Endopart

Endometriosis: Improving the well-being of couples

Issue 2

Sept 2012

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Study update

Welcome to the second 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.

We have had a busy few months and are pleased to report that the study is progressing well.

In the first phase of the study we carried out 'key informant' interviews with 11 individuals including clinicians, nurses, GPs, support group representatives, women with endometriosis and their male partners. These interviews were invaluable in enabling the team to better understand the complexities of living with endometriosis, and they have informed the rest of the study. Thank you to all who took part.

The second phase of the study consists of interviews with women living with endometriosis and their male partners. We have received a lot of interest from couples volunteering to take part in the study, and would like to extend a big thank you to all those couples who have volunteered, as well as those who have taken part in interviews. More information on our publicity and recruitment can be found overleaf.

We have now completed 28 interviews which have yielded important data regarding: the impact of endometriosis on various aspects of life including paid and unpaid work, social lives, sex lives and having children; the communication and support activities couples engage in; the tensions and challenges that arise from living with endometriosis and the type of support and information that couples require.

> *'The biggest thing it affects is sometimes you are not able to live a normal life, that's hard.'*
> (Male interviewee, Endopart study)

> *'The toll on relationships is enormous.'*
> (Female interviewee, Endopart study)

We discussed progress and next steps at an Advisory Group meeting on 20 September 2012.

We are currently in the process of completing the interviews and will provide an update in the next newsletter.

DE MONTFORT UNIVERSITY LEICESTER

The University of Nottingham

BIRMINGHAM CITY University

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

Recruitment of couples

The study has been publicised to potential participants in a variety of ways including:

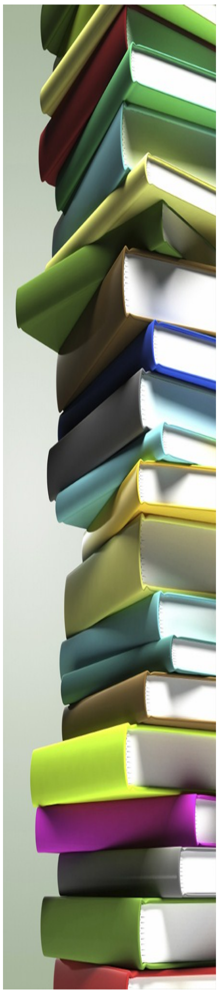
- several support and information organisations have publicised the study via their websites, newsletters, Facebook pages, etc.;
- NHS staff and private healthcare providers have disseminated information about the study to patients;
- the team has passed information on to various networks and contacts, and to South Asian cultural and religious organisations.

General recruitment is now closed. However, we are still interested in speaking to couples of South Asian origin (Indian, Pakistani and Bangladeshi) who may be willing to talk to us about their experiences. We are interested in talking to heterosexual, South Asian couples:

- who have been living together for at least one year;
- where the woman has experienced endometriosis-related symptoms for at least one year; and
- where the woman has a diagnosis of endometriosis following laparoscopy.

If you are of South Asian origin and would like to find out more, or you are able to help the team in recruiting South Asian couples, please visit www.endopart.co.uk or contact Caroline Law on 0116 2506124 or at claw@dmu.ac.uk.

Literature review



We are making good progress with our literature review on the socio-psychological impact of endometriosis.
Approximately 46 papers will be included in the review, which will report on what past research into endometriosis has told us about:

- understanding endometriosis and diagnostic uncertainty;
- self-management and therapeutic strategies;
- pain and its impact;
- the impact of endometriosis on daily life; and
- mental health and emotional wellbeing.

Dissemination

Analysis of the data from the study will continue into 2013, but we have been accepted to present the early findings at the following conferences:

- British Sociological Association’s Medical Sociology Annual Conference, September 2012;
- International Institute for Qualitative Methodology’s Qualitative Health Research Conference, October 2012;
- Common Ground International Conference on Science in Society, November 2012.

We are keen to publicise the findings and raise awareness of the experiences of couples to patients 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.