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Endometriosis and cultural diversity: improving services for minority ethnic women

June 2010

Final Report for Research for Patient Benefit Grant PB-PG-0906-11145

Report prepared by
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Executive Summary

Introduction

Endometriosis is a chronic, disabling condition. Symptomatic disease is usually characterised by pelvic, abdominal pain and lower back pain, and dyspareunia. Other symptoms such as urinary and bowel dysfunction may be present in some women and endometriosis is associated with up to 40% of attendance at fertility clinics. Although there are several medical and surgical treatments for endometriosis there is no definitive cure. Estimates of incidence vary between 5 and 15% of the adult female population. Research with women from majority communities has shown that endometriosis impacts on all aspects of a woman's life, and may severely disrupt normal functioning. This research project is the first UK study which has explored the ways in which minority ethnic women experience endometriosis and its treatment.

Research question

What are the specific needs of women from minority ethnic groups who are living with endometriosis, and how can these effectively be met in the delivery of NHS services?

Aim

To develop, in collaboration with community groups and patients, evidence based and culturally sensitive resources for women with endometriosis and good practice guidance for health professionals providing services to women of minority ethnic origin.

Objectives

- To elicit cultural meanings of reproduction and sexuality and the potential impact on access to services using community focus group discussions.
- To explore the impact of the socio-cultural context on understandings and experience of endometriosis, for women of African Caribbean, Chinese, Greek/Greek Cypriot, Indian and Pakistani ethnic origin.
- To develop and pilot culturally appropriate information resources for women with endometriosis, in English, Chinese, Greek, Gujarati and Urdu.
- To develop and pilot 'good practice' guidance in the provision of culturally competent care for providers of endometriosis services in primary and secondary care.

Methods

NHS Ethical approval was obtained for the study in February 2008 [REC reference number: 08/H1204/8]. Following a systematic literature search and narrative

literature review, the research consisted of four phases:

- Focus groups with women from each of the minority ethnic communities included in the study to elicit community perceptions of endometriosis and related constructs of menstruation, fertility and motherhood. Five focus groups were held with women aged between 18-50 years (n= 42).
- Semi-structured, in depth interviews with a sample of women aged 18-50 with a clinical diagnosis of endometriosis, (n= 29). Interviews explored their experience of living with endometriosis and access to healthcare and support.
- Semi-structured interviews with a sample of health professionals providing care for women with endometriosis (n=8) to explore their perceptions of the needs of minority ethnic patients, understandings of the socio-cultural background of patients and their own information needs regarding culturally appropriate patient care.
- Using the data obtained in the previous phases of the research and advice from community groups, user representatives and the project advisory group members, resource materials for patients and service providers were developed and piloted.

Key findings

Focus Group data revealed many similarities and several differences in the perceptions of the significance of ethnic and gender identity, ideas about menstruation, motherhood and fertility across the ethnic groups and also within them.

- The role of women as mothers and homemakers was evident as a key part of women's identity in all of the groups. However, some women felt that they had more power and control in the conduct of their lives generally than others, with the African Caribbean women viewing themselves as having most control, and Pakistani women least.
- Many of the women in all groups thought that women would tend to normalise severe period pain, and thought that fertility problems rather than pelvic pain would be the most likely spur to seeking professional help.
- In the communities where there was a strong emphasis on motherhood, childlessness (whether voluntary or involuntary) was heavily stigmatised. In the African Caribbean community where women reported more acceptability of voluntary childlessness, infertility was nevertheless stigmatised in a similar way.
- Very few women in the focus groups had heard of endometriosis.

Interview data revealed many similarities with research carried out with dominant ethnic communities: a lack of awareness of endometriosis prior to diagnosis; delay in diagnosis; a life of pain; severe impact on relationships and on working life. There were, however, many instances where the specific cultural or religious context emerged as a significant element of the experience of endometriosis. For example:

- Pakistani and to a lesser extent Indian women found it difficult to discuss gynaecological issues within the family, and described how suspicion could be raised about the cause of gynaecological problems. Pakistani women expressed concern about the potential impact of extensive internal examinations on proof of virginity (essential to marriage) and concern that if a woman had treatment with oral contraception (a common treatment for endometriosis) this might be interpreted as her being sexually active, which would also compromise marriage prospects.
- Greek women were open about discussing menstruation within the family and with friends. They were also open about dyspareunia, and did not object to being examined by male health professionals. Being treated with respect by staff was more important to them. The Chinese women valued privacy very highly, were more circumspect about discussing any personal issues with health professionals and placed great importance on confidentiality.
- With the exception of the Chinese community, the majority of women spoke of their religion as being important to them. They or their family members carry out religious rituals or go on pilgrimages in order to help alleviate the symptoms of endometriosis or to try to achieve a pregnancy. Most find comfort in their faith.
- In common with other women with endometriosis, women in this study reported instances of both positive and negative interactions with individual healthcare providers. Some of their negative experiences were related to cultural insensitivity or misunderstandings, however women were also concerned at health professionals' more general insensitivity to their symptoms.
- Most of the women in this study were competent English speakers, but several expressed concern at the lack of adequate communication support for those with lower proficiency in English, and many commented on the failure of consultants to fully explain procedures in easy to understand terminology.

Interviews with health professionals indicated varying degrees of knowledge and concern about the impact of ethnic identity on endometriosis. All expressed the view that it was important to treat patients as individuals, rather than focus on ethnicity. Nurses were more likely to acknowledge the potential impact of culture on access to care and experience of care, though this was often done in somewhat stereotypical ways. Consultants explicitly argued that women's concerns were primarily around getting a diagnosis and appropriate treatment to relieve their pain and address any fertility concerns. Ethnic origin was not perceived to be of major importance, though some ethnic differences were identified, and poor communication with people whose English is not good was seen as a problem.

Recommendations

- Although the concerns of women in this study arise for many women regardless of ethnicity, differences of culture, language and religion are often important to women in gaining a diagnosis and in the experience of living with endometriosis.

For all women therefore, it is important that health professionals and those supporting women have a good understanding of the socio-cultural context of people living with endometriosis. Healthcare providers should access training specifically on the way in which ethnicity might impact on endometriosis.

- Within minority ethnic communities there is limited awareness of endometriosis. Support groups should consider engaging with key opinion formers and other partners within minority ethnic communities to increase understanding of endometriosis.
- Healthcare providers should be encouraged to analyse data by ethnic group and establish any patterns of differential diagnosis, treatment or indeed access to treatment.
- The study reinforces the view that GPs require more information about endometriosis to assist in timely referral and diagnosis.
- There is a clear need for interpreting services to be available in NHS Trusts, alongside measures to increase the confidence of users in the effectiveness and confidentiality of services.
- Support groups should ensure that the support and advice offered to minority ethnic patients is culturally and linguistically appropriate.
- Patient and public involvement in research takes time to develop if it is to avoid being tokenistic and can, of course, add to the costs of the project. These issues need to be considered by research teams at the outset, so that the many benefits of user and consumer involvement can be attained.

Keywords

Endometriosis; qualitative research; minority ethnic health; culture; diversity

Chapter One – Introduction

The project 'Endometriosis and cultural diversity: improving services for minority ethnic women' was funded by the Research for Patient Benefit programme in July 2007, and commenced on 1st December 2009. The study was completed in May 2010. Endometriosis is a chronic, disabling condition, and a common cause of chronic pelvic pain. Estimates of incidence vary between 5 and 15% of the adult female population (Damewood et al, 1997; Ballard et al, 2006). Symptomatic disease is usually characterised by pelvic and abdominal pain, lower back pain, and dyspareunia, but other symptoms such as urinary and bowel dysfunction may be present in some women. Usually symptoms fluctuate in a cyclical nature, but pain can be constant. As the majority of women experience the worst of their symptoms around menstruation many find that these are treated as dysmenorrhoea, which tends to be viewed by medical practitioners as a 'normal' part of the menstrual cycle.

A woman who is diagnosed as having 'mild' disease by diagnostic categorisation may experience severe symptoms, while another who has extensive disease may be asymptomatic, and is only diagnosed opportunistically, for example 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 treatments for endometriosis there is no definitive cure, so the experience needs to be made as positive as possible.

While there is a knowledge base regarding the experience of living with endometriosis (e.g. Denny, 2004a; Huntingdon & Gilmour, 2005), there are no data available on women from culturally and linguistically diverse communities. Studies demonstrate that cultural beliefs and practices can contribute to women's reproductive health (Rice, 1994; Rossiter, 1998). The fit between dominant western biomedical models of treatment and care and beliefs and practices of minority ethnic groups needs to be understood if appropriate and effective care is to be available. There are no robust published data on ethnic differences in the prevalence of endometriosis (Shaw, 2003). However, the researchers are aware from their experience of the NHS of an under-representation of minority ethnic women as endometriosis patients. While barriers to service access may arise from a number of factors, including socio-economic status and racism (Karlsen, 2007; Culley & Dyson, 2009), accessible and culturally appropriate information is important in encouraging women to recognise the symptoms of endometriosis and to present for treatment. It is also important for service providers to have a good understanding of the specific socio-cultural context of patients in order to provide appropriate care. There are, however, few information resources on endometriosis available for women from minority ethnic communities that are culturally sensitive and linguistically appropriate and no guidance for health professionals working with women from diverse ethnic backgrounds who have this condition. Because endometriosis is a debilitating condition affecting women's reproductive system and sexuality, and

because reproduction is attributed with deeply held meanings by different cultural groups (Culley et al, 2006), there are likely to be complex constructions of endometriosis and how it should be regarded and treated (Letherby, 2002). Thus, research into the experiences of women from minority ethnic groups with endometriosis, how they understand and cope with the condition and how it is embedded into social relations of particular cultural groups will assist in developing culturally appropriate information and resources for women, community groups and health care providers.

Aim

To develop, in collaboration with community groups and patients, evidence based and culturally sensitive resources for women with endometriosis and to develop good practice guidance for the health professionals providing services to women of minority ethnic origin.

Objectives

1. To elicit cultural meanings of reproduction and sexuality and the potential impact on access to services using community focus group discussions.
2. To explore the impact of socio-cultural context for minority ethnic women with endometriosis (African Caribbean, Chinese, Greek/Greek Cypriot, Indian, and Pakistani women).
3. To develop and pilot a culturally appropriate information resource for women with endometriosis in English, Chinese, Greek, Gujarati and Urdu.
4. To develop and pilot good practice guidance in the provision of culturally competent practice for providers of endometriosis services in primary and secondary care.

In 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). We argue that culture is an important aspect of the way in which people make sense of a health condition, but at the same time acknowledge 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). We further acknowledge that there are many similarities between cultural groups in the way in which they experience health and illness, and many differences within cultures. These will become apparent within the findings of the study.

Chapter Two - Review of Literature

Endometriosis

Non clinical research into endometriosis has mainly consisted of qualitative designs conducted in the UK, Australia and the USA, with a smaller amount of research in other Western countries. This literature focuses largely on the experience of patients within formal health care systems recruited from hospital clinics or self help groups. A smaller body of work that tends to appear in non peer reviewed journals consists of unsolicited, self reported narratives which although providing interesting data do not conform to academic standards of methodological rigour. This review will concentrate on peer reviewed articles from academic journals. Many common themes recur in the literature which may to some extent reflect recruitment methods and research design.

The journey to diagnosis

Most studies report the experience of diagnosis, but as this is typically after five or more years (Cox et al, 2003a; Ballard et al, 2006) what they are really exploring is women's journey towards finding an explanation for their symptoms. Ballard et al (2006) describe this delay as being at the level of the individual patient and at the medical level. Other research makes this distinction more implicitly (Cox et al, 2003b; Denny, 2004a; 2004b; Markovic et al, 2008). Patient delay occurs when women do not present to a health professional at the onset of symptoms. Women tend to normalise symptoms associated with menstruation, viewing themselves as 'unlucky' (Ballard 2006) or 'weak' (Markovic et al 2008). This normalisation is often reinforced by others, for example Markovic et al (2008) reporting the expectation of teachers that students miss school during bad period days. Other studies (Denny 2004a; 2004b) suggest that some women recognise their experience as not being a normal experience, but as Denny (2009) and Seear (2009) point out, the concept of 'normal' and 'excessive' menstrual pain is an elusive and highly subjective one, despite attempts to quantify it in a pain scale.

Doctor delays occur when women do present and their symptoms are trivialised or denied. Studies make reference to women making repeated visits to the GP, while Cox et al (2003b) report women spend years looking for a doctor who would be 'sympathetic to their plight'. Findings from Manderson et al (2008) support this view and they further argue that the term 'doctor shopping' to describe this behaviour plays down the trauma of the journey to diagnosis. Many of the women in the study by Cox et al (2003b) had to be assertive and insist on a referral to a specialist from the GP. Women in the same study report being told by GPs that they were too young to have endometriosis. Denny (2009) also reports that one of the women in her study was repeatedly told she was 'too young' to have endometriosis. It is interesting to note that the normalisation of period pain at the medical level was often directed at adolescents. These findings suggest stereotyping by doctors especially in relation to adolescents and younger women.

The reaction to a diagnosis of endometriosis is frequently reported as one of relief (Ballard et al, 2006; Denny 2004b; Huntington and Gilmour, 2005), and Denny (2009) further reports that women feel a sense of vindication for pursuing matters when they were disbelieved and dismissed by doctors. Ballard et al (2006) found that diagnosis provides legitimization of symptoms, and women found it easier to deal with them when they knew they had a 'condition'. A medical diagnosis brought about options for appropriate treatment and allowed women to learn about their condition and access support groups (Huntington and Gilmour, 2005). A few women were relieved that they did not have cancer. Diagnosis presented a need to review priorities, particularly for women who had not started or completed their families, and many became anxious about the threat to their fertility (Markovic, 2008).

The findings on disclosure of endometriosis are limited. Findings from Gilmour et al, (2008) suggest two levels of disclosure; disclosure of diagnosis and disclosure of the full extent and nature of symptoms. They suggest that women are reluctant to disclose details of their symptoms because these are intimate and therefore deemed private. Jones et al (2004) also found a reluctance to discuss symptoms with colleagues, particularly with male employers and a respondent in Denny (2004b) called it a 'personal disease'. Following Goffman (1963) Seear (2009) argues that menstruation is a discrediting attribute and that reluctance to disclose menstrual problems contributes to delay, and this is discussed further below.

The experience of endometriosis

For women with symptomatic disease pain is the overriding experience and it is reported in all of the literature. Pelvic pain is the most common type of pain discussed, and for most women this was severe. However, as the range of pain experienced varies even among symptomatic women from mild to severe, recruitment via clinics and self help groups may have resulted in a biased sample of more acutely affected women in several research studies. Qualitative research highlights the experience of pain which is most commonly experienced in the pelvis, and around menstruation. However back pain, abdominal pain, and deep dyspareunia (pain during or following sexual intercourse) are also common and pain may be constant. The pain is chronic and findings portray the debilitating nature of endometriosis. The literature provides graphic descriptions of pain, in particular pelvic pain, as like a knife (Denny, 2004a) crippling, and legs like lumps of iron (Huntington and Gilmour, 2005)

Dyspareunia is not as predominant a finding as menstrual pain. However as researchers who explicitly explored this symptom reported that it was prevalent within their sample, this may be because it is not actively explored in other studies. Jones et al (2004) found that all the women in their study who were sexually active had some level of pain with and / or after intercourse, and consequently the majority avoided intercourse. Many studies adopt a narrative approach and it is possible that women choose not to volunteer information regarding sexuality, albeit casual references are sometimes made to painful sex. For example, in the study by Cox et al

(2003a) women reported that they found intercourse painful but were embarrassed to discuss this with anyone.

Dyspareunia is explored in detail by Denny and Mann, (2007). They report that 86% of their study sample experienced painful sex, mostly with deep penetration; of these more than half experienced pain for several hours following intercourse. Most women in this study managed this by either avoiding or abstaining from sexual intercourse. For women in this category who continued to have sexual intercourse, it often meant enduring pain, and for some the motivating factor was the hope of a pregnancy. Research findings to date relate to experience of dyspareunia following diagnosis, and what is unclear is the role that it plays in help seeking behaviour.

Women reveal that painful sexual intercourse has an impact on their relationships and that loss of sexual activity also has a negative effect on their self-esteem.

Relationships are robbed of physical intimacy because of the fear that any type of intimacy may lead to sexual intercourse. The strain that this results in leads some women to feel very insecure in their relationships, and they report the arguments and frustration that results (Denny and Mann, 2007).

The impact of endometriosis

A common assertion throughout the endometriosis literature is that it impacts on all aspects of a woman's life, and may severely disrupt her normal functioning. Pain may result in many women taking time off work, or continuing to work while unfit. Cox et al (2003a) report women losing jobs as a result of extended periods of sick leave. Women in their study felt pressured to work whilst ill in order to hold on to their jobs as they were aware their sickness record would make it challenging to find new work.

Women expressed concern about disclosing their problem in the work environment and this affected their life choices (Gilmour et al, 2008). Study and career goals were affected because some women were unable to complete education and training towards desired careers (Huntington and Gilmour, 2005). Also many were forced to alter career choices due to a need for flexible working and part time work, and some women had to give up work altogether (Gilmour et al, 2008).

Findings in Jones et al (2004), and Denny (2004a) suggest that although some women had supportive work environments these women were in the minority. More of the evidence presented implies that endometriosis impacts negatively on the work experience.

Many studies report that the condition limits the ability of women to participate in social life (Gilmour et al 2008, Huntington and Gilmour 2005, Denny 2004b, Jones et al, 2004). Women were physically restricted when in severe pain, and Jones et al (2004) also found that women wanted to withdraw from social contact when in pain. They spoke about the restrictions that having endometriosis put on their lives, which necessitated careful planning of social activities and meant not participating in social events. Findings also reveal that women withdrew from social life because they were

uncomfortable to discuss the condition and disclose symptoms. This was fuelled by the perception that they would not be understood or that they would be judged within the context of menstrual pain being 'normal'. For many women endometriosis took over their lives. (Jones et al, 2004)

There is evidence that endometriosis may be a factor in the breakup of relationships: the strain of the illness, the mood swings that often come with medication, fear of physical intimacy affects the dynamics of women's relationships and contributes to break-ups. This seems particularly true for younger women without children in less stable relationships (Denny 2004b).

Cultural aspects of menstruation

Experience does not take place within a vacuum, but is mediated by social and cultural context (Denny 2009), and the experience of endometriosis is bound up with cultural representations of menstruation. Although ideas around menstruation are historically and culturally specific, most societies have some taboos or rituals concerned with the menstruating woman. In her research carried out with men in the UK Laws (1990) uses the term 'etiquette of menstruation' to describe the expected behaviour of women during this time. The majority of cultures do emphasise menstruation in some way. Interestingly, it is cultures other than the dominant White British one that have most frequently been studied in terms of menstrual taboos. This, Laws argues, demonstrates complacency towards how menstruation is dealt with in the United Kingdom, and by extension in other Western post-industrial countries. It also reflects a common tendency to view only minority ethnic communities as having 'culture'. 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. Laws further suggests that menstruation is an obvious physical function to use as a marker of femaleness, to help define a woman's place in patriarchal society.

The etiquette is associated with menstruation in purely negative terms i.e. feelings of shame, embarrassment, and the need for concealment. Britton (1996) found that from an early age women learned negative images of menstruation, connected to bleeding and pain. Yet women are also told that menstruation is a normal and natural event, something that marks you as a mature woman, capable of reproduction. Health education messages convey the idea that menstruation is not something that should restrict normal activities.

The tension between ideas of menstruation as 'normal' and menstruation as 'shameful' leaves some believing that for women 'normal' equates with 'secretive' and 'shameful', their 'natural' state being dirty and polluted (Raftos et al 1998). The idea of menstruation as pollution is common in many cultures and influences practices and taboos. Helman (2007:47) for example talks about cultural conceptions of the 'polluting power' of menstrual blood believed to cause weakness in males, and of menstruating women perceived 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: 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 during this vulnerable time and to protect men from the polluting power of menstrual blood. It has to be remembered that for many societies and for much of history menstruation was a relatively rare occurrence for women who were either pregnant, breastfeeding or malnourished for many of their reproductive years, and therefore may also have been viewed as something out of the ordinary. 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.

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 trivialising of pain by family, employers and others deters them from seeking professional help.

Ethnic inequalities in health

In the 2001 census, 7.9% of the population of the UK categorised themselves as belonging to a non-white ethnic group. The largest single group described themselves as Indian (23%). Sixteen per cent gave their ethnic origin as Pakistani, 12% as Black Caribbean, 10% as Black African, 6% as Bangladeshi, and 5% as Chinese. A further 12% identified their ethnic origin as 'mixed'.

Members of minority ethnic groups consistently report worse health than the general population, though the range of illnesses experienced is broadly the same (Aspinall and Jacobson, 2004; Sproston and Mindell, 2006; Bhopal, 2007). There are for example, higher rates of heart disease, diabetes and mental illness in some minority ethnic groups. Much of the observed difference, however, can be accounted for by differences in socio-economic circumstances (Nazroo, 2001).

Health inequalities are the result of a complex and wide-ranging network of factors. People who experience material disadvantage, poor housing, lower educational attainment, insecure employment or homelessness are among those more likely to suffer poorer health outcomes and an earlier death compared to the rest of the population (Randhawa, 2007)

Many of these underlying health determinants appear to be more prevalent among certain minority ethnic populations. The Bangladeshi and Pakistani populations, for example, report the worst levels of general health and are also the most deprived minority populations in the UK, after gypsy travellers. Social and economic inequalities are also underpinned by racism, which has also been shown to have both direct and indirect effects on health (Karlsen, 2007).

The evidence on ethnic differences in the utilisation of and quality of healthcare received by minority ethnic groups is less well developed, but there is a growing body of work which suggests that the NHS at all levels, has not always catered well to our

multi-ethnic population and does not always offer care which is easily accessible and culturally competent (Papadopoulos et al, 2008). Studies across Europe have identified many potential barriers to the use of health services among ethnic minorities (Scheppers et al, 2006). Several studies also show that some minority ethnic users report higher levels of dissatisfaction with NHS services and there are some examples of serious lapses in service provision (Aspinall and Jacobson, 2004).

A study undertaken by the Commission for Health Improvement (Raleigh et al, 2004) found ethnic differences in service users rating of their care in terms of:

- service access and coordination
- the environment in which services were provided
- the provision of information
- their involvement in healthcare decisions
- the level of choice regarding care pathways
- consideration of their physical and emotional needs
- being treated with respect

(Karlsen 2007, p.5)

There are no data regarding experience of endometriosis care, however in a related field, a study of the provision of infertility services to British South Asian communities found a high degree of stigma related to childlessness and little knowledge of infertility and its treatment in South Asian communities. The study also found that some of the needs of South Asian patients were not met in primary or secondary care services in the NHS (Culley et al 2006).

Conclusion

The literature on the experience of endometriosis demonstrates that the disease impacts on all aspects of a woman's life. There are strong and consistent findings on the delay in diagnosis, the experience of pain, and problematic encounters with health professionals. Qualitative research has added a great deal to our understanding of the lived experience of endometriosis and there are many important messages for healthcare practice identified in this work. However, most studies have been conducted in majority populations of the UK, USA and Australia and as such underplay the role of ethnicity in the experience of endometriosis.

Although not a disease of menstruation, the fact that symptoms are commonly experienced at this time means that constructions of endometriosis are bound up with conceptions of menstruation. These in turn are historically and culturally specific but most of the taboos or 'etiquette' surrounding menstruation are negative, resulting in shame and secrecy.

The problematic nature of endometriosis and the tendency to trivialise or normalise

symptoms makes the experience difficult for any woman, but for those from minority ethnic groups this is compounded by inequalities in health and a health care system which is not easily accessible and culturally competent. However, no research to date has considered the effect that ethnicity and cultural values have on the experience of endometriosis, and the ability of the NHS to meet the needs of minority ethnic women.

Chapter Three - Methodology

Research question

What are the specific needs of women from minority ethnic groups who are living with endometriosis, and how can these effectively be met in the delivery of NHS services?

The research question was addressed by undertaking a phased project that involved groups of healthy women from the communities listed in the objectives, women from these ethnic groups who live with endometriosis, and the health professionals who treat them. We were interested in eliciting how socio-cultural context impacts on the experience of endometriosis, and how this affects the acceptability and accessibility of service delivery. We also explored the information needs of patients and health professionals, including considerations of context, format and presentation. The data obtained from this research was used in order to develop resource materials to the piloting stage for use by the communities, women and health professionals which will assist providing culturally sensitive information and appropriate care.

The sensitive nature of the topic, the characteristics of the communities under study and the need for interaction and collaboration in the development of resources meant that a qualitative and highly participatory design was deemed most appropriate for this project (Aitkin & Chattoo, 2006). The study consisted of four phases which corresponded with objectives 1-4 above.

Ethical approval

The project team submitted a research ethics application to the North Staffordshire Research Ethics Committee on 20 December 2007 and received ethical approval on 27 February 2008.

REC reference number: 08/H1204/8

Sample

Five ethnic groups: African Caribbean, Chinese, Greek/Greek Cypriots, Pakistani, and Indian origin were selected as the focus of the study. This constituted a convenience sample of minority ethnic groups in the UK, but it was felt that it also represented a range of ethnic and religious tradition. The problematic nature of any ethnic categorisation is acknowledged (Aspinall, 2000). However, it was felt that these categories provided a workable approach in operationalising the potential impact of ethnic origin on beliefs, attitudes, constraints and facilitators to healthcare access (Bradby, 2003). Women in the study had no difficulty in identifying with these labels in a general sense, although some of them did add to the categories where they felt that this was important.

The process of identifying, approaching and recruiting participants in each category is detailed below:

(i) Community focus groups

Focus groups were held with women from each of the identified groups. The target population were people who were not necessarily suffering from endometriosis, but were in a position to discuss their own perceptions of key issues relevant to the research and also to speak about their perceptions of what other women in their community might feel or experience. The premise here is that the socio-cultural context is one important aspect of individual experience which is likely to impact on behaviour. Participants were approached in two ways: through a snowball approach via existing contacts of the research team and through networking with community groups and community organisations. All prospective participants were given an invitation letter and a participant information sheet. They were given at least one week in which to make a decision regarding whether or not to participate. For those willing to participate in this phase of the study a mutually convenient date, time and place was arranged for the focus group discussion.

(ii) Interviews with women from minority ethnic groups with endometriosis

Women with endometriosis were recruited from mainstream health care services (NHS) within the area of the universities collaborating in the research. Women meeting the inclusion criteria were given a participant information sheet. They were approached and recruited using the protocol specified in (i). Members of the research team have established networks with some of the community groups, and some women with endometriosis were also identified through these networks, and recruited using the same protocol. A website was also set up for the project and some women approached the research team having accessed the site and volunteered to participate. Endometriosis UK and the Endometriosis SHE Trust also publicised the research in their websites.

(iii) Interviews with health professionals

A sampling frame of gynaecologists and gynaecological nurses involved in the treatment of women with endometriosis was drawn from the clinics collaborating with the research. A convenience sample from this list and other contacts of the research team were approached by giving them an invitation to participate and an information sheet. The researchers contacted those interested in participating in the study and arranged a mutually convenient time for interview.

General Practitioners who are involved in the care of women with endometriosis were identified through consultation with recruited gynaecologists and through Primary Care Trust lists. A convenience sample of identified General Practitioners was sent an invitation pack with information sheet and response slip. As response from this was very low visits were made by the research team to local primary care facilities, which did not prove successful.

Written consent was obtained and permission sought to have the sessions audio-taped from all participants. A semi-structured interview schedule for the face to face interviews was developed using the results of the focus group discussions.

Methods

Phase One: Cultural meanings of sexuality, reproduction, endometriosis and access to health services

Focus group discussions were held with women from each of the minority ethnic groups in the study in order to explore their views on menstruation, reproduction and sexuality (n=5). The strength of this method is that commonly held beliefs will emerge, rather than individual views. In using focus group discussions as a prelude to the main study we were able to capture issues of importance to the women from each of the minority ethnic groups chosen, and to utilize these to ensure that the conduct of the remainder of the study was meaningful and acceptable to participants.

A convenience sample of between 6 and 12 participants per group (Bryman, 2008) was the target, recruited through the existing contacts of the research team with the targeted groups.

Focus group facilitators (see Appendix 1) were recruited from the target minority ethnic communities in order to organise and conduct the discussions, and to advise the research team on culturally appropriate language for the participant information sheet and focus group guide (appendix 2), where necessary verifying the translated versions of these documents. In addition they transcribed the audiotaped discussion. Most were experienced in conducting focus groups and all attended a one day training event organized by the research team to familiarize themselves with the aims of the project and to gain background information on endometriosis. The training day provided an opportunity for the research team to discuss a draft of the focus group guide prepared by them with the facilitators, who were able to input suggestions relevant to the cultural context of their own communities. In discussing this guide the team of facilitators was able to develop conceptual consistency of the instrument across the different cultures and languages. The guide was subsequently amended in the light of these discussions.

Table 1.1 Focus group participation

Group	Number of women	Language used
African Caribbean	8	English
Chinese	10	Chinese
Greek	8	English with some Greek references
Indian	10	English and Gujarati
Pakistani	6	English with some Urdu references
Total	42	

Focus groups were held in the language of preference of the participating group. A focus group guide was used to ensure consistency between the topics raised in each group. Focus group discussions lasted between one and two hours.

Inclusion criteria:

- Women of African Caribbean, Chinese, Greek/Greek Cypriots, Pakistani, or Indian origin
- Aged between 18 and 50 years old
- Participants did not have to have endometriosis

The findings from the focus groups informed the interview guide for the individual interviews with women with endometriosis and the analysis for phases two and three. They also contributed to the formulation of the resource materials.

Phase Two: Semi-structured interviews with women with endometriosis

Semi structured interviews with patients from the minority ethnic groups in the study were undertaken by members of the research team using the storytelling/narrative method of inquiry to explore their experience of living with endometriosis and their perceived needs for information and the provision of health services (see Appendix 3 for pre interview questionnaire and Appendix 4 for interview schedule).

Based on previous experience, we estimated that a minimum of 5 and a maximum of 10 participants from each ethnic group would create a sufficient samples size ($n=25-50$), but the basic rule of data saturation was observed.

Table 1.2 Phase 2 recruitment: individual interviews with women with endometriosis

Group	Number
Pakistani	7
Indian	6
Greek	6
African Caribbean	7
Chinese	3
Total	29

Inclusion criteria:

- Women of African Caribbean, Chinese, Greek/Greek Cypriots, Pakistani, or Indian origin
- Aged between 18 and 50 years old
- With a current clinical diagnosis of endometriosis
- Duration of illness >1 year prior to the study
- Receiving care from mainstream health care services (NHS)

Interviews took place in the preferred language of patients, in locations agreeable to them, and were tape-recorded with permission. Apart from one interview conducted in Urdu using an interpreter all of the rest were in English. The interviews explored the experiences of women receiving endometriosis services, and focused on their information needs and suggestions for service improvement.

Phase Three: Semi structured interviews with health professionals

Semi structured interviews were intended to be undertaken with approximately 15 health professionals (gynaecologists, gynaecological nurses, general practitioners) involved in the treatment of women with endometriosis. Gynaecological nurses were recruited easily from NHS wards and clinics, but although sufficient gynaecologists expressed initial interest in the research, actually arranging interviews, either face to face or by telephone proved extremely difficult. Attempting to interview General Practitioners (G.P.s) coincided with the outbreak of swine flu, which impacted considerably on primary care workloads. The interviews explored the views of health professionals regarding the needs of minority ethnic patients, their understandings of the socio-cultural background of patients and their own information needs regarding culturally appropriate treatment and patient care (See Appendix 5 for interview schedule).

Table 1.3 Phase 3 recruitment: Individual interviews with health professionals

Professional Group	Number
Consultant gynaecologist	2
Gynaecology nurses	5
G.P.s	1
Total	8

Phase Four: the development and piloting of resource materials

Using the data obtained in the previous phases of the research and advice from community groups, user representatives and the project advisory group members, resource materials for patients and service providers have been developed and piloted. Piloting focused on acceptability of the content of the materials, accuracy and appropriateness of translations, and appropriateness and acceptability of language. Greater detail on the translation of research findings into resource materials is given in Chapter 5.

The following information resources have been developed:

- Leaflets for each of the community groups in English, and in Greek, Gujarati, Punjabi, Urdu and simplified Chinese.
- DVDs for each of the community groups in English for women of African Caribbean origin; simplified Chinese for women of Chinese origin; Greek for women of Greek/Greek Cypriot origin; Gujarati for women of Indian origin; Urdu for women of Pakistani origin

- An on line educational Adobe Breeze presentation for health professionals

The resources developed and the knowledge gained from this study will form the basis for an evaluative intervention study for which further funding will be sought.

Data analysis

All focus group discussions and individual interviews were transcribed verbatim, and where necessary translated into English.

Following the focus groups the research team sampled the transcripts and independently identified themes from the data. A meeting of the team was then held to decide upon the issues of importance to the women arising from the data which could then be used to formulate interview schedules for phases 2 and 3 of the research. Verification occurred through discussion of the analyses, comparison and subsequent consensus. The community facilitators also had an input into this analysis by commenting on and validating the themes identified, and providing additional insight to the context.

The principles of Framework Analysis (Ritchie and Spencer, 1994) were utilized for a more systematic analysis of the individual interviews with women. This comprises of five key stages – familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation – which were employed by the research team using NVivo.

Because of the small numbers, data from phase 3 were interpreted manually using thematic analysis, with the research team identifying and verifying the themes.

The themes that emerged from analysis of phase 2 and 3 were sent to community facilitators and members of the study advisory group for comment and verification. A final form of verification is the comparison of findings with, and their embeddedness in the available literature.

Project management

Management of the study was overseen by the Project Management Committee (PMC) (Appendix 6) The PMC comprised the research team and advisors with expertise in women's reproductive health and minority ethnic health. It met six times over the duration of the project and monitored the conduct and the progress of the research.

The PMC was assisted in its role by the Project Advisory Group (PAG) (Appendix 7). This was a virtual group made up of members from each of the target communities, patients, self help and academic representatives who gave advice on various aspects of the study by email. Members were consulted on issues such as recruitment, research tools, appropriate use of language, and the development of resources.

Patient and public involvement

Various stakeholders were involved in all stages of the project. These included endometriosis self help groups, women from the target community groups, women with endometriosis, and health professionals who roles included treating women with endometriosis.

- Two self help groups Endometriosis UK and the Endometriosis SHE Trust were consulted before a funding application was submitted to gauge opinion on the need for the project.
- Community facilitators from the ethnic groups represented in the study were recruited and trained by the research team to organise and conduct the focus groups, and were involved in the development of the interview schedule. This added greatly to the validity of the project, in particular by ensuring that questions were sensitive to the culture and language needs of participants.
- The focus groups were conducted with women from the target communities who reported community values and customs around reproduction, sexuality and menstruation. These insights informed the rest of the project.
- Representatives from the target communities were recruited to the project advisory board.
- The community facilitators and the advisory group members were asked to comment on and adapt the themes that emerged from analysis of the focus groups, adding rigour to the analysis of data.
- These themes formed the basis of the interview schedule for individual interviews with women with endometriosis and with health professionals.
- Endometriosis UK, the SHE Trust and community facilitators aided in recruitment for individual interviews, and have been generally supportive of the project.
- The community facilitators and interviewees from the five communities were actively involved in the production of resource materials, in particular linguistic and cultural sensitivity.
- Translation of materials was by native speakers.
- The quality of translations was assessed by separate native speakers including community facilitators for linguistic and conceptual accuracy.
- Actors used for DVD voiceovers were native speakers who also commented on and suggested adaptations to the scripts to enhance authenticity and relevance to the communities concerned.
- Everyone with any involvement in the project has been invited to the launch of the information materials produced by the project to be held at Birmingham Women's Hospital.

- The team has plans to further disseminate the resources produced via community groups and community contacts established during the course of the project, and via a dedicated website.

Chapter Four - Findings and Discussion

Focus groups

In conducting focus groups we were interested in discovering dominant views and values within the communities in order to guide the development of meaningful interview schedules and to provide further insight into the social context that women living with endometriosis would experience in some aspect of their lives. Biographical details of focus group participants can be found in Appendix 8.

Ethnic and gender identity

The focus group findings demonstrate both similarities and differences between the groups consulted, and between them and the white majority population. They also highlighted differences within each community group, and the influence of generation and acculturation. 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 faults 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.”

There were quite marked differences between how groups perceived gender and ethnic identity, and all agreed that traditional identities were being increasingly influenced by younger women living, and for some being educated, in the UK. The Caribbean group described women in their community as leaders, in the forefront of community life. They appeared to be empowered and independent. All were in paid work and the main bread winner 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 viewed living in the UK as different from living in China. Whilst in China most women will be working outside of the home, in the UK there are limitations such as language, expensive childcare, and difficulty in getting a suitable job as a migrant. So many women within this community remain unemployed and at stay home, or work in a family business. There was also a perceived lack of integration in the UK and a stronger identity with the Chinese community than gender identity.

The Greek Cypriot focus group included a wide age range and perceived that women in the UK are in the process of breaking out of the traditional female Greek Cypriot mould; they are more liberal and have more choice than the traditional Greek Cypriot woman who was viewed as being subservient to men. This group perceived themselves as strong, and multi-tasked, not relinquishing their responsibility for the home and children as they moved to more outside roles. The generational

differences between Greek women was summed up by a young woman born in the UK

“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).”

According to the Indian group children in their community are brought up to respect the family and in-laws, and being a Gujarati woman means having close family ties, and respecting the older generation. Gujarati women in the UK see themselves as more liberal and open than their counterparts living in India. They relate more to their children; the children born in the UK are exposed to other cultures and tend to question Gujarati ways, parents therefore need to be able to deal with this. The Gujarati women felt it important to keep their culture alive within their children.

The Pakistani women described women in their community mainly as housewives. However they viewed this as changing as the younger generation are UK educated and now 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.

“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.”

“They’re not appreciated either.”

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 is played out, particularly in the amount of power and control that women feel they have, with the African Caribbean women viewing themselves as having most control, and Pakistani women least. Acculturation within a dominant British culture was increasingly influencing gender and ethnic identities, particularly for those women born and/or educated in the UK, and all groups recognised that there were generational differences within their community, for example younger Greek Cypriot women did not expect to do paid work as well as all of the work in the home as many of the older women did.

Menstruation

The groups all spoke of menstruation in negative terms, and told of menstrual taboos, such as Indian women not being allowed in the kitchen during menstruation, or Pakistani women not able to pray. Women used terms like ‘curse’ (either the Devil’s or God’s), and spoke of embarrassment at buying sanitary towels or of 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 persist.

"I don't know what is the thing about having a period and being dirty?"

"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."

"Yes that's what my yiayia [grandmother] says."

"And it could be disastrous. But nowadays I don't know why it's carried on."

"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. Menstruation was also seen as a marker of not being pregnant which could be positive or negative, depending on the wishes of a woman at that point in time.

Women were asked about the experience of menstrual pain and how this is dealt with within their community. All groups felt that it would be treated as something normal and to be expected. This is discussed further below in relation to endometriosis.

Women from the African Caribbean and Chinese groups mentioned traditional remedies that might be used for menstrual pain, but within these groups there was not always agreement about whether they were effective, or whether Western medicine is preferable. So some African Caribbean women mentioned white rum containing ganja, and the Chinese women spoke of brown sugar and ginger soup.

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

The other three groups talked about taking analgesia, and discussing possible remedies with family members and friends, but there was no consensus within the groups as to whether friends or mothers would be the main source of advice for dealing with menstrual pain. This seemed to depend on the openness with which issues around menstruation were discussed within the family. There was more consensus that it would need to be a female, whether family member, friend or health professional.

A Pakistani woman commented:

"We know lots of girls that just wouldn't go to the doctors 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."

One of the Indian group members spoke of how the closeness of the community

made it hard 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.”

Many of the women in all groups thought that women from their community would normalise severe period pain, which is consistent with previous research in endometriosis (Denny, 2009; Markovic et al, 2008), and thought that fertility problems would be more likely to result in seeking professional help. This contrasts with research on symptomatic women from majority communities in Australia (Butt & Chesla, 2007) and the UK (Jones et al, 2004) where pain was usually the impetus for seeking health care, and fertility problems emerged later in the patient journey.

Reproduction

Motherhood was important to all of the groups and 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 having male children. Greek women also spoke of the pressure on them to have children, as in this quote:

“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 not feeling, you know, that something is wrong with yourself, so there are loads of pressures around them to becoming a mother.”

For Chinese and African Caribbean women reproduction was seen more as an individual choice, and these groups generally felt that there was no familial or communal pressure on women 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 providing fulfilment in their lives that previous generations would have achieved from motherhood. There was less consensus among this group about community perceptions of the importance of motherhood, with one woman stating that for men reproduction is an indication of their masculinity and a woman who does not conceive may feel she has failed her husband or partner, who may then move on to someone with whom he can have children.

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

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

“We have no pressure”

All groups felt that by living in the United Kingdom ideas about motherhood were changing, including the acceptability of working mothers, and as in earlier responses, generation and assimilation appear to be strong influencing factors in community groups' views.

Although there were varying community views around the importance of motherhood to women's roles and status, all reported views of involuntary childlessness in their community in negative terms. The Caribbean group thought that infertility was not a great problem within their community, but one woman thought that this perception may be because health issues of black women are under-represented in the media. They 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 problematic to women of from all of the groups, including the Chinese and African Caribbean who were more accepting of voluntary childlessness. Most 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 stigma.

“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.”

The Chinese, Pakistani and African Caribbean groups thought that some men from their communities may look for a woman who could have children. Pakistani and Chinese women thought that men would divorce their wives in order to do this, but African Caribbean men would take an additional partner.

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.”

Within the African Caribbean community the reaction to infertility, as expressed below, is 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.”

In the communities where there was an expectation that women would reproduce childlessness whether voluntary or involuntary was stigmatised, and women felt pressure from family and a sense of worthlessness. In the African Caribbean community where women reported more acceptability of voluntary childlessness, infertility was nevertheless stigmatised in a similar way. These findings confirm those of Culley et al (20006) who highlight the considerable stigma attached to involuntary childlessness in British South Asian communities, but also the influence of generation and educational background on women's ability to resist such stigma.

There is little information available on perceptions of infertility in other minority ethnic groups in the UK. While 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 specific cultural specificity.

Endometriosis

Issues around menstruation and fertility are at the centre of the problems experienced by women with endometriosis. Very few women in the focus groups had heard of the disease and all were interested to learn from the facilitator about the symptoms and treatments for it.

The groups were all shown diagrams of the female pelvic anatomy by the facilitators, and an explanation of endometriosis was given. Following this all 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 in the Greek group had been diagnosed with endometriosis, but no one in the other groups even knew anyone who suffered from it.

The groups all wondered how you can tell a 'painful period' from the pain of endometriosis. Many 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.

For example a Pakistani woman commented:

"Women in our community would treat it as a normal period and dismiss it"

And an African Caribbean woman made a similar point:

"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."

Some women, in particular from the Pakistani and Indian groups seemed to think that the experience of deep dyspareunia would be a more likely trigger to seeking help within their community than painful periods, but even this was not universally agreed. There was agreement that wanting to become pregnant would lead to them seeking help from their general practitioner, but within the Chinese groups it was thought that it may be first discussed with friends and partners. However there was some disagreement within this group, as the follow exchange demonstrates.

"I think it must be the doctor, women won't talk to others."

"I think she would talk to people around her and then go to see the doctor."

"I think she 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."

For the African Caribbean group sex was seen as a private topic and not one that

was readily discussed, and Pakistani and Indian women would feel embarrassed to discuss it except with a female doctor.

The Indian focus group was initially silent, followed by nervous laughter at the mention of painful sex, but one then commented:

“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.”

The Pakistani group also thought that women in their community may be more likely to seek help for dyspareunia, either because of implications for fertility or because of their husband's desire for sexual activity.

“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.”

The African Caribbean women were most likely to refrain from sexual activity if it was painful, as one commented ‘If I had sex and it was painful, then I just wouldn't want it’. However, many women from 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 many of them would respond to. Very little previous work has specifically considered the impact of dyspareunia but those that have report women's feelings of guilt and inadequacy, but relate this to loss of a shared intimacy, rather than privileging one partner's needs (Denny & Mann, 2007; Jones et al, 2004).

Summary

By conducting focus groups before individual interviews the team was able to gain insight into community views on reproductive issues of relevance to the study of endometriosis in order to inform the development of schedules for individual interviews. However the data that were obtained also proved of value in developing the resources for communities and health professionals, and indeed has added valuable insight as data in its own right, giving a unique insight into perceptions of a range of related issues in British minority ethnic communities.

Individual interviews with women with endometriosis

In contrast to the focus group discussions where community beliefs and values were being sought, interviews with women with endometriosis were concerned with individual experience within the context of their lives. Culture was influential in the way women made sense of their experience, but the importance that women gave to this varied within and between the communities. The African Caribbean women interviewed were all born in the UK and identified fewer pressures that they felt were influenced by their cultural background than other groups. Five out of the six Greek/Greek Cypriot sample were also born in the UK, but all identified strongly with their

Greek culture. The Indian and Pakistani women reported most cultural differences, and community influence on their lives.

Overview of the participants from each minority ethnic community

The women were recruited from endometriosis clinics.

The interviews with women demonstrated more similarities between them than differences and confirmed findings of previous studies with majority ethnic women in the UK and the USA. However, there were culturally specific issues identified in all of the groups studied.

Seven African Caribbean women were interviewed for Phase 2. Four were aged between 26 and 30 and the remaining three aged between 41 and 50 years. The minimum level of education was college/A-level and four were educated to university level. All seven were born in the UK, reported English as their mother tongue and rated their competency in English as high. Only two were married. Most were Christian (n=5) including one Jehovah's Witness and one describing herself as atheist.

Generally the African Caribbean women were quite open about their endometriosis. They had all told family and close friends and for most family was a strong source of support. Some had also told their employers about their condition and found this made it easier to take time off when they needed to.

Although the motherhood mandate is fairly universal, the data here do not suggest pressure on the participants to have children. According to the mothers in the Caribbean group it was not an 'expectation' that their daughters had children. Out of the two married women, one of the women had children and one was undergoing fertility treatment. The others were single, one with a daughter, and three expressed the desire to have children in the future.

Some of the women reported using traditional Caribbean herbs/teas like cease and peppermint tea to help control period pain. Some had used this prior to diagnosis and continued to do so. A few of the African Caribbean sample had the perception that black women experience greater difficulty in being diagnosed, and also that health professionals were more likely to recommend hysterectomies to Caribbean women. Data from the African Caribbean focus group also suggest lack of confidence in health professionals, particularly in primary care but to a lesser extent in secondary care. These perceptions may influence health seeking behaviour and it is interesting that the Caribbean group had more participants reporting A & E visits due to extreme symptoms than any of the other groups. Three of the group had fibroids as well as endometriosis, and it was sometimes difficult to disentangle the effects of each condition, although for the women it was the combination that affected their lives.

Three Chinese women between 26 and 52 years of age were interviewed, and this was the smallest sample within the groups. Two were born in China, the third in the

UK, two rated their competency in English as high, and the other moderate. The one woman who gave English as her first language was the only one who was born in the UK. They were all educated to university level and two were in full time employment. Two were married, and one single. Two gave their religion as Christian and the other had no religion.

The Chinese sample was small and perhaps as a consequence their stories are quite different. One recurring theme among the Chinese interviews is the use of Chinese herbal medicine. Two of the women had used it extensively, but with differing results. One believed that it 'cured' her endometriosis, but the other found it had not helped with her infertility. The third was considering using it as a long term measure to control symptoms and prevent a recurrence of endometriosis. The mother of one woman brought a Chinese broth onto the hospital ward following her daughter's surgery to aid recovery, but was not allowed by staff to give it to her.

Motherhood was important to all the women. Of the two married women, one had succeeded in having a child, despite having another health problem that made the little likelihood of this very low, and the other is exploring the option of fertility treatment in the UK after successive treatments in China. The single woman expressed anxiety about her fertility and a desire to have children in the future. The desire for motherhood comes across as a personal aspiration and there is no indication of community or family pressure. This is consistent with data from the Chinese focus group.

The data suggest that single women may find gynaecological issues embarrassing. The single participant was reluctant to disclose the details of her condition to her family. For example she had not informed her parents with whom she was living about her endometriosis even though they were aware of her surgery and her mother came to see her in hospital. This may be because her primary symptom was painful sex which she felt unable to discuss with them. She did not report severe dyspareunia to her GP despite being prompted by her partner until she experienced additional symptoms.

Six Greek/Greek Cypriot women were interviewed for Phase 2. They were between 28-38 years old. Five of them had attended university whilst the sixth had a college/A-level education. One of the six participants was born in Greece and had been living in the UK for the last 15 years. She reported Greek as her mother tongue but rated her competency in English as 'high'. The other five were all born in the UK and reported that their mother tongue was English. Four were married and two single. They were all employed –five full time and one part-time. They all reported to be Greek Orthodox Christians and their religion was important to them.

Generally the Greek/Greek Cypriot women were quite open about their endometriosis, and the symptoms such as dysmenorrhoea. They had all told family and close friends and for all, family was a strong source of support. Some had also told their employers about their condition and found this made it easier to take time off when they needed to, even though they felt guilty for being away from work more often than

they would have liked to. A strong work ethic was apparent within the Greek women. However, they reported that employers often did not know anything about the condition and it was stressful for them to have to explain.

All the participants reported that motherhood was very important to them and their families. The married women spoke of the sorrow associated with their attempts to get pregnant and the efforts and pain involved in undergoing numerous surgical procedures. Women reported on the efforts they had made themselves to try to increase their chances of a pregnancy including travelling to Greece or Cyprus for second opinions or visiting religious monasteries associated with fertility. They were also willing to try alternatives to medical care such as special diets recommended by nutritionists or family members. Women also reported having to endure their stereotyping as hypochondriacs by their GPs, however these women readily sought medical treatment in the NHS but would complain if not satisfied with their treatment and would opt for the private sector. The single women reported being anxious of the possibility of having fertility problems as they both wanted to have children once married.

Six Indian women were interviewed, all aged between 36 and 40 years. Most were married ($n=5$) and one separated, and five were in full time employment. Two were educated to secondary school level, two had A levels or college education, and two were educated up to university level. All six were born in the UK and four rated their competency in English as high and two moderate. Three gave their mother tongue as Gujarati or Punjabi. Three gave their religion as Hindu, one Sikh, one Hindu-Sikh and one Jehovah's Witness.

Indian women reported having children as the main purpose of marriage in their community and an expectation that women will have children fairly soon after marriage. Half of the Indian sample were undergoing fertility treatment and felt under a lot of pressure due to the age limits on fertility services. The data suggest an element of stigma and of blame, it was generally considered the woman's 'fault' when a couple have problems conceiving, and some of the women dealing with infertility blamed themselves for not having children earlier in life, that is in their early twenties.

Only one participant made reference to faith or religion while narrating her fertility problem and spoke of the use of special prayers and fertility charms. Reference was also made to the community perception that pregnancy cures painful periods, and painful periods was something some women had to endure until they have children. Some of the women were quite open about their condition and had told family and close friends, but two participants expressed a preference to keep it secret. Of these, one was concerned that she would be looked down on and not regarded as a proper woman by family and friends. However importance of secrecy was not as great for Indian as Pakistani women, many of whom went to great lengths to keep their diagnosis a secret.

A total of seven Pakistani women were interviewed, representing 24% of the sample

for phase two. They were aged between 26 and 40, with the majority being below 35. Four were married, one single, one separated and one divorced. The majority (n=5) had been educated up to university level with the other two being educated up to college level. Four of the women were born in the UK and the other three were born in Pakistan. With one exception, all had been living in the UK for at least 20 years. Six rated their competency and English as high and were interviewed in English. Five gave their mother tongue as Punjabi, Urdu or Mirpuri. One was interviewed with the assistance of an Urdu interpreter; she understood some basic English but could not read English and spoke very little English.

Culturally specific issues were more apparent in this group than any other. The data indicate a stigma surrounding gynaecological problems in the Pakistani community, which stems from the general community perception that they are either an indicator of fertility problems or related to abortion which is forbidden in Islam. The data demonstrate that fertility is very significant in the Pakistani community and women would rather not have anyone suspect that they have gynaecological problems as it raises questions about fertility and could potentially have an impact on one's marriage prospects. The importance of fertility was also linked to feelings of self worth. One participant who already had children was still careful to keep her condition private and was concerned that if people found out they would say negative things about her to her husband. Another narrative demonstrated denial, not being able to face it because of all the cultural implications and the participant put off seeking treatment until symptoms got significantly worse. The primacy of fertility meant women with endometriosis experiencing fertility problems felt strong pressure from those around them. Even though women preferred to keep their condition private, it was very difficult in a close knit community.

It is an expectation in the Pakistani community that women remain virgins until they get married and premarital sex is frowned upon. Participants spoke of concerns about the physical effects of extensive internals and other tests, which could be a barrier to accessing health care. There are also findings relating to reluctance for unmarried girls to take oral contraceptives as it can create suspicion of premarital sexual activity.

Pakistani women also spoke about impact of religion. Examples are the inability to practice their religion due to religious restrictions while menstruating and also the physical effects of endometriosis made it difficult to participate in fasting during Ramadan. Within Islam, sex is seen as a marital duty and women experiencing painful intercourse find it particularly distressing at not being able to fulfil this duty. Others pretend everything is normal because of concerns of possible consequences on their marriage.

The sample as a whole has a higher level of education than the general population. The majority of the women interviewed were born in the UK, or had spent most of their life here, yet retained strong links to their cultural and religious traditions.

Thematic analysis

Many of the narratives raised issues and concerns that are similar to findings from previous qualitative research, and which appear to be ubiquitous among all women with endometriosis.

The endometriosis journey

In common with the focus groups the majority of women interviewed had not heard of endometriosis before they were diagnosed with it. For some women it was one of a number of conditions that came up on an internet search of their symptoms, or others had friends who had been diagnosed with endometriosis who commented on the similarity of their symptoms. African Caribbean women were more familiar with fibroids and would sometimes think that was what their problem was, a misconception frequently compounded by health professionals.

“The only thing I had heard of was fibroids because I know they are more prone in Afro Caribbean and even in Asian women. And, and I know at one point when I did see a doctor ages ago, she did actually mention fibroids to me.” (AC06)

One African Caribbean woman felt that the similarities of symptoms for all gynaecological conditions made it difficult to make sense of what she read on the internet.

For most women the first symptom they experienced was severe pain during menstruation. Other initial symptoms include pain on opening the bowels and post-coital pain. Only one participant described herself as being asymptomatic and she was discovered to have endometriosis during investigations for fertility problems. However during the interview she disclosed that she experienced pain during intercourse, but she had not associated it with endometriosis.

Women’s graphic descriptions of the pain they experienced, as severe and prolonged, is consistent with previous research.

“I was in so much pain, it was like my head, back, from the lower back down to my legs was just collapsing, it’s like somebody’s crushing, crushing that whole area, but it’s in a circle from you know your pelvis all the way round to your lower stomach to your lower back, crushing, crushing and crushing and you just don’t know what to do, don’t know how to, how to get rid of the pain.” (P04)

“I thought this must be what it is like to be in labour, but I wanted to die because it was so bad. I just thought death would be a relief from this pain and it caused me to vomit.” (G03)

“Just before the surgery I was basically unable to walk. I would pass out on a regular basis from the pain. For several weeks I was just basically completely laid up” (P02).

Despite experiencing severe pain women often felt that they were not taken seriously by doctors when they tried to seek an explanation for their symptoms. They found that their symptoms were trivialised or they were made to feel that they were

exaggerating a normal condition.

“They did make me feel that I was a bit of a hypochondriac that it was all in my mind. They did make me feel like that. Why not investigate something? Why not say something. Why just keeping fobbing me off with medication?” (G03)

Women themselves did not always recognise their symptoms as anything different from other women, and rationalised their experience as ‘just period pain’. This is consistent with previous research [Seear, 2009; Denny 2009], and also with the focus group finding that women would normalise menstrual pain.

“Yeah, I’ve always had like really awkward periods and like painful periods and uh I just thought oh it’s just the normal thing you get period pains.” (I03)

“If the doctors are telling you that, that oh it’s just you know heavy periods, it’s normal and, then you’re like well ok it must be normal cos you’re a doctor and you know what you’re talking about.” (I06)

These issues were associated with a delay in the diagnosis of endometriosis, as was diagnosis of another condition such as irritable bowel syndrome (IBS) or in the case of African Caribbean women, fibroids, which was usually a misdiagnosis rather than co-morbidity.

Once women had a diagnosis the immediate feeling was one of relief that they had a name for what was happening to them, and an answer for something that had not made sense in their lives.

“It wasn’t all in my head, like some doctors would have you believe for years basically they had you believe that that it was all in my head and I kept thinking no, so the biggest impact was the fact they diagnosed something and it suddenly made sense.” (AC05)

“I have to say that there was a relief when I was diagnosed eventually because all these years I had all these symptoms and you know, the heavy periods and I was thinking ok, so there is something. I’m not going completely mad here.” (G04)

However, the implications of a diagnosis soon became apparent for some women, particularly possible implications for present or future fertility, or the thought that daughters could have the same thing.

“I was really, really upset about it. When they came and told me about it last year I was just upset because I wanted to have children.” (PO3)

“I think my biggest concern is that they say it could be hereditary even though nobody before me has had it, but having two daughters that is a big concern.” (PO2)

All of the women found that to a greater or lesser degree endometriosis impacted on their lives. The experience of pain necessitated adaptations to work and social life as did the commonly experienced feeling of fatigue. Some women’s lives were totally dominated by endometriosis, so that any kind of social life became impossible, which was not always understood by family and friends, particularly in communities where

social responsibility is very strong.

"It came to the point that I had to take days off work. I couldn't go in because it was just so painful and there was a point when I remember I collapsed on the floor at home because I just couldn't walk with the pain, so my Mum had to lift me up to get me to bed." (AC01)

"Endometriosis has impacted my sick leave in a lot of jobs, and sometimes I have had to change jobs. My last job I had to change because no one really believed me when I was really sick." (AC04)

"My house is like a tip. I have no energy to do my housework. I feel embarrassed if people come round and I make excuses. Also most of my friends are married now and settled down, so it has had a direct impact on my social life." (PO3)

Most women had good support either from partners or from female friends and relatives. Many commented on the physical and emotional support they had such as these African Caribbean and Greek women who said:

"He [partner] is very supportive. He knows that whenever I am at that time of the month and I start to feel the pain it is 'do you want this tablet? Do you want a peppermint tea? A hot water bottle?' He's there whenever I have any pain at all. He always comes to the hospital with me for check-ups, ultrasound scans or anything that has got to do with it. He is always here." (AC01)

"My sister and my friends are very supportive. Because when I am on my period I can't move for three days. I lose the feeling in my legs so I need to be looked after. I can't cook, I can't tend to my personal hygiene, and I become disabled." (G02)

However, some women did feel that no one could really understand the reality of living with endometriosis, particularly men who did not experience or understand menstruation, and even with supportive partners women found that living with endometriosis put their relationship under strain.

"A man will never know what a woman goes through every month. Because women get on with it, and because I get on with it, my husband doesn't fully understand the pain I am in. Because I don't moan about it every month, it's non-existent in his eyes." (I01)

"I don't have relationships any more, I've just resigned to being single because I don't think there is anyone out there who I can explain it all to." (AC04)

Support was to an extent influenced by the willingness of women to discuss endometriosis with people. Disclosure revealed quite marked differences between the groups. The Greek women were all very open with family and friends, male and female.

"He [father] can always tell when he phones me up and he can hear that I am in pain, and he says 'you are on your period today'. It is quite common for Greek dads to be like that with their daughters." (G02)

Other groups were more circumspect, demonstrating different levels of willingness to speak about menstruation, with some disclosing to others, for example colleagues, for more pragmatic reasons.

"I have told them during a team meeting because I thought that everybody thought I was a 'sick note'. I am always sick every month. They didn't know why, they didn't know what was wrong with me, so I felt that I had to." (G02)

There were also worries expressed by Indian and Pakistani women about the implications of disclosure for their life within the community, and the assumptions that members of the community might make about them, particularly around sexuality and fertility. This is discussed in greater detail below.

The endometriosis journey of the women in the study parallels that described in previous research from the UK, The USA and Australia (Denny 2004a; Ballard et al, 2006; Gilmour et al, 2008). There would appear to be some universal themes that emerge from the experience of endometriosis, such as pain, the delay in diagnosis and the impact on all aspects of a woman's life. However, other themes emerged from the data that were either culturally specific or played out differently within different cultural communities and these have implications for the way in which endometriosis is experienced and made sense of within the lives of the participants.

Fertility

While previous research has highlighted consideration of fertility issues as important for women with endometriosis (Manderson et al, 2008; Markovic et al, 2008; Denny and Mann, 2007) for many of the women in this study fertility was the overriding concern. In addition in both the focus groups and interviews reproduction and fertility were portrayed as not just a matter for individual couples but of concern to the wider family and the community. This view was particularly prevalent among the Indian and Pakistani women, although family pressure was also evident in the interviews with Greek women.

"Maybe in our culture it is quite a big deal if you can't have children you know, and it's very personal as well and I guess traditionally in our culture women who haven't been able to have children have been talked about, have probably been called names, they haven't been treated as proper human beings, they've been treated probably lesser because of it." (I04)

"Our Pakistani people tend to ask questions if you've been married for more than 2 years and still have no children." (P07)

"My Dad cracked a joke with me the other day. He turned round, because I am the youngest of three, we are all single, none of us have had children, and he turned round and remarked he had no grandchildren and said may be you should have your eggs frozen, just in case, because your clock is ticking and you are nearly 29 years old. When Mum was 29 she had all three of you already. It was a little joke but you could tell he meant it. I think it is something that is expected." (G02)

As the quote from the Indian woman above shows women who could not conceive

were highly stigmatised, and this was reflected in all communities.

“Asians are very, ‘why can’t you have children then? You know, there must be something wrong with you, it’s not a good thing you can’t have children’. In India when you can’t have children, there’s a name for it, isn’t it? Barren.” (I01)

Despite this family and community pressure to reproduce some women felt that whether or not they became pregnant was the will of God. Greek women spoke of praying to particular saints, or going on a pilgrimage to enhance their chances of conception, and Pakistani women also spoke of saying particular prayers. However, two of the Pakistani women were more resigned to leave their fertility in God’s hands.

“They are doing their treatment and they have done all their checks and they have said that there is nothing wrong so if God wills I will be able to conceive.” (P07)

This woman’s family concurred with this view and were very supportive to her, attaching no blame on her inability to conceive.

One Indian woman described how her religious beliefs led her to believe that things would only happen if they were meant to be, but in the meantime she would do whatever she could in terms of medical treatment to achieve a pregnancy. So women managed the tension between family and community expectation, individual responsibility and acquiescing to the will of God in quite personalised ways.

However, although recognising community expectations within interviews women also spoke about having children as a personal desire, and the personal pain of not being able to conceive.

“I find it like a bit embarrassing and a bit of um a failure, I feel like a failure you know like, I haven’t had kids and this and that and I can’t have kids is like a bit, yeah so I’m quite upset about that, I can’t have kids.” (I03)

During the focus groups women from the Greek, Indian and Pakistani communities expressed more pronatalist views than the Chinese and African Caribbean women, and this was more or less reflected in the individual interviews. However, the African Caribbean women with endometriosis did have stronger views than those expressed in the focus group about the importance of motherhood to them, and of pressure from family to reproduce.

“My mum nags all the time. Despite the fact I’ve got endometriosis, my bladders and my bowels just about work, she’s like yes you need to settle down and get married and have kids and stuff.” (AC04)

Interestingly one of the Pakistani women stated that she would only considering marrying an older man who already had children, in order to avoid the potential problem of future infertility.

The importance that most of the women placed on fertility gave symptoms such as dyspareunia a greater importance for some women than other symptoms they

experienced, as it restricted their ability to have sexual relations. It also influenced the acceptability to them of some hormonal treatments, with those that could suspend ovulation not being acceptable to women who were trying to conceive.

“I don’t think there are any other forms of treatment that aren’t going to risk my fertility further, so I just think I should stay where I am and suffer the pain rather than doing anything about because I am a bit scared about never being able to have a child.” (G02)

Painful sex is reported by some women from each of the communities, and one of the Indian women did not seem to acknowledge it as a symptom of endometriosis. Sex was uncomfortable and she did not find it pleasurable, but she perceived that as her personal experience, rather than part of her endometriosis. She had not reported painful sex during consultations with her gynaecologist and only volunteered it when queried about it during an investigative procedure to check her fallopian tubes.

“I guess it’s one of those things you don’t really talk about, you think it’s just you and you think well maybe you’re just too small sort of thing. So you think the fact that you’re being stretched is probably what’s causing the pain, so no it’s not something I’ve ever taken to the doctor.” (I04)

In summary fertility, either present or in the future was a great concern to women and this finding is consistent with other research (Denny and Mann, 2007; Markovic et al, 2008) but this is usually expressed as an individual desire to have children. What is different here is the family and community expectation for couples to marry and reproduce in quick succession, and the stigma and blame that is afforded to women who do not conceive, which is seen to be a legitimate concern of those outside of the couple. This is a particular feature of the Indian and Pakistani interviews, and to a lesser extent the African Caribbean and Greek Cypriot. Infertility was perceived more as a personal problem by the three Chinese participants.

Cultural issues around endometriosis

Endometriosis is a reproductive health issue and as such shares with other gynaecological problems cultural meanings and interpretation.

All of the women identified with their traditional background, whether or not they were born in the UK. They used their origin in their description of their cultural identity, sometimes adding it to British, so for example Greek Cypriot, black British, British Indian. Although the extent to which women identified with Britain or the background of their family of origin varied the following quote from a Greek Cypriot woman sums up how many felt.

“Because I am close to my family, my community, I feel close to my roots still. Even though I am a British citizen and I consider my nationality British, at heart inside I am still feel like I am Greek.” (G03)

The majority of the women agreed that to some extent their experience of endometriosis was influenced by values dominant within their community, but there

was variation in this. Pakistani and to a lesser extent Indian women found it difficult to discuss gynaecological issues within the family and community, and described how suspicion is raised about the cause of any gynaecological problems. Firstly there is suspicion within the community that any gynaecological condition could lead to infertility, as discussed above, and this could make an unmarried woman unmarriageable, which would be stigmatising in a culture where marriage is so highly valued. There is also suspicion within some communities that any gynaecological problem may be due to an abortion which is also not acceptable.

“When my sister had surgery we couldn’t tell people that it was to do with ‘down there’. She had surgery and she was really ill and because she was in intensive care they thought we might lose her. We had to say it was appendix because if we told them what had happened people would think it was something like an abortion something like that and would ask ‘can’t your sister have children now’. So it’s very taboo, you don’t tell people.” (P04)

Another important issue particularly within the Indian and Pakistani communities is virginity at marriage. Pakistani women expressed concern that extensive internal examinations may compromise proof of virginity. Treatment with oral contraception may also be viewed as evidence of sexual activity.

“The most obvious problem that you would face as a single woman is the fact that when you go and see a doctor the first thing they would say is that they want to do an examination and that would be a problem because you have the whole aspect of you must be a virgin when you get married. If you have had extensive internal examinations then obviously there are problems with bleeding [on first sexual intercourse] and then suspicions are raised. There is obviously nothing wrong with that in a moral or cultural sense but it is because of prejudices, so because of that I don’t know what a single woman would do.” (P02)

“Well, there was a bit of controversy, cos my mum said why are you on the pill and I was like the doctor gave me the pill to help, it kind of makes them a little bit suspicious about whether you are sexually active.” (P04)

In a similar vein unmarried women found it offensive to be told by health professionals that pregnancy would cure their endometriosis, as this would obviously require them to engage in pre-marital sex. Some Indian women however, did report being told within their community that pregnancy ‘cures’ painful periods.

So worries about family and community reaction, and for single women concerns about maintaining physical evidence of virginity, led to some reticence around seeking medical help for their pain, and it also led to concerns about disclosing either their symptoms or the diagnosis of endometriosis to others, which limits the sources of support such women can access.

As discussed above Greek women were open about discussing menstruation within the family and with friends. They were also open about dyspareunia, and did not object to being examined by male health professionals. Being treated with respect by

staff was more important to them. African Caribbean women were also open about endometriosis, but although they reported being open with health professionals they were reticent about discussing sexual relations more generally, and described it as a taboo. The small Chinese sample valued privacy and were more circumspect about discussing any personal issues and place great importance on confidentiality. For some of the Indian and Pakistani women the option of choosing who to tell about their symptoms or diagnosis was not always available, as it was felt that whatever you did the community would become aware of it.

“For someone who is living at home with family members then just going out to see the GP and having hospital appointments would be very difficult and if I go to my local hospital I meet three people I know there, so it is ‘what are you here for dear?’ ” (P02)

Some women did attempt to divert suspicion, such as the woman quoted above who told people her sister had had an appendectomy, and some refused to discuss it with people unless they chose to.

“My husbands’ parents just wouldn’t understand. To me, it’s not even their business. Unless I make it their business, so unless we have to tell them, we wouldn’t really.” (I01)

However, this feeling was not universal and some Indian and Pakistani women did speak openly about endometriosis.

“In my family I think everyone’s completely aware of the situation, I haven’t kept it a secret um and you know it’s brought me closer to some of the people in my family.” (I06)

Apart from the Chinese group the majority of women spoke of their religion as being important to them. They or their family members would carry out religious rituals or go on pilgrimages in order to help alleviate the symptoms of endometriosis or to try to achieve a pregnancy. Most find comfort in their faith, as these Greek Orthodox and Hindu women demonstrate.

“I believe in God. I believe in Jesus and Mary and saints. I believe that I have got a guardian angel and just pray. I believe prayer can change things.” (G03)

“I think it’s a form of comfort and you know it gives you a bit stability when, when things aren’t going very well.” (I06)

The Pakistani women were the only ones to speak of sexual intercourse between husband and wife as a duty in their religion. This led to women feeling that not only were they failing as a wife but also within Islam if they were unable to have sex due to dyspareunia. One woman also pointed out that this was not a question of female subservience as it is often stereotypically portrayed, but a matter of marital obligations to and by each partner.

“I think they need to realise that [Muslim women] are sexually active and they are quite clued up, they do engage in that and they do have needs, just like everyone

else. It's not that we're very submissive, and we don't voice our concerns but within ourselves we do, with our husbands we do. We don't discuss it with the doctor as much because of barriers, they need to realise that we are sexually active and painful sex affects us. They probably think, you know, she probably doesn't want to have sex as much or anything because she is religious, but it's not the case, it's probably completely the opposite." (P04)

Women's experience of service delivery

Dissatisfaction with health services in general and with some health professionals has been a feature of much research on the experience of endometriosis (Cox et al, 2003a; Jones et al, 2004; Ballard et al, 2006; Denny and Mann, 2008), and this has been briefly commented on above. There is also evidence of ethnic differences in service user rating of health care (Karlson, 2007) and that patients from minority ethnic groups evaluate care more negatively than white patients (Mead and Roland, 2009). However, while there were common issues in the experience of endometriosis, such as not being taken seriously by doctors, there were additional issues that arose in this study issues pertaining to the experience of health service delivery.

A number of women in the study attended Accident and Emergency (A&E) departments with acute symptoms of endometriosis, which is not a common feature of previous research in the UK. Eight women, including three from the African Caribbean group, attended A&E, some by emergency ambulance, in severe pain. One African Caribbean woman spent eight years seeing her GP and two gynaecological consultants who did not find any cause of her pain, and would regularly be taken to A&E as the only place that would address her pain. From A&E she was eventually referred to another gynaecologist who diagnosed her endometriosis. So A&E was used to circumvent what women saw as deficiencies in the service being offered to them. Another woman who had also been seen by a consultant reported:

"One day at work I collapsed again and the pains were getting really bad and I wasn't on a period then, it was the week before. It was very severe and I couldn't keep anything down, so I went to A & E." (AC02)

Some women felt that individual doctors did not respect their culture or religion and there were also instances of very negative behaviour, although in the case that follows of a woman who was a Jehovah's Witness an apology was later given.

"I think yes definitely for things like religion and even culture as well, because when I spoke about it the consultant just kind of brushing off my thoughts and fears about infertility and taking a hormone tablet every day, going against nature, she just had no regards for my beliefs really and just kind of said almost don't be so silly." (GC01)

"Before the anaesthetic, because I had put that I was a Jehovah's Witness, they weren't very kind and they said you are wasting our time because if we cut you open and can't give you blood you are going to die. I was kind of taken aback because I wasn't expecting them to be so prejudiced even though there are things that you can have instead of blood." (AC02)

Women did give examples of the way in which their cultural preferences were not taken into account during procedures, however, women made a distinction between identifying with their cultural background and conforming to cultural stereotypes. They were more concerned that their stated preferences were respected.

“I think they understand that you’re Muslim but they don’t understand what being Muslim entails, you know there’s certain things like, like they’ll give you a bed bath but they don’t realise you need to be covered when you’re having a bed bath, you know you don’t want to be exposed because that’s not our religious practice to expose ourselves.” (P06)

By contrast some of the women were happy that their cultural and religious views were understood and incorporated into their care:

“I went into hospital and I asked if I could leave the scarf on to the operations theatre. The assistant was Muslim as well so she had a scarf on, they were absolutely fine.” (P01)

With the exception of one Pakistani woman, all women in the sample rated their English as fair or good, but some expressed concern over the lack of facilities for those who do not speak the language or understand the health system in the UK. One woman who felt that the explanation of her surgery given by the gynaecologist was not clear commented:

“So you know I felt I know how to get a point across and I know what I was having done but there’s probably other women that don’t, who can’t speak the language, don’t have a clue and these consultants don’t, aren’t explaining properly.” (P05)

Pakistani women were particularly worried about the quality of translation services and that a woman’s lack of English may lead to more stereotyping of them.

“I think may be perhaps because someone’s English may not be good or somebody might have a stereotype of an Asian woman they are dismissed. If I were a middle class, very assertive white woman are you going to take that more seriously? I think that is another factor as well. Asian women we are considered as subservient, quite quiet and docile, so I think that also is another stereotype.” (P02)

In common with other women with endometriosis women in this study had criticisms of their interactions with health professionals. Many of them had both good and bad experiences as they encountered many staff in their endometriosis journey. Some of their negative experiences were related to cultural insensitivity or misunderstandings, however women were at least if not more concerned at health professionals’ insensitivity to their symptoms. So some women did express the view that their ethnicity was irrelevant to their experience.

“When it comes to this condition I haven’t really thought about the culture or my religion I have just merely gone to the facts, the symptoms I was getting and I went to see my GP about it but didn’t think of it from the religion side of it all.” (I05)

Summary

In summary, the women in this study shared a lot of experiences and concerns with other women who have endometriosis. The findings reported here demonstrate that there are, however, issues related to culture that influence the way that they live with the disease. The sense of family and community is strong, and these structures influence the way in which individuals live their lives. Religious beliefs are also important as a moral code and also as a source of comfort. Previous research has concentrated on the individuals involved; the women, their partners and, to a lesser extent, children, rather than interpret findings within a cultural context.

Some of the procedures and treatments for endometriosis that are taken for granted within the NHS, such as vaginal examinations and treatments that suspend ovulation, are more problematic for some of the women here. Pakistani women in particular expressed concern that the virginity of unmarried women would be compromised by internal examinations, and both Indian and Pakistani women thought that taking oral contraception would lead to suspicion of sexual activity. This creates barriers for women from communities that place great value on virginity at marriage in accessing health care, particularly if health care professionals are perceived as not being sensitive to their beliefs and values.

Similarly, for Pakistani women any gynaecological problem may be treated with suspicion within their community, many believing they are caused by abortion or by infertility, again providing a barrier to obtaining treatment.

Although infertility is stigmatized within most societies, this is lessening in many Western countries, particularly when it is reinterpreted as a 'lifestyle choice' (van Balen & Inhorn, 2002). However, a distinction is often made, as with the African Caribbean women in this study, between voluntary and involuntary childlessness. In communities where marriage is deemed primarily for the continuance of families no such distinction is made, and all childlessness is assumed to be involuntary, and subject to stigma. So for many women in this study dyspareunia was more of a trigger to help seeking than other symptoms and real or potential infertility is the greatest worry, eclipsing their experience of pain. It is the primacy given to fertility issues by women with endometriosis in this study that differentiates it from previous research.

Cultural background is only one factor in the interpretation of experience, although all of the women in the study identified with their 'traditional' community. This study has highlighted other influences on women's experience and values, such as education, age and generation, or levels of acculturation. It is the synthesis of these and other factors which create the multiple identities that people possess and determine how they make sense of their lives.

Interviews with health professionals

Despite considerable efforts by the research team recruitment of health professionals to the study proved very disappointing. Only the sample of gynaecological nurses

reached the target number of five, all of whom were recruited via personal approaches by the team.

Six GP practices in one PCT were targeted after approaches via contacts of the team proved fruitless despite 50 information sheets being sent out. The targeted practices received information sheets with follow up visits, faxes, and telephone calls. These methods only attracted one participant. The reasons for this are unclear but recruitment of GPs coincided with the outbreak of swine flu, with the consequent additional pressure on workloads.

Two gynaecologists were recruited via contacts of the team, three more recruited in this way did not respond to requests for interview dates. An appointment with one consultant was cancelled as she was delayed on the wards, and was subsequently unable to confirm a new date. An approach to two further consultants did not yield any response. A request for assistance from Birmingham and Black Country CLRN was refused, as it does not recruit for studies.

Interviews with nurses

Of the five nurses interviewed three were employed in gynaecological clinics (one as an advanced nurse practitioner) in two NHS Acute Trusts, both of which held dedicated endometriosis clinics (N1, N2, N3). One was a manager of a gynaecological ward (N5) and the other was a manager on a ward in an acute private hospital (N4), which had a range of patients including gynaecology. One of the nurses was African Caribbean, one white Irish, and three white British.

The clinic nurses assessed their endometriosis patients as being mainly white, which did not reflect the geographical area they were working in or their other clinics, but none of them had given any thought as to why this was the case. One contrasted it with the high number of Asian patients that were seen in the fertility and general gynaecological clinics and on the hospital wards. This is consistent with the interview findings with the women in this study on the importance of fertility, and also with the demography of the local population.

Although the nurses generally did not profess much knowledge of culturally diverse beliefs and values, they nevertheless did feel they possessed a lot of experiential knowledge in caring for women from varied cultural backgrounds, and in particular in dealing with women whose English is limited. The nurses tended to make observations about aspects of various cultures as they perceived them, which tended to be somewhat piecemeal and stereotypical such as

“The [African Caribbean] men like to try out their women, their fertility first before they marry them, but marriage comes very much as a second. And uh the girls that I worked with on occasions have got children and haven’t been married and there is no stigma attached to that in the Caribbean.” (N1)

“Indians and Pakistanis are very religious. They do not speak about sexuality, but then their families are always around.” (N4)

"In the Asian race the pain threshold can sometimes be low." (N5)

The nurses, more than the doctors, reported taking a woman's cultural background into account when caring for her. One nurse said that when going for gynaecological procedures in theatre Sikh women could keep one leg in their trousers. Another reported that she was aware that pain could be expressed in different ways and it was up to her to find out when a woman was in pain and not make assumptions based on a woman's behaviour. However, the nurses all asserted that they treat people primarily as individuals.

The nurses were all concerned at the quality of translation for women whose proficiency in English was low. Two of the clinic nurses claimed that doctors did not like to use the telephone translation service as it takes time to set up, and are happier using family members. Nurses themselves had little confidence using family members to translate due to issues of confidentiality, and not knowing whether the person doing the translating knows what is being asked. They were also worried that the woman's concerns would not be passed to the health professional, particularly if the interpreter was male.

"I'm absolutely certain information gets missed or deliberately misinterpreted. You find on some occasions, they think it might upset daughter or mum or whoever and they won't pass that piece of information on and I mean I wouldn't know if that had happened, that's the risk. You don't know what's being passed on so you know we're having this 3 way conversation, you have absolutely no idea what's being received and you can tell that sometimes by the answers that the women may up give. You think she hasn't understood a word of that, she's not been told correctly and some of the doctors will pick up on that and some won't." (N1)

Interviews with doctors

As there were so few doctors recruited to the study they will be analysed as one group, and quotes will not be identified as coming from a particular individual. Two gynaecological consultants were interviewed, both of whom diagnose and treat patients with endometriosis. One GP was interviewed who practiced in a predominantly white neighbourhood. One consultant was white British, the other of Pakistani origin, the GP was of Indian origin, two were male and one female. Both of the consultants are involved in the care of direct and tertiary referrals of women with suspected and diagnosed endometriosis.

There was some resistance to categorising women by ethnicity, and the doctors pointed to other structures of diversity such as age and gender which they felt were important. Social factors were also seen to influence a woman's experience

"To be very frank I think to label an experience because of ethnicity is probably not appropriate because I think the experience of pain is highly individual experience. So if a family's supportive in a Chinese or Pakistani ethnic background, their experience of pain will be similar to another culture which is supported in the same way. On the other hand if there is history of abuse, tensions in the household in a

white population they will be affected by the experience of them, from their background."

The participants were of the opinion the women from minority ethnic communities do not have needs that are different from the general population, although one expressed the view that minority ethnic women do not seek help for certain ailments. They felt that essentially what all women need, regardless of cultural background is diagnosis and treatment of symptoms. One commented that he would tailor his communication with a patient more on perceived educational level than ethnicity.

"Tailoring treatment does not, should not have anything to do with ethnicity, it should need to do with individual requirements."

"Needs are the same, to be pain free. I don't think just before some pitches up from a different culture I'm going to treat them differently, unless your research gives evidence for a reason to."

However, although they expressed the view that women have the same needs the doctors all pointed to differences that they felt existed in the different groups. Some of these perceived differences, as in the case of the following quotes, can be contrasted with comments made in individual interviews.

"Asian women won't consider sexuality important, they are meant to be mothers and have children, also don't come with menopausal symptoms. They don't come on their own normally, and won't come for sexual things, and would come with husband."

"Chinese depend on health service more as many don't have family in the UK, and if they have symptoms they tend to worry about them. Before coming to the GP many would already have seen a private Chinese doctor for antibiotics, and have fixed ideas of what treatment they should be given."

"African Caribbean women I feel are some of the easiest to manage because they seem very similar actually most, most similar to indigenous white population in terms of well there is never a problem you know in terms of that we can't examine this patient."

Only one of the doctors spoke of 'Asians' as a single group, the other two distinguishing between Indian and Pakistani women, but again there were views expressed about their attitudes and behaviour.

"There are a group of women as well in Pakistan who are markedly overweight and they have diabetes and that's partly because of the fact that they are not encouraged to mix outside, not encouraged to get jobs, they get depressed, no exercise and the rest of it."

The consultants did not necessarily advocate a diagnosis as significant in the care and treatment of women with pain indicative of endometriosis. They felt a formal diagnosis was not needed in all cases, and women could be treated symptomatically

for suspected endometriosis. One expressed the view that diagnostic procedures had risks and would advocate treating with medication as this was as effective as a surgical approach in many cases. They would consider laparoscopy if the woman had a long history and experienced severe pain, or a scan to pick up cysts.

“Simply because you can pick up a problem early does not guarantee that the outcome will be better.”

Again this contrasts with this and other research (Ballard et al, 2006; Manderson et al, 2008) which points out the importance of diagnosis for women, although one doctor did acknowledge that a diagnosis can give an explanation for and acceptance of symptoms.

Problems of communication were perceived as the biggest problem of caring for minority ethnic women, and the poor quality of translated material was commented on. It was recognised by one of the doctors that direct translation is not sufficient to improve communication.

“I think it’s also possible words do not translate exactly when you make translations, for example I’m aware that when English information leaflets are translated into Urdu, they do not make sense in the Pakistani culture, the translation may be linguistically correct but culturally insensitive.”

The health professionals all saw treating people as individuals as the most important aspect of their interaction with women, and although nurses did concede that this included acknowledging their cultural values and beliefs, the doctors seemed to perceive it as being inconsistent with individualised care. Knowledge of different cultures was low and seemed to be arrived at opportunistically, for example through having worked abroad or having trained with people from different backgrounds, and it was not a feature of in service training or continuing professional development. Knowledge also seemed to some extent to rely on stereotypes of different ethnic groups.

Conclusion

The findings from each phase of the study have shown that there are many similarities between the experience of women from majority and minority ethnic communities. There are also differences within each group, but data reveal these as emanating from differences of generation, education, and assimilation which impact on the expression of cultural beliefs. In addition to many similarities, then, we can also see the impact of values specific to the individual cultural contexts within which the women live and we would argue that a knowledge of such socio-cultural contexts is important in fully understanding the needs of women with endometriosis.

The health professionals in the study do not appear to have a good knowledge of these issues and the barriers they may create in women receiving appropriate and sensitive care. While health care providers are keen to promote individualised care this does not appear to include incorporating cultural values that women may hold.

At the same time however, many stereotypical observations were made about the generalised character of specific minority populations.

While we have argued in this chapter that culture may be an important aspect of the way in which a woman gives meaning to her endometriosis, we are not suggesting that this is the only aspect of identity which will be of relevance. We also argue that it is important for healthcare providers to approach ethnicity and culture in a way which does not rely on generalised notions of culture (Culley, 2006). Although we present the narratives and themes from the ethnic groups represented in our study, there are two important points to bear in mind when interpreting our data. Firstly, we see many similarities of experience of endometriosis across all groups, and secondly, given the complex and multiple identities which women hold it is important that healthcare providers do not see women as holders of a set of cultural traits, but take seriously their own definitions of who they are and do not operate with stereotypes of women in their care. It is also important to recognise that while all women (and men) are influenced by cultural context, they are not passive subjects, compelled by cultural rules to behave in certain ways. A growing number of authors recognise minority ethnic women as active agents and are able to draw on social and cultural resources to resist or challenge what might be regarded as 'traditional' elements of culture (Culley & Hudson, 2006; Ramji, 2007; Phillips, 2007). Examples of both the importance of traditional culture and resistance to it have been illustrated within the narratives, as has the view that many experiences of endometriosis transcend culture. Cultural meanings are best seen not as prescriptive codes but as broad guidelines for action, internally contested, open to fluid interpretation, and highly dynamic (Bradby, 2003; Culley & Hudson, 2009).

Chapter Five – Development and Dissemination of Resources

Resources for women with endometriosis and their communities

This project is based on the premise that effective communication between healthcare providers and service users requires an understanding of the attitudes, values and beliefs of different user groups and the ways in which these might influence understandings of endometriosis and access to services. This is an approach which has been recommended in successive publications and policy guidance from the in the Department of Health and recently re-iterated in the Darzi Report (2007). It is also fundamental to the project that engaging users in the development of resources is the most effective way to ensure that such resources are culturally as well as linguistically appropriate and meet the needs of those they are intended to reach.

Therefore, in deciding what resources to produce and how to produce them we were strongly influenced by what women and health professionals told us during focus group discussions and interviews. Resources were developed for women with symptoms indicative of endometriosis; the five community groups and health professionals. At every stage of development materials were sent to women with endometriosis, members of the Advisory Group, and health professionals for comment and amendment on content and on translation. The feedback that we received on these draft were incorporated into the final resources.

Information needs: translation

A potentially important aspect of healthcare provision for some members of minority ethnic communities is the provision of adequate communication support for those with low proficiency in English (Mir, 2007). The failure to meet the needs of such people is one of the most common problems identified in research studies on ethnic inequalities in accessing healthcare (Culley & Dyson, 2009). Although all but one of the women interviewed for this study spoke English, a number expressed concern about meeting the information needs of those who did not.

Between 400,000 and 1.7 million people have difficulties with English and many will face barriers accessing health care (Office of the Deputy Prime Minister, 2005). It is important that culturally sensitive interpretation and translated material are available. Direct translations of existing health promotion material, however, may not be suitable. They may not contain information or advice which is relevant to the lives of those they are intended to reach, and/or contain images which are not appropriate to the target audience. Furthermore, it is also important to note that some people may not be literate in their 'mother tongue' and require audio versions of health materials and internet based resources. Some of the Indian and Pakistani women in this study also reported that not everyone could read or write in their first language or English and that this needed to be taken into account when producing resources. Combinations of verbal, written and multi-media resources are likely to prove more effective than written translations alone (Culley & Dyson, 2009).

Much of the research on ineffective communication between health services and users has focused on the South Asian communities. Latif (2010) has argued, however, that communication issues can also be important within Black Caribbean communities, as non-verbal gestures and nuances of communication can also be misinterpreted by service providers.

In translating resources for women and their communities we utilised the best practice recommendations from the London Ideas Translation Project (Mehta, 2005). Initial translation of materials was conducted by a professional translation service that uses native speakers for its work. Translated text was sent to independent native speakers, most of whom had been involved in the project and were aware of its aims and the target audience for the resources. Mehta (2005) recommends aiming for a balance between faithfulness to the original text and readability in the target language, and the role of the independent native speakers was to point out both inaccuracies in the translation, and to ensure a culturally and linguistically sensitive resource. Involving patients and the public in reviewing resources was described in chapter 3 p27.

Information needs: content

All of the women reported that awareness of endometriosis within their community was very low, but some felt that this was general and not confined to any one community. This lack of awareness was contrasted to diseases such as cancer, HIV/AIDS or diabetes where a lot of health information is available, and consequently people are more aware of them. Some women felt that people would consider that endometriosis was the same as painful periods without information on the impact of symptoms on life in general and fertility in particular. They recommended that information should be targeted at girls and women who may well be suffering in silence, as well as the general population who may be more aware of symptoms within their family and friends. The women in all groups obtained a lot of their information from the internet, but pointed out that this option was not available to everyone, and therefore a range of materials was needed. Indian and Pakistani women pointed out the limitations of on line resources for women who were non English speakers, or unable to read. Although women from all of the groups recognised the need for more information for communities only the Greek women suggested that information such as '*top ten facts about endometriosis*' could be directed specifically to the men of the community such as fathers and brothers who, although sympathetic and supportive, lack knowledge about menstruation, the female reproductive system and endometriosis.

Specific ideas for raising awareness and providing information included leaflets, video links in GP surgeries, community and local media campaigns, health education in schools, social centres and places of worship. The Greek/Greek Cypriot women suggested that easily accessible and user friendly information would enable the women with endometriosis to gain control of their suffering. One African Caribbean woman did not feel that the whole community needed to be educated about endometriosis, as she believed it was not a problem that was widespread, which contrasted with the vast majority of women in all the groups.

Resources for health professionals

A number of women commented on the need for health professionals, particularly GPs to be more knowledgeable about endometriosis. Greek/Greek Cypriot women, for example, reported that their GPs were not well informed about endometriosis as it was often they, who, after years of suffering, linked their symptoms to the condition through internet searches. Many from all of the groups reported that health professionals needed greater knowledge of endometriosis and of cultural differences in ideas around sex and reproduction.

The nurses were all interested in findings from the research relating to cultural issues that impact on choice of treatment and outcomes, but as reported in Chapter 4 doctors were more reluctant to consider ethnicity as a factor in their encounters with women.

The opinion from health professionals, particularly the doctors, is that there are too many leaflets and protocols for different health conditions. Health professionals all pointed to the amount of new information that they are faced with and the lack of time to read, so that something that can be returned to during short breaks etc was considered to be of more value. The preferred format of resources would be in the form of a podcast that can be downloaded, and a publication in a good periodic journal. As there is little money or time available for courses or in service training audio and visual resources that could be used for CPD, and that people can access in spare moments were considered more useful than written information.

Project Website

www.endocul.co.uk

A website was set up at the start of the study in order to provide information about the project and updates on its progress. It also acted as a recruitment agent both for women wishing to be interviewed and for reviewers of resources. The website will remain live after completion of the project and will host the resources that have been developed for women and communities from the target groups, a generic information resource in English, and resources for health professionals. These can be downloaded or ordered free of charge. It will also provide links to other resources of interest to anyone with a personal or professional interest in endometriosis.

Dissemination of findings

Conference presentation abstracts

BSA Medical Sociology Conference, Durham, September 2010

Endometriosis and cultural diversity: The experience of minority ethnic women
Denny, E., Culley, L., Papadopoulos, I.

Endometriosis and cultural diversity' (the Endocul project) explored the experience of women from minority ethnic groups living with endometriosis and their needs for

culturally specific information and support. The study focused on five minority ethnic groups: African Caribbean, Chinese, Greek/Greek Cypriot, Indian and Pakistani.

The project aimed to develop, in collaboration with community groups and patients, evidence based and culturally sensitive resources for women with endometriosis from these communities and for the health professionals providing services to them.

In order to meet this aim primary research was first conducted with women from community groups, women with endometriosis from the target communities, and health professionals.

This paper is concerned with individual interviews with minority ethnic women with endometriosis. Semi-structured interviews were conducted with women from each community (n=29) which focused on the meaning of endometriosis in their lives, their experience of health service provision, and their information needs.

The women studied had many similar experiences and concerns to other women previously reported in the literature (e.g. Denny, 2004; Gilmour and Huntington 2005, Seear, 2009). They also identified cultural factors as having an impact on their experience of endometriosis and of health services. These factors centre on the role of women and the importance of reproduction within their communities, and the influence of religious beliefs.

Cultural values can generate unique meanings and experiences of endometriosis. In order to develop culturally sensitive resources and services for women these need to be incorporated, whilst resisting essentialising culture as a fixed and bounded concept.

BSA Medical Sociology Conference, Manchester, September 2009

'Grin and bear it.' Socio-cultural constructions of endometriosis

Apenteng, P., Denny, E., Culley, L., Papadopoulos, R., Mann, C.

Women from minority ethnic communities with reproductive health conditions represent diverse conceptions of health, disease and healing practices. They also experience physical, emotional and spiritual needs that require consideration in their care planning. This paper is based on findings from focus group discussions with women from minority ethnic groups, conducted as the first phase of a qualitative study that seeks to explore endometriosis (a debilitating condition affecting women's reproductive system) and cultural diversity.

Five focus groups were carried out with women from each of the minority ethnic groups being recruited to the main study (n=42). These are women of Greek, African-Caribbean, Indian, Pakistani, and Chinese origin. The discussions aimed to understand the socio-cultural context of women from these groups and explored cultural meanings of menstruation, reproduction, sexuality, awareness of endometriosis and access to health services. Findings reveal cultural constructions and taboos around menstruation, and fertility appeared to be of particular significance to the women who participated in these focus groups. The focus groups also inform of a limited awareness of endometriosis and a tendency to normalise

menstrual pain, a common symptom of endometriosis.

This paper examines the main themes identified in the focus groups and suggests that in order to provide culturally sensitive care there is a need to take into account specific issues around sexuality and reproduction which may constitute barriers to care for women from particular ethnic groups with endometriosis.

**Faculty of Health Annual conference, Birmingham City University,
November 2009**

Perceptions and experiences of Pakistani women with endometriosis

Elaine Denny, Patricia Apenteng, Lorraine Culley, Irena Papadopoulos, Chris Mann

Introduction:

The project 'Endometriosis and cultural diversity' seeks to explore the needs of women from minority ethnic groups who are living with endometriosis and how these can be met effectively. The study focuses on five minority ethnic groups: African Caribbean, Chinese, Greek/Greek Cypriot, Indian and Pakistani.

Aim:

To develop, in collaboration with community groups and patients, evidence based and culturally sensitive resources for women with endometriosis and to develop good practice guidance for the health professionals providing services to women of minority ethnic origin.

Method:

This paper is from the second stage of a larger four stage study.

Semi-structured interviews were conducted with women with endometriosis from each of the target groups in their preferred language to discover their specific needs. Interviews focused on the meaning of endometriosis in their lives, and their experience of health service provision.

Results/Findings:

The findings being presented here are the experiences of the women of Pakistani origin in the study. Seven women with endometriosis who described themselves as Pakistani were interviewed and while there are many experiences that are shared across cultures, there are also differences in meanings and in the way some cultural values such as fertility are played out.

Discussion/Conclusion:

The Pakistani women were more likely to view cultural factors as having an impact on their experience of endometriosis and of the NHS than the other groups in the study. Cultural values can generate unique meanings and experiences of endometriosis. In order to develop culturally sensitive services these need to be highlighted, although it is important to avoid essentialising culture and viewing it as a fixed and bounded concept.

Next steps to patient benefit

Resource Launch Day

This was held at the Education Resource Centre, Birmingham Women's Hospital on June 7th 2010.

Health professionals, the press, academics and women who contributed to the project were invited to hear about the findings from the study and to view the resources that have been developed. An outline of the study was presented followed by a demonstration of the audio-visual resources and distribution of hard copies of leaflets and DVDs.

Funding will be sought to produce extra hard copies of resources for distribution to clinics and primary care centres beyond the local areas of the research team, and to evaluate the resources in use.

Further dissemination

Endometriosis self help groups will carry links to the resources.

All the community groups involved in the project will receive copies of the outputs of the study and research summaries and be asked to alert members and contacts to the community resources.

We will actively publicise the resources on academic and community networks
For example:

- jiscmail minority-ethnic-health
- Transcultural research centre at Middlesex University,
- The Mary Seacole Centre at DMU
- MIGHEALTHNET, a Europe wide network.

The health professional resource will be sent to relevant professional groups and journals for review and submitted to the NHS Evidence for Ethnicity and Health site (NICE): www.library.nhs.uk/ethnicity/

Links to the Adobe Breeze presentation have been requested by the publishers of the journals *Midwives* and *Evidence Based Midwifery* for their readers to access.

The research team will attend health professions' conferences (e.g. RCN Conference) in order to disseminate the findings and resources, and will write comment pieces for health professions journals.

Articles in the planning stage are

- A literature review on endometriosis
- Findings from the focus group discussions
- Findings from individual interviews with women

Future conference attendances

- International Council of Nursing Conference, Malta, May 2011
- World Endometriosis Congress, Montpellier, September 2011

Intended outcomes of the study

- Increased awareness of endometriosis among women from the targeted groups and their communities leading to earlier access to diagnosis and treatment.
- More culturally sensitive resources for women with symptoms indicative of endometriosis to support women in managing their condition and treatment choices.
- Increased awareness for health professionals of cultural barriers to accessing health care for endometriosis, and awareness of issues of importance to minority ethnic patients, leading to more culturally sensitive care.
- Dissemination of the methodology for evidence based, collaborative production of health resources via targeted publications should enable its adoption for use in research on other health conditions.

Chapter Six - Conclusion and Recommendations

Culture, health and illness: avoiding essentialism

We conducted the study with five ethnic communities, but we were also conscious that by using these categories we were not necessarily referring to homogeneous groups. We have referred to generation and acculturation as influencing the extent to which women conformed to what they perceived as their traditional culture or defined themselves by it, but there were also issues around using geographical area to define ethnicity. As one woman in the study commented:

“The other thing is we talk about ethnic minorities. To be from Pakistan for instance it is a huge country with a huge different array of backgrounds, levels of education, levels of income. Everything makes a difference when it comes to this and the ability to communicate. I think the blanket term ‘ethnic minority’ is quite difficult any way, and even someone with a relatively similar sort of background to me can have difficulties.” (P02)

Some women also commented that although their culture is important to them they did not want assumptions to be made about them based purely on stereotypes of their background.

A range of commentators have challenged an essentialist view of ethnicity and health, which sees ethnicity as all encompassing and defining of a person's identity, to the exclusion of other statuses and identities, particularly for those from minority ethnic groups. This presentation of ethnicity as fixed and homogenous has been one commonly found within nursing and healthcare in particular and has often led to a cookbook approach to addressing diversity in healthcare practice (Culley 2006). But not every aspect of a person's identity can be reduced to ethnicity, and it is also the case that not every encounter with health services will be influenced just by ethnic identity. Age, gender, education and social class are other important dimensions of identity which can impact on our health status and on our experiences of health care, and this is clearly important in the case of a gendered condition such as endometriosis. The sample of women in phase 2 were better educated than the average in the UK population, with eight women educated to at least A level standard, and 19 had attended university.

Culture and ethnicity are aspects of our identity which can impact on how we understand health and illness but must be seen in the context of other important positions in social systems and relations. It is important to note that there are many similarities in experiences across all ethnic groups as well as issues that might be specific to some cultural locations (Atkin & Chattoo, 2006; Culley & Hudson, 2009). There is a growing body of work which is trying to identify when and how ethnicity makes a difference and when it does not (Atkin & Chattoo, 2007).

This research project is cognisant of such differences and the importance of exploring similarities as well as differences between and within ethnic groups. It

takes culture seriously, but does not see culture as necessarily the determining aspect of a health care experience or encounter. We do, however, accept the view that culture can be an important part of the context of constructing and understanding health and an important element in experiencing a health condition and its treatment in the health care system (Helman, 2007). Cultural identity can potentially operate as a mechanism for interpreting and understanding illness, and it can be an important source of support for people suffering from chronic conditions such as endometriosis. It will also interact with other social statuses such as gender. The gendered nature of endometriosis has been shown to be important in understanding the experience of the condition (Manderson et al, 2008; Denny, 2009; Seear, 2009) and is likely to be implicated in any healthcare encounter.

Limitations of the study

Although by including healthy women and women with endometriosis from all of the target communities, and health professionals we incorporated a wide sample of participants, the sample constituted the main limitation of the study. The sample of women was self selecting or recruited through clinics and comprised well educated, English speaking participants who had some level of acculturation into British society. Women who live in communities with little integration with other communities and possessing low levels of English were not recruited despite the team's efforts to broaden recruitment. Their exclusion may have missed a very different perspective on the accessibility and acceptability of health services. This seemed particularly noticeable in the Chinese community where great efforts were made to contact and recruit women in different parts of the country, but with little success. Recruiting through community groups and the contacts of the team may have produced homogeneous samples from each of the communities.

Health professionals proved very difficult to recruit, with primary care staff and gynaecologists being particularly hard to recruit. This calls into question the representativeness of their responses, although it is consistent with other research on minority ethnic groups and health care (see for example Vydelingum, 2006; Puthussery et al, 2008; Beagan & Kumas Tan, 2009).

Recommendations

- The needs and concerns articulated by women in this study arise for many women who experience endometriosis, irrespective of ethnicity. Differences of culture, language and religion are often important to women, in gaining a diagnosis and in the experience of living with endometriosis. For all women therefore, it is important that health professionals and those supporting women have a good understanding of the socio-cultural context of people living with endometriosis. Healthcare providers should access training specifically on the way in which ethnicity might impact on endometriosis. Hopefully the resources developed from this project, will go some way to achieving these important policy objectives.

- Within minority ethnic communities there is limited awareness of endometriosis. Support groups should consider engaging with key opinion formers and other partners within minority ethnic communities to increase understanding of endometriosis. Approaches could be made through women's centres, places of worship and local media.
- In order to get a clear idea of the prevalence of endometriosis, healthcare providers should be encouraged to analyse data by ethnic group and establish any patterns of differential diagnosis, treatment or indeed access to treatment.
- The study reinforces the view that GPs require more information about endometriosis to assist in timely referral and diagnosis.
- Most of our participants spoke good English, however they did identify that there is a clear need for interpreting services to be available in NHS Trusts, alongside measures to increase the confidence of users in the effectiveness and confidentiality of services.
- Support groups should ensure that the support and advice offered to minority ethnic patients is culturally and linguistically appropriate.
- Overall, people from the respective minority ethnic communities have played a major role in the study, and this involvement has had a substantial impact on the development of culturally appropriate research tools, access to communities, data collection and interpretation of the social meanings of endometriosis in their specific socio-cultural context. It must be acknowledged that such involvement takes time to develop if it is to avoid being tokenistic and can, of course, add to the costs of the project. These issues need to be considered by research teams at the outset, so that the many benefits of user and consumer involvement can be attained.

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Appendices

Appendix 1: Role description for community facilitators

Purpose:

Community facilitators will be recruited from the Chinese, Greek and Indian communities to organise, facilitate and fully transcribe focus group discussion with women from the community.

Principal Duties and Responsibilities:

- To undertake a short programme of training relevant to their duties, responsibilities and skills needed.
- To identify with the help of the project team, suitable participants and to recruit them to take part in a focus group (between 6 and 12 people per group).
- To arrange a suitable venue and time with the participants.
- To explain the purpose of the study and to provide a leaflet about the study to participants.
- To obtain written consent for the focus group interview and to obtain agreement for it to be tape recorded.
- To record basic demographic details about the participants.
- To conduct the focus group in an appropriate manner, and to maintain written notes.
- To translate the discussion into English and provide a full (verbatim) transcription
- To liaise with the project team concerning the analysis of the data from the focus group.

Selection Criteria:

Essential	Ability to speak and write English and either Urdu, Cantonese, Greek or Gujarati.
Essential	Ability to use a computer.
Desirable	Experience in conducting focus groups (training will be provided)
Disposition	Genuine interest in the study. Flexibility. Able to use her knowledge of the ethnic community in a constructive and reflexive manner.
Duration	Each focus group should last approximately two hours. The project research fellow will act as co-facilitator for focus groups conducted in English and observe focus groups conducted in ethnic language.

Accountability Interviewers/researchers will be accountable to the project team and liaise with the site manager and research fellow with regards to recruiting the sample and arranging the focus group.

Payment Travel expenses to training event.
£100 attendance fee for the training event (half day).
£200 per completed focus group discussion in English or
£400 per completed focus group and fully transcribed and
translated from ethnic language.
£100 attendance consultation event on analysis/interpretation of data
and development of resources.
Payment will be made by cheque and it will be the responsibility of
each facilitator to make arrangements for tax payments.

Appendix 2: Focus group guide

Welcome to the group and thank you for taking the time to come along. We have asked you to come along today to share your expertise about an important health issue for your community. This discussion is part of a research project led by Professor Elaine Denny from Birmingham City University.

Today we'll be discussing your views about some health issues which affect women in particular. We would also like to explore what is the best way to get across messages about health issues to the community.

I will ask some questions and we are really interested to hear your views. There are no right or wrong answers, but just differing points of view. So please feel free to share your views, even if they are different from what others have said. Negative comments are welcome as well as positive ones.

Before we begin, let me suggest some things that will make our discussion more productive. Please speak up, one person at a time. We are tape-recording the session because we don't want to miss any of your comments. If more than one person speaks at a time, the tape will get garbled and we'll miss your comments.

We will be on a first name basis, but in our reports there will be no names attached to comments. You may be assured of confidentiality.

My role here is to ask questions and then to listen. I won't be joining in the conversation, but feel free to talk among yourselves. Let's begin. Let's go round the room and say a little bit about ourselves.

Thank You

A: Introductory

1. To start we want to explore what it means to be a (ethnic group) woman. How would you describe a (ethnic group) woman?
PROMPT: what words and symbols come into your head when you think of a woman?
PROMPT: What is the role of women in your community? What is the status of women in your community? Give examples.
2. What do you think are the main health issues for women in your community?
(Flip chart list)

B. Reproductive health

Can we look more closely at issues around reproductive health – menstruation, fertility and childbirth for example.

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?
PROMPT: explore cultural practices and taboos

C. Menstruation

7. How do women in your community think about menstruation?
PROMPT: How does your community/culture view menstruating women?
8. Are there any particular cultural or religious ideas about women and menstruation which you can tell us about?
PROBE: how do these ideas affect women in your view?
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?
PROMPT: PMT, no periods, heavy periods, period pain
11. If a woman had one of these problems what would she do?
PROBE: Seek help from GP, ask a friend, ask a relative, try to get some information
PROBE: Would it be easy for her to talk about these things?

D. Endometriosis

12. Has anyone ever heard the word 'endometriosis', does anyone know what this means?
Facilitator: GIVE A SHORT DESCRIPTION IN LAY TERMS
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 these symptoms, what do you think she would do?
PROMPT: Who might she ask for help and advice?
15. Do you think she would be happy to go her GP about this? (yes/no/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.
PROBE: How do you think this would affect a woman?
19. Who would she be able to talk to about this, do you think?
PROBE: Female family member: Husband/partner? Doctor? Nurse?
PROMPT: explore communication and decision – making patterns. Explore barriers to communication such as shame, guilt, religion, taboos, attitudes of society etc.
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?

PROMPT: explore pain responses in your culture, use of traditional medicine, etc. Explore cultural practices around 'talking about sex'. Give examples.

21. What do you feel would be of most help to women who have this condition?

PROMPT: explore culturally sensitive methods of support and information seeking.

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?

PROMPT: format? When? Where? Who?

23. Is there anything that we have missed in this discussion? Anything you would like to add?

SUM UP

Does this seem a good summary? Anyone got any further comments?

THANK YOU

Very much for your time and sharing your views with us. If you would like some more information about this issue, please have a word with me before you leave.

Appendix 3: Pre-interview questionnaire

1. Age	<input type="text"/>	
2. Marital status:	<input type="checkbox"/> Single	<input type="checkbox"/> Widowed
	<input type="checkbox"/> Married	<input type="checkbox"/> Separated
	<input type="checkbox"/> Divorced	
3. Highest level of education attained:	<input type="checkbox"/> No formal education	<input type="checkbox"/> College/A levels
	<input type="checkbox"/> Primary school	<input type="checkbox"/> University
	<input type="checkbox"/> Secondary school	
4. Employment status:	<input type="checkbox"/> Employed full time	
	<input type="checkbox"/> Employed part time	
	<input type="checkbox"/> Unemployed	
5. Country of birth:	<input type="text"/>	
6. How long have you lived in the UK?	<input type="text"/>	
7. What is your ethnic origin?	<input type="text"/>	
8. What is your mother tongue?	<input type="text"/>	
9. Competency in English:	<input type="checkbox"/> High	
	<input type="checkbox"/> Moderate	
	<input type="checkbox"/> Low	
	<input type="checkbox"/> No English	
10. Religion:	<input type="text"/>	

Appendix 4: Interview schedule (women)

A: Socio-cultural background/context

Use details on demographic form to explore for a sense of how they see themselves.

Probes:

1. On the form you describe yourself as *****[ethnicity], can you tell me what that means to you?
2. Does anything make you feel different from the English girls that you grew up with?/attended college with? etc

B: Women's experiences of the condition

We are interested to hear your story, we want to hear your experiences with endo, the treatment you have had and your views on this, explore your information and support needs and we are also keen to hear your suggestions on how to improve the services for endometriosis for women from minority ethnic groups.

1. So, tell me your journey and your experience, from onset of first symptoms.
Journey to diagnosis Probe positive and negative aspects
2. Do you think your cultural background has affected your experience of endo?
How/Why?
3. Has religion been important to you?
4. What has been the biggest impact of having endo on your life?

C: Women's experiences of care/treatment issues

I would like to ask you about your experiences in seeking help from doctors and other health professionals for your endo.

1. Tell us about your experiences of getting treatment for your endo.
Probe positive and negative aspects
Probe GP and then hospital experiences
2. What treatment have you had?
Views on this: has this been acceptable to you?
Why/why not?
3. Do you think your experience is typical for women of your community?
Would they be comfortable in coming forward for help with their symptoms?
4. Do you think that your cultural or racial background has had any impact on the treatment or care you have received? (ask them to describe)
5. Do you feel that healthcare staff have been aware of any religious, spiritual or cultural needs that you might have?

6. Have you ever used an interpreter? What are your feelings about this? And how do you think other women in your community who might not speak good English would feel? - *only for those who use an interpreter*
7. Have you ever tried alternative therapies/remedies or approaches to treating your endo?

D: Information needs

1. Do you feel you were given enough information on endo when you were diagnosed?
Probe: has GP been helpful in giving information?
2. Do you feel you have enough information now?
3. Where have you got information from? And what information has been most useful to you?
4. What would be the best way to provide information for people in your situation and from your community? *Probe: format, sources, amount of detail etc.*

E: Support issues

1. How do you cope?
2. Have you shared your diagnosis/condition with anyone? Who? (Partner/family/friends/ethnic community) What was their reaction?
3. Do you feel supported?/Who do you feel most supported by?
4. What has been the impact of endo on your relationships with others?
5. What are your current support needs? And have these changed over time?
6. Has anyone given you help with your feelings or emotional needs about endometriosis or your treatment?
7. Have you heard about any support groups for endo?
8. What would make it easier for you living with endo?
9. How do you view the future?

F: Suggestions for service improvement

From your experience:

1. What would you say to NHS providers if they asked you how they could improve the treatment and support they give to you or others with endo?
2. Are there any specific messages you would like to send to doctors (probe: consultants, GPs) and other staff?
3. How can we improve endo care for other women in your community especially?

4. How would you rate the level of awareness about endo in your community?
5. What would be a good way to raise awareness? And would this help people with the condition.

G: Concluding remarks

1. Is there anything else you would like to tell me that we have not discussed so far?

Appendix 5: Interview schedule (health professionals)

Get an idea of ethnicity of caseload and of patients with endo

A: Knowledge and experience of endometriosis

What symptoms would suggest endo to you?

Who is most likely to suffer from it?

How easily do women describe these symptoms? What terms are used by different women?

What action would you take/protocol for referrals?

What do you consider your role in managing women with endo?

B: Understanding of socio-cultural background

Do you have any knowledge/understanding of any of the following cultures:

Caribbean, Greek, Chinese, Indian, Pakistani? (prompt: role of women, reproduction, sexuality, religious values, ideas of health and healing)

What is different from the White British population?

Do you think any of these cultural differences affect the experience of endometriosis/ your management of patients?

Do you tailor your treatment to take account of cultural norms and values?

If yes, how does this influence the care you give to women from these ethnic groups?

Do you consider ethnicity when giving care?

C: Views on the needs of minority ethnic patients

Do you think patients from minority ethnic groups have needs that are different to that of the general population?

If so, what are some of these needs/issues?

Is there any specific knowledge that you feel you need to help you meet these needs?

D: Needs regarding cultural appropriate treatment and patient care

Do you feel confident caring for women from minority ethnic groups?

Do you think there are any challenges?

If yes, what are some of the challenges/issues in caring for women from minority ethnic groups?

E: Appropriate format for information resources

Explore current information given on diagnosis and during treatment?

Are you happy with this/do you think it is adequate?

Do you think information on endometriosis should be generic to all communities/do you think minority communities need tailored information?

What specific differences need to be addressed?

Do you have any other suggestions for improving our endometriosis services for minority ethnic women?

Appendix 6: Management committee

The 'Endocul' Management Committee

STATEMENT OF PURPOSE

1. The membership of the Management Team shall be relevant to the Project and agreed by all co-applicants.
2. The Management Committee composition shall be:
 - Project Co-applicants – Elaine Denny, Lorraine Culley, Christopher Mann, and Rena Papadopoulos
 - Project Research Fellow – Patricia Apenteng
 - R & D manager of the lead site (Sue Elkin, Birmingham Women's Hosp)
 - Medical expert in endometriosis (Christopher Mann)
 - Academic representative with expertise in researching minority ethnic groups (Fatemeh Rabiee-Khan, Birmingham City University)
3. The Management Committee will meet four times a year.
4. The overall responsibilities of the Management Committee are to:
 - provide advice and support to the research team relevant to each member's professional/pastoral role with the research participants
 - ensure that the research undertaken complies with the Project proposal
 - monitor the project to ensure good research practice
 - ensure that the necessary quality and financial probity is maintained
 - receive progress reports
 - advise on the dissemination of information about the project
 - receive and approve the final report

Appendix 7: Advisory group

The 'Endocul' Advisory Group

STATEMENT OF PURPOSE

1. The membership of the Advisory Group shall be relevant to the Project and agreed by all co-applicants.
2. The Advisory Group composition shall be:
 - Representatives from each ethnic group – African Caribbean, Chinese, Greek/Greek Cypriot, Indian and Pakistani
 - Patient representative
 - Representatives from self help groups (Jayne Tullett, SHE Trust)
 - Experts in qualitative research, ethnic health and inequalities (Mark Johnson, Paula McGee)
3. The Advisory Group will be a virtual advisory group; as such, all communication will be by email. The research team will consult the advisory group on each stage of the project and replies are to be shared via the advisory group distribution list. The research team will then make a decision based on members' contributions. Consultations will normally follow quarterly project team meetings.
4. The overall responsibilities of the Advisory Group are to:
 - provide advice and support to the research team relevant to each member's professional/pastoral role with the research participants
 - advise on the dissemination of information about the project
 - advise on development of resources

Appendix 8: Focus group participants

Demographic profile of focus group participants

African Caribbean

- N=8
- Mixed age group; 5 aged 18-25 and rest above 40
- Majority single (6) one married, one separated
- Half had been to university and half educated to college/A-levels
- 6 employed, 2 part time
- 4 were born in the UK
- Majority been in UK for over 10 years
- 4 record English their mother tongue
- All rate themselves as having a high competency in English
- 1 professed no religion, the rest Christian

Chinese

- N=10
- Majority in 26-35 age range
- 60% single, rest married
- Mixed group in terms of education, 60% had been to university and 30% had no formal education
- 60% unemployed
- All born in China
- All been in UK for less than 10 years
- All record Chinese as their mother tongue
- 60% rate their competency in English as moderate to high, and 1 speaks no English at all
- 6 are Christian and 4 have no religion

Greek

- N=8
- Age of participants ranged from 19 to 46 years
- Half were married and three single
- 7 out of the 8 had been to university
- Most were born in the UK and have stayed in UK for at least 10 years
- All rate themselves as having a high competency in English
- All Greek orthodox religion
- All employed, half of them part-time

Indian

- N=10
- All aged 35+
- 9 married, 1 divorced
- 2 been to university, 5 educated to College/A levels
- 8 employed, 3 part-time

- 1 born in UK
- All been in UK for at least 20 years
- Mother tongue described as Gujarati
- 9 rate competency in English as moderate to high
- All record religion as Hindu

Pakistani

- N=6
- Participants aged 26-40
- 4 married, rest divorced
- Half been to university, others college/secondary school.
- All employed, 4 full time
- 2 were born in the UK
- More than half lived in the UK for over 30 years
- All consider competency in English either moderate to high
- All Islam religion

