

Original Research**A Study to Explore the Impact of Endometriosis in the United Kingdom: A Qualitative Content Analysis****Babu Karavadra, BSc, MBBS, AFHEA^{1*}; Paul Simpson, MA, BMBS, MRCOG, MD¹; Edward Prosser-Snelling, BMBS, MRCOG²; Edward Mullins, BMedSci, BMBS, MRCOG, PhD³; Andrea Stöckl, MA, MSc, PhD⁴; Edward Morris, MBBS, BSc, MD, FRCOG¹**¹Department of Gynecology, Norfolk & Norwich University Hospital, Norwich, NR4 7UY, England²Department of Obstetrics and Gynecology, Norfolk & Norwich University Hospital, Norwich, NR4 7UY, England³Department of Obstetrics and Gynecology, Queen Charlotte's Hospital, Du Cane Road, London W12 0HS, UK⁴Department of Sociology, Norwich Medical School, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ, UK***Corresponding author****Babu Karavadra, BSc, MBBS, AFHEA**Clinical Research Fellow, Department of Gynecology, Norfolk & Norwich University Hospital, Norwich, NR4 7UY, England; E-mail: paul.simpson@nnuh.nhs.uk**Article information****Received:** September 26th, 2019; **Revised:** October 7th, 2019; **Accepted:** October 11th, 2019; **Published:** October 14th, 2019**Cite this article**Karavadra B, Simpson P, Prosser-Snelling E, Mullins E, Stockl A, Morris E. A study to explore the impact of endometriosis in the United Kingdom: A qualitative content analysis. *Gynecol Obstet Res Open J*. 2019; 6(1): 11-19. doi: [10.17140/GOROJ-6-150](https://doi.org/10.17140/GOROJ-6-150)**ABSTRACT****Objective**

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

Design

A qualitative content analysis of an online survey.

SettingOnline 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.¹ As a result, women experience a myriad of symptoms including pelvic pain, menorrhagia and dyspareunia.¹ Endometriosis is also associated with infertility.¹ Endometriosis affects 1.5 million women in the United Kingdom and can have a host of physical, psychological and social sequelae.² The average time to diagnose endometriosis is approximately 7.5-years in the United Kingdom.³

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.”⁴

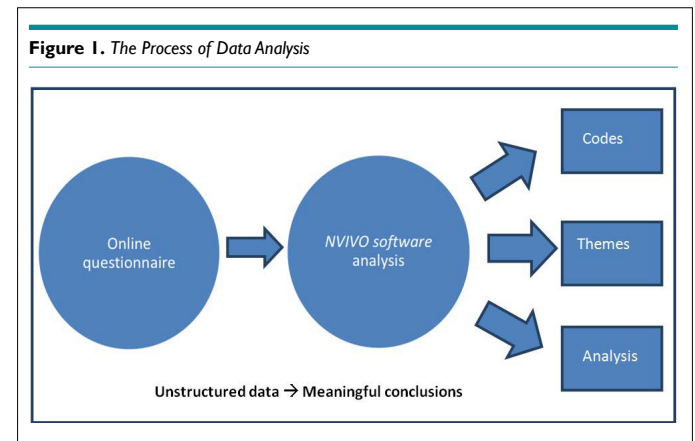
Qualitative research is based on personal experience and has a role in obtaining detailed information on why people behave the way they do and the impact of various life experiences. Data are generally obtained through structured or semi-structured interviews, focus groups or observations.⁴ Approaches 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.^{3,4} The different types of content analysis include conventional, directed and summative approaches.⁵ 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.⁵ 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.⁶ 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.⁷⁻¹⁰ 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 re-iterated 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.¹¹ The software creates links between common words (codes), and these links allow data to be placed in categories (also known as themes).¹¹ 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

Figure 2. Number of Women Reporting 1, 2, 3 and 4 Areas of the Impact that Endometriosis had on Them

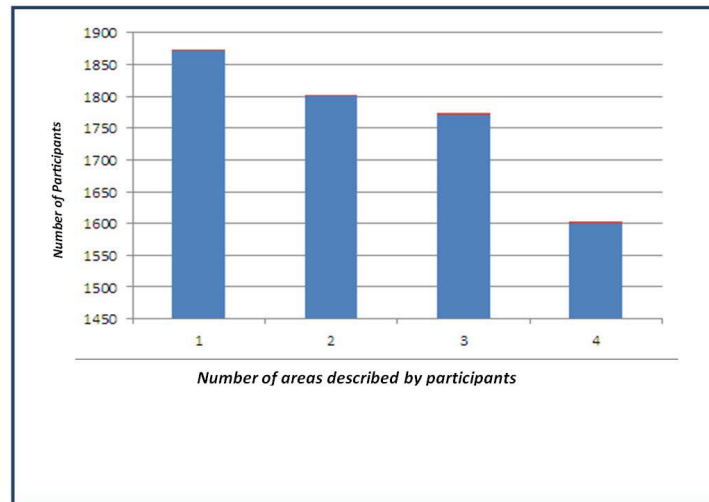
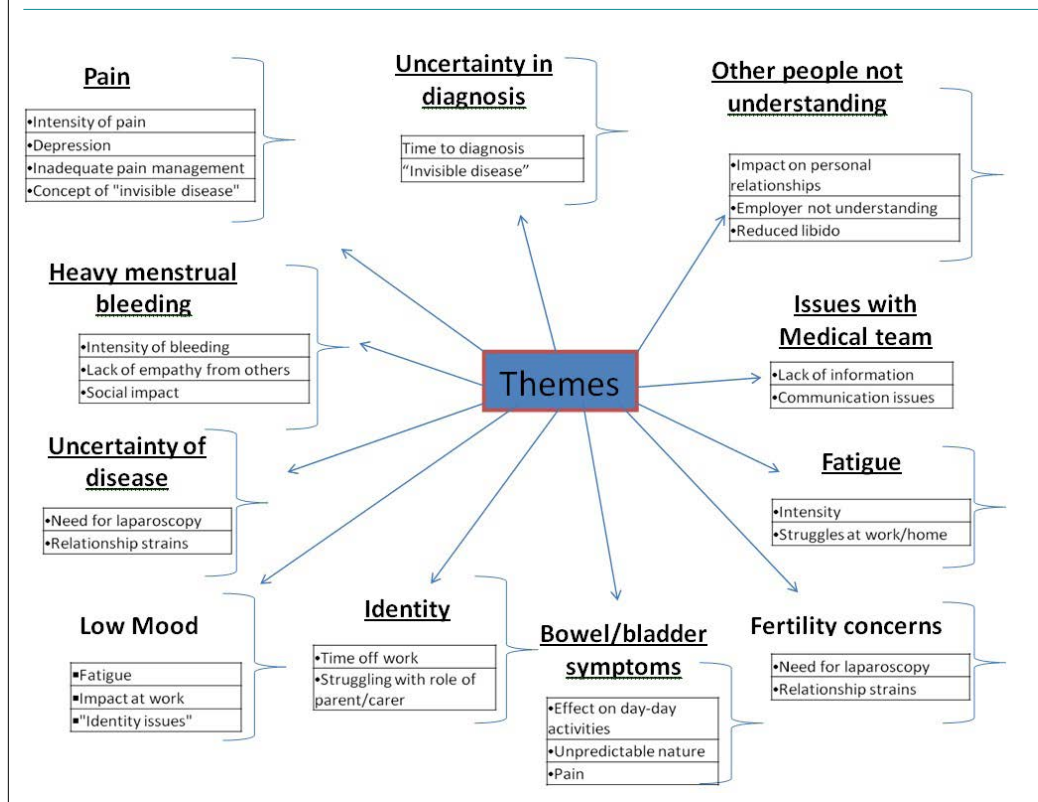


Figure 3. The Main Areas of Endometriosis that Affected Women the Most as Derived from Analysis of the Questionnaire Responses



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).

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.

Other areas that concerned women included impact on

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 “it’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 on to 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”.

– *“Its 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.¹² 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.⁷

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

No funding was required for this research work.

ETHICS APPROVAL

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

ACKNOWLEDGEMENTS

We are very grateful to all those women who have taken time to complete the online questionnaire. We are also grateful to Endometriosis UK who was able to distribute the questionnaire through their website.

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;

REFERENCES

1. Agarwal N, Subramanian A. Endometriosis - morphology, clinical presentations and molecular pathology. *J Lab Physicians*. 2010; 2(1): 1-9. doi: 10.4103/0974-2727.66699
2. Understanding Endometriosis. Web site. <https://www.endometriosis-uk.org/understanding-endometriosis>. Accessed January 20, 2016.
3. Hadfield R, Mardon H, Barlow D, Kennedy S. Delay in the diagnosis of endometriosis: A survey of women from the USA and the UK. *Hum Reprod*. 1996; 11(4): 878-880. doi: 10.1093/oxfordjourn-

[als.humrep.a019270](#)

4. Ritchie J, Lewis J. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London, UK: Sage Publishers; 2003.
5. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005; 15: 1277-1288. doi: [10.1177/1049732305276687](https://doi.org/10.1177/1049732305276687)
6. Creswell JW. *Research Design: Qualitative, Quantitative, and Mixed Method Approaches*. Thousand Oaks, CA, USA: Sage Publishers; 2003.
7. Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. Impact of endometriosis on women's lives: A qualitative study. *BMC Womens Health*. 2014; 14: 123. doi: [10.1186/1472-6874-14-123](https://doi.org/10.1186/1472-6874-14-123)
8. Denny E. Women's experience of endometriosis. *J Adv Nurs*. 2004; 46(6): 641-648. doi: [10.1111/j.1365-2648.2004.03055.x](https://doi.org/10.1111/j.1365-2648.2004.03055.x)
9. Brosens I, Gordts S, Benagiano G. Endometriosis in adolescents is a hidden, progressive and severe disease that deserves attention, not just compassion. *Hum Reprod*. 2013; 28(8): 2026-2031. doi: [10.1093/humrep/det243](https://doi.org/10.1093/humrep/det243)
10. Facchin F, Buggio L, Dridi D, Vercellini P. A woman's worth: The psychological impact of beliefs about motherhood, female identity, and infertility on childless women with endometriosis. *J Health Psychol*. 2019; 12: 1359105319863093. doi: [10.1177/1359105319863093](https://doi.org/10.1177/1359105319863093)
11. NVIVO. Web site. <http://www.qsrinternational.com/what-is-nvivo>. Accessed January 20, 2016.
12. Young K, Fisher J, Kirkman M. Women's experiences of endometriosis: A systematic review and synthesis of qualitative research. *J Fam Plann Reprod Health Care*. 2015; 41(3): 225-234. doi: [10.1136/jfprhc-2013-100853](https://doi.org/10.1136/jfprhc-2013-100853)

APPENDIX

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 school	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	