

Endometriosis: improving the wellbeing of couples

Summary report and recommendations

Funded by the UK Economic and Social Research Council

Project reference: ES/J003662/1



Endometriosis: improving the wellbeing of couples

Summary report and recommendations

October 2013

Prof. Lorraine Culley¹

Dr. Nicky Hudson¹

Dr. Helene Mitchell¹

Ms. Caroline Law¹

Prof. Elaine Denny²

Dr. Nick Raine-Fenning³

¹ De Montfort University, Leicester, UK

² Birmingham City University, Birmingham, UK

³ Nurture Fertility, University of Nottingham, Nottingham, UK

www.dmu.ac.uk/endopart

Contents

Acknowledgements.....	1
Abbreviations used in this report	1
Executive Summary.....	3
Introduction	5
Methods: What did we do?	6
Key findings: the impact of endometriosis	8
Understanding endometriosis	8
Diagnosis	9
The impact of endometriosis on daily activities: working lives, social lives and household tasks ...	10
Endometriosis, sex and intimacy	12
The impact of endometriosis on planning for and having children.....	15
Couples managing endometriosis symptoms	17
Couples' encounters with healthcare practitioners	20
Emotions and endometriosis	21
Support within relationships.....	23
What partners identified as the 'single biggest issue'	26
Suggestions for improving support.....	27
Gender, ethnicity and life stage.....	28
Conclusion.....	31
Recommendations	33
Recommendations for women living with endometriosis, their partners, and family and friends .	33
Recommendations for policy, strategy and professional bodies.....	33
Recommendations for healthcare practitioners.....	35
Recommendations for support, information and campaigning organisations.....	36
Recommendations for future psychosocial research	37
Your feedback	39
References	39
Appendix 1: study outputs.....	41

Acknowledgements

First and foremost, we would like to extend our sincere thanks and appreciation to the women with endometriosis and their male partners who so generously shared their personal stories with us.

We also thank the healthcare practitioners, support groups representatives and others who took part in interviews to help us to develop the study in the early stages.

We acknowledge the important contribution made to the project by our Advisory Group, and in particular Dr. Miriam Baumgarten who contributed significantly in the early stages, especially with the recruitment of participants. We thank the individuals who attended the stakeholder workshop and shared their expertise with us. In particular we would like to thank Endometriosis UK for their continued involvement and assistance with publicising the study.

Finally, we would like to thank the funding body, the UK Economic and Social Research Council (grant reference ES/J003662/1) for supporting the research.

Abbreviations used in this report

BFS – British Fertility Society

BSGE – British Society for Gynaecological Endoscopy

CCG – Clinical Commissioning Group

ESHRE – European Society of Human Reproduction and Embryology

ESRC – Economic and Social Research Council

IVF – In vitro fertilisation

NICE – National Institute for Health and Care Excellence

RCGP – Royal College of General Practitioners

RCN – Royal College of Nursing

RCOG – Royal College of Obstetricians and Gynaecologists

Executive Summary

Endometriosis is a chronic gynaecological condition. Common symptoms include chronic pelvic pain, fatigue, heavy and painful periods and pain during sex. It is also estimated that 47% of infertile women have endometriosis. Treatments include analgesics, hormone treatments and surgery but there is no definitive cure. A recent large-scale study of the costs of endometriosis suggested that the annual direct and indirect costs associated with endometriosis in the UK alone were €9.9 billion. Endometriosis has been shown to impact substantially on women's quality of life, but little is known about how this impacts on male partners and there are few qualitative studies of the impact on couples.

Research Aim

The study aimed to explore the impact of endometriosis on heterosexual couples and to contribute to improving the wellbeing of people living with endometriosis by providing an evidence base for improving couple support.

Methods

A systematic review of the literature on quality of life and endometriosis and interviews with key informants (e.g. healthcare practitioners, women with endometriosis and their partners, and representatives from the national charity Endometriosis UK and from other support groups) were followed by in-depth interviews with 22 heterosexual couples living with endometriosis. Men and women were interviewed separately. Data were analysed thematically and anonymised findings were discussed with lay and professional experts at a stakeholder workshop to assist the development of recommendations.

Key Findings

Detailed qualitative data revealed that endometriosis symptoms and especially pain have a substantial detrimental impact on quality of life of couples in complex and multidimensional ways.

- Endometriosis negatively impacts on daily life and physical functioning, affects household activities and impacts on social lives.
- For several women, despite being heavily motivated about their working lives, endometriosis symptoms impacted negatively on their paid work and on work productivity and satisfaction.
- Emotional distress is a pervasive feature of life with endometriosis and many women reported experiencing feelings of frustration, inadequacy, loss, guilt and powerlessness.
- Men are often marginalised in relation to endometriosis: there is little awareness of their feelings and needs, and there is little information and support for male partners. Whilst this is understandable, it is clear that men's experiences and responses are different to those of women, and that men also have unmet needs. Despite the tasks men undertook to help their partners, many still appeared to feel helpless and frustrated that they could not do more to alleviate their partner's symptoms.
- The emotional impact of endometriosis on couples is substantial. A negative impact on intimate relationships, especially sexual relations, is apparent, including but not limited to the impact of painful intercourse.
- Either actual or *anticipated* infertility was a significant issue for the vast majority of the couples in our study. Couples discussed a range of impacts including effects on decision-making about whether or when to have children and how many, and distress at not having children.
- In many cases, the overall impact on relationships is profound. In some cases, living with endometriosis has strengthened bonds, and in others it has led to significant strain.

- The communication patterns of couples were complex and there was considerable variation in how effectively partners seemed to communicate with each other. Whilst some appeared to communicate about their experiences of endometriosis frequently, clearly and effectively, others reported on-going patterns of non-communication or mis-communication resulting in tensions and misunderstandings. Overall couples were more likely to discuss treatment and healthcare and less likely to discuss their feelings – particularly men’s feelings – about the experience of endometriosis.
- Participants would welcome information and support aimed at helping partners and other family members to understand endometriosis and its impacts. This information could usefully help partners and family members to support women with endometriosis effectively, and help partners cope themselves. Men felt that support and information specifically aimed at male partners should be provided online.
- Overall participants were in favour of the development of resources and support aimed at couples.

Conclusion

The management of endometriosis must address the emotional, sexual and relational impact of this disease. A more holistic, biopsychosocial and gender inclusive approach to endometriosis management and support is urgently needed.

Recommendations

A series of recommendations have been derived from the study. For full details see the main report. Key recommendations include:

- NICE should produce a guideline on the management of endometriosis and chronic pelvic pain. This should also include a consideration of the evidence on the psychosocial impact of endometriosis on women and those around them, especially their partners. Guidance on how assessment, intervention and management can encompass a focus on these psychosocial aspects of living with the condition should be included.
- Relevant professional bodies (RCN, RCOG, RCGP, BFS, BSGE, NICE) should further incorporate information about endometriosis, the associated delays in diagnosis, the problematic approaches to treatment and management, and the psychosocial impact on couples into the training and development of healthcare practitioners.
- UK and European guidelines on the management of endometriosis, in particular the RCOG and ESHRE guidelines, should adopt a more couple-focused approach.
- Consultations should be inclusive of the impact of endometriosis on quality of life, and on women, partners and the couple relationship.
- Healthcare practitioners can also improve women’s and couples’ experiences by referring them to specialist services (e.g. pain clinics, psychosexual counselling); by signposting women and couples to support and information organisations such as Endometriosis UK; and by utilising existing resources produced for women, partners and couples.
- Following diagnosis, healthcare practitioners should raise the topic of planning for and having children, and open up a discussion that allows women and couples to explore this important issue and to receive evidence-based information, advice and support from appropriately trained individuals.

Introduction

Endometriosis is a chronic gynaecological condition with an estimated prevalence among women of reproductive age of between 2 and 17% (Damewood *et al.*, 1997; Eskenazi and Warner, 1997; Bernuit *et al.*, 2011). Common symptoms include chronic pelvic pain, fatigue, heavy and painful periods, and pain during sex. It is also estimated that 47% of infertile women have endometriosis (Meuleman *et al.*, 2009). There are a range of treatments available including analgesics, hormone treatments and surgery but there is no definitive cure. The impact on the quality of life of women with endometriosis is substantial and occurs across a range of domains including a negative impact on daily activities, education and work, and social and mental wellbeing (Culley *et al.*, 2013). Whilst many women gain some relief from treatment, a substantial proportion still suffer pain of various kinds (De Graaff *et al.*, 2013). A recent large-scale study of the costs of endometriosis suggested that the annual direct and indirect cost associated with endometriosis in the UK was €9.9 billion and that annual healthcare costs were similar to those of major chronic conditions such as diabetes (Simoens *et al.*, 2012).

Several studies have explored the impact of endometriosis on intimate relationships, many of which have focused on the incidence and impact of dyspareunia (pain during or after sex) (for example, Jones *et al.*, 2004; Ferrero *et al.*, 2005; Fernandez *et al.*, 2006; Butt and Chesla, 2007; Tripoli *et al.*, 2011). Studies report that women feel that the symptoms and experience of endometriosis have had a negative impact on their relationships and have in some cases contributed to relationship breakdown (Cox *et al.*, 2003; Denny, 2004; Jones *et al.*, 2004; Huntington and Gilmour, 2005; Fagervold *et al.*, 2009). However, having a partner can improve quality of life (De Graaff *et al.*, 2013) and women report that partners can be an important source of support (Denny, 2004).

Whilst previous research has shown that endometriosis can have a negative social and psychological impact on women, relatively little is known about the impact on male partners or about how *couples* experience living with the condition. The Endopart study is the first UK-based study to include interviews with male partners as well as women with endometriosis and has a unique focus on couples. The study aimed to explore the impact of endometriosis on couples and to contribute to improving the wellbeing of people living with endometriosis by providing an evidence base for improving couple support. This document outlines some of the key findings and our recommendations arising from the study.

To access an electronic copy of this report, please visit www.dmu.ac.uk/endopart or contact Caroline Law at claw@dmu.ac.uk.

Methods: What did we do?

At the start of the study we carried out a critical narrative review of literature reporting on the social and psychological impact of endometriosis on women¹. We also carried out interviews with 11 'key informants' including healthcare practitioners, women with endometriosis and male partners, and representatives from the national charity Endometriosis UK and from other support groups. These activities assisted us in preparing a set of issues to raise in interviews with couples in the main phase of the study.

We interviewed couples to explore their experience of endometriosis and the impact it had on their lives. We recruited heterosexual couples who were living together, in which the female partner had received a diagnosis of endometriosis following laparoscopy and had experienced symptoms for at least one year. The experiences of gay couples and couples living apart are, of course, also important, but we were particularly interested in how men are affected by a condition they themselves cannot experience, and in how endometriosis impacts on daily life together. Couples who were interested in taking part in interviews were asked to provide the study team with basic biographical and medical information. We then selected a sample, based on achieving a diverse range of ages and illness and relationship experiences. As our previous research had revealed ethnic differences in the experience of endometriosis (Denny *et al.*, 2011) we also sought to include a sub sample of South Asian couples (Pakistani, Bangladeshi and Indian).

Twenty two couples were recruited from support groups, hospital clinics and word of mouth. The average age of women in the study was 34.8 years (range 25-50) and the average age of men was 36.3 years (range 26-57). Amongst the women, 14 were White British, six were South Asian and two identified themselves as coming from 'other' ethnic backgrounds. Amongst the men, 13 were White British, six were South Asian and three identified themselves as coming from 'other' ethnic backgrounds. The average length of relationship, at the point of interview, was 9.1 years (range 3-21 years). The average length of time since onset of symptoms was 13.6 years (range 2-37 years) and the average length of time since diagnosis was 4.5 years (range 1 month – 20 years).

We carried out face to face, detailed interviews with women and men using a semi-structured interview schedule. Men and women were interviewed separately. We asked people to tell us about symptom onset and the journey to diagnosis, their understanding of the causes of endometriosis, the impact endometriosis had on everyday life and on their relationship, experiences of healthcare and treatment, communication and support within relationships, external support and information, and their feelings about the future. Participants were also invited to write to us after the interview whenever endometriosis subsequently had a particular impact on their lives.

¹ Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, Raine-Fenning N. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Human Reproduction Update* 2013; doi: 10.1093/humupd/dmt027.

The interview data were then analysed thematically (identifying key themes in the data) and dyadically (taking each couple as a 'unit of analysis' and exploring similarities and differences in partners' accounts). We then held a full day workshop attended by healthcare practitioners (including consultant obstetricians/gynaecologists, pain consultants, nurses, clinical psychologists, counsellors, clinical research fellows), women with endometriosis and their male partners, academic researchers, and support group representatives. At this workshop we presented the preliminary findings from the study and invited participants to make suggestions about how support for couples could be improved using knowledge of our findings and their respective expertise.

Key findings: the impact of endometriosis

The study generated very detailed accounts of life with endometriosis. In this short report we have purposively given emphasis to those issues which are particularly relevant to the couple relationship and to the experiences of men. This is not to deny the considerable burden of endometriosis in women's lives, but reflects the unique couple centred focus of the study and the relative absence of research which directly reports men's accounts. We have grouped our description of the findings under the following themes: understanding endometriosis; diagnosis; endometriosis and daily activities; endometriosis, sex and intimacy; the impact of endometriosis on planning for and having children; managing symptoms; interactions with healthcare practitioners; emotions in endometriosis and support within relationships. We outline what participants reported as the 'single biggest issue' in life with endometriosis and their suggestions for improving support. We then discuss the influence of gender, ethnicity and life stage on couples' experiences of living with endometriosis

Understanding endometriosis

Endometriosis is an enigmatic condition in many ways. The cause of endometriosis is unknown and its course is unpredictable. Furthermore, symptoms are largely invisible and there is no correlation between severity of pain symptoms and stage of disease. Historically, endometriosis has been inaccurately perceived as a disease caused by women's lifestyle or personality. In particular, inferring psychological disturbance as a cause of chronic pain in endometriosis led to many women not being taken seriously by the medical profession and significant others.

In our study, the accounts of most participants reflected the lack of a clear 'cause' of endometriosis. Both women and men discussed a range of possible causal mechanisms including genetic causes and hormonal imbalances, but most were of the opinion that a clear cut explanation does not exist. Whilst neither men or women accepted a purely psychological explanation for endometriosis, men were more likely than women to discuss how psychological factors may interact with endometriosis; for example, it was suggested that stress can make endometriosis symptoms worse, that 'unhappiness' is implicated in development of endometriosis and that having a positive attitude can aid faster recovery. In general, participants placed less importance on the causes of endometriosis and instead focused more on how the symptoms could be alleviated. Women viewed endometriosis as something to be managed, whereas men were more likely to see it as something that should be cured or 'sorted out' (by medical interventions). The difference in how women and men understand endometriosis could be significant in relation to how well couples cope, given the typically progressive and often incurable nature of endometriosis.

As a condition that men cannot themselves directly experience, we were interested to explore how men understand and respond to endometriosis. Men and women had different perceptions of how 'well' men understood endometriosis. Some women spoke of how it was not until they lived with their partner, or until he witnessed her having and recovering from surgery, that he fully understood what she was going through. However, other women suggested that whilst their partner might be able to list the symptoms, he did not and could not fully understand how it felt physically.

I don't think anyone really understands unless they are going through it. [Partner] tries to be understanding but I don't think he really understands. (Female participant)

Some men felt that being in a relationship with and living with their partner gave them a special insight into what it was like to have endometriosis; one described it as being 'in on a secret that no one else knows'. In response to a lack of understanding by healthcare practitioners and, in some cases, by family and friends many men reported being protective of their partner and challenging attitudes that downplayed the severity of endometriosis symptoms or their effects. However, several men explicitly recognised the limitations to how much they could really understand endometriosis.

I can't feel the pain, I don't even know what a period feels like, whether it's a particularly heavy one or whether it's bad or the period pain beforehand. I don't know what any of that feels like. I can try and put myself in her shoes as best as possible but I will still never understand. (Male participant)

Importantly, participants also spoke about the general lack of awareness and understanding of endometriosis in wider society. Both women and men reported that family members and friends (even those that were generally supportive) did not fully understand the condition, its impact on women's feelings and behaviours or its impact on male partners. This sometimes resulted in both women and men feeling isolated.

I think the family don't really understand what she's going through, and they've kind of just distanced themselves ... they don't understand and my family don't really understand what endometriosis is. Because no-one's ever heard of endometriosis, they don't know what endometriosis is, what its symptoms are and what its effects are - they don't understand that. (Male participant)

Whilst women reported variable experiences in the workplace, many reported working with employers and colleagues who did not understand endometriosis and who were not sympathetic.

Unfortunately there's a lot of employers out there that just aren't understanding. It's hard to find a good employer ... in the end you end up being forced out. It's as simple as that. (Female participant)

Diagnosis

Previous research has shown that many women experience considerable delays between the start of symptoms and the diagnosis of endometriosis, and that many are mis-diagnosed during this time. The delays amongst our sample were between six months and 28 years, and the average was 9.1 years. Some reported being misdiagnosed with irritable bowel syndrome, appendicitis or an infection. Many women spoke of the difficulties and distress they experienced in trying to get healthcare practitioners to investigate their symptoms. Many men encouraged and supported their

partners to go to the doctor, sometimes repeatedly, to pursue investigations for their symptoms and a few men attended healthcare appointments with their partners prior to diagnosis.

It was a really, really stressful time before my diagnosis actually ... the whole burden of trying to figure it out on my own because I didn't feel I was getting enough help from the doctors. I think they should have suspected this sooner. (Female participant)

The majority of women reported that they felt relief upon diagnosis, primarily because it was confirmed that their symptoms were real and not imagined. Women also spoke of worry and distress about potential infertility when first diagnosed. Men had less to say about their feelings upon diagnosis and some reported that at that stage they had little understanding of endometriosis and little awareness of the implications of the diagnosis. Several men reported feeling relieved, and a small number described themselves as upset, worried, helpless and shocked when their partner was first diagnosed.

However, having a diagnosis enabled women and men to better understand, make sense of and accept their situation. Diagnosis provides a legitimization of symptoms and several women reported, for example, that having a diagnosis helped them to access support in their workplace. A diagnosis helped men especially to make sense of the symptoms and to begin to understand the causes behind their experiences, particularly in relation to the impact of endometriosis on sex and intimacy.

At the moment, it [sex] is infrequent but it's not a problem in that ... there's a reason, it's the endometriosis ... knowing the cause, it's acceptable. It doesn't cause big arguments and fights because I'm not getting it or whatever, because the reasons are there and there are genuine reasons. It would be unreasonable then of me to not take notice of that and say come on, I need sex. (Male participant)

The impact of endometriosis on daily activities: working lives, social lives and household tasks

Chronic illness brings with it many disruptions in the day to day lives of the ill person and their partners. Endometriosis impacted on the working lives of couples, on their ability to socialise with friends and family and on the household division of labour.

Working lives

Previous research has indicated a significant impact of endometriosis on women's employment, with endometriosis associated with more sick days, work disturbances and reduced productivity (Fourquet *et al.*, 2010; Fourquet *et al.*, 2011; Nnoaham *et al.*, 2011; Simoens *et al.*, 2012). In our study, many women spoke of the significant impact of endometriosis on their working lives. Women described several strategies they had adopted to manage this impact, such as working reduced hours, changing jobs, or choosing self-employment to enable them to work flexibly. A small proportion of women reported that endometriosis prevented them working at all. As a

consequence, for some couples, endometriosis impacted on the family income and some spoke of how the impact on women's employment had created a change in their relationship.

She wants to go out and get a job, she wants to earn money, she wants to earn her own money because at the moment if she wants anything she has to ask me for money. We have accidentally become a traditional 1950s household, the man goes out to work all day and the little lady is at home! (Male participant)

Women were unhappy about losing an independent income and being less able to contribute to the household economy, whilst some men reported feeling the added pressure of providing a larger share of the household income.

It was less common for endometriosis to affect men's working lives, although a minority did suggest that at times of crisis in particular, the strain of endometriosis affected their productivity and concentration at work.

Social lives

The disabling and unpredictable nature of endometriosis impacted significantly on the social lives of couples. Endometriosis prevented many women from socialising and taking part in activities, such as seeing friends and family, participating in classes and hobbies, and taking part in physical activity. At the couple level, going out with friends and family, going on trips and holidays, going on walks, and going to events such as weddings, concerts and parties were all affected.

Couples reported having to plan social activities carefully according to the fluctuating, cyclical symptoms of endometriosis. However, it was often difficult to plan effectively, and women reported having to cancel plans and leave events early. A small proportion of couples reported that whilst they socialised less with others as a result of the endometriosis, they went out *together* more frequently (e.g. to dinner). When female partners were unwell and unable to go out, whether or not men went out alone appeared to vary according to whether or not partners thought that socialising alone was a normal or acceptable part of being in a couple. Overall, men tended to stay in with their partner on most occasions but sometimes to go out on their own.

There's been times in the past where basically she hasn't been up to going out, and I've said 'right well I'm going out anyway because it's the weekend' ... I need that time and that space, she knows that. I'm quite a social person. (Male participant)

Some men indicated this was important for their own mental wellbeing: they needed to engage with friends, or to engage in stress reduction activities such as exercise. The vast majority of women in these couples did not express any resentment that their partners went out without them on some occasions.

Couples appeared to feel more loss about not being able to do things together as a couple (e.g. holidays, trips and going for walks), than they did about not being able to socialise with others

outside the couple unit. In several couples, the impact on social lives was reported to have caused some relationship tensions and arguments. However, overall this negative impact of endometriosis did not appear to be as significant, or to represent a considerable loss for couples when compared with other negative impacts of the condition on daily life and on relationships.

Household tasks

In the majority of couples, the symptoms of endometriosis meant that women were less able to undertake household tasks, such as cleaning (especially hoovering), washing up, ironing, and food shopping, in the way they wanted to. Some reported feeling frustrated and also guilty about having to rely on their partners to undertake tasks they had previously seen as their responsibility. This was particularly acute in couples with a more 'traditional' relationship.

For me I get most upset about how I am as a wife to my husband because I struggle to look after the house ... I struggle with the housework, doing the cooking and the cleaning. (Female participant)

Some men discussed particularly stressful times such as following their partner's surgery, when they had to manage running the household, caring for their partner and in some cases also for children, while also having to manage paid work.

Whilst all couples mentioned the stress and strain that endometriosis put on different aspects of their daily lives at certain points, for a minority of couples endometriosis was perceived as having an all-encompassing, devastating impact on daily life.

You don't have a life, if you can just describe it like that. I think it's the best description, you don't have a life because you can't go anywhere, you can't do anything, you just can't do anything, that's it. You've got no choice. (Male participant)

Endometriosis, sex and intimacy

Endometriosis symptoms and treatment disrupt the day-to-day lives of couples but have a particularly profound impact on intimate relatedness. Several studies have shown that endometriosis can cause a severe impairment of sexual function, relationship and psychological wellbeing in women, though there is little research that directly explores men's perspectives. Sex was a major concern in this study, and the sexual relationships of all couples had been affected by endometriosis to a greater or lesser extent. Pain during or after sex (dyspareunia) was common but women reported a range of other factors which impacted on intimacy: bleeding during and/or after sex, general fatigue and feeling unwell, reduced sexual desire as a result of medication, having a low mood, the stress of trying to get pregnant and feeling generally unattractive and unfeminine. In nearly half of the couples sex was reported to be non-existent or rare, either at the time of the interview or in a recent phase, and others reported reduced frequency of sex.

We don't make love as often as we did and sometimes when we do I'm aware that it's uncomfortable for [partner] and there have been times when we've actually stopped. (Male participant)

Over the last two years we've had sex probably once or twice a month because I just couldn't bear the pain. (Female participant)

Women, more than men, reported a significant loss of intimacy, closeness and affection. The absence or infrequency of sex meant that couples did not have opportunities to experience intimacy through sexual relations, and some couples had not found alternative ways of expressing closeness.

For most women this resulted in feelings of grief, sadness and guilt. Some imagined that their partners felt guilty, or felt frustrated about this, which fuelled their concerns. Women often blamed themselves for the lack of intimacy and described the feelings of loneliness that this gave rise to.

You kind of like lose the, like your sex life, we've kind of lost that completely really. And then you feel like you're drifting apart almost because you haven't got that closeness. (Female participant)

Dyspareunia was mentioned as a symptom by 19 women, although the severity and frequency of this and its impact on sex varied. For a minority, this was not perceived as a major problem, but for some the pain was significant and the impact profound:

When we did get down to it, it was just, it was kind of, it was an ordeal really. (Female participant)

It was the sheer agony. It was like somebody putting a knife in me. (Female participant)

Dyspareunia meant that some women had to make a difficult choice between avoiding sex, which resulted in them feeling guilt, loss and worry about how this would affect the relationship, or enduring painful sex in order to be intimate and close with their partner. Four of the women we interviewed reported that they concealed dyspareunia from their partners, or had done so in the past, in order to minimize the impact of endometriosis on their relationships.

Men also spoke at length about the impact of endometriosis on sexual relations with their partners. Most men were aware of the potential for pain, and this fundamentally affected their feelings and behaviour regarding instigating sex. Many men spoke of feeling hesitant and tentative, and were often reluctant to approach their partner. For a minority these feelings were very intense.

You almost feel, I would say quite like it, because obviously I've never done it, but you almost feel like you're abusing that person, almost like a sort of rape. (Male participant)

A small proportion spoke of a situation where they felt guilty if they engaged in sex, and others suggested they were frustrated if sex was infrequent.

It can be frustrating. I am a young guy and like any young guy I get frustrated when your partner's sex drive, or ability to have sex without pain, doesn't match your own. (Male participant)

In the absence of awareness of strategies to alleviate these difficulties and in the context of prioritising their partner's wellbeing above their own needs (which was a common approach throughout the interviews with men), it was common for men to suggest that, over time, they had come to understand the need for change in their sexual relationship and had some acceptance of this. However, the extent to which it was discussed in interviews by both women and men, the loss of closeness, grief and guilt reported by female partners, as well as the significant tensions some couples experienced (described further below), together suggest the impact of endometriosis on sex and intimacy is profound.

From comparing accounts of women and men *within* each couple, it appears that most partners had a shared perspective about the impact of endometriosis on sex and intimacy and the extent to which this was a problem in their relationship. However, in their interviews men were less likely than women to discuss how the impact of endometriosis on sex and intimacy affected the female partner emotionally, or to discuss dyspareunia and bleeding during and/or after sex. Men were also less likely than women to express feelings of loss in relation to intimacy and less likely to discuss the idea of seeking help with this aspect of their lives.

A minority of couples reported that the impact of endometriosis on sex and intimacy had caused them very significant stress and distress. For some couples, sex had become a minefield, so fraught with difficulties that they wanted to avoid physical contact altogether – resulting in a loss of closeness and intimacy. For a minority of couples, there was a significant lack of communication about this aspect of their lives, which resulted in relationship tension and arguments. These couples reported miscommunication: for example, when one partner was reluctant to initiate sex for fear of pain, the other interpreted this as rejection. Because they did not fully communicate how they felt to one another, behaviours were open to misinterpretation and women and men were left to 'second guess' how their partner felt.

Sometimes I've not been near her for six, eight weeks because I'm scared of hurting her because sex is painful. And then my partner will be like, I've not been near her and that will cause an argument and she'll say to me 'I'll tell you if I don't want to if it's too painful' ... It's me knowing that I'm going to hurt her, I don't like it, puts me off basically ... we do talk about it but it's always when it's too late rather than before me saying anything or my partner saying anything, we both just leave and leave it and leave it. Then a bit of an argument and then it's sorted, back to normal for a couple of months and then it starts again. (Male participant)

It's fair to say there were times when she would try and I wouldn't and times I would want to try and she wouldn't. To some extent we were walking on egg shells when it came to that topic. (Male participant)

You don't want to, it's not worth the pain, you kind of get in that mindset. So you go to bed and you avoid the kiss and the cuddle. So then you get the hump with each other and then he starts avoiding me with the kiss and the cuddle ... If we have a conversation about it it's generally because he has been distant with me and I think he just switches off, the affection just switches off. So then you switch off and then you get the hump. (Female participant)

[Pre-diagnosis] we had to have a time where we had no physical contact ... I used to think she's getting away from me, or something like that, has she got somebody else now? We had loads of arguments. (Male participant)

In spite of these sometimes intense difficulties, very few couples had been given information about the possible impact on sex and intimacy and few had sought or been offered help with the sexual implications of endometriosis or its treatment side-effects.

The impact of endometriosis on planning for and having children

The impact of endometriosis on fertility is unclear, but a substantial proportion of couples will experience problems getting pregnant, though not all will seek fertility treatment. In our sample, 18 out of 22 couples reported that endometriosis had in some way affected their plans to have children. The data, therefore, strongly suggest that either actual or *anticipated* infertility was a significant issue for the vast majority of the couples in our study. Couples discussed a range of impacts including effects on decision-making about whether or when to have children and how many. Just half of these couples had sought and/or received medical fertility investigations or treatment. When talking of their fertility problems, women spoke of feelings of loss, grief, distress and upset.

It's a complete nightmare to realise that you're not able to have children and you still have to keep trying. There is this pressure on you to keep trying, you kind of feel that it might not work. It's heart breaking, it's been very hard. So yes, we've had some very low points. It's just yes, very, very stressful. (Female participant)

However, even those women who had not, for a variety of reasons, sought advice on fertility issues expressed considerable anxiety about the *possible* impacts of endometriosis on childbearing. These women also spoke of the emotional distress caused by anticipated infertility.

It always comes back to this: my panic to have a child ... the panic is there when really our first year of marriage should be very calm and enjoyable. But for me there's that underlying panic. (Female participant)

The biggest concern for me is will I be able to have children? So I'm very emotional about my period and the pain every month. So it's kind of slipped into another dimension now ... I accept it, I'm ok that I've got endometriosis, but now I'm worried about the impact it's going to have. (Female participant)

Several women had suggested to their partners that he should leave the relationship because of the possibility that they might not be able to bear a child.

Men also spoke of their emotional experiences in relation to fertility issues. Amongst couples who were receiving or had experienced fertility treatment, men spoke of feelings of disappointment, distress and upset.

Coming to terms with not having children of our own and the whole process of IVF, going through it, is really traumatic and for me that's been the most painful element of the whole process. (Male participant)

However, men, more than women, spoke of strategies they employed to minimise their distress and resist the impact on their lives and their wellbeing. These included: limiting the number of IVF cycles they are prepared to engage in, avoiding talking about it excessively, downplaying the importance of having children, looking for positive aspects of having a child-free life, resisting being overly involved in family members' pregnancies, or for those who described themselves as having a faith, taking comfort that their fate was 'in God's hands'.

I think the fertility has kind of hit me quite hard and I'm kind of trying to come to terms with it. Just trying to put myself in the worst case scenario and just trying to see myself in that situation and think ok if I can't have a family, can't have children then if that's the way it's got to be, that's the way it's got to be. (Male participant)

Amongst couples who were currently trying or had been able to conceive naturally, men appeared to experience considerably less anxiety and worry about anticipated infertility than women, and had more of a 'wait and see' attitude.

Endometriosis treatments often act as a contraceptive or may create risks to fertility. Some couples, therefore, were faced with a difficult choice. Accepting treatment would bring much needed relief from debilitating pain but would mean delaying any attempt to conceive or in the case of hysterectomy, foregoing a pregnancy. However, rejecting treatment because of a desire for children meant sometimes having to live with extreme pain. The decision-making process surrounding this issue was further complicated when partners had different priorities in this regard. For example, in the case of one couple, the male partner was desperate for his wife to have a hysterectomy, due to the severe impact of endometriosis on her wellbeing and their life together. He felt that this was the way for her to live a more normal, pain free life. However, the female partner refused to do this as she felt that whilst she could just about cope with the physical pain of endometriosis, she would be unable to cope with the emotional pain of not having a child. This had caused significant tension between the partners.

Exploring accounts from women and men within each couple suggests that most partners have a shared understanding of the impact of endometriosis on planning for and having children within their relationship, and the extent to which this was a problem. However, some participants misinterpreted how *big* a problem this was for their partner (see 'single biggest issue' below). Both

men and women reported that within their relationships they were more likely to discuss the emotional impact of actual or anticipated infertility on the female partner, than they were to discuss men's feelings in relation to planning for and having children. Men also spoke of providing emotional support to their partner on this issue more often than women did. For a minority of couples the impact of endometriosis on planning for and having children had caused tensions and arguments between partners.

A small number of participants who had conceived reported that female partners had experienced difficulties in pregnancy and/or labour, although the extent to which this was related to endometriosis was not always known to participants. For example, women reported miscarriages, adverse reactions from IVF drugs and problematic experiences with delivery. Women also reported that drugs used in IVF worsened their endometriosis symptoms.

Couples managing endometriosis symptoms

All participants spoke in detail about the symptoms experienced, but women spoke about these more, and in greater detail, than men. The most common endometriosis-associated symptoms reported were pain, heavy menstrual bleeding, fatigue and bowel related symptoms. Participants also described a vast range of other associated symptoms including nausea and vomiting, digestive problems, dizziness and problems with concentration, heavy legs, fainting, urine or bowel incontinence and mobility difficulties.

Medical Management

Couples were asked about how decisions about medical management and surgical treatment were made. The majority of couples reported discussing options and making decisions together. However, this decision making process between partners was complex and couples employed a variety of approaches. At one end of the spectrum, couples appeared to have a shared agreement that it was the male partner's role to listen and support, and that it was appropriate for the female partner to make the ultimate decision. At the opposite end of the spectrum, in one couple the male partner had insisted on a hysterectomy which the female partner had agreed to but appeared to feel uncertain about. Participants spoke about what they felt the male partner's role should be in treatment decisions. A small proportion of women reported that their partner was a useful person to bounce ideas off and also someone who could usefully help gauge the impacts, good and bad, of current medications and therefore help to assess next steps. It was also clear throughout the interviews that treatment decisions had implications for both partners, and one man stated that he felt he had a right to influence decisions as these impacted on both his partner's and his own quality of life.

To be honest I feel I deserve a say because it affects everything. We are going to have a life together and her fertility, our day to day, all of that sort of thing, it's a big thing ... it's her decision in the end, but I am her partner so I deserve to say what I feel. And yes, like I said we discuss everything, it's great. And she will listen to my opinion which is nice. It makes me feel involved, as I want to be. (Male participant)

There were few tensions or disagreements between partners regarding treatment, and overall participants suggested their discussions were supportive and harmonious.

He definitely has a say. I obviously make the final decision, but he will always help me come to it, he will always give me all the other opinions that could be there. He is really good at helping me see things from other points of view. (Female participant)

We talk it through and I think, because it affects me as well, so we kind of function as a unit when we are making decisions. Because she lives it, I live it too ... I would like to think I offer a well-informed opinion but from a different perspective. (Male participant)

There was variation in how couples negotiated treatment decisions with consultants. Some couples were entirely led by their consultant, and did not question decisions or make their own suggestions. Others felt they had the right to determine their own treatment, based on their own experiences and research. In the case of one couple when their chosen treatment – a hysterectomy – was denied by their consultant, this resulted in them feeling utterly powerless and frustrated.

Women and their male partners discussed their experiences of a range of medical and surgical treatments, as well as self-management approaches and experiences with alternative treatments including acupuncture, physiotherapy, homeopathy, and herbal medicines. Finding a long term, acceptable approach to managing and minimising endometriosis symptoms was described by most couples as a constant battle which caused significant frustration for both women and men.

Women had typically received several forms of treatment. As previous research has also shown (De Graaff *et al.*, 2013), there was huge variation in how effective these were. Whilst some treatments were reported to be very effective, at least for a period of time, women encountered significant difficulties and frustrations when treatments were ineffective, only effective (or advised to be taken) in the short term, and/or caused side effects (either straight away or after a certain time period). Subsequently, many had a ‘trial and error’ approach to medical treatments, and changed their treatments on a regular basis. Men tended to be quite aware of what treatments had been effective and what treatments had not, and, as discussed above, engaged in discussions with their partner about treatment decisions.

Women described a vast range of treatment side effects they experienced including constipation, hot flushes, aches, insomnia, weight gain, pains, fatigue, poor concentration, and loss of libido. Men were also aware of the side effects their partners experienced, but men discussed them less in interviews than women. These side effects had a considerable impact on quality of life, for both women and their male partners, and some found it difficult to disentangle the impacts of the endometriosis and the impacts of treatment side effects. In particular, women and men found it difficult to cope with the impact of treatment on women’s moods, and some men found it a challenge to understand the ways that treatment could affect their partner’s emotions and behaviours.

The second time around she had Zoladex and that affected her quite badly, she got severe headaches, a lot of mood swings ... it was very hard for me to understand what she was going through. To me it was just injections and get on with it. To me, that solved all the problems, there is nothing else to worry about. It took me a good few months to realise what was going on ... to me the injection was like having an inoculation when you go abroad, that's what I thought it was. I didn't realise the effect it could have. (Male participant)

Overall, dealing with the side effects of medication appears to significantly compound the difficulties of living with endometriosis. Some felt that healthcare practitioners only considered the endometriosis symptoms in treatment decisions, and did not take sufficient account of the side effects experienced.

I am very frustrated and angry that the side effects of being on this drug are not taken into consideration. This drug has stopped the pain and bleeding, however it has masked a problem with other problems that have equally reduced my quality of life. (Female participant)

Self-management

In addition to medical and surgical management, participants described a range of self-management strategies used to alleviate symptoms, including using hot water bottles, heat pads and wheat sacks, using TENS machines and altering diet. Women also spoke of trying and testing different combinations of over the counter medicines, and ultimately deciding upon the best combination and dosage for them. Very few men were actively involved in helping women to self-manage their endometriosis symptoms. The few men that did discuss this described how they prepared hot water bottles and heat pads, or helped to remind their partner of her medication timings and record medication taken.

It's what I have learnt as I have gone along, how to manage your partner's pain. I would have never of thought about the TENS machine or getting heat pads for [partner] when she was really uncomfortable. Putting the wheat sack in the microwave for a couple of minutes and giving that to her in an evening, quite often she won't realise that she needs it and then when she does have it it calms everything down. It's all through experience. (Male participant)

Women discussed other strategies they employed to cope with symptoms. These included rest, pacing activities, and prayer. For those still able to work, their job was viewed as important as it could provide a distraction from symptoms, and women who were still working had made changes that enabled them to cope more effectively, including altering their role, moving from employment to freelance work, prioritising certain tasks (e.g. desk work when in severe pain), reducing responsibilities and adapting their work pattern (e.g. using annual leave to break up the week).

Most women and men talked about the importance of positive thinking (e.g. focusing on the good things they have, thinking everything will work out) in relation to their future wellbeing and/or, for those trying to conceive, in relation to getting pregnant. Over half the women, and a smaller proportion of men, talked about adopting a strategy of 'just getting on with it', which included 'not

giving up', 'pushing through', and 'putting on a brave face'. This often stemmed from a realisation that they would have to live with endometriosis, and so needed to find a way of maintaining as 'normal' a life as possible.

Couples' encounters with healthcare practitioners

In line with previous research, women in this study reported a range of experiences of encounters with healthcare practitioners. Some reported entirely positive experiences with healthcare practitioners who had taken their symptoms seriously, been understanding, supportive and informative, and had given them high quality care. Others reported more negative experiences including doctors not believing in the existence or severity of symptoms, doctors having dismissive attitudes, receiving conflicting advice from different professionals, and experiencing delays in accessing consultations and treatments. Overall, many couples reported they did not receive enough information from healthcare practitioners about endometriosis or its treatment and management and did not have sufficient opportunity to discuss their condition and in particular its impact on their relationship.

This is in a nutshell what is so frustrating about my disease, all the conflicting messages I am receiving, and trying to seek the best possible treatment and dealing with various GPs all the time, just to make me feel like I am always going back to square one. Why can't I go straight to a designated specialist or walk-in clinic? I have a chronic disease that GPs are clearly not knowledgeable about. I am just so frustrated that I do not have access to someone who is able to treat all the aspects of the disease. (Female participant)

In the vast majority of couples, men attended all or most consultations with their partner (after diagnosis). Some men reported taking active roles in consultations (e.g. asking questions and voicing opinions) whereas others took more passive roles. Some women reported that it was useful to have their partner with them at consultations. They found it difficult to be assertive in this situation and so welcomed having a second voice to reinforce to healthcare practitioners how severe the symptoms were and how endometriosis was affecting their lives. Some also appreciated having a second person to 'take in' information. Some couples approached consultations as a shared undertaking, agreeing in advance what role each partner would take and what they would say.

When we went in January to see the gynaecologist again, when I wanted the Mirena coil removed, beforehand I said to [partner], you know, I do not want to leave that consultation with this coil still in, I really want to be shot of it ... I said, I know if I have a wobble in there, and if I go all sort of like meek submissive patient and say, 'oh yes, yes of course I'll give it some more time', I said, you will stand up for me won't you and you will say, 'no this really does need to be removed now, this is doing neither of us any good'. But it was a case, you know, we talked about it beforehand, that was our strategy. (Female participant)

Men, more than women, saw endometriosis as something to be cured or 'sorted out' as opposed to managed and, as a result, some took a particularly assertive stance in consultations to try to arrange 'effective' treatment.

I actually lost my temper at the [hospital] ... I said 'I'm not being funny, I'm sick of this. I said I'm sick of looking at my wife in pain. How would you like it if you came home every day and that was somebody you loved in pain like that ... I ain't going anywhere until I've got somebody here who can sort this. (Male participant)

It was common for men to express considerable anger, frustration and criticism of NHS healthcare and healthcare practitioners. They reported dissatisfaction with the quality and timeliness of their partners' treatment and care. Whilst women were often critical of NHS healthcare and healthcare practitioners, they appeared to be less *angry* about their care. Their frustration with endometriosis was not usually directed at healthcare provision *per se*. This may be because women, unlike their male partners, appeared to perceive endometriosis as something which could hopefully be managed but which could not necessarily be cured.

Emotions and endometriosis

Endometriosis had a significant impact on emotions, for women and for men. Women reported feeling frustrated, most commonly because the condition prevented them from having the life they wanted. They also spoke of feeling guilty about the impact on their partner and on their relationship. They felt guilty about anticipated or actual infertility, sexual relationships, their limited abilities to look after the house and the way in which endometriosis prevented them and their partner from living as a 'normal' couple. The majority of women also reported that living with constant or regular pain, fatigue and other physical symptoms significantly affected their psychological wellbeing, resulting in them feeling low, depressed, tearful and/or irritable and angry. Some spoke about how hormonal fluctuations related to the condition made them feel low. For some, hormonal medical treatments were also seen to negatively affect their mood. Several women spoke of feelings of depression and in four couples it was reported, by women and men, that the female partner had felt suicidal.

You can get really, really low, I am sure I have been clinically depressed with it ... when you get down in those dumps it can really feel like you are not worth anything, like why am I here, I can't work, I can't have sex, I can't even cook dinner. What is the point of me even existing? (Female participant)

However, there were also some positive ways in which endometriosis impacted on women's emotions: a small number of women spoke about feeling proud when looking back at how they had survived the most difficult times.

I really feel I can do anything ... I look back and I think god I have gone through that, I have done it, I am stronger than I think, I can deal with things. (Female participant)

Men also talked about a range of emotions. Most commonly, men reported worry about their partner's wellbeing. They appeared to feel helpless at not being able to alleviate their partner's symptoms. Many spoke of feeling frustrated: for some this was a result of their helplessness at not

being able to relieve their partner's pain and other symptoms; others reported frustration that endometriosis prevented them and their partner having the life and the relationship they wanted to have.

You just feel helpless, try to do as much as you can for them like but, and try to do the best you can, but there's not much that you can do. Nothing you do will relieve their pain. So I guess feeling just really helpless. (Male participant)

Men also spoke of feelings of disappointment, distress and upset in relation to the impact of endometriosis on fertility. For some men, their helplessness and frustration resulted in anger toward the perceived inadequacies of medical management and healthcare practitioners.

In many cases, the interview was the very first time that men had been asked about their own feelings and experiences. Men were acutely aware that their partners were the key concern. In reflecting on their own emotions, however, it was often evident that men felt somewhat marginalised.

People don't really think about the guys. But it is, it's an awful lot of emphasis is put on the lady, but the guy has to deal with an awful lot as well. And especially because it's not very well known, it's hard to find someone to talk to who understands. (Male participant)

The emotions women and men experienced impacted on couples' relationships in complex ways. Women's feelings of guilt caused a minority of women to suggest their partners should leave them, or to emotionally detach from their partner. Most men appeared to be aware of and have some understanding of their partner's feelings of guilt and lowness, as well as the anxiety and distress associated with actual or anticipated infertility. Men appeared to be less aware of their partner's frustration. Within the majority of relationships it was reported that the female partner's emotions were discussed more than the male partner's. However, in a minority of couples men were resistant or unreceptive to their partner talking about her emotions. Some women felt their partners did not truly understand what they were going through. Men also found women's irritability and anger difficult to cope with and participants reported that this resulted in tensions and arguments within relationships.

[You are] the verbal punch bag so to speak, just get it all because she's so down and depressed or wound up over it and in pain. (Male participant)

Whilst male partners felt 'snapped at', women felt their feelings of irritability and anger were outside of their control and that their partners did not always understand this.

Men's emotions appeared to be somewhat overlooked within relationships. Most men suggested that they had given their own emotions little consideration prior to interview. They appeared to identify their own emotions less readily than women, and were less likely than women to discuss their emotions within relationships. In some cases this appeared to be because they felt their own feelings were insignificant in comparison to their partner's, and so were dismissive of them. Other

men actively concealed their emotions so as not to worry their partners. Women appeared to be aware of the helplessness and frustration their partners felt, but less aware of their worry. Overall, women also discussed how they were aware that endometriosis must impact on their partner emotionally, but few could specify *how* men were affected. Being unaware of their partner's emotions caused some women to worry and to wish their partners would be more open about their emotions; for some couples, sharing distress in this way may help to reduce feelings of isolation, for both women and men.

Support within relationships

Participants talked in detail about the ways in which men support their female partners. Men supported female partners in three broad areas.

Firstly, men provided support in relation to healthcare and treatment. Participants described a range of things men did including attending consultations, discussing treatment options and helping to make decisions, helping women with self-management, and providing care after surgery.

Men also provided support in relation to managing everyday life. Men took on additional tasks in managing the home and looking after children, both on a day to day basis and/or while female partners recovered from surgery. Participants also described additional practical support such as driving their partner to and from work, and contributing more financially.

Thirdly, men provided emotional support to their female partners. Participants described men being caring, listening, understanding, 'being there', being available to talk things through and taking their partner's feelings and needs into consideration. Some men talked about how they conceal their own emotions and put on a brave face in order to protect or shield their partner, and try to 'stay strong' and demonstrate positivity. Some men described how they simply did not know how to provide support and felt they could not 'get it right'. Others discussed how learning from their partner's family, developing a better understanding, and being reflexive of what works helped them to better emotionally support their partner. A small number of men spoke about how supporting their partner had strengthened their character, making them more understanding and sympathetic. A small proportion of men were less supportive than the majority, describing how they were not receptive to their partner talking about or displaying her emotions.

Overall, most women were extremely grateful and appreciative of the range of ways in which their partner supported them. Some considered themselves extremely lucky to have this support. However, even the most appreciative of women did identify ways in which their partner could better support them. Most frequently women wanted their partners to be more understanding, sympathetic and perceptive about their feelings. Whilst men felt that their strategies of 'being positive' were effective, a small proportion of women wanted their partners to be less stoical and less positive, as this made them feel that they were not understood and actually increased their feelings of isolation. A small proportion of women also said that they wished their partners would be more honest and open about how they were feeling themselves. Almost a third of couples described tensions and arguments in relation to the support men did, or did not, provide to partners.

Participants spoke far less about the support women provide to male partners. Many male partners stated that they did not feel they needed support from their partners. Several felt that their role was to give support, rather than to receive support, and some felt it would be unfair to expect support given the impact of endometriosis on their partner.

It has been hard because, not that I would want it to be the other way, the focus clearly has to be on the woman for obvious reasons, she's the one in pain and discomfort ... but you do at times think 'what about me, no-one's asked me how I'm feeling'. There are times when you think the bloke doesn't get a look in. (Male participant)

I don't think I fully understand the impact that it's had on me because I've been so preoccupied with [partner]. (Male participant)

However, women and men did describe a range of ways in which women provided support to partners. In nearly half of all couples, women reported concealing or holding back on communicating their own feelings (including worry about infertility, their general distress, but also dyspareunia) so as to protect their partner from worrying too much. Women also described providing emotional and talking support; as with male partners, women described being caring, listening, understanding, 'being there', being available to talk things through and taking their partner's feelings and needs into consideration. Some women encouraged their partners to speak about their own feelings, needs and wellbeing – in relation to endometriosis and more generally. When they were well enough, women strived to have a 'normal' relationship, undertake household related tasks, and to talk to their partner about non-endometriosis related issues; they described how the fluctuating nature of endometriosis symptoms meant they could be a supportive partner and have a balanced relationship when they were having 'well' periods. Finally a small proportion of women worked to assure their partner that, 'in the grand scheme of things, they were, and were going to be, alright'.

Overall, although endometriosis does impact on men in various ways (see, for example, emotions and endometriosis) the impact of endometriosis on men, understandably, was not often discussed within relationships.

Communication

The communication patterns of couples were complex and there was considerable variation in how effectively partners appeared to communicate with each other. In some couples, partners appeared to communicate about their experiences of endometriosis frequently, clearly and effectively. Some had already been adept at communicating well before the onset of endometriosis. Others had proactively worked to improve their communication and understanding of one another, sometimes with the help of outsiders such as a counsellor, in order to reduce the strain of endometriosis on their relationship and better support one another. Conversely, in other couples, partners seemed to have much more difficulty knowing how to communicate effectively with one another and reported on-going patterns of non-communication resulting in tensions and misunderstandings. Overall

couples were more likely to discuss treatment and healthcare and less likely to discuss their feelings – particularly men’s feelings – about the experience of endometriosis.

The ways in which endometriosis strengthens and strains relationships

In interviews, women tended to reflect on whether endometriosis had strengthened or strained their relationship (or sometimes whether it had both strained *and* strengthened the relationship) more than men. Women were also more likely than men to report relationship strain.

Relationships were strained by a variety of factors, which have been discussed throughout this summary document. In particular participants described how not conceiving and/or using IVF had strained the relationship. In addition, the ways in which endometriosis symptoms and treatment side effects impacted on women’s emotions were said to have caused relationship strain.

In terms of relationship, you are more short with each other, you are stressed. It’s quite hard when you are having to deal with it [not conceiving] ... it has strained the relationship as each stage of the process has gone on. (Male participant)

It’s had an impact on our relationship from the word go and it’s hard, it’s hard. Along with everything else that a relationship throws at you, and life throws at you, that is an extra burden. And it is a burden and it has affected us both. (Female participant)

The strain it puts on your relationship - especially when you can see your partner’s in pain and you want to help and you’re trying to do things and know it’s not right. (Male participant)

However, whilst participants talked about how it had strained their relationship, either in the past or at the time of the interview, most did not feel their relationships were ever at risk of breaking down.

Whilst endometriosis clearly had a negative and often devastating impact on many areas of life, several participants also spoke about how the experience with endometriosis had made them closer as a couple and had strengthened their relationship. They described how dealing with the endometriosis together had cemented their relationship and brought them closer. Women described how it had made them appreciate their partner’s supportive qualities, and men described how seeing their partner in pain had amplified their love for them. Others described how it had helped them to get to know and understand one another better.

[The endometriosis has helped] me get closer to him. I think the fact that he seems to understand me so easily actually enhanced the relationship initially because I was so in awe with the fact that he was so accepting and supportive that it just made me sort of I suppose fall deep in love with him. (Female participant)

I think it’s had quite a positive impact as well because it’s kind of something we can share together. Because I know a lot about the disease, because she has the disease, we can talk about things about it and it’s something that you can both relate to and you can both get

involved with ... it can split you apart but it can again bring you together. I think the ball for that is very much in the partner's court because you can either decide to get involved with it or you can decide to segregate yourself from it. And you find that if you get involved with it it's far more beneficial for your relationship because it will bring you together, it will create this bond that ties you together and makes you stronger. (Male participant)

In some strange way sometimes it feels like it brings us ... the feeling that you don't want someone you love to be in pain, it amplifies your feelings for them and makes you realise how much they mean to you. Whereas if we were a normal couple who didn't have to deal with all that stuff and didn't talk and didn't have that closeness and didn't have that intimacy, I may never get to be that close to [partner]. (Male participant)

What partners identified as the 'single biggest issue'

During the interviews women and men were asked what they felt was the 'single biggest issue' for them in relation to endometriosis, and what they thought was the 'single biggest issue' for their partner. In the analysis phase these were grouped under thematic categories. Women and men identified the following single biggest issues²:

<i>Issue category</i>	<i>Number of women</i>
Living with the physical symptoms (excluding pain)	10
Planning for and having children	8
Pain	7
Sex and intimacy	2
Feeling 'different'	1
Low mood	1
Impact on relationship	1

<i>Issue category</i>	<i>Number of men</i>
Feeling helpless	5
Living with partner's physical symptoms (excluding pain)	4
Planning for and having children	4
Delayed diagnosis and problems with treatment	4
Sex and intimacy	2
The low profile of endometriosis	2
Partner's pain	1
Partner's mood swings	1
Feeling 'different'	1
Impact on relationship	1

² Numbers do not total 22 as some participants identified multiple significant issues.

These findings suggest that the physical experience of the condition, and its impact on planning for and having children, were the most prominent issues for women. Women spoke about the emotional impact of these issues (e.g. loss, guilt and worry relating to planning for and having children) and their social consequences (e.g. the ways in which the physical symptoms prevented them from doing what they wanted to and affected their quality of life). On the other hand, men's 'single biggest issues' were more diverse. Feeling helpless was common: men spoke of their helplessness and frustration at not being able to alleviate the symptoms, at the absence of a cure, and at not being in control. Some also spoke about the wider context of endometriosis: they spoke critically of delayed diagnosis and of limited and unsatisfactory healthcare and treatment, and highlighted the lack of awareness, support and funding relating to endometriosis. Again, data from men suggested they saw endometriosis as a problem to be 'sorted out' and suggested they were frustrated that this was not easily achievable.

The team examined the data from each couple unit, to compare what women thought were their male partners' single biggest issues with what the male partners said themselves, and vice versa. This was undertaken in order to identify the extent to which participants were aware of the most prominent and important aspects of living with endometriosis for their partners.

In answer to the question 'What do you think is the single biggest issue for your partner?' only seven out of 44 participants (five women, two men) identified their partner's 'single biggest issue' wholly accurately, and another four participants (two women, two men) identified this partially accurately (i.e. participants accurately identified one issue from a range of issues). This could suggest that there were some difficulties with understanding of partners' experiences and feelings.

Suggestions for improving support

Participants were asked whether they thought increased information or support for male partners and for couples would be valuable.

Whilst most men did talk about a range of impacts of endometriosis on them, when asked explicitly about their information and support needs, many suggested that they themselves did not need more information or support. Instead they felt that based on their experiences, other men might benefit from such an intervention. Some did however express the view that they themselves would benefit from more information or support. Women appeared to be less ambivalent about whether information and support for men would be welcomed: overall women were in favour of this. Overall participants were in favour of the development of resources and support aimed at couples.

It might be beneficial to have a resource that was aimed at the couple rather than the individual. Because then it would create that sort of bonding, this is something we can do together, so this is something we can look at together ... and it would hopefully bring them closer and make them more open to talking about it and discussing it. (Male participant)

Men felt there was a need for more and better information about the medical and biological aspects of the disease and about treatment options, and practical advice on how to better support their

partners and cope with living with endometriosis themselves. Women more than men felt there was a need for more and better information about the ways in which endometriosis impacted on women, and on relationships: information about the common symptoms and how these impacted on women's feelings and behaviours and on relationships, what to expect as a couple unit, stories about how other couples have coped, communicated and supported one another, and advice regarding how to cope with endometriosis as a couple. Women felt that this would enable male partners to better understand the condition and its social and psychological impacts, and would better help couples to cope with the impact of endometriosis.

Participants were asked about their preferred format for information and support. Men felt that support and information specifically aimed at male partners should be provided online. Some men welcomed the idea of talking support with someone with expertise in endometriosis, but there were mixed views amongst men about whether this was needed, and about whether men would feel comfortable accessing emotional support and sharing their feelings with others (see 'gender', below). There appeared to be some appetite for support groups for couples, particularly among women. Other suggestions included books, leaflets, forums, DVDs, email/call back support, couple counselling and online live chats.

Gender, ethnicity and life stage

The impact of endometriosis on individuals and on couples is extremely variable, and how each couple experiences living with endometriosis will depend on a range of factors. Within the study, gender, ethnicity and life stage appeared to impact on participants' experience of endometriosis.

Gender

'Femininity' and 'masculinity' refer to a range of qualities and roles stereotypically associated with being a woman and with being a man. These vary according to different cultures and different time periods. Within many societies, femininity can refer to the importance placed on being a wife, homemaker and mother, and to being sensitive and non-aggressive; masculinity tends to be associated with traits such as being strong, rational, unemotional and assertive. Although many people resist stereotypes associated with femininity and masculinity, nonetheless these concepts can have important implications for how individuals feel and behave.

For our participants, endometriosis often appeared to challenge women's femininity and to reinforce men's masculinity. Women reported feelings of guilt and loss relating to sex and intimacy, anticipated or actual infertility and/or inability to carry out household/domestic tasks. A few spoke of not feeling 'feminine' or being an 'adequate wife' and several had suggested that their partners should leave them in case they could not have children.

Conversely, men drew on traditionally masculine behaviours to cope, to support their partners and to advance treatment and care. Men described a 'stoic' approach to supporting their partner and in coping themselves: they tried to be calm and in control and tended to hide their own emotions as they tried to 'stay strong'. They reported feeling angry and frustrated about experiences with the

healthcare system and healthcare practitioners and, as discussed above, some took on assertive roles in consultations. These 'gender scripts' had implications for couples' relationships. The need to 'stay strong' prevented men from expressing their own emotions in relationships.

I don't really tend to show a lot of emotion ... if she breaks down and she sees me sort of faltering, it's not going to give her much support. So I guess the old male stereotype kicks in and you have to be seen to be the stronger one. (Male participant)

Ethnicity

The experiences of South Asian couples were similar to those of White couples in most respects, but it is possible to identify issues which had more emphasis for these couples. As discussed above, some women reported not feeling that they were an 'adequate wife'; this was especially pronounced amongst South Asian women who were more likely than the White women to describe experiencing strong cultural expectations around the role of a wife. Again, this had implications for couples as women suggested their partners should leave them in order to find a new partner. South Asian participants also spoke more about the importance of wider family members and the impact of endometriosis on these family members. Having supportive and understanding family members was reported to have a considerable positive impact on couples, whereas a lack of support compounded the strains of living with endometriosis. Whilst this was true for all couples in the study, it was particularly pronounced for South Asian couples. Social and cultural events which are often perceived as 'mandatory' such as weddings, also caused particular difficulties for some South Asian women, who had to navigate their attendance and duties around their endometriosis symptoms and surgery recovery. In addition, some South Asian couples experienced considerable family and community pressure to have children, which made it more difficult to cope with actual or anticipated infertility.

The Asian stereotype, as it is, is that if you haven't had a child within a certain amount of time, then the extra pressure comes from, not your parents, but your grandparents ... 'what's the problem, why have you not had kids, can't you have any kids?' etc. (Male participant)

Life stage

The difference endometriosis made to the lives of couples also related to what was important to them at their current stage of life. Anxiety about possible infertility was more common amongst couples in their 20s and early 30s. Couples in this life stage were more likely to be trying to conceive, or predicted that they would try to conceive in the future, and so the potential impact of endometriosis on planning for and having children was a key concern. Loss and distress associated with infertility was more common in older couples, including those who had unsuccessfully been through IVF and those who had not been through IVF. However, some older women also expressed relief and feelings of closure at having decided to stop pursuing IVF treatment or at having had a hysterectomy. The impact on sex and intimacy appeared to be more distressing for couples in their late 30s and older. As we have seen, endometriosis did prevent couples from being able to go out and about and socialise with others. However, whilst some participants felt disappointed, frustrated

and restricted, generally couples (including couples in their 20s) felt that as they got older a less active social life was a 'normal' part of settling down. Overall it was apparent that the impact of endometriosis is not static but changes over time and over the life course.

You don't realise it's going to have that much effect. It slowly, slowly takes away little things and you don't realise then when you look back and you think, how was I five years ago and how am I now? Then you think, how am I going to be in five years' time? (Female participant)

Conclusion

Most studies focus, understandably, on the impact of endometriosis on the lives of women, only occasionally reporting on women's interpretations of the impact of the condition on their partners and other close family members. This study has uniquely enabled us to more directly explore how endometriosis might be differently interpreted and experienced by male and female partners within a (heterosexual) couple relationship and it has generated information about how couples cope with living with endometriosis. As a consequence, the study has offered significant insights into the needs of women *and* men and demonstrated an important need for couple-centred interventions to improve wellbeing.

This study confirms the findings of others that endometriosis has a significant social and psychological impact on the lives of women across several domains. Endometriosis symptoms and especially pain have a detrimental impact on quality of life in complex and multidimensional ways. Endometriosis negatively impacts on daily life and physical functioning, affects household activities and impacts on social lives. For several women, despite being heavily motivated about their working lives, endometriosis symptoms impacted negatively on their paid work and on work productivity and satisfaction. Emotional distress is also a pervasive feature of life with endometriosis and many women reported experiencing feelings of frustration, inadequacy, loss, guilt and powerlessness. A substantial number of women also reported uncertainty and worry about their fertility, even where infertility had not been medically established. Our study also confirms common findings of delayed diagnosis, insufficient information from health professionals and variable quality of healthcare.

The study has also shown that men are marginalised in relation to endometriosis. Whilst this is understandable, it is clear that men's experiences and responses are different to those of women, and that men also have unmet needs. Despite the tasks men undertook, many still appeared to feel helpless and frustrated that they could not do more to alleviate their partner's symptoms. Addressing these issues could impact positively, not just on the wellbeing of men, but also on the women who are living with this debilitating condition.

The practical and emotional impact of endometriosis on couples is substantial. A negative impact on intimate relationships, especially sexual relations, is apparent, including but not limited to the impact of dyspareunia (painful intercourse). In many cases, the overall impact on relationships is profound. In some cases, living with endometriosis has strengthened bonds, and in others it has led to significant strain. It is important however, to resist broad generalisations. Responses to this condition in couples vary according to a range of factors including the stage of the life course, the presence of fertility problems, and the length and nature of the underlying relationship.

The evidence from this research project suggests that as with many chronic conditions, the management of endometriosis must address the emotional, sexual and relational impact of this disease. A more holistic, biopsychosocial and gender inclusive approach to endometriosis management and support is urgently needed.

Limitations and strengths of the study

Participants were recruited from a number of sources in an attempt to reduce bias, but it is acknowledged that the self-selected participants may represent those with more severe symptoms. The sample lacks diversity in terms of socio-economic status, though we purposively sampled a proportion of couples from South Asian backgrounds which allows us to explore the impact of ethnicity and we have a range of ages and length of relationships among the sample. We also purposively sampled couples where the endometriosis pre-dated the relationship and vice versa. It is also acknowledged that the couples interviewed are in effect 'survivors' in relationship terms and that this may underestimate the impact on relationship breakdown. Whilst couples were reflecting on their relationships, which in many cases were longstanding, a longitudinal approach would allow more insights into how endometriosis is accommodated by couples and its impact over the life course. The participants were purposively limited to heterosexual couples and though many similar issues may be faced by same-sex couples, this requires further exploration.

A major strength of the study is the inclusion of separate interviews with male partners. To the best of our knowledge this is the first European study of couples living with endometriosis, which has included interviews with men. Previous work on the impact on relationships has largely been derived from women's interviews and interpretations. Interviewing men and women separately, both simultaneously and with different interviewers, enabled each participant to tell their story from his or her own perspective without having to consider the reaction of their partner when voicing criticism or bringing up sensitive topics which increased the likelihood that each partner would disclose information that they would be unwilling to share in a joint interview. The interviews permitted men's accounts to be heard unmediated by their female partner's participation. By looking for contrasts and overlaps in the couple accounts of the same phenomena we were able to explore how men and women in the same couple described the impact of disruption at the couple level. The small scale qualitative nature of the study means that generalisation is not appropriate but in-depth interviews have given a voice to men and women affected by endometriosis and provided valuable data and insight into the relational aspects of living with and managing endometriosis that is often missing from large scale questionnaire studies. It provides reliable evidence for the development of relationally focused care.

Recommendations

The recommendations arising from this study are based on an analysis of the findings from interviews with couples living with endometriosis and from a participatory stakeholder workshop attended by healthcare practitioners, women with endometriosis and their male partners, academic researchers, and support group representatives. Recommendations have also been discussed with key support organisations and other experts in the field.

Recommendations for women living with endometriosis, their partners, and family and friends

- Experiences of living with and alongside endometriosis are highly variable. However, this qualitative research study has shown some of the ways in which women, men and couples can be affected by endometriosis, some of the difficulties couples may encounter, and some of the strategies they adopt to manage their lives. For women and men, being aware of the range of ways that endometriosis can affect a partner is likely to increase understanding, care and support within relationships. Family and friends are also urged to consider the complex and subtle ways in which endometriosis can impact on women and their partners.

Recommendations for policy, strategy and professional bodies

- It is recommended that NICE produce a guideline on the management of endometriosis and chronic pelvic pain. This should include guidance on diagnosis and referral procedures in order to address the longstanding and well described problems of delayed and mis-diagnosis of endometriosis. This should also include a consideration of the evidence on the psychosocial impact of endometriosis on women and those around them, especially their partners, and guidance on how assessment, intervention and management can encompass a focus on these psychosocial aspects of living with the condition.
- A newly developed NICE guideline could be used as a basis from which to commission services and pathways leading to quality improvement and service redesign. This will empower GPs/CCGs and patients and should reduce the time to diagnosis and ensure patients are seen by the right people in the right environment.
- Whilst there are separate guidelines on endometriosis and infertility there is no single combined guideline that addresses when these two problems co-exist. As such there is no clear guidance on how to treat infertile women or couples with endometriosis which can range from mild disease to severe and be associated with minimal symptoms or have a significant impact on everyday life. This is further complicated by the fact these extremes do not always correlate and women with severe endometriosis may have minimal symptoms but still be infertile. The approaches to the assessment and treatment of endometriosis are complex therefore and not necessarily consistent. Recent data regarding the response to ovarian stimulation and the outcome of IVF as well as the effect of endometriosis on

pregnancy outcome are timely and would support the development of a new guideline focusing specifically on this which would help patients and healthcare providers make informed decisions about their care. The British Fertility Society and Infertility Network UK would be well placed to develop and disseminate these guidelines for healthcare providers and patients respectively.

- When establishing and developing BSGE centres of expertise, it is recommended that care and management, particularly that which is delivered by endometriosis specialist nurses, should incorporate a more couple-focused approach. This research and other studies demonstrate the need for management to be informed by an understanding of the multidimensional impact of endometriosis and underpinned by a biopsychosocial approach that includes emotional support, stress reduction, adaptive coping strategies, psychosexual treatment, effective pain management, and a focus on quality of life issues, sex and intimacy, career counselling, and the potential impact on relationships – both relationships with partners and relationships with others such as family, friends and employers. The development of guidance on the principles of practice for endometriosis specialist nurses, who may be working within or outside a centre of expertise, encompassing a focus on the psychosocial impact of endometriosis on women and on couples, would be a welcome addition.
- It is recommended that the relevant professional bodies (e.g. RCN, RCOG, RCGP, NICE, BFS, BSGE) further incorporate information about endometriosis, the associated delays in diagnosis, the problematic approaches to treatment and management, and the psychosocial impact on couples into the training and development of healthcare practitioners. This should also extend to undergraduates who should develop a better understanding of endometriosis in medical school, which can be delivered throughout their training but particularly during their obstetrics and gynaecology attachment, which the RCOG and their representative in the various Deaneries could oversee. This will help to counter a lack of knowledge amongst healthcare practitioners which leads to unsupportive attitudes and practices that women and their partners frequently report. This is particularly recommended for the training and development of nurses, who are well placed to offer the psychosocial support required by couples. A factsheet for nurses not working in endometriosis specialist roles should be developed. The continued development and support of endometriosis specialist nurses will also help this.
- It is recommended that UK and European guidelines on the management of endometriosis, in particular the RCOG and ESHRE guidelines, adopt a more couple-focused approach throughout and advise healthcare practitioners to: recognise the potential impact of endometriosis not only on female patients but also on those around them especially their partners; recognise the support that partners may provide to patients; recognise the insights partners might be able to provide into patients' experiences of endometriosis (e.g. regarding symptoms, treatment efficacy, treatment side effects, etc.); and to therefore be more inclusive of partners. As the RCOG guideline has not been updated since 2006 (with minor

revisions in 2008), and in light of recent studies into the psychosocial impact of endometriosis on women, a revised guideline would be timely.

- The RCOG could approve and/or produce resources to support these recommendations. These can be informed by the RCOG's Menstrual Disorders Clinical Study Group, which includes gynecological endoscopy and endometriosis.

Recommendations for healthcare practitioners

- As with previous research, women in this study reported significant delays between presenting symptoms to healthcare practitioners and getting a diagnosis, and reported that this was a difficult and distressing process. A greater awareness of the symptoms of endometriosis, as well as improved practices and pathways for referring to secondary care, would help to address this. Similarly a greater awareness of the symptoms of endometriosis, effective referral processes and the use of accurate and reliable investigative practices in secondary care would improve women's experiences.
- The impact of endometriosis is not confined to women: it also affects partners and couple relationships. Consultations should be inclusive of the impact of endometriosis on quality of life, and on women, partners and the couple relationship. Healthcare practitioners should ask both women and partners (where relevant and if present) how endometriosis is affecting them and how it is affecting the couple relationship. In particular, whilst many couples experienced difficulties with sex and intimacy as a result of endometriosis, few had spoken to healthcare practitioners or sought advice. Therefore, healthcare practitioners are advised to include a focus on sex and intimacy during their consultations. Healthcare practitioners can also improve women's and couple's experiences by referring them to specialist services (e.g. pain clinics, psychosexual counselling, etc.), by signposting women and couples to support and information organisations, and by utilising existing resources produced for women, partners and couples.
- As endometriosis treatments often act as a contraceptive or create risks to fertility, some couples had to make a difficult choice to either accept treatment and reduce pain, or reject treatment to try to conceive. Healthcare practitioners need to be aware of these difficult dilemmas, and of the fact that partners may have differing priorities, and take account of women's and couple's wishes and difficulties in deciding courses of treatment.
- A small proportion of couples received contradictory advice from endometriosis consultants and fertility consultants, or reported that their fertility treatment was not considered in relation to their endometriosis. Joined up working and better communication between endometriosis consultants and fertility consultants is recommended to ensure that couples receive consistent messages and a collaborative approach to treatment. It is recommended that, upon diagnosis, healthcare practitioners raise the topic of planning for and having children, and open up a discussion that allows women and couples to explore this important issue and to receive evidence-based information, advice and support from appropriately

trained individuals. Couples who are trying to conceive should also be advised when and how they can be referred for fertility investigations and/or treatment should they require it. Couples should be signposted to fertility support groups such as Infertility Network UK.

- The above recommendations are aimed at healthcare practitioners generally. However, nurses, and where possible endometriosis specialist nurses, may be particularly well placed to deliver these recommendations. The potential role of nurses in improving the psychosocial and couple-focused support outlined above should be considered when planning services, especially outpatient clinics. For example, giving patients and partners an opportunity to speak to a nurse about the psychosocial impact of endometriosis after a consultant appointment would provide an ideal and timely opportunity for couples to ask questions, to talk about their concerns and experiences, and to access further support and information.

Recommendations for support, information and campaigning organisations

- As previous studies have also suggested, improved awareness and understanding of endometriosis amongst girls and women, and also amongst wider society in general, is likely to help address the problems in delayed diagnoses and the limited understanding and support of endometriosis, which contributes to impaired quality of life. This research reinforces the need for support, information and campaigning organisations to continue their efforts to raise the profile of endometriosis through schools and the media. It is also recommended that efforts need to be made to increase awareness of the effect of endometriosis on partners and on couple relationships, to counter the current marginalisation of men and the limited understanding of how endometriosis can affect relationships. Awareness raising activities should also highlight the ways in which endometriosis can affect people from different ethnic groups in similar and in different ways, and of the need for greater understanding amongst some minority ethnic communities such as South Asian communities. Continued efforts to work with the media to raise the profile of endometriosis, and to ensure the dissemination of accurate, up-to-date information, would be of benefit.
- It is recommended that organisations consider the development of a range of information and support resources aimed at improving understanding amongst partners and other family members of how endometriosis can affect women, partners and couple relationships. This should include information about the common symptoms of endometriosis and side effects of treatment and how these can impact on women's feelings and behaviours and on relationships. It should also cover what to expect as a couple unit, advice on how to support female partners, advice on how to minimise the impact on various aspects of life and advice on considering and addressing the impact on themselves. In addition, it may be beneficial to provide opportunities for partners to provide advice to other partners based on their own experiences. Organisations could also consider developing similar resources aimed at couples, including audio-visual recordings, and couple-focused support group sessions.

- In relation to the recommendations for healthcare practitioners above, support organisations might be well placed to produce guidance for healthcare practitioners on how to ensure a more couple- and relationship-focused approach in clinical encounters, and on how to adapt consultations and working practices to better address the impact of endometriosis on couples.
- Organisations working to improve the management of endometriosis and chronic pelvic pain, such as the RCN, RCOG, BSGE, Endometriosis UK and the Pelvic Pain Support Network, could usefully work together to influence developments in this area, such as the development of the NICE guideline outlined above and ultimately a care pathway.
- Bodies such as The James Lind Alliance, Endometriosis UK, the Pelvic Pain Support Network and Infertility Network UK should work to empower women to influence research objectives and help identify uncertainties and areas of importance.

Recommendations for future psychosocial research

- A large-scale, longitudinal, quantitative study with couples living with endometriosis would help to identify predictors of outcomes such as quality of life. Findings could then be used in the development of an evidence-based intervention for couples.
- There is a clear need for the development and feasibility testing of a psychosocial intervention aimed at couples. This might take the form of an expert patient and partner programme.
- A review of evidence on psychosocial interventions to improve quality of life would be a useful guide for service commissioners and providers.
- There has been little high quality, academic research into the impact of endometriosis on adolescents. However, this and other studies suggest that the symptoms of endometriosis may impact on adolescents in complex ways, such as in the development of friendships and relationships, in early experiences of sex and sexual identity, and on educational achievement. Adolescents may find pursuing diagnosis particularly difficult, and may live with undiagnosed endometriosis for many years. Qualitative research into the impact of endometriosis or chronic pelvic pain amongst adolescents would improve understanding of this important issue and aid the development of support, information and healthcare for adolescents. It would also help develop pathways for referral to ensure young women are referred to the appropriate services and not dismissed.
- There are various guidelines and similar documents regarding the management of endometriosis. A mapping of these guidelines would be a useful assessment of the current status of healthcare practitioner advice. Similarly, internationally there are various information and support resources aimed at partners, family and friends of women with

endometriosis. A mapping exercise of these would enable better sharing and utilisation of resources, as well as an identification of the gaps in resources.

- Further research is needed on the experiences of infertility investigations and treatment of women with endometriosis and on their experiences of pregnancy and maternity care.
- All endometriosis research with couples should consider including same sex couples.

Your feedback

We are keen to receive feedback on the Endopart study. We would very much welcome your comments on the content of this report, our recommendations or suggestions for how this research could be continued or built upon. We are also very keen to hear if this study has had an impact on individuals and organisations.

Please send any comments, feedback or suggestions to claw@dmu.ac.uk or write to Caroline Law, De Montfort University, Hawthorn Building, The Gateway, Leicester, LE1 9BH.

References

Bernuit D, Ebert AD, Halis G, Strothmann A, Gerlinger C, Geppert K, Faustmann T. Female perspectives on endometriosis: findings from the uterine bleeding and pain women's research study. *J Endometriosis* 2011;2:73–85.

Cox H, Henderson L, Wood R, Cagliarini G. Learning to take charge: women's experiences of living with endometriosis. *Complement Ther Nurs Midwifery* 2003;2:62–68.

Butt F, Chesla C. Relational patterns of couples living with chronic pelvic pain from endometriosis. *Qual Health Res* 2007;5:571–585.

Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, Raine-Fenning N. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013;doi:10.1093/humupd/dmt027.

Damewood M, Kresch AJ, Metzger D, Begany T. Current approaches to endometriosis. *Patient Care* 1997;31:34–43.

De Graaff AA, D'Hooghe TM, Dunselman GAJ, Dirksen CD, Hummelshoj L, WERF EndoCost Consortium, Simoens S. The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Hum Reprod* 2013;10:2677-2685.

Denny E. Women's experience of endometriosis. *J Adv Nurs* 2004;6:641–648.

Denny E, Culley L, Papadopoulos I, Apenteng P. From womanhood to endometriosis: findings from focus groups with women from different ethnic groups. *Diversity in Healthcare* 2011;3:167-180.

Eskenazi B, Warner ML. Epidemiology of endometriosis. *Obstet Gynecol Clin North Am* 1997;24:235–258.

Fagervold B, Jenssen M, Hummelshoj L, Moen M. Life after a diagnosis with endometriosis: a 15 years follow-up study. *Acta Obstet Gyn Scan* 2009;8:914–919.

Fernandez I, Reid C, Dziurawiec S. Living with endometriosis: the perspective of male partners. *J Psychosom Res* 2006;4:433–438.

Ferrero S, Esposito F, Abbamonte LH, Anserini P, Remorgida V, Ragni N. Quality of sex life in women with endometriosis and deep dyspareunia. *Fertil Steril* 2005;3:573–579.

Fourquet J, Gao X, Zavala D, Orengo JC, Abac S, Ruiz A, Laboy J, Flores I. Patients' report on how endometriosis affects health, work, and daily life. *Fertil Steril* 2010;7:2424–2428.

Fourquet J, Ba'ez L, Figueroa M, Iriarte RI, Flores I. Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril* 2011;1:107–112.

Huntington A, Gilmour J. A life shaped by pain: women and endometriosis. *J Clin Nurs* 2005;9:1124–1132.

Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obst Gyn* 2004;2:123–133.

Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. *Fertil Steril* 2009;1:68–74.

Nnoaham KE, Hummelshoj L, Webster P, d'Hooghe T, de Cicco Nardone F, de Cicco Nardone C, Jenkinson C, Kennedy S, Zondervan K. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011;2:366–373.

Simoens S, Dunselman G, Dirksen C, Hummelshoj L, Bokor A, Brandes I, Brodsky V, Canis M, Colombo G, DeLaire T *et al.* The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;5:1292–1299.

Tripoli TM, Sato H, Sartori MG, de Araujo FF, Giraõ M, Schor E. Evaluation of quality of life and sexual satisfaction in women suffering from chronic pelvic pain with or without endometriosis. *J Sex Med* 2011;2:497–503.

Appendix 1: study outputs

Journal articles:

Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, Raine-Fenning N. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013;doi:10.1093/humupd/dmt027.

<http://humupd.oxfordjournals.org/content/early/2013/07/23/humupd.dmt027.short?rss=1>

Conference presentations and posters:

Mitchell, H, Culley, L, Hudson, N, Law, C, Denny, E, Baumgarten, M Raine-Fenning, N. 'Pain management decisions amongst couples living with endometriosis', paper presented to the 2nd *European Congress on Endometriosis*, Berlin, Germany, 28-30 November 2013 (forthcoming).

Denny, E, Culley, L, Hudson, N, Mitchell, H, Law, C, Raine-Fenning, N, Baumgarten, M 'Gender differences in the emotional impact of living with endometriosis', paper presented to the 18th *World Congress on Controversies in Obstetrics, Gynecology & Infertility (COGI)*, Vienna, Austria, 24-27 October 2013 (forthcoming).

Culley, L, Hudson, N, Law, C, Denny, E, Mitchell, H, Raine-Fenning, N 'Disrupted reproduction: the impact of endometriosis on couples' plans for childbearing', poster presented to the *Conjoint Meeting of the International Federation of Fertility Societies and the American Society of Reproductive Medicine*, Boston, USA, 12-17 October 2013 (forthcoming).

Mitchell, H, Culley, L, Law, C, Hudson, N, Denny, E 'Coping with endometriosis: strategies employed by women with endometriosis and their male partners', poster presented to the *British Psychological Society Division of Health Psychology Annual Conference*, Brighton, 11-13 September 2013.

Hudson, N, Culley, L, Law, C, Mitchell, H, Denny, E 'Conducting dyadic research in chronic illness: men, women and endometriosis', paper presented to the *British Sociological Association's 2013 Medical Sociology Annual Conference*, University of York, UK, 11-13 September 2013.

Law, C, Culley, L, Hudson, N, Denny, E, Mitchell H 'Endometriosis, biographical appraisals and the couple unit', paper presented to the *British Sociological Association's 2013 Medical Sociology Annual Conference*, University of York, UK, 11-13 September 2013.

Hudson, N, Culley, C, Law, C, Denny, E, Mitchell, H, Baumgarten, M, Raine-Fenning, N 'Improving the wellbeing of couples living with endometriosis', poster presented to the *European Society of Human Reproduction and Embryology Annual Meeting*, London, UK, 7-10 July 2013.

Hudson, N, Culley, L, Law, C, Denny, E, Mitchell, H, Baumgarten, M, Raine-Fenning, N "'I've gone into a consultancy to really lay the law down, you know, get it sorted': men's perceptions of their role in

treatment-seeking for endometriosis', paper presented to the *17th International Congress of the International Society of Psychosomatic Obstetrics and Gynaecology (ISPOG)*, Berlin, Germany, 22-24 May 2013.

Culley, L, Hudson, N, Law, C, Denny, E, Mitchell, H, Baumgarten, M, Raine-Fenning, N 'Pain management, intimacy and parenthood amongst couples living with endometriosis', poster presented to the *British Pain Society Annual Scientific Meeting*, Bournemouth, UK, 16-19 April 2013.

Law, C, Culley, L, Hudson, N, Denny, E, Baumgarten, M, Raine-Fenning, N, Mitchell, H '*I don't know what sex is like without pain*': the impact of endometriosis on sexual relationships in couples', paper presented to the *Royal College of Nursing (RCN) International Nursing Research Conference 2013*, Belfast, UK, 20-22 March 2013.

Culley, L, Hudson, N, Law, C, Denny, E 'Technologies of Hope? Men's Perceptions of Endometriosis and Its Treatment', paper presented to the *Fourth International Conference on Science in Society*, University of California, Berkeley, USA, 15-17 November 2012.

Culley, L, Hudson, N, Denny, E, Law, C, Baumgarten, M, Raine-Fenning, N, Mitchell, H 'Men's perceptions of improving couple support in endometriosis: the role of qualitative research', paper presented to the *18th Qualitative Health Research Conference*, Montreal, Canada, 23-25 October 2012.

Hudson, N, Culley, L, Denny, E, Mitchell, H, Raine-Fenning, N, Law, C 'Men, gender and endometriosis: accounts of chronic illness from the 'well' partner', paper presented to the *British Sociological Association's 2012 Medical Sociology Annual Conference*, University of Leicester, UK, 5-7 September 2012.

Policy:

Findings from the study informed a response to the draft ESHRE Guideline on the Management of Women with Endometriosis and influenced the development of the finalised guideline. See further information, including reviewers' comments, at <http://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline.aspx>.

Impact:

Preliminary findings were distributed to attendees at the 1st World Congress on Abdominal and Pelvic Pain, May/June 2013.

Details of the study and preliminary findings were included in degree student Laura Adams' radio production 'Bloody Hell! Episodes by Shonotell Productions'. This was a third year project as part of drama degree at Kingston College.

A meeting was held with representatives from Endometriosis UK and the Royal College of Nursing in July 2013 to discuss study findings and recommendations and to plan further research and development activity.

For further information:

For further information and to find out details of study outputs that occurred after October 2013, visit our study website at www.dmu.ac.uk/endopart or the ESRC webpages at <http://www.esrc.ac.uk/my-esrc/grants/ES.J003662.1/read>.

