

## APPENDICES

### APPENDIX 1. SEARCH STRATEGY ON MEDLINE

Search for: 32 and 33 and 34

Results: 112

Database: Ovid MEDLINE(R) <1946 to August 6 2021>

Search Strategy:

- 
1. burden.mp. (258025)
  2. burden\$.tw. (251685)
  3. illness experience\$.mp. (1736)
  4. (liv\$ adj2 experience\$).mp. (11821)
  5. HRQoL.tw. (18459)
  6. (quality adj2 life).mp. (385412)
  7. quality of life.mp. (381541)
  8. exp "Quality of Life"/ (218063)
  9. "cost of illness"/ or exp health care costs/ (92507)
  10. cost of illness.mp. (30363)
  11. exp Health Care Costs/ (68518)
  12. healthcare cost\*.mp. (13430)
  13. impact.mp. (1102787)
  14. societal burden.mp. (783)
  15. distress\*.mp. (157449)
  16. consequence\*.mp. (444820)
  17. disability.mp. (246978)
  18. exp absenteeism/ or exp presenteeism/ (9605)
  19. absenteeism.mp. (12872)
  20. presenteeism.mp. (1496)
  21. exp burnout, psychological/ or exp occupational stress/ (16577)
  22. (productiv\$ adj2 loss\*).mp. (3565)
  23. endometriosis.mp. (29759)
  24. endometrio\$.tw. (32527)
  25. exp endometriosis/ (22973)
  26. qualitative research\*.mp. (80873)
  27. (qualitative adj2 method\*).mp. (29286)
  28. interview\$.tw. (389483)
  29. theme\*.tw. (105005)
  30. focus group\*.mp. (58280)
  31. (nurs\$ methodolog\$ adj2 research).mp. (16414)
  32. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 (2422758)
  33. 23 or 24 or 25 (36415)
  34. 26 or 27 or 28 or 29 or 30 or 31 (507634)
  35. 32 and 33 and 34 (112)

\*\*\*\*\*

## APPENDIX 2. SEARCH STRATEGY ON PsycINFO

Search for: 15 and 19 and 20

Results: 12

Database: PsycINFO <1806 to August Week 1 2021>

Search Strategy:

- 
1. exp "Quality of Life"/ (40394) 46022
  2. (quality adj2 life).mp. (73555) 85281
  3. quality of life.mp. (81493) 93930
  4. stigma.mp. (23604) 29284
  5. effect\*.mp. (1354985) 1493654
  6. significance.mp. (89664) 99490
  7. depression.mp. (312469) 349184
  8. exp Coping Behavior/ or exp "Quality of Life"/ or exp Pain Perception/ or exp Health/ or exp Chronic Illness/ or exp Chronic Pain/ or exp Pain/ or exp Gynecological Disorders/ or exp Infertility/ or exp Menstrual Disorders/ (352205) 480345
  9. exp Distress/ (20692) 24431
  10. distress.mp. (66633) 76680
  11. (psycholog\* adj2 impact).mp. (4141) 4813
  12. burden.mp. (36382) 43396
  13. meaning\*.mp. (163267) 179737
  14. exp Chronic Pain/ (12734) 14345
  15. endometriosis.mp. (261) 330
  16. exp Qualitative Methods/ (13729) 17704
  17. qualitative research\*.mp. (33915) 41900
  18. qualitative method\*.mp. (18535) 21793
  19. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 (1976591) 2225648
  20. 16 or 17 or 18 (50849) 62922
  21. 15 and 19 and 20 (8) 12

\*\*\*\*\*

### APPENDIX 3. SEARCH STRATEGY ON EMBASE

Search for: 28 and 29 and 30

Results: 236

Database: Embase Classic+Embase <1947 to 2021 August 6>

Search Strategy:

- 
1. burden.mp. (377942)
  2. exp "chronic pain"/ (66614)
  3. chronic pain.mp. (88312)
  4. illness experience\$.tw. (2125)
  5. exp "quality of life"/ (542760)
  6. quality of life.mp. (661157)
  7. (psychosocial adj2 impact).mp. (4475)
  8. impact.mp. (1611061)
  9. consequence.mp. (218383)
  10. (live\$ adj2 experience\$).tw. (8919) 11983
  11. aftermath.mp. (6466)
  12. challenge\$.mp. (931168)
  13. distress\*.mp. (267608)
  14. exp social disability/ or exp work disability/ (9695)
  15. (productiv\* adj2 loss\*).mp. (6056)
  16. meaning\$.mp. (203759)
  17. dyspareunia.mp. (12951)
  18. exp dyspareunia/ (11328)
  19. endometriosis.tw. (37428)
  20. exp endometriosis/ (42513)
  21. endometriosis.mp. (46387)
  22. exp qualitative research/ (91203)
  23. qualitative research.mp. (102155)
  24. qualitative method\*.mp. (15243)
  25. interview\$.mp. (548597)
  26. video\$ recording\$.mp. (9310)
  27. ethnograph\$.tw. (13118)
  28. 1 or 2 or 3 or 5 or 6 or 7 or 8 or 9 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18  
(3894846)
  29. 19 or 20 or 21 (46387)
  30. 22 or 23 or 24 or 25 or 26 or 27 (606645)
  31. 28 and 29 and 30 (236)

#### APPENDIX 4. SEARCH STRATEGY ON CINAHL Plus

#	Query	Results
S20	S11 AND S18 AND S19	151
S19	S12 OR S13 OR S14 OR S15 OR S16 OR S17	365,565
S18	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10	3,369,942
S17	Interview* or focus group*	328,680
S16	field stud*	4,505
S15	confirmability	306
S14	reflexivity	1,289
S13	qualitative research	13,180
S12	qualitative stud* or qualitative research or qualitative method*	124,848
S11	endometriosis	7,024
S10	infertility	15,413
S9	chronic pain	28,812
S8	dyspareunia or sexual pain or painful intercourse	1,823
S7	psychosocial impact	1,239
S6	results or effects or outcomes	2,588,885
S5	burden or stress or fatigue or burnout or strain or belasting	346,266
S4	quality of life or well being or well-being or health-related quality of life	231,641
S3	challenges or barriers or difficulties or issues or problems or limitations	806,735
S2	significance, or importance, or impact, or implication, or consequences	793,923
S1	impact or effect or influence or outcome or result or consequence	2,780,706

## APPENDIX 5. SEARCH STRATEGY ON WEB OF SCIENCE

January 1<sup>st</sup> 1908 till August 6<sup>th</sup> 2021

Set	Results	Save History / Create Alert Open Saved History
# 21	117	#20 AND #19 AND #15
# 20	460,471	#18 OR #17 OR #16
# 19	6,326,967	#14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1
# 18	363,382	TS=qualitative stud*
# 17	265,701	TS=qualitative method*
# 16	198,186	TS=qualitative research*
# 15	26,585	TS=(endometriosis)
# 14	293,270	TS=disability
# 13	4,212	TS=dyspareunia
# 12	128,082	TS=chronic pain
# 11	580,872	TS=quality of life
# 10	240,618	TS=(health* cost)
# 9	709,619	TS=(barrier*)
# 8	463,010	TS=(quality near/2 life)
# 7	48,958	TS=(stigma)
# 6	26,799	TS=(psychosocial impact)
# 5	49,787	TS=(health* near/2 cost)
# 4	21,975	TS=(societ* burden)

# 3	348,243	TS=(burden*)
# 2	1,531,659	TS=(challenge*)
# 1	3,281,551	ALL=(impact*)

## APPENDIX 6. SEARCH STRATEGY SCOPUS

Combine queries...e.g. #1 AND NOT #3

8 ( ( TITLE-ABS-KEY ( quality W/2 life ) OR TITLE-ABS-KEY ( "impact" ) OR TITLE-ABS-KEY ( significance ) OR TITLE-ABS-KEY ( "burden" ) OR TITLE-ABS-KEY ( psychosocial AND impact ) OR TITLE-ABS-KEY ( distress ) OR TITLE-ABS-KEY ( chronic\* AND pain\* ) OR TITLE-ABS-KEY ( chronic AND pelvic AND pain ) OR TITLE-ABS-KEY ( loss\* ) ) ) OR ( TITLE-ABS-KEY ( "impact" ) ) OR ( TITLE-ABS-KEY ( "quality of life" ) ) ) 6,771,856 document results

7 ( ( ( TITLE-ABS-KEY ( qualitative AND research\* ) OR TITLE-ABS-KEY ( qualitative AND stud\* ) OR TITLE-ABS-KEY ( qualitative AND method\* ) ) ) AND ( endometriosis ) ) AND ( TITLE-ABS-KEY ( "endometriosis" ) ) AND ( ( ( TITLE-ABS-KEY ( qualitative AND research\* ) OR TITLE-ABS-KEY ( qualitative AND stud\* ) OR TITLE-ABS-KEY ( qualitative AND method\* ) ) ) ) 224 document results

6 TITLE-ABS-KEY ( "quality AND of AND life" ) 754,105 document results

5 ( ( TITLE-ABS-KEY ( qualitative AND research\* ) OR TITLE-ABS-KEY ( qualitative AND stud\* ) OR TITLE-ABS-KEY ( qualitative AND method\* ) ) ) 280,652 document result

4 TITLE-ABS-KEY ( "endometriosis" ) 40,021 document results

3 ( ( TITLE-ABS-KEY ( qualitative AND research\* ) OR TITLE-ABS-KEY ( qualitative AND stud\* ) OR TITLE-ABS-KEY ( qualitative AND method\* ) ) ) AND ( endometriosis ) 411 document results

2 TITLE-ABS-KEY ( "impact" ) 3,507,404 document results

1 ( TITLE-ABS-KEY ( quality W/2 life ) OR TITLE-ABS-KEY ( "impact" ) OR TITLE-ABS-KEY ( significance ) OR TITLE-ABS-KEY ( "burden" ) OR TITLE-ABS-KEY ( psychosocial AND impact ) OR TITLE-ABS-KEY ( distress ) OR TITLE-ABS-KEY ( chronic\* AND pain\* ) OR TITLE-ABS-KEY ( chronic AND pelvic AND pain ) OR TITLE-ABS-KEY ( loss\* ) ) 8,080,160 document

## APPENDIX 7. Inclusion and Exclusion Criteria

### Box 1 Inclusion and Exclusion Criteria

- a) Research participants should only be women who have been surgically diagnosed with endometriosis, usually through a laparoscopic procedure followed by a histological confirmation of biopsy taken during the surgical procedure (Ballard et al., 2006).
- b) To be included in this paper, the aim of the study had to be clearly stated and must be in tandem with the aim of this research, which is to investigate the impact of endometriosis on the patients' lives, from the patients' perspectives.
- c) The study also must have been published in English Language, in a peer-reviewed journal

#### Some excluded papers:

- a) All quantitative research studies were excluded: this comprises studies which used techniques such as surveys or questionnaires; cross-sectional or analytical methods.
- b) Studies which utilized both quantitative and qualitative methods were excluded if it was not possible to disentangle qualitative pieces from the quantitative.
- c) Studies investigating patients' perspectives on the effect or efficacy of a medical treatment, surgical technique or therapy on QoL of endometriosis patients.
- d) Studies exploring the perceptions, experiences or attitudes of clinicians that treat women living with endometriosis.
- e) Studies investigating patients' opinions or attitudes only towards diagnostic delays, healthcare services or coping strategies used in dealing with endometriosis.
- f) Studies exploring only the views or experiences of care-givers, partners and families of women living with endometriosis.
- g) Studies which investigated the opinions of couples (endometriosis patient with her partner) and reported the patients' views and perceptions discretely from their partners' were included.
- h) Therefore, studies which had participants who had not been clinically diagnosed with endometriosis were excluded.

**APPENDIX 8** Seven steps of Noblit and Hare's meta-ethnography (Noblit and Hare, 1988)

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis

**APPENDIX 9** Quality Assessment of 17 papers which met the inclusion criteria, using the CASP (2018) tool

S/N	AUTHOR, YEAR OF PUBLICATION	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
1	Namazi et al, 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	DiBenedetti et al, 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3	Cole et al, 2020	No	Can't tell	Can't tell	Can't tell	Can't tell	Yes	Yes	Yes	Yes	Yes
4	Hällstam et al, 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5	Roomaney & Kagee, 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6	Mellado et al, 2016	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
7	Hudson et al, 2015	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
8	Moradi et al, 2014	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
9	Denny et al, 2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
10	Seear, 2009	No	Can't tell	Can't tell	Can't tell	Can't tell	No	Yes	Yes	Yes	Yes
11	Markovic et al, 2008	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
12	Denny and Mann, 2007	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
13	Butt and Chesla, 2007	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
14	Huntington and Gilmour, 2005	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
15	Jones et al, 2004	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
16	Denny, 2004	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
17	Helen Cox, 2003	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

**APPENDIX 10 Data extraction from selected studies<sup>1</sup>**

<b>Author, Publication Year, and Reference</b>	<b>Study aim</b>	<b>Location, Sample size, Age Range [yrs], and Gender<sup>2</sup></b>	<b>Sampling, Recruitment &amp; Informed Consent</b>	<b>Data Collection Methods</b>	<b>Coding/Data Analysis Methods</b>	<b>Study Quality</b>
Namazi et al., 2021, 1	To explore the impact of endometriosis on Iranian women's lives.	Tehran, Iran. Sample Size: 20 Age range: 23-43 Mean age: 34.3	Purposeful sampling from a tertiary clinic	Semi-structured interviews	Content Analysis using MAXQDA software	Reliability: High  Usefulness: High
DiBenedetti et al., 2020, 2	To better understand the experience of women who suffer from endometriosis-related fatigue as a result of moderate to severe endometriosis-related pain	USA Sample size: 22 Age range: 27-48 Mean age: 38.6	Convenience sampling	Indepth interviews	Thematic Analysis/ATLAS-ti version 7.5	Reliability: High  Usefulness: High
Hållstam et al., 2018, 3	To examine women's experience of painful endometriosis including long-term aspects, social consequences, impact of treatment and development of own coping strategies.	Stockholm, Sweden Sample size: 13 Age: 24 -48	Participants were recruited among women diagnosed with endometriosis in a pain clinic	Interviews	Grounded theory	Reliability: High  Usefulness: High

Roomaney .R and Kagee A, 2018, 4	To build on research from Africa, by reporting on the health-related quality of life (HRQoL) among a sample of women with endometriosis in South Africa.	Capetown, South Africa Sample size: 25 Age:25- 42 years (mean 33)	Convenience sampling among women diagnosed with endometriosis at public and private healthcare facilities. Written informed consent was obtained	Semi-structured interviews	Atlast-ti/ Thematic Analysis	Reliability: High  Usefulness: High
Mellado B. et al, 2016, 5	To evaluate the perceptions of women with endometriosis and pelvic pain, with regards to their social ties.	Southwest Brazil Sample size: 29 Age: 21–49 (mean 39 ± 6 years)	Women diagnosed with endometriosis at Clinics Hospital of Ribeirão Preto Medical School, Brazil. Informed consent was obtained	Focus Group Discussion	WebQDA/ Grounded theory	Reliability: High  Usefulness: High
Hudson et al, 2015, 6	To explore the impact of endometriosis on women and their male partners; contribute to the development of theory in chronic illness and contribute to improving the wellbeing of people living with endometriosis.	Country: England Sample size: 22 heterosexual couples Age: women 34.8 years (range 25–50) Men: 36.3 years (range 26–57).	Systematic and purposive sampling from endometriosis support groups, NHS clinics	Indepth, semi-structured interviews	NVivo/ Thematic analysis using an interpretivist relational approach	Reliability: High  Usefulness: High

Moradi et al, 2014, 7	To explore women's experiences of endometriosis and its impact, involving three different age groups.	Canberra, Australia Sample size: 35 Age range: 17-53 years	Purposive sampling among women that were diagnosed of endometriosis attending a public teaching hospital and endo* patients residing in the community. Written consent	Focus group discussions	NVivo/ Thematic analysis	Reliability: High  Usefulness: High
Denny et al., 2009, 8	To explore women's experience of living with endometriosis in a prospective study over a 1-year period.	Birmingham United Kingdom	Purposive sampling from an endometriosis clinic. Consent was obtained.	Interviews/Story-telling approach	Narrative	Reliability: High  Usefulness: High
Markovic et al, 2008, 9	To enrich our understanding of the relationship between the patient's socio-demographic background and health-related phenomena, by identifying distinctive differences among women's narratives.	Victoria Australia Sample Size: 30 Age: 20-78 years (Mean age: 43.8)	Criterion Sampling, Snowballing  Written consent was obtained	Storytelling/In-depth interviews	Atlas-ti/ Grounded theory	Reliability: High Usefulness: High
Denny & Mann, 2007, 10	To understand the impact of endometriosis-associated dyspareunia on women's lives	England Sample size: 30 Age: 19-44 years (mean 31)	Purposive sampling of women attending a dedicated endometriosis outpatient clinic. Written consent was obtained	Semi-structured interviews	Thematic analysis	Reliability: High  Usefulness: Medium

Butt & Chesla, 2007, 11	To investigate responses in the couple's relationship to living with CPP from endometriosis	San Francisco, USA* Sample size: 13 heterosexual couples Age of women:23-48 (mean age 34) Age of men: 24-50 (mean age 38)	Sampling from public and private clinics, as well as endometriosis support groups.  Consent was obtained	Narrative interviews	ATLAS-ti/ Thematic analysis	Reliability: High  Usefulness: High
Huntington & Gilmour, 2005, 12	To explore women's perceptions of living with endometriosis, its effects on their lives and the strategies used to manage their disease	Location: New Zealand Sample size: 18 Age: 16-45 years	Sampling from support group Verbal consent was obtained	Semi-structured Interviews	Thematic analysis	Reliability: High  Usefulness: High
Jones et al., 2004, 13	To understand from the patient's perspective, the areas of HRQoL that are affected by endometriosis and to address the benefits of using a qualitative methodology for item generation in the development of disease-specific health status questionnaires.	Oxford, England Sample size: 24 Age:21.5-44 (mean 32.5) Written consent	Convenience sampling from a women's clinic in Radcliffe	In-depth interviews	Grounded Theory	Reliability: High  Usefulness: High

Denny, 2004, 14	To report a study exploring women's experience of living with endometriosis.	Sample size: 15 England	Convenience sampling	Semi-structured interviews	Thematic analysis	Reliability: High Usefulness: High
Cox et al., 2003, 15	To increase awareness of women's experiences of endometriosis and the lack of support for women sufferers	Sample size: 61 Age: 20-64 years Melbourne, Australia	Purposive Sampling from Epworth clinic.	Focus group discussions	Thematic analysis	Reliability: High Usefulness: Medium

<sup>1</sup>Study design is qualitative for all studies

<sup>2</sup>Gender is female for all participants except where indicated otherwise

**APPENDIX 11a Concepts, 1<sup>st</sup> and 2<sup>nd</sup> order interpretations**

<b>Concepts</b>	<b>Namazi et al. (2021)</b>	<b>DiBenedetti et al. (2020)</b>	<b>Hållstam et al. (2018)</b>	<b>Roomaney &amp; Kagee (2018)</b>
<b>Disease symptoms</b>	Menstrual disorders (severe bleeding, clotting, spotting before/after period and irregular menstruation), disabling pelvic pain, dyspareunia, infertility.	Fatigue, painful periods, heavy bleeding, pelvic pain, back pain, leg pain, nausea, headaches, migraines, gastrointestinal disturbances, infertility and painful intercourse	Intensive pain, copious bleeding and fatigue	CPP, irregular menstrual cycle, heavy menstrual bleeding
<b>Health Services Experience</b>	Patients commented on the recurrence of illness despite surgeries and medications and failure of assisted reproductive technologies (ART).	-	Attitudes towards health care ranged from interest to pure indifference.	Participants reported communication barriers with HCPs and varying levels of satisfaction with healthcare.
<b>Isolation &amp; Limited Social Participation</b>	Patients explained that due to lack of understanding of the illness by relatives, friends and colleagues, they prefer to be alone:	Participants reported limited interactions with their children and family; cancelling or modifying social plans and staying indoors because of endometriosis-associated fatigue.	Women were compelled by pain, to stay in bed and lost the feeling for basic physical needs such as food and toilet visits. Fatigue and reluctance to go out worsened inactivity and functional impairment.	Participants stated that when they were in pain, they withdrew from social activities.

<b>A Coterie of Emotions</b>	Frustration, disappointment, self condemnation are some emotions the participants reported.	Moodiness, irritability and depression are some of the emotions reported by the women.	Women had to deal with feelings of difference, dependence and a ruined life, thus struggled for understanding and meaning.	Women reported feelings of distress, anxiety, moodiness, uncertainty, isolation, frustration, hopelessness, helplessness.
<b>Limited physical functioning</b>	The severity of symptoms (e.g. dysmenorrhoea) in some women resulted in their inability to carry out routine activities.	Fatigue resulted in avoiding physical activities, delaying or putting off chores like laundry, grocery shopping, cleaning, cooking and self-care activities.	Physical limitations, missed opportunities and thus participation in life, induced existential grief.	Some participants reported that at times, they could not care for themselves due to pain.
<b>Sex &amp; Intimate relationships</b>	Women experienced marital instability, multiple sexual problems (e.g. low libido, dyspareunia, inability to achieve orgasm) due to endometriosis.	Women reported reduced intimacy with their partners.	While intercourse was commonly interrupted by pain, some couples had found satisfying alternatives for intimacy and sex.	Pain, moodiness, infertility and dyspareunia negatively impacted women's relationships with partners.
<b>Infertility</b>	Women reported that their inability to conceive made them feel different	-	-	Some participants reported feeling stigmatised by their childlessness.

<b>Work life &amp; Education</b>	Severe bleeding and pain often resulted in patients staying at home- rather than going to work	Participants reported a decrease in their productivity, ability to focus, and quality of work; owing to fatigue. Some reported absenteeism at work.	Endometriosis was the reason for lost opportunities in education and career. It forced some women to work part-time, some even lost their jobs.	Some women did not seek better work opportunities if they felt that they were in a supportive work environment.
<b>Coping strategies and Support</b>	Education about the disease, being busy with their jobs, fun activities with friends helped some patients cope. Others reported that traditional medicine, water therapy and heat therapy seemed to alleviate pain symptoms.	-	Women described they had learnt to cope by not feeling victim to the disease, but taking responsibility for living.	Women used problem-focused and emotion-focused strategies to cope.
<b><u>2<sup>nd</sup> Order Interpretations</u></b>	Endometriosis can adversely affect women's lives including physically, sexually, psychologically and socially. There is a need for improved health services and support for endometriosis patients.	Treating the major symptoms of endometriosis like dyspareunia, dysmenorrhea and non-menstrual pelvic pain may be helpful in reducing fatigue significantly.	Living with severe painful endometriosis signified a struggle for coherence. To live with the condition, women searched for understanding, coping and meaning.	Understanding patient experience with regard to living with endometriosis is valuable in assessing the needs of patients, developing interventions and improving patients' well-being.

**APPENDIX 11b Concepts, 1<sup>st</sup> and 2<sup>nd</sup> order interpretations**

<b>Concepts</b>	<b>Mellado et al. (2016)</b>	<b>Hudson et al. (2015)</b>	<b>Moradi et al. (2014)</b>	<b>Denny et. al (2009)</b>
<b>Disease symptoms</b>	Pain	Painful sex, infertility, fatigue	Severe pain sometimes accompanied by vomiting and nausea	Painful periods, heavy bleeding, painful sex, pains
<b>Health Services Experience</b>	Lack of understanding and misconception about endometriosis among the patients.	-	Women were often misdiagnosed and treated for appendicitis, ovarian cyst, ectopic pregnancy, etc.	Some patients endured the side effects of treatment in order to reduce pain, but others found them unbearable and discontinued treatment.
<b>Isolation &amp; Limited Social Participation</b>	Several women reported isolation from family and friends.	Endometriosis prevented many women from meeting friends and family, participating in classes, hobbies, physical activity and sports.	Women reported a reduction in social activity, opted to stay at home and missed events especially because of pain, bleeding and fatigue.	Pain caused disruption to their social relationships.
<b>Coterie of Emotions</b>	-	Women experienced feelings of loss, grief, distress that their lives had not followed the expected trajectory, due to infertility.	Most women felt angry, depressed, powerless, weak, defeated, frustrated, exhausted, and felt like a burden to others.	For women, the pain and other symptoms were severe and worrying.
<b>Limited physical</b>	-	Walks, attending events	Women who had little	-

<b>functioning</b>		such as weddings, concerts and parties were all disrupted.	children were unable to care for them as they would like.	
<b>Sex &amp; Intimate relationships</b>	Disease resulted in avoidance of partner intimacy and sometimes the end of a relationship.	Sex was reported to be non-existent or rare in their relationships.	Decrease in frequency of intercourse, avoiding sex for fear of pain and failure to have orgasm caused frustration and put a strain on their relationships.	-
<b>Infertility</b>	-	Cultural dialogues tend to position parenthood as a normative biographical expectation for women to a greater extent than is the case for men.	Infertility was a reported concern and a threat for breaking up a relationship.	-
<b>Work life &amp; Education</b>	-	Disruption to working lives was experienced not only by women but also by their partners. An impact on women's ability to work full time or in their chosen careers resulted in a reduced household income.	Women reported taking time off school and being less productive at work and in school. Whilst some had to give up their favourite job or lost a promotion.	-

<b>Coping and Support</b>	-	Being in a marriage or relationship can both reduce and compound the stresses associated with living with endometriosis	In addition to current medical treatments, complementary or alternative therapy and lifestyle changes such as exercise, diet and good sleep were used to manage their endometriosis.	Women viewed the possibility of future pain and continuous treatment as the nature of endometriosis, rather than as failure of biomedicine
<b><u>2<sup>nd</sup> Order Interpretations</u></b>	A cycle involving miscommunication between women and HCPs led to frustration, then to various degrees of isolation. Social isolation, in turn, decreases interaction between women and their partners, family, friends, as well as with HCPs.	The patient's illness experience is shaped by intersecting mediating factors like gender, ethnicity and being in a relationship.	Better understanding of the long term and wide-ranging impact of endometriosis on women's lives could be useful in improving patient's life experiences.	The gendered perception about endometriosis is integral to the uncertainty around the diagnosis, disease trajectory experienced and the future envisaged by women.

**Appendix 11c Concepts, 1<sup>st</sup> and 2<sup>nd</sup> order interpretations**

<b>Concepts</b>	<b>Markovic et al. (2008)</b>	<b>Denny &amp; Mann (2007)</b>	<b>Butt &amp; Chesla (2007)</b>	<b>Huntington &amp; Gilmour (2005)</b>
<b>Disease symptoms</b>	Period pain, heavy periods	Dyspareunia	CPP, dyspareunia	Abdominal pain, heavy periods, abdominal 'bloating', bowel problems, diarrhoea, constipation, backache, painful urination, dyspareunia.
<b>Health Services Experience</b>	Women believed that they got the required support from doctors due to their confidence in rejecting the 'psychologization' of their physical pain, ability to navigate the healthcare system and negotiate their healthcare needs.	-	Erroneous explanations were frequently offered by HCPs and self-advocacy often led to adversarial relationships with HCPs.	Women opted for medical and hormonal options which were palliative but disruptive to normal functioning, work and relationships.

<b>Isolation &amp; Limited Social Participation</b>	Painful periods and stigma prevented some from participating in many social events.	Women who experienced endometriosis-associated dyspareunia reported a negative effect on their self-esteem.	A regimented healthy lifestyle eliminated eating out at restaurants and socializing during late hours with friends.	Reduction in social activities as a response to pain and other symptoms.
<b>A Coterie of Emotions</b>	Drug treatments sometimes led to weight gain, loss of libido, depression and poor emotional health.	Women reported feeling guilty, unfeminine or unattractive when they were not able to engage fully in sex.	Making sense of symptoms and getting appropriate care were puzzling and fraught with uncertainty for the women.	Fear, helplessness, feelings of need to regain control.
<b>Limited physical functioning</b>	-	-	CPP had a disabling and unpredictable out-turn for all of the women.	Pain resulted in diminishing work hours.
<b>Sex &amp; Intimate relationships</b>	Women who were told to fall pregnant quickly to avoid infertility believed that their bodies were seen independently from their intimate relationships with men.	Some women would begin sex with their partner, but this would sometimes have to be curtailed or endured.	Couples developed strategies or positions to make sex more comfortable.	-
<b>Infertility</b>	For some women, uncertainty about their fertility potential, rather	-	Possibilities of childbearing were dramatically altered.	Women were told to have children as a 'treatment' option for endometriosis.

	than pain, was pivotal in their experience of endometriosis.			
<b>Work life &amp; Education</b>	-	-	Previously active, healthy and productive women had their capabilities significantly compromised.	Women feared they might be perceived as malingerers for missing work.
<b>Coping and Support</b>	Women sought information by talking to other endometriosis patients.	Most women described their partners as very supportive.	Women learned to conduct business out of their homes. Supportive partners prioritized the healthcare needs of women.	Women made major lifestyle changes after experiencing the limitations of conventional surgical and medical treatments in controlling pain.
<b><u>2<sup>nd</sup> Order Interpretations</u></b>	Physician–patient communication is critical for effective care. Women’s socio-demographic background, family health history and wider social beliefs, shaped illness experiences.	Dyspareunia was experienced differently. Some women curtailed sexual activity, others coped with the pain; either because they desired pregnancy or because of the importance attached to physical intimacy.	It is essential to provide healthcare that extends beyond the traditional biomedical model to include a relational focus of care when caring for women with endometriosis-associated CPP.	Case studies focusing on endometriosis in health professional education programmes would enhance diagnostic skills and knowledge development.

Appendix 11d Concepts, 1<sup>st</sup> and 2<sup>nd</sup> order interpretations

Concepts	Jones et al. (2004)	Denny (2004)	Cox et al. (2003)
<b>Disease symptoms</b>	Severe pains, generally feeling unwell.	“Intense, overwhelming pain”. Nausea and vomiting when pain is at its worst.	Dysmenorrhea
<b>Health Services Experience</b>	Pain was passed off by doctors as merely “women’s problems” or “normal menstrual pain”, warranting no further investigation.	Women generally found more relief from surgical than medical treatments, and suffered fewer complications.	Women felt that gynaecologists who did not specialise in endometriosis were just as dismissive as general practitioners (GPs).
<b>Isolation &amp; Limited Social Participation</b>	Believing that others felt their symptoms were being made up led many women to doubt themselves and stay isolated.	Women found their social lives curtailed, others found that their social contacts diminished as illness forced them to cancel events.	Women reported feeling worthless and hated being compared to other women who are able to manage monthly periods and ‘get on with life’.
<b>A Coterie of Emotions</b>	Women expressed worry and despair over the disease.	Patients expressed a mixture of optimism and pessimism.	A sense of relief and validation brought on by getting a diagnosis.
<b>Limited physical functioning</b>	Participants reported having problems with mobility.	-	-
<b>Sex &amp; Intimate relationships</b>	Women described themselves as a ‘bad person’ because they could not enjoy intercourse and	Sexual difficulties put a strain on relationships and was a major reason for break-ups.	-

	because of the effect it was having on their partners.		
<b>Infertility</b>	Women reported feeling inadequate, depressed, worried about infertility.	-	Some women reported marriage breakdown because it was so hard for partners to live with the persistence of the disease.
<b>Work life &amp; Education</b>	Participants described feeling guilty for taking time off work.	Living with severe pain usually entailed lost productivity. While taking strong analgesia limited the type of work that the women could undertake.	Women reported losing jobs because of having to take too much sick leave.
<b>Coping and Support</b>	Women managed their symptoms by experimenting with various combinations of drugs. Some used non-drug therapy (heat) and nutrition.	Women with supportive partners tended to feel that they were lucky to have such support, rather than view it as an expected part of the relationship.	Getting information about endometriosis was liberating and helped patients to be more assertive. Women used natural therapies, diet and spiritual healing.
<b><u>2<sup>nd</sup> Order Interpretations</u></b>	A greater awareness of the multi-dimensional impact of endometriosis should be beneficial in the management of patients	Endometriosis affects every aspect of a woman's life. Nurses can also be advocates for women who find that their symptoms are trivialized or dismissed.	The endometriosis experience is one of marginalisation, loss, struggle and grief. Where nurses aim to give holistic care, an understanding of the experience of living with this chronic illness is vital.

**APPENDIX 12a** Key concepts from the studies with quotes from respondents

Concepts	Namazi et al. (2021)	DiBenedetti et al. (2020)	Hållstam et al. (2018)	Roomaney and Kagee (2018)
Disease symptoms	<p>“[...] under my belly was very painful, pain was very severe and not tolerable at all”.</p> <p>“My periods are very irregular [...]”</p> <p>“My hemorrhage is very severe during my period” [...]</p>	<p>“Like somebody completely drained your energy out of you. And it’s really hard to like function and complete your daily tasks as you normally would if it wasn’t that time of the month.”</p>	<p>”Bleeding, there’s so much you don’t understand where it’s all coming from. And such pain. Well the pain is indescribable!”</p>	<p>“I would be climbing the walls with pain, it would be just – I couldn’t function, I couldn’t do anything I would be screaming and crying.”</p>
Health Services Experience: delayed diagnosis, inadequate information about disease, perception about gynaecological services	<p>“I have undergone surgery for several times, but my illness is recurring.</p> <p>“I was disappointed with the treatment of the</p>		<p>”just lying in the chair ... it’s pure trauma. For me it’s just, like, an assault in this chair where they’ve, sort of, almost pushed me down and, like, just now, ‘you ... you’re a</p>	<p>[no quotes]</p>

	disease”.		woman, now we’re going to push that up you....”	
Isolation and limited social participation	“My mother-in-law always asks me when I want to have children. So, I would prefer not to see them”.	“I’d rather stay at home than to go and be social.”	“It was...it was ... It was like a great big hole just to disappear into”.	[no quotes]
Limited physical functioning: immobility, role performance	“When I have pain, I can’t do anything at all.”  “My bleeding and pain during menstruation is so much, which I can’t go to work at all.”	“Well if I needed to do laundry on that day, during that period, it probably wouldn’t get done.”  “I don’t do anything. I will sit at home. I don’t really even go to church with this. I don’t feel like doing nothing.”	”But I feel ... hopeful is the word, I think. You feel limited and, not free, somehow... You sort of want to do things and be active and that, that part of me is no longer there ... So it’s taken away much of the spark of life, my joy of living and that”.	“It does make me feel like I can’t do things and I don’t want too ... My body feels like it wants to run, wants to walk fast, but I just can’t. I feel like I’m trapped sort of”.
A Coterie of Emotions: uncertainty, sadness,	“I did not like to be alive, I was very annoyed, [...]	“It’s more just kind of feeling disappointed	”then I was back down in that dark hole again,	“for a long time, I felt ... this deep, deep, deep

<p>despair, grief, guilt, depression, worry, lethargy, panic, optimism, hope</p>	<p>It was so hard to breathe, I wanted to die”</p>	<p>because you can't do as much as you want to do.”</p> <p>“I would say I'm a little more depressed during my period. A little bit more emotional. More sensitive.”</p> <p>“[When fatigued, I am] Short tempered, irritable, less understanding and patient.”</p>	<p>'cos then you don't know when this is coming again, aha, is it here again?... even though I've had operations ...? you wonder every day, you want answers, you don't get any answers for there is no answer.”</p>	<p>sadness ... it's as if there's this heaviness over me... It feels like I can't overcome it. (It is like a dark cloud or something”.</p>
--	--	---	--	--

<p>Sex and Intimate Relationships</p>	<p>"I constantly say to my husband that we should be separated" [...]</p> <p>"It's so annoying that I have no desire for intercourse at all".</p> <p>"During intercourse, I have pain so much that I never enjoy it".</p>	<p>"Our sex life sometimes sucks. Because I'm just like, 'I don't feel like it.'"</p>	<p>"he [partner] said: I see no future for us and, er... you're sick and things don't look very bright, he said. Er: I want to be able to, I want to be together with a girl who I can go running with and skiing with and do things together with. And you can't do these things."</p>	<p>"It's [sex is] painful ... but he doesn't understand because you are my wife and I want us to be intimate and you're always running away, so I would work late to avoid that. So and one day he just didn't come home".</p>
<p>Infertility</p>	<p>"Sometimes I think I have weakness due to endometriosis and I can't be a mother, so I feel I'm different from others".</p> <p>"I tried all the techniques of fertility, but it did not work. I'm disappointed with</p>	<p>[no quotes]</p>	<p>[no quotes]</p>	<p>"I was in a long relationship then as well and then you have this fear at the back of your mind ... what if he leaves me for another woman because I can't give him a child?"</p>

	having a child”.			
<p>Coping strategies and Support:</p> <p>acceptance; resignation; alternative therapies; hormonal, palliative or surgical treatment; spirituality; supportive and non-supportive partners, employers or families.</p>	[no quotes]	[no quotes]	<p>”When I saw that I could manage, when I decided there’d be no excuses, then I got my life back ”[...]</p>	<p>“I will get home. I will be in pain. I will go to the kitchen, I will cook food, I’ll do everything I have to do. I will tell him I’m in severe pain. He won’t help me in any way. [...] and he would still expect me to have intercourse with him.”</p>
Work life and Education	<p>“I have to take leave to follow up treatment, but in most cases, my chairman disagrees with the leave request”.</p>	<p>“On those bad days when I’m at work, it’s hard to focus during those days, and so I would say sometimes I do leave the office early because I’m useless.”</p>	<p>[<i>speaking of her work</i>]</p> <p>“But things aren’t the slightest bit like they were supposed to be, kind of. This disease ruined everything”.</p>	<p>“I feel that I am stranded here I think I’m in a comfort zone. ... I don’t know if another place or company will be so understanding”.</p>

Appendix 12b Key concepts from the studies with quotes from respondents

Concepts	Hudson et al. (2015)	Mellado et al. (2016)	Moradi et al. (2014)	Denny et. al (2009)
Disease symptoms	“The fertility thing yeah it’s a big worry and I think I like to think I’ll deal with it but I think I haven’t dealt with it” [...]	“I would like to understand why I am having this pain all over again”.	“I remember getting the first lot of symptoms like someone had heated a knife and was ripping it up through my stomach. That’s how it felt. I didn’t know how else to explain it”.  “Yeah, lots and lots of pain and I couldn’t move. There was always constant pain. I didn’t have a day without pain...”	“I always suffered from quite bad periods, painful periods, heavy bleeding for the first couple of days every cycle... It just became a way of life. It became the norm and I assumed that’s just what happens.”
Health Services: delayed diagnosis, inadequate information about disease,	[no quotes]	“I actually do not know what my problem is”.	“With two of my doctors, I had to explain to them what endometriosis is and how to treat it”.	[...] “I went subsequent times [to the doctor] and I always just got told, I mean it was dismissive, it’s what girls go through

		<p>"I've had a strong desire of stopping the treatment".</p>	<p>"I even got banned from some doctors' surgeries for getting angry at them for not listening".</p>	<p>it's what happens, it's period pain.</p> <p>"I first sought medical advice when I was 32–33, but with hindsight I would say that I was getting it for 5 or 6 years before that. I just went with it really thinking I was getting older, my body was changing".</p>
<p>Isolation and Limited social participation</p>	<p>"You can't plan anything. Can you go on holiday? No, you can't go on holiday because I don't know how I'm going to feel. Can we plan a weekend away? No I can't because I might be on or I might be ovulating or I might just be in pain".</p>	<p>"My relatives always avoid my company. No one understands me"</p>	<p>"I don't tend to socialize and keep to myself because of pain and bleeding. As a result, I have missed out on travel, concerts, ... and school... events etc".</p> <p>"Overall endometriosis has made me live a very solitary life".</p>	<p>[no quotes]</p>

<p>Limited physical functioning: immobility, role performance</p>	<p>“Like, when my cousin got married . . . I have no choice but to go to the wedding whether I was fit enough or not fit enough [... ] was like, ‘If I don’t go it’s going to cause a problem between dad and his brother’ . . . just to keep the peace I went to the wedding”</p>	<p>“I cannot wait for the weekend to stay at home alone”.</p>	<p>“Prior to having endometriosis, I used to run every day and was very active. For the last six months... my level of exercise was severely reduced. I could only walk about once or twice a week and it was very painful”.</p>	<p>[no quotes]</p>
<p>Coterie of Emotions: uncertainty, sadness, despair, grief, guilt, depression, worry, lethargy, panic, optimism, hope</p>	<p>“It always comes back to this, my panic to have a child . . . the panic is there when really our first year of marriage should be very calm and enjoyable. But for me there’s that underlining panic”.</p>	<p>“I am always in a bad mood. I stay at home all the time”.</p>	<p>“I gained weight and felt dissatisfied with my body. It also impacted on my self-confidence. I began wearing more baggy clothes [...] and had general feelings of being lethargic and spaced out”.</p> <p>“And I even feel depressed with myself. I feel angry with myself and</p>	<p>“At the moment I’m very positive but slightly apprehensive as to what the future holds, e.g., fertility issues...”</p> <p>“Personally don’t think I will ever be pain free, and I don’t think I will ever get rid of endometriosis”.</p> <p>“Hopefully I’ll get better</p>

			I go I don't want to deal with it anymore".	and better".
Sex and Intimate Relationships	<p>"I would have liked to have had lots more sex in my life".</p> <p>"I do feel bad that we probably haven't got, as they say, a normal sex life, to say like our other friends and couples" ...</p> <p>"It was just painful and then it just got to a point where we just didn't have sex. We went through a period where we hadn't had sex for 3 years... I just felt I wasn't doing my wifely duties and just being abnormal".</p>	<p>"I'm divorced. I do not have a boyfriend, and I no longer want to be in a relationship".</p> <p>"My sexual life ended".</p> <p>"I always avoid my husband"</p>	<p>"It got progressively worse to the point where I would actually be crying during and after sex".</p> <p>"I have never, ever had sex that wasn't painful. I'm nearly 30 years old. I want to have sex. I mean it affects my relationships..."</p>	[silent]

<p>Infertility</p>	<p>“Amongst Asian couples if you can’t have a child, it’s almost like you’re a waste of space, they don’t want to have a daughter-in-law or a wife who can’t have a baby?”</p> <p>“The fertility thing yeah it’s a big worry... And I have accepted it but it scares me still...”</p>	<p>[no quotes]</p>	<p>“have been married and the marriage broke up...because I couldn’t fall pregnant plus I guess I was moody and in a lot of pain and he couldn’t put up with that...”</p>	<p>“I think it did take a long time to get pregnant, which makes me think now, looking back, that perhaps this had been going on for longer than I’d realized”.</p>
<p>Coping strategies and Support:</p> <p>acceptance; resignation; alternative therapies; hormonal, palliative or surgical treatment; spirituality; supportive and non-supportive partners, employers or families.</p>	<p>“I was new to this . . . this whole world of endometriosis and if it had happened before I was married or a little bit later, that would have been alright for me, but it all came at the same time. I think that’s what threw me...”</p>	<p>“One thing I have learned, never to complain”</p>	<p>“I guess I’m lucky in my employer... working for the public service quite understands”.</p> <p>“I did at one stage try marijuana [...]”</p> <p>“I used to be a smoker... and I just quit and like yeah it’s all good, I’m over</p>	<p>“It would be great not to suffer from any pain. Hopefully this forthcoming lap [laparoscopy] will be my last, and the pain and bleeding will stop”.</p> <p>“It’s a hard illness because you don’t die of it and therefore it is given a secondary importance.”</p>

			it now”.	
Work life and Education	“gave up my job because I couldn’t cope ... I kind of felt like I’d failed . . .”	[no quotes]	<p>“I left my part time job because I was not able to work due to severe symptoms and undergoing two surgeries...”</p> <p>“Financial [impact]; massive, because you’re taking so much time off work. ... not being able to pay those bills, it does put a massive stress on you”.</p> <p>“I’ve been an elite athlete [Sport name] on [Name] team since I was 14 .... Pain, tiredness and fatigue due to endometriosis had big impact on my sporting life”.</p>	[no quotes]

**Appendix 12c Key concepts from the studies with quotes from respondents**

<b>Concepts</b>	<b>Markovic et al. (2008)</b>	<b>Denny and Mann (2007)</b>	<b>Butt and Chesla (2007)</b>	<b>Huntington &amp; Gilmour (2005)</b>
Disease symptoms	<p>“All through my teenage years I had very painful, heavy periods ... I would see doctors that always say things are fine ... They would say that’s normal ...”</p>	<p>“The intercourse will start but I have to say ‘no’, and then there’s other times when I’ll just suffer in silence.”</p>	<p>“I always feel pain during intercourse” [...]</p> <p>“Sometimes it feels like I have got a shovelful of burning hot charcoals that have been placed in my pelvis and are just sort of burning a hole in the pelvic area. Sometimes it feels like, as I mentioned, sitting on a dagger or having a knife impaling me” [...]</p>	<p>[...] “I was in excruciating pain constantly”</p>

<p>Health Services: delayed diagnosis, inadequate information about disease, perception about gynaecological services</p>	<p>“When I first went to see the gynaecologist, he said, go out and have a child. You’re telling an 18-year-old girl who’s single to go out and have a baby” [...]</p> <p>“went to a lady doctor ... and she just said, ‘Well, look, I think you’ve got depression’ and tried to give me some antidepressants”.</p>	<p>[no quotes]</p>	<p>[...] “I really find it’s very shameful the way it’s not addressed by physicians whether it be during the whole endo thing or whether it be now with the hysterectomy. They just don’t address the aftermath or the side issues and even just like trying to find books, it’s difficult” [...]</p>	<p>“there’s nothing to show there’s no scar, there’s no spots there”</p> <p>[...] “didn’t get diagnosed and just took lots of drugs and really I couldn’t do anything”</p>
<p>Isolation and Limited social participation</p>	<p>“[...] and I do get a bit cranky I guess and I know I shouldn’t”.</p> <p>[...] “I was embarrassed to go to school because of breakthrough bleeding.”</p>	<p>[no quotes]</p>	<p>[...] “When you have pain all the time, it wears on you. You get very tired. Not only emotionally, because it reminds you all the time, but physically” [...]</p>	<p>“it can be quite a secret little world you live in”</p>

Limited physical functioning: immobility, role performance	[no quotes]	“He feels rejected. You know he tries to put a brave face on it. He tries to be understanding, but he is a bloke. Yes he feels totally rejected.”	“It hurts too much to bend over . . . He [partner] has to sit there on the toilet and wait. I have to have him pick up the shampoo and stuff for me” [...]	[...] everything shut down really at that stage I mean at that acute stage you know... I couldn't work anymore. I couldn't really function” [...]
A Coterie of Emotions: uncertainty, sadness, despair, grief, guilt, depression, worry, lethargy, panic, optimism, hope.	“[...] Basically I got to the point where pretty much four out of four weeks were painful and uncomfortable ... I was all worried about it. I went and had an ultrasound and had a really large cyst on, on my ovaries”.	“I do get worried that he's going to go off and meet someone who can give him a lot more than I can.”  “I felt guilty and inadequate because I didn't want sex...I've felt that I blame myself, and feel inadequate.”	[...]” I feel guilty because I cannot provide what I should to him [partner]”.  [...] “I'm hesitant because he [doctor] really would have to watch the endo because it could come back. And that scares the living daylights out of me”.	“very hard journey but it's also been a doorway, to something else to something new”.
Sex and Intimate Relationships	[silent]	“The intercourse will start but I have to say 'no', and	[...] ”And he always thinks that I don't like	[no quotes]

		<p>then there's other times when I'll just suffer in silence."</p> <p>"You're with the person you love and ... You're having sex and you have to stop because it starts hurting".</p>	<p>him or I don't love him because I don't want to have sex with him. And I keep explaining to him that I don't feel comfortable. It always hurts . . . It is really, really so painful" [...]</p>	
Infertility	<p>"But after all those operations I've had, to this day, I'm now 27 years old, I still have trouble".</p>	[no quotes]	<p>[...] "And then, of course, there's hysterectomy . . . And have I considered a hysterectomy? Yes".</p>	[no quotes]
Coping strategies and Support: acceptance; resignation;	<p>"I struggle with it, and that's the way I've dealt with it, it's just a struggle,</p>	[no quotes]	<p>"[...] He [partner] dries my legs when I get out of the shower so that I</p>	[no quotes]

<p>alternative therapies; hormonal, palliative or surgical treatment; spirituality; supportive and non-supportive partners, employers or families.</p>	<p>and I've just learnt that it is a part of my life"</p> <p>'I've got energy now, I'm positive and it's so lovely not having pain".</p>		<p>don't have to bend over and dry them".</p> <p>"[...] And, yeah, do other things in my life that are positive so I don't have this on my mind all the time so it does consume me [...] because it's going to be a richer life for me and for Frank [husband] too".</p>	
<p>Work life and Education</p>	<p>"[...] I was taking more and more time off school, and I thought this was no good" ...</p> <p>'I would have at least two days off a month of school, so it was pain with heavy periods".</p>	<p>[no quotes]</p>	<p>"When I had my second surgery, he [husband] had to take, he took two weeks off and that was the only vacation he got. He took it off because he needed to take care of me, because I, I couldn't do anything. I couldn't get</p>	<p>"[...] And I told her [manager] what it was like and she said 'oh god it's really terrible well maybe we should look at whether you should be working at all.'"</p> <p>"Couldn't work for a year after the surgery. Had to</p>

			out of bed. I couldn't move. I couldn't go to the bathroom. I couldn't do anything".	sell business, didn't have the energy to advertise so didn't get much for it."
--	--	--	--	--

Appendix 12d Key concepts from the studies with quotes from respondents

Concepts	Jones et al. (2004)	Denny (2004)	Cox et al. (2003)
Disease symptoms	<p>“When the pain comes you know, just round on the right hand side that’s where the pain actually comes and it is severe”.</p> <p>“I couldn’t stand up straight because I felt as if I was just cramped all inside the stomach . . . some points I couldn’t even sit down because it was painful in the back passage.”</p>	<p>“The best way I can describe it is if you, sort of, imagine someone with nails clawing inside your stomach. It’s that intense and it almost comes in waves”.</p>	[no quotes]
Health Services Experience: delayed diagnosis, perception about gynaecological services	<p>[...] “now I realize I had it for a very long time, since I was probably about twenty, twenty-two and I’m now thirty-nine and I didn’t get diagnosed properly until 1996.’</p>	<p>“And the doctor said ‘You are unlucky. You suffer from bad periods’”.</p> <p>“So when I saw the consultants they would basically say ‘So you’ve got pain?’ And I’d say ‘Yes’, and that would be it. And I’d want someone to</p>	<p>[...] “the victim of their (GP’s) disbelief and trivialization”.</p> <p>“too young to have endometriosis”.</p>

		say 'Well, what type of pain is it?'...They just seemed to be writing a lot, and not really looking at me".	
Isolation and Limited Social Participation	<p>"It is just the restrictions it puts on you. You just have to think before you do anything. If you are invited for a night you have to say how am I going to feel. Am I going to be able to make it work [...] It is part of my life."</p> <p>"I think that's the worst part. You know not being able to tell people how you feel. People expect you to always, always, be chirpy and chippy.'</p>	<p>"[Social activities] just went by the board...At the moment, I've got no social life at all".</p> <p>"I wasn't able to go out and enjoy myself, and I was in a serious relationship for 3 years at that point and ultimately [endometriosis] made my relationship break up. My partner couldn't cope with the way I was".</p>	[no quotes]
Limited physical functioning: immobility, role performance	<p>"Now I really am beginning to feel it is affecting my quality of care that I give to the children . . . I don't feel well enough to give them the care" [...]</p>	<p>"Sometimes it was so bad that I couldn't move. I was paralyzed with the pain – really intense. I would say it was like someone knifing you".</p>	[no quotes]

<p>Coterie of Emotions: uncertainty, sadness, despair, grief, guilt, depression, worry, lethargy, panic, optimism, hope.</p>	<p>[...] “You’re trying all these different things and you end up with a cocktail of tablets and there is nothing that anybody can do about it.”</p>	<p>[...] “So it is quite a frightening thought. Because you can look at your life in the hands of doctors and these drugs, but none of it’s that proven and it’s all got pretty horrible side-effects”.</p> <p>“I just don’t know how I am going to put up with this for the rest of my life. At the moment I feel that I’ve got, I suppose, a sentence over me of pain”.</p>	<p>[no quotes]</p>
<p>Sex and Intimate Relationships</p>	<p>[...] “it [sex] will really hurt and sometimes it hurts during [...] but it is afterwards, about half an hour or so afterwards I am in a lot of pain for about 2–4 hours after that . . . it makes me feel not very nice as a wife to my husband” [...]</p>	<p>“I was experiencing a lot of pain on penetration...I went to the doctors” [...]</p> <p>[...] “Sex was painful, and that would cause a problem because I wouldn’t be able to have sex quite as much [...] That put a strain on the relationship”.</p>	<p>[no quotes]</p>
<p>Infertility</p>	<p>“Obviously it [endometriosis] gave me five years of infertility for a start. Desperation for children... I used to cry a lot</p>	<p>[no quotes]</p>	<p>[no quotes]</p>

	and feel desperate. I used to hate looking in peoples prams [...]"		
Coping strategies and Support:	"my boss is very understanding but I always felt guilty about it so I would always try and work an extra day to try and make it up."	"I'm blessed with a husband who has stuck through so much and has been to every medical appointment I've ever had. He has held my hand through the internal examinations...What would life be like if I didn't have him?"	[no quotes]
Work life and Education	"[...] The pains were getting worse, and obviously I was off work again, not going to work . . . because of the pains I just couldn't [...]"	"Work have been brilliant. They literally told me [to] take as much time off as I want, work what hours I want. [They asked] is there anything they could do to help, i.e. write to the consultant"	[no quotes]

