

Research paper

From womanhood to endometriosis: findings from focus groups with women from different ethnic groups

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What is known on this subject

- Endometriosis is a gendered condition both culturally and physically.
- Little is known about the experience of endometriosis among women from minority ethnic groups.
- Cultural values are important in influencing attitudes to reproductive health issues.

What this paper adds

- It discusses the way in which cultural values and understandings influence women's response to symptoms of endometriosis.
- It provides examples of how endometriosis is perceived in five specific ethnic groups.
- It explores the importance of fertility in the perceived response to endometriosis.

ABSTRACT

Endometriosis is a long-term, disabling condition, and a common cause of chronic pelvic pain, yet little is known about the experience of the disease among women from minority ethnic groups. This paper reports on the first phase of a UK-based study (the Endocul Project), which explored community awareness of endometriosis and the experience of living with the disease in a sample of women from a range of minority ethnic communities (Indian, Pakistani, African Caribbean, Chinese and Greek/Greek Cypriot). Focus groups were conducted with healthy women from these five communities on contextual issues surrounding endometriosis and

the women's awareness of the condition. The data reveal many similarities between the groups, and between them and the majority white population. They also highlight cultural differences in perceptions of reproduction, fertility and menstruation. While not wishing to stereotype women, the findings of this study demonstrate the importance for providers of healthcare of recognising socio-cultural differences.

Keywords: ethnicity, focus groups, qualitative research, reproduction, women's health

Introduction

Endometriosis is a chronic, disabling condition, and a common cause of chronic pelvic pain. Estimates of its incidence range between 5% and 15% of the adult female population (Damewood *et al*, 1997; Ballard *et al*, 2006). It is usually characterised by pelvic and abdominal pain, lower back pain, and deep dyspareunia (pain on deep penetration during sexual intercourse); other symptoms, such as urinary and bowel dysfunction, may be present in some women. The symptoms usually fluctuate in a cyclical manner, but the pain can be constant. However, a woman who is diagnosed as having 'mild' disease by diagnostic categorisation may experience severe symptoms, while a woman who has extensive disease may be asymptomatic, and is only diagnosed opportunistically (e.g. during investigations for infertility). Endometriosis is associated with up to 40% of attendance at fertility clinics (Lessey, 2000). Although there are many medical and surgical interventions for endometriosis, there is no definitive cure.

There is growing evidence in the research literature about the experience of living with endometriosis. Within this body of work, a picture of many years of pain is consistently catalogued, along with difficulties and delay in getting a diagnosis and treatment, negative effects on work, social relationships and family life, and poor experiences in the healthcare system (Cox *et al*, 2003; Whelan, 2003, 2007; Denny, 2004a; Jones *et al*, 2004; Huntington and Gilmour, 2005). These studies contain descriptions of many problems for women with endometriosis, some of which derive from the enigmatic nature of the condition and the highly gendered 'delegitimation' of women's accounts by the medical profession (Whelan, 2007). However, such important studies are largely confined to women from majority white communities. Little is known about the incidence of endometriosis by ethnicity, or of the specific experiences or needs of minority groups (Cramer and Missmer, 2002; Kyama *et al*, 2004).

In this article we report the first phase of a UK-based study (the Endocul Project) which used focus groups to explore community awareness of endometriosis and experiences of living with endometriosis in a sample of women from a range of minority ethnic communities (Indian, Pakistani, African Caribbean, Chinese and Greek/Greek Cypriot). Within the study, which was funded by the UK National Institute for Health Research, we also explored the experiences of women with endometriosis from these five minority ethnic groups (phase 2), and the attitudes and information needs of healthcare providers (phase 3). A paper addressing the second phase of the study and the overall outcomes is in preparation.

Background

Endometriosis is a condition characterised by a largely hidden stigma (Goffman, 1963), which affects intimate aspects of female bodies. The majority of women experience the worst of their symptoms around the time of menstruation, and many find that these are treated as dysmenorrhoea, which tends to be viewed by medical practitioners and others as a 'normal' part of the menstrual cycle (Denny, 2009). This normalisation is described as a 'narrative of endurance' (Markovic *et al*, 2008), both in the interpretation of pain by women and in their acceptance of the often dismissive response of medical practitioners. Doctors will frequently undermine patients' accounts of their illness, and therefore their credibility, by portraying them as nervous and irrational women who exaggerate their symptoms (Whelan, 2007). The experience of endometriosis is thus gendered, both physiologically and culturally, and concepts surrounding it are bound up with other gendered and culturally variable concepts such as womanhood, menstruation and reproduction.

There are no robust published data on ethnic differences in the prevalence of endometriosis (Shaw *et al*, 2003), or data on how women with endometriosis, who are members of minority ethnic communities, experience healthcare. We know from many other studies that healthcare systems in many societies do not always respond appropriately to the needs of minority groups, and that minority ethnic patients in developed societies generally evaluate care more negatively than white majority patients (Aspinall and Jacobson, 2004; Bhopal, 2007; Mead and Roland, 2009).

The experience of both illness and healthcare is multifaceted. Illness behaviour and the medical response to this are clearly mediated by ethnic and cultural difference (Denny, 2009). The experience of endometriosis for all women is bound up with cultural representations of menstruation. Although ideas relating to menstruation are historically and culturally specific, most societies have some taboos or rituals concerned with the menstruating woman. In her research among men in the UK, Laws (1990) uses the term 'etiquette of menstruation' to describe the expected behaviour of women during this time. Interestingly, it is cultures other than the dominant white cultures that have most frequently been studied in terms of menstrual taboos. This, Laws argues, demonstrates complacency about how menstruation is dealt with in the UK, and by extension in other developed, post-industrial countries. It also reflects a culturalist approach to ethnic inequalities whereby only minority ethnic communities are seen as having 'culture.' Laws argues that the meaning of menstruation is bound up with ideas that

it is something that must be hidden, and derives more strongly from the social rules surrounding it than from its biological nature. The 'etiquette of menstruation' is often associated with negative connotations, including feelings of shame, embarrassment, and the need for concealment. Britton (1996) found that, from an early age, women learned negative images of menstruation, associated with bleeding and pain. Yet women are also told that menstruation is a normal and natural event, something that marks one as a mature woman who is capable of reproduction. Seear (2009) argues that the stigmatisation of menstruating women as discreditable is associated with concealment and a consequent reluctance to disclose the symptoms of endometriosis. Even when women identify that their experience is not normal, obstacles such as criticism and the trivialising of pain by family, employers and others deter them from seeking professional help.

The idea of 'menstruation as pollution' is common in many cultures, and influences practices and taboos. For example, Helman (2007, p. 47) talks about cultural conceptions of the 'polluting power' of menstrual blood, which is believed to cause weakness in males, and of the perception of menstruating women as having a contagious pollution by South African Zulu peoples: 'Crops may be ruined or cattle fall ill if she walks among them' (Helman, 2007, p. 48). He further argues that the menstruating woman can also be viewed as 'vulnerable', and that customs and taboos are designed to symbolically protect women while also shielding men from the polluting power of menstrual blood. However, Laws (1990) warns against the conflation of these types of taboo and the rules of etiquette, which may be quite minor cultural markers of menstruation, and emphasises diversity of cultural practice. It has to be remembered that, for many societies and for much of history, menstruation was a rare occurrence for women, who were either pregnant, breastfeeding or malnourished for many of their reproductive years, and therefore it may also have been viewed as something out of the ordinary.

Cultural ideas of reproduction and motherhood can also influence how women experience endometriosis, because it is implicated in infertility. Helman (2007) states that, in societies where the desire for high rates of childbearing is low and where contraception is easily available, sex gradually becomes divorced from fertility, and practices that do not lead to pregnancy are more widely tolerated. Conversely, if large families are highly desirable, then sex and fertility are conceptually intertwined, and sex outside marriage is not tolerated. Whether or not sex is seen as purely for the purpose of procreation, most contemporary societies are pronatalist (Letherby, 1999). They display attitudes and policies that are pro-motherhood and encourage reproduction at least in some sections of the population

(Culley and Hudson, 2009). Infertility, whether voluntary or not, is considered deviant or abnormal, and childless women are seen as not real women (Letherby, 1999; Culley and Hudson 2009). Those women for whom being childless has traditionally been socially sanctioned, such as widows, nuns and nannies, have been defined by loss, self-sacrifice or the nurturing of other people's children, thereby bolstering pronatalist cultural discourse (Gillespie, 2003).

Although expectations about childbearing for normative adulthood are dominant in most societies, the intensity of such attitudes and the impact on women and men is culturally diverse. A range of studies of cultural differences in the experience of infertility within low-resource and developed countries (van Balen and Inhorn, 2002; Culley *et al*, 2006) have demonstrated the often devastating consequences for the social and psychological well-being of women in particular. In their study of infertility in South Asian communities in the UK, Culley and Hudson (2006) found a very intense pronatalist ideology, with marriage being almost universal and infertility being highly stigmatised.

Study design

The sensitive nature of the topic and the need to sensitise the research team to the views of the communities in the study meant that a qualitative design was deemed appropriate for this study (Green and Thorogood, 2004; Atkin and Chattoo, 2006). A multi-phased approach was adopted in order to obtain the views and experience of a range of stakeholders whose attitudes and behaviours may influence the experience of endometriosis (Whelan, 2007).

Phase 1 of the Endocul Project focused on healthy women, who were each invited to take part in one focus group with other members of the minority group to which they belonged (see Table 1). The aim was to gain insight into community views, values and practices regarding reproductive issues such as womanhood, reproduction and sexuality which gave a cultural context for the experience of endometriosis among women from minority ethnic groups.

Focus groups can serve a useful function by setting data in context during the exploratory phase of a project (Culley *et al*, 2007). They can also allow participants to bring to the fore issues of significance to them (Bryman, 2008), and offer a reflexive framework for the nature of attitudes and the construction of issues (Waterton and Wynne, 1999).

Although the term 'focus group' may be used to describe any form of group interview (Wilkinson, 1999; Green and Thorogood, 2004), there are various types of grouping, and those involved in this study may more accurately be described as 'natural groups', since

Table 1 Details of focus group participants

Group	African Caribbean	Chinese	Greek/Greek Cypriot	Indian	Pakistani
Number of participants	8	10	8	10	6
Age range (years)	18–40+	18–35	19–46	> 35	26–40
Number born in the UK	4	0	6	1	2
Marital status	6 single 1 married 1 separated	6 single 4 married	3 single 4 married 1 divorced	9 married 1 divorced	4 married 2 divorced
Stated proficiency in English	All high	6 = moderate to high, 1 = no English	All high	9 = moderate to high	All moderate to high
Religion	7 Christian 1 none	6 Christian 4 none	All Greek Orthodox	All Hindu	All Muslim
Employment	4 full-time 2 part-time	4	4 full-time 4 part-time	5 full-time 3 part-time	4 full-time 2 part-time

a number of the women who participated came from the same geographical location, and some of them already knew each other. This was particularly appropriate in order to maximise interactions between the participants, and in providing access to a shared culture. In researching sensitive issues such as sexuality and reproduction, a natural group with similar people may encourage more openness than other types of interview situation, and solidarity stemming from shared problems may encourage more free expression of opinions (Wilkinson, 1999). The researchers in this study were particularly interested in how the participants discussed the issues raised as members of a social group, rather than as individuals. The goal was to elicit community perspectives rather than personal views. Thus, as well as showing solidarity, individuals could challenge or refute the views of another as not reflective of the culture (Bryman, 2008).

Ethical approval

Ethical approval for the study was obtained from North Staffordshire Local Research Ethics Committee in March 2008.

Method

Community facilitators were recruited from the target minority ethnic communities to conduct the focus groups. Their role was to organise, facilitate and transcribe focus group discussions that took place with members of their community group, and to verify the

translated participant information sheets. Most of them were experienced in conducting focus groups, and all of them attended a one-day training event designed to familiarise them with the aims of the project and to provide background information on endometriosis. They also played an important role in discussing a draft of the focus group guide drawn up by the research team, and were able to input suggestions relevant to the cultural context of their own communities. In discussing this guide the team of facilitators were able to develop some conceptual consistency of the instrument across the different culture and languages (Culley *et al*, 2007). As endometriosis is a gendered condition that can potentially affect fertility, the focus group guide included issues for discussion about gender and ethnic identity, menstruation, and reproductive health, as well as endometriosis (see Box 1).

The rationale for using community facilitators was both to ensure cultural competence and to enable the project to benefit from the advantages of the 'insider' researcher (Culley *et al*, 2007; Gunaratnam, 2009). They were all well placed to use their knowledge of their own cultures in a constructive and reflexive manner prior to, during and after fieldwork, and could also conduct the focus groups in the target group's language if necessary. It was important that the main issues raised during discussions were interpreted with relevance, as meanings are often lost in the literal translation of terms (Mehta, 2005).

Women were recruited to the focus groups by the community facilitators and through contacts of the research team. The only criterion for selection was a

Box 1 Focus group guide (a more complete version of this guide, with prompts and probes as well as further biographical details of the participants, is available from the first author)

A: Introduction

1. To start with we want to explore what it means to be a (minority ethnic group) woman. How would you describe a (minority ethnic group) woman?
2. What do you think are the main health issues for women in your community?

B. Reproductive health

3. How important is it for a woman to become a mother in your community?
4. Are you aware of any reasons why some women are not able to have children? What is the impact of this on women?
5. How are women who cannot have children viewed within your community/culture?
6. How do women in your community feel about using contraception?

C. Menstruation

7. What do women in your community think about menstruation?
8. Are there any particular cultural or religious ideas about women and menstruation which you can tell us about?
9. Do you have any idea how men view menstruation?
10. What kinds of problems are you aware of that women can have with menstruation?
11. If a woman had one of these problems, what would she do?

D. Endometriosis

12. Has anyone ever heard the word 'endometriosis'? Does anyone know what this means?
13. Do you think this is at all common in your community? Do you know anyone who has it?
14. If a woman had some of the symptoms, what do you think she would do?
15. Do you think she would be happy to go to her GP about this? (yes/no/give reasons why)
16. How do women feel generally about going to GPs in your community?
17. What kinds of problems do they have in getting to the GP and talking to the GP about their health?
18. One of the symptoms some women have with this condition is pain when they have sex. How do you think this would affect a woman?
19. Who would she be able to talk to about this, do you think?
20. Do you feel that women would seek help if they had painful periods or if they had pain when having sex? If not, why not?
21. What do you feel would be of most help to women who have this condition?
22. We are hoping to provide information about the condition and what to do about it for women from your community. What advice do you have for us?
23. Is there anything that we have missed in this discussion? Is there anything that you would like to add?

SUMMING UP: Does this seem to be a good summary? Has anyone got any further comments?

willingness to discuss issues relating to reproductive health with other women from their community. Four of the five focus groups were co-facilitated by the same member of the research team (PA), while the focus group with members of the Greek/Greek Cypriot community was co-facilitated by a different member of the team, who is a Greek Cypriot (IP). This ensured a consistent approach, thus increasing reliability (Kidd and Parshall, 2000). The researcher and facilitator set ground rules for the conduct of the groups, in terms of keeping the discussion confidential and respecting the views of other members. The Indian, Pakistani and Greek/Greek Cypriot focus groups were conducted in English, with some references being made in the

Gujarati, Urdu or Greek languages. The Chinese focus group was conducted solely by the community facilitator in Chinese. The researcher had no understanding of the language, and merely sat through the discussion, although they noted non-verbal cues. This is consistent with the findings of Chiu and Knight (1999), who observed an effect on group dynamics when discussion was interrupted by translations. The focus group discussions lasted between 54 minutes and 2 hours.

Participants in the focus groups were each given a £20 high-street store gift token in appreciation of their giving time to a research project with no immediate benefit to themselves.

Analysis

Each focus group discussion was transcribed verbatim, and, in the case of the Chinese discussion, translation was carried out by the community facilitator, and verified by one of the Chinese focus group members (Mehta, 2005). All members of the research team familiarised themselves with the transcripts and identified initial themes. The team then discussed these at length and reached a consensus on key themes. Verification occurred through discussion about the analyses, comparison and subsequent consensus (Braun and Clarke, 2006). The community facilitators also had an input into this analysis by commenting on and validating the themes identified and providing additional insight into the context, thus enhancing the dependability of the research process (Culley *et al*, 2007).

One member of the team then performed an in-depth analysis drawing on the information generated from the preliminary analysis, which was guided by framework analysis (Ritchie and Spencer, 1994), which categorises data analysis into five key stages, namely familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. The team member who had been present at all but one of the focus groups verified the transcripts, which added to the credibility of the study. She was involved in the preliminary analysis, and had therefore internalised the data. A framework was developed from the themes previously agreed by the research team. Indexing, charting and coding were aided by qualitative software (NVivo version 8). The data were coded in accordance with the thematic framework, again using NVivo version 8. The final stage of framework analysis, namely mapping and interpretation, was undertaken by sorting the data by theme, identifying patterns in the data and piecing these together to form a story. This stage was further refined as each member of the team fed in their interpretation of various quotes, and during discussion at team meetings.

Findings

The data are presented here using the key themes identified by the analytical process, which were 'ethnic and gender identity', 'menstruation', 'reproduction' and 'endometriosis.'

Ethnic and gender identity

There were marked differences in the ways in which groups perceived gender and ethnic identity, but all agreed that traditional identities were being increasingly

influenced by younger women living (and in some instances educated) in the UK.

The African Caribbean group described women in their community as leaders, in the forefront of community life. They felt themselves to be empowered and independent. All of them were in paid work and were the main breadwinners for their families.

'I think we have high status. I think especially nowadays men realise our worth and the balance has moved from men being the providers to women. Most black women tend to earn more than black men.'

(African Caribbean woman)

The Chinese women (C) viewed living in the UK as different from living in China. Whereas in China most women work outside the home, in the UK they faced language difficulties, expensive childcare and other problems in getting suitable jobs. Many women within this community were unemployed and stayed at home, or worked in a family business. There was also a perceived lack of integration into the UK, and a stronger identity with the Chinese community than with gender.

The Greek/Greek Cypriot focus group included a wide age range. Members of the group perceived Greek women as being in the process of breaking out of the traditional female Greek/Greek Cypriot mould. They were more liberal and had more choice than the traditional Greek/Greek Cypriot woman, who was viewed as being subservient to men. This group perceived themselves as strong and able to multi-task while maintaining their responsibilities for their home and children as they moved to new roles. The generational differences between Greek women were summed up by a young woman who was born in the UK, as she spoke of older Greek women:

'They were quite powerless really. Also they worried about what other people thought, you know your house had to be clean if anybody came round, whereas now women are out a lot of hours working, whereas my mum was at home looking after the children. It was very different.'

(Greek Cypriot woman)

According to the Indian group, children in their community were brought up to respect the family and in-laws. Being a Gujarati woman meant having close family ties and respecting the older generation. Gujarati women in the UK saw themselves as more liberal and open than their counterparts living in India. They related more to their children. The children born in the UK were exposed to other cultures and tended to question Gujarati ways, and parents therefore needed to be able to deal with this. The Gujarati women felt that it was important to keep their culture alive within their children.

The Pakistani women described women in their community mainly as housewives. However, as the

following three extracts demonstrate, the younger generation were educated in the UK and were engaging in paid work.

‘Women manage the home and organise the family, which is seen as their main role, but although they view it as an important one, they are generally not given the credit for this.’

(Pakistani woman)

‘I think personally the women are most important because they do everything and they make a lot of decisions, they do most of the housework, run around the children, they basically do everything. But in some families they’re not seen as dominating.’

(Pakistani woman)

‘They’re not appreciated either.’

(Pakistani woman)

In summary, the traditional role of the woman as mother and homemaker was evident in all of the groups, but there were differences in the way that this was played out, particularly with regard to the amount of power and control that women felt they had, with the African Caribbean women viewing themselves as having most control, and the Pakistani women least. Acculturation within a dominant British culture was increasingly influencing gender and ethnic identities, particularly for those women who had been born and/or educated in the UK, and all of the groups recognised that there were generational differences within their community. For example, in contrast to the older women, younger Greek/Greek Cypriot women did not expect to do paid work as well as all of the work in the home.

Menstruation

The experience of menstruation was viewed negatively by all of the groups. Women used terms such as ‘curse’ by either the Devil or God, and spoke of embarrassment about buying sanitary towels or about the private and personal nature of menstruation. The Indian, African Caribbean and Greek/Greek Cypriot groups also mentioned that menstruation was regarded as unclean, and yet, as the following exchange from the latter group demonstrates, women were often unclear why such views persisted.

G/GC1: ‘I don’t know, what is the thing about having a period and being dirty?’

G/GC2: ‘Well, I thought that it originated from the fact that when women used to be on their periods many, many years ago, and there wasn’t proper sanitary towels.’

G/GC3: ‘Yes, that’s what my yiayia [grandmother] says.’

G/GC2: ‘And it could be disastrous. But nowadays I don’t know why it’s carried on.’

G/GC4: ‘Yes, but I’ve heard that is a myth, because a cousin of mine who is quite religious asked a church elder, he’s one of the monks who go to Mount Athos, and he said, it’s better you go to church and kiss the icons if that’s what you feel to do rather than not kiss them.’

Paradoxically, some women simultaneously viewed menstruation positively as a cleansing process. Menstruation was also seen as a marker of not being pregnant, which could be positive or negative, depending on the wishes of the woman at that point in time.

All of the groups spoke of religious or cultural taboos relating to menstruating women, based on the idea of the menstruating woman as unclean, or as potentially causing harm to others. For example, it was reported that Rastafarian men will not eat with their wives while they are menstruating, and the Indian women spoke of not being allowed into the kitchen at that time.

I7: ‘I do know of a friend here who this is happening to ... she lives with her mother-in-law and she is not allowed into the kitchen.’

I2: ‘I was not allowed into the kitchen ... no. I was not allowed to even cook. I know this also happens in India.’

I3: ‘It is considered “dirty”, and that is why we are not allowed into the kitchen ... but why? It is natural ... yes.’ [all in agreement]

Not being allowed into places of worship was also mentioned by the Indian, Pakistani and Chinese groups, but most of the women reported knowing about these restrictions rather than experiencing them. Pakistani women reported that they were not allowed to read the Quran or pray during menstruation, and this was the only group which stated that sexual intercourse was forbidden at this time. The fact that these restrictions seem to be widespread across different religious traditions is consistent with the assertion of Laws (1990) that most societies emphasise menstruation in some way. There is also some evidence that these restrictions are not imposed by women themselves as protection during a time of vulnerability, but rather that they are imposed by a sexual hierarchy intended to demonstrate the inferiority of women (Laws, 1990).

Women were also asked about the experience of menstrual pain, and how this was dealt with within their community.

‘Women in our community would treat it as a normal period pain and dismiss it.’

(Pakistani woman)

‘If it’s just period pain I think they would think that it is normal.’

(Chinese woman)

Women from the African Caribbean and Chinese groups mentioned traditional remedies that might be used for menstrual pain, but within these groups there was some disagreement as to whether these were effective, or whether Western medicine was preferable. Some African Caribbean women mentioned white rum containing ganja, and the Chinese women spoke of dietary therapy, mainly soups such as brown sugar and ginger.

'It [the brown sugar and ginger soup] helps [the body drive] the cold Qi out of body. Because coldness in uterus, and the cold cannot get out, then causes period pain.'

(Chinese woman)

The Chinese group also spoke of people having traditional remedies sent from China, but commented that Chinese medicine was expensive compared with western drugs.

The other three groups talked about taking analgesia, and consulting with family members and friends. The Indian women thought that women in their community would talk to a friend rather than a family member, and that this person being of a similar age was important. Discussion of personal topics between the age groups was difficult, and the group thought that older women would be inhibited. One of the Indian group members spoke of how the closeness of the community made it hard for women to discuss what are seen as personal issues.

'For example, if my in-laws know or are related to my doctor I would not be physically able to say look this is my problem because they would know. Even though I would hope the doctor would not tell them in my mind I would know that what if they find out.'

(Indian woman)

The women in the Pakistani group felt embarrassed to talk to a doctor, but felt that they could talk to family members or a friend.

'We know lots of girls that just wouldn't go to the doctor's and talk about a problem, because it's so embarrassing, especially if it's a male doctor. "I can't tell a bloke about this", and hope the pain will go away.'

(Pakistani woman)

The African Caribbean women felt that painful periods were a very personal, private affair and not open for discussion. Some members of the group disliked what they described as their white British colleagues openly discussing menstruation.

The Greek women were the only ones who felt that, within their community, issues relating to menstruation could be discussed openly, not only with other female family members and friends, but also with men.

All of the focus groups demonstrated that Laws' idea of a menstrual etiquette is quite widespread among many ethnic groups, but the way in which this is played out varies. The feeling that menstruation is polluted or dirty is common, but it is also clear that although these beliefs are perpetuated, there is no clear indication of their origin. They are generally accepted as part of a specific religion. Secrecy about menstruation was a feature of all the groups except the Greek/Greek Cypriot group, and reinforced the notion of menstruation as a discrediting attribute, which, as Sear (2009) has argued, can influence help-seeking behaviour, as will be demonstrated below.

Reproduction

Motherhood was important to the women in all the groups. The Indian and Pakistani groups in particular felt that women in their communities were defined by this role, and emphasised the status that came with motherhood, particularly from bearing male children. The Greek women also spoke of the pressure on them to have children:

'You feel pressured to become a mother. It's also not the norm to say we don't want to have children. It's expected of you, I think. Then if it's not your own personal family, your mother, father, it's your in-laws and family around you. Friends start having children once they get married, you feel pressured from them as well. You start feeling, you know, that something is wrong with yourself, so there are loads of pressures around them to becoming a mother.'

(Greek/Greek Cypriot woman)

For the Chinese and African Caribbean women, reproduction was seen more as an individual choice, and members of these groups did not experience familial or communal pressure to become mothers. The African Caribbean group also spoke about the role of black women changing from mother to provider, and the importance of a career in fulfilling their lives in the same way that that motherhood had done for previous generations. There was less consensus among this group about community perceptions of the importance of motherhood, with one woman stating that, for men, reproduction was an indication of their masculinity. A woman who did not conceive might feel that she had failed her husband or partner, who might then leave her for someone with whom he could have children.

The only group that was unequivocal in their view that it was acceptable for women not to have children was the Chinese women, who reported that the pressure to be educated and have a career was greater than the imperative of motherhood. This may be reflective of China's population policies, particularly the 'one child' policy.

‘According to Chinese tradition of course you should have [a] child, but [we] won’t discriminate [against] you because of that.’

(Chinese woman)

‘We have no pressure.’

(Chinese woman)

However, within this group all of the Chinese women who had children felt pride in becoming mothers.

All of the groups felt that, as a result of living in the UK, women’s ideas about motherhood were changing, including the acceptability of working mothers and smaller family size. As in earlier responses, generation and assimilation appeared to be strong influencing factors with regard to community groups’ views.

Although there were varying community views about the importance of motherhood to women’s roles and status, all reported negative views of involuntary childlessness. The Caribbean group thought that infertility was not a major problem within their community, but one woman thought that this perception might be because health issues of black women are under-represented in the media. The Caribbean group also thought that women would be willing to adopt children, as did the Chinese, but this practice was unacceptable to the Pakistani group.

Involuntary infertility was regarded as problematic by the women in all of the groups, including the Chinese and African Caribbean women, who were more accepting of voluntary childlessness. Most of the groups talked about the pity felt by the community for infertile women. It was usually the woman who was ‘blamed’ for the inability to conceive, even when there was no evidence of this, and women bore the brunt of the stigma, as one Pakistani woman demonstrated.

‘The in-laws give them a hard time, and the husband as well, and they’re under constant pressure. Some are under abuse as well, mental and physical.’

(Pakistani woman)

The Chinese, Pakistani and African Caribbean groups thought that in their communities some men in childless relationships might look for a woman who could have children. The Pakistani and Chinese women thought that men would divorce their wives in order to do this, but the African Caribbean women thought that men would take an additional partner instead. A Pakistani woman commented:

‘If the woman does not have a child the man would just leave them, they won’t have themselves checked out, and they’ll just divorce the wife and move on. And later on maybe find out they’re the ones with the problem.’

(Pakistani woman)

Within the African Caribbean community the reaction to infertility, as expressed below, was in contrast to the acceptability of voluntary childlessness reported above.

‘A woman may feel she has failed her husband or partner, who may then move on to someone who can conceive. It then means the woman must decide whether to leave him or to share him with another, which as a woman I find unacceptable.’

(African Caribbean woman)

In the communities where there was an expectation that women would reproduce, childlessness, whether voluntary or involuntary, was stigmatised; childless women felt pressure from family and a sense of worthlessness. In the African Caribbean community, where women reported greater acceptability of voluntary childlessness, infertility was nevertheless stigmatised in a similar way. These findings confirm those of Culley *et al.* (2006), who highlighted the considerable stigma attached to involuntary childlessness in British South Asian communities. However, it is also clear that generation and educational background influence women’s ability to resist such stigma. There is little information available about perceptions of infertility in other minority ethnic groups in the UK. Although there are some similarities in understandings and perceptions of infertility in these accounts and reports of the dominant white community (Letherby, 2002), there are also areas of cultural specificity.

Endometriosis

The above discussion has provided a glimpse of the way in which different cultures view aspects of femaleness. When we moved on to discuss awareness and cultural perceptions of endometriosis we found that most of the women had not heard of the disease, and there were differing ways in which they would respond to its symptoms. The groups were all shown diagrams of the female pelvic anatomy by the facilitators, and an explanation of endometriosis was given. Following this all of the groups asked questions and were keen to know more, expressing the view that more information needed to be available. One participant in the Indian group and two participants in the Greek group had been diagnosed with endometriosis, but no one in the other groups even knew anyone who suffered from the condition.

The groups all wondered how to tell a ‘painful period’ from the pain of endometriosis. The discussion reflected that about menstruation, and many of the participants felt that, in their community, women would think that it was normal, and would discuss it with friends and family rather than seek professional help.

‘Women in our community would treat it as a normal period and dismiss it.’

(Pakistani woman)

‘I don’t think there is much she can do, we all have different periods, different symptoms. It is relative to how you feel. What some people call painful periods to others are not.’

(African Caribbean woman)

Normalisation of period pain, and the problems for women of either differentiating their pain themselves, or of having others take them seriously, are a feature of much research on endometriosis (Denny, 2004b; Ballard *et al*, 2006; Markovic *et al*, 2008). Seear (2009) argues that this is compounded by the secretive and stigmatised way in which menstruation is dealt with in most societies.

Some women seemed to think that the experience of deep dyspareunia would be a more likely trigger for help seeking than painful periods, but even on this there was not universal agreement. It was generally agreed that inability to become pregnant would lead them to seek help from their general practitioner, but the women in the Chinese group felt that friends and partners might be consulted in the first instance. However, there was some disagreement within this group.

C9: ‘I think it must be the doctor, they won’t talk to others.’

C3: ‘I think they would talk to people around her and then go to see the doctor.’

C2: ‘I think they will not talk to people around her, she must talk to her husband, but if it is abnormal, I think if there is pain it should be abnormal, and will then go to see GP, I think.’

Opinions about painful intercourse reflected the earlier discussion on menstruation. For the African Caribbean group, sex was regarded as a private topic and one that was not readily discussed. The Pakistani and Indian groups reported that, in their communities, women would feel embarrassed to discuss painful intercourse except with a female doctor. The women in the Indian focus group were initially silent, and this was followed by nervous laughter at the mention of painful sex.

‘An Asian man would not understand this ... [all agree]. ... I am not blaming all Asian men, but some Asian men do not understand that sex can be painful for some women, but they would not understand and when he does not understand what his wife is going through he would just demand it ... and so for her [for the woman] it would be a stigma because if he cannot have what he wants ...’

(Indian woman)

‘I think when the man knows it’s to do with sex he would tell her to go to the doctors and sort it out, otherwise he wouldn’t get any sex.’

(Pakistani woman)

The African Caribbean women were most likely to refrain from sexual activity if it was painful. As one of them commented, ‘If I had sex and it was painful, then I just wouldn’t want it.’ However, many women in all of the groups worried about the effect of abstinence on their husbands, and it seemed to be their husband’s needs rather than their own pain that that these women would respond to.

The common symptoms of endometriosis, menstrual pain, painful sexual intercourse and infertility are all problematic in terms of help-seeking behaviour. The social stigma of menstruation constituted a barrier to open discussion and help seeking, although conversely the stigma of infertility provided an impetus, which could lead to a diagnosis of endometriosis.

Discussion

In each of the groups the women spoke freely about the issues that were raised. Their discussions highlighted similarities and differences between the five groups and between them and the white majority population. This is consistent with the findings of other research (Atkin and Chattoo, 2006; Salway *et al*, 2007). They also highlighted differences within each community group, and the influence of generation and acculturation on the views of women. For example, one Indian woman commented:

‘The children raised in this country are very confused. Many a time even we are confused about what is going on around us. So we cannot explain our culture and concepts to our children. So we blame the children and find fault with them. We can try and teach them in our way, but they question our ways and ask if there is anything wrong with the culture in school and at work.’

The main limitation of the study was the representativeness of the sample. The focus groups were recruited via the community facilitators or the researchers’ own contacts, and consisted of well-educated, English-speaking women who had some level of acculturation into UK society. They were also willing to discuss sensitive issues about reproduction in an open forum. We were not able to recruit women who lived in communities with little contact outside of their own ethnic group, or those unable to speak English confidently. The exclusion of these women may mean that we failed to capture a sufficiently diverse perspective of the issues under discussion.

The data illustrate the potential significance of the cultural context of the experience of endometriosis, and demonstrate that although the women shared experiences that transcended culture, each individual group also discussed issues that were specific to them. For example, the economic independence of the African Caribbean women was unique to that group, and cultural taboos surrounding menstruation were stronger in the Pakistani group than in the other groups.

The data also show that women within the five ethnic groups had multiple identities, or intersecting statuses, that transcended ethnicity (Culley and Hudson, 2009). They were clear that aspects of their ethnic identity were important. However, other social divisions were much in evidence both within and between the groups. Perhaps the most obvious of these was generation, with all of the groups discussing the impact of living in the UK on traditional beliefs, and expressing the view that there were significant differences between those who had migrated to the UK as children or adults and those who were born and educated within the host society (Bradby, 2007). Thus, younger women were viewed as being less focused on the home and more engaged in higher education and paid work. However, most still retained responsibility for the home and children, but saw this role as undervalued both by men within their community and by society more generally. However, the younger Greek women spoke more of the dual responsibility of men and women, rejecting the 'double shift' of their mothers' generation. Probably the starkest difference between the generations was expressed by the African Caribbean women, where young women with good educational qualifications viewed themselves as empowered and independent. Here generation, gender and level of education all intersected with ethnicity to produce a complex articulation of concepts of menstruation and motherhood. This complexity serves to repudiate a deterministic notion of ethnicity as fixed; rather it suggests a cultural fluidity (Culley and Hudson, 2009), and the dangers of generalisations that are based on categories of ethnicity.

This fluidity is highlighted by the relationship between individual choices and family and community obligations. Discussions about reproduction and (in) fertility illustrated this very well. All of the groups, to some extent, demonstrated adherence to pronatalist cultural values in common with most other societies. The Indian and Pakistani groups viewed having children as the primary purpose of marriage, and felt great personal and community pressure to start a family soon after marriage. The Greek women also reported pressure from family and friends to have children. Decisions on optimum family size were also assumed to be of community concern, in contrast to the dominant white culture, which would view such matters as a personal choice (Gillespie, 2003). Although such

pressure was difficult to resist, particularly in close-knit communities, younger women were reported to be delaying childbearing and developing careers, making decisions about their own families for themselves, rather than in response to community obligation. Within the African Caribbean and Chinese communities, reproduction was seen as a personal choice rather than a community concern, although these two groups made a distinction between voluntary and involuntary childlessness. This relationship between personal choice, family and community obligation is shifting in most communities as strong ties to the country of origin loosen and the balance of people's motives for having children moves from the economic to the social and psychological (Gürtin-Broadbent, 2009). Both conformity and resistance to cultural norms were apparent within all of the groups.

One theme running through the discussions on menstruation, reproduction and the symptoms of endometriosis was that of stigma. Although only the African-Caribbean group actually used this term, all of the groups described stigmatising acts and attitudes. In his seminal work on stigma, Goffman (1963, p. 14) describes 'discreditable' individuals whose stigma is not immediately apparent, and argues that they are often labelled as weak. The stigma of menstruation is reinforced by rituals and behaviours that are common within most religions, such as the restrictions on food handling and preparation mentioned by the African-Caribbean, Indian and Pakistani groups. In contrast to the study by Seear (2009), we also found some positive aspects of menstruation, as a perceived cleansing process, or a marker of a (non-)pregnant state. The important point here is the consequence of menstruation as a stigmatised state for help-seeking behaviour. Seear's study of Australian women's experience of endometriosis points to the stigma surrounding menstruation positioning women as discreditable individuals, who then conceal their menstrual state in order to avoid social sanctioning. Where menstruation is problematic, as is the case in symptomatic endometriosis, this is complicit in the well-documented delay in diagnosis. Seear's findings are consistent with this study, in which women had firm ideas about whom menstruation should be discussed with, and even whether it should be discussed openly at all. The exception to this was the Greek group, who were very open with family and friends of both sexes.

Although all of the ethnic groups demonstrated a pronatalist culture, with infertility being regarded as a deeply stigmatising state, within the Greek, Indian and Pakistani groups this was particularly pronounced, which is consistent with the findings of Culley and Hudson (2009) in their study of South Asian women. All of the groups spoke of the blame and stigma attached to infertile women, and the fact that women were always held responsible for lack of children

within a marriage. Stigma is more likely to be discussed in the literature on infertility (Donkor and Sandall, 2007; Slade *et al*, 2007; McCarthy, 2008) than in that on endometriosis. Imeson and McMurray (1996) studied women's experience of infertility, and although they did not use the term 'stigma', they reported that women felt socially isolated from their peers and excluded from the social groupings that come with parenthood.

Although much of the literature on endometriosis discusses fertility and the possible threat posed to it by the disease (Butt and Chesla, 2007; Denny, 2009), most of this discussion is about the importance attached to various symptoms both by women and by health professionals. For example, Markovic *et al* (2008) suggest that infertility is taken more seriously than other symptoms of endometriosis, and Seear (2009) states that women who present to health services with infertility will receive an endometriosis diagnosis in around half the time that other women do.

An important finding of this study was the suggestion that, for some minority ethnic women, childlessness rather than menstrual problems or pain would perhaps be the major motivating factor for seeking professional help for symptoms of endometriosis. This is in contrast to women from the majority community, where those presenting with infertility who are subsequently found to have endometriosis frequently report no other symptoms (JK Gupta, Professor of Obstetrics and Gynaecology, personal communication, 2010).

Conclusion

The data presented here demonstrate some important values and beliefs which are likely to influence the understanding of endometriosis and behaviour in relation to it. Many of these are consistent with research about the dominant white community in the UK (Letherby, 1999). The data also highlight issues where there are likely to be significant differences, both within and between groups. Although the women felt that specific cultural values might influence the experience of endometriosis, other markers of difference were clearly also significant. When addressing issues relating to cultural influences on women's experience of endometriosis and the provision of health services to manage it, we are conscious of the need to avoid essentialising culture and ethnicity (Culley, 2006; Phillips, 2007). Culture is an important aspect of the way in which people make sense of a health condition, but at the same time it must be acknowledged that other dimensions of identity, such as age, gender and socio-economic status, will also influence experience

to a greater or lesser extent (Nazroo, 1997). Culture will not necessarily be the determining factor in a health and illness experience or a healthcare encounter.

Barriers to accessing services may be caused by a number of factors, not least the power relationships inherent in biomedicine (Seear, 2009) and the difficulties of accessing appropriate treatment that were experienced by many of those with lower socio-economic status in the UK and elsewhere. Nevertheless, this study suggests that an accessible service will also need to take account of potentially important socio-cultural differences in the experience of endometriosis, which may provide additional barriers to presentation to healthcare providers.

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CONFLICTS OF INTEREST

None.