**Article**

**Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis**

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**Abstract**

Endometriosis is currently poorly understood by the medical sciences; contemporary healthcare has been evidenced as failing to meet the diverse needs of the women who live with the condition. This study examined women’s experiences of navigating knowledge and power within medical encounters for endometriosis. In-depth interviews were conducted with twenty-six women who have been diagnosed with endometriosis about their experiences of the condition and associated healthcare. Women valued both their own knowledge and their doctor’s clinical expertise; as to which they privileged was situational but it was essential the woman dictated which it would be. Women were wary of the social status and power of doctors to reduce their wellbeing through medical labels they did not identify with or by inhibiting their access to care. They identified the need for doctors to listen to and believe them as being essential to the provision of healthcare that meets women’s needs and addresses the complexities of endometriosis. Our findings suggest that medical education needs to equip doctors with the skills to acknowledge and incorporate women’s knowledge of their bodies within the medical encounter, and to understand how their practice affects women’s social and economic participation.

**Key Words**

Endometriosis, women, knowledge, power, delivery of health care

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**Partners instead of patients:**

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Endometriosis, a chronic inflammatory condition experienced predominantly by women, is attracting increasing feminist scholarly attention (Jones, 2015; Seear, 2014). Historically, the causal pathways of endometriosis were understood as being associated with and through women’s psyche and ‘lifestyle’ choices (Jones, 2015; Nezhat, Nezhat, & Nezhat, 2012), a distinction endometriosis shares with other conditions imputed to women (e.g., breast cancer: Lantz & Booth, 1998; infertility: Wischmann, 2003). The ‘solution’ often reinforces women’s socially constructed roles of wife and mother. For example, women (Young, Fisher, & Kirkman, 2015, 2016) and clinicians (Young, Fisher, & Kirkman, In press) report that pregnancy is often prescribed as a treatment. (This has been recently challenged in the research literature: Leeners, Damaso, Ochsenbein-Kölble, & Farquhar, 2018.) For a substantial part of the 20th century, endometriosis was known as ‘the career women’s disease’ on the assumption that it predominantly affected childless women in paid employment with ambitions to progress (Carpan, 2003; Nezhat et al., 2012). The limited medical understanding of endometriosis is attributed in the medical literature to the inherent enigma of the disease (Seear, 2014). Feminist scholars have, however, suggested that our gains in understanding conditions gendered to women are limited by the male lens—and the narrow perspective of women and their bodies that this has generated—through which medical research and practice has historically taken place (Martin, 1987; Seear, 2014; Ussher, 2006). This masculine lens is evident, for example, in research on the association between women’s physical attractiveness and the severity of endometrial disease (Vercellini et al., 2013).

The medical literature defines endometriosis by the presence of lesions containing endometrial-like tissue outside the uterus (Dunselman et al., 2014). Disease is typically diagnosed within the pelvis but can appear anywhere in the body (Machairiotis et al., 2013). Internationally, there is a diagnosis delay of an average 5.5 years, 3.4 years of which is healthcare-related (period from woman seeking health care for symptoms to being diagnosed; De Graaff et al., 2013). Endometriosis can be diagnosed only through surgery, biopsy, and histopathological examination (Dunselman et al., 2014). Women report symptoms including pelvic pain during menstruation and other times, bowel and bladder problems (such as cyclic constipation/diarrhoea), and heavy menstrual bleeding (see Lemaire, 2004 for a comprehensive list). Although endometriosis has long been thought to dramatically increase the risk of infertility in women, population studies indicate that only 10-13% of women with endometriosis experience infertility (Fuldeore & Soliman, 2017; Herbert, Lucke, & Dobson, 2009; Paris & Aris, 2010) in comparison with 9% in the general population (Boivin, Bunting, Collins, & Nygren, 2007). Treatment includes surgical removal of the disease and hormonal therapy to inhibit its growth (Dunselman et al., 2014). However, treatments are associated with side effects (e.g., scar tissue adhesions and reduced bone density) and about 50% of women experience symptom recurrence after surgery (Guo, 2009) and hormonal therapy (Becker, Gattrell, Gude, & Singh, 2017). The medical literature defines endometriosis as a gynaecological disorder although the disease is observed among men (for further explanation, see Rei, Williams, & Feloney, 2018), symptoms and disease are experienced across the body (Lemaire, 2004; Machairiotis et al., 2013), and recent aetiological theories focus on the immune system’s response to dislocated tissue (Burney & Giudice, 2012).

Investigations of women’s experiences of healthcare for endometriosis have suggested the perpetuation by clinicians of gendered stereotypes of women and their bodies (Young et al., 2015, 2016), inadequate knowledge of the disease among medical professionals (Culley et al., 2013; Young et al., 2015), and neglect of women and their pain (Culley et al., 2013; Facchin, Saita, Barbara, Dridi, & Vercellini, 2018; Young et al., 2015). The few investigations from the clinician perspective often lack in-depth inquiry and analysis but are largely consistent with women’s accounts of care (Fauconnier et al., 2013; Grundström, Kjølhede, Berterö, & Alehagen, 2016), including that clinicians draw on sociohistorical constructions of women and their bodies (such as the hysteria discourse: Jones, 2015) to provide patients with ‘answers’ when medical science has none (Young et al., In press). Collectively, these findings suggest that endometriosis presents a potential minefield of knowledge and power struggles between women and doctors. This is encapsulated by Seear’s (2014, p. 29) description of endometriosis as the “literal and metaphorical point at which various ‘threats’ to the gendered, natural, human, traditional body are enacted.”

To have knowledge is to have power: *“*there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time, power relations” (Foucault, 1977, p. 27). Medicine has gained the social currency of knowing the ‘truth’ about the body; patients’ knowledge of their own bodies has historically not been valued in the medical encounter, being viewed as subjective and inferior (Lupton, 2012; Nettleton, 2013). Female patients are further devalued because women’s embodied knowledge is secondary to the androcentric Western medical canon (Martin, 1987; Pringle, 1998; Ussher, 2006). There has been a recent social push for the inclusion of patient knowledge in medical knowledge production (British Medical Journal, 2018) and practice (Stewart, 2014). Nevertheless, research suggests that clinical expertise (as opposed to science, the “epistemological face” of medicine: Whelan, 2009) tends to dominate the medical encounter (Lupton, 2012; Nettleton, 2013), including for endometriosis (Whelan, 2009). Clinicians embody and maintain the social power of the medical institute through their everyday clinical practice (Foucault, 2003), but they do not necessarily exert this power through overt coercion nor deliberately subordinate patients, and patients are not always submissive (Lorentzen, 2008; Lupton, 2012). The social interaction between doctor and patient is complex, with opportunities for power to be both productive and oppressive for each (Foucault, 1977; Lupton, 2012). No research has yet explicitly examined women’s experiences of navigating knowledge and power in medical encounters for endometriosis.

We aimed to investigate how women navigate knowledge and power within the medical encounter to receive healthcare that assists them in managing endometriosis. Informed by a feminist social constructionist perspective, we examined women’s perceptions of knowledge and power held by doctors and themselves. (We have also reported clinicians’ perceptions of knowledge and power held by women and themselves; Young et al., In press.)

**Method**

The research reported here is part of an investigation into the psychosocial aspects of endometriosis from the perspectives of both women and clinicians.

*Theoretical framework*

A feminist social constructionist framework informed the research design and data analysis and interpretation. At each stage we endeavoured to produce knowledge both about and for women, contributing to medical knowledge and practice that recognises their full humanity (Letherby, 2003). Social construction theory is based on the belief that knowledge is created not as a reflection of one ‘true’ reality but as a product of humans’ collective assumptions about the world as shared through language (Lupton, 2012). We sought to make transparent the processes by which medical science knowledge comes to exist and be socially privileged, and the implications of this for women (Backhouse, 1996). We considered the literature on the medicalisation of the human body, women, and endometriosis (as reviewed in Young et al., In press) to position women’s perspectives within the broader sociocultural and historical contexts.

*Setting*

This research was conducted in Victoria, a south-eastern state of Australia. Australia has a two-tier healthcare system: a publicly funded universal scheme and a private insurance funded scheme, with approximately half of all citizens holding private (hospital and/or ancillary) cover (Australian Bureau of Statistics, 2017). Endometriosis care in Australia is typically led by a gynaecologist (to whom women are referred by a general practitioner [GP]) and monitored by a GP, varying according to geographic proximity of gynaecological specialist services; the exception to this is admission to an emergency department which may result in direct referral to specialist services (Manderson, Warren, & Markovic, 2008).

*Participants and recruitment*

Women aged at least 18 years living in Victoria, Australia, who had been surgically diagnosed with endometriosis were eligible to participate. In August and September 2013 calls for volunteers were distributed in a national women’s health magazine (Jean Hailes for Women’s Health, 2013) and at three Women’s Health Week events (Jean Hailes for Women’s Health, 2018).

Purposive recruitment was also used to ensure diversity among participants (in both socio-demographic factors and experience), an essential component of rigorous qualitative research (Hammarberg, Kirkman, & de Lacey, 2016). We aimed to address the knowledge gap in the qualitative literature on women’s experiences of endometriosis, in which participants were predominantly White, heterosexual, and recruited from specialised treatment clinics and support groups (Young et al., 2015). The demographic profiles and experiences of the first 20 participants were assessed to identify gaps to be addressed by purposive recruitment. This revealed that, although their experiences of endometriosis were diverse, these women were of similar demographic background (born in Australia, heterosexual, in a relationship). Purposive recruitment was conducted to increase demographic diversity: advertisements were placed with queer-friendly organizations (e.g., social venues, university student groups) and cultural services (e.g., government organizations, university services).

*Data collection*

In-depth interviews were conducted (by the first author, January-September 2014) in person or by telephone and audio-recorded, with permission. An interview guide consisting of broad questions and conversation prompts was used to encourage further exploration of topics, but the primary focus was what each woman deemed to be important. The opening question was, ‘Please tell me about your experience of endometriosis. You can start from whatever point you like and include whatever you find necessary.’ After the interview, participants completed a short demographic form, chose a pseudonym and indicated whether they would like to receive a copy of their interview transcript to “check for accuracy and resonance with their experiences” (Birt, Scott, Cavers, Campbell, & Walter, 2016, p. 1802).

*Data analysis*

Recordings were transcribed into a Microsoft Word document and all potentially identifying information was removed. The first author extracted all interview content pertaining to medical encounters, with thematic analysis of any discernible indication of knowledge and power using a data-driven method following Braun and Clarke’s (2006) six steps of thematic analysis. This is the most widely cited thematic analysis method, offering a flexibility that enables application within a range of theoretical frameworks and types of data (Clarke & Braun, 2017). We took a phenomenological approach in that we privileged interactions that women deemed to be significant and sought to understand them from their perspective (Liamputtong, 2013). NVivo10 was used to manage the data. Analysis, the hierarchy of themes, and final categories of data were discussed among all authors until consensus was reached.

*Ethics*

Approval for the research was granted by the Monash University Human Research Ethics Committee (CF13/2892-2013001551). We also practised reflexivity and ethical mindfulness throughout the research (Bowtell, Sawyer, Aroni, Green, & Duncan, 2013; Liamputtong, 2013). There was potential for participant distress given that several aspects of the endometriosis experience—such as menstrual irregularities and painful sexual intercourse—may be considered ‘sensitive topics’ by some women (Denny, 2004; Seear, 2009). In addition to the standard provision of available support services, the interviewer made it clear to each woman prior to their interview and throughout that they could stop or take a break whenever they desired, or choose not to speak about a specific topic; a discreet supply of tissues was always kept in the interview pack.

**Results**

Twenty-six women participated in the research; their characteristics are summarized in Table 1. The majority were aged in their thirties, had been diagnosed (on average) three-and-a-half years previously, were born in Australia, were living with a partner, and identified as heterosexual. Approximately half had completed tertiary studies and about half reported having experienced infertility. Five women had children; two women were pregnant with their first child. Purposive recruitment yielded six additional women with diverse sexual identities and places of birth; four women spontaneously identified with a non-Anglo culture.

Fifteen participants were interviewed in person and the remainder by telephone. The content and tone of the interviews did not differ by mode. Interviews lasted 34–103 min (mean 63 min). Seventeen women opted to receive a copy of their interview transcript. Several women were visibly upset during their interviews by the matters they were describing. Even so, participants have been found to say (and did so in this case) that they value the opportunity to tell their story and to be heard by an empathic listener (Wolgemuth et al., 2015).

Women spoke of many aspects of living with endometriosis. Their experience of negotiating doctors’ knowledge and power was an important theme that arose spontaneously. All women spoke about this to varying degrees; it tended to be more prominent in accounts from women whose diagnosis was prompted by symptoms rather than by infertility. Women emphasised healthcare received from GPs and gynaecologists; emergency room doctors, surgeons, and radiologists were also mentioned.

*Women’s perceptions of doctors’ knowledge and power*

*The expertise of doctors.* Women positioned themselves within a discourse of medical knowledge while simultaneously reporting their own evidence of doctors’ failures to exemplify it. This discourse was most often endorsed when recounting their early experience of endometriosis and was increasingly challenged with each additional medical encounter experienced:

*When I first got diagnosed I just did everything the doctor said. … Even though things felt uncomfortable to me … I just thought I don’t really have a choice. … They don’t offer you much except surgery and Mirena* [intrauterine device] *which to me doesn’t really deal with the cause of why this disease is growing in your body. –* Lucy

Women gave the following examples of doctors’ lack of expertise: perceived lack of knowledge about endometriosis among doctors (*She didn’t know the aspects of the disease. … That’s pathetic.* [Leigh]), no associated improvement in symptoms (*I just gave up listening to the experts … ‘cause it didn’t help.* [Maree]), having doctors repeatedly do the same routine tests and examinations (rather than consider a new approach), and the normalisation of women’s pain and discomfort (which, Lucy said, “*needs to be challenged*”). Some women explicitly stated that they “*don’t expect doctors to know everything”* (Sera) but that they should be “*honest*” about what they do not know “*because it’s not a weakness*” (Maree).

One participant is not only a woman with endometriosis but also a doctor and the partner of a woman with endometriosis. She stated that, “*I probably diagnose endo more than anyone else at my clinic*” because she was “*more vigilant of it and aware of it.*” She found it “*really hard to separate*” being a doctor and a patient but, when she receives care, “*I’m just a patient and I have to ask stupid questions and not be a doctor*.”

*The authority of doctors.* Regardless of their perceived expertise, doctors (typically gynaecologists) were recognised by women as an “*authority*” with “*the power of your life*” (particularly during surgery) and “*the power of* [your] *quality of life*” (Lucy). Helen said that “*you’ve got be careful*” because doctors can label you “*a hypochondriac*” and thus a “*mad woman*.” Women therefore reported often feeling “*nervous*” (Annie, Eleanor), “*scared*” (Annie, Tikvah), and “*confronted*” (Lucy) when going into a consultation. However, these feelings reduced with repeated medical encounters where they learnt “*what to expect*” (Annie), realised doctors were “*very limited in what they can offer you*” (Lucy), or decided not to “*put up with*” any aspect of healthcare they were not happy with (Emerald).

When healthcare caused physical or emotional harm, some women sought to have their doctor reprimanded. They typically did so through formal complaint processes at their doctor’s place of work, to medical boards, and to their local member of parliament. They also shared their experience with other women “*because I don’t want anyone else to suffer that arrogance and the callousness*” (Emerald). Other women did not complain to authorities because it was “*your word against theirs, and who are they going to believe? A patient or a doctor?*” (Tikvah) and because “*you just want to get on with your life, and never see that person ever again*” (Rachael).

Several women noted that the fees doctors charged for their services reinforced the social power divide between doctor and patient: “*they’ve got money and we don’t*” (Tikvah). Women expressed concern over clinicians who were both endometriosis and fertility specialists. For example, Lucy perceived this to be a “*conflict of interest*” because “*that’s their speciality so that’s* [prescribing IVF] *their focus*” and “*it’s making them money.*” Bianca had a similar concern:

*I’ve seen two endometriosis specialists who work for two major IVF companies in Victoria and both of them have said, … obviously because they’re IVF sales people, … let’s do some IVF. … That’s actually cruel because you know what I’m going through.* – Bianca

Bianca stated a need for “*somebody to talk to*” who is not going to say “*Give me all your money. I’ll fix you*.”

*Women’s perceptions of their own knowledge and power*

*I know my body.* A strong theme in women’s accounts was the use and value of their embodied knowledge in the medical encounter. Women talked about “*know*[ing] *your own body*” and “*when something isn’t right*” (Rebecca). This typically concerned their initial consultation about their symptoms, or when symptoms returned after diagnosis and treatment. Doctors were reported as favouring their own perspective despite women’s efforts to convince them of the validity of their own knowledge:

*I know my body better than what he does so I knew there was something more to it rather than just being psychological and all in my head, as he put it.* – Tash

*I think understanding that, potentially, your patients know more about themselves than you do, because you’ve only met them 10 minutes ago, is something that all GPs should listen to*. – Nat

Some women recalled “*doubt*[ing]” (Tash, Audrey) knowing their body when experiencing symptoms they could not explain and that a doctor could (or would) not treat:

*“This is my body, but why don’t I understand what’s going on? Why can’t someone look inside me and tell me what’s not quite right and then how can I fix it?”* – Audrey

*Women’s positioning of their knowledge within the medical encounter.* Women spoke of their embodied knowledge as being an important piece of “*evidence*” (Lucy, Olive) to guide their own self-management and for their doctors to guide diagnosis and treatment. Eleanor said that she has “*learnt to understand what my body’s telling me and then treat it*” while Jane A stated that “*you can tend to feel when* [the] *endo is back; … you can start to work out what’s going on*”. Bianca asserted that she is “*living proof*” that endometriosis is “*not ‘just’ cramps*” (as it is often represented in social and medical discourses: Lemaire, 2004).

Olive said that what she could “*feel and observe*” in her body “*completed the story*” to which her doctors also contributed with medical testing, imaging, and surgery; what they do “*joins the dots for you*”. However, Lucy recalled that her gynaecologist “*almost laughed at*” her when she initiated a discussion around the potential benefits of dietary changes; he believed there to be “*no evidence for that kind of thing*”. Lucy responded: “*There is. The evidence is my body, that when I eat something, what happens?*”

*Be your own doctor.* It was common for women to claim that “*you have to be your own doctor”* (Rachael) for endometriosis, given the limitations of the healthcare they received. Some reached this conclusion when seeking a medical diagnosis, while others arrived at it after being diagnosed and trialling several treatments.

*Pre-diagnosis.* Several women “*worked it out*” (Emerald) that they had endometriosis and requested a formal diagnosis from their doctor. Women came to believe they had endometriosis based on information encountered in medical journals, Google Scholar and the internet, support groups for IVF and endometriosis, university courses, and accounts from female friends and family. For example, Rachael “*was getting really frustrated and no one was helping*” her so she “*just Googled”* her symptoms and found they matched the symptoms of endometriosis; she “*put that forward to the specialist*.” However, some did not feel able to suggest a diagnosis to their doctor: “*I’m not one to sit there and tell the doctor I think it’s endo. You’re the doctor. Why can’t you fix me?*” (Eleanor).

Women reported their doctors as typically “*unwilling to diagnose*” (Emerald) endometriosis if the woman made the initial suggestion. They said that doctors told them that the woman was “*far too young*” or “*wouldn’t be able to function*” if they had it (Bianca), or that they were “*on the Pill* [so] *don’t worry about it*”; if they had “*problems when you look to have children, … then we’ll look at it*” (Jane B). Women usually continued to request that their doctor “*investigate me for endometriosis*” (Bianca), having “*decided that he was wrong and I was right*” (Emerald). Others “*put it out of my mind* … [because] *your doctor tells you that it’s normal*” (Jane B) until later diagnosis by another clinician.

 *Post-diagnosis.* Once a diagnosis was received, being one’s own doctor was described by women as investigating and managing their symptoms, often with the (sometimes reluctant) assistance of their doctors. Women tried various types and combinations of pharmaceutical pain relief, worked out “*foods and things that seemed to exacerbate the pain*” (Emerald), requested doctors check their “*hormonal levels*” (Bianca), inquired with their doctor or looked online for any “*break-throughs*” (Bianca) in treating endometriosis, requested surgery to check disease progression, requested symptomatic sites be checked in surgery, requested endometriosis be surgically removed prior to doing an IVF cycle, and did their own investigating (“*I’ve become very educated on the topic*” [Rachael]).

These women deemed it necessary to take agentive action to make it more likely that healthcare and treatment would assist them to manage their symptoms; relying solely on their doctor had proven inadequate. Bianca’s sarcasm is illustrative: “a*ll they’re really saying is come and do surgery, or try and have a baby. ‘Cause a baby will fix everything*.” In contrast, Olive thought women should “*trust your GP and rely on them to find the useful information*.” By this she meant not “*that you put all your faith in the doctor and … kneel at their desk*” but “*trust them to put you into contact with reliable support networks*.”

*Advocate for yourself.* Many women spoke of self-advocacy as a standard part of contemporary healthcare for endometriosis (and, to a lesser extent, women’s healthcare in general) to ensure their needs were met. For example, Charlotte said that “*even though my doctors were amazing and they’ve done a great job, you … need to be an advocate for yourself*” because doctors will not always have the “*right answer*” for you. By ‘advocating for yourself’, women meant: “*just keep asking questions*” (Charlotte), not being “*afraid to question what a doctor has to say*” (Eleanor), “*keep pushing your doctor* [for answers]” (Rebecca), “*make them do something about it* [the symptoms]” (Eleanor), not accepting “*second rate treatment*” that can “*waste a lot of time*” and cause “*damage*” (Jane B), “*insist if something isn’t quite right*” and you want it “*looked at*” (Emerald), and taking “*ownership of their* [the woman’s] *medical care*” (Nat).

Annie placed less importance on advocating for oneself than did others. She has sometimes said “*no*” to her doctor’s suggestions but, for the most part, did not “*give a lot of thought*” to decisions about her treatment because she trusted that her doctors were “*doing the best thing for me*.”

*Change doctors.* Women spoke about having to change doctors several times to find one that could assist in managing their endometriosis; some were still searching at the time of their interview. Most often, this was to seek specialist care with a gynaecologist (rather than their GP) or changing to a different GP or gynaecologist.

 *Pre-diagnosis.* Several women spoke of a power struggle with their GP when the woman sought to consult a gynaecologist but her GP was reluctant or refused to refer. (In contrast, Tash stated that “*most of the time they* [GPs] *just write the referral”*.) Marjorie, for example, said her GP was “*quite willing to just keep changing Pills around*” and that it was not until “*I stopped* [the Pill] *myself*” that “*she relented”* and *“let me go to the gynaecologist*.” Marjorie’s interpretation was that “*GPs like to be the hero*” (to diagnose and treat the woman’s illness); Eleanor was also concerned about this and stated that she is not “*an experiment*” for doctors. Jane B faced a similar dilemma with her GP: “*I pushed but it took me … about 6 years”* before she was referred to a gynaecologist. Even then, “*It wasn’t actually, ‘I think you have something wrong with you and we need to get this diagnosed’. It was, no, with the view to having children*”; her GP thought it would be “*good if I knew an obstetrician*”. Emerald summed up GPs’ reluctance to refer women to a specialist as:

*GPs are not experts. They are general practitioners, and that doesn’t mean that they don’t have skills and knowledge that is of value; they do. But part of that skills and knowledge is knowing where to go to get the specific expert help that is required. They are not experts in women’s reproductive organs*. – Emerald

 *Post-diagnosis.* Once diagnosed, women continued to change doctors (GPs and gynaecologists) for a variety of reasons. When Audrey encountered a GP who did not “*know about endometriosis*”, she did not “*trust*” them so found another doctor with knowledge. Rebecca gave her first gynaecologist “*the flick*” because “*she didn’t specialise in endometriosis*”; she then received “*better care and support*” from a specialist.

Power struggles often revolved around whether further treatment was ‘necessary’ and what it should be. Jane A recalled that her gynaecologist “*refused to treat me, saying there was nothing wrong*”. She changed to a gynaecologist (recommended by a friend) who “*operated within two days”* and found that the previous gynaecologist “*not only left half the cyst but … there was endometriosis everywhere*.” Jane B said it was “*time that I spoke to somebody else*” when her gynaecologist told her it was “*Provera* [progesterone hormonal therapy] *or nothing*” and that she should “*suck it up*.”

Alex and Lucy wanted to change doctors but found it difficult. Alex was unhappy with her obstetrician-gynaecologist but “*felt guilty, in a sense, like disloyalty or betrayal*” at the prospect of change. It was not until her doctor advised medication that she feared might harm her baby that Alex felt “*empowered enough to say, look, I’m not happy with the service you’re providing*.” This was made difficult by living in a rural area where Alex had a limited choice of doctors. Lucy had wanted a new gynaecologist but “*didn’t feel confident enough to do it*” because a new doctor would not have that “*intimate knowledge of your disease*” because “*you can’t really tell just from notes*.” However, she suggested she might be “*ready for a fresh approach*” for her next surgery.

*What women want: To be heard and believed*

Women often spoke of encountering doctors who did not listen to them, denying them an opportunity to contribute their embodied knowledge while exerting their own power and knowledge. This was typically when women were seeking a diagnosis, when deciding to have a surgery or try a new hormonal therapy, or when there was a disagreement around the treatment plan (or lack of one) for the woman. For example, Alex said “*it would have been nice to actually have some time to explore the different issues*” instead of the doctor saying, “*this is what you’re going to do*.” While Annie said of her previous gynaecologist: “*he didn’t take much notice of things that I was saying*” and gave the example of attempting to discuss her concerns about gaining weight only to be dismissed with the statement that, “*it’s annoying when women put their weight gain down to hormonal therapy*.” And Rachael said:

*I ended up in emergency again and … for the first time the gastroenterologist sat down with me and said, ‘I want to hear everything, tell me from the beginning.’ … I think that was the first time a doctor had ever asked me what my opinion was. … Some doctors are willing to sit down with you and listen to … how you would explain it, whereas other doctors think that they know best.* (Rachael)

In addition to being heard, women also wanted their doctors to believe what they said. For example, Emerald advised doctors that if their “*patient is telling you that they have pain, assume they’re telling you the truth. … Don’t dismiss it*.” Four women spoke of being accused of “*looking for drugs*” (Leigh) and being a “*drug seeker*” (India) by GPs and emergency room doctors when seeking a prescription for their usual pain killers, typically after they had been diagnosed (and their usual doctor was unavailable). Marjorie was frustrated that her gynaecologist did not believe that she did not want to have children: “*That’s making an assumption on me and my character, and you don’t even know me*.” Jane B stated that not believing women makes endometriosis “*more difficult than it is.*”

**Discussion**

We examined women’s experiences of navigating knowledge and power within the medical encounter for endometriosis to receive healthcare that assists them in the management of their disease. Women valued both their own embodied knowledge and doctors’ clinical expertise; when these were in conflict the source they privileged varied, but it was essential that the woman (and not the doctor) dictated which it would be. Women recognised their relational power to request specific services of their doctor and to change doctors if these were not provided. However, they were wary of the social status and power of doctors to reduce their wellbeing through medical labels they did not identify with or withdrawing care completely. Women identified the need for doctors to listen to and believe them as being essential to the provision of healthcare that meets women’s needs and addresses the complexities of endometriosis.

This study is the first to have investigated women’s experiences of navigating knowledge and power within the medical encounter for endometriosis and is one of few to have included a diverse community sample and the unique perspectives this fosters (De Graaff et al., 2015; Young et al., 2015). Diversity was lacking, however, in the inclusion of younger (18-21 years) and older (60+ years) women. The findings of our research may not translate to settings that differ from a high-income Anglophone country with both universal public and private healthcare systems. Several women indicated feeling confronted by how inarticulate they perceived themselves to be in their transcript and one asked to have a small section redacted. These women’s reactions are consistent with Barbour’s (2001) suggestion that it is perhaps an “exploitive or distressing” task to ask of participants (p. 1117). However, inhibiting women’s access to their contribution risks paternalism and may not reflect feminist research principles (Letherby, 2003). Further research is needed on this aspect of research practice.

Women’s reported experiences of having their knowledge dismissed and devalued are consistent with our recent investigation of clinicians’ perceptions of women with endometriosis: clinicians reported dismissing women’s knowledge as unnecessary (their clinical expertise told them all they needed to know) or viewed it with great suspicion (because it was “subjective”; Young et al., In press). Our findings also corroborate previous investigations from women’s perspectives in that they have consistently reported clinicians as dismissing their knowledge and experience (Culley et al., 2013; Facchin et al., 2018; Young et al., 2015). Collectively, this research suggests that, despite momentum for the inclusion of the patient perspective in contemporary clinical practice (Stewart, 2014), the woman patient continues to be ignored or silenced as she historically has been (Martin, 1987; Pringle, 1998; Ussher, 2006). (Male patients may also have their perspective treated similarly by clinicians, but not with the consequence of reinforcing gendered norms that inhibit their full social and economic participation, as it does for women; Laqueur, 1992; Malterud & Hollnagel, 1999; Schiebinger, 1986.) Women’s accounts (and our previous research with clinicians: Young et al., In press) suggest this may particularly be a problem when the clinician confronts aspects of a woman’s care that are not easily guided by current medical knowledge (for example, women who trial available treatment options but experience minimal relief and continue to seek care). Our findings and interpretation are consistent with research on other conditions with little medical explanation—which are disproportionately diagnosed in women—such as fibromyalgia and chronic fatigue syndrome (Shattock, Williamson, Caldwell, Anderson, & Peters, 2013).

Women were wary of their doctor’s power to have adverse effects not only on their illness experience but on their lives more broadly. They appeared to be aware that it was not in the very distant past that doctors labelled women as mad when their symptoms (or behaviour) could not otherwise be explained and that they remained vulnerable to such practice; labelling might now be less overt but still results in harmful consequences for women and their health (Jones, 2015; Ussher, 2011). Women, however, did not perceive themselves to be entirely powerless in the medical encounter. The relational power they held was most often discussed about addressing a limitation of the care they were given or denied (‘being their own doctor’ and changing doctors, for example). Women are entitled to healthcare that meets their diverse needs and that fosters their full social and economic participation in society; women’s active participation in their care is essential to achieving this (World Health Organization, 2009). Nevertheless, such participation should not be expected of women as a means of addressing the gaps in care created by a medical system that has historically failed to incorporate their perspectives in both knowledge production and practice (Lupton, 2012; Schiebinger, 1989). Clinicians have an obligation to women to provide quality care regardless of available medical knowledge (World Health Organization, 2009). This is complicated by a strong social expectation that they should always have the answers to one’s bodily conundrums (Lupton, 2012; a feat that inevitably they cannot always perform), and the delivery of little associated education and training to guide clinicians in managing this within the medical encounter (Malterud, 2002). Women’s knowledge and experiences of their bodies provide clinicians with an additional source of information to guide quality care (Frank, 1995; Kleinman, 1988; Malterud & Hollnagel, 1999). Thus, the interests of both women and clinicians are served by a medical encounter in which each party’s knowledge (and power) is acknowledged and incorporated.

A useful framework to facilitate doctor-patient communication for chronic conditions—which, by definition, have no cure and require long-term care and management—such as endometriosis, is that of ‘illness narratives’ (Frank, 1995; Kleinman, 1988). The stories women tell their doctors of their endometriosis and how they are received “connect body, self and society,” and are an opportunity for clinicians to either increase suffering by dismissing them or to aid healing by acknowledging and incorporating them into their care (Kleinman, 1988, p. xiii), as women in our study discussed. Several publications offer clinicians guidance on how to approach illness narratives within the time constraints of the modern medical system (see, for example, Kleinman, 1988; Malterud & Hollnagel, 1999). (Although implementation research is needed to determine feasibility and acceptability among women and clinicians.) However, it is likely to be more effective if associated training were included in medical curricula and in-service training, in a way that preserves illness narratives as the act of “reach[ing] out as one human to another” rather than reducing it to another formulaic medical assessment (Frank, 1995). We argue that for doctors to do this—particularly with patients who have been historically excluded and devalued by the medical institution such as women and those identifying as GLBTQI (Lupton, 2012)—they need an understanding of the social, economic and political factors that shape burden of disease and the role of healthcare to improve (and not impede) people’s lives. ‘Social medicine’ address these facets of medical care, and there are several models available to be considered for inclusion in medical curricula (see Westerhaus et al., 2015 for a summary).

**Conclusion**

Women navigated knowledge and power within the medical encounter for endometriosis through a complicated dance between their own embodied knowledge and the clinical expertise of their doctors. While they valued and utilised their own knowledge and power, they were wary of the power of their doctors to deny them healthcare and to diminish their wellbeing through inappropriate and ineffective care. Our findings suggest that medical education needs to equip doctors with the skills to acknowledge and incorporate women’s knowledge of their bodies within the medical encounter, and to understand how their practice can foster (or impede) women’s full social and economic participation. We conclude with our participant, Emerald’s, summation: *If … those messages can get through to GPs and surgeons, so that women are treated as partners in their health, instead of patients that have things done to them, that would be a good thing.*

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