


Endometriosis, infertility, and self stigma: findings from a study of Greek and Greek Cypriot women living in the UK

By

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Abstract

This article reports the findings of a sub-group of Greek and Greek Cypriot women within a UK-based larger study (the Endocul Project) which explored the awareness and experience of menstruation, fertility and endometriosis amongst women from minority ethnic groups.

Endometriosis is a disabling, long-term condition that is associated with pelvic pain, dyspareunia and infertility. Greek and Greek Cypriot women were found to suffer public and self stigma related to endometriosis and fertility concerns. The participants described their experiences of living in pain, worry over the effect on their relationships and work, and their frustration trying to access healthcare. The Greek and Greek Cypriot women were found to have culturally specific behaviours and characteristics (openness about endometriosis, support from family and comfort from their religious faith). The findings demonstrate the need for health professionals to recognise socio-cultural differences.

Keywords

Endometriosis, infertility, self-stigma, Greek, Greek Cypriot women.

Introduction

Endometriosis is estimated to affect 5-15% of women of reproductive age, and 70 million are affected worldwide (Ballard et al 2006, Bulun 2009). The most common symptom is cyclical pelvic pain often with abdominal and low back pain, although some women experience constant pain. They may also complain of deep dyspareunia and pain on passing stool and urine. There is a strong correlation between infertility and endometriosis (Fourquet et al 2010, Lessey 2000). Clinically, endometriosis describes a condition where endometrial cells grow on structures outside the uterus, for example the fallopian tubes or ovaries, or even intestines. It is not understood why this occurs, although there appears to be a genetic link (Grchukhina et al 2012). Although there are many medical therapies for endometriosis there is no definitive cure. Medical treatments are non-specific, involving hormonal suppression of the growth of the endometrium, as well as the endometriosis. Surgical techniques are effective but the endometriosis reoccurs within five years in over 50% of women (Hadfield et al 1996). There is published evidence demonstrating that endometriosis negatively affects the quality of life of many women (Denny 2004, Huntingdon & Gilmour 2005, Denny et al 2010). This may be due to living with pain for many years, difficulty getting a diagnosis, the affect on relationships and work, the stigma of infertility and the frustration of interacting with healthcare systems. There is less evidence demonstrating how women from ethnic minority backgrounds experience endometriosis. It is known that many cultures have taboos about menstrual blood (Helman 2007); Seear (2009) described the stigmatisation of menstruation. Therefore the symptom of dysmenorrhoea may be concealed. This paper reports on a study of Greek and Greek Cypriot womens' experiences of reproduction, menstruation and endometriosis taken from the larger Endocul project (Denny et al 2010).

The impact of endometriosis on fertility is significant. Contemporary Greek and Greek Cypriot societies remain pro natalists. Greek women speak of mothering as “within the nature” of a woman, despite the fact that Greece has the highest incidence of abortion and one of the lowest fertility rates in Europe (Paxson 2004). Studies in Greece and elsewhere identify that women experience stigma when faced with infertility (Whiteford & Gonzalez 1995, Slade et al 2007, Gourounti et al 2012). Lykeridou et al (2009) found that Greek women seeking infertility treatments suffer varying levels of anxiety which may be linked to stigmatisation. However, other research findings suggest that stigma may be lessening in some developed countries (van Balen & Inhorn 2002). In their study on infertility among British South Asian communities Culley and Hudson (2006) discovered that although childless women suffered the consequences of public stigma, some of the younger women in particular described strategies and practices which they used to confront and resist the stigma of infertility. Similarly Riessman (2000) reported that stigma may not always have a totalising impact on women’s lives and even in extreme cases of public scrutiny of infertility, some women are able to resist community pressure through their everyday practices.

The term ‘stigma’ was originally adopted by the ancient Greeks who used it to represent the marks that were pricked onto slaves to demonstrate ownership and to reflect their inferior social status (Papadopoulos 2009). Much of the theorising around stigma originates from the seminal work of Goffman (1963) the context of which was mental institutions. He stated that stigma reflects a social attitude toward mental illness that is deeply discrediting and is a position of social disgrace. This can lead to assumptions about the person’s character and can dehumanise the individual because he or she is appraised as being ‘marked’, flawed and different from others thus making the person less desirable than others.

Not only do women with fertility problems experience public stigma, but having been socialised in

the same society, they share the same values and their reaction can be one of self rejection and feelings of worthlessness. This internalised stigma, feelings of guilt, shame and inferiority and a wish for secrecy and concealment has been defined as self-stigma (Corrigan 2004, Stuart 2005).

The British Endocul Project (Denny et al 2010) asked the 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?” This paper focuses on the specific attitudes and experiences of the Greek and Greek Cypriot participants in the Endocul project. Ethical approval was obtained for the Endocul study from a relevant National Health Service Research Ethics Committee [NHS REC reference number: 08/H1204/8].

Following a systematic literature search and narrative literature review, the study consisted of four phases:

▲ Focus groups with women from five minority ethnic communities (African Caribbean, Greek/Greek Cypriot, Indian, Pakistani and Chinese) 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 purposeful 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 convenient 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 the provision of 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.

Eight women participated in the Greek/ Greek Cypriot focus group, aged 19-46 years. The facilitator was a Greek Cypriot woman. The aim was to explore their cultural meanings of womanhood - including sexuality, and menstruation-, motherhood- including reproduction-, endometriosis and access to health services. Two of the eight women had been diagnosed with endometriosis but the others had not heard of the condition.

In-depth, semi-structured interviews were then conducted with six Greek/Greek Cypriot women aged 28-38 years old, with a current clinical diagnosis of endometriosis for more than one year prior to the study. These women were receiving care from mainstream health care services (NHS). Five out of the six women were born in the UK but all identified strongly with their Greek culture. The one who was born in Greece had lived in the UK for 15 years. She reported Greek as her mother tongue, but rated her competency in English as “high”. Five of them had attended university whilst the sixth had attended a college of further education. Four were married and two single. They were all employed – five full-time, one part-time. They all reported to be Greek Orthodox Christians and that their religion was important to them. Semi-structured interviews were carried out in English, the preferred language of the participants, in locations agreeable to them, and were tape-recorded.

The focus group discussion and the individual interviews were transcribed verbatim. Narrative analysis, guided by the work of Riessman (1990) and Polkinghorne (2007), was used to analyse the data. The decision to use this method was based on the fact that the data consisted of stories which the women told as they tried to make sense of their personal experiences. It is the truth of their experiences and not an objective generalisable truth the research was seeking to discover. Because

of this premise, it is the readers who will make the judgment about the plausibility of a knowledge claim based on the evidence reported by the researchers who, having read and discussed the transcripts agreed on how to present the women's stories (results) in the format that follows.

Results (Focus group)

Womanhood

The participants of the Greek and Greek Cypriot focus group 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 choices than their mothers did. This group perceived themselves as strong and able to multi-task, family centred, not relinquishing their responsibility for the home and children as they moved to roles outside the home. The generational differences between Greek women were summed up by a young woman born in the UK:

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

Motherhood and fertility

Focus group participants agreed that motherhood was very important in the family orientated Greek community. Many women felt that there was pressure from family, and to a lesser extent from friends, to have children. One participant explained:

You have a free choice, but you also have lots of pressure. No one can force you to do anything. It's just, can you live with it, with that pressure?

Most of the participants had no or little knowledge about endometriosis but when information was given to them by the facilitator, they all agreed that the Greek / Greek Cypriot communities in the UK should be provided with information in order to reduce suffering and the potentially avoidable physical and psychological consequences linked to this condition.

The findings of the focus group were explored in more depth during the individual interviews with women who had been diagnosed with endometriosis.

Results (Interviews)

The journey to diagnosis

The Greek and Greek Cypriot women who were interviewed described how they had suffered with dysmenorrhoea for years before seeking help from their doctors. Their mothers had told them that they were having 'bad periods'. One woman described her periods in this way:

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. It is bad.

When they eventually sought their doctor's help they invariably were dismissed as young women making too much fuss about something which happens to most women. The subtle message from their doctors was that they were 'hypochondriacs', a label which made them feel ashamed of themselves. Half of them mentioned that at some point they turned to the internet to obtain information about their symptoms.

One of the single participants described how she tried to ‘diagnose’ herself with information she found on the internet. She said:

It [the information] just scared me, most of it. Just because it spoke about infertility and it was on every page that I read anything about endometriosis, it would always say something about it affecting your fertility, which it would do because it is a risk, but that was something I found quite hard to accept. When I eventually had a scan, I remember coming home and I was very upset and I convinced myself I wasn't going to be able to have kids. I was in tears for weeks.

The married participants sought medical help due to inability to conceive. One woman described the shocking experience of being diagnosed with endometriosis following some investigations:

They put a dye in your tubes to see whether your tubes are blocked and the results of that test was that they were inconclusive, basically they could not tell me either way, therefore my next stage in fertility investigations was to have the laparoscopy, so then I had the laparoscopy and basically they found that I had endometriosis and that it was quite extensive, and I was actually very shocked to be diagnosed with this thing, because I never knew I had this thing, this condition, I never knew what it was all about.

In contrast to other ethnic minority women, Greek and Greek Cypriot women were quite open about their endometriosis and the symptoms such as dysmenorrhoea and dyspareunia. They had told family and close friends and for all, the 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 work when they needed to, even though they felt guilty for being away from work. A strong work ethic was apparent with all participants. However it was said that employers often did not know anything about the condition and it was stressful for them to explain. These findings contradict the

explanation of self stigma which is characterised by feelings of guilt, shame, inferiority and a wish for secrecy and concealment (Corrigan 2004, Stuart 2005), which was also apparent in the data as will be explained in the next theme. The practices of these women are akin to the notion of stigma resistance described by Culley and Hudson (2006).

Self stigma and fertility concerns

The individual interviews confirmed the focus group's findings that motherhood is very important to the Greek and Greek Cypriot women. The two single women said that they were anxious of the possibility of having fertility problems as they both wanted children once they were married.

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 their acts of confronting and resisting actual and potential public stigma such as their efforts to try to increase their chances of pregnancy including travelling to Greece or Cyprus for second medical opinions, visiting religious monasteries in Greece and Cyprus associated with saints said to have performed fertility related miracles, wearing blessed items of clothing, eating certain foodstuffs, praying and so on.

The following excerpts from the interviews with women demonstrate how important it was for them to be able to have children. Their words are commented on using Peterson et al's (2008) model of understanding self stigma (see box 1):

Excerpt 1

The first thing to say is that I have been married for five years now, I have been trying to get pregnant since I got married because I love children. A child would make me feel complete as a

woman. As a married woman I want to be a good wife and this means giving my husband a child. Our parents would also love to have a grandchild. I want to make them happy and be a good daughter to them too. ... I think the fact that we are from Greek background it's even more difficult because there is a lot of stereotypical things going on like when you should get married, when you are going to have a baby, and when these things don't happen like that, well they don't appreciate what the problems might be, you know cos in their generation things were a lot different

This excerpt illustrates the first stage in the self stigma model. The woman acknowledges that there is 'something wrong with me ...' and goes on to express how this makes her feel different in comparison to the acceptable cultural norms.

Excerpt 2

You feel pressured to become a mother. It's 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 you to becoming a mother.

Excerpt 3

...the endometriosis was quite widespread by then again and he cleared me [laparoscopic excision or ablation]. And I remember it being an extremely emotional time because you know, I couldn't stop crying because by then I was thinking that's it, I'll never have a child. ...it's [endometriosis] at the back of my mind in terms of conceiving and then I have these, I do have sudden thoughts, I can never have children and I always wanted children and I'd have to adopt and that kind of thing, so it

does, you know that, it is always a worry until I get pregnant I think, at the back of my mind I think will I ever be able to have my own children. ...I think almost the biggest fear from what I've established with this, is the concern about infertility because that seems to come up quite a lot when you read about endometriosis on a website you do have this kind of scare about infertility.

Excerpts 2 and 3 correspond to the second stage in the self stigma model. There is a sense of inevitability that things cannot change, recovery may not be possible and motherhood may never happen.

Excerpt 4

I think culturally Greeks are expected to reproduce....and he [her father] turned round and remarked he had no grandchildren and said "maybe you should have your eggs frozen 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 [having children] is something that is expected.

In this excerpt the woman is using a 'joke' made by her father to express her embarrassment, anxiety, and to allude to the fact that she is less worthy of her mother.

Excerpt 5

It can be frowned upon a little bit if you can't have babies. Some Greek people will say "she is no good for my son, I am not going to be able to have a grandchild" type of thing... . I remember my mum telling me how her generation used to set people up to get married. Some of the villagers

would say “you can’t go with that family because they have some sort of illness”, particularly mental illness. I imagine it would be a bit similar for people with problems having babies which would be associated with endometriosis. There is a stigma there as well.

Here the woman expresses the last two stages of the model. Through the internalisation of societal stigma she imagines herself letting down her family through her limitations.

Discussion

Greek and Greek Cypriot women experienced pain, delay in diagnosis and concerns related to fertility which is similar to the experiences described by the other ethnic groups. Whilst most of the Greek and Greek Cypriot women who took part in this study expressed the view that their generation of women are very different from their mothers’ generation they nevertheless acknowledged the view that the Greek community remains very family orientated with children at the very heart of it. This means that childlessness remains stigmatised and many women continue to experience self stigma. But the new generation of women appear to be gradually getting more capable of challenging and resisting the dominant views about fertility and infertility. In most cases family members have close relationships with one another and are able to discuss sensitive issues, such as those linked to endometriosis. All the women who were interviewed reported that they had support from their families when dealing with their symptoms.

The women reported that the Greek and Greek Cypriot community needs to be better informed about endometriosis, which some referred to as a “disability”. They suggested that easily accessible user-friendly information would enable the women to gain control of their suffering. They also suggested that such information could be directed to the men of the community such as fathers, brothers and husbands who, although sympathetic and supportive, lack knowledge about

menstruation, the female reproductive system and endometriosis. Their suggestions seem to embody their determination to challenge the community's stigmatising views about menstruation and infertility.

Greek and Greek Cypriot women reported that their clinicians were not well informed about endometriosis as it was often they, who, after years of suffering, linked their symptoms to the condition through their internet searches. The reported tendency by general practitioners to dismiss the women's concerns by either normalising their symptoms or even by not believing them, added to their feelings of embarrassment leading to self stigmatisation. In addition, taking into consideration the value placed on motherhood, any delays in investigating the women's symptoms and concerns can have catastrophic results on the women and their families.

The Endocul project has produced a booklet on endometriosis aimed at the Greek community. This is accessible and user friendly and is available in both in Greek and English. It will enable the women with endometriosis to understand the symptoms of their condition and manage the implications. Members of the older generation –both men and women- will also benefit from this simple and culturally appropriate information and it is hoped that this should help in bringing issues such as infertility into the open among the community thus eliminating any public stigma which may exist. An on-line presentation about endometriosis and the target groups of the Endocul project has been produced to help health professionals gain knowledge on endometriosis in general whilst highlighting the specific issues as these were constructed by the participants of the Endocul project. DVDs using the words of women from each of the five minority ethnic groups have also been produced to be used for community campaigns and the education of health professionals.

Conclusions

Healthcare providers need to be aware that for minority ethnic women in particular, certain

conditions, especially those related to fertility issues, are heavily influenced by social and cultural contexts. Cultural and religious differences impact on the women's experience of endometriosis and on their attitudes to treatment. Although the Greek and Greek Cypriot women who participated in this study were all recruited from one London location, and the sample was purposive and small, we believe that the findings reported in this paper provide insights into the complex issues which affect the Greek and Greek Cypriot women who suffer with endometriosis, such as the fear of infertility and stigmatisation. The women recommended that steps must be taken to raise awareness about endometriosis amongst health professionals and the Greek/ Greek Cypriot communities living in the UK.

The resources produced with the involvement of this study's participants are based on the findings of the Endocul project and are available on the project's website (www.endocul.com.uk).

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Box 1: Understanding self-stigma (modified from Peterson et al 2008)

Component	Response
Something is wrong with me	Feeling not normal, different, not fitting in Believing what others say
That won't change	Having a sense of inevitability, that things can't change and recovery is not possible Fearing discrimination
Which means I'm less worthy than other people	Comparing oneself to others Feeling not good enough, hopeless, useless Feeling shame, a loss of face, guilt and embarrassment Being insecure, lacking confidence and being anxious
And less entitled than other people	Feeling less worthy and inadequate, having low self-esteem Feeling a burden to others, needing support Beating oneself up, having negative thoughts
Therefore, I	Feeling withdrawn, isolated, lonely, vulnerable Having limitations Engaging in negative self-dialogue Family – rejection, letting them down, self-exclusion Experiencing self-doubt Blaming oneself Feeling a failure and weak