Coping with endometriosis: Strategies employed by women with endometriosis and their male partners.

Helene Mitchell, Lorraine Culley, Caroline Law, Nicky Hudson, Elaine Denny
1 De Montfort University, Leicester, UK; 2 Birmingham City University, UK

Introduction
Endometriosis is an enigmatic, chronic gynaecological condition of unknown aetiology affecting women of reproductive age. Common symptoms are severe dysmenorrhoea (pain during menstruation), chronic pelvic pain, fatigue, heavy menstrual bleeding, and dyspareunia (pain during sex). It is also associated with 60% of attendance at infertility clinics. As there is no cure for endometriosis the management focuses on removal of ectopic endometrial tissue and symptom relief which can involve a range of interventions including analgesic, hormonal therapy, surgical interventions and, where relevant, fertility treatment, with varying and unpredictable rates of success. Previous work on the experience of living with endometriosis has highlighted the impact of the condition across several life domains, including upon intimate relationships (Culley et al., 2013). However, there has been little previous research into how experiences of endometriosis and coping with pain are shared. The most commonly used definitions of coping can be summarised as the efforts an individual makes in trying to deal with a problem. These efforts may include cognitive and behavioral strategies (e.g. Lazarus & Folkman, 1984) and reflect the need to reduce the psychological, physical and emotional burden of an issue (Snyder & O'Grady, 1999). The aims of this UK based endpoint study was to explore the impact of endometriosis on couples; this work in progress poster describes participants’ accounts of coping with the condition.

Methods
- Qualitative, in-depth, face-to-face interviews with 22 heterosexual couples were conducted. Women with endometriosis and their male partners were interviewed separately (n=44). Pseudonyms were used to protect participants’ identities.
- Inclusion criteria were a hypercopic diagnosis of endometriosis and that couples were living together at some time in their relationship.
- Principles of systematic sampling were employed to ensure diversity regarding age, ethnicity, illness trajectory, and recruitment route. Data were analysed thematically, informed by an interpretivist approach.
- Extracts relating to coping were coded for each participant in NVivo. Women’s and men’s accounts of coping with endometriosis were analysed separately.

Findings
The women’s accounts of coping with endometriosis focused mainly on day-to-day disruption and symptoms, the more general, overarching impact of the condition, and its effect on relationships. Day-to-day disruption centred around symptoms, and coping with work. Strategies for dealing with pain and fatigue included not, past, present activities, taking positives, using medication and prayer. For those still able to work, their job was viewed as important as it provided a distraction, and every effort was made to remain productive. Having understanding colleagues and flexible working arrangements were key, and women who were still working had made changes that enabled them to cope more effectively, including altering their role (e.g. from a clinical to academic post), moving from employed to freelance, 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).

One participant described the couples’ day-to-day life and the amount of impact endometriosis had on their relationship.

Interviewer: It’s something that you always have once a week, isn’t it?

Amy: Yes, yes, try and get out of the house.

Interviewer: And time together.

Amy: Yes, yes, at the end of the week. Talk over the week, look through our phone, our 2 year plan, our 5 year plan and our 10 year plan and it’s really good.

Interviewer: So you are able to do that.

Amy: Yes, that sounds really important.

Interviewer: And so you are able to do that.

Amy: Yes, as a normal couple, you know, and it’s really good, I really enjoy that. (Jasmin)

Other participants talked about how they tried to lean on each other, and how they were able to share their experiences. For example, one participant described how they would always have special days to focus on their relationship.

Interviewer: It’s something that you always have once a week, isn’t it?

Amy: Yes, yes, try and get out of the house.

Interviewer: And time together.

Amy: Yes, yes, at the end of the week. Talk over the week, look through the property section of the paper and, yes, talk about our 2 year plan, our 5 year plan and our 10 year plan and it’s really good.

Interviewer: And so you are able to do that.

Amy: Yes, that sounds really important.

Interviewer: And so you are able to do that.

Amy: Yes, as a normal couple, you know, and it’s really good, I really enjoy that. (Jasmin)

Other cognitive strategies included acceptance of the condition and infertility, denial and just getting on with it (although this was not as prominent as in the women’s interviews).

Discussion and Conclusion
To enable them to cope with endometriosis, women and their partners used a range of coping strategies that were both problem- and emotion-focused, depending on the particular situation they were faced with, and often a combination of the two approaches were used (e.g. for some women, analysis and a ‘just get on with it’ attitude got them through their working day). This flexibility reflects the fluid nature of situational coping and highlights the wide-ranging impact that a chronic condition such as endometriosis can have on a woman and her partner. Whilst emotion-focused coping has traditionally been viewed as dysfunctional, there has been a move towards acknowledging the positive role that emotional approach coping can play in living with a chronic illness (Austenfeld & Stanton, 2004). The cognitive and behaviourally focused coping skills proposed by Moos & Stanton (2004) were evident in both the women’s and men’s accounts, including positive appraisal, acceptance and resignation, and taking things ‘one day at a time’.

The women also talked about the impact endometriosis had on their relationship and how they coped with it. This primarily involved managing their partner’s low mood or anger, which occurred as a result of living with endometriosis symptoms and/or treatment side effects, and arguments that arose between them. Several of the men talked of learning to read the cues and generally chose to leave their partner alone and wait for her to calm down, whilst recognising that the endometriosis was responsible for the conflict rather than the partner.

The data presented here form part of the accounts of coping from the interviews: data on self-management and support relating to coping still have to be analysed and these data will provide a full account of how couples cope with living with endometriosis. It is important to acknowledge that there is no means of evaluating how successful the coping strategies employed by our participants were, or whether specific coping strategies are more appropriate for particular issues in endometriosis than others. In addition, the length of time couples have been together is an important factor as it may influence the choice of coping strategies used. However, gathering detailed information on how women and their male partners report coping with endometriosis will aid in the development of an evidence-based intervention to support couples living with this gendered chronic condition.

References

Acknowledgements
The EndPoint study was funded by the UK Economic and Social Research Council: ES/E000354/1. Ethical approval was received from De Montfort University and from East Midlands Leicester NHS Local Research Ethics Committees.

We wish to thank the couples who participated in this study.

For more information visit our website: www.endopart.co.uk