# Management of endometriosis in general practice: the pathway to diagnosis

*Zoë Pugsley and Karen Ballard*


## ABSTRACT

### Background

The prevalence of endometriosis is estimated to be around 10%. Diagnosis is through visualisation of the lesions, mostly via laparoscopy. Studies reveal that there is an average delay in the diagnosis of endometriosis of between 8 and 12 years. Little is known about the reasons for delays in diagnosis women's experiences of primary care prior to diagnosis.

### Aim

To investigate women's experiences of endometriosis from first presentation to diagnosis.

### Design of study

Retrospective analysis of data collected from primary care records in four general practices.

### Setting

General practice in south-east England.

### Method

Women with a Read Code diagnosis of endometriosis were recruited to the study. Details of consultations, investigations, and referrals related to endometriosis were recorded from the notes. Data were analysed using descriptive statistics.

### Results

The prevalence of endometriosis in women aged over 16 years was 1.44%. A third of women had consulted their GP six or more times before being diagnosed. Ultrasound was frequently requested by GPs, but was helpful in diagnosing endometriosis in only 10.6% of women who underwent a scan. Thirty-nine per cent of women were referred to gynaecologists two or more times before a positive diagnosis was made. The median time from first presentation with symptoms to diagnosis was 9.0 years (interquartile range = 4.5–13.5 years).

### Conclusion

Repeated consultations and negative investigations contribute to a median delay of 9.0 years before diagnosis of endometriosis. Further research into GPs' interpretation of symptoms and patients' experiences of negative investigations and consultations may lead to a more positive outcome for women with this condition.



### Keywords

diagnosis; endometriosis; family practice; gynaecology.


## INTRODUCTION

Epidemiological studies show a high community prevalence of chronic pelvic pain in women of reproductive age, with reported rates of 15% in the US,[1] 24% in the UK,[2] and 25% in New Zealand.[3] Possible gynaecological causes include endometriosis, pelvic congestion syndrome, and pelvic inflammatory disease.

Estimates of the frequency of endometriosis vary but epidemiological studies indicate that the prevalence of the condition in women of reproductive age is around 10%,[4] suggesting that almost half of women with chronic pelvic pain may have endometriosis.

Endometriosis is the presence of endometrial glands and stroma outside the uterine cavity,[5] the pathogenesis of which is disputed.[6] Symptoms vary but typically include any or all of the following: dysmenorrhoea, pelvic pain, deep dyspareunia, pain with defecation, pain during micturition, and subfertility.

A positive diagnosis of endometriosis is generally made by laparoscopy. For many women there is a significant delay in diagnosis, with studies showing a mean delay of 11.7 years in the US compared with an 8-year delay in the UK,[7] and a 6.7-year delay in Norway.[8]

The delay in diagnosis is greater for women reporting with pelvic pain compared with those reporting with infertility.[9,10] Little is known, about the reasons for these delays or about women's experiences prior to a diagnosis.


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## METHOD

### Practices and patients

Patients were selected from four general practices in Surrey and Hampshire (list sizes 10 000–12 000). All practices are in urban areas; Practice 3 is near a district general hospital where the local gynaecologist has a research interest in endometriosis.

A list of patients over the age of 16 years with a Read Code diagnosis of endometriosis was retrieved by a computer search at each practice. Patients were sent a letter by their GPs requesting consent for their notes to be used, along with an information sheet about the study. The search strategy was validated by carrying out a pilot search at one of the practices to identify patients with prescribed drug treatments commonly used in endometriosis and patients consulting for sub- fertility. These records were then checked to see if a diagnosis of endometriosis had been omitted from the computerised Read Code summarisation. No new case of endometriosis was highlighted by this search.

### Data collection

Medical records were read and coded for details of consultations, investigations, and referrals related to symptoms of endometriosis. Symptom data were categorised into 'primary' and 'related' symptoms, and 'other gynaecological symptoms' (Table 1) as indicated in the literature.[5,11] A code of 'sub-fertility' was also used where indicated. The terms 'pelvic pain' and 'low abdominal pain' appeared to be used interchangeably in the medical records; therefore data have been analysed for these symptoms separately, and a category of the combined symptom of pelvic pain and/or low abdominal pain was used.

If a woman was pregnant at the time of the consultations, data relating to this time period were excluded for that patient. Data were collected chronologically from each record until a definitive surgical diagnosis of endometriosis by laparoscopy or histology was made. Several of the records were coded to ensure validity and reliability of data collection.

### Analysis

SPSS for Windows was used for general descriptive statistics.

## RESULTS

A total of 17 740 women from all the practices were aged over 16 years (Figure 1). Computer searches identified 256 women as having a diagnosis of endometriosis, giving a prevalence of 1.44%. The prevalence of endometriosis varied between practices, ranging from 0.7% (Practice 4) to 2.3% (Practice 3).

Thirty-nine women were excluded from the study before consent was sought for reasons such as mental health problems and an inability to consent (Figure 1).

One hundred and eighteen (54%) women with a Read Code diagnosis of endometriosis consented to their medical records being used. Seventeen records were excluded (four sets of notes were largely incomplete and 13 records could not confirm a surgical diagnosis of endometriosis), resulting in records of 101 women used in the study (Figure 1). Mean age of responders (41.8 years) and non-responders (41.9 years) was similar.

### Presenting symptoms

Three primary symptoms of endometriosis were frequently recorded in the notes of the 101 women:

## How this fits in

Previous studies have demonstrated an average delay in the diagnosis of endometriosis of between 8 and 12 years. This study illustrates factors that may contribute to this delay, such as negative investigations. It highlights the need for greater awareness among primary care professionals of the variation in endometriosis symptomatology and the limitations of diagnostic investigations.

**Table 1. Symptoms recorded from medical notes.**

| | |
|---|---|
| Primary symptoms | Dysmenorrhoea<br>Deep dyspareunia |
| Symptoms commonly associated with endometriosis | Pelvic pain<br>Low abdominal pain (with no bowel symptoms and no vomiting) |
| Related symptoms | Low back pain not due to mechanical problems<br>Irregular bleeding<br>Abdominal pain on urination<br>Urinary symptoms not specified as with cycle (frequency, dysuria, haematuria, presumed urinary tract infection)<br>Menstrual haematuria |
| Symptoms associated with endometriosis, non-specific pelvic, and abdominal symptoms | Pain on defecation not due to haemorrhoids or anal fissure<br>Abdominal bloating<br>Bowel symptoms specified in notes as due to IBS<br>Rectal bleeding not due to haemorrhoids or anal fissure<br>Cyclical extrapelvic pain |
| Other gynaecological symptoms | Post-coital bleeding<br>Menopausal symptoms<br>Premenstrual symptoms<br>Superficial dyspareunia |

*IBS = irritable bowel syndrome.*

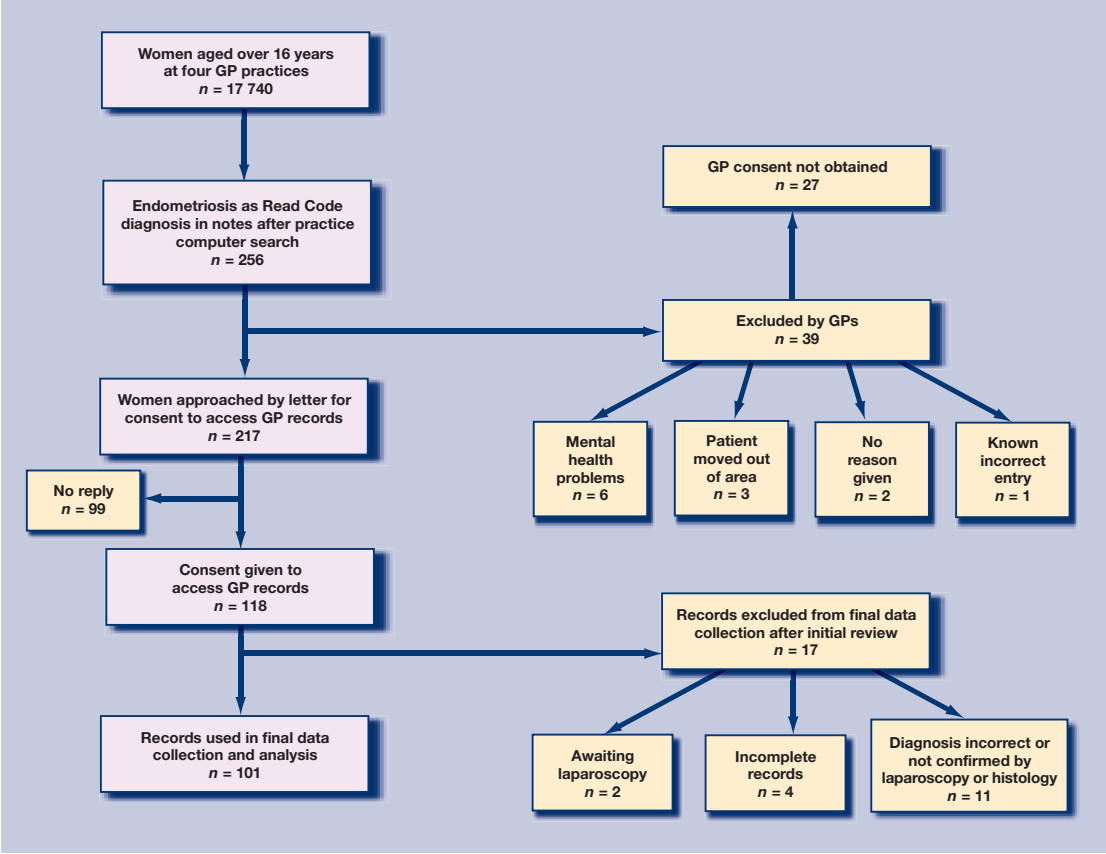



*Figure 1. Selection of records for data collection.*

dysmenorrhoea (*n* = 67), low abdominal pain (*n* = 62), and pelvic pain (*n* = 58) (Table 2). Thirty-one women were reported as having had all three symptoms, 64 had two of the three symptoms, and 92 women were reported as having at least one of these symptoms. The remaining primary symptom, deep dyspareunia, was reported by just under a third of women (*n* = 29). Almost all women (*n* = 97) consulted with at least one of the four primary symptoms.

Records show that many women also reported a range of what can be termed 'related' symptoms of endometriosis: irregular bleeding (*n* = 47), low, non-mechanical back pain (*n* = 34), and menorrhagia (*n* = 29). In addition to these endometriosis-related symptoms, women frequently consulted with symptoms of urinary tract infection (*n* = 55), which were not confirmed by pathology. Symptoms attributed to definite urinary infections were not included in the data collection. Two women presented more than 10 times with unexplained urinary symptoms (Table 2) before being diagnosed with endometriosis. One of these women was found to have widespread endometrial deposits on the bladder. Twenty women presented to GPs with subfertility and all but one of these women experienced one or more of the 'primary' endometriosis symptoms prior to their endometriosis diagnosis. Nineteen women presented with symptoms that were recorded as irritable bowel syndrome.

The level of other gynaecological complaints was relatively low, with only 19 women experiencing symptoms such as superficial dyspareunia and vaginal discharge.

### Frequency of consultation

A significant minority of women experienced multiple GP attendances for primary symptoms (Table 3). Twenty women consulted a GP five times or more with the combined symptom of pelvic pain and/or low abdominal pain; seven of these women consulted more than 10 times with this symptom.

Overall, 32 women consulted 1–2 times with one or more of the primary symptoms; 32 women consulted 3–5 times with these symptoms; and 33 consulted 6 or more times with these symptoms before diagnosis.

### Investigations

In the sample of 101 women, 60 were investigated for their symptoms before they had a positive surgical diagnosis of endometriosis. Eighteen women (30% of those investigated), had three or more investigations before diagnosis. The most common investigation was ultrasound, with a total of 63 transvaginal or abdominal scans carried out on 47

**Table 2. Presentation and referral with symptoms and median time to diagnosis.**

| | Number of women presenting with symptom | Number of women with symptom referred to secondary care | Duration from presentation of symptoms to diagnosis of endometriosis, years | |
|---|---|---|---|---|
| Symptom | *n* | *n* | Median | IQR |
| Dysmenorrhoea | 67 | 39 | 8.2 | 1.5–13.1 |
| Deep dyspareunia | 29 | 21 | 2.4 | 0.4–7.4 |
| Pelvic pain | 58 | 24 | 3.2 | 0.7–7.5 |
| Low abdominal pain | 62 | 22 | 6.9 | 2.3–10.9 |
| Pelvic pain and/or low abdominal pain | 78 | 39 | 6.8 | 2.2–11.1 |
| Subfertility | 20 | 17 | 1.5 | 0.7–6.0 |
| Back pain | 34 | 6 | 4.8 | 1.0–11.7 |
| Irregular bleeding | 47 | 17 | 8.0 | 2.6–13.5 |
| Menorrhagia | 29 | 11 | 4.3 | 1.4–10.0 |
| Other gynaecological symptoms | 19 | 6 | 5.7 | 1.3–9.3 |
| Menstrual haematuria | 3 | 0 | – | – |
| Abdominal pain on urination | 1 | 0 | – | – |
| Pain on defecation | 5 | 0 | – | – |
| Cyclical extrapelvic pain | 0 | – | – | – |
| Cyclical painful urination | 2 | 0 | – | – |
| Rectal bleeding | 4 | 0 | – | – |
| Urinary symptoms | 55 | 5 | 5.3 | 2.9–13.3 |
| Abdominal bloating | 19 | 2 | 4.5 | 1.1–7.6 |
| Irritable bowel syndrome symptoms | 19 | 2 | 4.5 | 3.0–7.9 |
| Haematuria | 1 | 0 | – | – |
| Premenstrual tension | 3 | 0 | – | – |

*IQR = interquartile range.*

women. Forty-nine scans were requested by GPs. As illustrated in Figure 2, 35 scans were reported as normal, 21 showed other abnormalities such as non-endometriotic cysts, and seven suggested a possible diagnosis of endometriosis. Three of the scans suggesting endometriosis were carried out on the same patient. Overall ultrasound correctly diagnosed endometriosis in five of the 47 women who had a scan (10.6%).

Ninety-five women were diagnosed with endometriosis on laparoscopy and six were diagnosed post hysterectomy. Eleven women had previously been investigated with a laparoscopy before having a definitive surgical diagnosis of endometriosis. One woman had two false-positive laparoscopies and one woman had three false-positive laparoscopies resulting in a total of 14 'negative laparoscopies' (Figure 2).

### *Referral to secondary care*

The most common symptom reported to GPs was dysmenorrhoea (*n* = 67). The symptoms most frequently prompting referral to secondary care were dyspareunia and subfertility, with 21 (72%) of the 29 women with dyspareunia and 17 (85%) of the 20 women with subfertility being referred to secondary

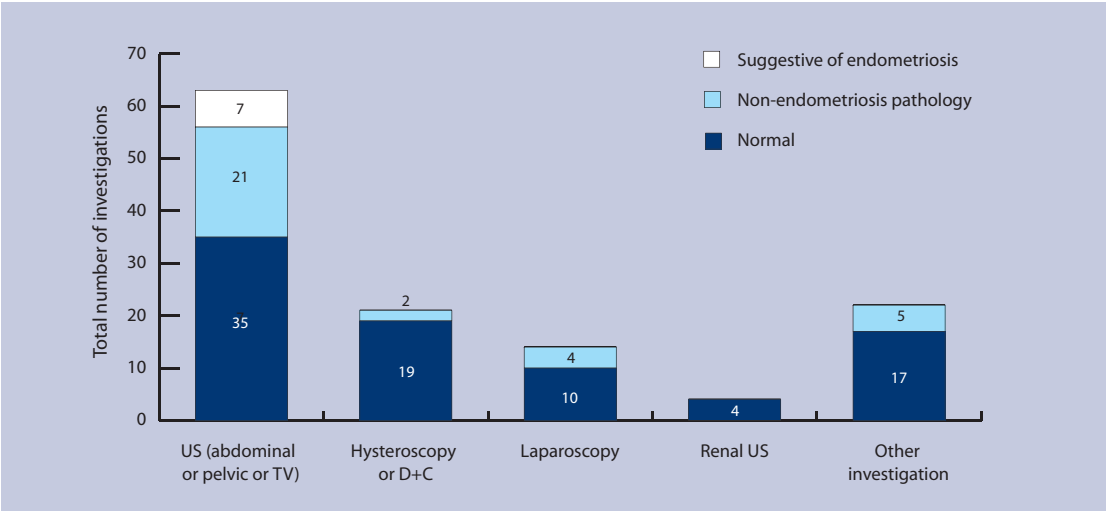



***Figure 2. Types and number of investigations carried out on women prior to a surgical diagnosis of endometriosis.***

***US = ultrasound. TV = transvaginal. D+C = dilatation and curettage.***

**Table 3. Frequency of GP consultations with symptoms.**

| Symptom | Number of visits 1–4 | 5–9 | >10 |
|---|---|---|---|
| Dysmenorrhoea | 54 | 12 | 1 |
| Deep dyspareunia | 27 | 2 | 0 |
| Pelvic pain | 49 | 7 | 2 |
| Low abdominal pain | 49 | 11 | 2 |
| Pelvic pain and/or low abdominal pain | 58 | 13 | 7 |
| Subfertility | 20 | 0 | 0 |
| Back pain | 33 | 1 | 0 |
| Irregular bleeding | 43 | 3 | 1 |
| Menorrhagia | 24 | 4 | 1 |
| Other gynaecological symptoms | 18 | 1 | 0 |
| Urinary symptoms | 47 | 6 | 2 |
| Abdominal bloating | 17 | 2 | 0 |
| Irritable bowel syndrome symptoms | 17 | 2 | 0 |

care with these symptoms (Table 2). This compares with the referral of 39 (58%) of the 67 women with dysmenorrhoea. Over half (*n* = 58) of the women presented with pelvic pain and this prompted referral in 24 (41.1%) of these women. Forty-nine women were referred twice or more to secondary care before reaching a diagnosis. Thirty-nine had at least two referrals to gynaecology before a diagnosis was made. Median time from symptom presentation to diagnosis was shorter for women consulting with deep dyspareunia (median 2.4 years; interquartile range [IQR] = 0.4–7.4 years) and subfertility (1.5 years; IQR = 0.7–6.0 years) compared with women consulting with dysmenorrhoea (median 8.2 years; IQR = 1.5–13.1 years), pelvic pain (median 3.2 years; IQR = 0.7–7.5 years), and low abdominal pain (median 6.9 years; IQR = 2.3–10.9 years; Table 2).

Median interval between first presentation with any primary symptom or subfertility until diagnosis was 9.0 years (IQR = 4.5–13.5 years).

## DISCUSSION

### *Summary of main findings*

The prevalence of endometriosis in women over 16 years in the study was 1.44%. One-third of women consulted GPs six or more times with a primary symptom before diagnosis. Ultrasound was frequently used to investigate symptoms but was not helpful in diagnosing the majority of women. A small proportion of women had at least one negative laparoscopy before diagnosis. Women presenting with dyspareunia and subfertility were more frequently referred to secondary care and experienced shorter delays in diagnosis than women with other symptoms. Over a third of women were referred to gynaecologists twice before a diagnosis was made. Median delay from first presentation to diagnosis was 9.0 years.

### *Strengths and limitations of the study*

In recognition of the limitations associated with retrospective data, considerable efforts were made to maximise the quality of the information collected. Ninety of the 101 records used were fully complete and four records that were largely incomplete were excluded (Figure 1). A pilot computer search using surrogate markers of possible endometriosis did not identify any further cases. However, it should be recognised that the inclusion criteria of a surgical diagnosis of endometriosis necessarily misses those women who have symptoms but have yet to be diagnosed, as well as those who are suspected of having endometriosis but have had a negative laparoscopy. From the findings in this study, the 'gold standard' of a laparoscopy for diagnosing endometriosis was shown to have its limitations, as false-negative results were found in a small but significant proportion of women.

Data collection was limited by interpretation of handwritten entries, however when a selection of records were independently coded, a high level of reproducibility of the data collected was found. Nevertheless, only the information recorded can be reported on, and therefore omissions and inaccuracies are inevitable. In addition, the data reflect GPs' interpretations of women's symptoms, thus increasing the subjective nature of the data. Of the 118 records identified as 'endometriosis cases' there were 11 false-positive results.

The response rate of 54% was disappointing, particularly as studies have shown that patients are generally happy for their medical records to be used for research purposes providing that they have been asked for their consent.[12] It was found that the responders were similar in age to the non-responders.

### *Comparison with existing literature*

This study adds to the body of evidence that describes endometriosis as a chronic condition that often remains undiagnosed for years.[13]

While the calculated prevalence of 1.44% appears to be low compared with estimates of 8–10% cited in the literature,[4,5] previous studies have used data from women presenting with gynaecological conditions who are therefore more likely to have endometriosis. Although a community-based study will provide the most accurate prevalence of endometriosis, it is important to recognise that the prevalence from all women over 16 years of age was calculated. Studies reporting on a narrower age band are likely to report a slightly higher prevalence. Prevalence estimates

are also likely to be influenced by diagnostic accuracy, as suggested by the finding of the highest prevalence at the practice referring to a gynaecology department with a research interest in endometriosis.

Although symptoms of chronic pelvic pain, dysmenorrhoea, and deep dyspareunia are commonly associated with endometriosis,[14] it was found that a large proportion of women also presented with low, non-mechanical back pain, menorrhagia, irregular bleeding, and urinary symptoms. The frequency of consultations for symptoms suggestive of endometriosis does not appear to have been reported in the literature before.

Since the disease can only be diagnosed through laparoscopy, it is not surprising that most women had presented to primary care on three or more occasions before being referred to secondary care. However, what may be surprising is that a third of the women in the sample attended more than six times with primary symptoms before they were diagnosed with endometriosis.

Due to the limitations in the study design it is not possible to know the extent to which these women experienced symptoms between consultations. It is possible that they were receiving appropriate analgesic and/or hormonal therapy that for some time, at least, was effective in reducing endometriosis symptoms. Therefore, the apparent delays in diagnosis may in part reflect a period of appropriate management rather than simply time awaiting a diagnosis.

Qualitative work by Ballard *et al,*[15] has shown that there are three key factors influencing a delayed diagnosis of endometriosis: normalisation of symptoms by women and doctors, medical treatment of undiagnosed symptoms, and false-negative investigations.

Women were often investigated for their symptoms, with almost half the sample having an ultrasound. Ultrasonography has been shown to be a poor diagnostic tool for identifying endometriosis,[16] as demonstrated over half of the scans carried out in the current study were reported as normal. While diagnostic laparoscopy is considered the gold standard for diagnosing endometriosis, it is important to note that even this investigation carries a false-negative risk.

Although almost all women consulted with what was termed 'primary symptoms' of endometriosis, similarly to other studies,[7,8] there were substantial delays in diagnosis, with women waiting a median of 9 years before diagnosis. Also similar to other findings,[9] the data suggest there is a shorter diagnostic delay associated with endometriosis related to subfertility than pelvic pain. It was also found that women presenting with deep dyspareunia experienced shorter delays than those presenting with dysmenorrhoea.

It has been shown that different symptoms are more likely to prompt referral to secondary care. Reasons behind the variation in GP referrals are unknown. Little *et al,*[17] conclude that perceived medical need is the factor most strongly associated with doctors' referral behaviour. This study was able to show that dyspareunia and subfertility prompted referral more frequently than other symptoms, such as dysmenorrhoea, suggesting that they may have been perceived as more medically important.

### *Implications for future research and clinical practice*

Qualitative research on women's experiences of reaching a diagnosis of endometriosis has shown that delays occur at both an individual and a medical level with most women waiting for many years before they even consult in primary care.[15] This qualitative research also shows that a diagnosis of endometriosis is valued by women as it provides a language with which to discuss their symptoms, legitimises absence from work and social roles, and provides relief from the fear that they may have some underlying sinister pathology such as cancer.

Having made the decision to seek medical advice, it is important that women receive reassurance as well as a possible explanation for their symptoms. In the first instance, GPs may elect to treat women empirically with hormonal therapies. This approach needs to be supported with a 'working diagnosis' that is communicated to the patient.

Referral to secondary care is necessary for definitive diagnosis, despite the small false-negative result rate of diagnostic laparoscopy. The use of ultrasound to investigate women with symptoms of endometriosis has limited value being largely useful for the diagnosis of endometriomas only.[16] Ideally, research needs to focus on the development of a non-surgical diagnostic measure of endometriosis, which can be easily used in primary care. At present GPs need to be aware of the different symptomatology associated with the condition and the limitations of ultrasound in investigating symptoms of endometriosis.

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**Ethics committee**

This study was approved by the South West Surrey Local Research Ethics committee (05/Q1909/17)

**Competing interests**

The authors have stated that there are none

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