# PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (http://bmjopen.bmj.com/site/about/resources/checklist.pdf) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

## **ARTICLE DETAILS**

TITLE (PROVISIONAL)	Experiences of health after dietary changes in endometriosis: A	
	qualitative interview study.	
AUTHORS	Vennberg Karlsson, Jenny; Patel, Harshida; Premberg, Aasa	

# **VERSION 1 – REVIEW**

REVIEWER	Sarah Holdsworth-Carson
	University of Melbourne
	Australia
REVIEW RETURNED	16-Jul-2019

GENERAL COMMENTS	The paper "Experiences of health after dietary changes in endometriosis: A qualitative interview study" by Jenny Vennberg Karlsson et al., used semi-structured qualitative interviews to assess the introduction of dietary changes in women with endometriosis and the associated symptom and health benefits. The authors conclude that women demonstrate significant health improvements following implementation of lifestyle changes. They also stress that healthcare professionals need to better acknowledge participants choices with respect to self-management of their endometriosis. The paper was easy to read; the language is appropriate, and I have no major concerns with the quality of the writing.  My main concerns, which require addressing, include:  1. The low study number of only 12 participants.  2. Lack of tabulated data. The paper would dramatically benefit from inclusion of patient demographic data (included stage of disease and type(s) of medical treatments being undertaken), and most importantly, results displayed in tables.  3. The authors have not reported if the questionnaire was validated, furthermore, the questionnaire should be included in the paper itself, even as an attached supplementary file (translated). The reader has limited knowledge as to the types of questions asked, and the format in which the participants answered (free text, multiple choice, binomial yes no). Inclusion of coded answers and thematic maps would also benefit the reader.  4. In the results section overall – much more detail is necessary. I have generalised the sorts of themes that require fleshing out. For example, "excluding or decreasing their intake of gluten, dairy products and carbohydrate": it would be useful to know the numbers, how many participant out of 12 chose to alter these specific dietary groups? Of these listed "individual dietary changes" or "lifestyle changes" or "decreased symptoms" were they the consensus, or were there others (and what were they)? "Had a positive impact on health", again the specific details

- 5. Is there information about what dietary changes participants trialled, but did not make an improvement to their health/symptoms?
- 6. Acknowledging that "this study contributes to filling the knowledge gap about dietary strategies in endometriosis" management, is acceptable if the authors stress the study was small and qualitative only, it is important that the paper highlights the next important steps in validating their findings so that meaningful clinical changes can be addressed.

Minor changes:

Introduction

Second paragraph: at times is it not clear if the self-management options described are relating to endometriosis and associated pain symptoms, or other chronic pain conditions.

Third paragraph: "despite the wide use of dietary changes among persons with endometriosis" please include the actual numbers / frequencies of women that are reported in the literature.

Methods

See comments above regarding inclusion of the questionnaire. Results

See comments above.

Discussion

The authors have not included the small study size as a limitation.

REVIEWER	Hanna Grundström Institution of Medicine and Health, Linköping University, Sweden
REVIEW RETURNED	23-Aug-2019

# **GENERAL COMMENTS**

Overall this is a well-written article concerning an important part of daily life for a considerable number of persons with endometriosis. However, I have some concerns as listed below:

- 1. Objective: The objective ends with ....., "and what affected their health experiences". This is a very broad aim. Do you mean "in the context of the diatary changes"? Otherwise, one can imagine that there should be a lot of aspects affecting Health experiences that do not relate to diatary changes and that are not included in this study. Please carify this last subordinate clause.
- 2. Introduction: It gives an introduction to the field but I would have liked more information on the link between diet and endometriosis. (page 5, line 42.) What did reference 18-21 acctually show?
- 3. Participants and setting: page 6, line 7. Did you invite persons directly from only one forum? Please explain why you chose to use this strategy in only one forum.
- 4. Results: Page 8, line 20-38. I'm not sure how this text relates to the aim? How does stress and use of chemicals fit in the context of diatary changes?

Page 9, line 6. "The participants believed in their body's reactions to food". I don't get what you mean here. Please clarify scentence. Page 11 line 5-13. How is this text linked to the name of the theme? Isn't this text more about norms and society rather than "Getting support in managing the diatary change"?

REVIEWER	Elaine Denny
	Birmingham City University
	United Kingdom
REVIEW RETURNED	27-Aug-2019

GENERAL COMMENTS	You have taken an important issue as the basis of your study, but I
	feel you have been overambitious in what you claim to have
	achieved. The terms 'complementary methods' and 'dietary
	changes' are rather vague, particularly when you have a small
	sample, and there are too many different dietary and lifestyle
	changes among the group to be able to draw any firm conclusions.
	The improvements that the participants report are consistent with
	other research findings but this body of work is very anecdotal,
	and what is needed is not more of the same, but research that can
	demonstrate which (if any) diet and lifestyle changes can improve
	endometriosis symptoms (you acknowledge this in your
	conclusion). While it is good that these 12 women found
	something that they feel improves their symptoms, more structured
	research is needed in order to produce advice for the wider endo
	community.
	Specific comments:
	P2 line 17: should be semi-structured
	P2 Conclusion. The study conclusions are not warranted by the
	small sample and different diet and lifestyle changes.
	P2 line 50: Lifestyle could be added as a keyword
	P3: you only list strengths and not weaknesses here
	P5 line 46-48: This aim rather overstates what can be obtained
	from 12 interviews with women who have made different diet and
	lifestyle changes.
	P6 line5-7: Participants recruited from 2 forums with a connection
	to diet may well produce a sample that is more likely to view any
	changes in symptoms positively. Women who found that dietary changes made no difference to them would probably not continue
	on the forum. You could address this possible source of bias in the
	limitations.
	P6 line 29: a copy of the interview guide as an appendix would be
	useful for the reader.
	P7 line 42-45: The dietary changes made are rather vague. For
	example, did most women exclude gluten, or only one or two?
	There are some interesting findings here that could be developed
	further, e.g. 'taking back control' (P8). Also, there is a thread of
	'embodiment' (i.e. the body as something that you are as well as
	something you have) running through the findings in all of the
	themes. You do touch on this in the discussion.
	P12 line 18-28: Did all participants report these improvements?
	Some had only recently changed their diet.
	P13 line 24-26: You are correct to say that qualitative research
	does not seek a causal relationship, however it does need to
	provide some new understanding.
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REVIEWER	Kate Young
	Monash University, Australia
REVIEW RETURNED	06-Sep-2019

GENERAL COMMENTS	Thank you for the opportunity to read your paper. This is an important area of research. I wish you the best of luck with your revisions and hope to see the paper published in the near future.  This paper addresses an important topic; one that has had little research conducted from the perspectives of those who live with endometriosis. However, the analysis presented appears to be quite basic and the authors have not clearly demonstrated how it is rooted in the participant perspective. I hope the authors find my
	comments useful and I wish them the best of luck with their revisions.

## INTRODUCTION

Page 5, line 6-7: This statement should be referenced. Further, population database studies (higher quality) suggest the prevalence of endometriosis is 1-2% (see, for example, 10.1111/j.1471-0528.2008.01878.x and

10.1371/journal.pone.0154227). The 10-15% figures come from clinic-based studies (lower quality) which are biased toward women more likely to report adverse outcomes.

Page 5, line 8: The definition of endometriosis is incorrect. The tissue is like the endometrium but not exactly the same.

Page 5, line 11: Best quality evidence suggests 10-15% of women with endometriosis experience infertility (compared to 9% in the general population; described in the introduction of 10.1080/13625187.2018.1539163). The statement that infertility is common in women with endometriosis is misleading.

Page 5, line 35: That the ESHRE guidelines don't recommend dietary changes etc does not necessarily mean that clinicians don't recommend this. Women have reported their doctor to recommend

Introduction, last paragraph: There is no sufficient research evidence to recommend a particular diet to women with endometriosis as a treatment or symptom management option. This needs to be clearly stated to the reader. Also, this reference is missing: 10.1016/j.ejogrb.2006.12.006

### **METHOD**

# Recruitment:

a range of 'lifestyle changes.'

Were the forums publicly accessible? If they were private, were members aware that that may be approached by researchers?
Was any effort made to include women who had not changed their diet? This is essential to capture counter examples to provide a comprehensive account of the phenomenon.

Interview guide: Were these additional themes asked with regards to dietary changes only? (e.g. dietary changes and relationship with a partner?) I suggest adding the interview guide as a supplementary material to increase transparency. RESULTS

Participants – Data on participants needs to be presented in a table by pseudonym. This enables the reader to assess diversity, an essential component to quality qualitative research. See, for example, the layout in this paper: 10.1093/humrep/dev337. Further, with statements in the discussion about it being strength to have people living in various areas etc, this is impossible to assess.

Need to integrate participant's voices more – use quotations in sentences in addition to block quotes. See, for example, 10.1093/humrep/dev337. Currently there is little evidence of rooting the analysis in the perspective of the participant. The analysis appears to be quite basic. Need to go further and consider the context of what women are saying. Braun & Clarke outline this in their paper (that the authors have cited as using). Control seems to be an important theme but it is not immediately obvious to the reader. I.e. dietary changes allow (some) people a sense of control over their bodies and experiences of endometriosis. This, to me, is the "most important clinical finding" – not that they perceived their symptoms to reduce (as stated in the first paragraph of the discussion), something that is difficult to measure or generalise to others, and is not the aim of a qualitative investigation.

DISCUSSION

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women from
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diet culture,
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REVIEWER	Ronald Uittenbroek Windesheim Universtiy of Applied Sciences
REVIEW RETURNED	11-Sep-2019

## **GENERAL COMMENTS**

Thank you for the opportunity to review this manuscript. It is well written and although a topic of interest, I find myself having some major issues with the recruitment of respondents, including selection bias and data analysis including saturation and therefor discussion an statements made.

Perhaps I am old fashioned, but recruitment via an internet forum does raises some questions; it would be very helpful if the authors elaborate more on this within the 'participants and setting' section and refer to other studies using these kinds of platforms for recruitment and its pros and cons regarding validity and reliability. This should also be addressed within the discussion section. Furthermore, for the recruitment, three forums were targeted and direct invitations were send. It remains unclear what strategy was successful and what, forum or direct invitation, led to inclusion in the end. In addition, a large group of respondents that were addressed did not want to participate and it remains unclear to what extend the 12 respondents included in this study relate to the non-respondents and in fact the total group of patient with endometriosis. This needs further elaboration within the recruitment, results and discussion section. Furthermore, although stated that rich material was gathered, it remains unclear whether data saturation has been established; given the relatively small group of respondents this could be an issue and needs to be adressed.

For the results section I have a gut feeling, but I might be wrong, that more than only dietary changes were addressed by the respondents, which might be logical given the results of previous research regarding complementary interventions for endometriosis. I would suggest adding more quotes related to the dietary changes per theme, as some quotes are multiple interpreatable, and if addressed by the respondents, not withhold statements regarding a more comprehensive approach on complementary interventions rather than focusing only on dietary changes.

Regarding the discussion section, author state that "The results of this study show that the participants experienced decreased symptoms of endometriosis and gained a greater understanding of their bodies after making individual dietary changes. The most important clinical finding is that the participants described reductions in symptoms, specifically pain and fatigue, which led to the positive experience of increased health". In line with my previous comments, I have trouble with these statements and especially 'clinical findings.' It is suggested to be a bit more cautious and reserved regarding such statements given the select group of respondents. Finally, a thought; perhaps it would be helpfull to have a dietician co-read your manuscript.

## **VERSION 1 – AUTHOR RESPONSE**

## Reviewer 1: Sarah Carson

The paper "Experiences of health after dietary changes in endometriosis: A qualitative interview study" by Jenny Vennberg Karlsson et al., used semi-structured qualitative interviews to assess the introduction of dietary changes in women with endometriosis and the associated symptom and health benefits. The authors conclude that women demonstrate significant health improvements following implementation of lifestyle changes. They also stress that healthcare professionals need to better acknowledge participants choices with respect to self-management of their endometriosis. The paper was easy to read; the language is appropriate, and I have no major concerns with the quality of the writing.

1. The low study number of only 12 participants.

Thanks. In qualitative research using interview as a data collection method; the optimal sample size is guided by data saturation. The purposive sampling is preferred to get data from the persons who can express verbally their experiences in qualitative inquiry.

Ref: Ulin, Priscilla R, Robinson, Elizabeth T, & Tolley, Elizabeth E. (2012). Qualitative Methods in Public Health: A Field Guide for Applied Research. Jossey Bass.

During data collection process, the last three interviews did not generate any new information. We therefore judged that the data saturation was fulfilled, and the number of participants were sufficient to address the purpose of the study. See page 14, paragraph 2, line 4-10.

2. Lack of tabulated data. The paper would dramatically benefit from inclusion of patient demographic data (included stage of disease and type(s) of medical treatments being undertaken), and most importantly, results displayed in tables.

Thanks. The table is included now (Table 1). See page 7-8. Data in table include: age, years since diagnosis, highest level of education completed, hormonal treatment at time for the interview and time for dietary changes.

The information about stage of the disease was not gathered during the interviews as it does not always reflect the symptoms of the disease.

Ref: Dunselman GA, Vermeulen N, Becker C, Calhaz-Jorge C, D'Hooghe T, De Bie B, et al. ESHRE guideline: management of women with endometriosis. Hum Reprod. 2014;29(3):400-12.

3. The authors have not reported if the questionnaire was validated, furthermore, the questionnaire should be included in the paper itself, even as an attached supplementary file (translated). The reader has limited knowledge as to the types of questions asked, and the format in which the participants answered (free text, multiple choice, binomial yes no). Inclusion of coded answers and thematic maps would also benefit the reader.

We did not use any structured questionnaire for data collection. Data was collected using semi-structured interview technique with the help of an interview guide. The opening question was: Will you please tell me about your experiences of health after the dietary change? Follow-up questions were used to clarify any unclear descriptions. Recapitulation was used on individuals who stopped talking; directing them back to previous comments to clarify or elaborate on any descriptions. The interview guide served as a reminder to cover the intended topics in the interview. The interview guide has been added as Appendix 2, see page 6.

Thank you for making this point. Definitely the thematic map will make it easier for readers to follow the process. The thematic map has been included as Appendix 3. See page 7, paragraph 2, line 9.

4. In the results section overall – much more detail is necessary. I have generalised the sorts of themes that require fleshing out. For example, "excluding or decreasing their intake of gluten, dairy products and carbohydrate": it would be useful to know the numbers, how many participant out of 12 chose to alter these specific dietary groups? Of these listed "individual dietary changes" or "lifestyle changes" or "decreased symptoms" were they the consensus, or were there others (and what were they)? "Had a positive impact on health", again the specific details of these are required and whether these changes are self-reported or clinically measured.

We appreciate your concern. In a thematic analysis the analysis is about the patterns of meaning in the participants description of the research question, and it cannot be subjected to the same criteria as quantitative approaches (Braun, V & Clarke). Qualitative research is primarily about text and the numbers are not interesting. The analysis is about describe what has been observed and interpretation wherever you can as a researcher (Ulin et al).

Ref: Braun, V & Clarke, C (2006) Using thematic analysis in psychology. Qualitative Research in Psychology.

Ref: Ulin, Priscilla R, Robinson, Elizabeth T, & Tolley, Elizabeth E. (2004). Qualitative Methods in Public Health: A Field Guide for Applied Research. Jossey Bass.

We added the sentence to clarify: Most of the participants excluded or decreased gluten, dairy products and carbohydrates. See page 8,

	paragraph 2 line 3: Selecting individual dista
	paragraph 2, line 3: Selecting individual diets and supplements.
5. Is there information about what dietary changes participants trialled, but did not make an improvement to their health/symptoms?	The aim was to explore how persons with endometriosis experienced their health after dietary changes and no questions were asked about diet that did not improve symptoms. However, one participant reported that a general Fodmap diet did not affect the endometriosis symptoms and the person thereby made own individual dietary changes instead. We have included this on page 10, paragraph 6, line 6-8: Experiencing decreased pain and regulated menstruation cycle
6. Acknowledging that "this study contributes to filling the knowledge gap about dietary	We appreciate your comment. The conclusion is rewritten now, page 2 and reads:
strategies in endometriosis" management, is acceptable if the authors stress the study was small and qualitative only, it is important that the paper highlights the next important steps in validating their findings so that meaningful clinical changes can be addressed.	This study contributes to fill the knowledge gap about dietary strategies in endometriosis and lifestyle change as a method of alleviating suffering and increasing wellbeing. The participants experienced decreased symptoms and increased wellbeing after adopting an individually-adapted diet. An important finding was that healthcare professionals need to consider the patients' knowledge and experience, and allow them to participate in their own care. Further research is required about endometriosis and dietary changes in order for HCP to give evidenced-based dietary advices.
Minor changes:	
Introduction	
Second paragraph: at times is it not clear if the self-management options described are relating to endometriosis and associated pain symptoms, or other chronic pain conditions.	Thanks for making us aware about clarity of the text. The text is rewritten and reads:  We have changed the text, see page 5, paragraph 2, line 3-5.
Third paragraph: "despite the wide use of dietary changes among persons with endometriosis" please include the actual numbers / frequencies of women that are reported in the literature.	Thank you for taking up this question. We have noticed on internet forum that it is quite common to do dietary changes but there is no actual number regarding this issue that has been addressed in the literature. This sentence has been rewritten now. See page 5, paragraph 3, line 13.

Methods	
See comments above regarding inclusion of the questionnaire.	Please see the responses above.
Results	
See comments above.	Please see the responses above.
Discussion	
The authors have not included the small study size as a limitation.	We appreciate your comment. This limitation has been added under limitations section.  See page 14, paragraph 2, line 4-10.

#### Reviewer 2: Hanna Grundström

Overall this is a well-written article concerning an important part of daily life for a considerable number of persons with endometriosis. However, I have some concerns as listed below:

Objective: The objective ends with ....., "and what affected their health experiences". This is a very broad aim. Do you mean "in the context of the diatary changes"? Otherwise, one can imagine that there should be a lot of aspects affecting Health experiences that do not relate to diatary changes and that are not included in this study. Please carify this last subordinate clause.

Thank you for pointing out this. The aim is revised to read it more explicitly. See page 2.

The aim of this study was to explore how persons with endometriosis experienced their health after dietary changes.

Introduction: It gives an introduction to the field but I would have liked more information on the link between diet and endometriosis. (page 5, line 42.) What did reference 18-21 actually show? Thanks, we appreciate your opinion and more information is added now about the link between endometriosis and diet. See page 5, paragraph 3, starting at line 5.

Participants and setting: page 6, line 7. Did you invite persons directly from only one forum? Please explain why you chose to use this strategy in only one forum.

Thank you for making us aware about that this was unclear to the reader. We have added more information in the method section. See page 6, paragraph 2, line 3-9.

Results: Page 8, line 20-38. I'm not sure how this text relates to the aim? How does stress and use of chemicals fit in the context of diatary changes?

The participants expressed that stress affected the endometriosis symptoms and that chemicals in e.g. parabens were affecting hormones. The text has been revised and more citations from the participants has been added to understand our interpretation/description of the interview data. See page 9, paragraph 3, line 1-2 and line 5-7.

Page 9, line 6. "The participants believed in their body's reactions to food". I don't get what you mean here. Please clarify sentence.

Thanks. The text has been revised and more citations from the participants has been added to understand our interpretation/description of the interview data. See page 9, paragraph 6, line 2-5.

Page 11 line 5-13. How is this text linked to the name of the theme? Isn't this text more about norms and society rather than "Getting support in managing the dietary change"?

Thanks, we appreciate your comment. The theme name has been revised to mirror the content to clarify that the theme is about support. See page 11: "Supports helps in managing the dietary change". We also added information about what support that was given to the person with endometriosis. See page 11, paragraph 11, line1-3. We have also changed one sub-theme name. See page 12, paragraph 4, line 1.

# **Reviewer 3: Elaine Denny**

You have taken an important issue as the basis of your study, but I feel you have been overambitious in what you claim to have achieved.

The terms 'complementary methods' and 'dietary changes' are rather vague, particularly when you have a small sample, and there are too many different dietary and lifestyle changes among the group to be able to draw any firm conclusions.

We appreciate your concern. The aim of the

study was not to define which dietary change

that was effective for persons with endometriosis. The aim was to explore how persons with endometriosis experienced their health after dietary changes. We have added information under "Method" See, page 6, paragraph 4, line 4-5. This issue has also been addressed under "Strength and limitations. See page 14, paragraph 2, line 1-10 to page 15, paragraph 2, line 1-8.

The improvements that the participants report are consistent with other research findings but this body of work is very anecdotal, and what is needed is not more of the same, but research that can demonstrate which (if any) diet and lifestyle changes can improve endometriosis symptoms (you acknowledge this in your conclusion). While it is good that these 12 women found something that they feel improves their symptoms, more structured research is needed in order to produce advice for the wider endo community.

You are right that other researchers have been reporting similar result, but they have not been aiming particularly for dietary changes and in their results the dietary changes are more a cofound to the results. For examples:

Ref: Cox, H. et al (2003) Learning to take charge: women's experiences of living with endometriosis. Complement Ther Nurs Midwifery

The aim here was to identify the information needs of women undergoing investigation or treatment for endometriosis... and one of the themes in the result is focusing on; "Control though complementary/alternative therapies". Where they are mentioning that the participants

	are using a combination of alternative therapies such as diet, exercise and positive thinking to manage their lives, but it is not investigated further.  Roomaney, R. & Kagee, A. (2016) Coping strategies employed by women with endometriosis in a public health-care setting. J Health Psychol
	The aim was to explore how participants in a resource-constrained setting coped with living with endometriosis. In the result one theme is "Engaging in self-management" and they are mentioning self-managing techniques as: relaxion, stretching activities and changing their diets, but it is not investigated further.
	Absolutely, in future we need to focus on the research about what dietary changes affects to relive the symptoms and ease suffering in persons with endometriosis. We are working on planning the studies with focus on this issue.
P2 line 17: should be semi-structured	Thanks, we appreciate your suggestion. The text has been revised page 2, line 9.
P2 Conclusion. The study conclusions are not warranted by the small sample and different diet and lifestyle changes.	We appreciate your comment. The conclusion is rewritten now, page 2 and reads:  This study contributes to fill the knowledge gap about dietary strategies in endometriosis and lifestyle change as a method of alleviating suffering and increasing wellbeing. The participants experienced decreased symptoms and increased wellbeing after adopting an individually-adapted diet. An important finding was that healthcare professionals need to consider the patients' knowledge and experience, and allow them to participate in their own care. Further research is required about endometriosis and dietary changes in order for HCP to give evidenced-based dietary advices.
P2 line 50: Lifestyle could be added as a keyword	Thanks for your suggestion. We have to choose keywords from BMJ Opens keyword list and the keywords are now: Endometriosis, dietary changes, qualitative research, nutrition & diets, gynaecology

P3: you only list strengths and not weaknesses here

Thank you for noticing this. "Strengths and limitations" section has been revised now. The weaknesses are also addressed. See page 3

P5 line 46-48: This aim rather overstates what can be obtained from 12 interviews with women who have made different diet and lifestyle changes.

Thank you for your comments. The aim has been revised to read more explicitly. Please see page 2, line 6-7.

In qualitative research the optimal sample size is less clear than in quantitative designs. The interviewer is guided by the incoming data answering aim of the research. A small purposive sample are ideally suited to qualitative inquiry. Data is collected until the data saturation is reached. After 9<sup>th</sup> interview we did not found any new information coming in from the interviews, the it was decided that desaturation has been reached. This has been discussed under the discussion section. See page 14, paragraph 2, line 4-12.

Ref: Ulin, Priscilla R, Robinson, Elizabeth T, & Tolley, Elizabeth E. (2004). Qualitative Methods in Public Health: A Field Guide for Applied Research. Jossey Bass.

P6 line5-7: Participants recruited from 2 forums with a connection to diet may well produce a sample that is more likely to view any changes in symptoms positively. Women who found that dietary changes made no difference to them would probably not continue on the forum. You could address this possible source of bias in the limitations.

Thank you for taking up this matter. We have clarified this under limitations. Se page 15, paragraph 1, line 3-8.

In a qualitative study the participants are drawn from a community wherever people are willing to share knowledge and experience related to the research topics. Because the purpose of qualitative design is to explore experiences, the researcher has to select carefully persons who can shed light on the objective of the study. Therefore, to identify and gain access to those who can provide you the rich information, the purposive sampling was chosen.

Ref: Ulin, Priscilla R., et al. Qualitative Methods in Public Health: A Field Guide for Applied Research, Wiley, 2012.

Thus, there might be persons who are active on the forum and might not have experienced improvement in endometriosis symptoms

	related to diet change but might not been interested to participate in the study to share their experiences. Actually, this is the limitation of the study and has been stated under limitation section. Please see page 15, paragraph 1, line 3-8.
P6 line 29: a copy of the interview guide as an appendix would be useful for the reader.	Data were collected via semi-structured interviews using an interview guide. The opening question was: Will you please tell me about your experiences of health after the dietary change? After this first question the interviewer let the participants to lead the interview. The interview guide served as a reminder to cover the intended topics in the interview. The interview guide has been added as Appendix 2, see page 6.
P7 line 42-45: The dietary changes made are rather vague. For example, did most women exclude gluten, or only one or two?	Thanks for your comment. In a thematic analysis the analysis is about the patterns of meaning in the participants description of the research question, and it cannot be subjected to the same criteria as quantitative approaches (Braun, V & Clarke). Qualitative research is primarily about text and the numbers are not interesting. The analysis is about describe what has been observed and interpretation wherever you can as a researcher (Ulin et al).
	Ref: Braun, V & Clarke, C (2006) Using thematic analysis in psychology. Qualitative Research in Psychology.  Ref: Ulin, Priscilla R, Robinson, Elizabeth T, & Tolley, Elizabeth E. (2004). Qualitative Methods in Public Health: A Field Guide for Applied
	We changed the text: Most of the participants excluded or decreased gluten, dairy products and carbohydrates. See page 8, paragraph 2, line 3: Selecting individual diets and supplements
There are some interesting findings here that could be developed further, e.g. 'taking back control' (P8). Also, there is a thread of 'embodiment' (i.e. the body as something that you are as well as something you have) running	Thank you for an interesting comment, that might be useful in coming studies. The purpose was to explore how persons with endometriosis

through the findings in all of the themes. You do touch on this in the discussion.

experienced their health after dietary changes.

Now that we see an indication that dietary changes might be helping it can be interesting to do a deeper analysis, for example to investigate the connection in the findings about 'control' and 'embodiment'. In this study we think that the health aspect and decreased symptoms are the most important aspect, but it would be interesting to look into 'control' and 'embodiment' in future research. We have added this in the discussion. See page 13, paragraph 2, line 14-24 and page 15, paragraph 4, line 6-7.

P13 line 24-26: You are correct to say that qualitative research does not seek a causal relationship, however it does need to provide some new understanding.

Thank you for joining us in the thought of qualitative research does not seek a causal relationship. We do think that the study provides a new understanding in form of that the participants describes improved wellbeing and improved symptoms. We added this information to "Strength and limitations". See page 15, paragraph 2, line 2-3. As said earlier other researchers have been reporting similar result, but they have not been aiming particularly for dietary changes. For examples:

Ref: Cox, H. et al (2003) Learning to take charge: women's experiences of living with endometriosis. Complement Ther Nurs Midwifery

Roomaney, R. & Kagee, A. (2016) Coping strategies employed by women with endometriosis in a public health-care setting. J Health Psychol

## **Reviewer 4: Kate Young**

This paper addresses an important topic; one that has had little research conducted from the perspectives of those who live with endometriosis. However, the analysis presented appears to be quite basic and the authors have not clearly demonstrated how it is rooted in the participant

perspective. I hope the authors find my comments useful and I wish them the best of luck with their revisions. Page 5, line 6-7: This statement should be Thanks. The reference has been added. See referenced. Further, population database page 5, paragraph 1, line 1-2. studies (higher quality) suggest the prevalence of endometriosis is 1-2% (see, for example, 10.1111/j.1471-0528.2008.01878.x and 10.1371/journal.pone.0154227). The 10-15% figures come from clinic-based studies (lower quality) which are biased toward women more likely to report adverse outcomes. Page 5, line 8: The definition of endometriosis is Thanks for noticing this. The definition has been incorrect. The tissue is like the endometrium but rewritten to be correct. See page 5, paragraph not exactly the same. 1, line 3. Page 5, line 11: Best quality evidence suggests Thank you for the information and the reference. 10-15% of women with endometriosis We have changed this. See page 5, paragraph 1, line 7-8. experience infertility (compared to 9% in the general population; described in the introduction of 10.1080/13625187.2018.1539163). The statement that infertility is common in women with endometriosis is misleading. Page 5, line 35: That the ESHRE guidelines Thank you for pointing this out. We have added don't recommend dietary changes etc does not new information to the text. See page 5, paragraph 2, line 17-18. necessarily mean that clinicians don't recommend this. Women have reported their doctor to recommend a range of 'lifestyle changes.' Introduction, last paragraph: There is no Thank you for the reference and for helping us sufficient research evidence to recommend a clarifying this. We have added the clear particular diet to women with endometriosis as a statement and the reference on page 5, treatment or symptom management option. This paragraph 3, line 3-4. needs to be clearly stated to the reader. Also, this reference is missing: 10.1016/j.ejogrb.2006.12.006 **METHOD** To join the Internet forums, the members needed to apply to become a member of the Recruitment: forum. We have added this information for the clarification. See page 6, paragraph 2, line 2-3. Were the forums publicly accessible? If they were private, were members aware that that Before the advertisement; the forum may be approached by researchers? administrators gave written consent to recruit the participants for the study. Approaching researcher introduced herself in the advertisement. See Appendix 1. See page 6, paragraph 2, line 5.

Was any effort made to include women who had not changed their diet? This is essential to

capture counter examples to provide a comprehensive account of the phenomenon.

Thank you for this comment. No, we did not invite persons who did not change, as the aim was to explore how persons with endometriosis experienced their health after dietary changes. However, one participant reported that a general Foodmap diet did not affect the endometriosis symptoms and the person thereby made own individual dietary changes instead. This information is added on page 10, paragraph 6, line 6-8.

Interview guide: Were these additional themes asked with regards to dietary changes only? (e.g. dietary changes and relationship with a partner?) I suggest adding the interview guide as a supplementary material to increase transparency.

Data were collected via semi-structured interviews using an interview guide. The opening question was: Will you please tell me about your experiences of health after the dietary change? After this first question the interviewer let the participants to lead the interview. The interview guide served as a reminder to cover the intended topics in the interview. The interview guide has been added as Appendix 2, see page 6.

## **RESULTS**

Participants – Data on participants needs to be presented in a table by pseudonym. This enables the reader to assess diversity, an essential component to quality qualitative research. See, for example, the layout in this paper: 10.1093/humrep/dev337.

Thank you for making this point. Qualitative research is primarily about the text, but in some research, images, body maps, and photos are considered and analysed as forms of visual language.

Ref: Ulin, Priscilla R, Robinson, Elizabeth T, & Tolley, Elizabeth E. (2004). Qualitative Methods in Public Health: A Field Guide for Applied Research. Jossey Bass.

The table (Table 1, page 7-8) with the demographic data about; age, years since diagnosis, highest level of education completed, hormonal treatment at

time for the interview and time for dietary changes has been attached.

Further, with statements in the discussion about it being strength to have people living in various areas etc, this is impossible to assess.

Thank you for your comment. In qualitative research we strived to understand how the studied phenomena was experienced among persons with endometriosis after dietary changes were made. Hence, a small number of participants that maximize the diversity relevant to the research question were selected. The variation can be partly be seen in the demographic data (table 1) and is presented in the results. Please see page 7-8. We also

added this in the discussion page 14, paragraph 3, line 2-5. Need to integrate participant's voices more -Thanks for important suggestion. We have added more quotations in the results section. use quotations in sentences in addition to block Starting on page 7. The new short quotation are quotes. See, for example, green font and new long citations are in red font 10.1093/humrep/dev337. Currently there is little color. evidence of rooting the analysis in the perspective of the participant. The analysis appears to be quite basic. Need to Thank you for your comments about the go further and consider the context of what analysis. The thematic analysis method can be women are saying. Braun & Clarke outline this in their paper (that the authors have cited as seen as a basic method but it was chosen as the using). subject of the study is not well explored it was necessary to keep the first study close to the descriptions of the interviewee's descriptions. Ref: Braun, V & Clarke, C (2006) Using thematic analysis in psychology. Qualitative Research in Psychology. Control seems to be an important theme, but it Thank you for an interesting comment, that is not immediately obvious to the reader. I.e. might be useful in coming studies. The purpose dietary changes allow (some) people a sense of control over their bodies and experiences of was to explore how persons with endometriosis endometriosis. This, to me, is the "most important clinical finding" - not that they experienced their health after dietary changes. perceived their symptoms to reduce (as stated in the first paragraph of the discussion), Now that we see an indication that dietary something that is difficult to measure or changes might be helping it can be interesting to generalise to others, and is not the aim of a qualitative investigation. do a deeper analysis, for example to investigate the connection in the findings about 'control' In this study we think that the health aspect and decreased symptoms are the most important aspect, but it would be interesting to look into 'control' in future research. We have added this in the discussion. See page 13, paragraph 2, line 14-23 and page 15, paragraph 4, line 6-7. We

Also added the thematic maps to strengthen the

	analysis. See Appendix 2, page 6, paragraph 5,
	line 1.
DISCUSSION  It needs to be more clearly highlighted that recruiting women from support groups and forums is biased toward those who experience more adverse outcomes (DOI: 10.1093/humrep/dev084).	Thank you for pointing out this. We have added information about this under "Strengths and limitations" See, page 15, paragraph 3, line 7-11.
The age range of participants is quite narrow. In the context of diet culture, it would be interesting to see what younger women would report. Conversely, it would be interesting to see what women in their midlife would report.	It is an interesting aspect you are noticing. Our participants are recruited from an Internet forum. This might mirror to the persons who are part of a patient association and it is more common with delayed diagnosis of endometriosis.
	Ref Quality of life outcomes in women with Human reproduction [0268-1161] De Graaff, A A år:2015 vol:30 iss:6 sidor:1331 -41)
	This might be an explanation why we don't have younger women in our study, since we have only included the women with a confirmed diagnosis by a physician.
	The participants in our study also mostly have higher education, which also which can be an indicator of higher age and is consistent with persons who uses Internet to search health related information.
	Ref: Internet Use for Searching Information on Medicines and Disease: A Community Pharmacy–Based Survey Among Adult Pharmacy Customers
	Monitoring Editor: Gunther Eysenbach
	Reviewed by Stephanie Shimada, Thomas Houston, and Hari Nandigam

# Reviewer 5: Ronald Uittenbroek

Thank you for the opportunity to review this manuscript. It is well written and although a topic of interest, I find myself having some major issues with the recruitment of respondents, including selection bias and data analysis including saturation and therefor discussion an statements made.

Perhaps I am old fashioned, but recruitment via an internet forum does raises some questions; it would be very helpful if the authors elaborate more on this within the 'participants and setting' section and refer to other studies using these kinds of platforms for recruitment and its pros and cons regarding validity and reliability. This should also be addressed within the discussion section.

Thank you for your suggestion. We have added more information under Participants and setting and Discussion. See page 6, paragraph 2, line 10-16. See also page 15, paragraph 3.

There is to suggest that Internet is a successful recruitment tool, and its use, therefore, should be considered in the health research. Benefits include reduced cost, shorter recruitment periods, better representation, and improved participant selection. This may spell the end for traditional methods, although currently the minor limitations of Internet access and the over representation of young white women may make its use inappropriate in some

settings.

Ref The Use of Facebook in Recruiting Participants for Health Research

Purposes: A Systematic Review

Monitoring Editor: Carlos Luis Parra-Calderón

Reviewed by Adriana Arcia and Miriam Ashford

Christopher Whitaker, BDS, Sharon Stevelink, MSc, PhD, and Nicola Fear, BSc, MSc, DPhil

Furthermore, for the recruitment, three forums were targeted and direct invitations were send. It remains unclear what strategy was successful and what, forum or direct invitation, led to inclusion in the end.

Thank you for taking up this matter. This has been rewritten for the purpose of clarification under "Participants and setting" See page 6, paragraph 2, line 3-10.

In addition, a large group of respondents that were addressed did not want to participate and it remains unclear to what extend the 12 respondents included in this study relate to the non-respondents and in fact the total group of patient with endometriosis. This needs further elaboration within the recruitment, results and discussion section.

Thank you for taking up this matter.

In a study the participants are drawn from a community wherever people are willing to share knowledge and experience related to the research topics. Because the purpose of qualitative design is to explore a phenomena of interest, the investigator carefully selects, the investigator carefully selects, the investigator carefully selects persons that can typify or shed light on the object of study. Therefore, to identify and gain access to those who can tell you the most about your topic, it follows that sampling methods will generally be

based on purpose rather than on statistical probability of selection. It means selecting participants for their ability to provide rich information. See page 6, paragraph 2, line 13-Ref: Ulin, Priscilla R., et al. Qualitative Methods in Public Health: A Field Guide for Applied Research, Wiley, 2012. Furthermore, although stated that rich material Thank you for pointing this out. We have added was gathered, it remains unclear whether data the information under Discussion/Strengths and saturation has been established; given the limitations" See side 14, paragraph 2, line 4-10. relatively small group of respondents this could be an issue and needs to be adressed. For the results section I have a gut feeling, but I Yes, your gut feeling is right, but the participants might be wrong, that more than only dietary emphasised that the dietary change was changes were addressed by the respondents, central in improving health. They which might be logical given the results of described that the dietary change aroused their previous research regarding complementary interest in making other lifestyle changes, not interventions for endometriosis. the other way around. See page 9, paragraph 5 and paragraph 6. I would suggest adding more quotes related to Thanks for important suggestion. We have the dietary changes per theme, as some quotes added more quotations in the results section. are multiple interpreatable, and if addressed by Starting on page 7. The new short quotation are the respondents, green font and new long citations are in red font color. Thank you for the comment, We choose to not withhold statements regarding a more comprehensive approach on complementary focus on dietary changes since other interventions rather than focusing only on researchers have been reporting similar result, dietary changes. but they have not been aiming particularly for dietary changes and dietary changes are more a cofound to their results. For examples: Ref: Cox, H. et al (2003) Learning to take charge: women's experiences of living with endometriosis. Complement Ther Nurs Midwifery The aim here was to identify the information needs of women undergoing investigation or treatment for endometriosis... and one of the themes in the result is focusing on; "Control though complementary/alternative therapies". Where they are mentioning that the participants are using a combination of alternative therapies such as diet, exercise and positive thinking to manage their lives, but it is not investigated further.

Roomaney, R. & Kagee, A. (2016) Coping strategies employed by women with endometriosis in a public health-care setting. J Health Psychol

The aim was to explore how participants in a resource-constrained setting coped with living with endometriosis. In the result, one theme is "Engaging in self-management" and they are mentioning self-managing techniques as: relaxion, stretching activities and changing their diets, but it is not investigated further.

Regarding the discussion section, author state that "The results of this study show that the participants experienced decreased symptoms of endometriosis and gained a greater understanding of their bodies after making individual dietary changes. The most important clinical finding is that the participants described reductions in symptoms, specifically pain and fatigue, which led to the positive experience of increased health". In line with my previous comments, I have trouble with these statements and especially 'clinical findings.' It is suggested to be a bit more cautious and reserved regarding such statements given the select group of respondents.

Thank you for this opinion. The participants gave a rich material of decreased symptoms during the interviews. In a thematic analysis the analysis is about the patterns of meaning in the participants description of the research question, and it cannot be subjected to the same criteria as quantitative approaches (Braun, V & Clarke). Qualitative research is primarily about text and the numbers are not interesting. The analysis is about describe what has been observed and interpretation wherever you can as a researcher (Ulin et al).

Ref: Braun, V & Clarke, C (2006) Using thematic analysis in psychology. Qualitative Research in Psychology.

Ref: Ulin, Priscilla R, Robinson, Elizabeth T, & Tolley, Elizabeth E. (2004). Qualitative Methods in Public Health: A Field Guide for Applied Research. Jossey Bass.

We changed the text: Most of the participants excluded or decreased gluten, dairy products and carbohydrates. See page 8, paragraph 2, line 3: Selecting individual diets and supplements

We changed the text to "The most important finding..." see page 12, paragraph 8, line 3.

Finally, a thought; perhaps it would be helpfull to have a dietician co-read your manuscript.

The preliminary result has been verbally presented for a group of dieticians. We discussed the result together, they found it

interesting and wants to continue to follow this
research in the future.

# **VERSION 2 – REVIEW**

REVIEWER	Sarah Holdsworth-Carson
	University of Melbourne, Australia
REVIEW RETURNED	29-Oct-2019
	T <del>-</del>
GENERAL COMMENTS	The authors have made some attempts to improve the paper, but I still believe it to be very vague with a lot of room for improvement. The language in this version is also not as high quality as before, repetitive at times and contradictory.  They are quiet augmentative with respect to some of the criticism they received from other reviewers in the previous version, seemingly making the methods / discussion unbalanced.  The paper would benefit from inclusion of numbers / percentages of participants who reported the thematic outcomes, for example, the following type of statement would be better supported with numbers: "After the dietary changes, the participants experienced a 'higher level of energy' and were less tired". How many out of 12 experienced 'higher level of energy'? It is difficult to believe that 100% of respondents reported identical outcomes to all the queries.  The images they provided in Appendix 3 requires figure legends.
REVIEWER	Hanna Grundström Institution for Medicine and Health, Linköping University, Sweden
REVIEW RETURNED	30-Oct-2019
GENERAL COMMENTS	I am pleased with the changes made and have no further comments.
REVIEWER	Ronald Uittenbroek Windesheim University of applied sciences, Zwolle the Netherlands
REVIEW RETURNED	06-Nov-2019
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GENERAL COMMENTS	Thank you for giving me the opportunity to review the revised version of this manuscript. I want to compliment the authors by a job well done. As far as I can see, they have responded appropriately to the various reviewers' comments, including my own. I have only minor comments remaining.  Within the introduction section, authors state that "Intake of omega-3 reduces the risk of endometriosis diagnosis by almost 50% and it has also been seen that people without endometriosis have a higher intake of omega-3 and omega-6 than women with endometriosis [35]." I am not sure what is meant by the statement in the last part of this centered.
	in the last part of this sentence.  Regarding the methods section, author state that their direct invitation was more successful. It remains however unclear how many persons respondent initially, and how many persons were (or were not) excluded due to the exclusion criteria. In addition, of the 13 persons that were interested, two could not participate,

however, including the pilot interview, a total of 12 persons were included. But 13 - 2 = 11...? So where did the 12th participant came from?

Finally, authors help the reader by explaining the use of forums / internet as recruitment tool. However, the part "There is growing evidence to suggest that...[]....Recruiting from Internet forums was considered to be an effective strategy as the members there had experienced dietary changes in endometriosis." would be better in place in the discussion section.

## **VERSION 2 – AUTHOR RESPONSE**

# Reviewer 1: Sarah Holdsworth-Carson

The authors have made some attempts to improve the paper, but I still believe it to be very vague with a lot of room for improvement. The language in this version is also not as high quality as before, repetitive at times and contradictory.

Thank you for your comment. We have now reviewed the language by native English-speaking person. See text marked with blue colour.

They are quiet augmentative with respect to some of the criticism they received from other reviewers in the previous version, seemingly making the methods / discussion unbalanced. We are extremely sorry if you find us augmentative in our answers. We just want to explain that in the qualitative research numbers are not important to understand the results but the strength in the results is interpretation and description. This paper is a qualitative research; hence our focus has been to follow that approach.

We have moved text from the methods to the discussion to make it more balanced.

We have moved the section There is growing evidence to suggest that..." to "Strength and limitations" See page 15, paragraph 3, line 4-7 and 11-12.

The paper would benefit from inclusion of numbers / percentages of participants who reported the thematic outcomes, for example, the following type of statement would be better supported with numbers: "After the dietary changes, the participants experienced a 'higher level of energy' and were less tired". How many out of 12 experienced 'higher level of energy'? It is difficult to believe that 100% of

We appreciate your concern. In a thematic analysis the qualitative analysis is about the participants descriptions of their experience (Braun & Clarke, 2006).

Qualitative research is usually based on in depth interviews with 10-15 persons which gives

respondents reported identical outcomes to all	not enough data for a quantitative analysis,
the queries.	therefore the numbers are not presented in our article.
	Ref: Braun, V & Clarke, V (2006) Using thematic analysis in psychology. Qualitative Research in Psychology.
The images they provided in Appendix 3 requires figure legends.	Thank you for noticing this: We have added a figure legend to Appendix 3.
	"Appendix 3 The thematic maps develop during the thematic analysis based on the conceptual framework proposed by Braun & Clarke"

## Reviewer 5: Ronald Uittenbroek

Thank you for giving me the opportunity to review the revised version of this manuscript. I want to compliment the authors by a job well done. As far as I can see, they have responded appropriately to the various reviewers' comments, including my own. I have only minor comments remaining.

Within the introduction section, authors state that "Intake of omega-3 reduces the risk of endometriosis diagnosis by almost 50% and it has also been seen that people without endometriosis have a higher intake of omega-3 and omega-6 than women with endometriosis [35]." I am not sure what is meant by the statement in the last part of this sentence.

Thank you for taking up this matter. This has been rewritten for the purpose of clarification. See page 5, paragraph 3, line 10-14.

One study showed that persons with endometriosis had intakes of omega-3 and omega-6 that were both below recommended levels and lower than those of the persons in the control group [35]. Overall, the literature suggests that an increased consumption of omega-3 has a positive effect on endometriosis [36].

Regarding the methods section, author state that their direct invitation was more successful. It remains however unclear how many persons respondent initially, and how many persons were (or were not) excluded due to the exclusion criteria. In addition, of the 13 persons that were interested, two could not participate, however, including the pilot interview, a total of 12 persons were included. But 13 - 2 = 11...? So where did the 12th participant came from?

Thank you for noticing this. One of the interview was pilot and this has been clarified in the text. See page 6, paragraph 3, line 16-18.

Of the 13 participants drawn from the forums, two were excluded from the study because they failed to attend the interview. The data from one pilot interview is included in the data analysis. This give a total of 12 participants. We have

	clarified this in the text. See page 6, paragraph 3, line 14-18.
Finally, authors help the reader by explaining the use of forums / internet as recruitment tool. However, the part "There is growing evidence to suggest that[]Recruiting from Internet forums was considered to be an effective strategy as the members there had experienced dietary changes in endometriosis." would be better in place in the discussion section.	Thank you for your suggestion. We have moved the section There is growing evidence to suggest that" to "Strength and limitations" See page 15, paragraph 3, line 4-7 and 11-12.

# **VERSION 3 – REVIEW**

REVIEWER	R.J. Uittenbroek
	Windesheim University of applied sciences
REVIEW RETURNED	10-Dec-2019
GENERAL COMMENTS	Authors adressed comments sufficiently.