



The etiquette of endometriosis: Stigmatisation, menstrual concealment and the diagnostic delay[☆]

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ABSTRACT

Endometriosis is a chronic gynaecological condition of uncertain aetiology characterised by menstrual irregularities. Several studies have previously identified a lengthy delay experienced by patients between the first onset of symptoms and eventual diagnosis. Various explanations have been advanced for the diagnostic delay, with both doctors and women being implicated. Such explanations include that doctors normalise women's menstrual pain and that women might delay in seeking medical advice because they have difficulty distinguishing between 'normal' and 'abnormal' menstruation. It has been suggested that the diagnostic delay could be reduced if women were trained in how to distinguish between 'normal' and 'abnormal' menstrual cycles. In this paper I argue that whilst these may be factors in the diagnostic delay, women's reluctance to disclose problems associated with their menstrual cycle may be a more significant and hitherto neglected factor. I argue women are reluctant to disclose menstrual irregularities because menstruation is a 'discrediting attribute' (Goffman, 1963) and disclosure renders women vulnerable to stigmatisation. Women actively conceal their menstrual irregularities through practices of the 'menstrual etiquette' (Laws, 1990) which involves the strategic concealment of menstrual problems. This argument is supported through an analysis of the experiences of 20 Australian women diagnosed with endometriosis. The ramifications of this analysis for chronic pain conditions more generally and for practical strategies designed to address the endometriosis diagnostic delay are considered.

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Introduction

Endometriosis is a chronic gynaecological condition, second only to uterine fibroids as the most common reason why women have gynaecological surgery (Overton, Davis, McMillan, & Calman, 2002: 15). The condition is characterised by the existence of tissue similar to endometrial tissue in places other than the uterus (Prentice, 2001). In women with endometriosis, the tissue situated outside the uterus responds to the hormones that trigger the menstrual period and often bleeds and swells so that lesions, cysts and nodules may develop. Although the exact number of women with the condition is unknown, it is thought to affect as many as 600,000 women in Australia (Cox, Ski, Wood, & Sheahan, 2003: 200). The principal symptom of the condition is pain upon menstruation, although pain can occur throughout the menstrual cycle, or alongside bowel or

bladder movements and sexual intercourse (Phillips & Motta, 2000: 11–15). The condition is not formally diagnosed until it has been visually identified by a qualified physician through a form of surgery called laparoscopy (Sutton & Jones, 2004: 17). As the condition does not manifest in external, visible symptoms, the woman's account of pain is pivotal to her eventual diagnosis.

Endometriosis and the diagnostic delay

In previous social scientific studies on endometriosis the subject given most attention is the period prior to diagnosis. The consensus is that most women with endometriosis experience lengthy delays to diagnosis, delays which often exceed those for other common chronic conditions such as rheumatoid arthritis (Hadfield, Mardon, Barlow, & Kennedy, 1996). One commonly cited study of 218 women with the condition found a delay between the onset of symptoms and diagnosis of 7.96 years in the United Kingdom and 11.73 years in the United States of America (Hadfield et al., 1996). An unpublished Australian study conducted in 1989 found a diagnostic delay of six years (Wood, 1992, cited in Cox, Henderson, Anderson, Cagliarini, & Ski, 2003).

The delay is a significant issue for a number of reasons. First, it has the potential to impact upon the lives of women. Previous

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studies reveal that women diagnosed with endometriosis can experience concern, worry, anxiety, self-blame, financial and relationship difficulties and a reduced quality of life (Abbott, Hawe, Clayton, & Garry, 2003; Bodner, Garratt, Ratcliffe, MacDonald, & Penney, 1997; Denny & Mann, 2007; Garry, Clayton, & Hawe, 2000; Jones, Kennedy, Barnard, Wong, & Jenkinson, 2001; Strzempko Butt & Chesla, 2007; Wright & Shafik, 2001). Fear, anger and depression are common features amongst sufferers. Women feel isolated and alienated because of their experience, with some of these studies suggesting that sufferers can feel overwhelmed and powerless in the face of the condition. The feelings reported by women are partly attributable to delays in diagnosis of the condition and partly a result of experiences with the medical profession, where most women report that their general practitioners have not taken their symptoms seriously (Carlton, 1996; Hadfield et al., 1996). Women with endometriosis are also considerably incapacitated. In a United States National Health Interview Survey, for instance, it was found that half of the women who reported suffering from endometriosis were bedridden because of the condition for an average of 17.8 days during the twelve months before the survey (Kjerulff et al., 1996 cited in Weir, 2001: 1201; see also Boling, Abbasi, Ackerman, Schipul, & Chaney, 1988). Whilst the achievement of diagnosis may not alleviate women's incapacitation altogether, it may result in a reduction of the amount of time women are incapacitated. This is because following diagnosis women may obtain assistance with pain management, or otherwise experience a reduction in their symptoms through existing treatment options.

The main forms of treatment are surgery and drug therapy. Many women resort to surgery and have the endometrial deposits burnt off (diathermy) or excised during a surgical procedure known as a laparoscopy. Drug therapies are common and range from those aimed at managing pain to those designed to stem the growth of endometrial tissue by suppressing hormonal activity or the entire menstrual cycle for a period of time (Brewer, 1995: 64). The focus of most medical treatments is to alter the menstrual cycle to produce a pseudo-pregnant or pseudo-menopausal state (Olive & Pritts, 2001: 266). It is believed that these situations reduce the optimal conditions for the growth of the endometrium and, thus, endometrial implants (Olive & Pritts, 2001: 266).

According to Matsuzaki et al. (2006) it is also possible that lengthy delays to diagnosis could have ramifications for women's fertility. In particular, they suggest that prolonged delays with painful symptoms can worsen the prognosis for fertility. The diagnostic delay may also contribute to the large economic burden of the condition to society. In a systematic review of research examining the economic burden of endometriosis, Gao et al. (2006) found a paucity of studies exploring the overall cost of the condition. Studies tended to address the costs associated with management of specific symptoms, or the cost of specific treatments, such as GnRH agonists (Gao et al., 2006: 1569). The authors concluded that 'the economic burden of endometriosis to society is substantial' (Gao et al., 2006: 1568). These findings were largely supported by the findings of a subsequent systematic review (Simeons, Hummelshoj, & D'Hooghe, 2007). Assuming that endometriosis affects ten per cent of women of reproductive age, the authors estimated the annual costs of endometriosis in the USA in a single year (2002) at US\$22 billion. This can be compared with the annual cost of diseases comparatively similar in terms of medication expense and medical/surgical options, such as Crohn's disease, with an estimated annual cost of \$865 million and migraines, with an estimated annual cost of \$13–17 billion. Cost estimates of diseases are important for public policy purposes because, according to Simoens et al. (2007: 396) they can 'underline the importance of a disease to society when considered alongside its impact on morbidity and mortality and when compared with the economic burden of other diseases'. Despite the apparently relatively

large economic burden of endometriosis, public health policy interest in the condition remains extremely low. Whilst not all of these costs can be attributed to the diagnostic delay it is possible that public health costs could be reduced if the diagnostic delay were shortened. This would require us to develop an understanding of what factors are associated with the diagnostic delay. Moreover, practical strategies would need to be implemented to address the factors which delay diagnosis.

Factors associated with the diagnostic delay

In previous studies, the reasons offered for the diagnostic delay vary. Hadfield et al. (1996) emphasised the role of women in the delay whereas most other studies emphasised the role of doctors, or of both doctors and women (Ballard, Lowton, & Wright, 2006; Ballweg, 1992, 1997; Ballweg & the Endometriosis Association, 2004; Barnard, 2001; Capek, 2000; Cox, Henderson, Anderson, et al., 2003; Cox, Henderson, Wood, & Cagliarini, 2003; Cox, Ski, et al., 2003; Denny, 2004a, 2004b; Husby, Haugen, & Moen, 2003; Shohat, 1998; Whitney, 1998). In the widely cited Hadfield et al. (1996: 879) study, which had a sample of 218 women with endometriosis recruited from self-help groups in the United States and the United Kingdom, explanations offered for the delay included the possibility that the sample was biased because participants were recruited from endometriosis self-help groups, that women might delay in reporting their symptoms to doctors or that they may have a 'poor recollection' of the precise date that symptoms commenced. Moreover, it was suggested that once women report symptoms to doctors 'the medical practitioner may have difficulty in distinguishing between other causes of pelvic pain' and endometriosis. In contrast to Hadfield et al. (1996), studies by Cox, Ski, et al. (2003) and Denny (2004a, 2004b) emphasised the role of doctors in the diagnostic delay. Women interviewed in each of the studies believed that doctors trivialised or normalised their pain complaints by suggesting that menstrual pain was a normal and non-pathological process. Denny (2004a: 42) also noted the significance of others in women's lives in influencing their decision to seek medical advice. She found that for some women, 'family and friends acted as a deterrent, frequently because of their perception of pain in general, and menstrual pain in particular' (Denny, 2004a: 42). Women might have been unwilling to attend a general practitioner about their symptoms, especially where they experienced pain during sexual intercourse, because they were 'embarrassed' to discuss this with physicians (Denny, 2004a; see also Arruda, Petta, Abrao, & Benetti-Pinto, 2003; Ballweg, 1997; Cox, Henderson, Anderson, et al., 2003; Dmowski, Lesniewicz, Rana, Pepping, & Noursalehi, 1997; Husby et al., 2003; National Endometriosis Society (UK) undated, cited in Prentice, 2001; Sinaii, Cleary, Ballweg, Nieman, & Stratton, 2002).

Whilst this literature makes an important contribution to our understanding of reasons for the delay, it does not explore why women might feel embarrassed to discuss menstrual or sexual issues with physicians, why others might normalise women's menstrual pain or who might benefit from such phenomena. The problem of menstrual pain normalisation is instead often personalised, with mothers being blamed for teaching their daughters 'bad attitudes' (Laws, 1990: 166) about menstruation. Where it has been suggested that women have normalised their own pain, academic studies have also been silent as to the reasons why this might occur or who might benefit from such practices. It is often suggested, for instance, that women find it inherently difficult to distinguish between normal and abnormal periods. In what follows, I argue that whilst women may have difficulty distinguishing between normal and abnormal levels of menstrual pain, the delay may also be attributable to social sanctioning processes associated with the disclosure of menstruation more generally, and menstrual problems in particular. Women's experiences with menstruation are part of an elaborate practice of

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