



FOCUS ON RESEARCH

Longitudinal History Patterns for Earlier Diagnosis of Endometriosis

Researchers

Dr Christopher Burton, Dr Lucky Saraswat, Dr Lisa Iversen, Dr Sohinee Bhattacharya, Dr Dolapo Ayansina, Prof Derek Sleeman. The research team included a GP, gynaecologist, epidemiologists, statistician and computer scientist.

Aim

Early diagnosis is a priority for patients and health services. Endometriosis is a distressing condition affecting women of reproductive age which is commonly diagnosed only after repeated consultation for symptoms.

We wanted to know if existing information in GP computer records might be used to lead to earlier diagnosis of endometriosis.

Project Outline/Methodology

We carried out the study using a database of fully anonymised medical records collected from GPs in Scotland between 1998 and 2010 and held by the University of Aberdeen.

Before we examined the database we carried out interviews with ten experts in endometriosis. They included gynaecologists, sexual health doctors / GPs, and women from endometriosis peer support organisations). We used the interviews to add expert's experience to standard medical knowledge to ensure we looked for a wide range of features which might suggest endometriosis.

In the database we grouped similar symptoms and prescriptions together. Next, we created new features as combinations of simpler ones e.g. period pain occurring close in time to abdominal symptoms (e.g. bloating or irritable bowel syndrome). These combinations came from our expert interviews.

We analysed data from 376 women with a diagnosis of endometriosis in the database. We compared these "cases" of endometriosis with data from two different "control" groups of women. Controls comprised 1489 women who did not have endometriosis and 1240 women who had consulted their doctor with gynaecological symptoms but did not have endometriosis. Each case with endometriosis was matched with up to 4 controls, who were the same

age and came from the same GP practice. We examined data up to the date of diagnosis (or the matched case's date of diagnosis for controls).

Key Results.

The two main features of endometriosis (pain and infertility) were recorded before diagnosis in only 49% of the women with endometriosis, although they were both much more common in these women than in either control group. Non-specific symptoms such as abdominal symptoms and fatigue were also more common in women before a diagnosis of endometriosis.

The new combined features were more common in women before a diagnosis of endometriosis than controls. They occurred more often even when we compared women diagnosed with endometriosis who had symptoms with controls who also had symptoms.

We found that some features such as infertility only appeared close to diagnosis, but others such as pain were more common in women diagnosed with endometriosis for several years before the diagnosis.

Conclusions

We were able to extract and structure useful information, from GP computer records, before women's diagnosis of endometriosis. Our method of collecting expert opinion, and processing the data can be used with other databases and for other conditions

What does this study add to the field?

This is a new way of processing data from GP records which has potential value in shortening the time to diagnosis for some women with endometriosis.

Implications for Practice or Policy

While further development is needed, we envisage that this approach could be run "in the background" of clinical IT systems to prompt earlier testing in women with several features of endometriosis.

Where to next?

We aim to conduct further studies of this method in a different database and with different conditions.

Further details from:

Dr Burton, c.burton@abdn.ac.uk