A Study to Explore the Impact of Endometriosis in the United Kingdom: A Qualitative Content Analysis

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ABSTRACT

Objective
To gain insight into the areas that impact women with endometriosis.

Design
A qualitative content analysis of an online survey.

Setting
Online questionnaire via Endometriosis UK.

Population
Women diagnosed with endometriosis of any age range.

Methods
Free-text online questionnaire through Endometriosis UK completed by women. Results were analysed using NVivo version 9, qualitative analysis software. The software creates links between common words (codes), and these links allow data to be placed in nodes (called themes) which are then developed into categories. Content analysis was used to understand this data.

Main outcome measures
Impact of endometriosis on women's lives.

Results
In total, 1872 questionnaires were returned but not everyone was able to identify ten separate features that affected them. As such, 1872 women provided at least one area that affected them, 1800 provided two areas, 1770 provided three areas and 1600 provided four areas. The results show that the main areas of concern for these women were pain (53%), heavy menstrual bleeding (11%), low mood (8%) and the perceived lack of understanding displayed by other people (7%). Other important factors were fertility concerns, impact on employment, problems with the medical team and uncertainty. These then impacted on their daily life whereby some women felt “guilty” for not ‘being a normal mother’. A key term that resonated was that endometriosis is an “invisible disease”.

Conclusion
This analysis provides us with insight into the complex psycho-social factors that interact with bio-physical symptoms. Further research is required in sub-population groups such as teenagers and ethnic minority women to explore any differences in impact and how care can be guided accordingly.

Keywords
Endometriosis; Impact; Qualitative methods; Quantitative methods; Online survey.
BACKGROUND

Endometriosis is a disease in which endometrial glands and/or stroma are found in areas outside of the endometrium including the ovaries, bowel and pelvis. As a result, women experience a myriad of symptoms including pelvic pain, menorrhagia and dyspareunia. Endometriosis is also associated with infertility. Endometriosis affects 1.5 million women in the United Kingdom and can have a host of physical, psychological and social sequelae. The average time to diagnose endometriosis is approximately 7.5-years in the United Kingdom.

A mixed-methods approach to research is quite commonly used. Qualitative research is a term used to cover a wide range of approaches and methods. A pragmatic definition is that “qualitative research is a naturalistic, interpretative approach concerned with understanding the meanings that people attach to actions, decisions, beliefs, values and the like within their social world.”. Qualitative research is based on personal experience and has a role in obtaining detailed information on why people behave the way they do and the impact of various life experiences. Data are generally obtained through structured or semi-structured interviews, focus groups or observations. Approaches taken to qualitatively analyse data include grounded theory (to generate a theory), phenomenology (to understand lived experience and how individuals make sense of this experience) and content analysis.

The different types of content analysis include conventional, directed and summative approaches. With conventional content analysis, categories are created from the text, summative content analysis involves counting key words and then analysing it and directed content analysis involves using a theory to guide which codes will be created. The ultimate aim of qualitative research is to obtain meaning from how people view the world and why people behave in the manner they do as well as how people feel within certain contexts. As the data was collected through an online questionnaire, content analysis was deemed to be the most appropriate method of analysing the data.

Using the Cochrane database, we found that there are a limited number of studies exploring the impact of endometriosis on women in the United Kingdom. The objective of this study was to gain insight into the main factors that impact the lives of women with endometriosis using mixed methods in order to further improve their clinical care. This mixed methods approach involved the administration of an online questionnaire and subsequent analysis via qualitative content analysis.

METHODS

Endometriosis UK charity collects information via a periodic online questionnaire to assess the experiences of their members with diagnosis and management of their condition. The final question in their questionnaire was, “Which aspects of endometriosis have the greatest impact on your life?” with up to ten unprompted free text responses allowed. The webpage also reiterated that all responses from the questionnaire will be kept confidential.

These results were collated onto a Microsoft Excel file and the data was analysed qualitatively using the software NVivo version 9 (Figure 1). Through this software, the data was uploaded and manually formatted according to text size, font and layout in order for NVivo to auto-analyse the data.

NVivo is a software that allows unstructured data, usually in the form of free text (for instance, patient interview scripts), to be qualitatively coded to generate meaningful conclusions. The software creates links between common words (codes), and these links allow data to be placed in categories (also known as themes). The researcher is then able to interpret the themes according to their area of research interest. Importantly, the results from NVivo can be stored in various formats including audio, text memos and other graphical displays. This method of analysis allows subtle detail to be generated. Content analysis was used to analyse the data for common codes and themes, whilst the quantitative aspect involved gaining insight into the frequency of code and theme occurrence.

RESULTS

In total 1872 participants responded to the questionnaire. Participant demographics are described in Table 1.

| Table 1. The Participant Demographics |
|--------------------------------------|
| Ethnicity | Caucasian 72% | Asian 5% | Other 23% |
| Age range | 16-20 22% | 21-30 31% | 31-40 24% | 41-50 20% | 51-60 3% |
| Location | England 71% | Wales 8% | Scotland 20% | Northern Ireland 1% |

One thousand, eight hundred and seventy-two women
responded to the questionnaire, but not all provided ten features that affected them. One thousand, eight hundred and seventy-two women provided at least one area that affected them, 1800 provided two areas, 1770 provided three areas and 1600 provided four areas (Figure 2). After the fourth set of impact, no new information was gathered from the software analysis of the data and therefore this was not included in this analysis. Based on 1872 replies, the top four concerns that women described were pain, heavy menstrual bleeding, fatigue and “other people not understanding” (Figure 3).

Other areas that concerned women included impact on employment, future fertility concerns, fatigue, and apparent lack of support (from clinical teams and personal support). The main areas described in depth by women will be explained below in further detail. Although the findings from this analysis are portrayed as various sub-headings, the reality is that all these factors are a representation of the complex interaction between them. Extracts from the questionnaire are included in quotation marks within this study.

The findings from the study are represented as quotes taken directly from the questionnaire responses and discussed
within in this study.

**Pain**

The analysis found that 995/1872 women (53%) stated that pain was the single most important issue that affected them. The impact of pain was described as “severe” “crippling” or “unpredictable”. Women felt that “other people” – partner’s, family members, friends and employers, were not able to always “appreciate the intensity of pain”. Women then went on to describe the intensity of the pain and how this impacted their day-to-day activities. Some respondents became “house bound” and “isolated”, which impacted on their social functioning. Approximately twenty percent of the women, who described pain as their main concern, went on to state that “depression” was the second greatest effect on their life. The majority of women said that pain management alone was inadequate treatment, mainly due to the side effects from the analgesia itself. A number of women went in to describe their illness as “invisible” because “other people” were not able to appreciate the intensity of the pain they experienced.

"Pain during menstruation stopped me doing normal things, at school, work and at home”.

"Severe Pain. Because it's taken 24-years for a surgeon to finally operate on me, I've been in horrendous pain on a daily basis. I'm currently taking 180mg of morphine per day. I hope my open surgery later this year will hugely improve my health”.

"Crippling pain meant I could not look after my son without help from my parents”.

**Heavy Menstrual Bleeding**

Eleven percent (201/1800) of the women stated that heavy menstrual bleeding was the second most important issue that concerned them. Menstruation was described as “flooding” and “unpredictable”. A number of women, who described heavy menstrual bleeding as affecting them the most, also explained that “other people” are not able to visualise the disease process and they felt the need to constantly justify their symptoms to other people. Some women found that if they described their symptom of heavy menstruation to women who do not suffer from endometriosis, then the extent of the understanding and empathy offered from them was limited.

Those women, who were unfortunate to experience heavy menstruation as well as irregular menstrual cycles, explained that this had a significant and “catastrophic” effect on their social lives; for instance women were not able to make concrete plans with friends, felt scared in case of “leaking” and were constantly cancelling pre-arranged plans.

"Constant flooding means I have to get to the toilet quickly and so this restricts my employment choices”.

**Low Mood**

Eight percent (142/1770) of the women stated that low mood was the third most important area that affected them. They explained that low mood also made them feel more fatigued, which had a significant impact on day to day activities such as shopping, maintaining family demands and socialising with friends and family. A number of the women explained that their fatigue caused performance issues at work and sadly, a few women even stopped working as a result. The extent of the fatigue was described as “unpredictable”.

- Due to fatigue and low mood, women were not able to spend quality time with children or family; and as a result, a proportion of women said this made them feel “guilty” They felt that their fatigue meant they were unable to take on the role of “a normal mother” and therefore also felt “guilty”. Ultimately, they described significant issues with their own identity as a result of this complex interaction.

- “I felt no-one believed me, I felt very alone, and at times I’ve been depressed-I thought I wouldn’t live past 30”.

- “Solitude and loneliness. I have, very rarely, been able to leave the house, because of pain and other side effects, since August 2013. I've lost contact with a lot of people. I’ve had to cancel so many meetings last minute due to pain and this has pushed people away”.

**Other People Not Understanding**

Seven percent (117/1600) of the women explained that the apparent lack of understanding from other people (partners, family, friends and employers) was the fourth area that impacted them the most.

Due to the chronic nature of the disease process and regularly experiencing various symptoms, women felt that their partners were not always able to appreciate or understand the symptoms they were going through. Some of those women, who opted to discuss their illness further with employers, found that, the employer did not always understand the impact this was having on them. One woman explained “my employer said, is your tummy pain not like a normal period pain?” and another woman described the words used by a female employer as “just get on with the pain, you will be fine”. Interestingly, some women explained that “male employers were more understanding” and female employers were less understanding because there was an expectation from them to “just get on and deal with it”. Another important area was that many women had significantly reduced libido (many did not expect this) and felt their partners also struggled to understand the impact of this.

- “I also find that people tell me that “it’s just period problems” or “I’ll go with a baby”. They are both totally dismissive reactions. Added to which, who suggests have a baby?! What if I didn’t want to/couldn’t afford it etc?”

- “My entire secondary school education was disrupted – a social worker was brought in and laughed at me whenever I tried to explain I was off school frequently due to bad periods”
Other Areas of Focus that Women Provided Insight into are Described Below

Conflicts with the medical team: A minority of women felt that information about their care between primary care and secondary care could be better communicated.

- Some women explained that post diagnostic laparoscopy; they would have preferred to have written information on endometriosis as well as any complications to be aware of from the procedure.
- Women felt there were constant referrals between various specialties including gynaecology and general surgeons before a formal diagnosis was made.
- A number of women said instead of a diagnostic laparoscopy, they also would have preferred to have surgical management at the same time for endometriosis, if appropriate.

- “I feel like I’m on a constant merry go round of referrals. Despite having a resurgence of symptoms, the latest gynaecologist has now told me it could be gastrointestinal and has referred me elsewhere. This is despite my history”.

- “Frustration that Doctors don’t understand impact”.

Fertility worries and concerns with intimacy: There were significant concerns about future fertility and endometriosis. Women were not only worried about their chances of becoming pregnant but were also worried if In-Vitro Fertilisation (IVF) would be available to them or not.

- “Not being able to have children because of having to have a hysterectomy”.

- “Lack of sexual contact. Unfortunately, my husband and I have been unable to carry out full sex for the past 5 years. I hate myself for this. I’m very lucky to have a very supportive husband. I fear if I don’t get better soon he will get fed up with me. He says that will never happen. Fingers crossed my surgery works this year”.

Impact on work: A few women explained that they were made redundant from their job due to “time off sick” and as a result had financial implications. Although the impact on employment is also described in the “other people not understanding section”. It is also important to note that some women felt very embarrassed to talk about endometriosis with their employer and some felt that some female employers perceived endometriosis “as not an illness”.

- “My job involves me standing for most of the day and dealing with people 1 on 1. Very difficult and embarrassing when in pain, and having to stop what you’re doing/saying”.

Uncertainty: Women described that they struggled to explain their symptoms and disease process to other people. Many went onto describe the uncertainty they faced during diagnosis as they had “many laparoscopies before diagnosis”. The uncertainty of the disease patterns (for instance sudden abdominal pain, irregular heavy menstruation) meant that women often cancelled social plans at short notice and overtime, felt isolated. A large number of women described endometriosis as an “invisible disease”.

- “It’s invisible so people not aware... Unless bloated then they ask if you are pregnant”.

Main findings: Women described pain; heavy menstrual bleeding, fatigue and “other people not understanding” as the top four concerns that impacted them. Other areas of concern to women included impact on employment, future fertility concerns, fatigue and apparent lack of support from either clinical teams or from personal relationships. A number of women described endometriosis as an “invisible disease” in addition to having worries about the disease process uncertainty and “feeling guilty” for not being able to “be a normal mother”.

DISCUSSION

To our knowledge, this is the first ever reported mixed-methods endometriosis study involving over 1800 participants whereby the data was collected online. The high number of participants allowed us to draw conclusions that are meaningful and robust. In the analysis of the results we could thus prove that the most common areas of concern that affected women with endometriosis who responded were pain, heavy menstrual bleeding, low mood and the perceived lack of understanding displayed by other people. Other areas that affected women included fertility concerns, impact on employment, problems with the medical team and uncertainty.

Pain was the most reported factor that impacted women with endometriosis. Women described this pain to varying intensities. A key term that resonated from the results was when women described endometriosis as an “invisible disease”. Content analysis showed that women said this for a number of reasons; namely due to other people not being able to appreciate the extent of pain suffered by these women. With freely available pharmacological and non-pharmacological analgesia, why are so many women with endometriosis still in pain? One suggestion to help tackle this issue could be to provide women with a holistic summary of the various methods to control pain, including alternative therapies, analgesia and hormonal therapies. In addition, having joint clinics between gynaecologists and anaesthetists specialising in chronic pain control are likely to be of use to women.10,11

Women also went on to describe that their symptoms had a significant impact on employment and that many women felt “embarrassed” to discuss their symptoms with a trusted employer. There is limited research in this area. Whilst there are patient and public educational resources on endometriosis created by Endometriosis UK and the Royal College of Obstetricians and gynaecologists (RCOG), not all women were aware of these resources. During clinical encounters, patients should be directed to these resources as they will also be able to direct their employers to such resources, should they wish.

The perceived lack of support, especially from partners,
was also made obvious by women in their answers. Women often felt “guilty” for “burdening” their partners with the symptoms they experience from endometriosis. Interestingly, some women explained that their partners struggled to cope with the sexual health implications from the disease (for instance, women experienced reduced libido). With the consent of the patient, involvement of partners in clinical consultations may also help address such issues. There are a number of local support networks around the country, including those provided through Endometriosis UK; however, there are still areas in the UK lacking such groups. This would certainly be an area of further focus.

Education forms a major part in raising awareness of endometriosis. Whilst menstrual well-being will be taught as part of the national curriculum in England by 2020, there is still scope to improve awareness in medical education. The findings from this study provide insight into the communication challenges women faced with their healthcare practitioners; developing this as part of communication skills teaching at medical school would be useful.

Women have described here how the social isolation and fatigue impacting upon day to day life had led to potential identity issues. Some women described feeling “guilty” as a result of not being able to spend quality time with their children. Again, self-identity and how this is impacted through the psycho-social sequelae of endometriosis is an area that does not appear to have been studied in great detail before. Our study has provided insight into the guilt some women with endometriosis have experienced and how this has influenced their self-identity. This is important as it will have an influence on how women cope with their symptoms.

A systematic review by Young et al analysed eighteen qualitative research papers and concluded that further studies were required to assess the impact of infertility due to endometriosis and impact of the social exclusion. An Australian qualitative study Moradi et al involved thirty-five women with endometriosis in semi-structured group discussions found that endometriosis had an impact negatively on women in all aspects of their lives, but more research was required on the impact in teenagers.

The results from this analysis clearly provide us with an insight into the complex psycho-social factors that interact with bio-physical symptoms. There are still very limited qualitative studies exploring the impact of endometriosis on women’s lives, particularly in the United Kingdom.

This study underpins the important of understanding patient experiences in endometriosis. It raises a number of important research and ethical issues.

CONCLUSION

Further research is required in sub-population groups to include teenagers, ethnic minority women, post-menopausal women and those from varying socio-economic classes as all these groups may have differing sequelae and may benefit from tailored services.

We feel that this study is mandatory reading material for all that care for women with endometriosis. It provides valuable insight into the physical and psychosocial effects of this disease from women unconstrained by investigator bias and restrictive drop/tick box surveys. It is the first of its kind in the UK; it highlights what women really think as it represents the voices of thousands of women with the disease.

STRENGTHS AND LIMITATIONS

This study highlights how useful the internet can be to obtain rich and detailed information from women suffering from endometriosis. There was no researcher bias and women were given the opportunity to write free flow text in the questionnaire.

This study did not involve direct face to face participant contact and therefore as researchers were unable to ask women further questions about their symptoms or impact.

FUNDING

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ETHICS APPROVAL

Ethical approval was obtained from the ethics committee at the University of East Anglia on July 13, 2017. Reference 2016/2017-87.

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CONFLICTS OF INTEREST

Dr. Morris reports grants and personal fees from Gedeon Richter, personal fees from Pfizer, personal fees from Chugai Pharma, outside the submitted work; and Trustee, Royal College of Obstetricians and Gynaecologists (RCOG) Trustee, British Menopause Society. Dr. Simpson reports grants and personal fees from Gedeon Richter, personal fees from Chugai Pharma, outside the submitted work.

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Below is the Raw Data in a Tabulated Form

### Table 1. The Number One Feature that Affects Women with Endometriosis (Pain)

| Reason Number 1         | Total Number | Percentage |
|-------------------------|--------------|------------|
| Pain                    | 995          | 53%        |
| Impact on work          | 176          | 9%         |
| Fertility worries       | 147          | 8%         |
| Fatigue                 | 97           |            |
| Heavy bleeding          | 84           |            |
| Pain during sex         | 60           |            |
| Tiredness               | 50           |            |
| Day to day activities   | 49           |            |
| Cannot understand disease | 40        |            |
| Having to take analgesia| 28           |            |
| Problems with medical team | 23        |            |
| Low mood                | 21           |            |
| Impact on work          | 17           |            |
| Relationship impact     | 16           |            |
| Bowel symptoms          | 15           |            |
| Menstrual cycle disturbance | 11       |            |
| Bloating                | 10           |            |
| Miscarriage             | 7            |            |
| Not feeling "normal"    | 6            |            |
| Fainting                | 4            |            |
| Infertility requiring IVF | 4         |            |
| Not sure                | 4            |            |
| Had to have an operation | 3         |            |
| Nausea                  | 2            |            |
| Not had much impact     | 2            |            |
| Migraine                | 1            |            |
| Total                   | 1872         |            |

### Table 2. The Second Most Common Feature that Affects Women with Endometriosis (Heavy Menstrual Bleeding)

| Reason Number 2         | Total Number | Percentage |
|-------------------------|--------------|------------|
| Pain                    | 362          | 20%        |
| Heavy bleeding          | 201          | 11%        |
| Fatigue                 | 144          | 8%         |
| Impact on work          | 143          |            |
| Fertility worries       | 108          |            |
| Tiredness               | 100          |            |
| Day to day activities   | 97           |            |
| Low mood                | 90           |            |
| Pain during sex         | 84           |            |
| Bowel symptoms          | 63           |            |
| Relationship impact     | 53           |            |
| Cannot understand disease | 48        |            |
| Menstrual cycle disturbance | 43       |            |
| Bloating                | 39           |            |
| Lack of support         | 39           |            |
| Problems with medical team | 36        |            |
| Having to take analgesia| 34           |            |
| Nausea                  | 25           |            |
| Sleep impact            | 19           |            |
| Had to have an operation | 15        |            |
| Impact on school        | 12           |            |
| Hormonal treatment needed | 8         |            |
| Fainting                | 7            |            |
| Fertility worries       | 7            |            |
| Infertility requiring IVF | 5         |            |
| Migraine                | 5            |            |
| Not feeling "normal"    | 5            |            |
| Embarrassed             | 4            |            |
| Miscarriage             | 3            |            |
| Not had much impact     | 1            |            |
| Not sure                | 0            |            |
| Total                   | 1800         |            |
### Table 3. The Third Most Common Feature that Affects Women with Endometriosis (Low Mood)

| Reason Number 3 | Total Number | Percentage |
|-----------------|--------------|------------|
| Pain            | 210          | 12%        |
| Day to day activities | 148          | 8%         |
| Impact on work  | 142          | 8%         |
| Low mood        | 142          | 8%         |
| Lack of support | 124          |            |
| Fertility worries | 111          |            |
| Heavy bleeding  | 110          |            |
| Pain during sex | 104          |            |
| Fatigue         | 94           |            |
| Tiredness       | 92           |            |
| Relationship impact | 88         |            |
| Bowel symptoms  | 84           |            |
| Bloating        | 56           |            |
| Having to take analgesia | 39 |            |
| Menstrual cycle disturbance | 37 |        |
| Problems with medical team | 37 |        |
| Cannot understand disease | 34 |          |
| Nausea          | 26           |            |
| Hormonal treatment needed | 17 |        |
| Had to have an operation | 12 |          |
| Sleep impact    | 10           |            |
| Fainting        | 9            |            |
| Migraine        | 8            |            |
| Impact on school | 7            |            |
| Not feeling “normal” | 7       |          |
| Embarrassed     | 6            |            |
| Follow up appointments | 6    |          |
| Weight issues   | 5            |            |
| Miscarriage     | 2            |            |
| Acne            | 2            |            |
| Isolating       | 1            |            |
| Infertility requiring IVF | 0 |            |
| Not had much impact | 0         |          |
| Not sure        | 0            |            |
| **Total**       | **1770**     |            |

### Table 4. The Fourth Most Common Feature that Affects Women with Endometriosis (Low Mood)

| Reason number 4 | Total Number | Percentage |
|-----------------|--------------|------------|
| Low mood        | 164          |            |
| Pain            | 157          | 10%        |
| Work impact     | 125          | 10%        |
| Other people not understanding | 117 | 8% |
| Tiredness       | 96           | 7%         |
| Bowel/Bladder issues | 86 |         |
| Day to day impact | 86           |            |
| Heavy bleeding  | 84           |            |
| Infertility     | 79           |            |
| Issues with medical team | 76 |          |
| Issues with sexual intercourse | 71 |        |
| Unpredictable disease process | 63 |        |
| Pain after sex  | 54           |            |
| Side effect of drugs | 54 |         |
| Social life impact | 46           |          |
| Nausea          | 43           |            |
| Bloating        | 42           |            |
| Relationship impact | 32         |          |
| Surgery         | 22           |            |
| Others not believing you | 15 |          |
| Sleep problems  | 15           |            |
| Isolated        | 11           |            |
| Headache        | 9            |            |
| Weight gain     | 9            |            |
| Embarrassed     | 7            |            |
| School impact   | 7            |            |
| No cure         | 7            |            |
| Stress          | 5            |            |
| Financial worries | 4            |          |
| Guilt           | 4            |            |
| Having to attend appointments | 4 |          |
| Acne            | 2            |            |
| Disease taking over life | 2 |          |
| Fear of hysterectomy | 1         |          |
| Miscarriage     | 1            |            |
| **Total**       | **1600**     |            |