

## What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis

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**Objective:** To investigate the reasons women experience delays in the diagnosis of endometriosis and the impact of this.

**Design:** A qualitative interview-based study of 32 women, 28 of whom were subsequently diagnosed with endometriosis.

**Setting:** Southeast England.

**Patient(s):** Women attending a pelvic pain clinic.

**Intervention(s):** Semistructured interviews.

**Main Outcome Measure(s):** Women's reported experiences of being diagnosed with endometriosis.

**Result(s):** Delays in the diagnosis of endometriosis occur at an individual patient level and a medical level, as both women and family doctors normalize symptoms, symptoms are suppressed through hormones, and nondiscriminatory investigations are relied upon. Women benefited from a diagnosis, because it provided a language in which to discuss their condition, offered possible management strategies to control symptoms, and provided reassurance that symptoms were not due to cancer. Diagnosis also sanctioned women's access to social support and legitimized absences from social and work obligations.

**Conclusion(s):** Although recent guidelines for the management of chronic pelvic pain suggest that diagnostic laparoscopy may be considered a secondary investigation after the failure of therapeutic interventions, the present study highlights the importance of an early diagnosis for women who suffer at physical, emotional, and social levels when they remain undiagnosed. (*Fertil Steril*® 2006;86:1296–301. ©2006 by American Society for Reproductive Medicine.)

**Key Words:** Endometriosis, diagnosis, delayed diagnosis, qualitative study

Epidemiologic studies reveal a high community prevalence of chronic pelvic pain in women of reproductive age, with reported rates of 14.7% in the U.S. (1), 24% in the U.K. (2), and 25.4% in New Zealand (3). Common gynecologic causes include endometriosis, pelvic congestion syndrome, and pelvic inflammatory disease. Epidemiologic studies indicate that the prevalence of endometriosis in women of reproductive age is around 10% (4), suggesting that almost half of women with chronic pelvic pain may be diagnosed as having endometriosis.

Endometriosis is the presence of endometrial glands and stroma outside the uterine cavity, the pathogenesis of which is disputed (5, 6). Symptoms vary but are typically dysmenorrhoea, pelvic pain unrelated to the menstrual cycle, deep dyspareunia, dyschezia, and dysuria. Subfertility is also commonly associated with endometriosis. For many women,

the pain may be so severe that they are bedridden for an average of 18 days per year (7), with symptoms often worsening over time (8). Indeed, the chronic nature and severity of endometriosis pain often leads to considerable deterioration in quality of life (9–11) and high psychological morbidity (12).

A confirmed diagnosis of endometriosis is generally made at surgery. There is, however, a significant delay in diagnosis that averages 11.7 years in the U.S., 8 years in the U.K. (13), and 6.7 years in Norway (14). Moreover, the delay in diagnosis has been shown to be greater for women reporting with pelvic pain compared with those reporting with infertility (15, 16), suggesting that there is greater laxity surrounding pelvic pain symptoms.

The diagnostic delay of endometriosis in the U.S. appears to be declining, with reports of a 9.2-year delay between 1979 and 1984, compared with 4.6 years between 1990 and 1995 (15). In the U.K., however, a rise in diagnostic delay may follow the recently published Royal College of Obstetricians and Gynaecology guidelines "The Initial Management of Chronic Pelvic Pain" (17), which suggest diagnostic

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laparoscopy for pelvic pain as a second-line investigation in the event of failed therapeutic intervention. To date, little is known about the reasons surrounding diagnostic delays in chronic pelvic pain and the impact that this has on women's experiences of endometriosis.

The present study investigates possible reasons for a delayed diagnosis of endometriosis and examines the impact that this has on women's experiences of the condition.

## METHODS

This is a qualitative study using in-depth face-to-face interviews. Following approval by the local Research Ethics and Research Governance Committees (approval number PORO 5-02), 32 women referred to a hospital pelvic pain clinic from May 2004 to April 2005, with either a suspected or confirmed diagnosis of endometriosis, were recruited.

Data were collected using semistructured interviews with individual women, 26 of which were carried out in the woman's home, 4 in a local community hospital, and 2 in a university. A topic guide (Fig. 1) was used to provide structure to the interview, although respondents were encouraged to talk freely about issues they deemed important. All interviews were carried out by K.B. and were tape recorded and transcribed verbatim. The topic guide was revised and refined throughout the initial stages of the interviewing process

to accommodate emerging themes following discussions with both diagnosed and undiagnosed women. Interviews lasted from 60 to 120 minutes.

At interview, women consented to K.B. accessing their medical notes to obtain information about their consultation and subsequent interventions. From this information, 28 (87%) women were confirmed as having endometriosis, and their data were included in the analysis.

Data were coded and analyzed using a thematic approach where the experiences and beliefs that women expressed were interpreted for key themes relating to meaning. Each transcript was read and a total of 28 codes assigned to sections of the text. The coding frame was developed using the first four interview transcripts and then used to apply codes to remaining transcripts. Data relating to each of the codes were then read several times, looking for similarities and differences in women's views and experiences, with particular reference to the impact of a diagnosis. The relationship between codes was then assessed before key concepts were developed. Finally, the full interviews were considered to determine the consistency of the key concepts.

Development of the coding frame and the initial analysis was carried out by K.B., a social scientist. The findings were then discussed with J.W., a consultant gynecologist and specialist in pelvic pain, and K.L., a social scientist. Based on these discussions, the analysis was further refined.

## RESULTS

The women were aged between 16 and 47 years (median 32 years, interquartile range (IQR) 28–36 years) and had experienced pelvic pain for a median of 15 years (IQR 8–19.5 years). All but one woman reported a minimum of 2 years' diagnostic delay of endometriosis, with just under half of the sample (46%) experiencing symptoms for over 10 years before diagnosis (see Table 1). The speed of diagnosis for five women was precipitated by the rapid onset of incapacitating symptoms; two of these required emergency surgery (Table 1). Diagnostic delays occurred at both an individual patient and a medical level.

### Delaying the Diagnosis at an Individual Patient Level

A delayed diagnosis appeared to be influenced by the women's inability to make clear distinctions between "normal" and "abnormal" menstrual experiences. Having had "difficult periods" from menarche, the women tended to consider their experiences as normal. Although they recognized their periods as problematic and often disruptive to their life, they perceived this as an extreme of normality, considering themselves to be "unlucky" rather than ill (Fig. 2). This "bad luck" was occasionally seen as familial, with women who were aware of their mother's similar symptoms tending to delay seeking medical help.

Very early experiences of pain were rarely disclosed to friends or family members. This was partly due to embar-

**FIGURE 1**

### Interview topic guide.

#### *Regarding initial illness experiences:*

- Can you tell me what happened when you first started experiencing symptoms
- Can you describe your symptoms (use prompts to get clear descriptions of symptoms over time)

#### *Regarding response to symptoms:*

- How did/do you deal with your symptoms?
- Did your symptoms stop you from doing anything – at school, at work, or at home?
- How have your friends/family/work reacted to your experiencing symptoms?
- Do you have any worries about your condition?

#### *Regarding medical consultation and gaining a diagnosis*

- What prompted you to go to the doctor in the end?
- What did you tell the doctor?
- What happened when you went to the doctor?
- What treatments/investigations did/are you have/having? What did/do you think they were/are looking for?
- How did you feel about your consultation with the doctor?
- Women who were undiagnosed with their pelvic pain at the time of interview were asked what they thought might be wrong with them.
- Women with a diagnosis of endometriosis were asked how they felt when they were diagnosed.

#### *Regarding future impact of symptoms:*

- How do you manage your symptoms now?
- Have your symptoms/illness experience altered the way you see yourself?
- How do you see your future with this condition?

#### *In summary:*

- What has been the least helpful aspect of your illness experience?
- What has been the most helpful aspect of your illness experience?

Ballard. *Delayed diagnosis of endometriosis. Fertil Steril* 2006.

**TABLE 1****Delays in the diagnosis of endometriosis (n = 28).**

	Range (months)	Median (months)	Inter-quartile range (months)
Total length of time with symptoms	24–408	180	96–234
Total diagnostic delay	12–324	102	48–207
Length of time before seeking medical help	0–84	18	6–48
Length of time from consultation in primary care to referral to secondary care	1–264	36	21–105
Length of time from referral to secondary care to diagnosis	0–84	9	0–12

*Ballard. Delayed diagnosis of endometriosis. Fertil Steril 2006.*

rassment but also because women did not want to appear weak and unable to cope with what they thought were normal, albeit painful, periods. In turn, the tendency to avoid disclosure meant that women lacked any comparative evidence from other women to indicate that symptoms warranted medical intervention. Preferring to accommodate rather than disclose their pain, women developed strategies for coping on their own, often withdrawing from social activities, spending time in bed, and at times taking potentially harmful levels of analgesia.

**Delaying the Diagnosis at a Medical Level**

Because it is not possible to make a definitive diagnosis of endometriosis without a laparoscopy, it is unsurprising that almost all women described a medical diagnostic delay. The length of delay in referral from primary to secondary care,

however, varied from 1 month to 22 years (Table 1), with most women reporting multiple visits to their family doctor before referral to a specialist. From the data analysis, it was possible to distinguish three key factors contributing to a diagnostic delay at a medical level: 1) pain normalized by family doctors; 2) intermittent hormonal suppression of symptoms; and 3) use of nondiscriminating investigations.

**1) Pain Normalized by Family Doctors** Women often described a sense of being “dismissed” by the family doctor.

**FIGURE 2****Causes of a delayed diagnosis at the individual patient level.****i) Normalisation of symptoms**

R21: I would stay at home a couple of days each month.... But I just, you know ... just assumed I was just one of them unlucky people that got bad period pains. I never really linked it to ... well, I'd never even heard of endometriosis before. So ... I just ... I lived on Nurofen while I like had a period - like every four or five hours. (Age 26; Symptoms for 4 years prior to diagnosis)

R10: I didn't think it was a problem because my mum had bad periods as well. In fact she found it worse than giving birth, so...I didn't think there was anything unusual about that at all....I didn't go to the doctor until I had the real bad pain at work and I had to go home (age 30; Sought medical help 9 years after initial symptoms).

**ii) Embarrassment and fear of being seen as unable to cope**

R8: I think I was embarrassed to talk to people about it [painful periods] at that time, you know. It wasn't the sort of thing you talk about when you're 14. I think it was like you know, I really didn't want anybody to know that I was having this problem that I thought everybody else was just fine with, and that I couldn't handle. (Age 33 years; Symptoms for 19 years prior to diagnosis)

R11: I used to get quite embarrassed about being in pain, so I'd always play it down. I didn't like the fuss and the attention so I wouldn't draw attention to it at all. If anything I'd try and act as normal as possible, or be more cheerful than I normally would just so people wouldn't guess (Age 41; undiagnosed at interview)

*Ballard. Delayed diagnosis of endometriosis. Fertil Steril 2006.*

**FIGURE 3****Delayed diagnosis at a medical level.****i) Normalisation of symptoms by Family Doctors**

R6: The doctor told me that the problem nowadays is that because women take the Pill, they don't know what a real period pain is. It's just the most dismissive, unhelpful comment ever! (Age 32; Diagnosed after 19 years of pain)

*Leading to women questioning the genuineness of their own experiences:*

R15: You know, I was thinking, I was in a very stressful job - was my job something to do with it? Am I psychologically making myself have this pain? I've just got to the point where I just don't understand it at all! I did think to myself, am I making this sort of thing happen? I mean that's how I felt eventually. I started thinking am I doing this on purpose so that I haven't got to go to work? But I don't really hate work that much that I would do that. (Age 32, diagnosed after 18 years of pain)

**ii) Intermittent suppression of symptoms with hormones**

R2: When I was 14 and I got prescribed the Pill. It was like "This'll help you, take it!" And that was that.... (Age 28; diagnosed after 5 years of pain)

R12: But I said to him [family doctor] "I don't want to be on the Pill!" because I want really to know what's the cause of the pain. I will take the Pill but I was struck by his "we don't know what's the cause". So I told him that I was not happy to have it [OCP]. He said, "You go home and think about it, and make appointment to see me the following week." .....So I carried on taking the painkillers (Age 32 years; diagnosed after 3 years of pain).

**iii) Non-discriminatory diagnostic investigations**

R20: It was awful just going for these flipping internals all the time and being told there's nothing there. To actually keep going backwards and forwards and having it, and then there's nothing showing up. And when I've then mentioned about having the ... is it the laparoscopy - having that done, they're "Well, no, it won't be done because there's nothing showing up on these [ultrasound]" (Age 28; 6 years of pain prior to diagnosis)

R27: And so I kept going to my doctor [family doctor] and asking whether it could be endometriosis .....because the signs were similar to my mum's. And I kept being told "no, it's not that, no can't be that". Then they sent me for a scan, which didn't show anything - a few irrelevant cysts, they said.....So it was 10 years of me going back and forth to my [family] doctor before they eventually made a diagnosis (Age 31; 10 years of pain prior to a diagnosis)

*Ballard. Delayed diagnosis of endometriosis. Fertil Steril 2006.*

Indeed, when asked to identify the least helpful aspects of their treatment of pelvic pain, the majority of women cited their perception of doctors' disbelief surrounding the genuineness or severity of their symptoms. Many recalled being told by the family doctor that because their pains were "just normal period pains" this was something they had to cope with (Fig. 3). They reported being advised to make lifestyle changes, such as increasing exercise levels, and being prescribed nonsteroidal antiinflammatory medication and analgesia. The impact of this advice, when considered alongside the women's lack of knowledge about "normal period pain," led many to question their experiences of symptoms, with the majority stating that at some point they had felt that they were "going mad" or that the "pain was in my head" (Fig. 3). If not tried already, the family doctor usually advised the oral contraceptive pill to "regulate" or "control" their periods.

**2) Intermittent Hormonal Suppression of Symptoms** Most women obtained episodes of symptom relief through the use of oral contraceptive drugs or during pregnancy, and ceased to seek further medical help at that point. All but two women reported being prescribed the oral contraceptive pill (OCP) specifically for symptom relief, which appeared to be fairly effective, for some time at least, in relieving pain and menorrhagia. However, owing to fertility choice, side effects associated with the OCP, or worsening pain, further medical advice and treatment was sought and different hormonal therapies prescribed. At this stage, however, women continued to be treated for "painful periods." Although they appeared generally compliant with this treatment, ultimately women continued to seek a cause for their symptoms (Fig. 3).

Having presented in primary care with persistent pelvic pain unresponsive to medical treatment, many women were referred for ultrasound investigation to exclude pelvic pathology. For the majority, however, the ultrasound report was negative.

**3) Use of Nondiscriminatory Investigations** Although transvaginal ultrasound has a high specificity and sensitivity for ovarian endometriosis (endometriomas) (18), it is a poor measure of nonovarian pelvic endometriosis, particularly of the uterosacral ligaments, vagina, and rectovaginal septum (19), and is not a good discriminator in pelvic pain (20). It is recommended, therefore, that transvaginal ultrasound is used only for the diagnosis of adnexal masses (17). All but three of the women interviewed, however, were referred for a diagnostic transvaginal ultrasound, some having two or three repeated tests. Only one woman, with a large endometrioma, received a positive diagnosis of endometriosis from ultrasound. For the remaining women, the ultrasound result failed to diagnose endometriosis, and appeared to reassure family doctors that further investigation or treatment was unnecessary.

Moreover, the false-negative result raised further doubt surrounding the genuineness of symptoms among doctors and the women's social groups (Fig. 3).

## Impact of a Diagnosis of Endometriosis

At the time of interview 17 women (61%) had previously been diagnosed with endometriosis, and the remaining 11 (39%) were diagnosed with endometriosis after interview. Drawing on these different diagnostic stages we now consider the impact of receiving a diagnosis.

With the exception of one woman, all study participants spoke positively about either the prospect of finding out or the reality of being informed of the cause of their symptoms. Negative impact of a diagnosis was expressed by a woman who, over the 7 years since being diagnosed, had undergone five surgical treatments of her endometriosis with little subsequent improvement in her quality of life. For the remainder, a diagnosis brought relief through providing a language to talk about symptoms, which in turn sanctioned access to social support and the potential for appropriate treatment strategies. Further relief arose from finding that they did not have a more sinister problem, such as cancer (Fig. 4).

Before diagnosis of endometriosis, women spoke about their difficulty in explaining what was wrong with them to others. This created problems at work, where employers were sometimes unsympathetic to absences, and within social environments, where women also had role obligations. Having a medical label, therefore, confirmed the genuineness of the symptoms and legitimized the women's inability to perform to their full capacity, providing the sanction required for social support (Fig. 4). In contrast, women who were undiagnosed at the time of interview spoke about difficulties explaining their absences from social and work engagements (Fig. 5).

Following diagnosis, women were offered hope for appropriate treatment, providing a sense of control over their

**FIGURE 4**

### Benefits of being diagnosed.

**i) Relief from social and work responsibilities**

R22: I mean ...basically over the last few years, people know that whenever they ask us to come out somewhere, and like if I say, "Oh yes, I will do whatever ..." you know, accept invitations or whatever, it's always subject to ... my feeling ok with my pain.....when you're more aware of what it is that you've got wrong with you, you can kind of like put a cap on it and deal with it (Age 32; diagnosed with endometriosis 7 years ago)

**ii) Provides a language to discuss the problem**

R8: it's only been the last maybe 2 or 3 years, since I was diagnosed, that I've suddenly come to this realisation that I can't do it by myself you know .....It's easier to accept this because you've got a hook to hang it on, and if people kind of say, "well what is wrong with you" – how do you answer that if you don't know? ...I feel better knowing what it is, even though it's not a particularly nice diagnosis to have, at least I can understand it, and it makes it just much easier to say to people "well I think my endometriosis has flared up" (Age 33 years; Symptoms for 19 years prior to diagnosis)

**iii) Provides a sense of control over symptoms**

R7 I'll never let it get to the pain that it was before. Now I know what I've got and you can have treatment...I'm quite positive about it; I'll just have laser treatment. Sod it, if I have to go in every other year, I'll do it; it doesn't bother me, I'm quite happy to go in and do it. If it stops the pain, then you know I'll have laser treatment every other year (Age 25; Diagnosed 4 years ago)

**iv) Relief that symptoms were not due to cancer**

R19: Because you don't understand the things that are happening to you, you do think dreadful things. And because my mum died of cancer and because her parents died of cancer, I thought I was dying with cancer; I thought I had something dreadful and, erm, it was quite reassuring really [to be told it was endometriosis!] (little laugh) (Age 36; diagnosed with endometriosis 15 years ago)

*Ballard. Delayed diagnosis of endometriosis. Fertil Steril 2006.*



**Reactions of women without a diagnosis.**

**i) Sense that others disbelieve them:**

R24: But you get sick of telling people that you're not well but not knowing why. You know, like when I phone up at work. I say, "I'm really sorry, but it's bad again"...normally you only come on once a month and this [pain] happens like twice a month - and you just think ... you know, I'm sure they don't believe me half the time. But if they want to sack me, they can sack me at the end of the day. That's the way I feel, I just ... you know. I've got to the stage now where I don't really care now (Age 28; undiagnosed at interview)

R3: They [friends] kind of know it's periods but when I tell them period pain, they think a little bit of pain and she shouldn't be having time off with that. But it's kind of worse than that, so ... and I don't tell them it's period pain anymore, I tell them it's stomach pain (Age 16 years; undiagnosed at interview)

**ii) Feel uncertain about the future:**

R1: I was meant to go to Uni [University] in September, but I'm going to have a year out because there's no way I could do this as well as university. Then I was meant to go travelling but I thought I can't go travelling in pain, so, em, I'm just putting my life on hold really until it gets sorted out (Age 18 years; undiagnosed at interview).

R20: I don't really see it being resolved as far as I've had so far. I mean having the letter from you [study invitation], I was a bit like, great, this is something I can actually talk to somebody and tell them how I'm feeling... you know, to get it across. But, every time I've been banging on doors before, it's never gone anywhere. So I just feel really that this is it, it'll just carry on like this, and I have to put up with it really (Age 28 years; undiagnosed at interview).

**iii) Fear something more sinister is wrong:**

R1: So, I just have all this big, big fear of I've got cancer and things. But I can't say that because I don't know if I have or if I haven't (Age 18; undiagnosed at interview)

R11: But waiting for 4 months for the scan, you know you're just so scared - what are they going to see? (Age 41; undiagnosed at interview)

*Ballard. Delayed diagnosis of endometriosis. Fertil Steril 2006.*

condition and a relatively long-term management strategy. For some, this involved making fertility decisions sooner than they otherwise would have done. This was in contrast to the experiences of women undiagnosed at interview, who spoke about an uncertain future with many aspects of life being put “on hold” (Figs. 4 and 5).

Almost all women expressed fear that their unexplained symptoms might be due to an ominous condition. Having persistent pain for which no obvious cause could be found led many women to question whether their symptoms were due to an early cancer that, as yet, was undetected. A diagnosis of endometriosis, therefore, brought some relief.

**DISCUSSION**

We recruited women for this study from a dedicated secondary care pelvic pain clinic. It is possible, therefore, that our sample over-represents the views of women with more severe disease, because 10 of the 28 women interviewed were tertiary referrals. The calculated delay in diagnosis, however, was from the time that symptoms were first reported until they received a diagnosis, wherever that had been made. Also of note is that all of the women in the study were expressing their experiences of being diagnosed with endometriosis within a U.K. health care system, where women must be referred to a gynecologist by a family doctor, and therefore women in other countries may have different experiences.

The present study confirms previous findings of an 8-year delayed diagnosis of endometriosis in the U.K. (13). It illustrates that delays in the diagnosis of endometriosis occur at both an individual patient and a medical level, with symptoms being normalized by both women and family doctors. Suppression of symptoms and a reliance on nondiscriminatory investigations also contribute to the diagnostic delay, the latter raising questions about the continuing use of transvaginal ultrasound to exclude nonovarian endometriosis.

The impact of a diagnostic delay was considerable. Women experienced pain for many years, they sensed a lack of understanding from others, they were fearful of what might be wrong with them, and they struggled to explain their inability to maintain work and home responsibilities. In order to reduce this suffering, it is necessary to improve both society's and the medical profession's understanding of what constitutes a “normal” menstrual experience. Such education should start before the age of menarche and would ideally be delivered through the school health education system, where attitudes towards menstruation could be discussed openly. Given the increasing evidence to support a genetic basis of endometriosis (21), it is important that parents are responsive to any abnormal menstrual problems experienced by their daughters.

Although the 2000 Royal College of Obstetricians and Gynaecologists (RCOG) guidelines (22) considered laparoscopy to be the “gold standard” diagnostic test in endometriosis, there has been a recent shift away from this view, with more recent guidelines stating that “[diagnostic laparoscopy] may be better seen as a second line of investigation if other therapeutic interventions fail” (17). As the guidelines note, diagnostic laparoscopy carries risks (23, 24) and if negative may be detrimental to women's emotional well-being (25). We have shown, however, that the time spent without a diagnosis can equally be harmful for women, and therefore any moves to extend the diagnostic delay would be a retrograde step in the clinical management of chronic pelvic pain. A possible solution would be to offer a “working diagnosis,” involving women in the evaluation of therapeutic interventions, as part of the process of reaching a diagnosis. This would provide a provisional language with which women could articulate their experiences and legitimate absence from normal social and work roles when necessary.

In conclusion, although the RCOG guidelines on the management of chronic pelvic pain emphasize the physical risks associated with diagnostic laparoscopy, we have shown that there are many factors contributing to a delayed diagnosis of endometriosis. It is important, therefore, to consider the physical, emotional, and social risks associated with the absence of diagnosis.

**REFERENCES**

1. Mathias SD, Kuppermann M, Liberman RF, Lipschutz RC, Steege JF. Chronic pelvic pain: prevalence, health-related quality of life, and economic correlates. *Obstet Gynecol* 1996;87:321-7.

2. Zondervan KT, Yudkin PL, Vessey MP, Dawes MG, Barlow DH, Kennedy SH. The community prevalence of chronic pelvic pain in women and associated illness behaviour. *Br J Gen Pract* 2001;51:541–7.
3. Grace VM, Zondervan KT. Chronic pelvic pain in New Zealand: prevalence, pain severity, diagnoses and use of the health services. *Aust N Z J Pub Health* 2004;28:4:369–75.
4. Vigano P, Parazzini F, Somigliana E, Vercellini P. Endometriosis: epidemiology and aetiological factors. *Best Pract Res Clin Obstet Gynaecol* 2004;182:177–200.
5. Redwine DB. Mulleriosis: the single best-fit model of the origin of endometriosis. *J Reprod Med* 1988;3311:915–20.
6. Garry R. The endometriosis syndromes: a clinical classification in the presence of aetiological confusion and therapeutic anarchy. *Hum Reprod* 2004;194:760–8.
7. Kjerulff KH, Erikson BA, Langenberg PW. Chronic gynaecological conditions reported by US women: findings from a national health interview survey 1984–1992. *Am J Pub Health* 1996;86:195–9.
8. Whelan E. Putting pain to paper: endometriosis and the documentation of suffering. *Health (Lond)* 2003;74:463–82.
9. Garry R, Clayton R, Hawe J. The effect of endometriosis and its radical laparoscopic excision on quality of life indicators. *BJOG* 2000;1071:44–54.
10. Wright J, Shafik A. Quality of life following excision of rectovaginal endometriosis associated with complete obliteration of the posterior cul de sac. *Gynaecol Endosc* 2001;10:107–11.
11. Abbott JA, Hawe J, Clayton RD, Garry R. The effects and effectiveness of laparoscopic excision of endometriosis: a prospective study with 2–5 year follow-up. *Hum Reprod* 2003;189:1922–7.
12. Peveler R, Edwards J, Thomas E. Psychosocial factors and chronic pelvic pain: a comparison of women with endometriosis and with unexplained pain. *J Psychosom Res* 1996;403:305–15.
13. Hadfield R, Mardon H, Barlow D, Kennedy S. Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK. *Hum Reprod* 1996;114:878–80.
14. Husby GK, Haugen RS, Moen MH. Diagnostic delay in women with pain and endometriosis. *Acta Obstet Gynecol Scand* 2003;827:649–53.
15. Dmowski WP, Lesniewicz R, Rana N, Pepping P, Noursalehi M. Changing trends in the diagnosis of endometriosis: a comparative study of women with pelvic endometriosis presenting with chronic pelvic pain or infertility. *Fertil Steril* 1997;672:238–43.
16. Arruda MS, Petta CA, Abrao MS, Benetti-Pinto CL. Time elapsed from onset of symptoms to diagnosis of endometriosis in a cohort study of Brazilian women. *Hum Reprod* 2003;184:756–9.
17. Royal College of Obstetricians and Gynaecologists. The initial management of chronic pelvic pain. Guideline number 41; London: RCOG, April 2005.
18. Moore J, Copley S, Morris J, Lindsell D, Golding S, Kennedy S. A systematic review of the accuracy of ultrasound in the diagnosis of endometriosis. *Ultrasound Obstet Gynecol* 2002;20:630–4.
19. Bazot M, Thomassin I, Hourani R, Cortez A, Darai E. Diagnostic accuracy of transvaginal sonography for deep pelvic endometriosis. *Ultrasound Obstet Gynecol* 2004;242:180–5.
20. Kuligowska E, Deeds L, Lu K. Pelvic pain: overlooked and underdiagnosed gynecologic conditions. *Radiographics* 2005;251:3–20.
21. Kennedy S, Bennett S, Weeks DE. Genetics and infertility: affected sib-pair analysis in endometriosis. *Hum Reprod* 2001;74:411–8.
22. Royal College of Obstetricians and Gynaecologists. The investigation and management of endometriosis. Guideline number 24; London: RCOG, July 2000.
23. Jansen FW, Kapiteyn K, Trimbos-Kemper T, Hermans J, Trimbos JB. Complications of laparoscopy: a prospective multicentre observational study. *BJOG* 1997;1045:595–600.
24. Chapron C, Querleu D, Bruhat M, Madelenat P, Fernandez H, Pierre F, et al. Surgical complications of diagnostic and operative gynaecological laparoscopy: a series of 29,966 cases. *Hum Reprod* 1998;13:867–72.
25. Moore J, Ziebland S, Kennedy S. “People sometimes react funny if they’re not told enough”; women’s views about the risks of diagnostic laparoscopy. *Health Expectat* 2002;5:302–9.