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ORIGINAL ARTICLE

Clinicians' perceptions of women's experiences of endometriosis and of psychosocial care for endometriosis

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Background: Endometriosis is a complex, chronic condition with known psychological and social implications for women. Little is known about clinicians' perceptions of the psychosocial aspects of endometriosis and associated care.

Aim: To describe clinicians' perceptions of women's experiences of living with endometriosis and of the provision of psychosocial care for endometriosis.

Materials and methods: A qualitative approach was taken using semi-structured interviews with eight gynaecologists and four general practitioners who provide care to women with endometriosis in Victoria, conducted by telephone and in person from June to December 2014.

Results: Clinicians' perceptions of women's experiences of endometriosis were consistent with those reported by women, particularly when discussing potential infertility. However, less comprehensive descriptions of the effects of endometriosis on women's work and social life and intimate relationships were observed. Some clinicians asserted that endometriosis is caused by poor mental health. General practitioners positioned themselves as best placed to provide psychosocial care to women with endometriosis; gynaecologists suggested various potential providers but rarely themselves. Most clinicians assessed themselves as not being adequately trained to understand and provide care for the psychosocial aspects of endometriosis; half of the gynaecologists did not believe it was necessary for them to do so.

Conclusions: The findings of this research demonstrate clinicians' need for further support in the provision of psychosocial care for women with endometriosis, potentially through expanded clinical guidelines and professional development opportunities.

KEYWORDS

endometriosis, healthcare, psychosocial

INTRODUCTION

Endometriosis is a chronic inflammatory condition characterised by endometrial-like tissue outside the uterus;[1] it is experienced by 1.5% (population-based studies) to 15% (women attending tertiary services) of women.[2] Common symptoms include painful menstruation, heavy menstrual bleeding, and bowel and bladder dysfunction.[3] Although there is evidence of an association between endometriosis and infertility, the strength of this association and the underlying mechanisms are not yet clear.[4] Several potential co-morbid conditions have been identified, including asthma and migraine.[5,6] There is currently no cure for endometriosis. Treatment options, such as surgical removal and hormonal therapy, aim to manage symptoms, but each is associated with side effects and may not be effective or tolerable in the long term.[7]

There is substantial research evidence of the psychosocial consequences of endometriosis. Surveys, predominantly in specialised clinics, suggest that women with endometriosis experience diminished quality of life, mental health and emotional well-being in comparison with the general population.[8] The only published Australian population-based study reported higher levels of psychological distress among women with endometriosis compared to the general population across two surveys conducted approximately 12 months apart; distress levels remained unchanged during this period for both those who were newly diagnosed and who reported a pre-existing diagnosis.[9] When comparing women who have endometriosis with and without chronic pelvic pain (CPP), those with CPP report reduced quality of life and mental health, suggesting that the experience of pain may explain reduced outcomes rather than endometriosis itself.[10,11] Qualitative research has revealed that endometriosis affects all areas of women's lives, including their work and social life, intimate relationships and self-perception.[12] Despite this pervasive evidence, the psychosocial consequences of endometriosis are not considered a research priority by the World Congress of Endometriosis delegates[13] nor is psychosocial care explicitly addressed in the current leading clinical guidelines.[7,14]

Women's reported experiences support the need for taking a biopsychosocial approach to endometriosis and for health professionals to tailor care to the needs of individual women.[4,12,15] However, few studies have examined clinicians' perceptions of women's experiences of endometriosis; these have focused on comparing women's and clinicians' perceptions of endometriosis symptoms. Gynaecologists' perceptions of the consequences of endometriosis for women have been found to be similar to those reported by women in France[16] and Iran.[17] However, gynaecologists' descriptions of severe pelvic pain, dysmenorrhoea and dyspareunia were less comprehensive,[16] and they gave less consideration to social life, daily activities and personal communication problems.[17] As far as the authors can discover, there has been no in-depth investigation of clinicians' perceptions of psychosocial care for endometriosis.

This research aimed to describe clinicians' perceptions of women's experiences of living with endometriosis and of the provision of psychosocial care for endometriosis.

MATERIALS AND METHODS

A qualitative method was selected as the most appropriate to achieve the research aims.[18] General practitioners and gynaecologists (the principal care providers to women with endometriosis) who practise in the state of Victoria, Australia, were invited to participate. Purposive recruitment was used to ensure diverse perspectives that could best illuminate the topic under investigation.[18] Gynaecologists were recruited through a letter of invitation emailed to all members on a public list of Victorian gynaecological surgeons (n = 59) and through communication within professional networks. General practitioners were recruited through advertisements in a medical school alumni newsletter, notices on clinic staff room noticeboards and communication within professional networks.

Semi-structured interviews were conducted by the first author during June–December 2014, in person or by telephone. Each began with a request for the clinician to describe their views of women's experiences of endometriosis, followed by specific prompts to discuss the role of endometriosis in women's work life, social life, intimate relationships, potential or diagnosed infertility, and mental health (areas identified by women as important).[12] Their opinions were sought on who is responsible for the psychosocial care of women with endometriosis and whether clinicians are adequately trained to provide such care. Finally, each clinician was asked whether they had anything else to say about women's experiences of endometriosis. Demographic information was collected at the end of each interview.

Interviews were audio-recorded, with permission, and fully transcribed. Potentially identifying information was removed. Data were analysed thematically,[19] using NVivo10 to assist in data management. Transcripts were read several times by Author A for content familiarisation and to note all identifiable themes and patterns. Transcripts were first coded for themes derived from the questions asked (work life, social life, intimate relationships, potential infertility, mental health),[8,12] whether they occurred directly in response to the questions or elsewhere in the interview. Transcripts were then searched for original themes in participants' contributions, using a data-driven approach. Identified themes were discussed among all authors to select those that (i) represented a patterned response or meaning across several interviews or (ii) captured something uniquely significant relative to the research aims.[19] All transcripts were searched again to ensure that the analysis was accurate and comprehensive and that the final selected themes represented one of the two criteria. The revised scheme was applied to each transcript and exemplary quotations were selected.

The research was approved by the Monash University Human Research Ethics Committee (CF14/1282-2014000580).

RESULTS

Participants

Twelve clinicians were interviewed by telephone (n = 9) and in person (n = 3) for an average of 11.94 min (range = 7.19–22.07). Their characteristics are summarised in Table 1.

TABLE 1 Participant characteristics

ID	Profession	Sex	Years in practice	Location	Sector	% caseload
GP1	GP	Female	28	Urban	Private	5
GP2	GP	Female	12	Urban	Private	5
GP3	GP	Female	29	Regional	Both	5
GP4	GP	Female	11	Regional	Private	5
GY1	Gynae	Male	20	Urban	Both	20
GY2	Gynae	Female	30	Urban	Both	5
GY3	Gynae	Female	6	Urban	Both	5
GY4	Gynae	Male	43	Urban	Both	75
GY5	Gynae	Male	23	Urban	Both	40
GY6	Gynae	Male	18	Urban	Private	70
GY7	Gynae	Female	39	Urban	Both	5
GY8	Gynae	Female	37	Urban	Both	15

GP, general practitioner; gynae, gynaecologist.

Perceptions of women's experiences of living with endometriosis

Work life and social life

When asked about the potential impact of endometriosis on women's work lives and social lives, all clinicians said that the condition can affect these areas of women's lives. Some related the effect on work life to menstrual pain; one general practitioner (GP) extended endometriosis' influence to 'pain or other symptoms' that occurred 'not just during their period' [GP1].

Two clinicians nominated the woman's employer as moderating the effect of endometriosis on her work life. One gynaecologist [GY4] was reassured to hear from his patients that some employers were 'understanding' but concerned to hear that others were not, and one GP [GP1] said that some of her patients prefer not to disclose their diagnosis to employers.

Some clinicians appeared to equate 'social life' with 'sex life'. For example:

> *Socially, I think it does affect women's intimate relationships, for some women. … Obviously, the sexual problems, in terms of being in pain and having sex, are one of the symptoms that can be really difficult for women to deal with, socially*
>
> *[GP1]*

One GP extended aspects of a woman's social life to the way that endometriosis 'can interfere with them being able to exercise and do activities but also go out and about' [GP4].

Intimate relationships

Most clinicians' responses to this question focused on sexual intimacy. One gynaecologist implicated a more complex set of factors; for example:

> *If they're having pain, that's going to affect their sexual relationships, and whether that's an issue in itself. And then there can be consequential things for someone whose mood and state of well-being is affected by their symptoms. … That has an impact on their relationships and their world, and the response of those around them to it, and the capacity to be supportive*
>
> *[GY8]*

Some gynaecologists described assisting women to manage the effects of dyspareunia on their relationships. One said he first searches for physical evidence from previous surgeries 'whether it would actually affect intercourse' but acknowledged that this method is 'really subjective' [GY1]. Another [GY4] finds it useful to invite a woman's male partner into a consultation where he describes (with diagrams) the potential for endometriosis to contribute to painful sexual intercourse. A third gynaecologist implements 'pain management' and refers women to 'appropriate counselling' [GY2].

Two clinicians reported rarely discussing the effects of endometriosis on their patients' intimate relationships because they perceived that women prioritise care for pain and heavy bleeding [GP2, GY7] and because time constraints limit exploration of secondary symptoms [GP2].

A partner's support (or lack thereof) was identified as affecting the impact of endometriosis on a woman's sex life and relationship. One GP said that some partners were supportive but many do not understand endometriosis and 'can be quite negative' [GP1]. This GP commented that lesbian women appear to receive 'more support and encouragement from partners' than women with male partners. However, two gynaecologists [GY1, GY7] reported encountering supportive partners.

Potential or diagnosed infertility

All clinicians except one GP discussed the impact of potential or diagnosed infertility on women with endometriosis. A frequent comment was that the association between endometriosis and infertility was likely to be much weaker than usually claimed by ‘Dr Google’, the general public, and some doctors. This overstatement was described as causing women to be ‘stressed,’ ‘anxious,’ ‘worried’ and ‘concerned’ about infertility, particularly when first diagnosed with endometriosis.

The majority of clinicians described how they communicate with women about potential infertility. They are ‘very careful not to say that anyone’s infertile’ [GP2], offering reassurance that most women with endometriosis conceive either spontaneously or with assisted conception. Additional strategies include normalising infertility, such as by informing patients that ‘couples aren’t 100% fertile anyway’ [GY1], and encouraging women to plan conception around ‘the plans for their life’ [GY3]. One gynaecologist [GY4] asserted the importance of working with patients on ‘a plan for reproduction within a plan of management of endometriosis,’ saying that it was ‘no good’ to subject a woman to major surgery in hopes of enhancing fertility only to discover post-operatively that she had no immediate plans for children.

Mental health

All clinicians commented on the potential for endometriosis to have an adverse effect on mental health, whether specifically in relation to depression and anxiety or in general terms such as ‘psychological issues’ and ‘mental or emotional health.’ Features of endometriosis that clinicians described as affecting mental health included living with symptoms and treatment side-effects, making decisions about treatment, receiving inadequate health care, living with uncertainty and receiving poor social support. Most spoke of one or two, usually including living with chronic pain.

A few clinicians said that problems with mental health could cause endometriosis symptoms. For example, one gynaecologist speculated, ‘Do mad people get endo or does endo make you mad? It’s probably a bit of both’ [GY5]. Women whose symptoms did not respond to treatment were more than once described as ‘difficult women’ whose problems were attributable to their psyche rather than their soma. It was said of one such woman:

> *In her case it was obviously a reflection of … more mental health issues somewhere else and I think it stemmed from a bit of parental, matrimonial disharmony. So there’s a little bit of a psychosomatic expression of the wider problem within the family*
>
> *[GY6]*

According to one GP, endometriosis is ‘very inter-related with their [women’s] mental health’; after expressing uncertainty about the causal direction, she concluded, ‘I guess the endo comes first’ [GP1]. A gynaecologist asserted that poorer mental health in women with endometriosis was a ‘reactive depression to their circumstances’ [GY4].

Perceptions of psychosocial care for endometriosis

Assisting women with the psychosocial impact of endometriosis

GPs discussed supporting women in managing the broader psychosocial implications of living with endometriosis while gynaecologists emphasised supporting women experiencing mental ill-health.

As gatekeepers, GPs saw themselves as best placed to identify those women with endometriosis who may need psychosocial support. Depending on need, they may provide care, refer to a psychologist, or recommend an endometriosis support group. Three gynaecologists made similar comments, although one expressed reservations about aspects of GP care:

> *I know that some GPs treat the psychological by giving light antidepressants and stuff which … we are not dealing with. But the treatment needs to be combined to look at all aspects of the disease*
>
> *[GY3]*

A gynaecologist recommended ‘probably a psychologist’ [GY2] to provide psychosocial support, while a gynaecologist and a GP preferred to ‘spread the load’ [GY4] to ‘holistic’ [GP1] complementary and alternative health care providers who do not consider only ‘local symptoms but … psychosocial wellbeing as well’ [GP1].

Half of the gynaecologists but no GPs said that family, friends and partners may have a role in providing support to women with endometriosis. However, one gynaecologist cautioned that such support ‘can be good for the patient; other times, family and friends can actually be worse for the patient’ [GY1]. Most GPs and some gynaecologists proposed endometriosis support groups as additional sources of psychosocial support. However, one gynaecologist was concerned that support groups encourage women to be ‘consumed by the whole endometriosis kind of way of life’ [GY8].

A few gynaecologists said that, while some women would benefit from psychosocial support and care, treating the physical mechanics of endometriosis would usually obviate the need:

> *They want me to do something to them that is going to help their symptoms and so I do something, whether it be surgical, whether it be medical; things like that, to try and help their symptoms and therefore improve their sort of quality of life*
>
> *[GY7]*

Clinical training for the provision of psychosocial care for endometriosis

There was a notable difference between the specialities in that most GPs identified providing psychosocial care to women with endometriosis as part of their job, whereas half of the gynaecologists did.

Half of the clinicians explicitly stated that doctors were not well trained 'to treat the psychosocial impact of a lot of diseases, let alone endometriosis' [GY2]. It was said that GPs are not well trained 'from even the physical side' [GP2] of endometriosis. A GP [GP3] who teaches early-career doctors argued for improvement in training, although one gynaecologist [GY8] thought training had improved and another [GY1] felt well trained by a university known to consider psychosocial aspects of care. One GP [GP4] said that all doctors are trained to be mindful of mental health in people living with any chronic illness but that teaching emphasised better-known conditions such as diabetes and chronic back pain. Some clinicians said that the fundamental determinant of whether women were assisted with the psychosocial impact of endometriosis was the doctor's interest:

> *We've been trained pretty well, I think, in the psychosocial aspects of medicine, if we chose to listen to that. ... Some doctors still tend to avoid those areas of medicine, but there's an onus on us to deal with the whole person*
>
> *[GP1]*

One gynaecologist said that the ability to assist women with the psychosocial impact of endometriosis often came from 'years of experience' and 'whether they see endometriosis sporadically, frequently, or that's the main part of their practice' [GY6]. Another [GY3] said that only those doctors who see patients with chronic pain need to be trained in the psychosocial aspects of these conditions. Most gynaecologists thought such training was unnecessary because others were better qualified to help:

> *I don't think that my role as a specialist gynaecologist is to try and cope with all the psychological ramifications of the disease. I'm probably more like the mechanic, but then, as I said, try and share the load with others who can help the patient*
>
> *[GY4]*

DISCUSSION

This study is the first to consider in detail medical professionals' perspectives of women's broader experiences of endometriosis and of the provision of psychosocial care for endometriosis. Although there have been several reports of the psychosocial consequences of endometriosis for women,[8,9,12] limited attention has been paid to the care required to address these consequences; the research reported here is therefore a valuable contribution to the literature on endometriosis. While the number of participants recruited is adequate for qualitative research where the goal is depth rather than breadth of knowledge,[18] the familiar recruitment difficulties in this population[20] meant that there were some gaps in the desired diversity. We acknowledge the absence of clinicians who practised outside urban areas, male GPs and recent graduates from tertiary medical education. Our participants did not include women's and allied health professionals' perspectives on psychosocial care for endometriosis; these are important targets for future research.

We found clinicians' perceptions of women's experiences to be consistent with those reported by women:[8,12] living with endometriosis can have a considerable impact on women's work and social lives, intimate relationships and mental health. However, clinicians provided less comprehensive descriptions of the effects of endometriosis on a woman's work life (limiting it to menstrual pain) and on social life and intimate relationships (often discussed in relation only to sexual activity). Some clinicians endorsed the historic 'medical myth' that endometriosis may be caused by poor mental health.[21] The weight of evidence suggests poorer mental health in women with endometriosis is the result of living with a condition for which little effective care and limited social support may be available.[8,10,15] Clinicians' comments on infertility reflected women's reports of clinical encounters[8,12] and their desire for empathic and individualised fertility care.[4]

Clinicians expressed varied opinions about who was responsible for assisting women with the psychosocial impact of endometriosis and whether they were well trained to do so. Their views could be summarised as endorsing a multi-disciplinary approach; GPs tended to position themselves as best placed to oversee this care, while gynaecologists suggested various potential providers but rarely themselves. These findings are consistent with a call by the World Endometriosis Society[1] and others[15] for women to receive individualised care from a multidisciplinary network of healthcare professionals, and access to endometriosis support groups and organisations. However, not all women need or want such services and consensus has not been reached on how such networks may best operate.[1] Models of care shown to benefit patients with other chronic conditions, such as diabetes,[22] may serve as guides to comprehensive endometriosis care.

Most clinicians assessed themselves as not adequately trained to understand and provide care for psychosocial aspects of endometriosis; half of the gynaecologists did not believe it was necessary for them to do so. Given that endometriosis is a complex chronic disease known to have significant psychosocial implications for women who live with it,[8,12] it may be appropriate for care to encompass more than the biological[23] and for formal consideration to be given to meeting the diverse needs of these women. While different professions may have varying degrees of expertise in providing psychosocial care, all should be able to identify when such support is needed and refer as appropriate. Increasingly, medical education in Australia and around the world is incorporating a biopsychosocial approach to practising medicine.[24–27] That some participants in this study took a more biological approach may reflect the years since they completed tertiary medical education (mean = 24.67); continuing professional development opportunities in psychosocial care may be appropriate. Further, this research supports the need for current clinical guidelines for endometriosis to address the psychosocial aspects of endometriosis and appropriate care.[7] Of note, some clinicians commented that training was currently inadequate for the psychosocial aspects of many conditions and also the physical aspects of endometriosis, suggesting a need for improved general training for psychosocial care and in all aspects of endometriosis.

Our findings suggest a need for clinicians to be further supported in the provision of psychosocial care for endometriosis, potentially through expanded clinical guidelines and professional development opportunities. Further research is needed to understand optimal care for the psychosocial aspects of endometriosis, including consideration of a diverse range of health professionals' perceptions and examining developed models of care which effectively address psychosocial factors for other chronic diseases. At a time when there is no cure available for the biological, attending to the psychological and social may facilitate better assistance to women in the lifetime management of endometriosis.

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