

"A protracted struggle" – A qualitative blog study of endometriosis healthcare experiences in Sweden

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ABSTRACT

Objective: The aim of this study was to identify and describe endometriosis healthcare experiences based on affected individuals' blog posts.

Background: Endometriosis is a chronic gynaecological disease that often has a negative effect on mental, physical, sexual and social health, resulting in lower quality of life. Endometriosis healthcare experiences have typically been described in terms of normalisation, trivialisation and a lack of knowledge from healthcare professionals. These experiences are often reported via individual interviews or focus group interviews. Studying internet blogs may contribute additional information that might not be disclosed during interviews. Therefore, observing and analysing content from blog posts may present an opportunity to gain additional understanding of how healthcare encounters can be experienced by individuals with endometriosis.

Study design and methods: This is an inductive qualitative study based on blog posts. The blog posts were written in Swedish and posted online without passwords. Sixteen blogs written between 2008 and 2019 by people aged 22-34 were included.

The bloggers had been diagnosed with endometriosis one to seven years prior to writing the blogs and lived all over Sweden. Data collection was performed in March 2019 using an online search engine. A combination of different research terms was used to find the blogs. After considering the blogs on the basis of inclusion and exclusion criteria, 12 blogs remained, and another four blogs were included via links from one of the blogs. The analysis was conducted using thematic analysis according to Braun and Clarke.

Results: The results are presented under one main theme, "A protracted struggle", and two subthemes, "The response plays a significant role" and "The value of competence". The bloggers described their healthcare experiences as a long struggle including contact with a large number of different healthcare professionals (HCPs), where the response was significant for their physical and mental health. They emphasised the advantages of person-centredness, competence and continuity in the HCP contact.

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Conclusions and implications for practice:

The results demonstrate that the journey through healthcare was experienced as a prolonged struggle, including normalisation, trivialisation and distrust. The results imply that more improvement work remains to be done within endometriosis healthcare. Taking patients' complaints seriously and providing prompt and effective investigations and treatment may lead to more positive healthcare experiences.

What is already known about the topic?

- Endometriosis healthcare experiences have typically been described in terms of normalisation, trivialisation and a lack of knowledge from healthcare professionals.
- Previous qualitative studies on the subject are interview studies, which may be influenced by the presence of researchers.

What this paper adds:

- The care-seeking behaviours involved a wide range of strategies. The descriptions varied from extensive care-seeking from different doctors and clinics, to refraining from seeking care due to a fear of being treated badly.
- The wording used in the blogs was tougher and more unforgiving, and included mostly negative aspects compared to what has been presented in interview studies. This may be explained by the "diary-like" characteristics of blogs and the free way of presenting narratives in a blog.

Keywords: Endometriosis, blogs, qualitative analysis, healthcare encounter, thematic analysis

BACKGROUND

Endometriosis is a chronic, inflammatory and oestrogen-dependent disease occurring in around one in every ten individuals of fertile age born with a uterus. It is characterised by the implantation and growth of endometrial-like cells outside the uterine area. The ectopic cells cause inflammation, bleeding and pain, and may result in the formation of lesions, adhesions and cysts. The most common symptoms are pain during menstruation, persistent pelvic pain, dyspareunia, fatigue/weariness, urinary and intestinal complaints and a reduced level of fertility. The symptoms often appear as early as menarche.¹

Within the field of endometriosis, the literature on healthcare experiences is growing, well cited and presented in meta-analyses and reviews.^{2,3} Many individuals with endometriosis report negative experiences when seeking care for endometriosis-related symptoms. They often report experiences of normalisation, trivialisation and a lack of knowledge from healthcare professionals (HCPs).²⁻⁴ The normalisation and trivialisation of one's own menstruation pain, together with normalisation and trivialisation by family members, society and HCPs, is often considered the main reason for delays in diagnosing the disease.^{2,5} This delay may cause considerable physical, mental and social damage and often has a negative impact on wellbeing and quality of life.⁶⁻⁹

The majority of research on experiences of endometriosis healthcare encounters consists of qualitative interview studies with either individual interviews or focus group interviews. Studying blogs in which patients provide detailed descriptions of experiences without the presence of probing researchers may provide additional information that might

not be disclosed during interviews.¹⁰ The blogs give unique access to the blogger's experiences and feelings without the influence of pre-defined research purposes.¹¹⁻¹³ Therefore, observing and analysing content from blog posts presents an opportunity to gain additional understanding of the experiences of healthcare encounters among those affected by endometriosis.

To our knowledge, only a few previous studies have used material from peer-written public domain websites to explore experiences related to endometriosis.^{5,14} Krebs and Schoenbauer analysed online narrative postings and revealed two dominant discourses related to the diagnostic delay in endometriosis: the discourse of biological normality that normalises the suffering as "just part of being female", and the discourse of psycho-abnormality, which trivialises the suffering as imagined and "all in the patients' heads".⁵ Neal and McKenzie focused on how bloggers presented and valued information sources about endometriosis on their blogs.¹⁴ We have found no studies analysing blog post about endometriosis healthcare experiences.

The aim of this study was to identify and describe endometriosis healthcare experiences based on affected individuals' blog posts.

METHOD**DESIGN**

This qualitative inductive study was conducted using blogs as the data source. When reporting on the study and writing this article, we were guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.¹⁵

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SETTING

This study was based on data from Swedish blogs. In some parts of Sweden, like other Western countries where research on endometriosis healthcare experiences has been conducted, patients have to be referred to a gynaecologist by a general practitioner, while in other parts, they can make appointments directly with the gynaecologist.

SAMPLING AND DATA COLLECTION

A purposive sampling was used, which involved blogs containing posts that responded to the aim.¹⁶ Inclusion criteria were blog posts written in Swedish, by individuals diagnosed with endometriosis, and which included descriptions of healthcare experiences related to endometriosis. Exclusion criteria were blogs protected by passwords, blogs written by individuals with other chronic diseases and blog posts regarding infertility treatment.

Data collection was performed in March 2019. An online search engine was used to find the blogs, using a combination of different research terms. The search generated 98 usable links, of which 26 were blogs. After considering the blogs based on inclusion and exclusion criteria, 12 blogs remained. One blog contained links to other blogs, and four blogs were included via these links. In total, 16 blogs were included in the study. The included blogs were written between 2008 and 2019 by people aged 22-34 (mean age 28). In two blogs, the bloggers' ages were not disclosed. The bloggers had been diagnosed with endometriosis one to seven years prior to writing the blogs (mean four years). They lived in both small villages and big cities all over Sweden. They all identified as female, but their ethnicity was not disclosed.

DATA ANALYSIS

Thematic analysis according to Braun and Clarke was chosen for the analysis of the blogs.¹⁷ To become familiar with the text and to get a sense of the content, the blogs were read through, and thoughts, ideas and patterns were identified. In the next phase, relevant extracts from the 16 blogs were copied into a Word document. Data that did not correspond to the aim was excluded during the process. This resulted in 155 pages (Times New Roman, font size 12) which included 431 data extracts. The document was printed and the data extracts were cut out and then grouped manually. All text writing was performed in Word.

The data extracts were labelled with preliminary codes and organised into 17 subthemes. Once each subtheme had been examined, certain subthemes were grouped together and nine new subthemes were generated. In the next phase, the subthemes were grouped and combined into one main theme and two subthemes. Again, they were labelled as described. Example of the analysis and the relationships between data extracts, codes and subthemes are presented in Appendix A.

Two of the authors (HD and EH) were responsible for the analysis process. To ensure the quality of the analysis process, a pilot analysis of one blog was conducted and discussed with all authors. This analysis was included in the study. The final themes and subthemes were discussed and agreed on within the research team.

ETHICAL CONSIDERATIONS

The study was conducted in accordance with the declaration of Helsinki.¹⁸ As this work was based on existing blogs and the work was conducted within the frame of university education, no ethics committee approval was necessary according to Swedish law.¹⁹ The advisory board for studies conducted within the frame of university education granted oral approval for the study according to standard procedure (date of approval: 21 December 2018). Due to blog-hosting websites declaring that text available on their websites is public and voluntarily published, consent was assumed.²⁰ To ensure confidentiality and to reduce the traceability of quotations via search engines, the research terms, names of blogs and names of blog writers were omitted. Only short segments from blog posts were used as quotations, and certain words in the quotations were replaced with other words with a similar meaning.²¹

RESULTS

The analysis resulted in one main theme, "A protracted struggle", and two subthemes, "The response plays a great role" and "The value of competence".

As the main theme suggests, having to make repeated visits to healthcare in order to get the proper care and treatment was experienced as a long struggle that often involved contact with a large number of different HCPs and healthcare institutions. The response from HCPs during these encounters was essential to the bloggers' physical and mental health. During the encounters, a person-centred and individually adapted approach, without normalisation, trivialisation and objectification, was warranted. When their symptoms were taken seriously, the bloggers described feeling seen and confirmed. To achieve this, the HCPs had to be competent, they had to have knowledge of endometriosis and they needed to be able to transfer their knowledge. The bloggers stated that gaining knowledge made them feel confident in accepting, understanding and managing the disease. Furthermore, they preferred to meet the same person, as continuity in HCP contact was valuable and made them feel secure. In the following, the main theme and the subthemes are described in detail, and are exemplified using quotations from the blogs. The names attributed to the quotations are aliases.

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A PROTRACTED STRUGGLE

The bloggers described their encounters with healthcare as a long struggle for which there was no end in sight. In order to get proper help, they had to seek care repeatedly and they encountered both organisational and personal obstacles. They expressed their frustration at having to wait for “their turn” in a state of acute or chronic pain. The waiting time to see a physician or a nurse who took their problems seriously, and the long journey towards a diagnosis, were described as persistent suffering. The bloggers described having to fight and badger to get the telephone calls, referrals and examinations they had been promised.

I wait for telephone calls from the Gynaecology Department and the doctor, and it can be a long week's wait without any contact at all. When that happens I feel betrayed, because you feel alone in the fight. It is not okay that this happens. – Anna

The struggle was described as being particularly hard during times of acute pain. The bloggers were disappointed and angry at having to beg for painkillers and care. Encountering the phrases “in a moment” or “soon” was unacceptable, and made them feel forgotten or left behind.

Another aspect of the struggle was the lack of continuity in their contact with HCPs. Many bloggers wrote that meeting new HCPs repeatedly made them feel exposed and vulnerable. They had to undergo many pelvic examinations. They also had to tell new people their life stories and provide them with detailed and sensitive information about areas of their lives that they considered private, such as sexual problems or concerns about fertility. It also somehow took them back to earlier periods of their lives and the struggles they had to endure in the past to get to where they were today. Returning to square one made some bloggers feel despair, while others just felt hopelessness. However, when there was continuity in their contact with the HCPs, the bloggers often felt secure and safe, and seeking care became less of a struggle.

How much fun is it to undergo gynaecological examination after gynaecological examination? Gynaecological examinations are something I will never get used to. It is always exposure. The doctor often asks difficult questions, when I lie there in that terrible chair. – Helene

Several bloggers pointed out that they felt it was time for the HCPs to take responsibility for the care they provide, and to work towards adapting the care to the individuals' unique needs. They were tired of having to fight for care when the HCPs did not take enough responsibility in trying to help them. In some cases, the bloggers were so dissatisfied that they brought charges against the HCPs based on inhuman treatment and not having their rights to proper care respected.

During their struggles for satisfactory care, some bloggers also felt the need to visit other hospitals or clinics. While the action itself was described as unacceptable, some bloggers also felt relieved and calmed as they could now replace arrogant HCPs with hopefully better ones.

For some, the struggle for satisfactory care had led to burnout, anxiety and depression. They felt that they had lost several years to this battle. Some bloggers even said that they would rather be dead than to continue with this struggle. As Josephine put it: *This struggle is so hard... You kind of have to be healthy to have the strength to fight for proper care.*

THE RESPONSE PLAYS A SIGNIFICANT ROLE

As patients, the bloggers felt dependent on the HCPs and the response they received when disclosing their symptoms to the HCPs. They attached a great deal of value to being seen and confirmed during their healthcare encounters. However, there were many stories of HCPs not wanting to prescribe painkillers, or where the bloggers felt that they had to beg to get proper pain relief. Several bloggers had been told that they were imagining or overstating their pain. Some HCPs had even called them drug addicts, which they found offensive and degrading.

I know all too well what it is like to be distrusted by the system, to be called a hypochondriac, an addict, to hear that I am too young to be sick. I am only 27 years old, but I have the body of a 70-year-old. The psyche died a long time ago. – Sophie

Several bloggers described encounters with HCPs who considered pain to be physically harmless, as pain during menstruation is something “normal”. They also described how stressful it was repeatedly having to hear that their problems were psychosomatic and that they should seek psychiatric care instead. Some bloggers had also been misdiagnosed with a number of different disorders, such as anxiety, irritable bowel syndrome, premenstrual syndrome or sexually transmitted diseases.

The bloggers described situations where HCPs had recommended pregnancy as the best cure for endometriosis. This made them feel hopelessness and fear, as some bloggers did not feel ready to have children, and some of them feared subfertility or infertility.

Also, I am starting to get tired of this rant that I should have children as soon as possible. I would love to do so if I was in a good financial situation, but I'm not! My husband is studying and I only work 75%... and some days I can barely take care of myself, so how does a child fit in there too. – Therese

Taken together, the blogs painted a picture of a healthcare that continually misinterpreted, normalised and trivialised endometriosis symptoms. When the bloggers received a negative response from HCPs, they described feelings of loneliness, violation and disbelief. This appeared to result in low self-esteem, low self-confidence and feelings of anxiety,

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resignation and despair. Some bloggers described how they stayed at home trying to endure extreme pain instead of seeking care, due to the fear of risking an encounter with a cold-hearted HCP. For Maria, the lack of trust and belief in HCPs had led to a phobia of hospitals:

After all my visits to idiot doctors, I now have a phobia about doctor's visits. Even when I go in with sinusitis, I think they will say I am making it up and should seek mental help. – Maria

While this dark picture of the responses received during their healthcare encounters dominated the blogs, some bloggers also described HCPs who gave them a positive response. Being seen as an individual and not as a body or an object was a key factor for a positive healthcare experience. Bloggers who felt confirmed often described gratitude towards the HCPs. They were filled with joy when they felt that the HCP listened to them, asked the “right” questions, was on their side, and confirmed their pain and symptoms. Furthermore, the bloggers appreciated engaged and interested HCPs who tried to adopt a person-centred approach, i.e. involving them in planning their treatment and care.

They have brought food, dried my tears, talked to me in a separate room and encouraged me a lot. Exactly what you need when you have a disease like this. Someone who shows understanding and doesn't judge you. Someone who comes back with a smile even though you have just vomited! – Linda

He started by saying: “Now I've read through your medical journal (!). I understand you've had a tough time. How can I help you?” NO doctor has ever said that to me. – Linnéa

THE VALUE OF COMPETENCE

In the bloggers' experience, HCPs' knowledge about endometriosis varied. Their expectations of encountering HCPs with competence in detecting, suspecting and treating endometriosis were often dashed. Instead, many bloggers found that HCPs lacked knowledge of the disease, were irresolute when it came to treatments, and spread old myths about endometriosis. This lack of competence led to what the bloggers considered incorrect treatments, and not having their care needs fulfilled. Several bloggers felt violated and frustrated when HCPs claimed to be experts but showed their lack of competence by asking inadequate questions or conveying inaccurate information. Many bloggers expressed their anger and distrust, sometimes with harsh words and profanities.

Healthcare in Sweden, damn it, is not as good as it should be, as it could be! We pay very high taxes to ensure good medical care, but instead we get unskilled staff who ignore your needs and do not believe you! Instead, they shrug their shoulders and think “You'll be fine”. – Molly

I think it is so terribly awful that many doctors do not even know what endometriosis is and how it works. I have been told incorrect facts about endometriosis by several doctors. However, one of the worst things is that so few people really know about the disease. – Sarah

There were also instances where bloggers met HCPs whom they considered competent. This often generated feelings of hope, joy and thankfulness. Receiving an explanation for their pain and symptoms made them feel calm and secure. Accurate information was experienced as being important in order to understand what the endometriosis was doing to their bodies and how they could best manage the situation. Sometimes the bloggers were referred to an endometriosis specialist for a second opinion, to a physiotherapist in order to help with non-pharmacological pain relief, for example, or to counsellors who could support them with the emotional consequences of the disease. Being referred to specialists and additional professionals was described in positive words, and the bloggers did not see this as a sign of weakness or incompetence in the HCP. Instead, they considered HCPs' ability to admit their own limits and turn to other professions for help as a sign of competence.

“Lisa, does it hurt when you have intercourse?” I nodded. “Okay. Are you in pain when you menstruate? Do you bleed? Do you have any vaginal discharge, and what is it like?” Well. Right. It was as if he was reading me like an open book. I just needed to nod. How strange it felt, suddenly someone understood me. Who knew. Who believed in me. I started to relax. He knew what he was talking about. – Lisa

DISCUSSION

This study examined the experiences of endometriosis healthcare encounters as described by affected individuals on their own blogs. By examining these blogs, we gained an exclusive insight into the accounts of their life stories. The encounters were thematised under one main theme, “A protracted struggle”, and two subthemes, “The response plays a significant role” and “The value of competence”. The bloggers described their healthcare experiences as a long struggle including normalisation, trivialisation and distrust in their contact with a large number of different HCPs. There were also positive encounters, which were often characterised by continuity, a person-centred approach and the HCP's high degree of competence.

The experience of healthcare encounters in Swedish settings as both positive and negative has been reported previously,^{4,22} and is validated by this study. Hence, the positive encounters seem to be real, and not just something that the interviewees may feel obliged to say when participating in a research project.

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However, there were far more blog posts about the negative aspects of healthcare experiences. The struggle of having an “invisible” disease that can have fatal consequences in terms of physical and mental health was an underlying theme in all the blogs. Although this struggle has been described in a number of earlier qualitative studies,^{2,3} the findings in this study are unique, since people may be more likely to speak from their hearts in their blogs. Sometimes very harsh language was used in the description of incompetent HCPs, and swearing and calling them names was common. This provides a new dimension of understanding for the bloggers’ situation, as unfiltered information was analysed. It could also be explained by the fact that bloggers often seemed to write their blog posts immediately after the experience, compared to retrospective accounts in many interview studies.

One should bear in mind that the distinctly negative or positive experiences could also be related to the diary-like function of blogs. The findings could be interpreted as results of an “online diary”, where it is possible that people tend to blog when they feel that they are being treated very badly, or very well.¹² Hence, the blog posts may be representative of only the worst or the best periods in life.

Diary-like or not, there is a growing body of research where information is received from social media, such as blogs, discussion forums or Twitter posts. This is part of what is called the Big Data revolution,²³ and although it may come with limitations as mentioned above, and potential ethical difficulties, there are advantages to hearing the voice of the patient with clarity and immediacy. This type of data can be used to evaluate and improve the quality of healthcare and healthcare encounters.¹⁰ Sharing experiences on social media and blogs may also provide affective support and epistemic experience to others in the same situation.¹⁴

The bloggers described that they appreciated when their HCP consulted other professions for additional treatment, for example counsellors or physiotherapists. The organisation of endometriosis care into multi-professional teams around the most complex cases is recommended in international guidelines for endometriosis care.¹¹ The number of professionals involved in the team may depend on resources and organisational or economic conditions, but ideally, the team should involve diverse professions with specialisations in different fields: a gynaecological surgeon, a urologist, a colorectal surgeon, a specialist nurse, a specialist gynaecology radiologist, a pain specialist, and a counsellor or a psychologist. Sometimes, representatives from patient support organisations are included in these teams. The benefits of these teams are multi-layered and lead to higher quality decision-making, standardised person-centred care and improved outcomes.

One possible disadvantage may be that the shared decision-making and patient involvement can be limited, as

patients typically do not attend the team meetings.²⁴ The bloggers in this study who had experiences from multi-disciplinary teams wrote only positive things about them. They appreciated when the gynaecologist involved other HCPs to support them with the emotional consequences of the disease (ie. contact with counsellors), or to provide self-care (ie. contact with physiotherapists). The wish for a biopsychosocial approach was a common theme in the bloggers’ thoughts about what was lacking in their current care situation. This corresponds with a recent study, in which we highlighted the gap between physicians’ ambitions to take a biopsychosocial approach and the experiences of such an approach among their patients.²⁵

Furthermore, the need for person-centred care was expressed in the blog posts. The bloggers wrote that having the HCP decide on medical and surgical treatment without asking for their input was outdated and old-fashioned. They demanded to participate in the planning of their care. The advantages of person-centred care have been described in both endometriosis literature and healthcare literature in general.^{26–29} Incorporating patients’ needs and perspectives into care delivery is part of a paradigm shift, where the patient’s engagement with their care is now considered a key to high quality healthcare and successful outcomes.^{27,28}

Rozenblum and Bates argue that patients today are more engaged with their care in general,³⁰ which may be a reason behind the increase in using the internet to share and rate their healthcare experiences with others. Using online discussion forums and groups is a common way to connect with others in the same situation, to share experiences of treatment and care, and to warn against or recommend treatments, hospitals or even HCPs, to others. Before the internet revolution, patients made choices about where to receive healthcare based largely on factors such as proximity or the recommendations of a friend. Easy access to patients’ feedback online may be a way for healthcare organisations and researchers to incorporate patients’ perspectives into the organisational quality improvement process.³⁰ This idea is highly relevant to endometriosis healthcare, where the implementation of person-centredness is an important part of international guidelines.^{1,31}

The present study has several strengths, including the methodology whereby bloggers wrote freely and voluntarily about what was important to them during their healthcare experiences. The recall bias that may occur with more traditional methods of data collection, such as focus groups or interviews, can be assumed to be decreased since blogs are often written in real time.³² The anonymity of the internet may also provide a more spontaneous, unfiltered way of sharing perceptions, thoughts and feelings.^{32,33} This anonymity comes with limitations, as we were not able to ask follow-up questions or get a deeper understanding of the stories; we simply had to rely on the text.

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Furthermore, as in other studies analysing blogs,³⁴ due to the bloggers' anonymity, we cannot ensure that they are who they claim to be online and that they had really experienced the situations they described. However, this limitation accounts for many data collection strategies. For example, there is no guarantee that participants are entirely truthful when answering posted questionnaires.

The blogs analysed in this study were all written by people who identified as women. There is a selection bias, as using blogs as a data source can only capture the experience of those who are willing to share their experiences openly in the public domain. The voices of those who do not blog, or who do not want to share their blogs, together with those who do not identify as female, are thus not included in this sample. The bloggers did not write about their ethnicity but the blog posts contained no information about being treated in a different way because of their skin colour.

The results might be transferrable to other contexts where individuals affected by endometriosis live in countries and regions with similar healthcare organisations.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE AND RESEARCH

The journey through endometriosis healthcare was described as a protracted struggle, where normalisation, trivialisation and distrust still seem to characterise a large part of the bloggers' healthcare experiences. However, there were also positive encounters and important aspects including continuity in HCP contacts, a person-centred approach and the competence of the HCP. This implies that a great deal of improvement work remains to be done within endometriosis healthcare, and that taking pain and symptoms seriously should be one of the main points to develop. Future research could focus on examining and improving the management of dysmenorrhoea and other early endometriosis symptoms, especially among HCPs who meet these people at a young age, such as school nurses and HCPs at youth centres. If awareness of endometriosis and its symptoms were to be a common theme at every healthcare setting providing care for uterus carriers of fertile age, including young people and teenagers, the protracted struggle could perhaps be shortened.

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