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# Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK

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**We investigated the length of time between the onset of pain symptoms and the surgical diagnosis of endometriosis in women from the UK and the USA. A total of 218 women with surgically confirmed disease, recruited through endometriosis self-help groups, completed a postal questionnaire. The mean ± SD delay in diagnosis for women from the USA was 11.73 ± 9.05 years, significantly higher than the equivalent delay of 7.96 ± 7.92 years for women from the UK ($P < 0.01$). The stage of disease did not affect the length of time between the onset of symptoms and diagnosis. Therefore there is considerable delay in the diagnosis of endometriosis for women from both the UK and the USA. Efforts to reduce this delay are required to minimize the suffering of women with this disease.**

*Key words:* diagnosis/endometriosis

## Introduction

Endometriosis self-help groups have, in two unpublished reports, highlighted the problem of the delay that endometriosis sufferers experience before the disease is diagnosed. In a 1993 survey of 2102 members of the National Endometriosis Society of Great Britain, the average delay between the onset of pain symptoms and a diagnosis of endometriosis was 6.8 years. A similar delay of 6.1 years was found in a survey of 748 women by the Australian Endometriosis Association. The Australian data showed a mean delay in reporting symptoms to a doctor of 1.7 years and a mean delay between the first report to a doctor and an eventual diagnosis of 4.4 years. The patient's age when symptoms were first reported to a doctor was related to the delay in diagnosis experienced. Thus, the average delay in diagnosis was 8.3 years for women aged 15–19 years and 1.3 years for those aged between 30 and 34 years.

Women with endometriosis contend that they are adversely affected by a delay in making the diagnosis. They believe the disease becomes progressively more severe and therefore more difficult to treat the longer it is left undiagnosed. They also believe that their general health is affected unnecessarily by such a delay (Kennedy, 1991).

Here, we present data from a postal survey of women from the UK and the USA with surgically confirmed endometriosis, investigating the relationship between the onset of pain symptoms and the time of diagnosis.

## Materials and methods

Women with endometriosis were recruited for a genetic linkage analysis by advertising in the newsletters of the American Endometriosis Association and the National Endometriosis Society of Great Britain. Women were also identified from the records of the John Radcliffe Hospital, Oxford, UK. The women completed a postal questionnaire which asked for details about their gynaecological care and the age at which they first experienced pain symptoms. Women were excluded from the study if the operative record was not obtained or if the diagnosis was uncertain; a histological confirmation of endometriosis was also obtained if available. The severity of the disease was assessed on the basis of the operative findings using the revised American Fertility Society (AFS) classification system (AFS, 1985), and the women were divided into two groups: stage I–II (AFS minimal–mild disease) and stage III–IV (AFS moderate–severe disease). The clinical details of some of the patients have been published previously (Kennedy *et al.*, 1995, 1996). The study had the approval of the Central Oxford Research Ethics Committee.

A statistical analysis was performed using a two-tailed *t*-test, unless otherwise stated, and significance was taken as $P < 0.05$.

## Results

Questionnaires were sent out to 337 women; 270 (80%) were returned. Endometriosis was confirmed in 218 (81%) of those who responded (UK, 134; USA, 84); the remaining 52 women were excluded from the study. The method of recruitment was through advertisements in the newsletters of endometriosis associations for 212 women (97%) and through the records of the John Radcliffe Hospital, Oxford, UK for six women (3%). The mean ± SD age at the onset of pain symptoms was 22.39 ± 8.88 years (range 10–46), and that at diagnosis was 31.80 ± 8.22 years (range 16–69); the mean ± SD delay in diagnosis was 9.41 ± 8.55 years (range 0–44). A total of 75 women had stage I–II (UK, 48; USA, 27) and 143 women had stage III–IV disease (UK, 86; USA, 57).

### *Comparison of disease severity with delay in diagnosis*

There was no significant difference in the mean delay in diagnosis between women with stage I–II and stage III–IV disease ($t = 0.703$). Similarly, no significant difference was found between the mean age at the onset of symptoms and the mean age at the time of diagnosis for the two disease severity groups ($t = 1.12$ and 1.79 respectively). These data are shown in Table I.

**Table I.** Stage of disease and its relationship to delay in the diagnosis of endometriosis [stage I–II = revised American Fertility Society (AFS) minimal–mild disease, and stage III–IV = revised AFS moderate–severe disease]. Values are means ± SD.

| | Stage I–II ($n$ = 75) | Stage III–IV ($n$ = 143) |
|---|---|---|
| Mean age at symptom onset (years) | 21.49 ± 8.28 | 22.86 ± 9.17 |
| Mean age at diagnosis (years) | 30.35 ± 9.19 | 32.57 ± 7.59 |
| Mean delay in diagnosis (years) | 8.85 ± 8.59 | 9.71 ± 8.55 |

### *Operative procedures*

A total of 223 laparoscopies, 91 laparotomies and 72 hysterectomies had been performed in the study population. The mean number of laparoscopies performed per patient was 1.46 ± 0.83 (range = 0–6). The mean number of laparotomies performed per patient was 1.20 ± 0.43 (range = 0–3).

### *Comparison of UK with USA cohorts*

The mean ± SD age at the onset of symptoms was 24.40 ± 8.58 years (range 10–46) for women from the UK and 19.19 ± 8.44 years (range 10–46) for women from the USA, a difference that was statistically significant ($t$ = 5.01, $P$ < 0.01). The mean age at diagnosis was 32.56 ± 7.99 years (range 16–50) for women from the UK and 30.92 ± 8.56 years (range 16–69) for women from the USA, a difference that was not significant ($t$ = 1.41).

The mean ± SD delay between the onset of symptoms and the diagnosis of endometriosis was 7.96 ± 7.92 years (range 0–33) for women from the UK and 11.73 ± 9.05 years (range 0–44) for women from the USA, a difference that was statistically significant ($t$ = 3.24, $P$ < 0.01). There was a steady increase in the delay in relation to the age at diagnosis (Table II), but a significant difference between the UK and USA women was only found in the 21–30 years age group ($t$ = 3.732, $P$ < 0.01). A delay in diagnosis of ⩾5 years was reported by 74 women (55%) from the UK and 61 women (73%) from the USA (Table III). This difference was not statistically significant.

The mean ± SD numbers (range) of laparoscopies performed per patient in the UK and USA groups were 1.31 ± 0.64 (0–4) and 1.69 ± 1.04 (0–6) respectively. The mean numbers (range) of laparotomies performed per patient in the UK and USA groups were 1.13 ± 0.33 (0–2) and 1.32 ± 0.55 (0–3) respectively. There were significantly more laparoscopies ($t$ = 3.01, $P$ < 0.01) and laparotomies ($t$ = 2.85, $P$ < 0.01) performed per patient in the USA group compared with the UK group.

## Discussion

This is the first study to investigate the time difference between the onset of pain symptoms and diagnosis in a group of women with endometriosis. We have confirmed the findings of unpublished surveys amongst the members of endometriosis self-help groups in Australia and the UK, which showed a symptom onset to diagnosis delay of 6–7 years. We only included women with surgically confirmed endometriosis,

**Table II.** Delay in the diagnosis of endometriosis and the relationship with age at diagnosis. Values are means ± SD. NS = not significant.

| Age at diagnosis (years) | Average delay in diagnosis (years) | | | | $t$-value | $P$ |
|---|---|---|---|---|---|---|
| | UK | | USA | | | |
| | $n$ | Mean ± SD | $n$ | Mean ± SD | | |
| ⩽20 | 6 | 4.83 ± 3.37 | 8 | 4.38 ± 2.39 | 0.279 | NS |
| 21–30 | 59 | 5.46 ± 5.05 | 36 | 9.64 ± 5.44 | 3.732 | <0.01 |
| 31–40 | 43 | 8.56 ± 7.78 | 30 | 12.33 ± 9.12 | 1.844 | NS |
| 41–50 | 26 | 13.38 ± 11.06 | 8 | 23.00 ± 9.29 | 0.621 | NS |
| >50 | 0 | 0 | 2 | 24.50 ± 27.58 | – | – |

**Table III.** Number of women from the USA and the UK with a delay in diagnosis of endometriosis, divided into groups depending on the length of delay. Values in parentheses are percentages.

| Delay in diagnosis (years) | UK | USA |
|---|---|---|
| <5 | 60 (45) | 23 (27) |
| ⩾5 | 74 (55) | 61 (73) |
| ⩾10 | 53 (40) | 48 (57) |
| ⩾20 | 14 (10) | 15 (18) |

which is important because documented proof of the disease was unobtainable in approximately 20% of the women in our study who were members of a self-help group.

The considerable delay from the time of the initial occurrence of pain symptoms to the diagnosis of endometriosis was reported by women from both the USA and the UK, but the mean delay in diagnosis was significantly greater for the American women; this may be in part because women in the USA reported their symptoms to commence ~5 years earlier. We have no explanation as to why the age at onset of endometriosis in the American women was significantly lower than that in women from the UK.

There are a number of factors that could have contributed to the apparent delay in making a diagnosis. First, there may be bias inherent in the methods used to recruit subjects for our study. Most of the subjects were recruited through endometriosis self-help groups, and women who belong to these groups may be more likely to have had bad experiences with the medical profession. In addition, women who made the effort to respond to an advertisement and subsequently complete a questionnaire may also be more likely to have had bad experiences. Women may also have a poor recollection of the precise date of the onset of their symptoms, and there may be different recollection of the symptoms between women in the UK and the USA.

We assume that many women do not report their symptoms to a medical practitioner immediately, which contributes to the delay in diagnosis. Once the symptoms have been reported, the medical practitioner may have difficulty in distinguishing between other causes of pelvic pain such as pelvic inflammatory disease and irritable bowel syndrome, especially if obvious clinical signs of endometriosis are absent. Empirical treatments such as the combined oral contraceptive or non-steroidal anti-inflammatory drugs may be used instead of obtaining a

definitive diagnosis, in view of the cost and morbidity related to laparoscopy. Accessibility to health care is yet another factor which could affect the delay in diagnosis and could account for the longer delay in diagnosis observed for American women. Differences between the health care systems in the UK and USA may also explain why women from the USA underwent significantly more laparoscopies and laparotomies than the cohort from the UK.

The fact that there was no difference in the delay in diagnosis between the two disease severity groups is not surprising because a strong relationship between pain symptoms and the severity of endometriosis does not exist (Mahmood *et al.*, 1991).

The delay in diagnosis for endometriosis is considerably longer than that for other chronic diseases such as rheumatoid arthritis. Chan *et al.* (1994) observed a median delay to diagnosis for rheumatoid arthritis of 36 weeks. In comparison, the median delay to diagnosis for endometriosis in this study was 7.5 years. It is likely that the long delay between symptom onset and diagnosis decreases women's ability to cope with symptoms related to endometriosis. These findings support the comments of Mary Lou Ballweg, President of the Endometriosis Association: '... we simply are not diagnosing this disease close to the time of onset'.

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