



Endopart

Endometriosis: Improving the well-being of couples

Study update

Issue 3

March 2013

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Welcome to the third Endopart newsletter. Endopart is a study funded by the ESRC to explore the impact of endometriosis (a common, disabling gynecological condition) on couples. More details on the aims and objectives of the study can be found at www.endopart.co.uk.

Data collection and analysis

Since our last newsletter we have completed in-depth interviews with 22 women with endometriosis and their male partners, comprising 44 interviews in total. Interviews allowed participants to tell the research team about the journey from symptom onset to diagnosis, their understanding of what endometriosis is, their experiences of healthcare and treatment, the impact of endometriosis on various life domains, and the impact on relationships. Following

interview, participants were invited to self-record additional data whenever endometriosis had a particular impact on their lives. The team would like to thank all the individuals who took part in interviews, and generously shared their experiences. Analysis of the data is well underway, and information about some of the early findings can be found overleaf.

Stakeholder Workshop

In January 2013 the team hosted a Stakeholder Workshop at De Montfort University, to present early findings and to collaboratively discuss recommendations that might arise from the study. Twenty-two participants attended, along with the Endopart study team. Participants included healthcare practitioners, women with endometriosis and their male partners, academic researchers, and endometriosis support group representatives.

Participants worked as small groups to propose recommendations to improve couple support and these will be incorporated into the recommendations in the final report.

Get in touch

We are keen to publicise the findings and raise awareness of the experiences of couples to patient support groups, healthcare practitioners, researchers, and other individuals and groups working in or concerned with the field of endometriosis. If you have any suggestions of conferences, events, groups or networks through which we might disseminate findings or raise awareness, please contact Caroline Law on 0116 2506124 or at claw@dmu.ac.uk or Lorraine Culley who is leading the project on 0116 257 7753 or at lac@dmu.ac.uk.



Early findings

Analysis of the data is well underway and the following early findings have been identified:

- Endometriosis had significant impacts on everyday life (including managing the home, paid work and social lives) for both women and men.
- Planning for and having children was a significant issue for many couples, not only those defined as having fertility problems.
- For all couples endometriosis impacted on sex and intimacy in a number of ways, although the extent of this impact varied.
- Both men and women engaged in strategies to support their partners and to minimise the impact of endometriosis, with varying levels of success. Many men reported taking on additional roles; some provided considerable emotional support, whereas others were unsure how to do this.
- Couples appeared to communicate more about issues such as healthcare and treatment, and less about how each of them felt about the experience of endometriosis.
- Experiences with healthcare practitioners varied considerably. Many men took on assertive roles in their pursuit of a cure.
- The impact of endometriosis on women, on men and on relationships varied but in some cases was profound. Participants suggested that more support aimed at helping couples would be valuable.

The team is continuing to analyse the data and will produce a report providing detailed findings later in 2013.

Dissemination and publications

In addition to presenting findings at three conferences in 2012 (see newsletter 2), the team is due to present findings at the following conferences in 2013:

- Royal College of Nursing (RCN) International Nursing Research Conference, March 2013.
- British Pain Society Annual Scientific Meeting, April 2013.
- 17th International Congress of the International Society of Psychosomatic Obstetrics and Gynaecology (ISPOG), May 2013.



The team has produced a review of the academic literature on the social and psychological impact of endometriosis on women's lives. Forty-two papers were included, and the review indicates a very significant impact on all areas of women's lives, including diagnostic delay and uncertainty; 'quality of life' and everyday activities; intimate relationships; planning for and having children; education and work; mental health and wellbeing; and medical and self-management. The review has now been submitted for publication.