Journal Club

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"Impact of endometriosis on women's lives: a qualitative study"

BMC Womens Health. 2014; 14: 123.
Published online 2014 Oct 4. doi: 10.1186/1472-6874-14-123

PMCID: PMC4287196
PMID: 25280500

Impact of endometriosis on women's lives: a qualitative study

Maryam Moradi, Melissa Parker, Anne Sneddon, Violeta Lopez, and David Ellwood

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Abstract

Background

This study aimed to explore women's experiences of the impact of endometriosis and whether there are differences across three age groups.

Methods

A qualitative descriptive design was conducted using semi-structured focus group discussions with 35 Australian women with endometriosis, in three age groups. All tape-recorded discussions were transcribed verbatim and read line by line to extract meaningful codes and categories using NVivo 9 software through a thematic analysis approach. Categories were then clustered into meaningful themes.

Results

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Title:

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Author:

Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D.

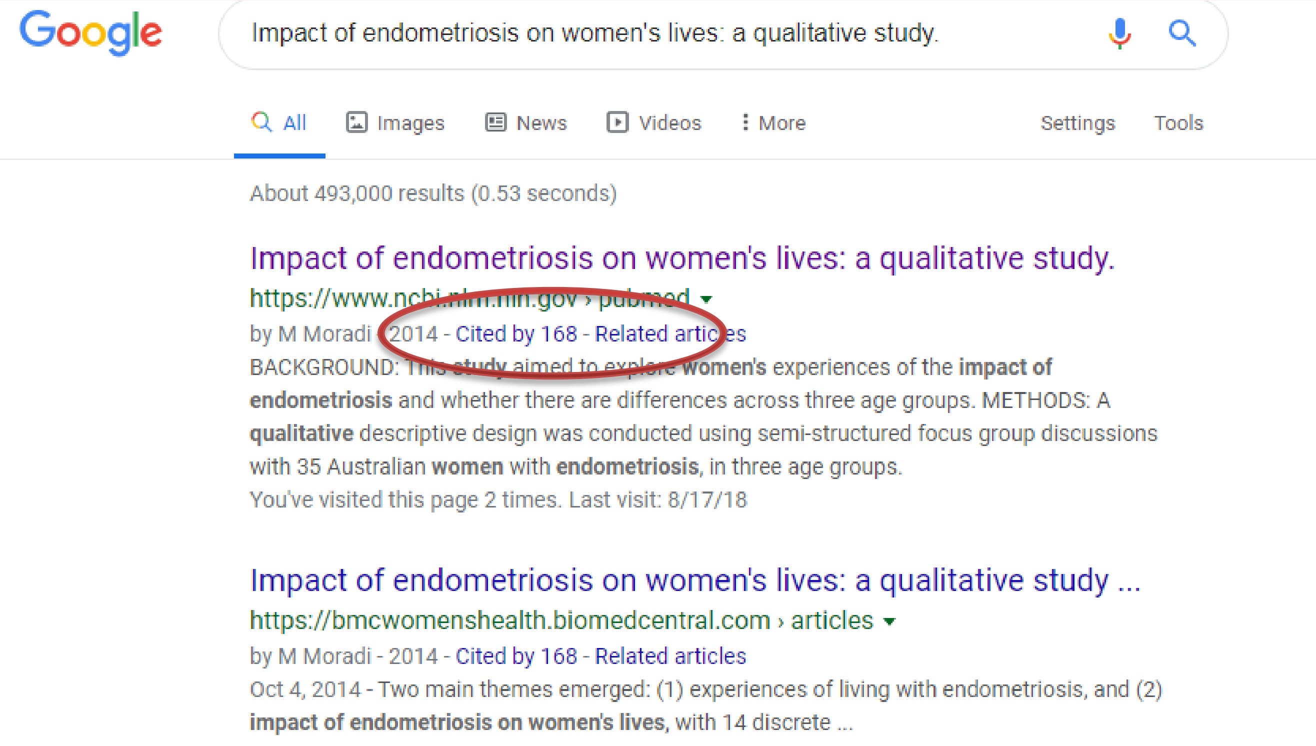
Journal:

BMC Womens Health.

Reference:

Moradi, M., Parker, M., Sneddon, A., Lopez, V., & Ellwood, D. (2014). Impact of endometriosis on women's lives: a qualitative study. BMC Women's Health, 14, 123. doi: 10.1186/1472-6874-14-123.

Article: Cited by 163



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BACKGROUND: This **study** aimed to explore **women's** experiences of the **impact of endometriosis** and whether there are differences across three age groups. METHODS: A **qualitative** descriptive design was conducted using semi-structured focus group discussions with 35 Australian **women** with **endometriosis**, in three age groups.

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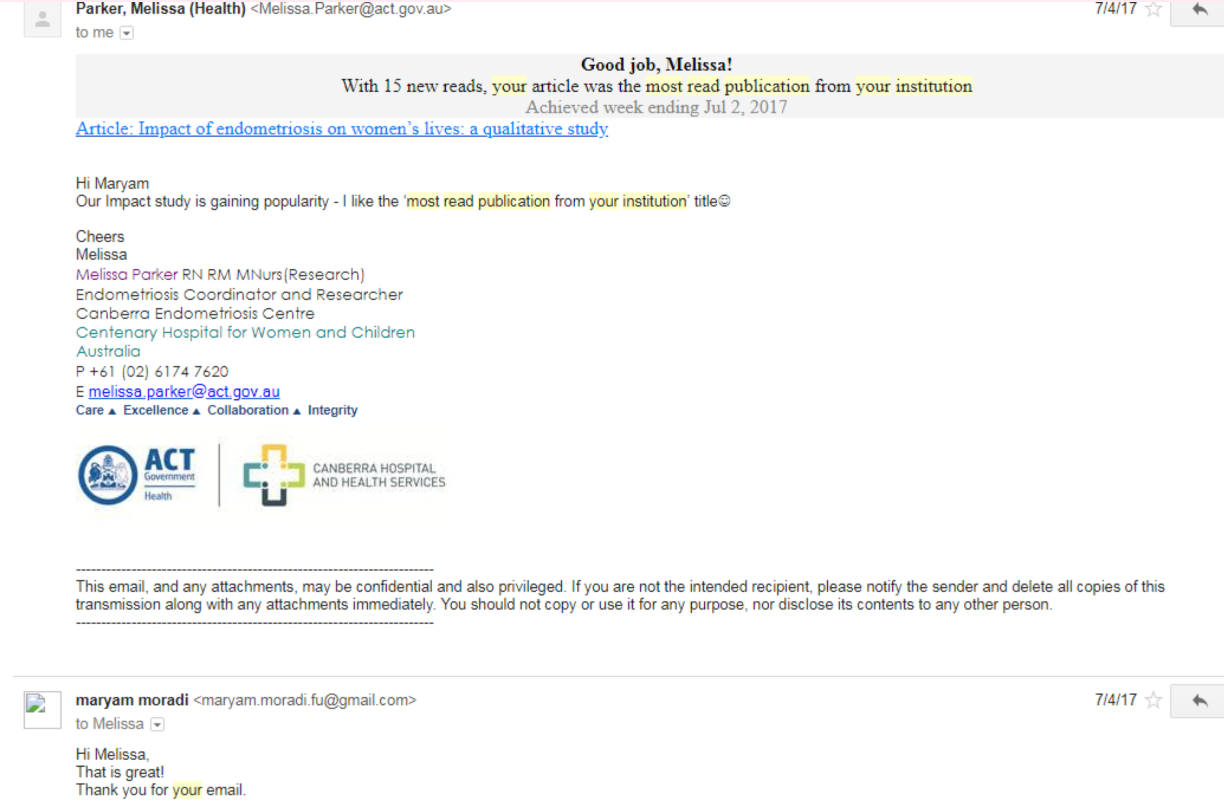

Parker, Melissa (Health) <Melissa.Parker@act.gov.au>
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Good job, Melissa!
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Article: Impact of endometriosis on women's lives: a qualitative study

Hi Maryam
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Cheers
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maryam moradi <maryam.moradi.fu@gmail.com>
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Hi Melissa,
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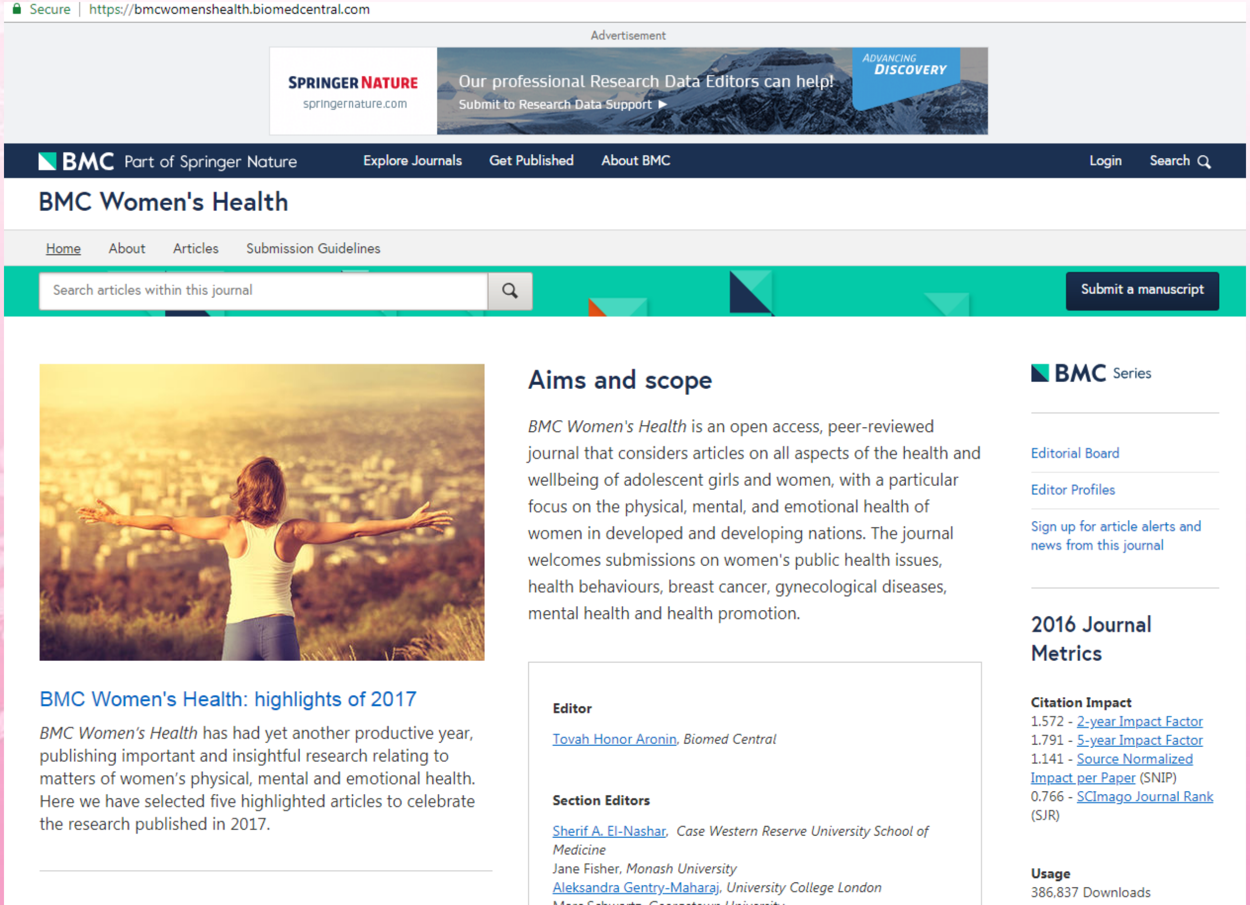
Journal information



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BMC Women's Health

Aims and scope

BMC Women's Health is an open access, peer-reviewed journal that considers articles on all aspects of the health and wellbeing of adolescent girls and women, with a particular focus on the physical, mental, and emotional health of women in developed and developing nations. The journal welcomes submissions on women's public health issues, health behaviours, breast cancer, gynecological diseases, mental health and health promotion.

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BMC Women's Health: highlights of 2017

BMC Women's Health has had yet another productive year, publishing important and insightful research relating to matters of women's physical, mental and emotional health. Here we have selected five highlighted articles to celebrate the research published in 2017.

2016 Journal Metrics

Citation Impact
1.572 - 2-year Impact Factor
1.791 - 5-year Impact Factor
1.141 - Source Normalized Impact per Paper (SNIP)
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is an open access, peer-reviewed journal that considers articles on all aspects of the health and wellbeing of adolescent girls and women, with a particular focus on the physical, mental, and emotional health of women in developed and developing nations. The journal welcomes submissions on women's public health issues, health behaviours, breast cancer, gynecological diseases, mental health and health promotion.

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Article history: peer review reports

Impact of endometriosis on women's lives: a qualitative study

Maryam Moradi, Melissa Parker, Anne Sneddon, Violeta Lopez and David Ellwood

BMC Women's Health 2014 **14**:123

https://doi.org/10.1186/1472-6874-14-123 | © Moradi et al.; licensee BioMed Central Ltd. 2014

Received: 30 May 2014 | Accepted: 29 September 2014 | Published: 4 October 2014

Back to article

Open Peer Review reports

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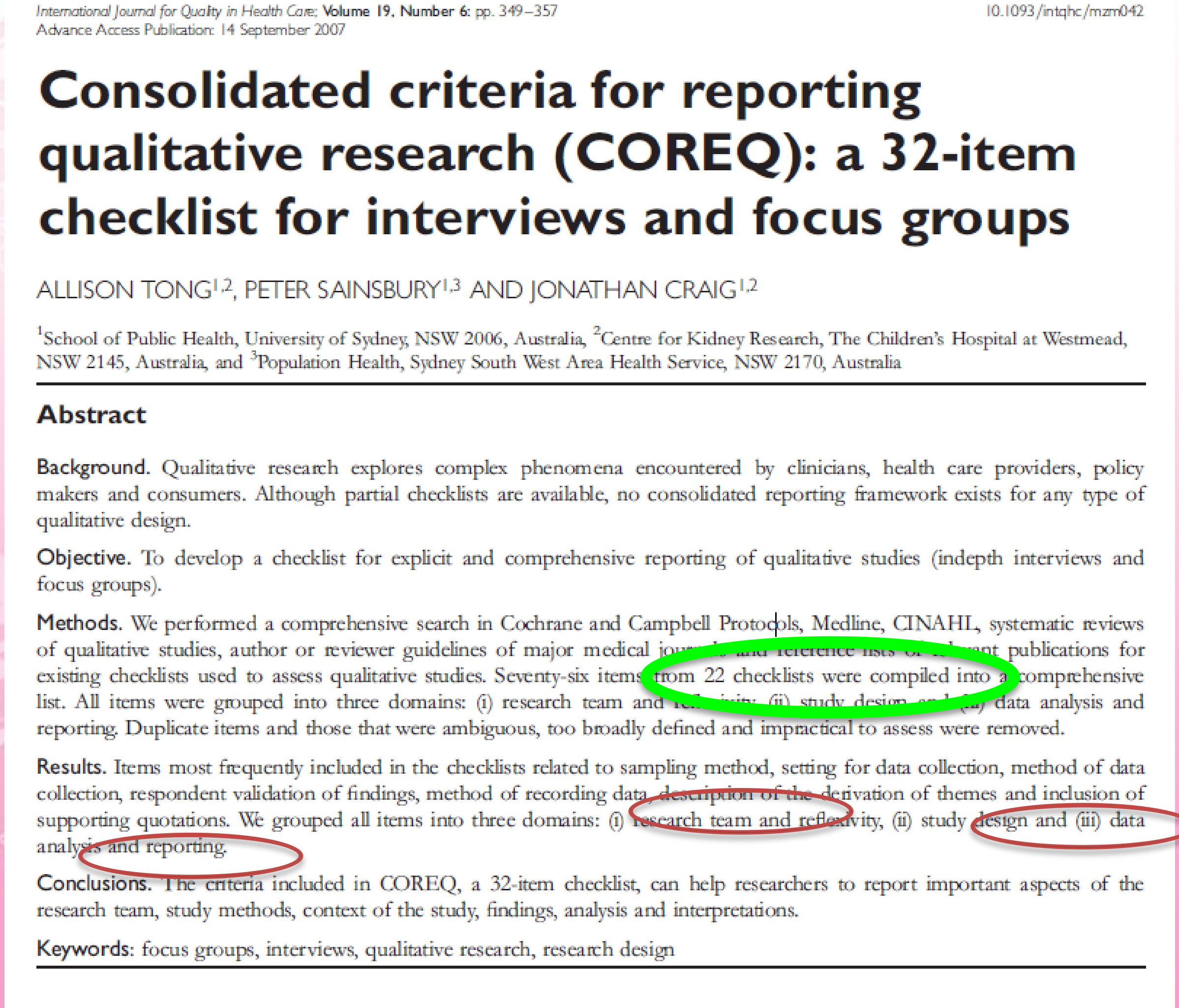
Original Submission		
30 May 2014	Submitted	Original manuscript
1 Jun 2014	Author responded	Author comments - Maryam Moradi
Resubmission - Version 2		
1 Jun 2014	Submitted	Manuscript version 2
19 Jun 2014	Reviewed	Reviewer Report - Jean Gilmour
23 Jun 2014	Reviewed	Reviewer Report - Carlos Souza
10 Aug 2014	Author responded	Author comments - Maryam Moradi
Resubmission - Version 3		
10 Aug 2014	Submitted	Manuscript version 3
12 Aug 2014	Author responded	Author comments - Maryam Moradi
Resubmission - Version 4		
12 Aug 2014	Submitted	Manuscript version 4
25 Aug 2014	Reviewed	Reviewer Report - Carlos Souza
30 Aug 2014	Reviewed	Reviewer Report - Jean Gilmour

Received: 30 May 2014,
Accepted: 29 September 2014,
Published: 4 October 2014

http://www.biomedcentral.com/1472-6874/14/123/prepub

Critical appraisal tools

- Journal instruction for Authors
- Mainly based on the Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist
- Overall use of the Critical appraisal skills programme (CASP)
- General checklist for all types of studies



International Journal for Quality in Health Care; **Volume 19, Number 6:** pp. 349–357
Advance Access Publication: 14 September 2007
10.1093/intqhc/mzm042

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

ALLISON TONG[1,2], PETER SAINSBURY[1,3] AND JONATHAN CRAIG[1,2]

[1]School of Public Health, University of Sydney, NSW 2006, Australia, [2]Centre for Kidney Research, The Children's Hospital at Westmead, NSW 2145, Australia, and [3]Population Health, Sydney South West Area Health Service, NSW 2170, Australia

Abstract

Background. Qualitative research explores complex phenomena encountered by clinicians, health care providers, policy makers and consumers. Although partial checklists are available, no consolidated reporting framework exists for any type of qualitative design.

Objective. To develop a checklist for explicit and comprehensive reporting of qualitative studies (indepth interviews and focus groups).

Methods. We performed a comprehensive search in Cochrane and Campbell Protocols, Medline, CINAHL, systematic reviews of qualitative studies, author or reviewer guidelines of major medical journals and reference lists of relevant publications for existing checklists used to assess qualitative studies. Seventy-six items from 22 checklists were compiled into a comprehensive list. All items were grouped into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting. Duplicate items and those that were ambiguous, too broadly defined and impractical to assess were removed.

Results. Items most frequently included in the checklists related to sampling method, setting for data collection, method of data collection, respondent validation of findings, method of recording data, description of the derivation of themes and inclusion of supporting quotations. We grouped all items into three domains: (i) research team and reflexivity, (ii) study design and (iii) data analysis and reporting.

Conclusions. The criteria included in COREQ, a 32-item checklist, can help researchers to report important aspects of the research team, study methods, context of the study, findings, analysis and interpretations.

Keywords: focus groups, interviews, qualitative research, research design

Domain 1: Research team and reflexivity

Domain 2: study design

Domain 3: analysis and findings

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

- ❖ Domain 1: research team and reflexivity
- (i) Personal characteristics
- (ii) Relationship with participants
- ❖ Domain 2: study design
- (i) Theoretical framework:
- Participant selection
- Setting
- Data collection
- ❖ Domain 3: analysis and findings
- Data analysis
- Reporting

Title:

short and clear ✓
reflect the content appropriately ✓
present a title that includes the study design ✓

Impact of endometriosis on women's lives: a qualitative study

Domain 1: Research team and reflexivity
Personal Characteristics

Research article | Open Access | Open Peer Review

Impact of endometriosis on women's lives: a qualitative study

Maryam Moradi ✉, Melissa Parker, Anne Sneddon, Violeta Lopez and David Ellwood

BMC Women's Health 2014 **14**:123

https://doi.org/10.1186/1472-6874-14-123 | © Moradi et al.; licensee BioMed Central Ltd. 2014

Received: 30 May 2014 | Accepted: 29 September 2014 | Published: 4 October 2014

Open Peer Review reports

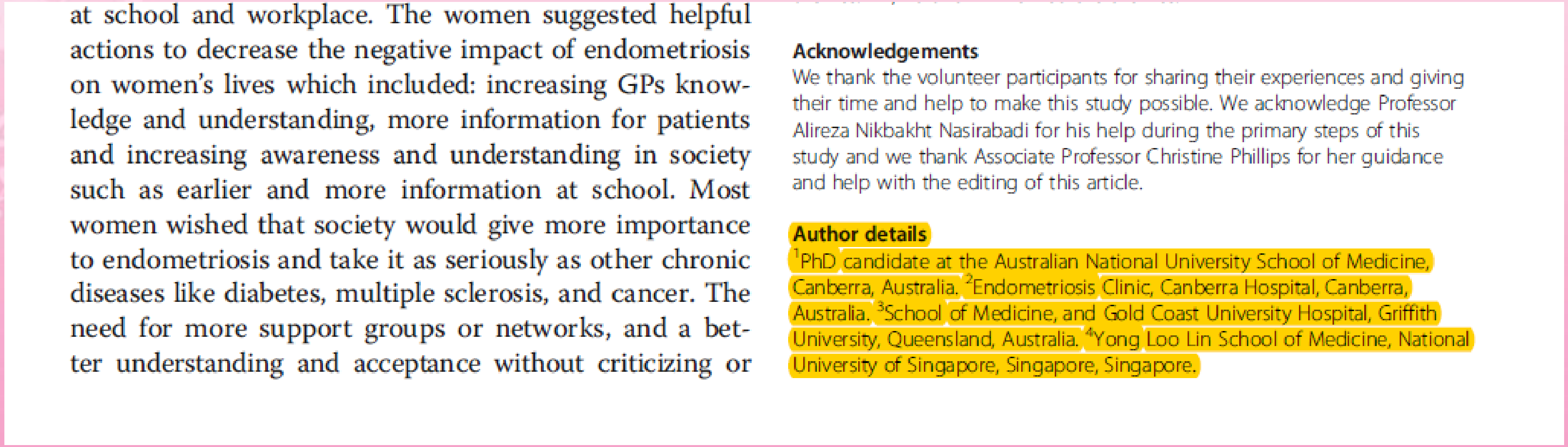
occupation
Affiliation/email address

Domain 1: Research team and reflexivity
Personal Characteristics

2.Credentials, What were the researcher’s credentials? E.g. PhD, MD

- ✓ 3. Occupation, What was their occupation at the time of the study?
- ✓ 4. Gender, Was the researcher male or female?

5. Experience and training What experience or training did the researcher have?



at school and workplace. The women suggested helpful actions to decrease the negative impact of endometriosis on women’s lives which included: increasing GPs knowledge and understanding, more information for patients and increasing awareness and understanding in society such as earlier and more information at school. Most women wished that society would give more importance to endometriosis and take it as seriously as other chronic diseases like diabetes, multiple sclerosis, and cancer. The need for more support groups or networks, and a better understanding and acceptance without criticizing or

Acknowledgements

We thank the volunteer participants for sharing their experiences and giving their time and help to make this study possible. We acknowledge Professor Alireza Nikbakht Nasirabadi for his help during the primary steps of this study and we thank Associate Professor Christine Phillips for her guidance and help with the editing of this article.

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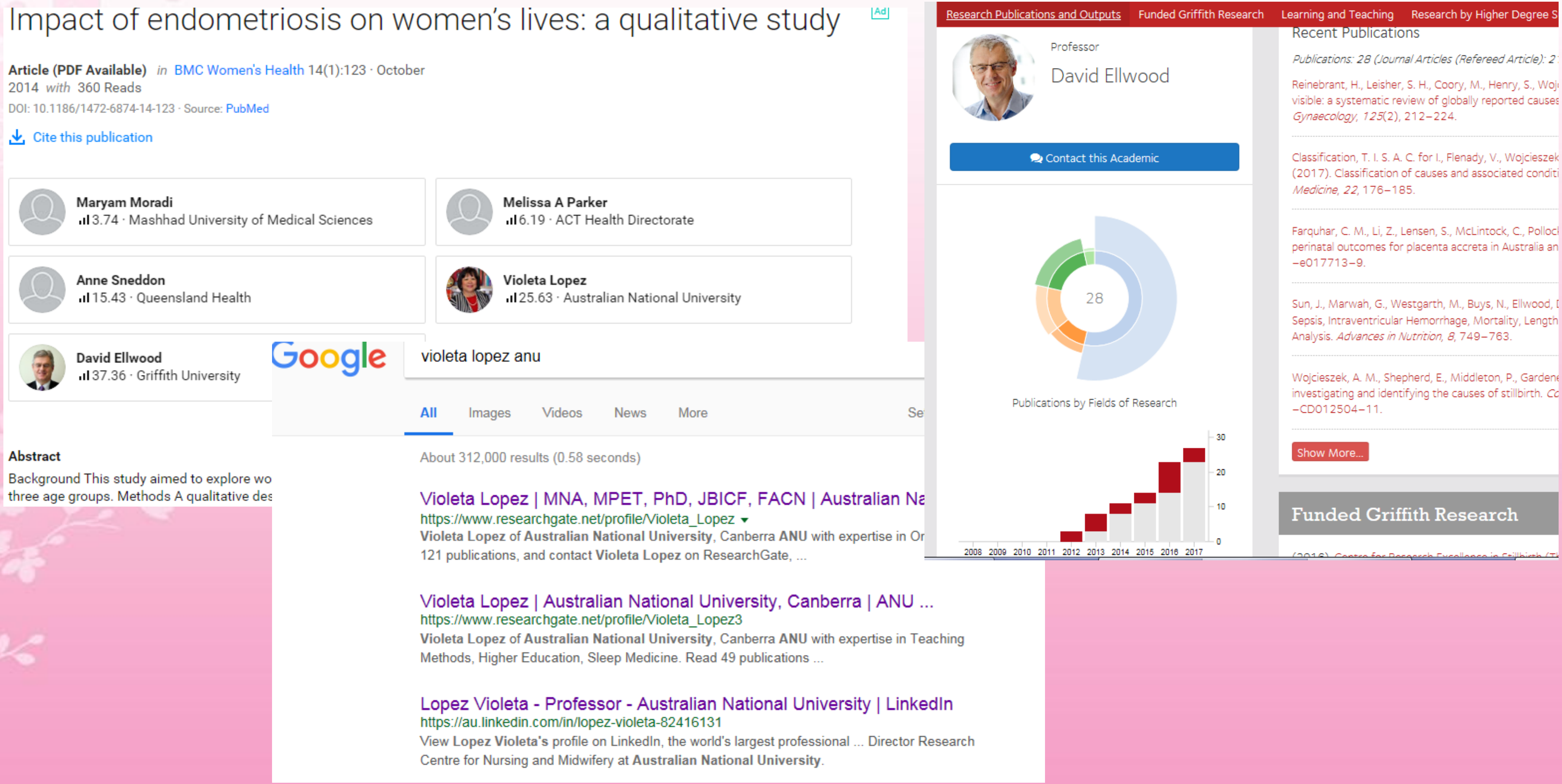
Researcher’s credentials



Impact of endometriosis on women’s lives: a qualitative study

[Ad]

Article (PDF Available) in BMC Women's Health 14(1):123 · October 2014 with 360 Reads

DOI: 10.1186/1472-6874-14-123 · Source: PubMed

Cite this publication

Maryam Moradi
3.74 · Mashhad University of Medical Sciences

Melissa A Parker
6.19 · ACT Health Directorate

Anne Sneddon
15.43 · Queensland Health

Violeta Lopez
25.63 · Australian National University

David Ellwood
37.36 · Griffith University

Abstract

Background This study aimed to explore wo
three age groups. Methods A qualitative des

violeta lopez anu

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Professor

David Ellwood

Recent Publications

Publications: 28 (Journal Articles (Refereed Article): 2

Reinebrant, H., Leisher, S. H., Coory, M., Henry, S., Woj
visible: a systematic review of globally reported causes
Gynaecology, 125(2), 212–224.

Classification, T. I. S. A. C. for I., Flenady, V., Wojcieszek
(2017). Classification of causes and associated conditi
Medicine, 22, 176–185.

Farquhar, C. M., Li, Z., Lensen, S., McLintock, C., Polloc
perinatal outcomes for placenta accreta in Australia an
–e017713–9.

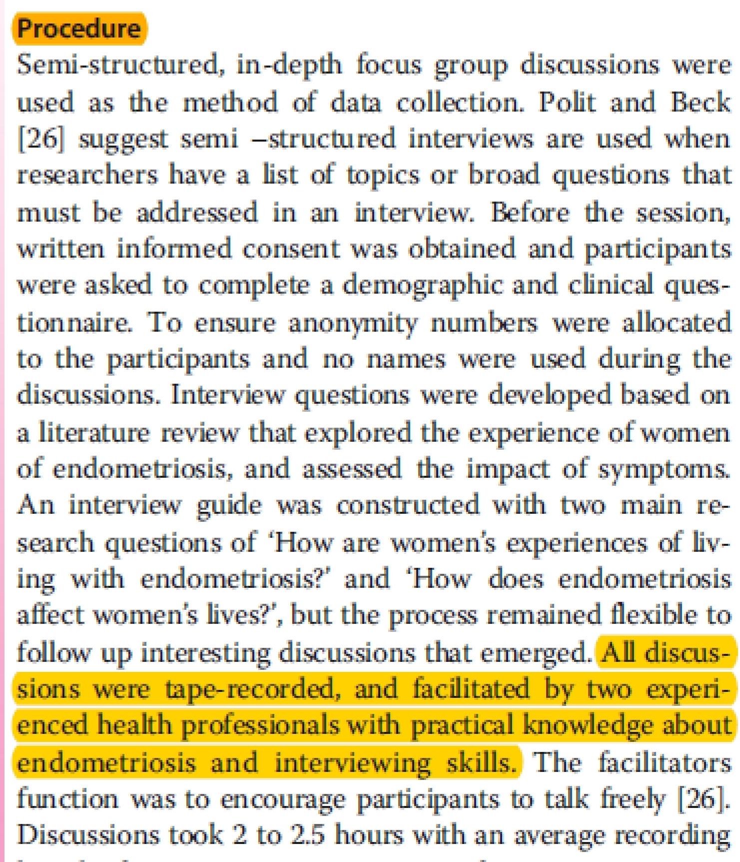
Sun, J., Marwah, G., Westgarth, M., Buys, N., Ellwood, D
Sepsis, Intraventricular Hemorrhage, Mortality, Length
Analysis. *Advances in Nutrition, 8,* 749–763.

Wojcieszek, A. M., Shepherd, E., Middleton, P., Gardene
investigating and identifying the causes of stillbirth. *Co*
–CD012504–11.

Funded Griffith Research

Domain 1: Research team and reflexivity
Personal Characteristics

5. Experience and training What experience or training did the researcher have?



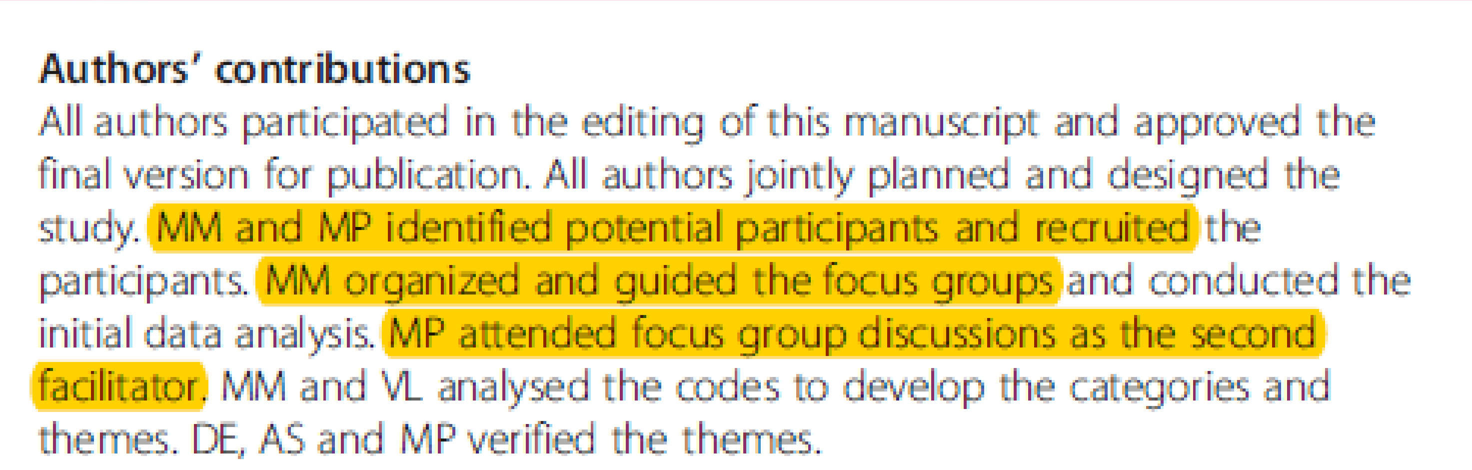
Procedure

Semi-structured, in-depth focus group discussions were used as the method of data collection. Polit and Beck [26] suggest semi –structured interviews are used when researchers have a list of topics or broad questions that must be addressed in an interview. Before the session, written informed consent was obtained and participants were asked to complete a demographic and clinical questionnaire. To ensure anonymity numbers were allocated to the participants and no names were used during the discussions. Interview questions were developed based on a literature review that explored the experience of women of endometriosis, and assessed the impact of symptoms. An interview guide was constructed with two main research questions of 'How are women's experiences of living with endometriosis?' and 'How does endometriosis affect women's lives?', but the process remained flexible to follow up interesting discussions that emerged. All discussions were tape-recorded, and facilitated by two experienced health professionals with practical knowledge about endometriosis and interviewing skills. The facilitators function was to encourage participants to talk freely [26]. Discussions took 2 to 2.5 hours with an average recording

Domain 1: Research team and reflexivity

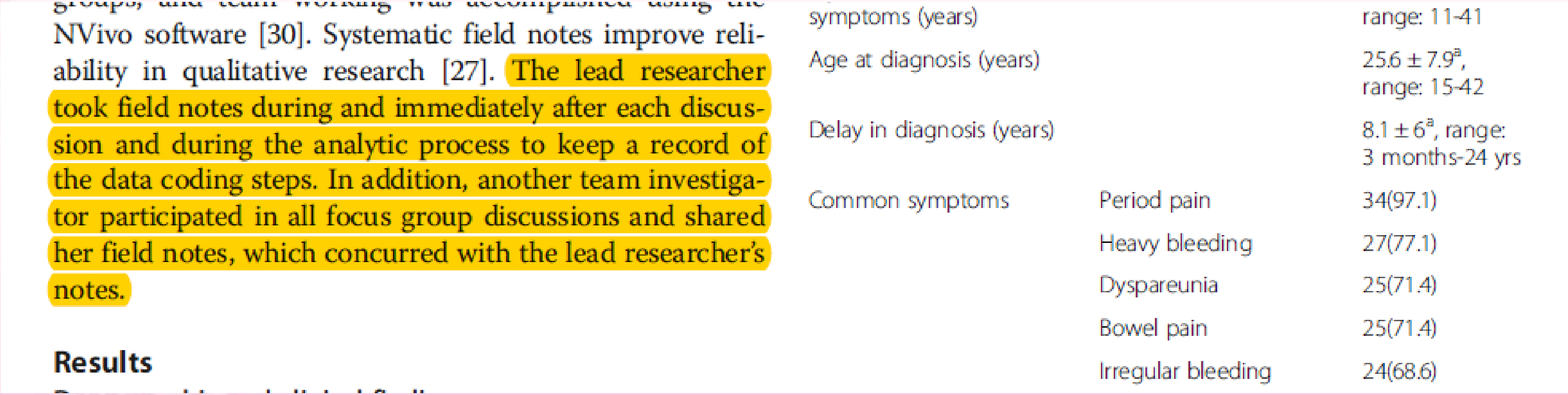
Personal Characteristics

1. Interviewer/facilitator: Which author/s conducted the interview or focus group?



Authors' contributions

All authors participated in the editing of this manuscript and approved the final version for publication. All authors jointly planned and designed the study. MM and MP identified potential participants and recruited the participants. MM organized and guided the focus groups and conducted the initial data analysis. MP attended focus group discussions as the second facilitator. MM and VL analysed the codes to develop the categories and themes. DE, AS and MP verified the themes.



NVivo software [30]. Systematic field notes improve reliability in qualitative research [27]. The lead researcher took field notes during and immediately after each discussion and during the analytic process to keep a record of the data coding steps. In addition, another team investigator participated in all focus group discussions and shared her field notes, which concurred with the lead researcher's notes.

Results

symptoms (years)		range: 11-41
Age at diagnosis (years)		25.6 ± 7.9[a], range: 15-42
Delay in diagnosis (years)		8.1 ± 6[a], range: 3 months-24 yrs
Common symptoms	Period pain	34(97.1)
	Heavy bleeding	27(77.1)
	Dyspareunia	25(71.4)
	Bowel pain	25(71.4)
	Irregular bleeding	24(68.6)

Contributor Information

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Anne Sneddon, Email: Anne.Sneddon@health.qld.gov.au.

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David Ellwood, Email: d.ellwood@griffith.edu.au.

References

1. Gao X, Yeh YC, Outley J, Simon J, Botteman M, Spalding J. Health-related quality of life burden of women with endometriosis: a literature review. Curr Med Res Opin. 2006;22(9):1787–1797. doi: 10.1185/030079906X121084. [PubMed] [Cross Ref]

Domain 1: Research team and reflexivity
Relationship with participants

✓6. Relationship established prior to study

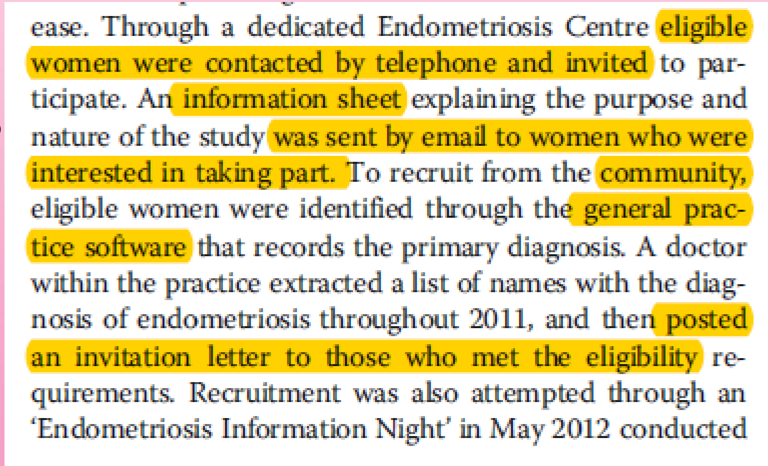
MM PhD candidate at the ANU, MP nurse coordinator of the Endometriosis clinic

✓ *MM and MP identified potential participants and recruited the participants. MM organized and guided the focus groups and conducted the initial data analysis. MP attended focus group discussions as the second facilitator.*

✓7-Participant knowledge of the interviewer

What did the participants know about the researcher? personal goals, reasons for doing the research?

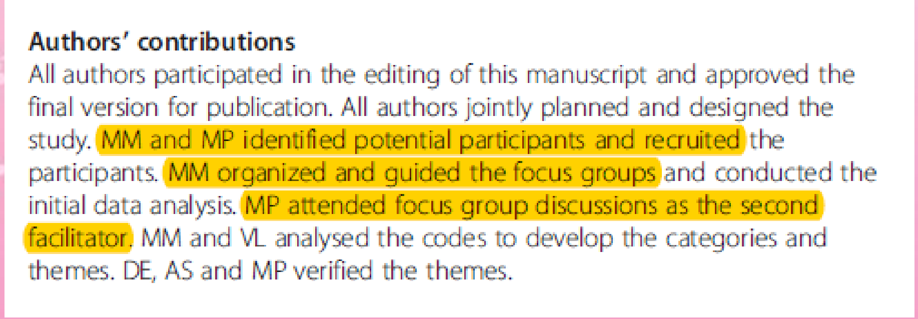
Before the session, written informed consent was obtained ….



ease. Through a dedicated Endometriosis Centre eligible women were contacted by telephone and invited to participate. An information sheet explaining the purpose and nature of the study was sent by email to women who were interested in taking part. To recruit from the community, eligible women were identified through the general practice software that records the primary diagnosis. A doctor within the practice extracted a list of names with the diagnosis of endometriosis throughout 2011, and then posted an invitation letter to those who met the eligibility requirements. Recruitment was also attempted through an 'Endometriosis Information Night' in May 2012 conducted

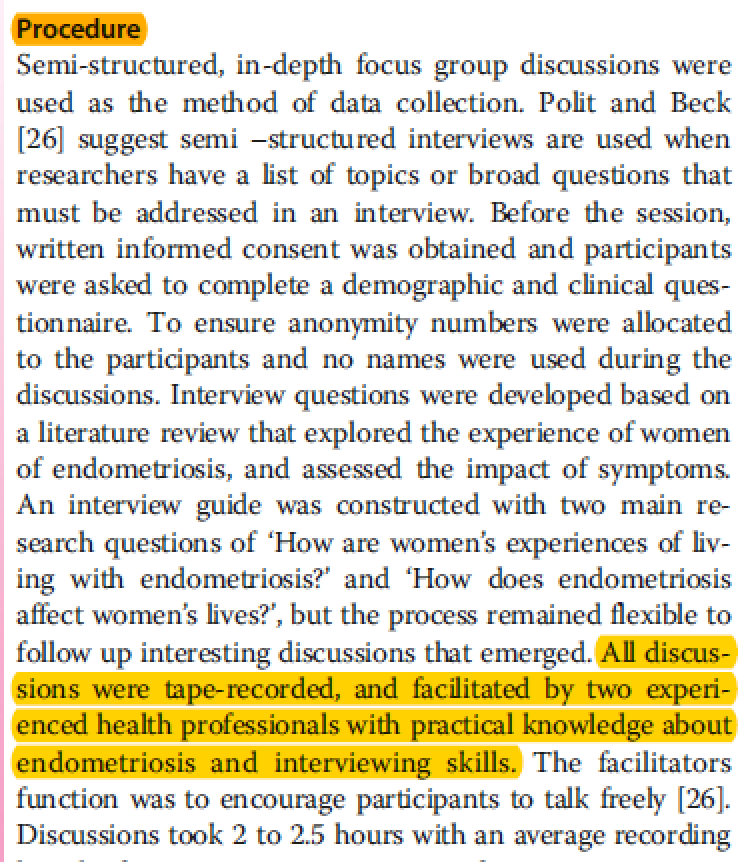
8. Interviewer characteristics

What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic



Authors' contributions

All authors participated in the editing of this manuscript and approved the final version for publication. All authors jointly planned and designed the study. MM and MP identified potential participants and recruited the participants. MM organized and guided the focus groups and conducted the initial data analysis. MP attended focus group discussions as the second facilitator. MM and VL analysed the codes to develop the categories and themes. DE, AS and MP verified the themes.



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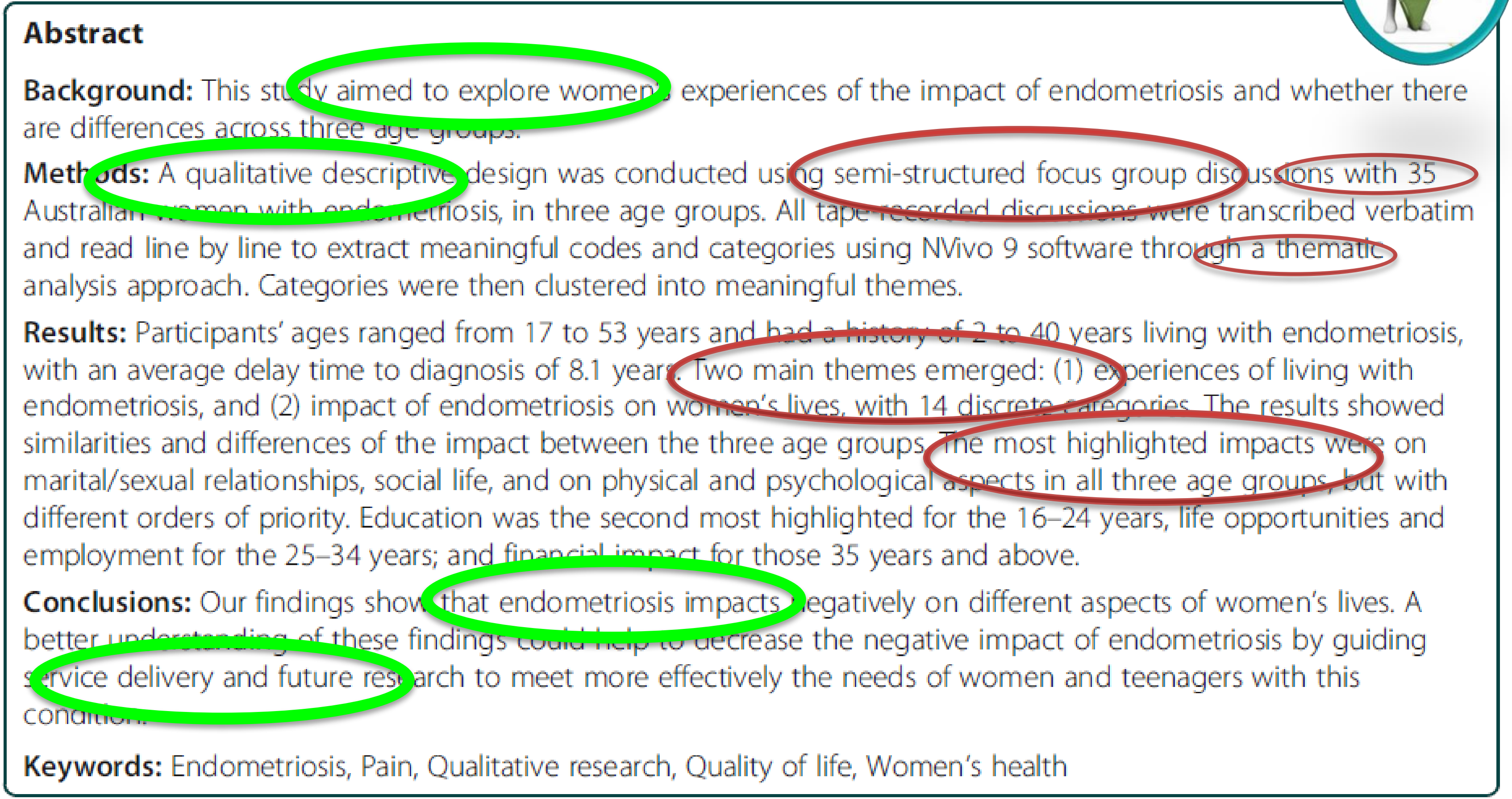
Abstract



Abstract

Background: This study aimed to explore women's experiences of the impact of endometriosis and whether there are differences across three age groups.

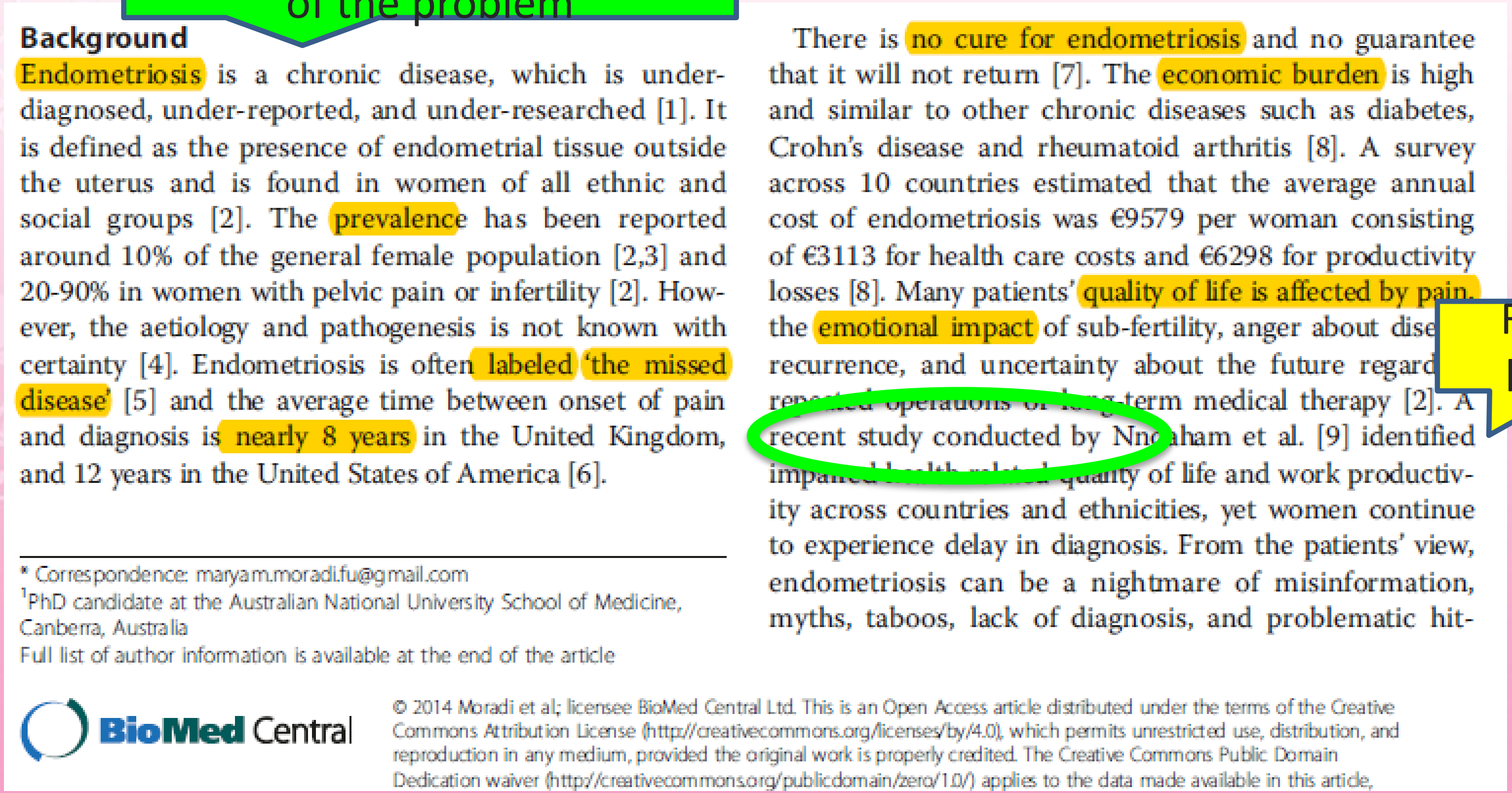
Methods: A qualitative descriptive design was conducted using semi-structured focus group discussions with 35 Australian women with endometriosis, in three age groups. All tape-recorded discussions were transcribed verbatim and read line by line to extract meaningful codes and categories using NVivo 9 software through a thematic analysis approach. Categories were then clustered into meaningful themes.

Results: Participants' ages ranged from 17 to 53 years and had a history of 2 to 40 years living with endometriosis, with an average delay time to diagnosis of 8.1 years. Two main themes emerged: (1) experiences of living with endometriosis, and (2) impact of endometriosis on women's lives, with 14 discrete categories. The results showed similarities and differences of the impact between the three age groups. The most highlighted impacts were on marital/sexual relationships, social life, and on physical and psychological aspects in all three age groups, but with different orders of priority. Education was the second most highlighted for the 16–24 years, life opportunities and employment for the 25–34 years; and financial impact for those 35 years and above.

Conclusions: Our findings show that endometriosis impacts negatively on different aspects of women's lives. A better understanding of these findings could help to decrease the negative impact of endometriosis by guiding service delivery and future research to meet more effectively the needs of women and teenagers with this condition.

Keywords: Endometriosis, Pain, Qualitative research, Quality of life, Women's health

Introduction



Background and significance of the problem

Background

Endometriosis is a chronic disease, which is under-diagnosed, under-reported, and under-researched [1]. It is defined as the presence of endometrial tissue outside the uterus and is found in women of all ethnic and social groups [2]. The prevalence has been reported around 10% of the general female population [2,3] and 20-90% in women with pelvic pain or infertility [2]. However, the aetiology and pathogenesis is not known with certainty [4]. Endometriosis is often labeled 'the missed disease' [5] and the average time between onset of pain and diagnosis is nearly 8 years in the United Kingdom, and 12 years in the United States of America [6].

There is no cure for endometriosis and no guarantee that it will not return [7]. The economic burden is high and similar to other chronic diseases such as diabetes, Crohn's disease and rheumatoid arthritis [8]. A survey across 10 countries estimated that the average annual cost of endometriosis was €9579 per woman consisting of €3113 for health care costs and €6298 for productivity losses [8]. Many patients' quality of life is affected by pain, the emotional impact of sub-fertility, anger about dise recurrence, and uncertainty about the future regard repeated operations or long-term medical therapy [2]. A recent study conducted by Nnoaham et al. [9] identified impaired health-related quality of life and work productivity across countries and ethnicities, yet women continue to experience delay in diagnosis. From the patients' view, endometriosis can be a nightmare of misinformation, myths, taboos, lack of diagnosis, and problematic hit-

Review of literature

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* Correspondence: maryam.moradi.fu@gmail.com
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Full list of author information is available at the end of the article

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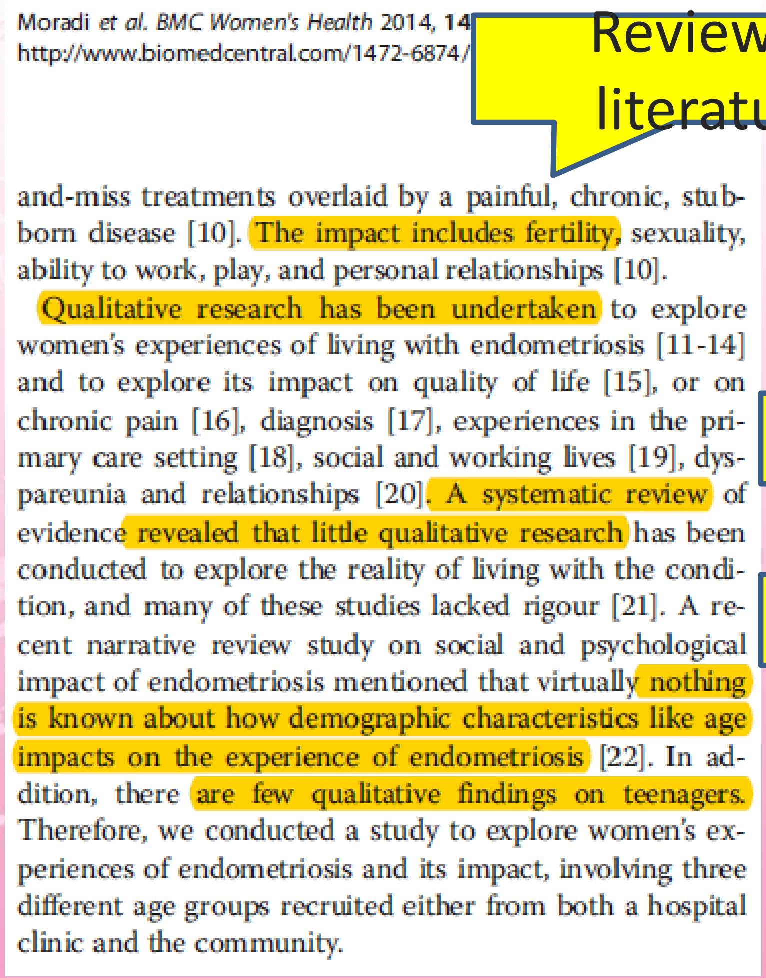
Introduction



Moradi *et al. BMC Women's Health* 2014, 14

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and-miss treatments overlaid by a painful, chronic, stubborn disease [10]. The impact includes fertility, sexuality, ability to work, play, and personal relationships [10].

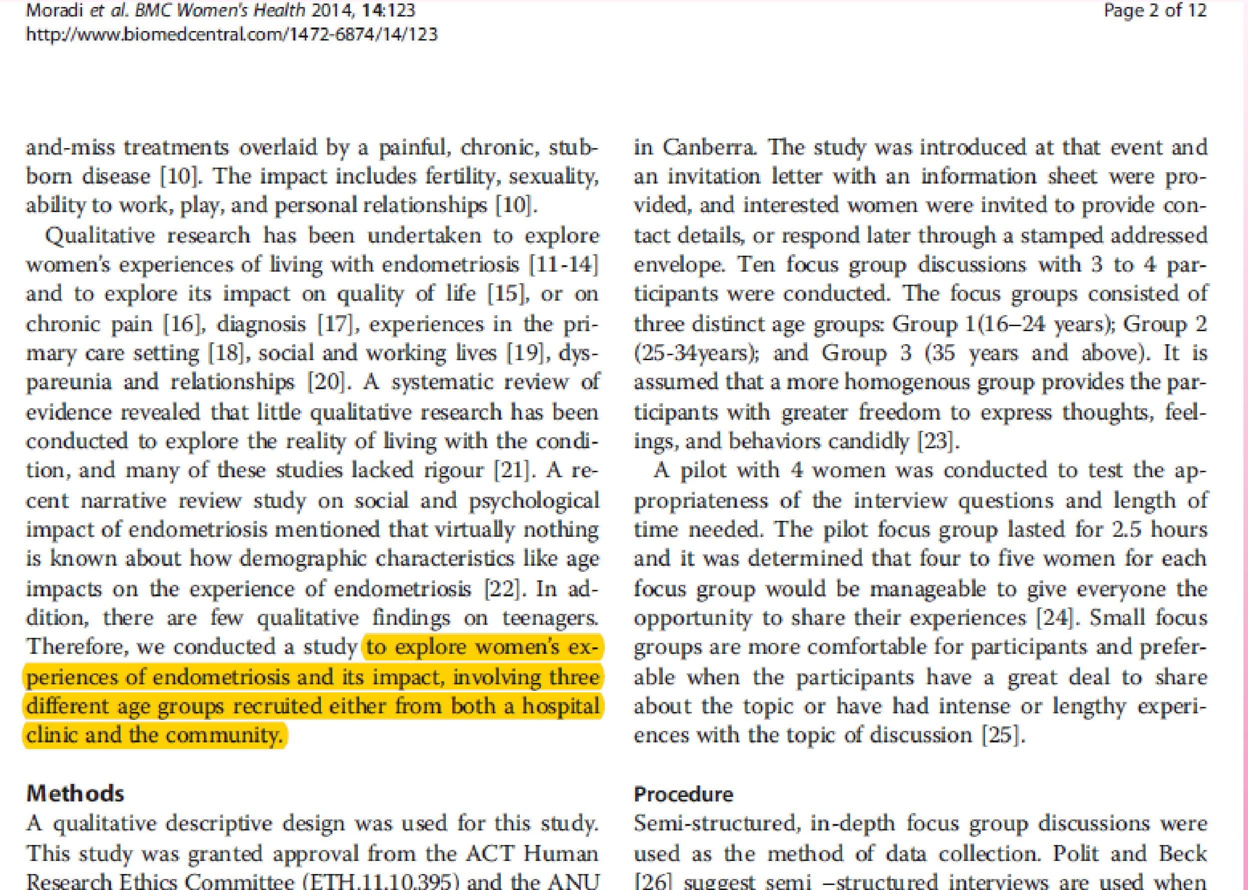
Qualitative research has been undertaken to explore women's experiences of living with endometriosis [11-14] and to explore its impact on quality of life [15], or on chronic pain [16], diagnosis [17], experiences in the primary care setting [18], social and working lives [19], dyspareunia and relationships [20]. A systematic review of evidence revealed that little qualitative research has been conducted to explore the reality of living with the condition, and many of these studies lacked rigour [21]. A recent narrative review study on social and psychological impact of endometriosis mentioned that virtually nothing is known about how demographic characteristics like age impacts on the experience of endometriosis [22]. In addition, there are few qualitative findings on teenagers. Therefore, we conducted a study to explore women's experiences of endometriosis and its impact, involving three different age groups recruited either from both a hospital clinic and the community.

Review of literature

What is known/unknown

Gap of knowledge

Aim



and-miss treatments overlaid by a painful, chronic, stubborn disease [10]. The impact includes fertility, sexuality, ability to work, play, and personal relationships [10].

Qualitative research has been undertaken to explore women's experiences of living with endometriosis [11-14] and to explore its impact on quality of life [15], or on chronic pain [16], diagnosis [17], experiences in the primary care setting [18], social and working lives [19], dyspareunia and relationships [20]. A systematic review of evidence revealed that little qualitative research has been conducted to explore the reality of living with the condition, and many of these studies lacked rigour [21]. A recent narrative review study on social and psychological impact of endometriosis mentioned that virtually nothing is known about how demographic characteristics like age impacts on the experience of endometriosis [22]. In addition, there are few qualitative findings on teenagers. Therefore, we conducted a study to explore women's experiences of endometriosis and its impact, involving three different age groups recruited either from both a hospital clinic and the community.

Methods

A qualitative descriptive design was used for this study. This study was granted approval from the ACT Human Research Ethics Committee (ETH.11.10.395) and the ANU

in Canberra. The study was introduced at that event and an invitation letter with an information sheet were provided, and interested women were invited to provide contact details, or respond later through a stamped addressed envelope. Ten focus group discussions with 3 to 4 participants were conducted. The focus groups consisted of three distinct age groups: Group 1(16–24 years); Group 2 (25-34years); and Group 3 (35 years and above). It is assumed that a more homogenous group provides the participants with greater freedom to express thoughts, feelings, and behaviors candidly [23].

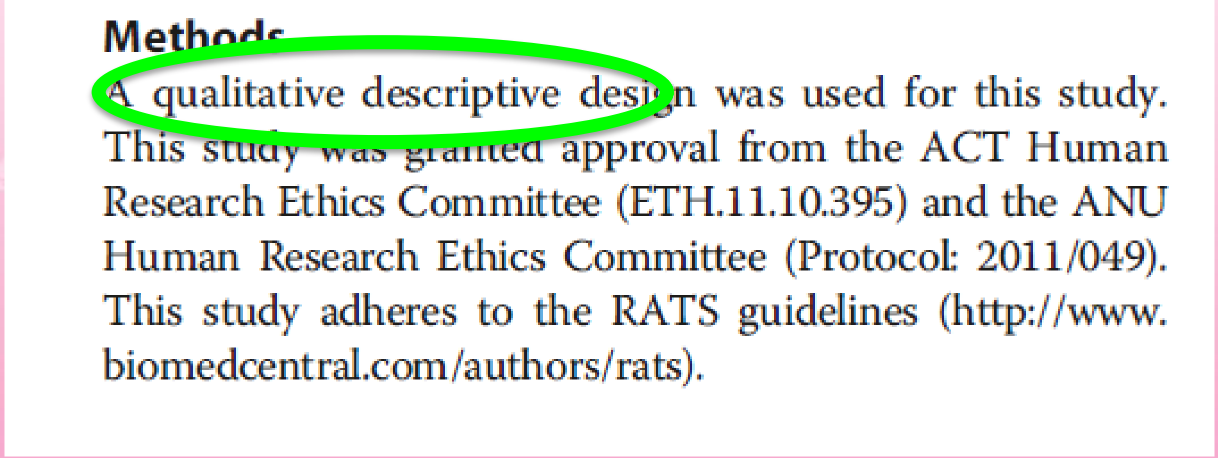
A pilot with 4 women was conducted to test the appropriateness of the interview questions and length of time needed. The pilot focus group lasted for 2.5 hours and it was determined that four to five women for each focus group would be manageable to give everyone the opportunity to share their experiences [24]. Small focus groups are more comfortable for participants and preferable when the participants have a great deal to share about the topic or have had intense or lengthy experiences with the topic of discussion [25].

Procedure

Semi-structured, in-depth focus group discussions were used as the method of data collection. Polit and Beck [26] suggest semi –structured interviews are used when

Domain 2: study design
Theoretical framework

9. Methodological orientation and Theory

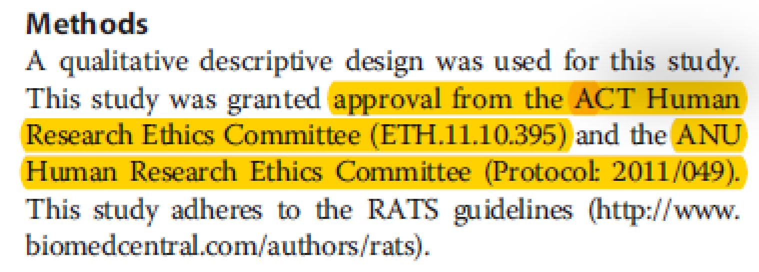


Methods

A qualitative descriptive design was used for this study. This study was granted approval from the ACT Human Research Ethics Committee (ETH.11.10.395) and the ANU Human Research Ethics Committee (Protocol: 2011/049). This study adheres to the RATS guidelines (http://www.biomedcentral.com/authors/rats).

Ethical considerations

Ethics approval



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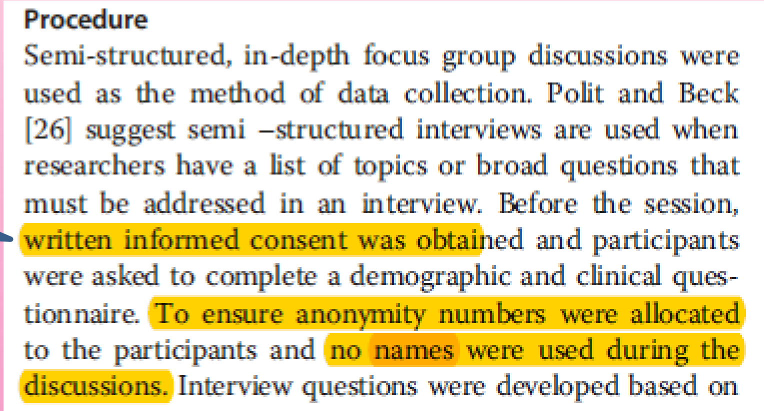
Confidentiality during findings reporting

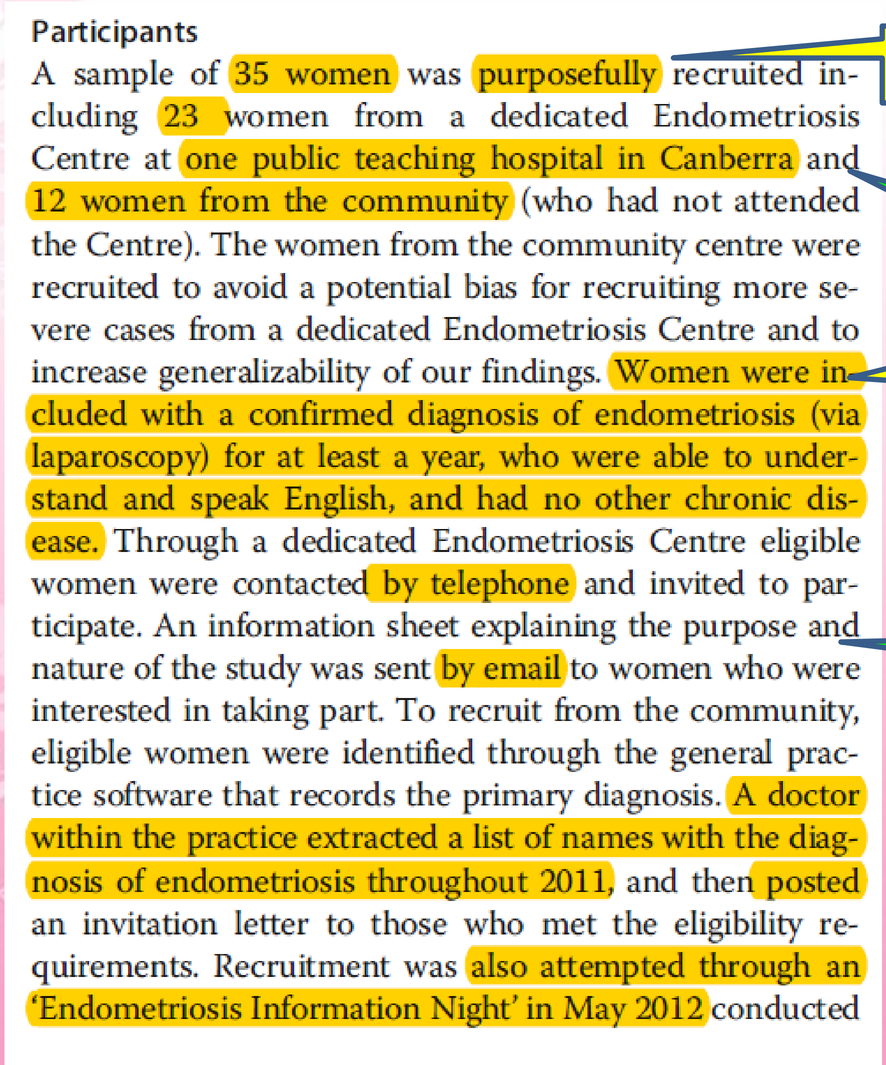
Written Informed consent
anonymity



Procedure

Semi-structured, in-depth focus group discussions were used as the method of data collection. Polit and Beck [26] suggest semi –structured interviews are used when researchers have a list of topics or broad questions that must be addressed in an interview. Before the session, written informed consent was obtained and participants were asked to complete a demographic and clinical questionnaire. To ensure anonymity numbers were allocated to the participants and no names were used during the discussions. Interview questions were developed based on

Domain 2: study design
Participant selection



Participants

A sample of 35 women was purposefully recruited including 23 women from a dedicated Endometriosis Centre at one public teaching hospital in Canberra and 12 women from the community (who had not attended the Centre). The women from the community centre were recruited to avoid a potential bias for recruiting more severe cases from a dedicated Endometriosis Centre and to increase generalizability of our findings. Women were included with a confirmed diagnosis of endometriosis (via laparoscopy) for at least a year, who were able to understand and speak English, and had no other chronic disease. Through a dedicated Endometriosis Centre eligible women were contacted by telephone and invited to participate. An information sheet explaining the purpose and nature of the study was sent by email to women who were interested in taking part. To recruit from the community, eligible women were identified through the general practice software that records the primary diagnosis. A doctor within the practice extracted a list of names with the diagnosis of endometriosis throughout 2011, and then posted an invitation letter to those who met the eligibility requirements. Recruitment was also attempted through an 'Endometriosis Information Night' in May 2012 conducted

sampling

setting

Description of sample
Inclusion criteria

Method of approach

Domain 2: study design
Participant selection

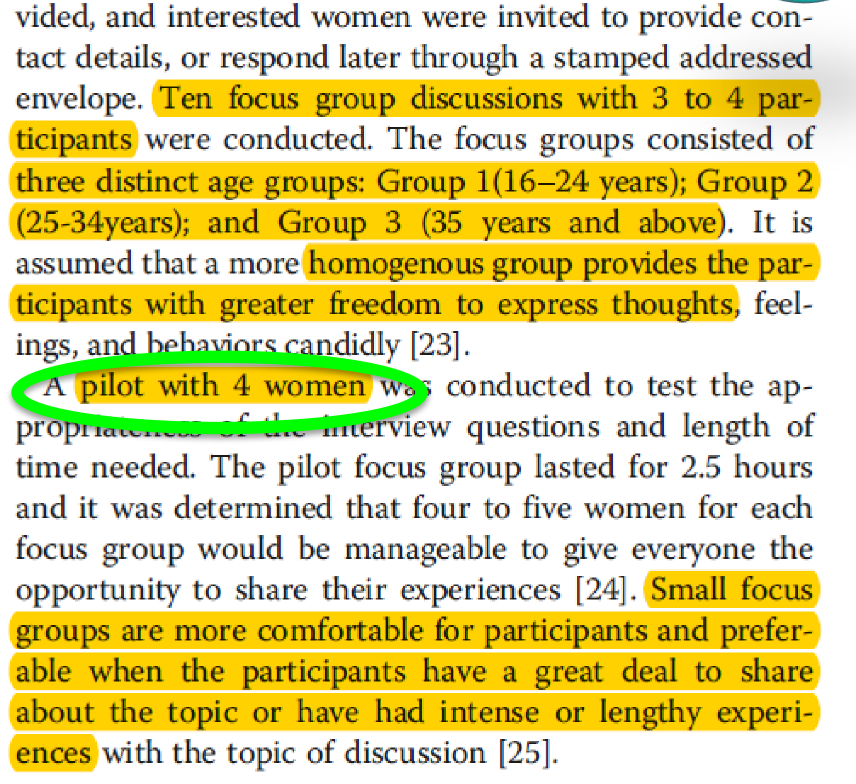
- ✓ 10.Sampling, How were participants selected?
- ✓ 11. Method of approach
- ✓ 12 sample size,
- ×13 non participation, How many people refused to participate or dropped out? Reasons?
- ✓ 14. Setting of data collection, Where was the data collected?
- ✓ 15. Presence of non-participants, Was anyone else present besides the participants and researchers?

- ✓ 16. Description of sample

Domain 2: study design
Data collection

✓ 17. Interview guide

Were questions, prompts, guides provided by the authors? Was it pilot tested?



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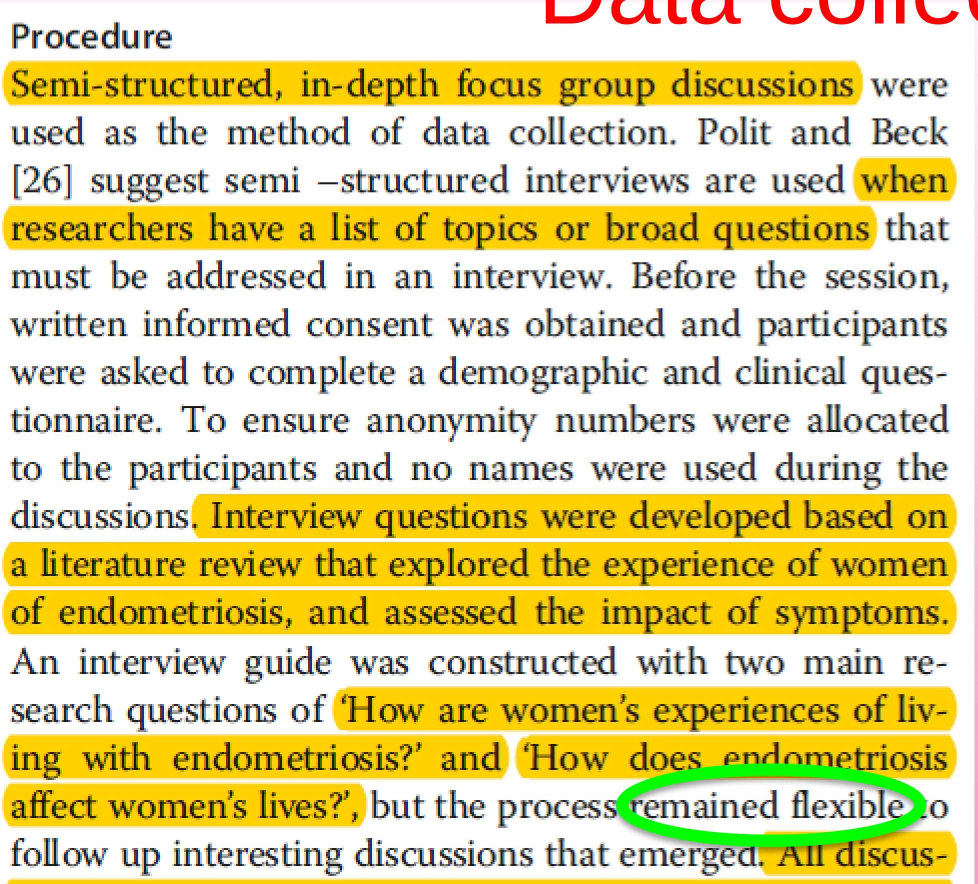
an invitation letter with an information sheet were

vided, and interested women were invited to provide contact details, or respond later through a stamped addressed envelope. Ten focus group discussions with 3 to 4 participants were conducted. The focus groups consisted of three distinct age groups: Group 1(16–24 years); Group 2 (25-34years); and Group 3 (35 years and above). It is assumed that a more homogenous group provides the participants with greater freedom to express thoughts, feelings, and behaviors candidly [23].

A pilot with 4 women was conducted to test the appropriateness of the interview questions and length of time needed. The pilot focus group lasted for 2.5 hours and it was determined that four to five women for each focus group would be manageable to give everyone the opportunity to share their experiences [24]. Small focus groups are more comfortable for participants and preferable when the participants have a great deal to share about the topic or have had intense or lengthy experiences with the topic of discussion [25].

Domain 2: study design
Data collection



Procedure

Semi-structured, in-depth focus group discussions were used as the method of data collection. Polit and Beck [26] suggest semi –structured interviews are used when researchers have a list of topics or broad questions that must be addressed in an interview. Before the session, written informed consent was obtained and participants were asked to complete a demographic and clinical questionnaire. To ensure anonymity numbers were allocated to the participants and no names were used during the discussions. Interview questions were developed based on a literature review that explored the experience of women of endometriosis, and assessed the impact of symptoms. An interview guide was constructed with two main research questions of 'How are women's experiences of living with endometriosis?' and 'How does endometriosis affect women's lives?', but the process remained flexible to follow up interesting discussions that emerged. All discus-

Data collection method

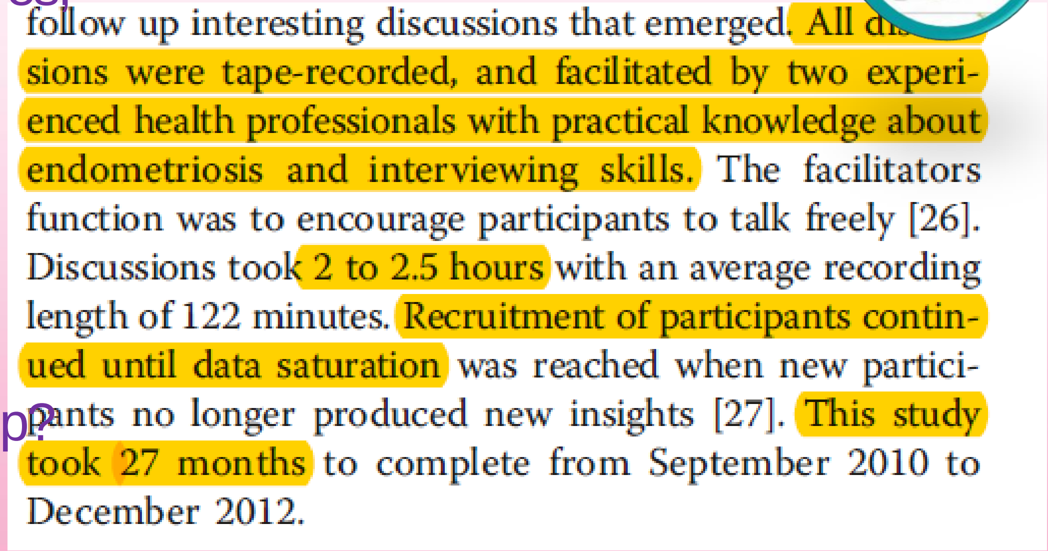
Interview guide

Domain 2: study design
Data collection

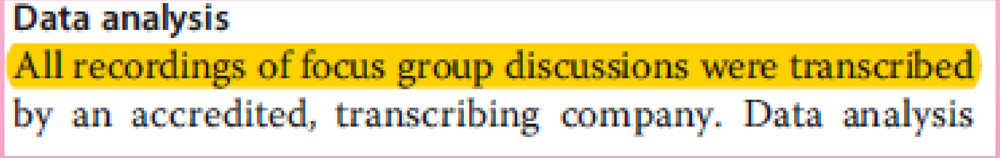
- × 18. Repeat interviews

Were repeat interviews carried out? If yes, how many?

- ✓ 19. Audio/visual recording Did the research use audio or visual recording to collect the data?
- ✓ 21. Duration, What was the duration of the interviews or focus group?
- ✓ 22. Data saturation, Was data saturation discussed?



follow up interesting discussions that emerged. All di sions were tape-recorded, and facilitated by two experienced health professionals with practical knowledge about endometriosis and interviewing skills. The facilitators function was to encourage participants to talk freely [26]. Discussions took 2 to 2.5 hours with an average recording length of 122 minutes. Recruitment of participants continued until data saturation was reached when new participants no longer produced new insights [27]. This study took 27 months to complete from September 2010 to December 2012.

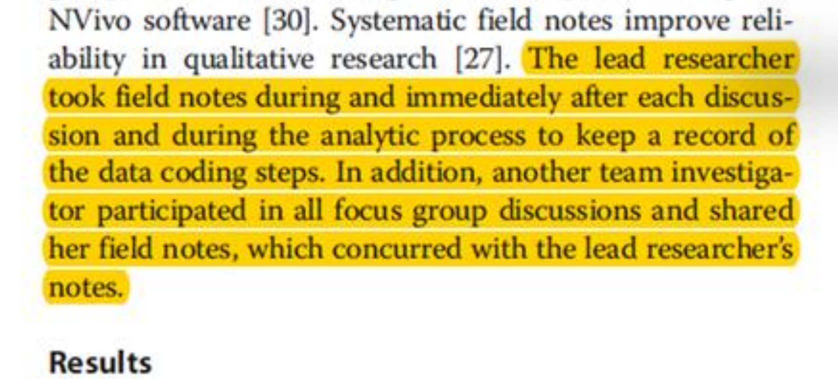


Data analysis

All recordings of focus group discussions were transcribed by an accredited, transcribing company. Data analysis

Domain 2: study design
Data collection

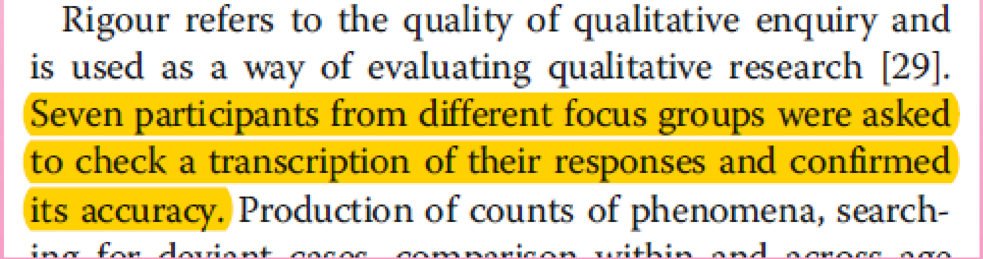
✓ 20. Field notes



NVivo software [30]. Systematic field notes improve reliability in qualitative research [27]. The lead researcher took field notes during and immediately after each discussion and during the analytic process to keep a record of the data coding steps. In addition, another team investigator participated in all focus group discussions and shared her field notes, which concurred with the lead researcher's notes.

Results

✓ 23. Transcripts returned, Were transcripts returned to participants for comment and/or correction?

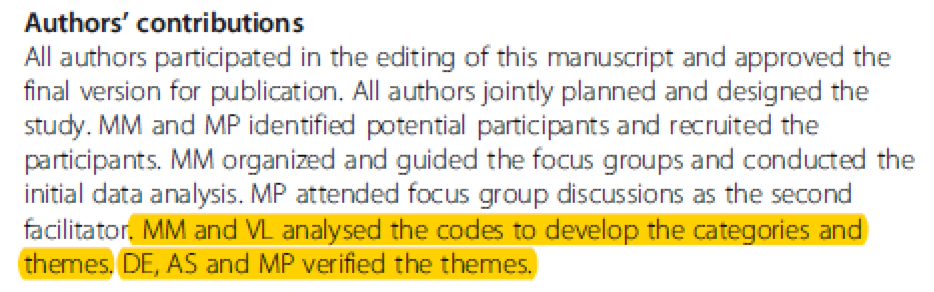


Rigour refers to the quality of qualitative enquiry and is used as a way of evaluating qualitative research [29]. Seven participants from different focus groups were asked to check a transcription of their responses and confirmed its accuracy. Production of counts of phenomena, search-

Domain 3: analysis and findings
Data analysis

✓ 24. Number of data coder

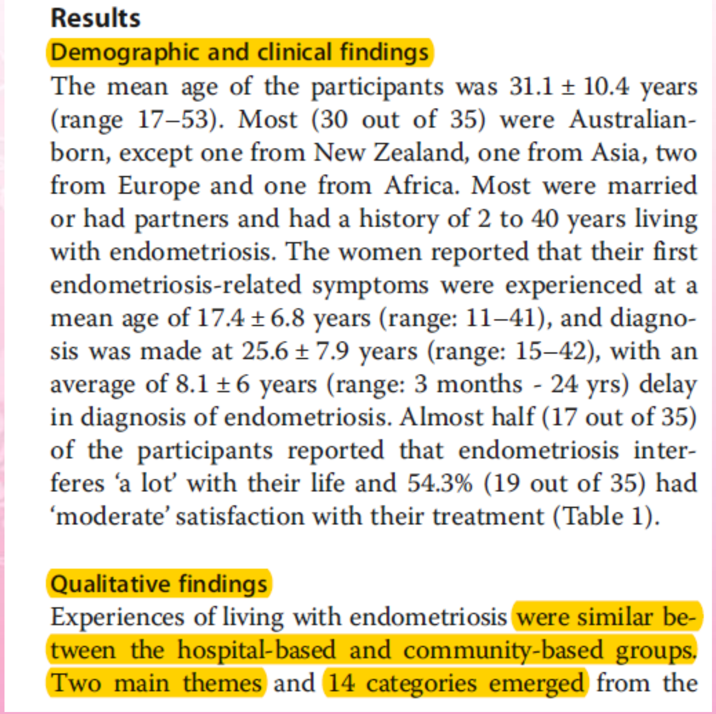
- How many data coders coded the data?



Authors' contributions

All authors participated in the editing of this manuscript and approved the final version for publication. All authors jointly planned and designed the study. MM and MP identified potential participants and recruited the participants. MM organized and guided the focus groups and conducted the initial data analysis. MP attended focus group discussions as the second facilitator. MM and VL analysed the codes to develop the categories and themes. DE, AS and MP verified the themes.

Results



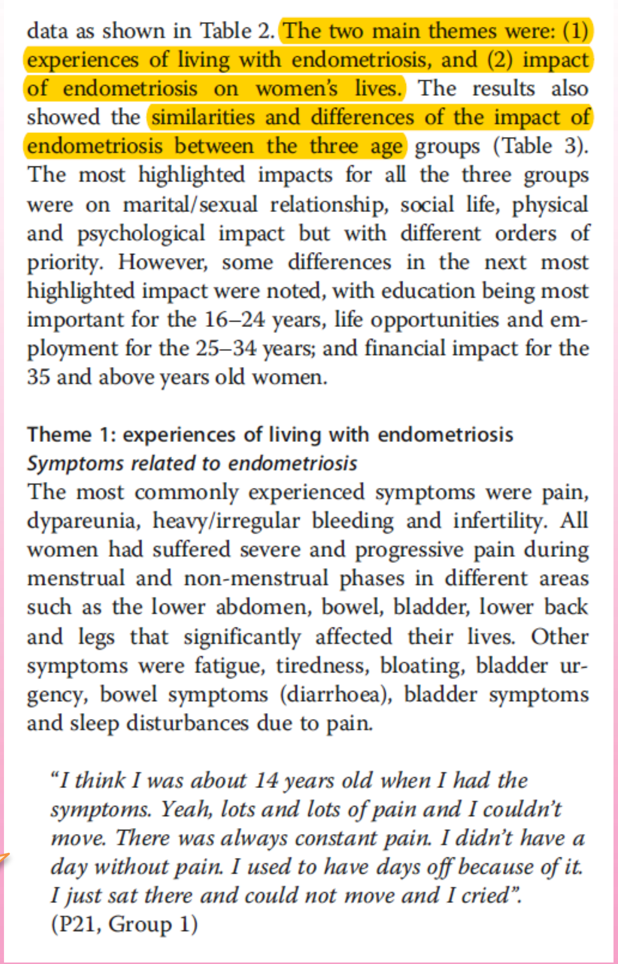
Results

Demographic and clinical findings

The mean age of the participants was 31.1 ± 10.4 years (range 17–53). Most (30 out of 35) were Australian-born, except one from New Zealand, one from Asia, two from Europe and one from Africa. Most were married or had partners and had a history of 2 to 40 years living with endometriosis. The women reported that their first endometriosis-related symptoms were experienced at a mean age of 17.4 ± 6.8 years (range: 11–41), and diagnosis was made at 25.6 ± 7.9 years (range: 15–42), with an average of 8.1 ± 6 years (range: 3 months - 24 yrs) delay in diagnosis of endometriosis. Almost half (17 out of 35) of the participants reported that endometriosis interferes 'a lot' with their life and 54.3% (19 out of 35) had 'moderate' satisfaction with their treatment (Table 1).

Qualitative findings

Experiences of living with endometriosis were similar between the hospital-based and community-based groups. Two main themes and 14 categories emerged from the



data as shown in Table 2. The two main themes were: (1) experiences of living with endometriosis, and (2) impact of endometriosis on women's lives. The results also showed the similarities and differences of the impact of endometriosis between the three age groups (Table 3). The most highlighted impacts for all the three groups were on marital/sexual relationship, social life, physical and psychological impact but with different orders of priority. However, some differences in the next most highlighted impact were noted, with education being most important for the 16–24 years, life opportunities and employment for the 25–34 years; and financial impact for the 35 and above years old women.

Theme 1: experiences of living with endometriosis

Symptoms related to endometriosis

The most commonly experienced symptoms were pain, dyspareunia, heavy/irregular bleeding and infertility. All women had suffered severe and progressive pain during menstrual and non-menstrual phases in different areas such as the lower abdomen, bowel, bladder, lower back and legs that significantly affected their lives. Other symptoms were fatigue, tiredness, bloating, bladder urgency, bowel symptoms (diarrhoea), bladder symptoms and sleep disturbances due to pain.

> *"I think I was about 14 years old when I had the symptoms. 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 used to have days off because of it. I just sat there and could not move and I cried".*
> (P21, Group 1)

Participants' quotations

Findings

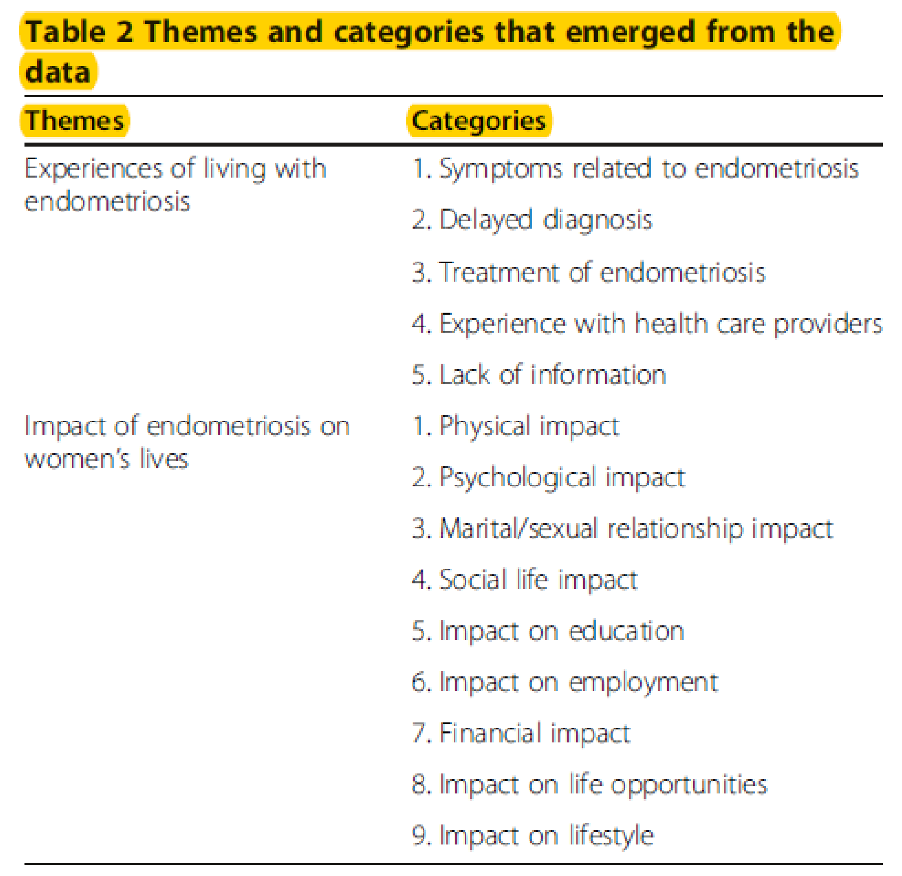
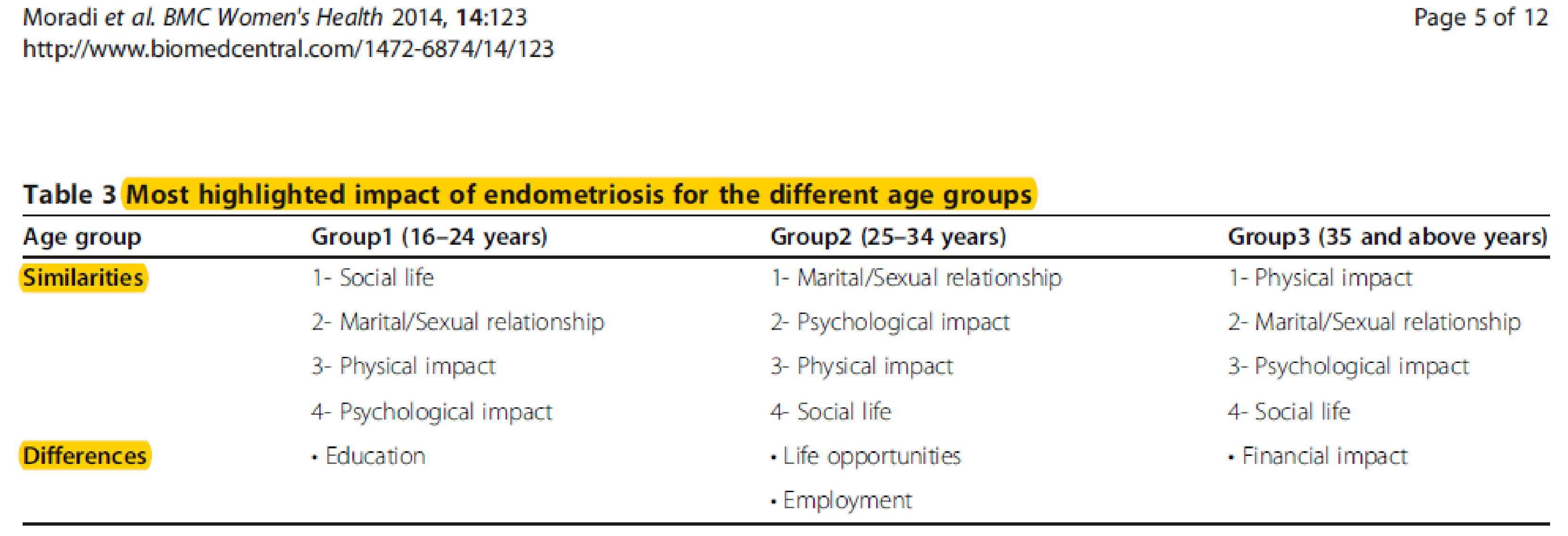


Table 2 Themes and categories that emerged from the data

Themes	Categories
Experiences of living with endometriosis	1. Symptoms related to endometriosis
	2. Delayed diagnosis
	3. Treatment of endometriosis
	4. Experience with health care providers
	5. Lack of information
Impact of endometriosis on women's lives	1. Physical impact
	2. Psychological impact
	3. Marital/sexual relationship impact
	4. Social life impact
	5. Impact on education
	6. Impact on employment
	7. Financial impact
	8. Impact on life opportunities
	9. Impact on lifestyle

Findings



Moradi *et al. BMC Women's Health* 2014, **14**:123
http://www.biomedcentral.com/1472-6874/14/123

Table 3 **Most highlighted impact of endometriosis for the different age groups**

Age group	Group1 (16–24 years)	Group2 (25–34 years)	Group3 (35 and above years)
Similarities	1- Social life	1- Marital/Sexual relationship	1- Physical impact
	2- Marital/Sexual relationship	2- Psychological impact	2- Marital/Sexual relationship
	3- Physical impact	3- Physical impact	3- Psychological impact
	4- Psychological impact	4- Social life	4- Social life
Differences	• Education	• Life opportunities	• Financial impact
		• Employment	

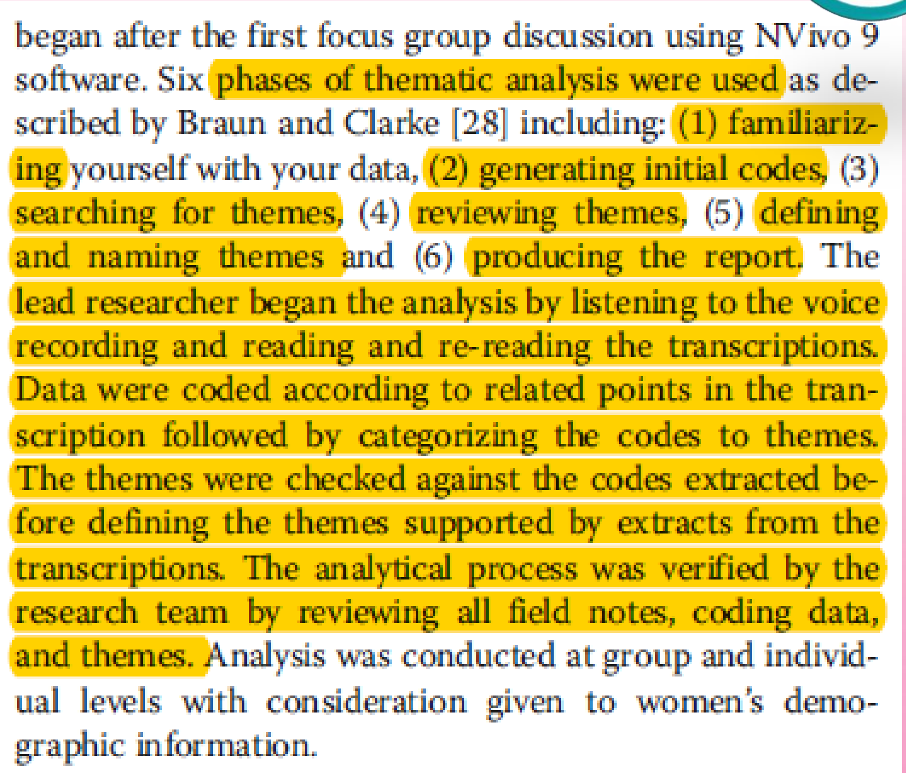
Domain 3: analysis and findings
Data analysis

✓ 25. Description of the coding tree

Did authors provide a description of the coding tree?

✓26. Derivation of themes

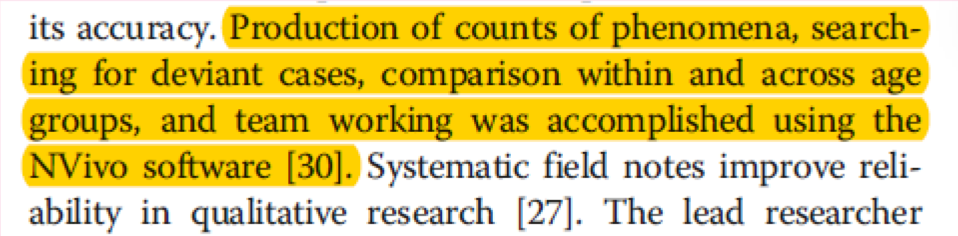
Were themes identified in advance or derived from the data?



began after the first focus group discussion using NVivo 9 software. Six phases of thematic analysis were used as described by Braun and Clarke [28] including: (1) familiarizing yourself with your data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes and (6) producing the report. The lead researcher began the analysis by listening to the voice recording and reading and re-reading the transcriptions. Data were coded according to related points in the transcription followed by categorizing the codes to themes. The themes were checked against the codes extracted before defining the themes supported by extracts from the transcriptions. The analytical process was verified by the research team by reviewing all field notes, coding data, and themes. Analysis was conducted at group and individual levels with consideration given to women's demographic information.

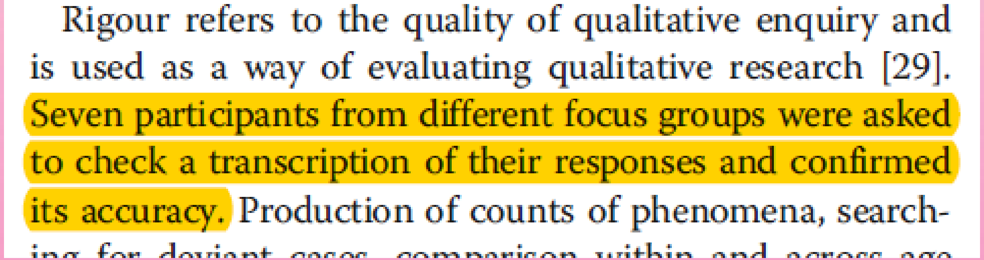
Domain 3: analysis and findings
Data analysis

- ✓ 27. Software, What software, if applicable, was used to manage the data?



its accuracy. Production of counts of phenomena, searching for deviant cases, comparison within and across age groups, and team working was accomplished using the NVivo software [30]. Systematic field notes improve reliability in qualitative research [27]. The lead researcher

- ✓ 28. Participant checking, Did participants provide feedback on the findings?



Rigour refers to the quality of qualitative enquiry and is used as a way of evaluating qualitative research [29]. Seven participants from different focus groups were asked to check a transcription of their responses and confirmed its accuracy. Production of counts of phenomena, search-

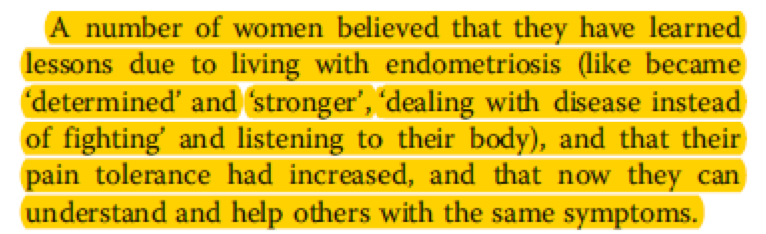
Domain 3: analysis and findings Reporting

- ✓ 29. Quotations presented, Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number
- ✓ yes
- ✓ 30. Data and findings consistent, Was there consistency between the data presented and the findings?

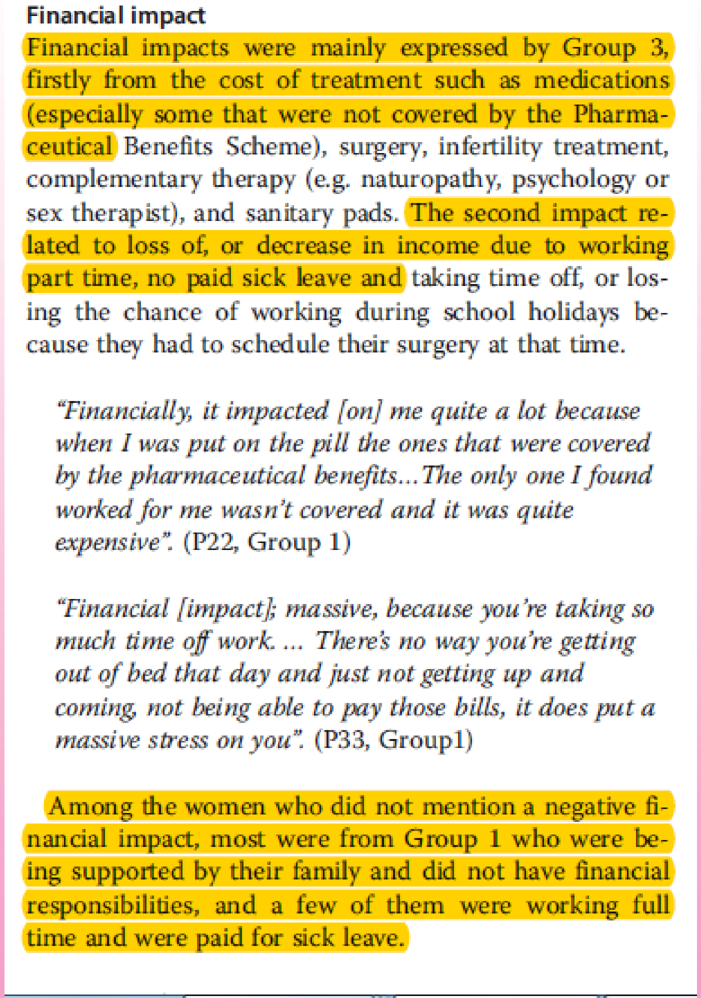
Domain 3: analysis and findings Reporting

- ✓ 31. Clarity of major themes, Were major themes clearly presented in the findings?

- ✓ 31. Clarity of minor themes, Is there a description of diverse cases or discussion of minor themes?



A number of women believed that they have learned lessons due to living with endometriosis (like became 'determined' and 'stronger', 'dealing with disease instead of fighting' and listening to their body), and that their pain tolerance had increased, and that now they can understand and help others with the same symptoms.



Financial impact

Financial impacts were mainly expressed by Group 3, firstly from the cost of treatment such as medications (especially some that were not covered by the Pharmaceutical Benefits Scheme), surgery, infertility treatment, complementary therapy (e.g. naturopathy, psychology or sex therapist), and sanitary pads. The second impact related to loss of, or decrease in income due to working part time, no paid sick leave and taking time off, or losing the chance of working during school holidays because they had to schedule their surgery at that time.

> *"Financially, it impacted [on] me quite a lot because when I was put on the pill the ones that were covered by the pharmaceutical benefits…The only one I found worked for me wasn't covered and it was quite expensive".* (P22, Group 1)

> *"Financial [impact]; massive, because you're taking so much time off work. … There's no way you're getting out of bed that day and just not getting up and coming, not being able to pay those bills, it does put a massive stress on you".* (P33, Group1)

Among the women who did not mention a negative financial impact, most were from Group 1 who were being supported by their family and did not have financial responsibilities, and a few of them were working full time and were paid for sick leave.

Discussion

- Discussion contains summary of main finding
- comprehensive
- Comparisons with other related studies
- Reveals new area of findings and contribution to the existing knowledge
- Reveals strengths and limitations of study
- implications

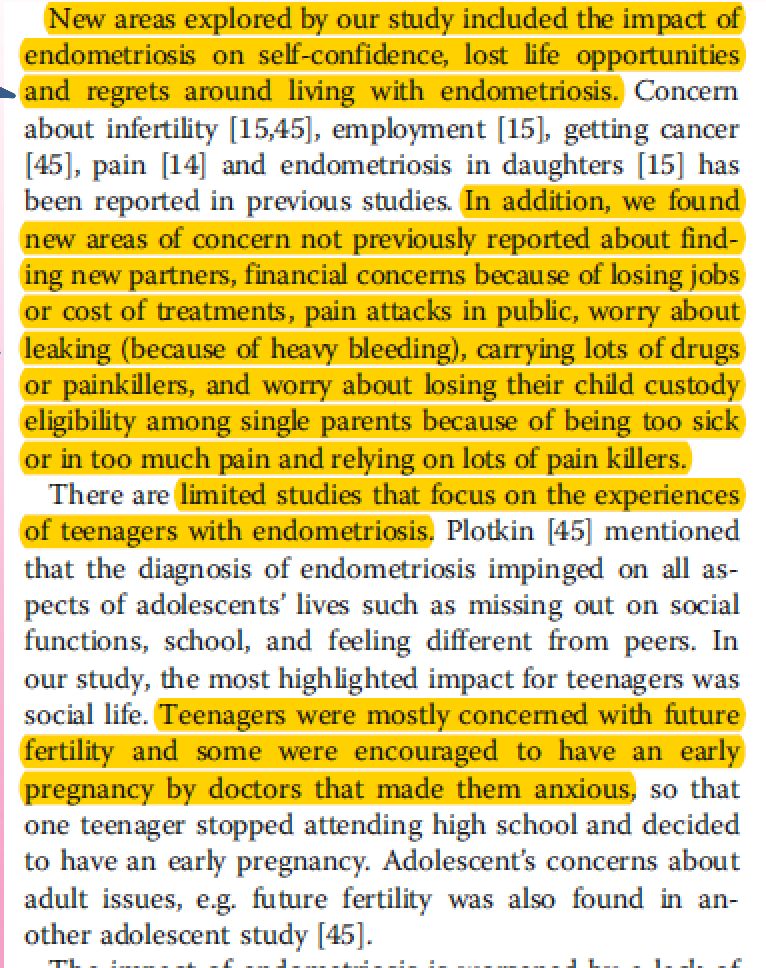
Discussion

New findings explored

Contribution to the existing knowledge

New findings explored

New findings explored



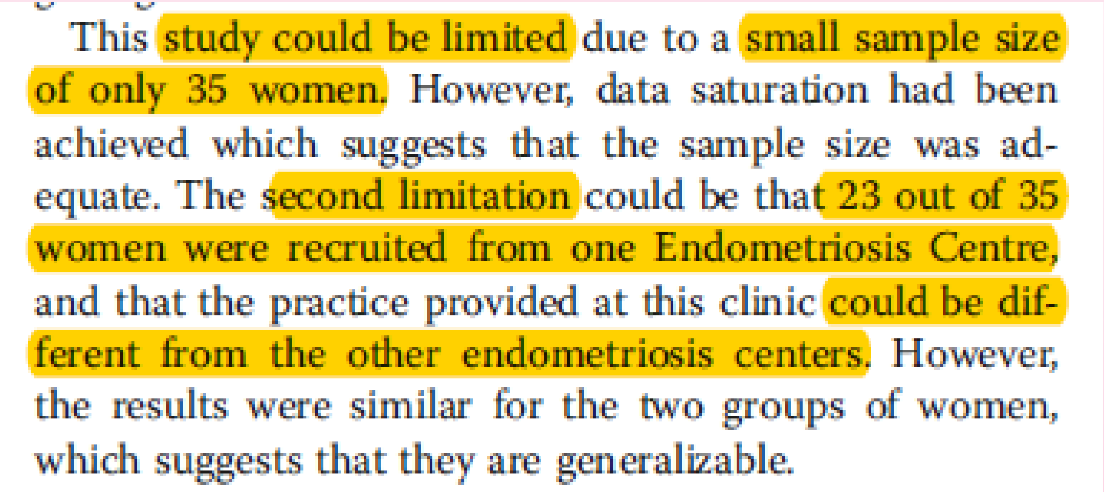
New areas explored by our study included the impact of endometriosis on self-confidence, lost life opportunities and regrets around living with endometriosis. Concern about infertility [15,45], employment [15], getting cancer [45], pain [14] and endometriosis in daughters [15] has been reported in previous studies. In addition, we found new areas of concern not previously reported about finding new partners, financial concerns because of losing jobs or cost of treatments, pain attacks in public, worry about leaking (because of heavy bleeding), carrying lots of drugs or painkillers, and worry about losing their child custody eligibility among single parents because of being too sick or in too much pain and relying on lots of pain killers.

There are limited studies that focus on the experiences of teenagers with endometriosis. Plotkin [45] mentioned that the diagnosis of endometriosis impinged on all aspects of adolescents' lives such as missing out on social functions, school, and feeling different from peers. In our study, the most highlighted impact for teenagers was social life. Teenagers were mostly concerned with future fertility and some were encouraged to have an early pregnancy by doctors that made them anxious, so that one teenager stopped attending high school and decided to have an early pregnancy. Adolescent's concerns about adult issues, e.g. future fertility was also found in another adolescent study [45].

The impact of endometriosis is worsened by a lack of

Discussion

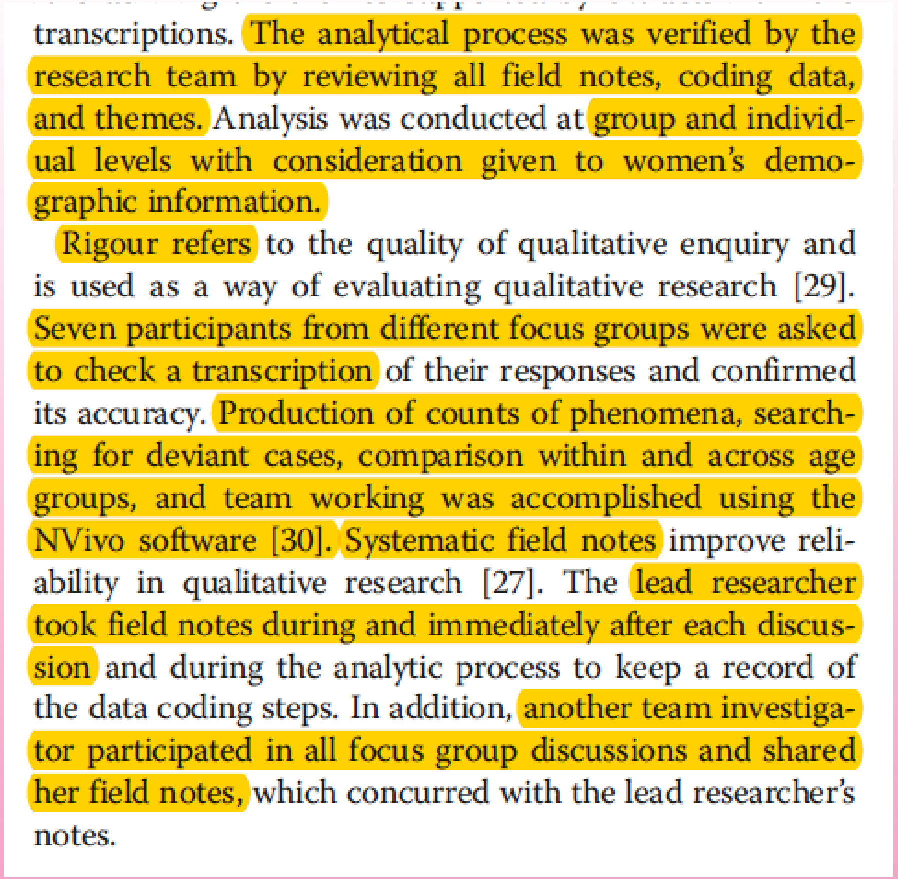
Study limitation



This study could be limited due to a small sample size of only 35 women. However, data saturation had been achieved which suggests that the sample size was adequate. The second limitation could be that 23 out of 35 women were recruited from one Endometriosis Centre, and that the practice provided at this clinic could be different from the other endometriosis centers. However, the results were similar for the two groups of women, which suggests that they are generalizable.

Rigour of study

- incorporate very diverse women into the study
- recruited from both a dedicated Endometriosis Centre and from the general community
- The second facilitator was familiar with the patients
- voice recording , transcribed verbatim
- Seven participants were asked to check a transcription
- NVivo software was used



transcriptions. The analytical process was verified by the research team by reviewing all field notes, coding data, and themes. Analysis was conducted at group and individual levels with consideration given to women's demographic information.

Rigour refers to the quality of qualitative enquiry and is used as a way of evaluating qualitative research [29]. Seven participants from different focus groups were asked to check a transcription of their responses and confirmed its accuracy. Production of counts of phenomena, searching for deviant cases, comparison within and across age groups, and team working was accomplished using the NVivo software [30]. Systematic field notes improve reliability in qualitative research [27]. The lead researcher took field notes during and immediately after each discussion and during the analytic process to keep a record of the data coding steps. In addition, another team investigator participated in all focus group discussions and shared her field notes, which concurred with the lead researcher's notes.

Rigour of study

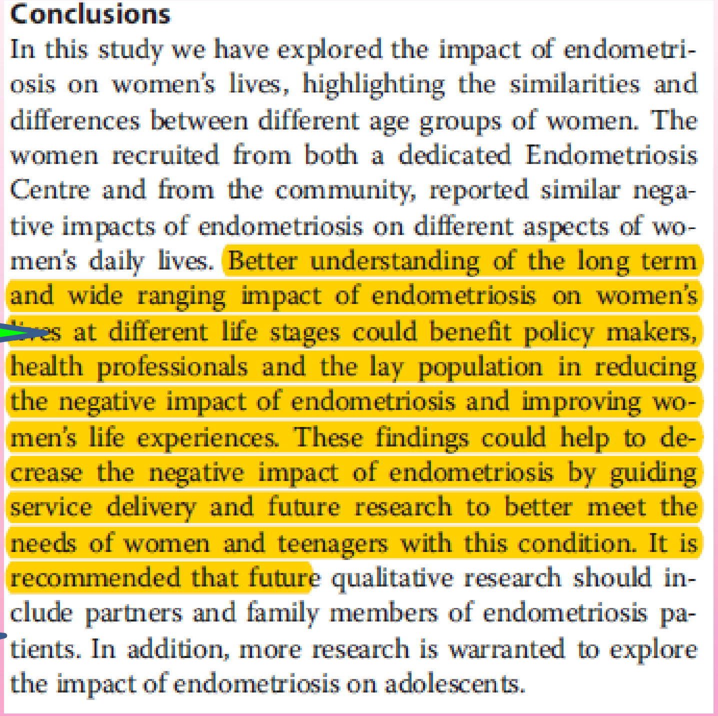
- taking field notes , the second facilitator shared her field notes
- analysis at group-level, individually
- The analytical process was verified by the research team by reviewing all field notes, coding data, and themes.

conclusion

Objective conclusion based on aim and main findings

Implication of the findings for policy and service practice

Suggestions for future studies

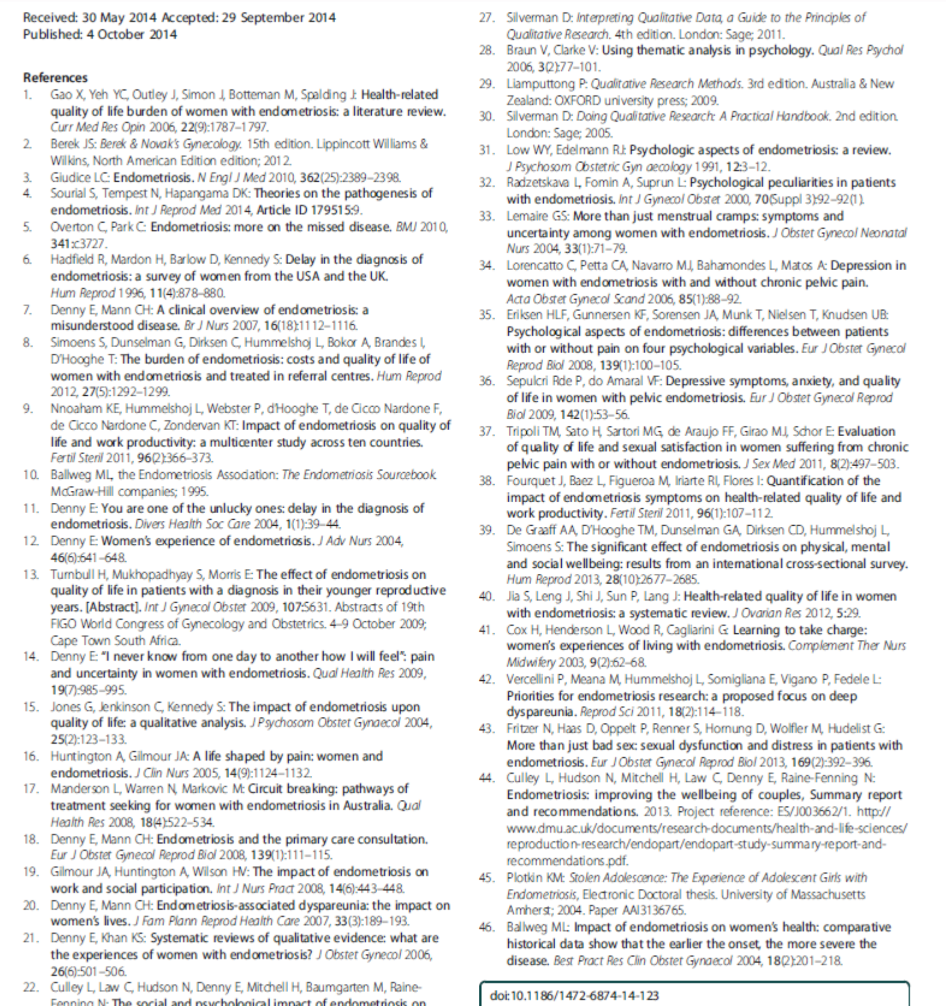


Conclusions

In this study we have explored the impact of endometriosis on women's lives, highlighting the similarities and differences between different age groups of women. The women recruited from both a dedicated Endometriosis Centre and from the community, reported similar negative impacts of endometriosis on different aspects of women's daily lives. Better understanding of the long term and wide ranging impact of endometriosis on women's lives at different life stages could benefit policy makers, health professionals and the lay population in reducing the negative impact of endometriosis and improving women's life experiences. These findings could help to decrease the negative impact of endometriosis by guiding service delivery and future research to better meet the needs of women and teenagers with this condition. It is recommended that future qualitative research should include partners and family members of endometriosis patients. In addition, more research is warranted to explore the impact of endometriosis on adolescents.

References

- Collection of main related References with the aim of study
- Cited based on the journal guide



Received: 30 May 2014 Accepted: 29 September 2014
Published: 4 October 2014

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doi:10.1186/1472-6874-14-123

Any question?

Thank you for your attention!

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