Disrupted reproduction: the impact of endometriosis on couples’ plans for childbearing

Lorraine Culley1, Nicky Hudson1, Caroline Law1, Elaine Denny1, Helene Mitchell1, Nick Raine-Fenning2

1 De Montfort University, Leicester, UK 2 Birmingham City University, Birmingham, UK 2 Nurture Fertility, University of Nottingham, Nottingham, UK

Introduction

Endometriosis is a chronic gynaecological condition affecting women of reproductive age with an estimated incidence of 2.1%-7 (Denny et al, 2009). Symptoms include severe dysmenorrhoea, chronic pelvic pain, fatigue, heavy menstrual bleeding and dyspareunia. It is estimated that 4% of women have endometriosis (Meuleman et al, 2009). There is evidence of a negative impact of endometriosis and fertility impacts on plans for parenthood. The UK

Methods

The Endnote study, funded by the UK Economic and Social Research Council (ref ES/S003682/1) was a UK-based cross-sectional qualitative study (2013-15). Individual interviews with key informants (n=11) were followed by in-depth, face-to-face, audio-recorded interviews with 22 heterosexual couples living with endometriosis. Women and their male partners were interviewed separately (n=44).

Results

Eighteen of 22 couples described endometriosis as affecting their plans of having a child. Half (n=11) had sought and received medical investigations or treatment for infertility. The remaining nine couples, though not considered infertile, also described a range of impacts on planning for and having children.

Biographical disruptions

Individually and couples have expectations about their life course and commitment to normative biographical expectations, including having children (Becker 1997; Becker 2000). Endometriosis disrupted couples’ plans to have children, challenged their notions of choice and control associated with planning for and having children, and caused them to appraise and revise their initial plans. Couples reported that endometriosis disrupted their decision making processes concerning having children. For example, some couples tried to conceive earlier than they would otherwise have planned, due to concerns that endometriosis may affect the female partner’s fertility. Others decided to stop trying for a first child before a second child due to the female partner’s infertility. Others pursued routes they would not have considered, had the female partner not had endometriosis such as IVF and adoption. Importantly, these impacts were experienced both by couples who were considered medically infertile and by those who were not, and uncertainty and anxiety about ‘anticipated’ infertility was common.

‘She'd only go the pill which was obviously going to make it worse... And we just sort of stopped, you know, what we are doing, you know, you’re getting it. Apparently we’re trying for kids but you’re too ill to actually do anything, you know. It was just we need to change the sort of mission statement of the marriage. It’s not about ‘let’s have kids’, it’s about ‘let’s get you better’.’ (David)

Emotions and gender relations

Women spoke of their feelings of guilt and several had suggested their partner should leave them because of possible infertility. Women also reported feelings of anxiety, panic, worry and fear relating to anticipated infertility and feelings of loss, grief, distress and anger. Men also spoke of their feelings of helplessness and their fear of not being able to help.

‘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.’ (Edward)

‘The fertility has kind of hit me quite hard and I’m kind of trying to come to terms with it... it’s quite difficult when you see other people and your friends and other men. Children. You try to show your happiness for them but at the same time it's always in the back of my head, ‘oh I wish I could have that as well’.” (Rashid)

Balancing desires for pain management and for parenthood

Many participants spoke of the chronic pain women experienced and the significant impact this had on their lives.

‘I’ve been in and out of the hospital for the pain. And it isn’t around the time of the period, it’s about 3 of the weeks that I was really suffering, even to the extent that the vibration of somebody walking by me would feel as if my uterus was being ripped out of my body.” (Jessa)

However, treatments that alleviate pain often prohibit conception: hormonal treatments for endometriosis include contraceptive medication (e.g. oral contraceptive pill, mino and progesterone) and GnRH analogues. Surgical treatments can also pose risks to fertility. Couples have to make difficult decisions about hormonal treatments or undergoing surgery in order to reduce pain symptoms, and rejecting treatment in order to pursue parenthood. The decision making process is complicated by several factors. For example, if couples opt for treatments that may reduce pain but may also prevent conception, they have to consider the potential impact of the treatment in the short term as well as their long-term options for a child. Couples also report uncertainty about the effectiveness of treatment in managing pain and in allowing them to conceive. In addition, partners may have different priorities: one partner may prioritise parenthood over pain reduction, while the other may not.

‘I’m so scared because I’ve actually now stopped the pill... to a view to start a family. But I’m also so petrified that the pain, at all kicking back in, because I haven’t got the hormones in me to control the bleeding... I haven’t got a choice because there isn’t anything else.’ (Sharan)

Conclusion

Disruption to planning for and having children caused by endometriosis impacts on couples’ relationships in complex ways, not simply what Becker et al, 1997; Eskenazi et al, 2009 defined as ‘choosing’ or ‘controlling’ associated with planning for and having children. Relationships are not only about ‘let’s have kids’ but also ‘let’s get you better’. Although healthcare practitioners may be aware of the range of emotions, difficulties and dilemmas facing women and their partners, and of the uncertainties and experiences experienced particularly by those not medically defined as infertile. Better communication between endometriosis consultants and fertility consultants is recommended to ensure that couples receive consistent messages and a joint approach to care. Healthcare practitioners need to be aware that healthcare practitioners can also pose risks to fertility. Couples have to make difficult decisions about hormonal treatments or undergoing surgery in order to reduce pain symptoms, and rejecting treatment in order to pursue parenthood. The decision making process is complicated by several factors. For example, if couples opt for treatments that may reduce pain but may also prevent conception, they have to consider the potential impact of the treatment in the short term as well as their long-term options for a child. Couples also report uncertainty about the effectiveness of treatment in managing pain and in allowing them to conceive. In addition, partners may have different priorities: one partner may prioritise parenthood over pain reduction, while the other may not.

References


Denny, E, ‘I never know from one day to another how I feel’ pain and uncertainty in women with endometriosis. J Obgyn Res 2009:35:295-305
