, there was variable credibility amongst them. Only 8% of the websites included either the name or the type of content provider, and only 28% indicated the name and credentials of the author. 44% of the websites declared the objectives of those who ran them and common conflicts of interests, such as financial rewards, were identified.

In light of the above, this study aims to assess the role of the Internet for endometriosis-related queries and in the support of those affected by endometriosis. Specifically, this research aims to address the following questions:

- Does the Internet have a role in guiding women to a diagnosis of endometriosis?
- Are the resources available online directing women to accurate information?

Methodology

Data collection

This study utilized a sequential mixed-methods approach comprising of an online survey and in-depth, semi-structured interviews as data collection tools to assess the use of the Internet as a source of information for those living with endometriosis. The survey consisted of 69 questions including participation consent questions, and was composed of two main parts: a demographics section was included to gather information on the characteristics of the sample; the second section included a version of the e-Health Impact Questionnaire (eHIQ, Kelly et al., 2015), adapted to make the questions suitable for general online searching rather than being website-specific. The eHIQ survey consists of two independently administered and scored parts:

- eHIQ-Part 1 covers general attitudes towards using the Internet to access health information;
- eHIQ-Part 2 measures an individual's ease with using online information, particularly emphasizing their openness to learning and gaining support from other people's experiences.

Both eHIQ parts of the survey had a five-point response scale for all items ranging from 1 (Strongly disagree) to 5 (Strongly agree).

The survey was piloted with seven consumers of endometriosis online information. Feedback on wording was incorporated into the final question set. The survey was distributed in March and April 2019 and a copy is reported in Appendix 1.

The interview questions (Appendix 2) were formulated from the findings of the online survey and revolved around participants' experience with the healthcare system and Internet usage. The interviews were carried out via telephone in June and July 2019. The interview script was piloted with two online information users to assess its understandability. No personal details were collected from the participants to the interviews and any information potentially leading to their identification was removed from or reworded in the transcripts.

Participants

Potential participants were identified as those living with symptoms of endometriosis. Responses were accepted from those with a presumptive clinical diagnosis by their doctor and those with a definitive diagnosis via surgery. To widen the international breath of the study, country-specific national endometriosis organizations were contacted and asked to distribute the survey link to their members. However, the study was limited to those who could read and reply in English, and it is noted that this excludes a large population worldwide. No restriction was placed on age or location. Ethical approval for this study was granted by the University of Sheffield Ethics Committee.

Results

Sample demographic profile

The survey yielded 895 valid responses. This section provides a summary of the demographic characteristics of the respondents. In Table 1, of the 892 respondents who stated their age, 75.9% were between 25 and 44, 15.1% were less than 24 and the remaining 9% were above 45 years old. As expected, the large majority of respondents were female (99.1%) and the remaining selected the option 'other' (0.7%) or preferred not to disclose their gender (0.2%). More than half of the participants (59.7%) had completed at least a Bachelor's degree or above. In terms of level of employment, 86.1% of the sample was composed of working people, students and homemakers. Overall, the survey received responses from 51 countries around the world; however, the seven countries listed in Table 1 contributed to 87.6% of the responses.

[insert table 1 here]

Quality of life with endometriosis

Endometriosis is often associated with relentless pain and respondents to this study were asked to rate their overall quality of life, both their daily and menstrual pain as well as fatigue on a scale from 0 (excellent quality of life; no pain/fatigue) to 10 (terrible quality of life; unbearable pain/fatigue). Results (Figure 1) show that the most significant pain burden is felt particularly during menstruation, which is to be expected with the condition, with 27.3% of respondents reporting unbearable pain. Considerable daily pain (a value of 5 or higher) not related to menstrual periods is experienced by 49.4% of the respondents. In line with what has been observed about the disease, the reported average pain score during menstruation is higher than the average daily pain level. There was a significant difference in the scores for daily pain (mean=4.37, sd=2.44) and period related pain (mean=8.08, sd=1.99); t=35.28, p<0.001 at 95%CI.

[insert figure 1 here]

Fatigue is a symptom that is often overlooked, but Ramin-Wright et al. (2018) have demonstrated the independent effect of endometriosis on fatigue levels, which should hence be addressed and treated in medical care. These authors showed that the prevalence of frequent fatigue was more than doubled in those living with endometriosis compared to the control group. Their recommendation is that fatigue should be addressed as part of routine endometriosis care to help improve quality of life. No daily pain was reported by 9% of respondents, dropping to 0.3% when describing pain at menstruation. Only 1% reported no fatigue, while 85% reported a fatigue score of 5 and above.

Quality of life scores for those living with endometriosis are low. Less than 1% of respondents described their quality of life score as excellent, with 71% reporting a quality of life score of 5 or more (this is an inverted scale where the higher the score the lower the quality of life). Poor sleep, perceived stress and lower activity levels may play a role in this reduction alongside pain, fatigue and general impact of living with a chronic disease (Marinho et al., 2018). Delays in diagnosis and, hence, treatment, can also contribute to a lower quality of life. Diagnostic delays are common in endometriosis, and many live with symptoms for many years before diagnosis (Nnoaham et al., 2011). Data collected in the current study show that the average delay to diagnosis in the respondents is around eight years. Around 4% of respondents were diagnosed within a year, with representations in all age groups. However, 33% lived with symptoms for more than ten years prior to their diagnosis.

Online information seeking behavior

The survey revealed that there is a good spread in the use of the online resources related to endometriosis (Table 2). The majority of respondents access multiple sites, but the most favored (selected by almost 70% or people) are the certified endometriosis websites from individual countries (e.g. Endometriosis UK) and the official Facebook groups associated to such national websites (50.5%). These are closely followed by privately owned Facebook groups (49.4%), the most popular being Nancy's Nook Endometriosis Education group. Although based in the United States, this group has now reached almost 100,000 members from around the world. Medical websites are consulted regularly by 48.1% of the respondents, particularly the national health portals, such as Healthdirect (https://www.healthdirect.gov.au/) in Australia or NHS Choices (https://www.nhs.uk/) in the UK. The majority of respondents (51.3%) spent less than one hour a day using the Internet in relation to endometriosis with 36.1% of respondents spending up to two hours online per day.

[insert table 2 here]

To identify the factors influencing how people with endometriosis seek health-related online information, Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA) were performed on the eHIQ modified questionnaire.

The 37 statements addressing the impact of digital resources were subject to EFA and the suitability of data for factor analysis was assessed. The analysis identified the presence of five components (or factors) explaining respectively 31.8%, 8.4%, 5.6%, 4.8% and 3.4% of the variance. PCA was used to test that items loaded onto the predicted factors, and to calculate the contribution of each component to online information seeking behavior. CFA was used to further verify the factor structure and to determine the adequacy of model fit to the data. Table 3 reports the CFA model fit statistics and Table 4 the final CFA model, including Cronbach's Alpha values calculated to assess the reliability of the scale. All factors still reflect the constructs in the e-HIQ impact survey, but PCA allowed refinement and highlighted the key aspects of each one.

[insert table 3 here]

[insert table 4 here]

For the most significant factor identified, ‘Understanding and motivation’, participants were asked to reflect on their preferred endometriosis online resource and on the consequences that this resource might have on their health. Participants were also asked about their motivation to take action after visiting their preferred website. Despite the strong responses to the other questions in this group, people were less inclined to consult the website if they had to make a decision about their health (mean=3.59) and only marginally more inclined to look after themselves after visiting the website (mean=3.67).

CFA reported ‘Information and Presentation’ as the second most important factor (overall mean=4.09). Participants were asked to focus on their preferred source of information online for endometriosis, specifically commenting on how the information was presented. The key elements of this factor are all linked to the concept of easiness: how easy is it to understand the information online is (mean=4.15), the language used to explain the information (mean=4.08) and use of the website (mean=4.04).

The third factor, ‘Attitudes Towards Sharing Health Experiences Online’, shows a positive attitude towards sharing health experiences online. In particular, respondents agree that the Internet is a good resource to find other people with similar health problems (mean=4.49) and to reassure oneself that they are not alone with a particular health concern (mean=4.35). These aspects are deeply felt by people affected by endometriosis, due to the stigma and sense of isolation associated with the condition (Griffith, 2017; Mackert et al., 2019).

The fourth factor, ‘Attitudes Towards Online Health Information’, asks participants whether they feel that the Internet is a reliable resource to help increase public awareness of a health condition, to help assess the seriousness of symptoms and whether medical help should be sought and to verify the advice that their doctor has given them. The overall mean for this aspect was 3.73, showing a moderately strong positive attitude towards the use of online health information.

In the fifth factor, ‘Confidence and Identification’, participants shared opinions on their preferred endometriosis related website, specifically, how the site is tailored to address their needs (mean=3.88), but, more importantly, how they can identify with the other people using the resource (mean=4.11) and how much they have in common (mean=3.97) and the sense of solidarity they feel for each other (mean=4.01). The overall scores in this group gave a mean of 3.99, which shows a good level of confidence and personal identification with their chosen website.

Qualitative results

Twelve participants from various European countries and ranging in age from 23 to 48 years took part in telephone interviews; the onset of their endometriosis symptoms ranged from the age of 11 to 20 (for ten of them, it started below the age of 18). Their time to diagnosis from onset of symptoms ranged from one to 27 years. Four participants experienced symptoms for more than 20 years before diagnosis; five were in the eight to ten year range and only one participant was diagnosed within a year of symptoms onset. Half of the interviewees were living with severe endometriosis with deep infiltrating disease affecting their ovaries, bowel, bladder and pelvic organs.

Each interviewee was asked how long they have lived with endometriosis, what treatments they have had, the time to diagnosis and their current quality of life as background to questions on Internet use and trust in information on endometriosis. The responses were manually coded independently by the two members of the research team using Braun and Clarke's (2014) approach to thematic analysis. This framework follows a six-step process involving, in order, becoming familiarized with the data, generating initial codes, searching for themes, reviewing the themes, defining the themes and finally writing up about them. Three main themes have been identified (Knowledge of endometriosis, diagnosis and healthcare support, Online information seeking behavior and Relevance of online resources) and are discussed below. All interviewees' names have been pseudonymized.

Knowledge of endometriosis, diagnosis and healthcare support

When asked if they knew of endometriosis prior to their diagnosis, seven participants had heard about it, either through friends or offline resources like books and magazines, while others had seen the term when searching for period pain online. The responses indicated that women encountered the term endometriosis as a possible cause of their symptoms after discussion with their primary care provider. The overall experiences with healthcare professionals is mixed, with most praising their current GP as someone who may not have all the knowledge or answers on endometriosis, but has learned from their patient and is willing to look at the research they have done (Skountridaki, 2019). Florence explained that:

"…my GP now said she knows more as a result of having me as a patient and has read more and would like to know more in depth information on endometriosis".

Kallie's experience was poor, apart from her own GP:

"Abysmal really, apart from my own GP, she educated herself on endometriosis since I first brought it up with her."

When Kallie went to see a consultant she felt that he was annoyed that she had done some research ahead of the appointment, a common experience in women diagnosed with endometriosis (Young et al., 2019). After being told by one consultant that she should "Count herself lucky she did not have cancer" she sought a second opinion, and encountered another negative experience:

"He did not like that I was very well informed, he told me my needs were too great for what he could do for me ... I was too much hard work for him and too much trouble, a very negative experience the whole way through."

Mareesa visited many GPs, and went from being told that: "You are going to have painful periods because psychologically you believe they are going to be painful. You just need to relax" to being dismissed entirely.

Muireann had a similar experience with her healthcare provider:

"[seen]... within 3 weeks, I am very lucky as it takes women years to get that far. It was good up to diagnosis then conflicting information at my follow up appointment. Disheartening."

She felt that, while her doctors were good, they have little consideration for what she was actually going through. Lisa has lived with severe pain and debilitating symptoms since she was 11, and the following comment encapsulates the lack of awareness about the condition, after she was left for ten years without a diagnosis:

"No, not a clue what it was. Never heard the word [endometriosis] from medical professionals - they treated symptoms."

Maeve was misdiagnosed with Irritable Bowel Syndrome (IBS) for ten years, which is common in those with endometriosis given the symptomatic overlap (Ballard et al., 2008). What was concerning in Maeve's case was that endometriosis was known to her GP:

"My GP's daughter had it [endometriosis] and never even mentioned a word about it but misdiagnosed me with IBS. Didn't even place me on the pill. Just given Buscopan [antispasmodic for

IBS]. I believed I had IBS as this is what I was told and did not look any further, I assumed my GP was a well-educated man.”

Online information seeking behavior

When asked about researching their symptoms online prior to their diagnosis, the interviewees experienced mixed feelings. Daisy had normalized her symptoms:

“I didn't consider heavy bleeding as a symptom, I felt it was just part of me.”

She did not have a diagnosis until she was scanned for severe right sided pain, which revealed an endometrioma. At this stage, her online research was based around the stages of endometriosis and the complexity of the condition rather than treatments.

Muireann highlighted the issues with searching symptoms online as it can bring about more worry than comfort:

“I would not have got any sense of relief off any of them (websites) other than knowing other people had this and would be ok as most sites lead you to believe you have cancer and going to die.“

On the other hand, Jennifer found that the Internet played a role in validating her symptoms:

“I knew it wasn't something that was in my head as a lot of doctors tried to tell me.”

Lisa also felt validated by what she had read online:

“Without the Internet I would have put it down to being in my head.”

Kallie was only diagnosed at 40 despite living with symptoms since she was 13, and had searched her symptoms online:

“…endometriosis probably came up but as it was not on my radar it never really sunk in.”

Lisa confirmed a common thread in women with endometriosis, that of doctors and patients not recognizing that something is wrong (Van Der Zanden et al., 2019):

“No, never, looking back feels ridiculous not to have, but the doctors said I was unfortunate with irregular periods.”

Niamh found the Internet and in particular the support group run by the EAI as vital to her diagnosis:
“Being part of the group and the support in the group is what pushed me to get a diagnosis, once I

*spoke to my own GP about endometriosi*s she was on board immediately. *She referred me then directly about endometriosis. The registrars were refusing a laparoscopy, wanting me to try all of the medical treatment first, I didn't want to because I had decided, again from reading other people's stories that I did not want to go down the road of hormone treatment."*

Relevance of online resources

Turning the conversation to the type of websites used, the majority of interviewees referenced national endometriosis associations and charities as a source of information. Health information sites like the Mayo Clinic (https://www.mayoclinic.org/), Irish Health Service Executive (HSE, https://www.hse.ie/eng/) and NHS (https://www.nhs.uk/) were mentioned but produced discording opinions. In fact, some found them a helpful source of information, while others pointed out the factual inaccuracies on the sites. Endometriosis doctors who have set up their own websites and social media also featured in the conversation. There was some skepticism that doctors could advertise as "specialists" and create a narrative to support it online, with little evidence to support their claims.

Questions were also asked about trust in specific sites in relation to endometriosis information. Kallie's comment summarizes the feeling shared by others as she mentioned the misinformation encountered on many sites, including the HSE website, which draws from the NHS website for conditions:

"I don't think their [HSE] definition of endometriosis is correct. These are the people who are providing us with doctors and information - the most basic thing is to get the definition of any condition right."

Mareesa found that other conditions were better referenced and contained more accurate and relevant information than endometriosis:

"When I searched endometriosis on Google, in the top 20 results there were wrong definitions of endometriosis - it is infuriating - I don't want to click on it (these links) to give it more traffic and move it up the search."

Kallie and Maeve agreed that online fora could have a positive influence. Specifically, Kallie said:

"The EAI [Endometriosis Association of Ireland] Facebook support group - it was really my saving grace, because endometriosis is such a scary word when you don't know what it is."

Karen addressed the disparity in public perception and the reality of endometriosis:

“The public think it is painful periods - don't see it as a multi-layered disease. Online you learn that there are more symptoms - it is a very individualized disease."

Patient-driven information far outweighs endometriosis organizations and medical based information online in terms of quantity, but it lacks accuracy, objectivity and transparency. Opinions differed among interviewees, some favoring the personal touch and feeling that only those living with the condition can truly understand, but all mentioned the importance of accurate information. Florence claimed:

“What works for one may not work for another. People have their own theories. Lot of diet and mindfulness advice may be inappropriate... need to be careful with this information. I prefer reputable sites from people who are qualified to give advice. "

Mareesa had a strong opinion on trusting patient-led information:

"They are not even regurgitating information because that would mean it would come out in the same format - they literally take it and put it on a rollercoaster ride and no matter what shape the information comes back in, no matter what order, they then post it and possibly substitute some of the words.”

Information produced by official endometriosis organizations is well received. According to Daisy:

“You would take on board information from people who spent time on the subject and focused on this topic, and want to see research back up.”

Their motivation was seen as altruistic and less likely to give misleading information.

Discussion

Those living with endometriosis are compelled to seek out information to help them cope with their symptoms, particularly when quality of life can be seriously compromised. They often become “expert patients” advocating for better recognition, developing strategies for sharing experiences and giving a voice to their chronic suffering. The proliferation of self-publishing online in the form of blogs and self-produced websites gradually expanded this repertoire to what it is experienced today where social media have almost exclusively dominated the endometriosis support arena. The results of this study show how Facebook groups linked to endometriosis organizations are among the preferred channels of both information and communication for patients. Such groups can play an important role with patients, offering a listening ear and emotional support, providing decision-making tools and vital access to current literature on the condition (Carneiro et al., 2020).

However, there are negative aspects associated with online groups, as there are in face-to-face support. Participants may find themselves involved in interpersonal arguments, jealousy, privacy and data breaches, exacerbations of feelings of depression and hopelessness and exposure to inaccurate and misleading medical information (Turner, 2017). Although reporting mixed feelings toward many online resources, this study has shown how the attitude toward online health information and support provided by official endometriosis organizations is mostly positive and welcoming, particularly in light of the lack of guidance provided by healthcare professionals. Participants emphasized the need to be listened to and believed by their doctors. They also felt that their research should be taken seriously, and should be allowed to make joint treatment decisions with their GP or consultant.

This study also corroborates the work of other researchers regarding reduced quality of life (Arruda et al., 2003; Nnoaham et al., 2011; Van Der Zanden et al., 2019). The results have shown how people living with endometriosis experience regular high levels of fatigue and both daily and period related pain, which align with a perceived compromised quality of life.

Accurate information and the personal experiences of others living with the disease has the potential to inform treatment lifestyle choices of those with endometriosis. For example, women may choose to conceive earlier, or avoid hormonal suppression and radical surgery in favor of more active disease management with lifestyle changes such as pelvic physiotherapy (Berghmans, 2018). Discussing this with their gynecologists may be difficult, as awareness and education among clinicians regarding endometriosis is perceived as lacking and outdated. Interviewees have highlighted the difficulties in attempting to have a balanced discussion around endometriosis with their gynecologist or GP. Rather than seeing it as an affront to their skills, healthcare professionals should be encouraged to embrace research and value the empowerment of their patients. Referral to a tertiary centre for endometriosis should be no different than for any other specialty.

Figure 2 shows a possible pathway for endometriosis patients' journey and scenarios that would prompt the need for additional information that can be used to enhance the interface between patient and healthcare professionals. At each stage in the pathway there is an opportunity to guide the patient through the process with accurate information to allow them to make informed choices which are right for them.

[insert figure 2 here]

Empowerment begins when the patient has all the facts and tools at their disposal. As seen both in this study and the literature, GPs often do not think of endometriosis as a primary diagnosis (Coleman & Overton, 2015). Stimuli by knowledgeable patients, and awareness of guidelines developed with physicians may help reduce time to diagnosis and improve access to timely and appropriate treatment. Moradi et al. (2014) highlighted the complexity of living with endometriosis and how diagnosis was dependent on the individuals' knowledge of symptoms and whether they knew someone who had been diagnosed. From the authors' experience, symptom checklists and media articles online help women identify their endometriosis symptoms. Well researched media articles can guide women to discuss their symptoms with their GP and also to access in depth information from appropriate organizations. Endometriosis New Zealand provides an exceptional "ME Program", which was the first to address menstrual health and endometriosis education in schools. This program has led to increased awareness and an earlier presentation to primary doctors (Bush et al., 2017).

Conclusions

This study has demonstrated that comprehensive, reliable information on the diagnosis and treatment of endometriosis is still lacking and patients are resorting to online peer-to-peer information exchange. Such online rapport is crucial to obtain the acknowledgement and validation that is missing in other aspects of their lives, where the condition is often dismissed, minimized or ignored altogether. Another core learning from this study is that there is trust among women in the information provided by endometriosis organizations online. This should be leveraged to produce consistent, accurate and accessible information that the patient can use to discuss treatment options with her healthcare team. Endometriosis patients should be guaranteed a path to early diagnosis, appropriate treatment, universal recognition and accurate and supportive online information. This can be achieved through engagement and discussion with all those affected - individuals, their healthcare team, family, friends and colleagues. It is recommended that information providers should continually audit and update the information needs relevant to those living with endometriosis and to engage actively with women.

This study advances previous research in the field of endometriosis by exploring individuals' information needs in a wide international setting, by addressing daily constraints and hindering factors such as pain and fatigue and by reporting on the key aspects to consider when creating online information content.

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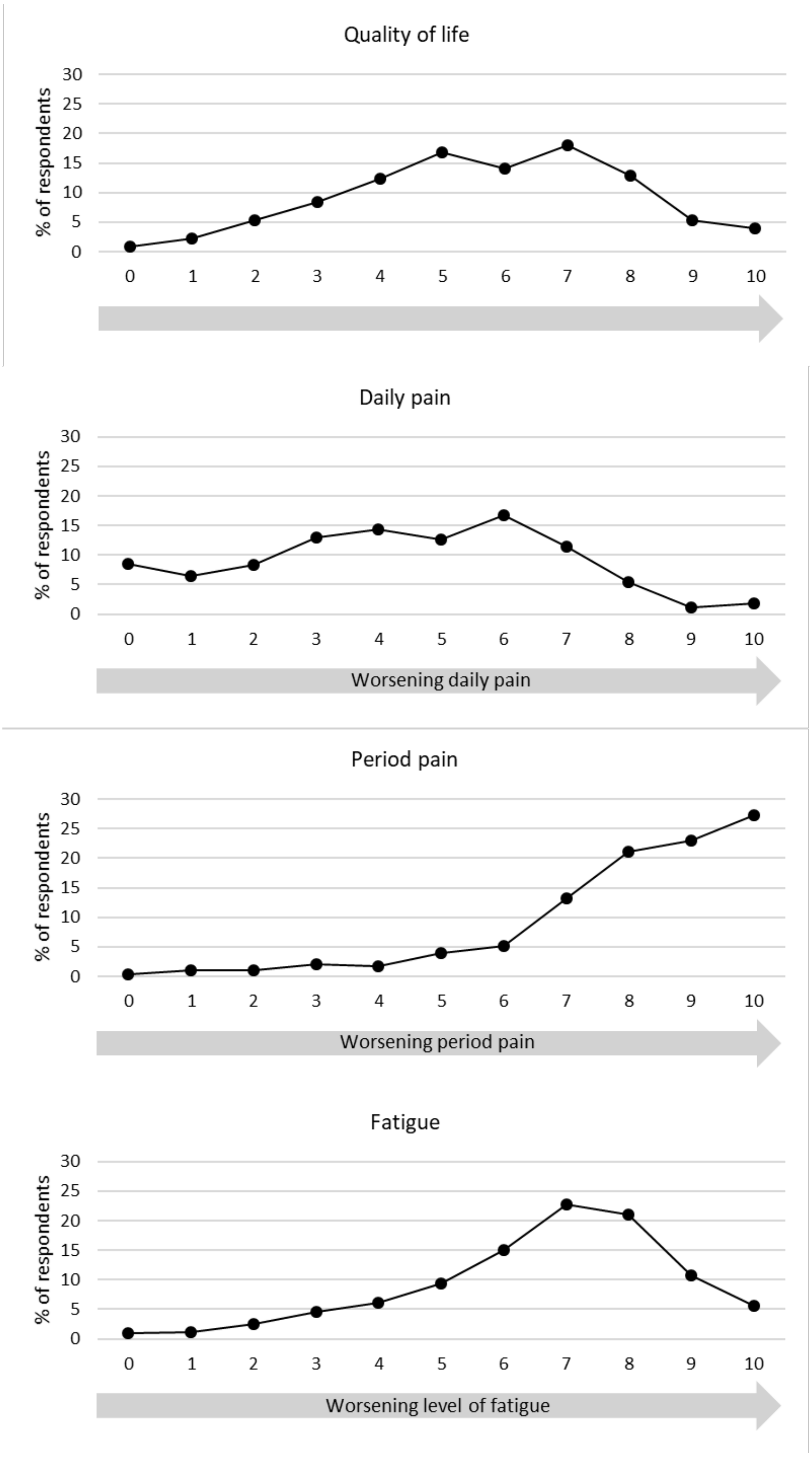
Figure 1. Pain, fatigue and overall quality of life scores.



Quality of life

Daily pain

Period pain

Fatigue

Figure 2. Endometriosis pathway and potential for online information.

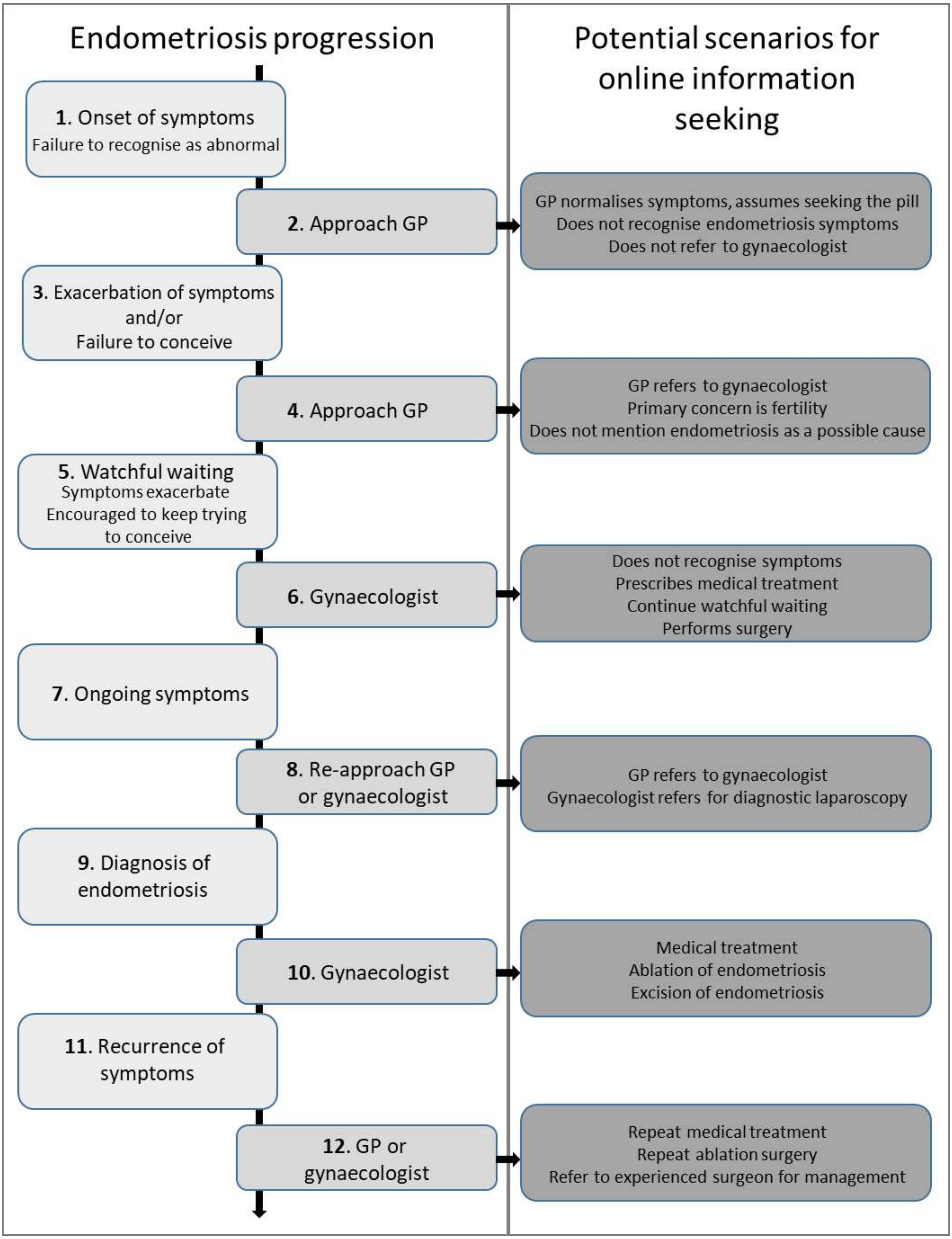


Table 1. Demographic aspects of the sample.

Demographic characteristics	N	*%*
Age		
Under 18	13	*1.5*
18-24	121	*13.6*
25-34	372	*41.7*
35-44	305	*34.2*
45-54	69	*7.7*
Over 54	12	*1.3*
Gender		
Female	884	*99.1*
Other	6	*0.7*
Prefer not to say	2	*0.2*
Highest level of school completed		
Primary Education	32	*3.6*
Secondary Education	99	*11.1*
Technical or Vocational	81	*9.1*
Advanced/Higher Certificate or Apprenticeship	104	*11.7*
Bachelor Degree	332	*37.2*
Professional Degree	39	*4.4*
Masters Degree	139	*15.6*
Doctorate	22	*2.5*
Some college, no degree	2	*0.2*
Prefer not to say	42	*4.6*
What is your current employment status?		
Employed full time	416	*46.6*
Employed part time	163	*18.3*
Student	94	*10.5*
Unable to work	92	*10.3*
Self-employed	60	*6.7*
Homemaker	36	*4.0*
Unemployed and currently looking for work	14	*1.6*
Unemployed and not currently looking for work	12	*1.4*
Retired	5	*0.6*
What is your nationality?		
United States	214	*24.0*
United Kingdom	192	*21.5*
Australia	145	*16.3*
Ireland	95	*10.7*
Other Europe	55	*6.2*
New Zealand	52	*5.8*
Canada	43	*4.8*
Sweden	40	*4.5*
Other Americas	17	*1.9*
Other Africa	9	*1.0*
Other East/Middle East	9	*1.0*
Not stated	6	*0.7*
Missing values	15	*1.6*

Table 2. Online information seeking characteristics.

Online behavior	N	%
What is your preferred source of endometriosis information online?		
Official Endometriosis Organization Websites	625	*69.8*
Facebook groups (run by endometriosis organizations)	443	*50.5*
Facebook groups (run by individuals)	434	*49.4*
Medical websites	424	*48.1*
Websites/Blogs set up by individuals living with endometriosis	308	*34.9*
Instagram accounts (run by endometriosis organizations)	137	*15.2*
Facebook pages (run by individuals)	135	*15.1*
Instagram accounts (run by individuals)	133	*15.0*
Reddit/Endometriosis	59	*7.2*
Non-medical websites (e.g. news, magazines)	52	*6.3*
Medical Journal Sites	8	*0.9*
Specific "other" sources of online endometriosis information		
Nancy's Nook Facebook Group*	265	*29.6*
Endometriosis UK (Website and Instagram)	115	*12.8*
Endometriosis Australia (Website and Facebook)	85	*9.5*
Endometriosis Association of Ireland (Website, Facebook and Instagram)	69	*7.7*
No preferences/Google	46	*5.1*
Endometriosis New Zealand	30	*3.3*
Endometriosis.org	15	*1.7*
Endometropolis Facebook Group	14	*1.6*
Center for Endometriosis Care Website	12	*1.3*
How many hours/day do you spend online reading or research about endometriosis (including social media accounts you follow)?		
Less than 1 hour	459	*51.3*
1-2 hours	323	*36.1*
3-4 hours	77	*8.6*
4-5 hours	16	*1.8*
5-6 hours	8	*0.9*
6-7 hours	4	*0.4*
7-8 hours	3	*0.3*
More than 8 hours	5	*0.6*

*Run by American retired nurse Nancy Petersen (https://www.facebook.com/groups/418136991574617/)

Table 3. CFA model fit statistics.

Fix index	Model value	Recommended value (Hu & Bentler, 1999)
TLI (Tucker-Lewis Index)	0.953	>0.95
CFI (Comparative Fit Index)	0.961	>0.95
RMSEA (Root Mean Square Error of Approximation)	0.047	<0.06
Chi-squared/degrees of freedom	2.997	<3
NFI (Normalized Ft Index)	0.943	>0.9
GFI (Goodness of Fit Index)	0.950	>0.8
AGFI (Adjusted Goodness of Fit Index)	0.933	>0.8
AVE (Average Variance Extracted)	See table 4	>0.5
CR (Composite Reliability)		>0.7

Table 4. CFA model.

Factor	Item	Mean	CR	AVE	Cronbach's Alpha
Understanding and Motivation	The website encourages me to take actions that could be beneficial to my health	4.09	0.86	0.52	0.85
	I feel more inclined to look after myself after visiting the website	3.67			
	I have learnt something new from the website	4.25			
	I would consult the website if I had to make a decision about my health	3.59			
	The website helps me to have a better understanding of my personal health	4.05			
	The website encourages me to play a more active role in my healthcare	4.06			
Information and Presentation	The language on the website made it easy to understand	4.08	0.83	0.62	0.81
	I can easily understand the information on the website	4.15			
	The website is easy to use	4.04			
Attitudes towards sharing health experiences online	The Internet is a good way of finding other people who are experiencing similar health problems	4.49	0.83	0.56	0.84
	It can be helpful to see other people's health-related experiences on the Internet	4.34			
	The Internet is a good way of finding other people who are facing health-related decisions I may also face	4.34			
	Looking at health-related websites reassures me that I am not alone with my health concerns	4.35			
Attitudes towards online health information	The Internet can be useful to help people decide if their symptoms are important enough to go to see a doctor	3.86	0.76	0.72	0.76
	I would use the Internet if I needed help to make a decision about my health	3.62			
	I would use the Internet to check that the doctor is giving me appropriate advice	3.79			
Confidence and Identification	The people who have contributed to the website understand what is important to me	3.88	0.86	0.61	0.84
	I feel I have a sense of solidarity with other people using the website	4.01			
	I can identify with other people using the website	4.11			
	I feel I have a lot in common with other people using the website	3.97			