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BFS – British Fertility Society
BSGE – British Society for Gynaecological Endoscopy
CCG – Clinical Commissioning Group
ESHRE – Eurt

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.

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.

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

Endometriosis is a chronic gynaecological condition with an estimated prevalence among women of reproductive age of between 2 and 17% (Damewood , 1997; Eskenazi and Warner, 1997; Bernuit , 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 , 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 , 2013). Whilst

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

(Female participant)

Some men felt that being in a relationship with and living with their partner gave them a special 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.

(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 legitimation 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.

(Male participant)

(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.

(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.

(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'.

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.

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.

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.

(Male participant)

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

(Female participant)

(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 , 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 o3(ss)8(o)-5(f luvMCID)]TJasis

(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.

(Female participant)

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.

(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 importaT109ale parte d.024 10 1 31

(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 about their care. Their frustration with endometriosis was not usually directed at healthcare provision 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.

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.

(Female participant)

can M

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.

(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.

(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.

(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

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.

In interviews, women tended to reflect on whether endometriosis had strengthened or strained their relationship (or sometimes whether it had both strained 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.

(Male participant)

These findings suggest that the physical experience of the 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 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 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.

(Female participant)

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 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.

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.

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.

It is recommended that NICE produce a guideline on the management of endometriosis and 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.

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.

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.

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.

A largeendometriosis. 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.

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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.

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 inform