Comparison of patient- and physician-based descriptions of symptoms of endometriosis: a qualitative study

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STUDY QUESTION: How do fully-comprehensive patient-centred descriptions of the symptoms of endometriosis compare with the physicians’ description of the symptoms?

SUMMARY ANSWER: The description of the painful symptoms due to endometriosis is based on numerous distinct parameters. The way these are used to describe symptoms and the way they are interpreted varies significantly between patients and clinicians. The descriptions of severe pelvic pain and dysmenorrhea and dyspareunia by the clinicians were incomplete compared with those of the patients.

WHAT IS KNOWN ALREADY: Painful symptoms due to endometriosis were found to be of little use to predict the location and severity of the disease. Currently there are few data on the patients’ description of symptoms and no questionnaire is available to derive data from patients.

STUDY DESIGN, SIZE, DURATION: Descriptions of painful symptoms by patients and by physicians were obtained by qualitative, interview-based study and analysed using Colaizzi’s method. The patients planned to be operated on for painful endometriosis were volunteers for preoperative interview. They were recruited by purposeful sampling to represent different types of endometriosis [i.e. superficial endometriosis, ovarian endometriosis or deeply infiltrating endometriosis (DIE)], the women were selected so that at least five sites of endometriosis were included in the study. The clinicians were experts in endometriosis management.

PARTICIPANTS/MATERIALS, SETTING, METHODS: Forty-one patients were recruited, in four reference centres. Among them, 33 had DIE in various locations, including intestinal endometriosis (n = 12) or bladder endometriosis (n = 5), 14 had ovarian endometriosis (including three without associated DIE) and 5 had only superficial endometriosis.

The nine experts were French-speaking gynaecological surgeons practicing in university teaching hospitals (seven), a general hospital (one) or a private centre (one).

MAIN RESULTS AND THE ROLE OF CHANCE: In total, 47 themes were identified of which 30 were perceived by both patients and clinicians, 12 by patients only and 5 by clinicians only. Themes fall into five general categories: (i) severe pelvic pain and dysmenorrhea, (ii) dyspareunia, (iii) gastro-intestinal symptoms, (iv) bladder symptoms, (v) other symptoms. Patients’ and clinicians’ descriptions of symptoms were in agreement for general categories, but the clinicians’ comprehensive description was incomplete, in particular concerning the severe pelvic pain and dysmenorrhea’s themes and the dyspareunia theme. Patients did not report any clear-cut distinction between pelvic pain and dysmenorrhea and expressed a dimension of suffering and impaired quality of life inherent to painful symptoms.

LIMITATIONS, REASONS FOR CAUTION: Most of the patients in the study had already had treatment for endometriosis, including ongoing hormonal treatment. Furthermore, all but a few patients had documented endometriotic lesions and no specific investigations to eliminate additional causes of functional pelvic pain were done. Finally due to the qualitative design of the study the result must be regarded as inferences.
Introduction

Detailed knowledge of pelvic pain characteristics was found to be helpful in the pre-operative assessment of patients with suspected endometriosis, especially when deep infiltrating endometriosis (DIE) was concerned (Fauconnier et al., 2002; Fedele et al., 2007). Appropriate measurement of pain symptoms in endometriosis patients remains a subject of debate (Vincent et al., 2010). One of the goals of questioning is to identify patients at risk of having endometriosis to achieve early detection of the disease. Diagnostic delays are very frequent with endometriosis and can have consequences at physical, emotional or social levels (Ballard, 2006; Matsuzaki et al., 2006). Appropriate identification of women reporting symptoms related to endometriosis and their referral to a gynaecologist before other specialists would reduce time to diagnosis and the number of physicians consulted (Greene et al., 2009). However, detailed analysis of the pain symptoms by standardized questionnaire and history-taking have shown limited efficacy to predict endometriosis accurately (Mahmood et al., 1991; Forman et al., 1993; Chapron et al., 2005; Ballard et al., 2008).

One explanation is that the questionnaires used were not designed to take patient-based perception of symptoms properly into account. Most of the previous symptom-based questionnaires concerning endometriosis were designed according to the physicians’ perception of the pain and were not centred on the patients’ description of symptoms (Vincent et al., 2010). Appropriate symptom-questionnaire development should be based on qualitative designs (Food and Drug Administration (FDA), 2009). Our hypothesis was that qualitative studies with in-depth interviews of women suffering from endometriosis might help to develop future pain assessment tools for endometriosis. The previous qualitative studies (Jones et al., 2004; Ballard et al., 2006) based on patients with painful endometriosis were not centred on the description by patients of their own pain symptoms.

We thus aimed to characterize the women’s perceptions and narrative description of symptoms of endometriosis and to compare them with those provided by physicians highly experienced in the diagnosis of endometriosis.

Materials and Methods

The study population consisted of selected patients attending at four French tertiary referral centres: (CHI Poissy – St Germain en Laye, CH Versailles, CHU Rouen, CHU Angers) for painful symptoms of a >3 months’ duration, with a visual diagnosis of endometriosis (by laparoscopic or specular examination) and histological confirmation of this diagnosis. Patients were selected by purposeful sampling to represent different types of endometriosis (i.e. superficial endometriosis, ovarian endometriosis or deeply infiltrating endometriosis (DIE)). Among patients with DIE, we included patients with common locations of DIE (i.e. utero-sacral, vaginal, intestinal or bladder endometriosis (Chapron et al., 2003b)). Patients with isolated adenomyosis were excluded. The process of the selection of the patient was the following: (i) patients were volunteers and had to be willing to share their experience related to painful symptoms of endometriosis and to accept the tape-recorded interview (ii) they had a visual documentation of endometriosis type and location with histological confirmation of this diagnosis. All the patients had painful symptoms sufficient to require surgery. The decision to perform the surgery was based on shared medical decision-making between the patient and the physician and was not specifically based on the results of the pre-operative work-up.

The patients were interviewed by the physician at the very beginning of the first consultation in the centre. Patients who subsequently were not confirmed to have endometriosis were excluded secondarily from the study. These interviews took place in an open fashion before any oriented questions were raised; no question grid was used but the patients were encouraged to describe in depth their perception of all the painful symptoms that might relate to their disease. The interviews lasted ~10 min. All the interviews were tape-recorded and transcribed. An adaptation of Colaizzi’s method (Colaizzi, 1978) was used for qualitative assessment of the full-length recordings and transcripts. Colaizzi’s method was chosen because it relies on a phenomenologic approach, i.e. on the progressive emergence of the patient’s subjectivity through an open interview (Colaizzi, 1978). As opposed to most methods used in sociologic or anthropologic studies, this approach is free of theoretical preconceptions and is therefore particularly well suited to medical situations. A female psychologist (SS) with special interest in pelvic pain and in the Colaizzi’s method, analysed all the interviews. Important words and sentences were collected. Topics and items reflecting common subjective experiences were extracted from the interviews. Meanings identified were grouped into themes, and then into theme clusters with common traits, and finally into more general categories. Lastly all the results were collated into a fully-comprehensive and understandable description of the painful experience of endometriosis as it was reported. The structure of the study was formulated on the basis of all the data.

The findings (themes and general categories collated) were shown to a random sample of the study patients interviewed previously who checked to see whether anything had been omitted and to ensure the items selected were completely understandable. The sample size was determined using quota sampling at a level that ensured a minimum of five locations of endometriosis were included (superficial endometriosis alone was counted as a location).

In the second phase, SS interviewed nine French-speaking, European gynaecologist surgeons (one woman, eight men) recognized for their expertise in the pre-operative assessment of patients with suspected endometriosis.
in the field of endometriosis. All these surgeons were aged from 42 to 63 years, practicing in university teaching hospitals (seven), a general hospital (one) or a private centre (one). All of them were involved in clinical research on endometriosis; their number of publications referenced in Pubmed ranged from 9 to 75. They were blind to the results of the patient interviews. From the nine surgeons interviewed, three participated to the inclusion of the patients (P.P., H.R. and P.D.) but were not involved in the analysis. Colaiazzi’s method was used in a similar fashion for patients and gynaecologists.

We complied with all French statutes concerning data about the subjects, confidentiality and restrictions (e.g. no religious or racial data). Ethical review board approval was given by the French ‘Comité d’éthique de la recherche en obstétrique et gynécologie’ (CEROG).

Results

Three patients refused the interview. Among the patients interviewed 14 were excluded secondarily for the following reasons: absence of endometriosis at laparoscopy \( n = 2 \); major previous operation for DIE \( n = 3 \); negative histology \( n = 2 \); non biopsy proven endometriosis with possible other cause \( n = 5 \); unusable tape recording \( n = 2 \). Forty-one women were analysed (CHI Poissy – St Germain en Laye: \( n = 27 \); CH Versailles: \( n = 3 \); CHU Rouen: \( n = 5 \); CHU Angers: \( n = 6 \)). The mean age of the sample population was 33 years (standard deviation = 6, minimum 21, maximum 45). All patients analysed except two had histological confirmation of endometriosis; the two remaining patients were not operated but had typical black-blush implants infiltrating the posterior vaginal fornix at speculum examination with a typical image of posterior DIE at MRI. These women were thus considered to have DIE involving the vagina. Among the 41 patients, 33 had DIE in various locations, including intestinal endometriosis (\( n = 12 \)) or bladder endometriosis (\( n = 5 \), 14 had ovarian endometriosis (including 3 without associated DIE) and 5 had only superficial endometriosis.

The patient analysis identified 42 themes falling into 5 general categories (Fig. 1, Table I):

(i) Severe pelvic pain and dysmenorrhoea (20 themes) was described as unbearable, overwhelming attacks of lower abdominal pain. The pain was clearly related with menstruation and none of the patients reported a clear-cut distinction between pelvic pain and dysmenorrhoea: the pain was reported as cyclic, with a maximum intensity during menses. Most of the women reported that the pain preceded menses, and some of them that the pain persisted after the end of bleeding (e.g. patient BA71; Fig. 1).

Pelvic pain was described with various locations including ‘ovarian pain’, unilateral pain, ‘spreading to the back’ or anal pain. It was notable that the pain was described as ‘severe’, ‘incapacitating’, ‘debilitating’ and interfering with daily life. Most of the patients suffered from pelvic pain for several years, describing the pain as ‘getting worse with time’ (e.g. patient GS78; Fig. 1).

(ii) Dyspareunia (five themes) was described as severe and ‘sharp’, and disturbing intercourse, with the classical descriptors ‘deep’ and ‘positional’ (e.g. patient GN68; Fig. 1).

Some women evoked another, different aspect of dyspareunia that involves the perception of ‘burning’ (e.g. patient FC68; Fig. 1). Most of the women avoided intercourse because of the pain.

(iii) Gastro-intestinal symptoms (eight themes) were very common whatever the location of endometriosis. Painful defecation was the most common symptom: it was described as pain or intestinal cramping immediately before defecation, or sharp and violent pain during defecation. The pain descriptor ‘anal’ pain was used sparingly and was found to relate to these symptoms. These symptoms were particularly marked during menstruation (e.g., patient FJ78; Fig. 1).

Other indicators of gastro-intestinal symptoms were nausea and vomiting, diarrhoea, constipation or both. These symptoms varied with the menstrual cycle, being accentuated or changing during menses (e.g. patient AM75; Fig. 1). They were not specifically reported by patients with endometriosis in an intestinal location.

(i) Bladder symptoms (six themes) may be dichotomized into urgency-frequency and painful bladder sensation. Urgency and frequency can be isolated or associated with burning or painful sensation. Bladder symptoms were frequently but not always related to menstruation (e.g. patients BA 86 and GC71; Fig. 1). Bladder pain/painful dysuria was described as pain located in the bladder area, related with bladder filling or with urination. Dysuria was found to be related with this painful sensation (e.g. patient LA80; Fig. 1).

Bladder symptoms were frequently found in women with bladder endometriosis (Table I), who often put them at the top of their list, but these symptoms were also found in patients without a bladder location. Indeed urinary symptoms were more frequently reported when patients re-examined the list during the later phase of the process.

(ii) Other symptoms (three themes): patients frequently reported a physical and psychological impairment of daily activity due to the painful symptoms, staying in bed, experiencing difficulties in daily life and work activities, impairment of sexual life and their relationship with their partner. All this resulted in a feeling of becoming increasingly tired and of extreme exhaustion and weariness (e.g. patient PS77; Fig. 1). It was noticeable that none of the patients worded that feeling as depression.

No major differences in the description of symptoms by the patients were found between the four participating centres.

The consultant/specialist interviews identified the same 5 general categories and a total of 35 themes (Table I). Clinicians and patients were in agreement for 30 themes, including: ‘Very painful menstruation, Lower abdominal pain, Pain depends on the time in the monthly cycle, Pain getting worse with time, Deep dyspareunia, dyspareunia related to position and dyspareunia disturbing intercourse. Physician descriptions of gastro-intestinal and bladder symptoms were exactly similar to those of patients.

Nonetheless, the description of severe pelvic pain and dysmenorrhoea by the clinicians was very incomplete: the clinicians identified 11 themes while the patients identified 20 (Table I). The discrepancies concerned the sensorial and narrative description of the pain, for example the patients described ‘Pain that is unbearable, overwhelming, violent, intense’ and ‘Continuous pain with peaks or attacks of more intense pain’ whereas the clinicians did not evoke these themes. The clinicians tended to separate the pain related to menstruation (dysmenorrhoea) and other sorts of pelvic pain.

The description of dyspareunia by the clinicians was also incomplete, since the clinicians identified three while the patients identified five themes. The discrepancies also concerned the sensorial and narrative description of dyspareunia, the patients describing dyspareunia as ‘Strong, sharp pain during sexual intercourse’ and ‘Burning feeling during or
after sexual intercourse.’ The word intromission or penetration was not used to formulate the themes because it had a different meaning according to patients and experts.

Concerning the ‘other symptoms’ topic, clinicians identified two symptoms that were not described by our patients (cyclic sciatic pain and pneumothorax). Depression was a descriptor used by the clinicians that was not found in the patients’ descriptions.

**Discussion**

Patients and consultants identified the same five categories of painful symptoms due to endometriosis: severe pelvic pain and dysmenorrhoea; dyspareunia; gastro-intestinal symptoms; bladder symptoms; other symptoms. Each of these topics involved numerous distinct descriptors and showed an important variability in symptom description and interpretation by patients and by physicians. The descriptions of the severe pelvic pain and dysmenorrhoea’s themes and dyspareunia’s themes by the clinicians were incomplete compared with those of the patients. Above of all, unlike the clinicians, the patients reported pelvic pain and severe dysmenorrhoea as two aspects of the same painful symptom. The pain was described as ‘severe’, ‘incapacitating’, ‘debilitating’ and ‘getting worse with time’ and in general had a great impact on daily life. Bladder and gastro-intestinal symptoms were commonly reported by the patients and the clinicians were in agreement with the patients’ descriptions.

To the best of our knowledge the various existing pain questionnaires and pain scales to assess symptoms related to endometriosis were primarily developed on the basis of clinician input (Biberoglu and...
Table I Number of individuals raising themes related to endometriotic pain.

<table>
<thead>
<tr>
<th>Items</th>
<th>Panel of patients (n = 41)</th>
<th>Physician panel (n = 9)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Subject: severe pelvic pain and dysmenorrhea</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very painful menstruation</td>
<td>29</td>
<td>9</td>
</tr>
<tr>
<td>Lower abdominal pain</td>
<td>26</td>
<td>2</td>
</tr>
<tr>
<td>Pain depends on the time in the monthly cycle</td>
<td>22</td>
<td>3</td>
</tr>
<tr>
<td>Paralysing, handicapping pain that affects mobility, difficulty walking</td>
<td>20</td>
<td>–</td>
</tr>
<tr>
<td>Pain that is unbearable, overwhelming, violent, intense</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>Continuous pain with peaks or attacks of more intense pain</td>
<td>16</td>
<td>–</td>
</tr>
<tr>
<td>Pain on one side, pain stronger on one side</td>
<td>13</td>
<td>2</td>
</tr>
<tr>
<td>Ovarian pain</td>
<td>13</td>
<td>–</td>
</tr>
<tr>
<td>The pain lasts longer than menstrual pain, and continues after the bleeding has stopped</td>
<td>13</td>
<td>–</td>
</tr>
<tr>
<td>The pain increases in intensity over time</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Pain starts a few days before menstruation begins</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>Pain throughout the monthly cycle, present all the time</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Pain spreads towards the back</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Pain before, during and after menstruation</td>
<td>9</td>
<td>–</td>
</tr>
<tr>
<td>Stabbing pain</td>
<td>9</td>
<td>–</td>
</tr>
<tr>
<td>Prickly pain, like being pricked or having an injection</td>
<td>9</td>
<td>–</td>
</tr>
<tr>
<td>Lower abdominal burning pain</td>
<td>7</td>
<td>–</td>
</tr>
<tr>
<td>The pain prevents sleep or wake up at night</td>
<td>7</td>
<td>–</td>
</tr>
<tr>
<td>Pain interferes with work or daily life</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Pain spreads to the legs and hips</td>
<td>4</td>
<td>–</td>
</tr>
<tr>
<td>Different types of pain at the same time, several different pain symptoms</td>
<td>–</td>
<td>3</td>
</tr>
<tr>
<td><strong>Subject: dyspareunia</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strong, sharp pain during sexual intercourse</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Deep internal pain felt during sexual intercourse</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>Pain in certain positions during sexual intercourse</td>
<td>12</td>
<td>4</td>
</tr>
<tr>
<td>Distracting pain that prevents or interrupts sexual intercourse</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Burning feeling during or after sexual intercourse</td>
<td>10</td>
<td>–</td>
</tr>
<tr>
<td><strong>Subject: painful bowel signs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain when passing a stool, painful bowel movements</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>Bloating, bloated abdomen</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Diarrhoea during menstruation</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Spasms, cramp, pain in the bowel before having a bowel movement</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Constipation during menstruation</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Nausea, vomiting</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Anal pain</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Diarrhoea alternating with constipation</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Bloody stools</td>
<td>–</td>
<td>2</td>
</tr>
<tr>
<td><strong>Subject: painful urinary tract symptoms</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling the need to urinate often, only small quantities at a time</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Pain with urge to urinate, pain when holding back</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Painful pressure on the bladder</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Pain or burning when urinating</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Difficult to start urination</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Bloody urine</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Subject: other signs</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Becoming increasingly tired, extreme exhaustion</td>
<td>13</td>
<td>1</td>
</tr>
</tbody>
</table>

Continued
Behrman, 1981; Mahmood et al., 1991; Forman et al., 1993; Chapron et al., 2005; Ballard et al., 2008; Nnoaham et al., 2009) including our own previous studies (Fauconnier and Chapron, 2005). The present study proposes a novel approach to explore the first-person viewpoint of the patients with the aim to obtain a fully-comprehensive description of the painful symptoms of endometriosis as a whole in a subjective, phenomenological perspective. The strength of our study lies in the fact that we have endeavoured to apply strict methodological standards (Food and Drug Administration (FDA), 2009): qualitative interview schedule, interview transcripts, themes derived from the transcripts and cognitive interview to evaluate patient understanding. Colaizzi’s method was chosen because it is based on a phenomenological approach, i.e. on the progressive emergence of the patient’s subjectivity through an open interview (Colaizzi, 1978). By contrast to most methods used in sociologic or anthropologic studies, this approach is free of theoretical preconceptions and is therefore particularly well suited to medical situations. Furthermore, a particular feature of our study lies in the fact that we chose to apply the same methodology to clinicians expert in the field of endometriosis.

There are nonetheless several limitations to our study. First of all, interviews were not performed by the psychologist but by the physicians who saw the patients. There is accordingly a risk that the clinicians may have influenced the patients during the interview. Nonetheless, in the interview procedure the patients were asked at the beginning of the consultation (and before any specific questioning) to document freely and comprehensively their painful symptoms associated with the disease (or perceived as such). Interviews did not include any grid question. This method helped to reveal symptoms as perceived by the patient. Furthermore the entire interview was recorded and then transcribed anonymously and the recordings were analysed remotely by a psychologist not involved in the patients’ medical care.

Secondly, because of the qualitative design of the study used during the identification of the main themes from the interviews, it was not possible to infer that the symptoms were unique to endometriosis. As most of the patients in the study had already had treatment for endometriosis, including ongoing hormonal treatment, there is accordingly a great risk that some of the emergent symptoms may relate to those treatments (Denny, 2004). Another problem lies in the fact that we did not perform any specific investigation to eliminate additional causes of functional pelvic pain, such as irritable bowel syndrome, interstitial cystitis/bladder pain syndrome that could be associated in the selected endometriosis patients (Mirkin et al., 2007). It is nonetheless obvious that the pain symptoms are probably due to endometriosis in most cases because the patients were suffering from pain symptoms at the time of the interview and all of them later had an operation that confirmed that the pain was due to endometriosis lesions; furthermore all patients had documented specific endometriosis lesions that are very liable to cause pain symptoms, including various locations of DIE (Fauconnier and Chapron, 2005).

Thirdly, one may question whether the inclusion of a greater number of patients that would have generated greater variability in subjects, and the use of some statistics (i.e. studying correlation between the types of pain and the different locations of the lesions) would have better characterized the painful experience of endometriosis patients. However, qualitative studies using descriptive and narrative methods to characterize a given phenomenon are fundamentally different from those used to deal with prevalences, distributions or numerical differences, in which large, random, representative samples are required (Malterud, 2001). It is a general property of qualitative methods that the important themes will emerge after inclusion of a small number of patients as a consequence of a proper selection procedure (i.e. by purposeful sampling) with inclusion of patients with different disease forms and severity in order to well-represent the core of endometriosis patients (Morse, 2003). We are reassured by the fact that in the present study, most of the themes we have identified were common to a majority of the patients, and after conducting the first half of the interviews, we reached saturation while no new themes were met at this point. It is nonetheless important to point that purposeful sampling, although very informative, cannot produce results that can be generalized to the population as a whole and the conclusions presented in the present study can only be regarded as inferences.

Apart from our study, three other studies involve qualitative assessment of women’s experience of suffering from endometriosis. Unfortunately, none of them were specifically centred on patient perception and description of pain symptoms. The first study (Jones et al., 2004) was designed to explore and describe the impact of endometriosis upon quality of life and did not involve the description of the painful symptoms. The second (Denny, 2004) aimed to explore women’s experience of all aspects of a woman’s life with endometriosis and included some of the aspects of pain symptoms. The method used was rather similar to ours but involved a grid with pre-identified key areas identified by women with endometriosis who were not participants. Although limited, the description of pain symptoms agrees with our results. The third study (Ballard et al., 2006) was designed to investigate the reasons why women experience delays in the diagnosis of endometriosis, and did not involve an exhaustive description of pain symptoms.

Previous quantitative studies on the relationship between pain and endometriosis based on symptom questionnaires identified all of the
five categories and the main themes that we found in our study: severe dysmenorrhea (Cramer et al., 1986; Mahmood et al., 1991; Fedele et al., 1992; Forman, et al., 1993; Vercellini et al., 1996; Muzzi et al., 1997; Al-Badawi et al., 1999; Gruppo Italiano per lo Studio dell’Endometriosis, 2001; Chapron et al., 2003a, 2005; Lemaire, 2004); deep dyspareunia (Mahmood et al., 1991; Fedele et al., 1992; Al-Badawi et al., 1999; Porpora, et al., 1999; Lemaire, 2004; Chapron et al., 2005). Painful defecation during menses (Anaf et al., 2001; Fedele et al., 2001; Chapron et al., 2005); other gastro-intestinal symptoms (Lemaire, 2004; Maroun et al., 2009); Bladder symptoms (Lemaire, 2004; Fedele, et al., 2007). This may explain the fair overlap between the symptoms description by patient and by physician we have observed.

The in-depth descriptions of severe pelvic pain and dysmenorrhea by the clinicians were nonetheless very incomplete compared with those of patients. This suggests that this issue is not accurately perceived by the clinicians. An important point was that the patients expressed a high degree of suffering and adverse effects on daily activity or work inherent to painful symptoms. From this point of view, some items of the Biberoglu

2007). This may explain the fair overlap between the symptoms description by patient and by physician we have observed.

Another interesting point of our study is that the patients did not make any clear distinction between pelvic pain and dysmenorrhea. This distinction features in fact in most questionnaires that distinguish dysmenorrhea from non-menstrual pelvic pain or non-cyclic pain, but appears to be a construction originating with the physicians. For the women there is a continuum between dysmenorrhea and other pelvic pain. In our study, dysmenorrhea is related to cyclic recurrent micro-bleeding within the lesions and the consequent inflammation (Brosens, 1997; Fauconnier and Chapron, 2005). On the other hand, chronic pelvic pain may be due to involvement of glandular lesions in fibrotic lesions with nerve impairment (Cornillie et al., 1990; Brosens et al., 1994; Anaf et al., 2000). While both lesions are associated, these microscopic features are concordant with the pain descriptions given by our patients.

‘Painful defecation during menses’ was the most frequent gastro-intestinal symptom reported. The fact that many of our patients had DIE involving the posterior area must be taken into account here. This symptom was indeed found to be specifically related to infiltration of the vagina, retrocervical area, rectovaginal septum or anterior rectal wall by DIE (Anaf et al., 2001; Fedele, et al., 2001; Fauconnier et al., 2002). ‘Painful defecation during menses’ must thus be interpreted as a location-indicating pain symptom (Fauconnier and Chapron, 2005). It could reasonably be related to cyclic micro-haemorrhages and inflammation occurring around or inside the rectum, over and above that of rectovaginal infiltration by the nodule itself (Romań et al., 2011). We found nonetheless frequent other gastro-intestinal symptoms whatever the location of endometriosis. Indeed systematic exploration of gastrointestinal symptoms in samples of women with endometriosis also found ‘irritative’ symptoms including diarrhoea, constipation, bloating, nausea or vomiting that were nearly as common as gynaecological symptoms in women with endometriosis (Lemaire, 2004; Maroun et al., 2009). These symptoms do not necessarily reflect bowel involvement (Maroun et al., 2009; Romań et al., 2011).

A similar phenomenon is likely for bladder symptoms in endometriosis. In case of bladder or anterior involvement these symptoms may obviously be interpreted as location-indicating pain symptoms as demonstrated in previous studies (Fauconnier and Chapron, 2005; Fedele et al., 2007). However, since we found these symptoms could be present even in patients without any bladder location, it is likely that other mechanisms may explain the bladder symptoms. It is important to point out that the three frequent most bladder symptoms we identified in this study matched exactly those of women with interstitial cystitis/bladder pain syndrome as defined by the ICS (Warren et al., 2006). The frequent association of pelvic gynaecologic pain with non-specific bladder or digestive symptoms suggests that the mechanism of pain symptoms may be related to some degree of interrelation between endometriosis implants and the peripheral or central nervous systems, as observed in rat models (Berkley et al., 2005). It has been demonstrated in animal studies on interstitial cystitis/bladder pain syndrome that chronic pelvic pain syndrome and irritable bowel syndrome indicate organ cross-talk in pelvic pain and modulation of pain responses by visceral inputs distinct from the inflamed site (Pezzone et al., 2005; Rudick et al., 2007). Cross sensitization was also found in the rat model of endometriosis (Berkley et al., 2005).

Another important source of variability in pain experience is that patients with identical gynaecological lesions clearly do not report the same aspects of pain related to endometriosis. The importance of the central processing of painful stimuli has been demonstrated in many chronic pain conditions (Aplarian et al., 2005). Since the CNS has a great deal of plasticity, the pain mechanisms related to endometriosis, as in other pain conditions, likely include central hormonal modulation, central sensitization and remote central sensitization (Stratton and Berkley, 2011).

Our results may have important implications for clinical or research practice. It has been emphasized that the pain associated with endometriosis bears little relationship to the type or location of the laparoscopically visible lesions (Hsu et al., 2011). Our results strongly suggest that there are several distinct mechanisms explaining the pain related to endometriosis, which could explain the important variability in perception and also in description and interpretations of the same pain experience by the patients. This could help to explain the difficulties encountered for building efficient symptom questionnaires. The wording of the questions is important and ambiguities can alter the diagnostic value of the items, as well as induce non-recognition of the relationship between endometriosis and lesions. The discordance between clinicians and patients might also reflect this kind of problem with the wording of the items. In future, if the goal is to properly understand the pain experienced by women with endometriosis, we conclude that assessment tools using the words and phrases used in narratives of pain would potentially be very useful (Grace and MacBride-Stewart, 2007). Future questionnaires should favour the pain descriptors used by patients rather than those used by physicians so that reliable questions are formulated.

Providing new insights into the painful experience of endometriosis by the patients and pointing out the difference of perceptions between the physicians and the patients might help in the future, to improve the assessment of symptoms in women with endometriosis. Qualitative research has become a standard for the development of disease-specific
questionnaires which aim to measure the subjective experience of health, for example, Polycystic Ovary Syndrome Questionnaire (Cronin et al., 1998) or the Endometriosis Health Profile (EHP-5) (Jones et al., 2004). Indeed the choice to use open interviews instead of the use of questionnaires, in which all the questions are predetermined and most answers are fixed choices, allows subjects to describe their personal experiences in their own words (Malterud, 2001), which is useful to generate reliable questionnaire items. Furthermore, as the present study provides a description of the painful experience of endometriosis as a whole and not location by location, an important application of the present study would be to develop screening questionnaires to help identifying patients with endometriosis in primary care.

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