



“A challenge” – healthcare professionals’ experiences when meeting women with symptoms that might indicate endometriosis



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ABSTRACT

Objective: The aim of the study was to identify and describe the experiences of healthcare professionals when meeting women with symptoms that might indicate endometriosis.

Methods: Semi-structured interviews were conducted with 10 gynecologists, six general practitioners and nine midwives working at one university hospital, one central hospital, one private gynecology clinic and five healthcare centers in south-east Sweden. The interviews were recorded and transcribed verbatim and analyzed using qualitative conventional content analysis.

Results: Three clusters were identified: the corroborating encounter, the normal variation of menstruation cycles, and the suspicion of endometriosis. The healthcare professionals tried to make a corroborating encounter by acknowledging the woman, taking time to listen, and giving an explanation for the problems. Healthcare professionals had different ways to determine what was normal as regards menstrual pain, ovulation pain and dyspareunia. They also needed to have the competence to act and react when the symptoms indicated endometriosis.

Conclusions: Meeting women with symptoms that might indicate endometriosis is challenging and demands a certain level of competence from healthcare professionals. Sometimes the symptoms are camouflaged as “normal” menstruation pain, making it hard to satisfy the needs of this patient group.

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Introduction

Endometriosis is the presence of endometrium in aberrant sites and is considered a chronic disease [1]. It can impact on physical, mental and social wellbeing and often has a negative effect on women's quality of life [2–6]. Some women with endometriosis do not have symptoms at all, but endometriosis usually causes menstruation pain (i.e. dysmenorrhea), often in combination with ovulation pain and/or dyspareunia [1,7]. Previous studies have shown difficulties in diagnosing the condition, and the delay between symptom onset and diagnosis varies from four to 12 years [8–13]. The delay in diagnosis can be explained according to two levels. At the individual level, women have difficulties determining what normal and abnormal menstrual pain is, leading to a normalization of their own experiences of pain. At the other level, the medical one, the pain is sometimes normalized by family doctors or general practitioners (GPs) [14].

Negative experiences when seeking medical care are common in this patient group, which may be a result of the difficulties in diagnosing the disease. The difficulty of being believed by the primary care staff, and the limited knowledge of endometriosis among GPs, are common themes in women's narratives of their experiences [4,8,9,15,16]. Gynecologists, GPs and midwives – described in this study as healthcare professionals (HCPs) – who meet women with symptoms that might indicate endometriosis, play an important role in finding and diagnosing endometriosis. More knowledge about their experiences when meeting women with these symptoms might result in faster diagnosis, consequently leading to better care and an improvement in the women's quality of life. We therefore conducted this qualitative study with the aim to identify and describe HCPs' experiences when meeting women with symptoms that might indicate endometriosis.

Methods

We conducted a qualitative interview study on the subject of HCPs' experiences when meeting women with symptoms that might indicate endometriosis. The study was approved by the Regional Ethical Review Board in Linköping (Dnr 2011/344-31; date of

Abbreviations: HCPs, Healthcare professionals; GPs, General practitioners.

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approval: 06 February 2012) and it was performed in accordance with the Declaration of Helsinki [17].

Setting

In Sweden, a woman with pelvic pain may either seek medical care from her GP or she can make an appointment directly with a gynecologist. It is also possible for women in Sweden to make an appointment with a midwife in antenatal care centers. The midwives are nurses specialized in sexual and reproductive care, and can give advice on sexual health and contraceptives.

Participants

To include a range of HCPs involved in the care of women with pelvic pain gynecologists, GPs and midwives were approached for inclusion in the study. The gynecologists and the midwives were recruited from the departments of Obstetrics and Gynecology at one university hospital, one central hospital and one private gynecology clinic in the south-east health region of Sweden. The GPs were recruited at five primary healthcare centers in the same area. By e-mail we invited all the gynecologists in the two hospitals and in a private gynecology clinic, and all the midwives associated with the antenatal care centers in the two hospitals to participate in the study. The GPs in the five primary healthcare centers were likewise approached and asked to participate. A total of 25 HCPs (10 gynecologists, six GPs, nine midwives) participated in the study. The median age of the HCPs was 53 years (range 33–71 years) and 18 were females. The HCPs had been in the profession for 5–46 years (median 20 years).

Interviews

The interviews were conducted by the first author (HG) at the participants' workplaces between February 2012 and May 2013. Before starting the interviews the participants were given written and oral information, and their written consent was obtained. The interviews lasted for 15–36 minutes (median 25 min), and were digitally recorded and transcribed verbatim by HG. The interviews were semi-structured (Table 1). All questions were covered in all interviews, but not necessarily in the same order, following the natural progression of the conversation.

Table 1
Interview questions.

Main questions
Can you tell me about your experiences of meeting women with pelvic pain?
How do you help a woman seeking medical care for increasing menstrual pain?
What are your concerns about taking menstruation case histories?
What treatment options do you consider when you meet a woman with difficult menstrual pain?
Have you observed some of the consequences that menstrual pain can cause?
Is there any particular diagnosis you think of when you have a woman suffering from menstrual pain, ovulation pain or pain during intercourse before you?
If you suspect that the woman has endometriosis, how do you then inform her about this?
How do you decide what is normal menstrual pain and what may be pain caused by endometriosis?
In your experience, what are the results of the different treatments that can be offered to a woman and which ones do you normally choose?
How do you diagnose endometriosis?
Follow-up questions
Can you clarify that?
Can you tell me more about that?
Can you give an example?

Data analysis

The transcripts of the interviews were analyzed using qualitative conventional content analysis, as described by Hsieh and Shannon [18]. To obtain a sense of the whole, the interviews were read through several times. Next, the text was read thoroughly and the exact words that seemed to capture key thoughts were highlighted. Then, the researchers made notes of their first impressions, thoughts and initial analysis of the text. The marked words were considered the codes. Labels for codes emerged that reflected more than one key thought, and these were used to create the initial coding scheme. Based on how these codes were linked and related, they were sorted into three clusters. Finally, definitions for each cluster were developed [18]. Data analysis was led by HG. The codes and clusters were discussed and agreed by all researchers.

Results

Three broad clusters were identified in the analyses of the interviews: the corroborating encounter, the normal variation of menstruation cycles, and the suspicion of endometriosis. These three clusters answered the question about HCPs' experiences of meeting women with symptoms that might indicate endometriosis. Verbatim quotes are presented in the text to illustrate the clusters.

The corroborating encounter

The HCPs experienced women with symptoms that might indicate endometriosis as a challenging group to meet in that sense that they required a high amount of responsiveness. Most gynecologists and some of the GPs stressed that it was particularly important to try to understand the situation of every single woman in order to identify what kind of help she needed. By acknowledging the woman, the HCPs increased the possibility of making the situation a corroborating encounter. They experienced that in a corroborating encounter the woman trusted them, understood that the HCP cared about her and had the competence to help her. The HCPs acknowledged the woman by listening to her and confirming her symptoms. Taking into consideration both the physical and the mental dimensions of the experience of pain was an important factor in establishing the corroborating encounter, while lack of time often was experienced as an obstacle.

I think it is really important that the patients feel that they (HCPs) can listen to them (patients) and that they (HCPs) not only hear what they (patients) are saying but also that they // show that they have understood, and they confirm in some way that "I have understood that you are or are not in pain", something like that.
– Informant 5

The HCPs reflected that there could be various explanations to the intensification of pain, such as former trauma, abuse or psychological disorders. If the woman had gone through many treatments without satisfactory improvement, it was sometimes necessary to try another approach. Some women needed help to learn how to accept and cope with the pain. The HCPs appreciated being able to discuss the cases in a multi-professional team or to refer the patient to a physiotherapist, psychologist or a gynecologist specializing in this particular area.

Sometimes, in the severe cases, it might not be possible to become completely pain-free, but you have to, like, I think it's more about basic body awareness and relaxation, being able to, to get out of a bad circle in one way. I imagine that a skilled physiotherapist could help out with that. – Informant 14

The HCPs experienced that if women felt acknowledged they often left the clinic with a feeling of satisfaction even though the

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