

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email editorial.bmjopen@bmj.com

BMJ Open

Experiences of health after dietary changes in endometriosis: A qualitative interview study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-032321
Article Type:	Original research
Date Submitted by the Author:	20-Jun-2019
Complete List of Authors:	Vennberg Karlsson, Jenny; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences; Västra Götalandsregionen, Primary Health Care, Research and Development Unit, Närhälsan Patel, Harshida; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences Premberg, Aasa; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences; Västra Götalandsregionen, Primary Health Care, Research and Development Unit, Närhälsan
Keywords:	Endometriosis, symptoms, wellbeing, health experience, diet, dietary changes

SCHOLARONE™
Manuscripts

1
2
3 **Title:** Experiences of health after dietary changes in endometriosis: A qualitative interview
4 study.
5
6
7

8 **Authors:** Jenny Vennberg Karlsson^{a,b}, Harshida Patel^a, Åsa Premberg^{a,c}
9

10
11 Jenny Vennberg Karlsson RNM, MSc
12 E-mail: jenny.vennberg-karlsson@vgregion.se
13

14 Harshida Patel RN, PhD
15 E-mail: harshida.patel@gu.se
16

17
18 Åsa Premberg RNM, PhD
19 E-mail: asa.premberg@gu.se
20
21

22
23 ^a Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg,
24 Sweden
25

26 ^b Primary Health Care, Research and Development Unit, Närhälsan, Region Västra Götaland,
27 Vanersborg, Sweden
28

29 ^c Primary Health Care, Research and Development Unit, Närhälsan, Region Västra Götaland,
30 Gothenburg, Sweden
31

32
33 Corresponding author: Jenny Vennberg Karlsson
34 Institute of Health and Care Sciences, Sahlgrenska Academy,
35 University of Gothenburg, Arvid Wallgrens Backe, Box 457, S-405 30
36 Gothenburg, Sweden
37 Mobile: +46 763189462
38 E-mail: jenny.vennberg-karlsson@vgregion.se
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objective

Endometriosis is a chronic disease with no known cure. Persons affected by this disease often use complementary methods to reduce their symptoms, and so it is important to investigate whether and how complementary methods, including dietary changes, have an impact on endometriosis symptoms. The aim of this study was to explore how persons with endometriosis experienced their health after dietary changes, and what affected their health experiences.

Design

Semi-structured qualitative interviews were conducted with twelve persons with endometriosis who had made individual dietary changes to diminish the experiences of their endometriosis symptoms. The interviews were recorded and transcribed verbatim, and analysed using thematic analysis.

Setting

Region Västra Götaland and the eastern part of central Sweden, Sweden

Participants

Twelve persons with endometriosis aged 28 – 44 were recruited from three Swedish endometriosis support forums on the Internet.

Results

Participants experienced an increase in wellbeing and a decrease in symptoms following their dietary and lifestyle changes. The dietary changes were also experienced as leading to increased energy levels and a deeper understanding of how the participants could affect their health by listening to their body's reactions. The participants understood that they could influence their symptoms through lifestyle changes. Support from family and friends was important in implementing and sustaining the dietary changes. However, the participants stressed the lack of support from healthcare professionals.

Conclusion

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 improved health after adopting an individually-adapted diet that resulted in decreased symptoms and increased energy levels. The most important message is that healthcare professionals need to consider the patients' knowledge and experience, and allow them to participate in their own care.

Keywords

Endometriosis, symptoms, wellbeing, health experience, diet, dietary changes

Strengths and limitations of this study

- This is the first qualitative study to examine how persons with endometriosis experience increased health after dietary changes.
- Persons with endometriosis makes individual diet- and lifestyle changes in an attempt to influence their health experience.
- Dietary changes led to experiences of decreased symptoms and improved well-being in everyday life.
- Support is important in implementing and sustaining dietary changes.

For peer review only

Abbreviations

IBS	Irritable bowel syndrome
FODMAPs	Fermentable oligo-, di-, monosaccharides and polyols. A low-FODMAP diet restricts all fermentable carbohydrates.
PCC	Person-centered care
HRQOL	Health-related quality of life
HCP	Health care professionals

For peer review only

Introduction

Endometriosis is a benign chronic gynaecological disorder that affects about 6-10 % of the population with female reproductive organs. In this disorder, tissue from the endometrium grows outside the uterus in areas which may include the ovaries, fallopian tubes, and peritoneum. The primary symptoms are pain, dysmenorrhea, pelvic pain, dyschesia, dysuria, and dyspareunia [1]. Fatigue, infertility, and bowel problems are common, but the disease can also occur without symptoms [2]. Endometriosis can affect several aspects of life including health, relationships, and performance, and can have a negative impact on employment and education [3-5]. Every day of life is influenced, with decreased possibilities to perform household task such as cooking, shopping, cleaning, and parenting [6].

There is no cure for the disorder, but traditionally pain medication, hormone therapy, and surgical treatment are used to decrease the symptoms [7]. Traditional treatment does not always have the desired effect on symptoms and health [4]. Self-management is common in chronic illnesses [8], and persons with endometriosis are known to use complementary therapies in addition to traditional treatment as self-management strategies to manage their symptoms [2, 9, 10]; these therapies include supplements, yoga/meditation, herbal medicines, transcutaneous electrical nerve stimulator (TENS), dietary changes, exercise, osteopathy, massage, acupuncture, herbalism and Chinese medicine [2, 11]. Several studies have also shown that persons with endometriosis uses dietary and lifestyle changes [10, 12-14], mainly focusing on a healthy diet free from dairy, wheat [12], and caffeine and with high vegetable and fruit content, and eliminating high oestrogen foods [14]. The main source used for information on dietary and life style changes is the Internet [12]. According to an Australian study, self-management strategies and lifestyle interventions are common and important approaches to reduce the symptoms of endometriosis [15]. The use of complementary methods can affect the experience of pain, improve mood, and increase quality of life [16]. However, there is uncertainty about their efficacy, and so they are not usually recommended by healthcare professionals [2].

The role of diet in endometriosis has gained more attention in recent years, since it has been observed that diet can affect several processes that are involved in endometriosis, including inflammation, prostaglandin metabolism, and oestrogen activity [11, 17]. Several studies suggest a link between diet and endometriosis [18-21]. Despite this, and despite the wide use of dietary changes among persons with endometriosis, there is a lack of studies focusing on dietary changes. This indicates a need to understand how complementary therapies such as dietary changes affect the experience of health among persons with endometriosis. The present study therefore aimed to explore how persons with endometriosis experienced their health after dietary changes, and what affected their health experiences.

Methods

Study design

A qualitative approach was considered suitable to study the the participants' lived experience of the phenomenon of interest [22].

Participants and setting

Participants were recruited from three Swedish endometriosis support forums on the Internet; two with a connection to diet and one with general topics. A general advertisement was placed on the forums and a directed invitation was sent to fifty randomly chosen persons in one of the forums, the sample was strategic with variation in age and residency. The inclusion criteria were being able to speak Swedish, being aged between 18 and 45 years, having a physician-established diagnosis of endometriosis, and having carried out one or several dietary changes. The exclusion criterion was having been diagnosed with diabetes, coeliac disease, or inflammatory bowel diseases (Crohn's disease and ulcerative colitis). Of the 13 persons who expressed interest, two were excluded from the study because they failed to attend the interview. A pilot interview was also conducted. Since the pilot interview was judged by the authors to be of good quality and content, the data was included in the analysis, giving a total of 12 participants, which gave a rich material for analysis.

Patient and public involvement

There was no patient or public involvement in setting the research agenda.

Data collection

The participants in this study made individual dietary changes as a complementary therapy. These dietary changes involved either increasing or decreasing in different kind of foods or adding or removing foods from the daily diet.

Data were collected via semi-structured interviews using an interview guide. The participants were asked about their experiences of individually chosen dietary changes. The opening question was: *Will you please tell me about your experiences of health after the dietary change?* The themes in the interview guide included: dietary change, information, pain, other symptoms, work/school, relationships, relationship with a partner, menstruation, health, and other changes. Probing 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. Credibility was insured by establishing a trusting and confidential relationship with participants and through use of referential adequacy via audio tape-recording [23]. The interviews were performed by one of the authors (JVK), from November 2016 to June 2017. The interviews took place in locations chosen by the participants: the participants home (n = 2), the participant's workplace/school (n = 2), by phone (n = 1), and via interview online with voice and video link (n = 7). The interviews were conducted in Swedish, were digitally recorded, and lasted between 32 and 64 minutes.

Data analysis

All interviews were transcribed verbatim and analysed using thematic analysis [24]. The research team consisted of two midwives, (JVK and ÅP) and (HP) a registered nurse. The analysis was data-driven, based on the Swedish transcript, and performed inductively by two researchers (JVK and ÅP). The analysis was based on the conceptual framework proposed by Braun & Clarke [24]. First, the text from all the interviews was read and reread to understand the depth and breadth of the data. In the next step, meanings units were identified, condensed, and coded. The codes were then compared and sorted into candidate themes in relation to the research question. A thematic map was developed with sub-themes and themes. The candidate themes were refined and adjusted to cover all meaning patterns in the text and to be coherent, sufficiently distinct from other themes, and internally consistent. In the next step, the whole data set was reviewed, and the potential themes were compared in relation to the data, and adjustments were made. Lastly, the final themes were defined and named to correspond to the

1
2
3 essential meaning of each theme. Annotations and memos were used to record ideas,
4 reflections, and coding decisions to support trustworthiness [25]. To establish trustworthiness
5 of the analysis [26], the third researcher (HP) has made critical revisions of the manuscript
6 together with (JVK and HP).
7

8 9 **Ethical considerations**

10 Ethical approval was obtained from the Regional Ethics Committee of Gothenburg (ref: 889-
11 16). The advertisements on the endometriosis forums were approved in writing by all forum
12 administrators. Participants received oral and written information and were asked for their
13 written consent. To ensure confidentiality, characteristics of the participants are presented at a
14 group level, and the quotes are labelled with P1 – P12 to maintain anonymity.
15
16

17 18 19 **Results**

20
21
22 Twelve persons with endometriosis who had made individual dietary changes were
23 interviewed. Their ages ranged from 28 to 44 years, their time since endometriosis diagnosis
24 from 0.5 to 17 years, and the time since initiating dietary change from 2 months to 3.5 years.
25 Eight of the participants had no hormonal treatment at the time of the interview, two had a
26 hormonal intra uterine device (Mirena), one used progestogen-only pills (Cerazette), and one
27 used natural progesterone. Their education background varied, including secondary school,
28 further education, and university education.
29

30
31 The thematic analyses of the data identified four main themes and nine subthemes. The four
32 main themes were *Making changes for better health*, *Understanding your own body*,
33 *Experiencing decreased symptoms* and *Getting support in managing the dietary change*.
34
35

36 37 **Making changes for better health**

38 39 **Selecting individual diets and supplements**

40
41
42 The participants made individual dietary changes, consisting of excluding or decreasing their
43 intake of gluten, dairy products and carbohydrates. Foods that were considered to stress the
44 body or to affect oestrogen levels or inflammatory processes were eliminated from the diet.
45

46
47 *“...then I removed everything that stresses the body. All gluten, all*
48 *dairy products...” (IP11)*
49

50
51 Foods were also added to their diets; for example, they increased their intake of fruit,
52 vegetables and fish. Meat and fish could also be excluded from the diet, but some of them
53 who previously ate vegetarian food, took up animal diet again. Meals were cooked from
54 scratch, and they avoided junk food. They also used supplements such as vitamins, minerals,
55 omega3, turmeric, and ginger.
56

57
58 One reason for dietary change was that medical treatment did not result in the desired effect.
59 When a dietary change had a positive impact on health, it became worthwhile to continue
60

1
2
3 with the change. The dietary change was used as an instrument to obtain control over their
4 health.
5

6 *“...It’s that I can have control somehow in my own life...being able to*
7 *do what I want...not being controlled by a disease.” (IP11)*
8
9

10 **Dietary changes leading to other life style changes**

11

12 The participants described that the positive effect from the dietary changes also aroused their
13 interest in making other life style changes, for example in their stress level, work situation,
14 physical activity, and use of chemicals. The combination of several lifestyle changes
15 amplified the effect of the dietary change and led to increased awareness of how to achieve
16 health.
17

18
19 Stress was considered to affect health negatively and to decrease the effects of dietary change.
20 Stress could be reduced by resting and not trying to conform to society. Physical activity was
21 also experienced to have a positive impact. Popular types of activities included walking, yoga,
22 mindfulness, meditation, and dancing.
23

24
25 *“...I have sometimes noticed that walking or exercising have relieved*
26 *[the pain] a little bit.” (IP4)*
27
28

29 Changing their use of chemicals was another life style change. The participants excluded
30 substances with effects on hormones, such as parabens (a preservative with hormone-
31 disturbing characteristics). Ecological and natural products were preferred. However,
32 although the participants also made other lifestyle changes, they felt that the dietary changes
33 were central to improving health.
34

35 *“...the dietary change is central, but other changes are there too...it*
36 *doesn’t matter how well you eat if you don’t sleep or exercise.” (IP1)*
37
38

39 **Understanding your own body**

40

41 **Becoming aware of your own body’s reactions**

42

43
44 Experimenting with dietary changes allowed the participants to become aware of their body’s
45 reactions to different kinds of foods, as they removed and reintroduced foods. A deviation
46 could also lead to the detection of positive effects. They felt that it was safe to try dietary
47 changes because of the lack of side effects, and if these changes did not have a positive effect
48 on their health then they could go back to eating as before. The participants emphasised that
49 reactions to dietary changes were individual.
50
51

52
53 *“...everybody reacts differently to diet...I think that you need to know*
54 *your body and sense whether something makes you feel good or*
55 *bad...” (IP3)*
56
57
58
59
60

Developing confidence in your own body

The participants believed in their body's reactions to food. They considered that the body could function more optimally if it was given the right conditions via necessary nutrients in the diet. Deviations from the diet led to more negative symptoms from the endometriosis. Their experiences of positive and negative bodily responses to dietary changes made them feel that they could trust and believe in their bodies.

"...began to eat [the person went back to eat as before the dietary changes]...still vegan but sugar, gluten, everything I'd taken away earlier...and in two weeks, I went back to not being able to get out of bed again. [painful symptoms re-emerged again]" (IP12)

The body's signals were trusted regardless of what the medical results showed. Participants who found that a gluten-free diet decreased their symptoms kept to the diet even if a coeliac test was negative or had not been performed.

"...stop eating gluten and then milk...quite quickly I noticed improvements...in my health...Nah, I don't give a damn about it. [coeliac testing]I don't even care." (IP8)

Experiencing decreased symptoms

Experiencing decreased pain and regulated menstruation cycle

Before the dietary changes, the pain was described as intense and disabling, but after the changes the pain decreased or disappeared. For some participants, menstruation no longer produced the previous symptoms. The reduced pain was described as ordinary pain, and the use of pain medication decreased.

"I could still feel...but it was more like a...normal menstruation" (IP11)

Some participants also experienced a decrease in the amount of bleeding and the number of days of bleeding. The length of their menstruation cycles increased to about 28 days.

"Before...I couldn't use tampons, it only took about an hour for them to fill up, now I use tampons and it works...without leaking...so that's also an...improvement...that I don't bleed as much." (IP5)

Experiencing a reduced feeling of illness

A general improvement of health was achieved after the dietary changes. The participants felt healthier even if they still had endometriosis symptoms. Inconveniences from the gastrointestinal tract decreased, and the abdomen felt calmer; normal and less swollen. Gases and the stool were normalized, and the body felt more comfortable.

1
2
3 *“I cut out gluten and noticed a very big difference in my stomach, I*
4 *became less swollen, less gassy...and then more normal stools.”* (IP6)
5
6

7 Dietary changes also affected mood. The pain had previously had a negative impact, but now
8 they became happier, had more patience, and could trust their feelings.
9

10 *“...my endometriosis has always been in control in a way, but now it*
11 *is in less control when you...[I] can trust [my feelings] a little more,*
12 *like, OK now I'm angry because I'm angry [not because I'm in*
13 *pain].”* (IP4)
14
15

16 Symptoms such as colds, headache, nausea and fever were reduced, as were allergic and
17 skin reactions. Their sleep improved, and they found it easier to fall asleep.
18
19

20 **Having the energy to live a normal life**

21
22 After the dietary changes, the participants experienced a higher level of energy and were less
23 tired. They were able to cope with work, home, and socializing with friends and family. They
24 could perform everyday chores such as cleaning and washing. Their increased energy levels
25 made them function better as a parent, for example by joining their children in activities.
26 Increased level of energy gave them a feeling of regaining their life and being normal again.
27
28

29 *“Alertness...I feel normal...I can do things without needing a*
30 *break...”* (IP 9)
31
32

33 After the dietary changes, the participants felt able to go back to work, and experienced better
34 functioning while being there. The number of sick days decreased. They believed that the
35 dietary changes were necessary to allow them to work and live a normal life.
36
37
38

39 **Getting support in managing the dietary change**

40 **Obtaining support for the dietary change**

41
42 It was important that the participants' families understood and supported the implementation
43 and maintenance of the dietary change. When family members saw positive results from the
44 change, this made them more engaged and they continued to support it. Support also came
45 from co-workers and friends, who adapted to the new circumstances.
46
47
48

49 *“...if I hadn't support from my friends and family, I'd have had it*
50 *much, much harder.”* (IP11)
51
52

53 Support also came from Internet forums where the participants shared information about
54 dietary changes and received tips and advices. The participants felt that there was increased
55 support in society for different diets, as restaurants and cafes had begun to offer dishes
56 adapted for allergies.
57
58
59
60

Coping with difficulties with the dietary change

The dietary change was associated with several difficulties. It could be hard to maintain, for several reasons; for example, meal planning took time and it was exhausting to always have to think about what to eat. It was harder to eat with family and friends, and at restaurants. Difficulties were handled by planning meals in advance or bringing their own meal when visiting other people; the easiest was just to eat at home. Social norms around food made the participants feel odd; from a norm perspective, it would have been easier just to eat in the same way everybody else. Another difficulty was the weak or non-existent support from health care professionals (HCP). Although HCP expressed interest in the dietary change, the participants' experiences were dominated by the lack of interest from HCP.

"...in the health care it's all...I hardly dare to talk about it [dietary changes] anymore, because... you...just get in a sour mood...It's just like meeting a brick wall, you just get a: 'Nah it's meaningless, just eat what you want.'" (IP12)

One reason why the dietary changes were difficult to maintain was that it could take weeks, months or even years before the change had any positive effect. Positive advantages from the dietary changes made it easier to handle the difficulties.

"Because I think the diet is a long-term change, it's a process that takes a long time." (IP3)

Discussion

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.

The main dietary changes described by the participants involved excluding or decreasing the amount of gluten and dairy products, adding more vegetables and fruit, and cooking food from the ground with "clean" ingredients. These results are in line with the findings of other studies showing that diet can influence the symptoms of endometriosis [27-29]. One study found that persons with endometriosis who ate a gluten-free diet experienced improvement in painful symptoms, physical function, overall health experience, vitality, social function, and mental health [27]. A study comparing diet treatment, hormonal treatment, and placebo after conservative surgery found that both postoperative treatment with hormones and diet were effective in reducing painful symptoms from endometriosis [28]. Another study showed that increased intake of antioxidants produced decreased oxidative stress [30].

Several studies have reported that pain is a major symptom in endometriosis and, one that affects both health and quality of life [31, 32]. Tiredness and fatigue are also common symptoms [2]. Quality of life can be influenced by both physical and psychological factors

[33]. The participants in the present study experienced increased health through decreased symptoms from menstruation and the gastrointestinal tract. Decreased symptoms from the gastrointestinal tract can also be explained by the feasible coexistence of endometriosis and irritable bowel syndrome (IBS). Previously studies have demonstrated that symptoms from IBS can be reduced by adapting the diet [34]. An Australian study showed that a diet low in fermentable oligo-, di-, mono-saccharides and polyols (FODMAPs) can reduce bowel symptoms in people with endometriosis [29]. Improvements in clinical status and organ function affect the experience of health and quality of life [33]. The participants in the present study described an increased sensory experience of the body. They achieved an awareness of their own body's reaction to diet, stress and sleep through listening to the body's reactions to adapting their diet and other lifestyle changes. Recognizing symptoms and finding patterns can be one path to taking control and regaining quality of life for persons with endometriosis [35]. A person's motor, cognitive, and sensory ability could influence their possibility to live a normal life [33]. After dietary changes, the participants in this study experienced an increased level of energy in the form of improved ability to do household chores, socialize with family and friends, exercise, and perform paid work. This can be interpreted as meaning that their "ability to perform" had increased, which furthermore increased their experience of health; an increased experience of health can be achieved via a person's ability to perform. Fitness, energy, and wakefulness all influence a person's possibility to make use of their abilities [33]. The participants in this study experienced that their mood was also influenced by the dietary changes; they were happier and had more patience. A person's health is likewise affected by how pleasant or unpleasant their health-related mood state is; for example, if they are focused and in harmony or anxious and depressed [33].

An important finding in this study is that the participants described that support from family, friends, and society as important for the implementation and maintenance of their dietary changes. They also described a lack of support from HCP. This suggests that support from HCP may make it even easier to continue with dietary changes and maintain health. In this context, person centered care (PCC) may improve these persons' experiences of health and caring. Health-related quality of life (HRQoL) has been shown to increase among persons with endometriosis when HCP pay attention to higher continuity, respect, and to individual preferences [36]. If HCP take the patient's pain seriously, the pain becomes legitimate and it is easier for the patient to understand and manage. A review highlighted that it is essential for HCP to evaluate HRQoL in persons with endometriosis [37]. Listening to the patient enables the development of a partnership which helps the patient to manage and regain control over pain and is crucial in empowering the patient to take an active part in decisions about their own care planning [38]. One study showed that a person-centered approach to patients with fibromyalgia syndrome can expand and strengthen the medical treatment. PPC enhances the patient-physician relationship and helps patients to develop their own treatment plan together with the HCP. HCP play an important role in empowering the patient to achieve better coping abilities, improved self-management and control of aggravating factors [39].

Strengths and limitations

A qualitative approach is a suitable method for capturing a person's lived experience [40], and qualitative research interviews are frequently used to obtain useful data about another person's lifeworld [41]. The narratives from the participants in this study were broad, the themes were recurrent, and the data from the interviews agreed well.

1
2
3
4 One strength of this study is that the participants varies in age and geographic area (Region
5 Västra Götaland and the eastern part of central Sweden). The majority of the interviews were
6 performed via online with voice and video link, meaning that verbal and non-verbal
7 communication could be mediated in a similar way to what is possible with a face-to face
8 interview [42]. Online interviews give participants a greater opportunity to choose the time
9 and place of the interview, and they are also cost-effective and environmentally friendly when
10 neither researcher or participants need to travel [43]. Such a method allowed participants who
11 lived at the geographical distance to take part in the study. However, technical hitches during
12 important questions can constrain the development of an intimate feeling during the interview
13 and may hinder resuming of the interview [44].
14
15

16
17 A weakness of the study is that it only reflects the experiences of health from persons with
18 endometriosis who had completed tertiary education and who experienced an increased health
19 after dietary changes. The Internet support forums also included persons who did not
20 experience any positive advantages from dietary changes, but they were not interested in
21 participating in the study.
22

23
24 The study took a qualitative approach, and so was not designed to find any causal relationship
25 between dietary changes and better health. Several questions still remain unanswered on the
26 current topic, and should become the focus of future research; for example, which dietary
27 changes can be positive for endometriosis symptoms, and how self-care affects experience of
28 health among persons with endometriosis. Another important issue for future research is the
29 connection between endometriosis and coeliac disease and IBS. Further research is required
30 about endometriosis and dietary changes in order for HCP to give evidenced-based dietary
31 advices.
32
33

34 35 36 **Conclusion** 37 38 39

40 This study contributes to fill the knowledge gap about dietary strategies in endometriosis and
41 lifestyle change as a method of alleviating suffering and increasing wellbeing. The
42 participants experienced improved health after adopting an individually-adapted diet that
43 resulted in decreased symptoms and increased energy levels. The most important message is
44 that healthcare professionals need to consider the patients' knowledge and experience, and
45 allow them to participate in their own care.
46
47
48
49

50 51 **Acknowledgements** 52

53 We acknowledge and thank the forum administrators who allowed us to advertise this study.
54 We also thank the participants in the study, who shared their experiences of health after
55 dietary changes.
56
57
58
59
60

Contributors

All authors contributed to this article, and all have approved the final manuscript. JVK and ÅP were involved in the design of the study and analysis of the data; JVK performed the recruitment and data collection and drafted the manuscript; all authors (JVK, HP and ÅP) have made critical revisions of the manuscript and contributed feedback.

Funding

The authors wish to express their gratitude to the funders of the project, the local research and development board for Fyrbodal. This financial partner had no involvement in the preparation of this article, the analysis or interpretation of the data or the decision to submit this article for publication.

Competing interest

None declared.

Patient consent for publication

Not required.

Ethics approval

The study was approved by the Regional Ethics Committee of Gothenburg (ref: 889-16).

Data sharing statement

Due to the sensitive nature of the data, they are not publically available.

References

1. Giudice LC, Kao LC. Endometriosis. *Lancet*. 2004;364(9447):1789-99.
2. 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. Rush G, Misajon R. Examining subjective wellbeing and health-related quality of life in women with endometriosis. *Health Care Women Int*. 2018;39(3):303-21.
4. Facchin F, Barbara G, Saita E, Mosconi P, Roberto A, Fedele L, et al. Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J Psychosom Obstet Gynaecol*. 2015;36(4):135-41.
5. Sperschneider ML, Hengartner MP, Kohl-Schwartz A, Geraedts K, Rauchfuss M, Woelfler MM, et al. Does endometriosis affect professional life? A matched case-control study in Switzerland, Germany and Austria. *BMJ open*. 2019;9(1):e019570.
6. Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obstet Gynaecol*. 2004;25(2):123-33.
7. Streuli I, de Ziegler D, Santulli P, Marcellin L, Borghese B, Batteux F, et al. An update on the pharmacological management of endometriosis. *Expert Opin Pharmacother*. 2013;14(3):291-305.
8. MacKichan F, Paterson C, Henley WE, Britten N. Self-care in people with long term health problems: a community based survey. *BMC Fam Pract*. 2011;12:53.
9. Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, et al. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update*. 2013;19(6):625-39.
10. Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. Impact of endometriosis on women's lives: a qualitative study. *BMC Womens Health*. 2014;14:123.
11. Buggio L, Barbara G, Facchin F, Frattaruolo MP, Aimi G, Berlanda N. Self-management and psychological-sexological interventions in patients with endometriosis: strategies, outcomes, and integration into clinical care. *Int J Womens Health*. 2017;9:281-93.
12. Seear K. The third shift: Health, work and expertise among women with endometriosis. *Health Sociology Review*. 2009;18(2):194-206.
13. Roomaney R, Kagee A. Coping strategies employed by women with endometriosis in a public health-care setting. *J Health Psychol*. 2016;21(10):2259-68.
14. Huntington A, Gilmour JA. A life shaped by pain: women and endometriosis. *J Clin Nurs*. 2005;14(9):1124-32.
15. Armour M, Sinclair J, Chalmers KJ, Smith CA. Self-management strategies amongst Australian women with endometriosis: a national online survey. *BMC Complement Altern Med*. 2019;19(1):17.
16. Pujol LA, Monti DA. Managing cancer pain with nonpharmacologic and complementary therapies. *J Am Osteopath Assoc*. 2007;107(12 Suppl 7):Es15-21.
17. Saguyod SJU, Kelley AS, Velarde MC, Simmen RCM. Diet and endometriosis-revisiting the linkages to inflammation. *Journal of Endometriosis and Pelvic Pain Disorders*. 2018;10(2):51-8.
18. Parazzini F, Vigano P, Candiani M, Fedele L. Diet and endometriosis risk: a literature review. *Reprod Biomed Online*. 2013;26(4):323-36.
19. Trabert B, Peters U, De Roos AJ, Scholes D, Holt VL. Diet and risk of endometriosis in a population-based case-control study. *Br J Nutr*. 2011;105(3):459-67.

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
20. Missmer SA, Chavarro JE, Malspeis S, Bertone-Johnson ER, Hornstein MD, Spiegelman D, et al. A prospective study of dietary fat consumption and endometriosis risk. *Hum Reprod*. 2010;25(6):1528-35.
21. Heard ME, Melnyk SB, Simmen FA, Yang Y, Pabona JM, Simmen RC. High-Fat Diet Promotion of Endometriosis in an Immunocompetent Mouse Model is Associated With Altered Peripheral and Ectopic Lesion Redox and Inflammatory Status. *Endocrinology*. 2016;157(7):2870-82.
22. Marshall C. *Designing qualitative research*. 6. ed. ed. Rossman GB, editor. Thousand Oaks, California: Thousand Oaks, California : SAGE; 2016.
23. Denzin NK, Lincoln YS. *Handbook of qualitative research*. Thousand Oaks, Calif.: Thousand Oaks, Calif. : Sage; 1994.
24. Braun VC, C. Using thematic analysis in psychology. *Qualitative Research in Psychology*. . *Qualitative Research in Psychology*. 2006;3(2):77-101.
25. Creswell JW, editor. *Research design : qualitative, quantitative, and mixed methods approaches*. 2nd ed: Thousand Oaks, Calif. [u.a.] : Sage Publ., 2003.; 2003.
26. Noble H, Smith J. Issues of validity and reliability in qualitative research. *Evid Based Nurs*. 2015;18(2):34-5.
27. Marziali M, Venza M, Lazzaro S, Lazzaro A, Micossi C, Stolfi VM. Gluten-free diet: a new strategy for management of painful endometriosis related symptoms? *Minerva Chir*. 2012;67(6):499-504.
28. Sesti F, Pietropolli A, Capozzolo T, Broccoli P, Pierangeli S, Bollea MR, et al. Hormonal suppression treatment or dietary therapy versus placebo in the control of painful symptoms after conservative surgery for endometriosis stage III-IV. A randomized comparative trial. *Fertil Steril*. 2007;88(6):1541-7.
29. Moore JS, Gibson PR, Perry RE, Burgell RE. Endometriosis in patients with irritable bowel syndrome: Specific symptomatic and demographic profile, and response to the low FODMAP diet. *Aust N Z J Obstet Gynaecol*. 2017;57(2):201-5.
30. Mier-Cabrera J, Aburto-Soto T, Burrola-Mendez S, Jimenez-Zamudio L, Tolentino MC, Casanueva E, et al. Women with endometriosis improved their peripheral antioxidant markers after the application of a high antioxidant diet. *Reprod Biol Endocrinol*. 2009;7:54.
31. Souza CA, Oliveira LM, Scheffel C, Genro VK, Rosa V, Chaves MF, et al. Quality of life associated to chronic pelvic pain is independent of endometriosis diagnosis--a cross-sectional survey. *Health Qual Life Outcomes*. 2011;9:41.
32. Sepulcri Rde P, do Amaral VF. Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. *Eur J Obstet Gynecol Reprod Biol*. 2009;142(1):53-6.
33. Brulde B. On how to define the concept of health: a loose comparative approach. *Med Health Care Philos*. 2000;3(3):305-8.
34. Bohn L, Storsrud S, Liljebo T, Collin L, Lindfors P, Tornblom H, et al. Diet low in FODMAPs reduces symptoms of irritable bowel syndrome as well as traditional dietary advice: a randomized controlled trial. *Gastroenterology*. 2015;149(6):1399-407.e2.
35. Cox H, Henderson L, Wood R, Cagliarini G. Learning to take charge: women's experiences of living with endometriosis. *Complement Ther Nurs Midwifery*. 2003;9(2):62-8.
36. Apers S, Dancet EAF, Aarts JWM, Kluivers KB, D'Hooghe TM, Nelen W. The association between experiences with patient-centred care and health-related quality of life in women with endometriosis. *Reprod Biomed Online*. 2018;36(2):197-205.

- 1
2
3 37. Bourdel N, Chauvet P, Billone V, Douridas G, Fauconnier A, Gerbaud L, et al.
4 Systematic review of quality of life measures in patients with endometriosis. PLoS
5 One. 2019;14(1):e0208464.
6
7 38. Howarth M, Warne T, Haigh C. Pain from the inside: understanding the theoretical
8 underpinning of person-centered care delivered by pain teams. Pain Manag Nurs.
9 2014;15(1):340-8.
10 39. Masi AT, White KP, Pilcher JJ. Person-centered approach to care, teaching, and
11 research in fibromyalgia syndrome: justification from biopsychosocial perspectives in
12 populations. Semin Arthritis Rheum. 2002;32(2):71-93.
13 40. Kvale S. Interviews: an introduction to qualitative research interviewing: Thousand
14 Oaks: SAGE; 1996.
15 41. Qu SQ, Dumay J. The qualitative research interview". Qualitative Research in
16 Accounting & Management. 2011;8(3):238-64.
17 42. Sullivan JR. Skype: An Appropriate Method of Data Collection For Qualitative
18 Interviews? The Hilltop Review. 2012;6(1):54-60.
19 43. Iacono V, Symonds P, Brown D. Skype as a Tool for Qualitative Research Interviews.
20 Sociological Research Online. 2016;21(2):1-15.
21 44. Seitz S. Pixelated partnerships, overcoming obstacles in qualitative interviews via
22 Skype: a research note. Qualitative Research. 2016;16(2):229-35.
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

SRQR: checklist to BMJ Open

	Page
Title and abstract	
S1 Title Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2 Abstract Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2
Introduction	
S3 Problem formulation Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	5
S4 Purpose or research question Purpose of the study and specific objectives or questions	5
Methods	
S5 Qualitative approach and research paradigm Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale	5-6
S6 Researcher characteristics and reflexivity Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6-7
S7 Context Setting/site and salient contextual factors; rationale	6
S8 Sampling strategy How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	6
S9 Ethical issues pertaining to human subjects Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7, 14
S10 Data collection methods Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, Iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	6
S11 Data collection instruments and technologies Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6
S12 Units of study Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6-7
S13 Data processing Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	6-7
S14 Data analysis Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	6-7
S15 Techniques to enhance trustworthiness Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	6-7
Results/findings	
S16 Synthesis and interpretation Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-11
S17 Links to empirical data Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-11
Discussion	
S18 Integration with prior work, implications, transferability, and contribution(s) to the field Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	11-13
S19 Limitations Trustworthiness and limitations of findings	13
Other	
S20 Conflicts of interest Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	14
S21 Funding Sources of funding and other support; role of funders in data collection, interpretation, and reporting	14

BMJ Open

Experiences of health after dietary changes in endometriosis: A qualitative interview study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-032321.R1
Article Type:	Original research
Date Submitted by the Author:	21-Oct-2019
Complete List of Authors:	Vennberg Karlsson, Jenny; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences; Västra Götalandsregionen, Primary Health Care, Research and Development Unit, Närhälsan Patel, Harshida; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences Premberg, Aasa; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences; Västra Götalandsregionen, Primary Health Care, Research and Development Unit, Närhälsan
Primary Subject Heading:	Obstetrics and gynaecology
Secondary Subject Heading:	Complementary medicine, Patient-centred medicine, Qualitative research, Reproductive medicine, Sexual health
Keywords:	Endometriosis, dietary changes, QUALITATIVE RESEARCH, NUTRITION & DIETETICS, GYNAECOLOGY

SCHOLARONE™
Manuscripts

1
2
3 **Title:** Experiences of health after dietary changes in endometriosis: A qualitative interview
4 study.
5
6
7

8 **Authors:** Jenny Vennberg Karlsson^{a,b}, Harshida Patel^a, Aasa Premberg^{a,c}
9

10
11 Jenny Vennberg Karlsson RNM, MSc
12 E-mail: jenny.vennberg-karlsson@vgregion.se
13

14 Harshida Patel RN, PhD
15 E-mail: harshida.patel@gu.se
16

17
18 Aasa Premberg RNM, PhD
19 E-mail: asa.premberg@gu.se
20

21
22
23 ^a Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg,
24 Sweden
25

26 ^b Primary Health Care, Research and Development Unit, Närhälsan, Region Västra Götaland,
27 Vanersborg, Sweden
28

29 ^c Primary Health Care, Research and Development Unit, Närhälsan, Region Västra Götaland,
30 Gothenburg, Sweden
31

32
33 Corresponding author: Jenny Vennberg Karlsson
34 Institute of Health and Care Sciences, Sahlgrenska Academy,
35 University of Gothenburg, Arvid Wallgrens Backe, Box 457, S-405 30
36 Gothenburg, Sweden
37 Mobile: +46 763189462
38 E-mail: jenny.vennberg-karlsson@vgregion.se
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objective

Endometriosis is a chronic disease with no known cure. Persons affected by this disease often use complementary therapies to reduce their symptoms, and so it is important to investigate whether and how complementary therapies, including dietary changes, have an impact on endometriosis symptoms. The aim of this study was to explore how persons with endometriosis experienced their health after dietary changes.

Design

Semi-structured qualitative interviews were conducted with twelve persons with endometriosis who had made individual dietary changes to diminish the experiences of their endometriosis symptoms. The interviews were recorded and transcribed verbatim, and analysed using thematic analysis.

Setting

Region Västra Götaland and the eastern part of central Sweden, Sweden

Participants

Twelve persons with endometriosis aged 28 – 44 were recruited from two Swedish endometriosis support forums on the Internet.

Results

Participants experienced an increase in wellbeing and a decrease in symptoms following their dietary and lifestyle changes. The dietary changes were also experienced as leading to increased energy levels and a deeper understanding of how the participants could affect their health by listening to their body's reactions. The participants understood that they could influence their symptoms through lifestyle changes. Support from family and friends was important in implementing and sustaining the dietary changes. However, the participants stressed the lack of support from healthcare professionals.

Conclusion

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. An important finding is that the participants experienced decreased symptoms and increased wellbeing after adopting an individually-adapted diet. The healthcare professionals need to consider the patients' knowledge and experience, and allow them to participate in their own care. Further research is necessary to give evidenced-based dietary advices in endometriosis.

Keywords

Endometriosis, dietary changes, qualitative research, nutrition & diets, gynaecology

Strengths and limitations of this study

- This is to the best of our knowledge the first qualitative study to examine how persons with endometriosis experience health after dietary changes.
- The strategy with recruiting from support forum on Internet might be limited since the interpretation of studies conducted with patients from a disease-specific patient organization often have a more adverse experience of the disease.
- Although study is qualitative in nature and direct comparison of dietary changes cannot be made, the explored experiences from the interview data facilitates our understanding of using dietary changes to relieve symptoms of endometriosis.

For peer review only

Abbreviations

IBS	Irritable bowel syndrome
FODMAPs	Fermentable oligo-, di-, monosaccharides and polyols. A low-FODMAP diet restricts all fermentable carbohydrates.
PCC	Person-centered care
HRQOL	Health-related quality of life
HCP	Health care professionals

For peer review only

Introduction

Endometriosis is a benign chronic gynaecological disorder that affects about 1,5 % (population-based studies) to 15 % (clinic-based studies) of the population with female reproductive organs [1, 2]. In this disorder, endometrium-like tissue grows outside the uterus in areas which may include the ovaries, fallopian tubes, and peritoneum. The primary symptoms are pain, dysmenorrhea, pelvic pain, dyschesia, dysuria, and dyspareunia [3]. Fatigue and bowel problems are common, but the disease can also occur without symptoms [4]. Infertility is more frequent among persons with endometriosis (10-15 %) than the general population (9%) [5]. Endometriosis can affect several aspects of life including health, relationships, and performance, and can have a negative impact on employment and education [6-8]. Every day of life is influenced, with decreased possibilities to perform household task such as cooking, shopping, cleaning, and parenting [9].

There is no cure for the endometriosis, but traditionally pain medication, hormone therapy, and surgical treatment are used to decrease endometriosis symptoms [10]. Traditional treatment does not always have the desired effect on symptoms and health [7]. Persons with endometriosis uses a range of self-care activities and complementary therapies in addition to traditional treatment to assist them to manage their symptoms [4, 11, 12]. These therapies include supplements, yoga/meditation, herbal medicines, transcutaneous electrical nerve stimulator (TENS), dietary changes, exercise, osteopathy, massage, acupuncture, herbalism and Chinese medicine [4, 13]. Several studies have also shown that persons with endometriosis uses dietary and lifestyle changes [14-17], mainly focusing on a healthy diet free from dairy, wheat [14], and caffeine and with high vegetable and fruit content, and eliminating high oestrogen foods [16]. The main source used for information on dietary and life style changes is the Internet [14]. According to an Australian study, self-management strategies and lifestyle interventions are common and important approaches to reduce the symptoms of endometriosis [18]. The use of complementary therapies can affect the experience of pain, improve mood, and increase quality of life [19]. However, there is uncertainty about their efficacy, and so they are not usually recommended by healthcare professionals, but they acknowledges that some persons with endometriosis who using complementary therapies may benefit from it [4].

The role of diet in endometriosis has gained more attention in recent years, since it has been observed that diet can affect several processes that are involved in endometriosis, including inflammation, prostaglandin metabolism, and oestrogen activity [13, 20]. Today there are no clear recommendations on what diet to eat to reduce symptoms of endometriosis [21]. Several studies suggest a link between diet and endometriosis [22-25]. The studies explore if diet increases the risk of being diagnosed with endometriosis. Dietary factors that are observed are, for example: fat, dairy products, calcium, Vitamin D, B, C and E, coffee, alcohol and fruit [24, 26-34]. For example: With a high intake of omega-3 there is a significantly lower risk for the diagnosis of endometriosis and a high intake of trans fats and potentially a diet consisting of higher animal fat was associated with a higher risk of endometriosis [24]. 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]. Despite this, there is a lack of studies focusing on dietary changes. This indicates a need to understand how complementary therapies such as dietary changes affect the experience of health among persons with endometriosis. The present study therefore aimed to explore how persons with endometriosis experienced their health after dietary changes.

Methods

Study design

A qualitative approach was considered suitable to study the the participants' lived experience of the phenomenon of interest [36].

Participants and setting

Participants were recruited from three Swedish endometriosis support forums on the Internet; two with a connection to diet and one with general topics. To be a member of the forum you needed to apply for membership, which the first author applied for and was granted. At first a general advertisement (Appendix 1) was placed in all three forums and only a few persons agreed to take part in the study. After that, a direct invitation was sent to fifty randomly chosen persons in one of the forums. This forum was chosen as it had a connection to naturally healing and diet. This approach was more successful. After the advertisement the participants came from the two forums with a connection to diet. The forum with general topics did not generate any participants. There is growing evidence 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 [37]. 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 [38]. Recruiting from Internet forums was considered to be an effective strategy as the members there had experienced dietary changes in endometriosis. The inclusion criteria were being able to speak Swedish, being aged between 18 and 45 years, having a physician-established diagnosis of endometriosis, and having carried out one or several dietary changes. The exclusion criterion was having been diagnosed with diabetes, coeliac disease, or inflammatory bowel diseases (Crohn's disease and ulcerative colitis). Of the 13 persons who expressed interest, two were excluded from the study because they failed to attend the interview. A pilot interview was also conducted. Since the pilot interview was judged by the authors to be of good quality and content, the data was included in the analysis, giving a total of 12 participants, which gave a rich material for analysis.

Patient and public involvement

There was no patient or public involvement in setting the research agenda.

Data collection

The participants in this study made individual dietary changes as a complementary therapy. These dietary changes involved either increasing or decreasing in different kind of foods or adding or removing foods from the daily diet. In this study we define dietary change as a change of diet from prior diet.

Data were collected via semi-structured interviews using an interview guide (Appendix 2). The participants were asked about their experiences of individually chosen dietary changes. The opening question was: *Will you please tell me about your experiences of health after the dietary change?* The participants answered the question freely with their own words. 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. Credibility was insured by establishing a trusting and confidential relationship with participants and through use of referential adequacy via audio tape-recording [39]. The interviews were performed by one of the authors (JVK), from

1
2
3 November 2016 to June 2017. The interviews took place in locations chosen by the
4 participants: the participants home (n = 2), the participant's workplace/school (n = 2), by
5 phone (n = 1), and via interview online with voice and video link (n = 7). The interviews were
6 conducted in Swedish, were digitally recorded, and lasted between 32 and 64 minutes.
7

8 9 **Data analysis**

10 All interviews were transcribed verbatim and analysed using thematic analysis [40]. The
11 research team consisted of two midwives, (JVK and AP) and (HP) a registered nurse. The
12 analysis was data-driven, based on the Swedish transcript, and performed inductively by two
13 researchers (JVK and AP). The analysis was based on the conceptual framework proposed by
14 Braun & Clarke [40]. First, the text from all the interviews was read and reread to understand
15 the depth and breadth of the data. In the next step, meanings units were identified, condensed,
16 and coded. The codes were then compared and sorted into candidate themes in relation to the
17 research question. A thematic map was developed with sub-themes and themes (Appendix 3).
18 The candidate themes were refined and adjusted to cover all meaning patterns in the text and
19 to be coherent, sufficiently distinct from other themes, and internally consistent. In the next
20 step, the whole data set was reviewed, and the potential themes were compared in relation to
21 the data, and adjustments were made. Lastly, the final themes were defined and named to
22 correspond to the essential meaning of each theme. Annotations and memos were used to
23 record ideas, reflections, and coding decisions to support trustworthiness [41]. To establish
24 trustworthiness of the analysis [42], the third researcher (HP) was involved to perform a
25 scrutiny of the result and has made critical revisions of the manuscript together with (JVK and
26 AP).
27
28
29
30

31 **Ethical considerations**

32 Ethical approval was obtained from the Regional Ethics Committee of Gothenburg (ref: 889-
33 16). The advertisements on the endometriosis forums were approved in writing by all forum
34 administrators. Participants received oral and written information and were asked for their
35 written consent. To ensure confidentiality, characteristics of the participants are presented at a
36 group level, and the quotes are labelled with P1 – P12 to maintain anonymity.
37
38
39
40

41 **Results**

42
43
44 Twelve persons with endometriosis who had made individual dietary changes were
45 interviewed. Their ages ranged from 28 to 44 years, their time since endometriosis diagnosis
46 from 0.5 to 17 years, and the time since initiating dietary change from 2 months to 3.5 years.
47 Eight of the participants had no hormonal treatment at the time of the interview, two had a
48 hormonal intra uterine device (Mirena), one used progestogen-only pills (Cerazette), and one
49 used natural progesterone. Their education background varied, including secondary school,
50 further education, and university education (Table 1).
51
52
53
54
55
56
57
58
59
60

Table 1 Demographic data

The thematic analyses of the data identified four main themes and nine subthemes. The four main themes were *Making changes for better health, Understanding your own body, Experiencing decreased symptoms and Supports helps in managing the dietary change.*

Making changes for better health

Selecting individual diets and supplements

The participants made individual dietary changes, consisting of excluding or decreasing their intake of different food. Most of the participants excluded or decreased gluten, dairy products and carbohydrates. Foods that were considered to stress the body or to affect oestrogen levels or inflammatory processes were eliminated from the diet.

...then I removed everything that stresses the body. All gluten, all dairy products... (IP11)

Foods were also added to their diets; for example, they increased their intake of fruit, vegetables and fish. The participants said that they '*ate much more vegetables.*' Meat and fish could also be excluded from the diet, but some of them who previously ate vegetarian food, took up animal diet again. Meals were cooked from scratch, and they avoided junk food. They also used supplements such as vitamins, minerals, omega3, turmeric, and ginger.

One reason for dietary change was that medical treatment did not result in the desired effect. When the treatment did not work for endometriosis symptoms the participants felt that there was no alternative than '*except you have to try it out [dietary changes].*' When a dietary change had a positive impact on health, it became worthwhile to continue with the change. The dietary change was used as an instrument to obtain control over their health.

...It's that I can have control somehow in my own life...being able to do what I want...not being controlled by a disease. (IP11)

Dietary changes leading to other lifestyle changes

The participants described that the positive effect from the dietary changes also aroused their interest in making other lifestyle changes, for example in their stress level, work situation and physical activity. The combination of several lifestyle changes amplified the effect of the dietary change and led to increased awareness of how to achieve health.

...I started to do diet changes and then I have also received a better effect of the diet changes when I also made lifestyle changes. (IP1)

Stress was considered to affect health negatively and to decrease the effects of dietary change. They emphasised that '*stress affects pretty much*' the endometriosis symptoms. Stress could be reduced by resting and not trying to conform to society. Physical activity was also experienced to have a positive impact. They used walking, yoga, mindfulness, meditation, and dancing '*to slow down stress*'. To minimize hormonal effect some participants stopped using hormone disturbing products, e.g. parabens. Ecological and natural products were preferred,

1
2
3 and they wanted to *'get rid of as much chemicals as possible'*.
4

5 ...I have sometimes noticed that walking or exercising have relieved
6 [the pain] a little bit. (IP4)
7

8
9 However, although the participants also made other lifestyle changes, they felt that the dietary
10 changes were central to improving health.
11

12 ...the dietary change is central, but other changes are there too...it
13 doesn't matter how well you eat if you don't sleep or exercise. (IP1)
14
15
16

17 **Understanding your own body**

18 **Becoming aware of your own body's reactions**

19
20 Experimenting with dietary changes allowed the participants to become aware of their body's
21 reactions to different kinds of foods, as they removed and reintroduced foods. A deviation
22 could also lead to the detection of positive effects. The participants noticed that if they did not
23 pay attention to the dietary change *'the endometriosis symptoms came back'*.
24
25

26
27 They felt that it was safe to try dietary changes because of the lack of side effects, and if these
28 changes did not have a positive effect on their health then they could go back to eating as
29 before. The participants emphasised that reactions to dietary changes were individual.
30

31 ...everybody reacts differently to diet...I think that you need to know
32 your body and sense whether something makes you feel good or bad...
33 (IP3)
34
35

36 **Developing confidence in your own body**

37
38 Their participants experience of positive and negative bodily responses to dietary changes
39 made them feel that they could trust and believe in the dietary change and their bodies and
40 said *'I believe in the diet'* They considered that the body could function more optimally if it
41 was given the right conditions via necessary nutrients in the diet.
42

43 ...I look at my endometriosis..as it is a symptom from that something
44 is not working properly in my body and then make sure I give the
45 body all conditions to feel as good as possible so maybe it
46 succeeds..to get well on its own. (IP1)
47
48

49 Deviations from the diet led to more negative symptoms from the endometriosis.
50

51 ...began to eat [the person went back to eat as before the dietary
52 changes]...still vegan but sugar, gluten, everything I'd taken away
53 earlier...and in two weeks, I went back to not being able to get out of
54 bed again. [painful symptoms re-emerged again] (IP12)
55
56

57 The body's signals were trusted regardless of what the medical results showed. Participants
58 who found that a gluten-free diet decreased their symptoms kept to the diet even if a coeliac
59 test was negative or had not been performed.
60

1
2
3
4 ...stop eating gluten and then milk...quite quickly I noticed
5 improvements...in my health...Nah, I don't give a damn about it.
6 [coeliac testing] I don't even care. (IP8)
7
8
9
10

11 **Experiencing decreased symptoms**

14 **Experiencing decreased pain and regulated menstruation cycle**

15 Before the dietary changes, the pain was described as intense and disabling, but after the
16 changes the participants reported that pain decreased or disappeared For some participants,
17 menstruation no longer produced the previous symptoms and menstruation came '*without any*
18 *premonition*'. The reduced pain was described as ordinary pain, and the use of pain
19 medication decreased. One person described that trying out a general diet of Fodmap did not
20 improve endometriosis symptoms and the person changed strategy and started to make own
21 individual dietary changes instead.
22

23
24 I could still feel...but it was more like a...normal menstruation. (IP11)
25

26 Some participants also experienced a decrease in the amount of bleeding and the number of
27 days of bleeding. The length of their menstruation cycles increased to about 28 days and
28 menstruation came regularly every month.
29

30
31 Before...I couldn't use tampons, it only took about an hour for them to
32 fill up, now I use tampons and it works...without leaking....so that's
33 also an...improvement...that I don't bleed as much. (IP5)
34
35

36 **Experiencing a reduced feeling of illness**

37 A general improvement of health was achieved after the dietary changes. The participants felt
38 '*healthier*' even if they still had endometriosis symptoms. Inconveniences from the
39 gastrointestinal tract decreased, and the abdomen felt calmer; normal and less swollen. Gases
40 and the stool were normalised, and the body felt more comfortable when the stomach was
41 '*functioning better*'.
42
43

44 I cut out gluten and noticed a very big difference in my stomach, I
45 became less swollen, less gassy...and then more normal stools. (IP6)
46
47

48 Dietary changes also affected mood. The pain previously had a negative impact in form of
49 that their pain you made '*you grumpy*'. After the dietary change they became happier, had
50 more patience, and could trust their feelings.
51

52 ...my endometriosis has always been in control in a way, but now it is
53 in less control when you...[I] can trust [my feelings] a little more,
54 like, OK now I'm angry because I'm angry [not because I'm in pain].
55 (IP4)
56
57

58 Symptoms such as colds, headache, nausea and fever were reduced, as were allergic and
59 skin reactions. Some of the participants said, '*my allergies disappeared.*' Their sleep
60

1
2
3 improved, and they found it easier to fall asleep.
4
5

6 **Having the energy to live a normal life**

7 After the dietary changes, the participants experienced a '*higher level of energy*' and were
8 less tired. They were able to cope with work, home, and socializing with friends and family,
9 since they did not experience tiredness in the evening in the same way as before the dietary
10 change. They could perform everyday chores such as cleaning and washing. Their increased
11 energy levels made them function better as a parent, for example by joining their children in
12 activities. Increased level of energy gave them a feeling of regaining their life and being
13 normal again.
14

15
16 Alertness...I feel normal...I can do things without needing a break...
17 (IP 9)
18

19 After the dietary changes, the participants felt able to go back to work, and experienced better
20 functioning while being there. The number of sick days decreased. They believed that the
21 dietary changes were necessary to allow them to work and live a normal life.
22

23
24 ...[The dietary change] enabled me to actually continue to work
25 and...live a decent normal life... (IP1)
26
27

28 **Supports helps in managing the dietary change**

29 **Obtaining support for the dietary change**

30 It was important that the participants' families understood and supported the implementation
31 and maintenance of the dietary change.
32

33
34 ...if I hadn't support from my friends and family, I'd have had it
35 much, much harder. (IP11)
36
37

38 The support was given in form of that family members had an understanding for the diet
39 change. They gave support by talking about it and they help explaining the diet change to
40 other people. They could also give economic help, for example expensive supplements. When
41 family members saw positive results from the change, this made them more engaged and they
42 continued to support it. Support also came from co-workers and friends, who adapted to the
43 new circumstances.
44

45
46 ...but then we all go somewhere else or someone has already been
47 there and says that they have other things to eat there too. (IP2)
48
49

50 Support also came from Internet forums where the participants shared information about
51 dietary changes and received tips and advices and they were seeking information from groups
52 on the Internet" The participants felt that there was increased support in society for different
53 diets, as restaurants and cafes had begun to offer dishes adapted for allergies.
54
55

56 **Coping with difficulties and lack of support with the dietary change**

57 The dietary change was associated with several difficulties. It could be hard to maintain, for
58 several reasons; for example, meal planning took time and it was exhausting to always have to
59
60

1
2
3 think about what to eat. It was harder to eat in '*social context*' with family and friends, and at
4 restaurants. Difficulties were handled by planning meals in advance or bringing their own
5 meal when visiting other people; the easiest was just to eat at home. They were '*not invited*'
6 to people as often as before. Social norms around food made some of the participants feel
7 odd; from a norm perspective, it would have been easier just to eat in the same way
8 everybody else. Other participants felt that many people '*eat differently*' and that it did not
9 matter to them what other people were thinking about their diet. Another difficulty was the
10 weak or non-existent support from health care professionals (HCP). Although HCP expressed
11 interest in the dietary change, the participants' experiences were dominated by the lack of
12 interest from HCP. The participants wanted it to be a '*shorter gap*' between their own desires
13 and knowledge and the healthcare professionals.
14
15

16
17
18 ...in the health care it's all...I hardly dare to talk about it [dietary
19 changes] anymore, because... you...just get in a sour mood...It's just
20 like meeting a brick wall, you just get a: 'Nah it's meaningless, just
21 eat what you want. (IP12)
22

23 One reason why the dietary changes were difficult to maintain was that it could take weeks,
24 months or even years before the change had any positive effect. Positive advantages from the
25 from the dietary changes made it easier to handle the difficulties.
26
27

28
29 Because I think the diet is a long-term change, it's a process that takes
30 a long time. (IP3)
31
32

33 34 35 **Discussion**

36
37 The results of this study show that the participants experienced decreased symptoms of
38 endometriosis and gained a greater understanding of their bodies after making individual
39 dietary changes. The most important finding is that the participants described reductions in
40 symptoms, specifically pain and fatigue, which led to the positive experience of increased
41 health.
42

43 The main dietary changes described by the participants involved excluding or decreasing the
44 amount of gluten and dairy products, adding more vegetables and fruit, and cooking food
45 from the ground with "clean" ingredients. These results are in line with the findings of other
46 studies showing that diet can influence the symptoms of endometriosis [43-45]. One study
47 found that persons with endometriosis who ate a gluten-free diet experienced improvement in
48 painful symptoms, physical function, overall health experience, vitality, social function, and
49 mental health [43]. A study comparing diet treatment, hormonal treatment, and placebo after
50 conservative surgery found that both postoperative treatment with hormones and diet were
51 effective in reducing painful symptoms from endometriosis [44]. Another study showed that
52 increased intake of antioxidants produced decreased oxidative stress, which affects
53 inflammation [46].
54
55

56
57 Several studies have reported that pain is a major symptom in endometriosis and, one that
58 effects both health and quality of life [47, 48]. Tiredness and fatigue are also common
59 symptoms [4]. Quality of life can be influenced by both physical and psychological factors
60

[49]. The participants in the present study experienced increased health through decreased symptoms from menstruation and the gastrointestinal tract. Decreased symptoms from the gastrointestinal tract can also be explained by the feasible coexistence of endometriosis and irritable bowel syndrome (IBS). Previously studies have demonstrated that symptoms from IBS can be reduced by adapting the diet [50]. An Australian study showed that a diet low in fermentable oligo-, di-, mono-saccharides and polyols (FODMAPs) can reduce bowel symptoms in people with endometriosis [45]. Improvements in clinical status and organ function affect the experience of health and quality of life [49]. The participants in the present study described an increased sensory experience of the body. They achieved an awareness of their own body's reaction to diet, stress and sleep through listening to the body's reactions to adapting their diet and other lifestyle changes. Persons with endometriosis sometimes feel that pain controls their lives and they have to arrange everyday life and social events to avoid times when pain can be severe. This can be experienced as that the pain is 'taking away their life' [9]. In this study the participants described the pain was intense and disabling before the dietary change. After the change they experienced positive and negative bodily responses from the dietary change, and this made them feel that they could trust and believe in the dietary change and their bodies. This echoes earlier research that states that recognizing symptoms and patterns can be one path to taking control and regaining quality of life for persons with endometriosis [51]. Several studies describes that use of that complementary therapies is an experience that allows persons with endometriosis to take control of their management [14, 16, 51, 52].

A person's motor, cognitive, and sensory ability could influence their possibility to live a normal life [49]. After dietary changes, the participants in this study experienced an increased level of energy in the form of improved ability to do household chores, socialize with family and friends, exercise, and perform paid work. This can be interpreted as meaning that their "ability to perform" had increased, which furthermore increased their experience of health; an increased experience of health can be achieved via a person's ability to perform. Fitness, energy, and wakefulness all influence a person's possibility to make use of their abilities [49]. The participants in this study experienced that their mood was also influenced by the dietary changes; they were happier and had more patience. A person's health is likewise affected by how pleasant or unpleasant their health-related mood state is; for example, if they are focused and in harmony or anxious and depressed [49].

An important finding in this study is that the participants described that support from family, friends, and society as important for the implementation and maintenance of their dietary changes. They also described a lack of support from HCP. This suggests that support from HCP may make it even easier to continue with dietary changes and maintain health. In this context, person centered care (PCC) may improve these persons' experiences of health and caring. Health-related quality of life (HRQoL) has been shown to increase among persons with endometriosis when HCP pay attention to higher continuity, respect, and to individual preferences [53]. If HCP take the patient's pain seriously, the pain becomes legitimate and it is easier for the patient to understand and manage. A review highlighted that it is essential for HCP to evaluate HRQoL in persons with endometriosis [54]. Listening to the patient enables the development of a partnership which helps the patient to manage and regain control over pain and is crucial in empowering the patient to take an active part in decisions about their own care planning [55]. One study showed that a person-centered approach to patients with fibromyalgia syndrome can expand and strengthen the medical treatment. PPC enhances the patient-physician relationship and helps patients to develop their own treatment plan together

1
2
3 with the HCP. HCP play an important role in empowering the patient to achieve better coping
4 abilities, improved self-management and control of aggravating factors [56].
5
6
7

8 9 **Strengths and limitations**

10
11 A qualitative approach is a suitable method for capturing a person's lived experience [57],
12 and qualitative research interviews are frequently used to obtain useful data about another
13 person's lifeworld [58]. The narratives from the participants in this study were broad, the
14 themes were recurrent, and the data from the interviews agreed well. One limitation of the
15 study might be the number of participants. Twelve participants may seem to be a low number
16 of participants, but the number of participants was considered to be enough. Saturation was
17 reached and no new themes or points in need of further exploration emerged in the process of
18 data collection amongst the last interviews. An indication that the data has reached saturation
19 and have been thoroughly examined is that no new themes or points in need of further
20 exploration emerge from the recursive process of data collection and analysis [59]. A large
21 study sample is not suited to meet the aim of qualitative studies since a large set of data will
22 not necessarily strengthen the data analysis [57].
23
24
25

26
27 One strength of this study is that the participants varies in age and geographic area (Region
28 Västra Götaland and the eastern part of central Sweden). In this qualitative research the strive
29 was to understand how the persons with endometriosis experienced their health after dietary
30 changes. Hence, a small number of participants that maximize the diversity relevant to the
31 research question were selected with a variation in different ages and geographic area [38].
32

33
34 The majority of the interviews were performed via online with voice and video link, meaning
35 that verbal and non-verbal communication could be mediated in a similar way to what is
36 possible with a face-to face interview [60]. Online interviews give participants a greater
37 opportunity to choose the time and place of the interview, and they are also cost-effective and
38 environmentally friendly when neither researcher or participants need to travel [61]. Such a
39 method allowed participants who lived at the geographical distance to take part in the study.
40 However, technical hitches during important questions can constrain the development of an
41 intimate feeling during the interview and may hinder resuming of the interview [62].
42
43

44
45 A weakness of the study is that it only reflects the experiences of health from persons with
46 endometriosis who had completed tertiary education and who experienced an increased health
47 after dietary changes. The Internet support forums also included persons who did not
48 experience any positive advantages from dietary changes, but they were not interested in
49 participating in the study. Persons who seeks a forum for diet might have a more positively
50 attitude towards dietary changes. This was a weakness of the study since persons who did not
51 experience any difference from dietary changes probably did not continue to use the support
52 forum.
53

54
55 The study is limited by the lack of definition for dietary changes. No scientific definition of
56 this has been found, thereby that we defined dietary change as a change of diet from prior
57 diet. Another limitation is also the lack of definition of self-management among persons with
58 endometriosis. A systematic review of all the components of self-management in relation to
59 endometriosis finds that there is often a lack of definition of self-management [11]. One study
60 defines it as 'steps taken by the participants to alleviate the symptoms of endometriosis' but

1
2
3 this definition is more consistent with the definition of 'self-care' than that of self-
4 management [15].
5

6
7 It was a strength to seek interview persons in Internet forums with a connection to diet, since
8 they can typify and shed light on the object of the study. In qualitative sampling,
9 purposiveness is a strategic approach to identify and gain access to those who can teach you
10 the most about your topic [38]. This may spell the end for traditional methods, although
11 currently the minor limitations of Internet access and the over representation of young white
12 women may make its use inappropriate in some settings [37]. Other researchers have used this
13 method and found the usable clinical implications in cancer pain [63]. To recruit from Internet
14 forums might also be a weakness since persons who participate in an association can have
15 severe symptoms comparable to those in tertiary care and a longer delay for diagnosis than
16 persons in secondary and tertiary care. Women recruited via a patient association report a
17 larger disease burden similar to those in tertiary care. This emphasizes that we should be
18 careful with the interpretation of studies conducted within the sole confines of a disease-
19 specific patient organization [64].
20
21

22
23 The study took a qualitative approach, and so was not designed to find any causal relationship
24 between dietary changes and better health, but provides a new understanding in form of
25 participants descriptions of improved wellbeing and improved symptoms. Several questions
26 still remain unanswered on the current topic, and should become the focus of future research;
27 for example, which dietary changes can be positive for endometriosis symptoms, and whether
28 it is something specific in the dietary change in itself or if it is the self-management and
29 feeling of control that affects experience of health. Another important issue for future research
30 is the connection between endometriosis and coeliac disease and IBS.
31
32
33
34

35 **Conclusion**

36
37
38
39 This study contributes to fill the knowledge gap about dietary strategies in endometriosis and
40 lifestyle change as a method of alleviating suffering and increasing wellbeing. An important
41 finding is that the participants experienced decreased symptoms and increased wellbeing after
42 adopting an individually-adapted diet. The healthcare professionals need to consider the
43 patients' knowledge and experience, and allow them to participate in their own care. Further
44 research is necessary to give evidenced-based dietary advices in endometriosis.
45
46
47
48

49 **Acknowledgements**

50
51
52 We acknowledge and thank the forum administrators who allowed us to advertise this study.
53 We also thank the participants in the study, who shared their experiences of health after
54 dietary changes.
55
56
57

58 **Contributors**

1
2
3 All authors contributed to this article, and all have approved the final manuscript. JVK and
4 AP were involved in the design of the study and analysis of the data; JVK performed the
5 recruitment and data collection and drafted the manuscript. HP was involved to perform a
6 scrutiny of the result and to contribute to the manuscript. All authors (JVK, HP and AP) took
7 part in the writing process with critical revisions of the manuscript.
8
9

10 11 **Funding**

12
13
14 The authors wish to express their gratitude to the funders of the project, the local research and
15 development board for Fyrbodal. This financial partner had no involvement in the preparation
16 of this article, the analysis or interpretation of the data or the decision to submit this article for
17 publication.
18
19

20 21 **Competing interest**

22
23 None declared.
24
25

26 27 **Patient consent for publication**

28
29 Not required.
30
31

32 33 **Ethics approval**

34
35 The study was approved by the Regional Ethics Committee of Gothenburg (ref: 889-16).
36
37

38 39 **Data sharing statement**

40
41 The qualitative interview data used to support the findings of this study have not been made
42 available due to the sensitivity and risk of identifying the participants.
43
44

45 46 **References**

- 47
48
49 1. Morassutto C, Monasta L, Ricci G, Barbone F, Ronfani L. Incidence and Estimated
50 Prevalence of Endometriosis and Adenomyosis in Northeast Italy: A Data Linkage
51 Study. PLoS One. 2016;11(4):e0154227.
52
53 2. Ballard KD, Seaman HE, de Vries CS, Wright JT. Can symptomatology help in the
54 diagnosis of endometriosis? Findings from a national case-control study--Part 1.
55 BJOG. 2008;115(11):1382-91.
56
57 3. Giudice LC, Kao LC. Endometriosis. Lancet. 2004;364(9447):1789-99.
58
59 4. Dunselman GA, Vermeulen N, Becker C, Calhaz-Jorge C, D'Hooghe T, De Bie B, et
60 al. ESHRE guideline: management of women with endometriosis. Hum Reprod.
2014;29(3):400-12.

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
5. Young K, Kirkman M, Holton S, Rowe H, Fisher J. Fertility experiences in women reporting endometriosis: findings from the Understanding Fertility Management in Contemporary Australia survey. *Eur J Contracept Reprod Health Care*. 2018;23(6):434-40.
6. Rush G, Misajon R. Examining subjective wellbeing and health-related quality of life in women with endometriosis. *Health Care Women Int*. 2018;39(3):303-21.
7. Facchin F, Barbara G, Saita E, Mosconi P, Roberto A, Fedele L, et al. Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J Psychosom Obstet Gynaecol*. 2015;36(4):135-41.
8. Sperschneider ML, Hengartner MP, Kohl-Schwartz A, Geraedts K, Rauchfuss M, Woelfler MM, et al. Does endometriosis affect professional life? A matched case-control study in Switzerland, Germany and Austria. *BMJ open*. 2019;9(1):e019570.
9. Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obstet Gynaecol*. 2004;25(2):123-33.
10. Streuli I, de Ziegler D, Santulli P, Marcellin L, Borghese B, Batteux F, et al. An update on the pharmacological management of endometriosis. *Expert Opin Pharmacother*. 2013;14(3):291-305.
11. O'Hara R, Rowe H, Fisher J. Self-management in condition-specific health: a systematic review of the evidence among women diagnosed with endometriosis. *BMC Womens Health*. 2019;19(1):80.
12. MacKichan F, Paterson C, Henley WE, Britten N. Self-care in people with long term health problems: a community based survey. *BMC Fam Pract*. 2011;12:53.
13. Buggio L, Barbara G, Facchin F, Frattaruolo MP, Aimi G, Berlanda N. Self-management and psychological-sexological interventions in patients with endometriosis: strategies, outcomes, and integration into clinical care. *Int J Womens Health*. 2017;9:281-93.
14. Seear K. The third shift: Health, work and expertise among women with endometriosis. *Health Sociology Review*. 2009;18(2):194-206.
15. Roomaney R, Kagee A. Coping strategies employed by women with endometriosis in a public health-care setting. *J Health Psychol*. 2016;21(10):2259-68.
16. Huntington A, Gilmour JA. A life shaped by pain: women and endometriosis. *J Clin Nurs*. 2005;14(9):1124-32.
17. Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. Impact of endometriosis on women's lives: a qualitative study. *BMC Womens Health*. 2014;14:123.
18. Armour M, Sinclair J, Chalmers KJ, Smith CA. Self-management strategies amongst Australian women with endometriosis: a national online survey. *BMC Complement Altern Med*. 2019;19(1):17.
19. Pujol LA, Monti DA. Managing cancer pain with nonpharmacologic and complementary therapies. *J Am Osteopath Assoc*. 2007;107(12 Suppl 7):Es15-21.
20. Saguyod SJU, Kelley AS, Velarde MC, Simmen RCM. Diet and endometriosis--revisiting the linkages to inflammation. *Journal of Endometriosis and Pelvic Pain Disorders*. 2018;10(2):51-8.
21. Fjerbaek A, Knudsen UB. Endometriosis, dysmenorrhea and diet--what is the evidence? *Eur J Obstet Gynecol Reprod Biol*. 2007;132(2):140-7.
22. Parazzini F, Vigano P, Candiani M, Fedele L. Diet and endometriosis risk: a literature review. *Reprod Biomed Online*. 2013;26(4):323-36.
23. Trabert B, Peters U, De Roos AJ, Scholes D, Holt VL. Diet and risk of endometriosis in a population-based case-control study. *Br J Nutr*. 2011;105(3):459-67.

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
24. Missmer SA, Chavarro JE, Malspeis S, Bertone-Johnson ER, Hornstein MD, Spiegelman D, et al. A prospective study of dietary fat consumption and endometriosis risk. *Hum Reprod*. 2010;25(6):1528-35.
25. Heard ME, Melnyk SB, Simmen FA, Yang Y, Pabona JM, Simmen RC. High-Fat Diet Promotion of Endometriosis in an Immunocompetent Mouse Model is Associated With Altered Peripheral and Ectopic Lesion Redox and Inflammatory Status. *Endocrinology*. 2016;157(7):2870-82.
26. Trabert B, Peters U, De Roos AJ, Scholes D, Holt VL. Diet and risk of endometriosis in a population-based case-control study. *British Journal of Nutrition*. 2011;105(3/4):459-67 9p.
27. Parazzini F, Chiaffarino F, Surace M, Chatenoud L, Cipriani S, Chiantera V, et al. Selected food intake and risk of endometriosis. *Hum Reprod*. 2004;19(8):1755-9.
28. Matalliotakis IM, Cakmak H, Fragouli YG, Goumenou AG, Mahutte NG, Arici A. Epidemiological characteristics in women with and without endometriosis in the Yale series. *Archives of gynecology and obstetrics*. 2008;277(5):389-93.
29. Harris HR, Chavarro JE, Malspeis S, Willett WC, Missmer SA. Dairy-food, calcium, magnesium, and vitamin D intake and endometriosis: a prospective cohort study. *American journal of epidemiology*. 2013;177(5):420-30.
30. Darling AM, Chavarro JE, Malspeis S, Harris HR, Missmer SA. A prospective cohort study of Vitamins B, C, E, and multivitamin intake and endometriosis. *Journal of endometriosis*. 2013;5(1):17-26.
31. Heilier JF, Donnez J, Nackers F, Rousseau R, Verougstraete V, Rosenkranz K, et al. Environmental and host-associated risk factors in endometriosis and deep endometriotic nodules: a matched case-control study. *Environ Res*. 2007;103(1):121-9.
32. Covens AL, Christopher P, Casper RF. The effect of dietary supplementation with fish oil fatty acids on surgically induced endometriosis in the rabbit. *Fertil Steril*. 1988;49(4):698-703.
33. Berube S, Marcoux S, Maheux R. Characteristics related to the prevalence of minimal or mild endometriosis in infertile women. Canadian Collaborative Group on Endometriosis. *Epidemiology (Cambridge, Mass)*. 1998;9(5):504-10.
34. Grodstein F, Goldman MB, Ryan L, Cramer DW. Relation of female infertility to consumption of caffeinated beverages. *Am J Epidemiol*. 1993;137(12):1353-60.
35. Hansen SO, Knudsen UB. Endometriosis, dysmenorrhoea and diet. *Eur J Obstet Gynecol Reprod Biol*. 2013;169(2):162-71.
36. Marshall C. Designing qualitative research. 6. ed. ed. Rossman GB, editor. Thousand Oaks, California: Thousand Oaks, California : SAGE; 2016.
37. Whitaker C, Stevelink S, Fear N. The Use of Facebook in Recruiting Participants for Health Research Purposes: A Systematic Review. *J Med Internet Res*. 2017;19(8):e290.
38. Ulin PR, Robinson ET, Tolley EE. *Qualitative Methods in Public Health : A Field Guide for Applied Research*. Hoboken: Hoboken: Wiley; 2012.
39. Denzin NK, Lincoln YS. *Handbook of qualitative research*. Thousand Oaks, Calif.: Thousand Oaks, Calif. : Sage; 1994.
40. Braun VC, C. Using thematic analysis in psychology. *Qualitative Research in Psychology*. . *Qualitative Research in Psychology*. 2006;3(2):77-101.
41. Creswell JW, editor. *Research design : qualitative, quantitative, and mixed methods approaches*. 2nd ed: Thousand Oaks, Calif. [u.a.] : Sage Publ., 2003.; 2003.
42. Noble H, Smith J. Issues of validity and reliability in qualitative research. *Evid Based Nurs*. 2015;18(2):34-5.

- 1
- 2
- 3 43. Marziali M, Venza M, Lazzaro S, Lazzaro A, Micossi C, Stolfi VM. Gluten-free diet: a new strategy for management of painful endometriosis related symptoms? *Minerva Chir.* 2012;67(6):499-504.
- 4
- 5
- 6 44. Sesti F, Pietropolli A, Capozzolo T, Broccoli P, Pierangeli S, Bollea MR, et al. Hormonal suppression treatment or dietary therapy versus placebo in the control of painful symptoms after conservative surgery for endometriosis stage III-IV. A randomized comparative trial. *Fertil Steril.* 2007;88(6):1541-7.
- 7
- 8
- 9
- 10 45. Moore JS, Gibson PR, Perry RE, Burgell RE. Endometriosis in patients with irritable bowel syndrome: Specific symptomatic and demographic profile, and response to the low FODMAP diet. *Aust N Z J Obstet Gynaecol.* 2017;57(2):201-5.
- 11
- 12
- 13 46. Mier-Cabrera J, Aburto-Soto T, Burrola-Mendez S, Jimenez-Zamudio L, Tolentino MC, Casanueva E, et al. Women with endometriosis improved their peripheral antioxidant markers after the application of a high antioxidant diet. *Reprod Biol Endocrinol.* 2009;7:54.
- 14
- 15
- 16 47. Souza CA, Oliveira LM, Scheffel C, Genro VK, Rosa V, Chaves MF, et al. Quality of life associated to chronic pelvic pain is independent of endometriosis diagnosis--a cross-sectional survey. *Health Qual Life Outcomes.* 2011;9:41.
- 17
- 18 48. Sepulcri Rde P, do Amaral VF. Depressive symptoms, anxiety, and quality of life in women with pelvic endometriosis. *Eur J Obstet Gynecol Reprod Biol.* 2009;142(1):53-6.
- 19
- 20 49. Brulde B. On how to define the concept of health: a loose comparative approach. *Med Health Care Philos.* 2000;3(3):305-8.
- 21
- 22 50. Bohn L, Storsrud S, Liljebo T, Collin L, Lindfors P, Tornblom H, et al. Diet low in FODMAPs reduces symptoms of irritable bowel syndrome as well as traditional dietary advice: a randomized controlled trial. *Gastroenterology.* 2015;149(6):1399-407.e2.
- 23
- 24 51. Cox H, Henderson L, Wood R, Cagliarini G. Learning to take charge: women's experiences of living with endometriosis. *Complement Ther Nurs Midwifery.* 2003;9(2):62-8.
- 25
- 26 52. Cox H, Henderson L, Andersen N, Cagliarini G, Ski C. Focus group study of endometriosis: struggle, loss and the medical merry-go-round. *Int J Nurs Pract.* 2003;9(1):2-9.
- 27
- 28 53. Apers S, Dancet EAF, Aarts JWM, Kluivers KB, D'Hooghe TM, Nelen W. The association between experiences with patient-centred care and health-related quality of life in women with endometriosis. *Reprod Biomed Online.* 2018;36(2):197-205.
- 29
- 30 54. Bourdel N, Chauvet P, Billone V, Douridas G, Fauconnier A, Gerbaud L, et al. Systematic review of quality of life measures in patients with endometriosis. *PLoS One.* 2019;14(1):e0208464.
- 31
- 32 55. Howarth M, Warne T, Haigh C. Pain from the inside: understanding the theoretical underpinning of person-centered care delivered by pain teams. *Pain Manag Nurs.* 2014;15(1):340-8.
- 33
- 34 56. Masi AT, White KP, Pilcher JJ. Person-centered approach to care, teaching, and research in fibromyalgia syndrome: justification from biopsychosocial perspectives in populations. *Semin Arthritis Rheum.* 2002;32(2):71-93.
- 35
- 36 57. Kvale S. *Interviews: an introduction to qualitative research interviewing*. Thousand Oaks: SAGE; 1996.
- 37
- 38 58. Qu SQ, Dumay J. The qualitative research interview". *Qualitative Research in Accounting & Management.* 2011;8(3):238-64.
- 39
- 40 59. Audrey AT, Elizabeth G. *Reviewing Qualitative Research in the Social Sciences*: Taylor and Francis; 2013.
- 41
- 42
- 43
- 44
- 45
- 46
- 47
- 48
- 49
- 50
- 51
- 52
- 53
- 54
- 55
- 56
- 57
- 58
- 59
- 60

- 1
2
3 60. Sullivan JR. Skype: An Appropriate Method of Data Collection For Qualitative
4 Interviews? *The Hilltop Review*. 2012;6(1):54-60.
5
6 61. Iacono V, Symonds P, Brown D. Skype as a Tool for Qualitative Research Interviews.
7 *Sociological Research Online*. 2016;21(2):1-15.
8
9 62. Seitz S. Pixilated partnerships, overcoming obstacles in qualitative interviews via
10 Skype: a research note. *Qualitative Research*. 2016;16(2):229-35.
11
12 63. Im EO, Lee SH, Liu Y, Lim HJ, Guevara E, Chee W. A national online forum on
13 ethnic differences in cancer pain experience. *Nurs Res*. 2009;58(2):86-94.
14
15 64. De Graaff AA, Dirksen CD, Simoens S, De Bie B, Hummelshoj L, D'Hooghe TM, et
16 al. Quality of life outcomes in women with endometriosis are highly influenced by
17 recruitment strategies. *Hum Reprod*. 2015;30(6):1331-41.
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

General Advertisement in the forums

ENDOMETRIOSIS STUDY

Request made with the approval of the administrator.

University of Gothenburg
Sahlgrenska Academy
Department of Health Sciences and Health
Box 457
40 503 Gothenburg

The study is about the how persons with endometriosis experienced their health after dietary changes.

Endometriosis, a chronic gynecological disease, affects about 10% of people with female genitalia in childbearing age. The treatment currently available is aimed at reducing symptoms, preventing progression and recurrence of the disease and, if possible, improving fertility. Today's treatment, hormonal and / or surgical treatment is not always effective for all people with endometriosis and many often experience symptoms after completed treatment. The diet and its composition are important for health and can both promote good health and prevent disease. It appears that people with endometriosis use complementary or alternative treatments, for example. dietary changes to improve one's health. This study aims to explore the experience of health following dietary changes in people with endometriosis.

You are hereby invited to this interview study to share how you experience health following dietary changes in endometriosis. To participate you need to be 18 years of age and have the diagnosis of endometriosis prescribed by a doctor. The study is about dietary changes and experience of health in endometriosis and therefore you must not have the diagnoses diabetes, celiac disease or inflammatory bowel disease (Crohn's disease, Ulcerative colitis).

Participation in the study is completely voluntary and you have the opportunity to cancel your participation at any time. Your answers and your results will be processed so that unauthorized persons cannot access them. Research data will be stored for at least 10 years to allow for review of the material, even if you cancel your participation. No financial compensation will be paid.

Jenny Vennberg Karlsson is conducting the study and is a legitimate midwife and works in primary care in Västra Götaland. The interview study is part of my master's thesis / master in reproductive and perinatal health at the University of Gothenburg. The supervisor responsible for the study is my supervisor Åsa Premberg, a qualified midwife and university lecturer.

If you have any further questions regarding this study or are interested in participating in the study, you are most welcome to contact the project manager.

Sincerely

Project manager: Jenny Vennberg Karlsson

Email: gusvennb@student.gu.se

Phone: 0763 189 562

Supervisor / Principal: Åsa Premberg

Email: asa.premberg@gu.se

Phone: 031 786 6087

Appendix 2**Interview guide**

The initial interview question was:

Will you please tell me about your experiences of health after the dietary change?

If the subjects below not where mentioned spontaneously, the interview person was asked about:

Information about dietary change

Pain and other symptoms

Menstruation

Health

Work/school

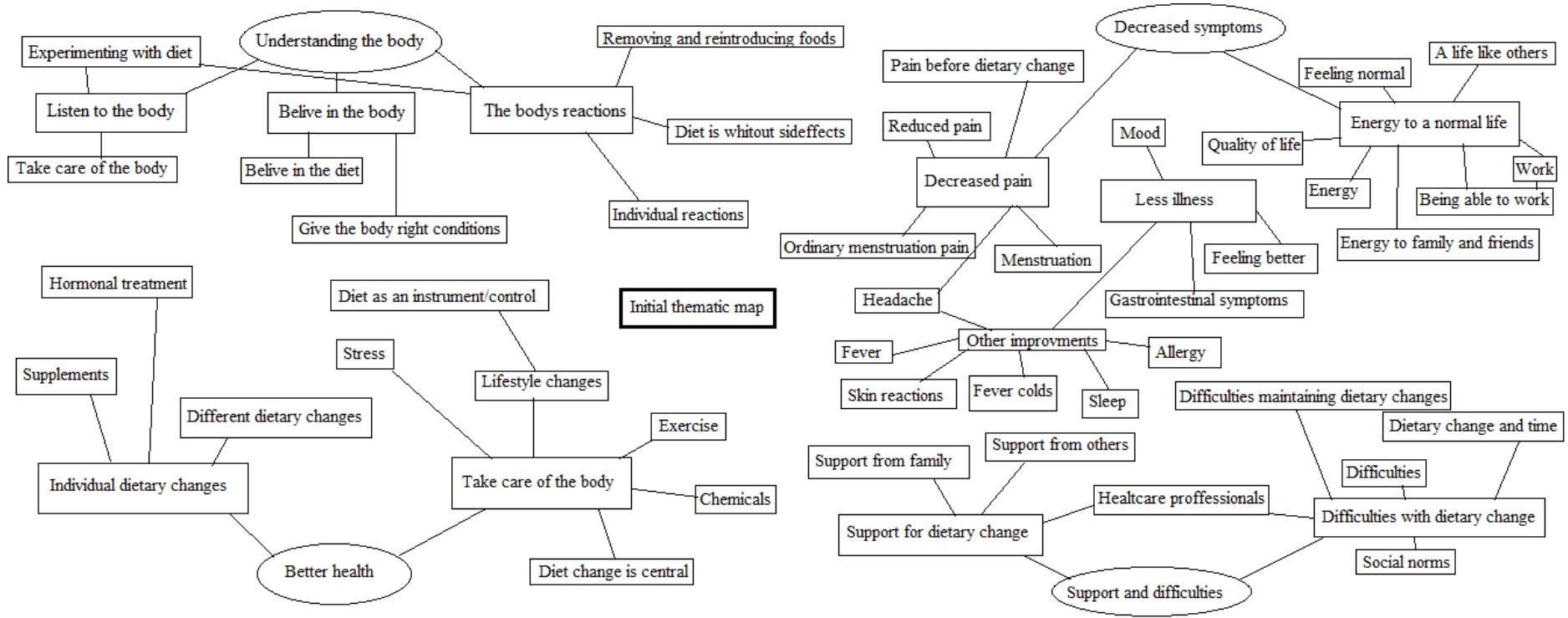
Relationships

Relationship with a partner

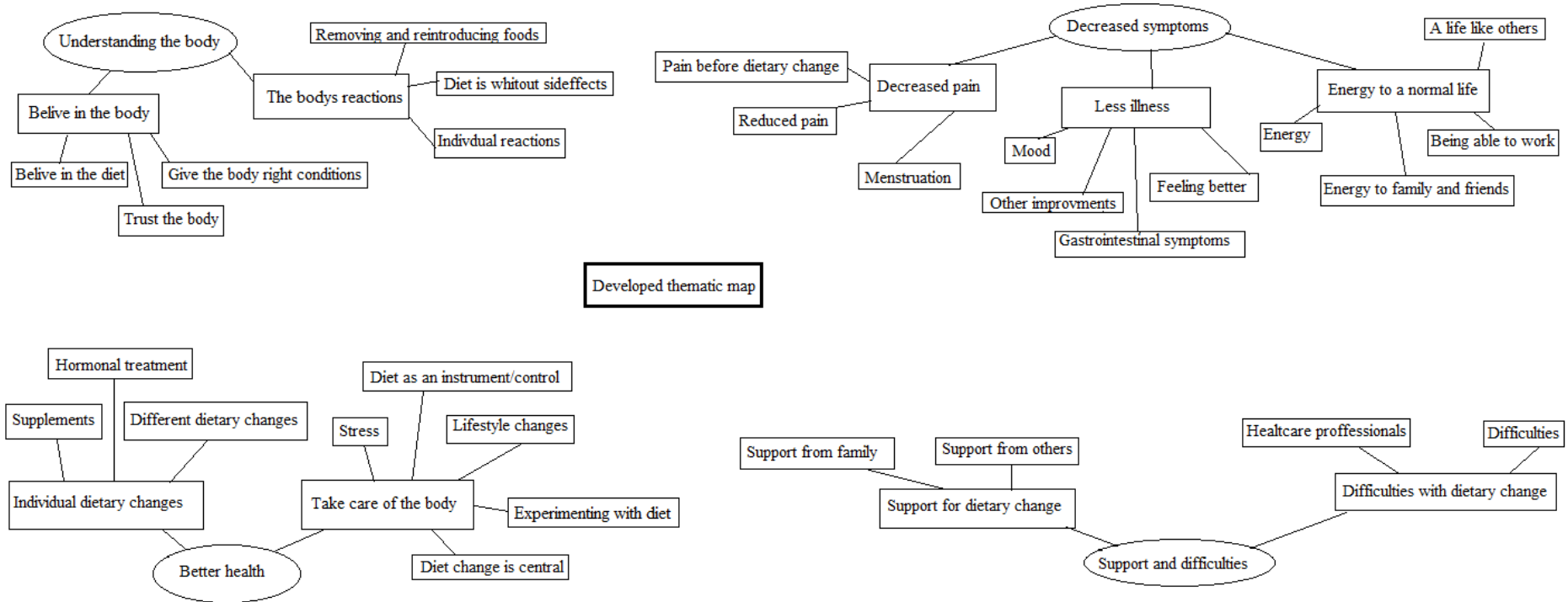
Other changes

Do you have anything else to add that I did not ask about?

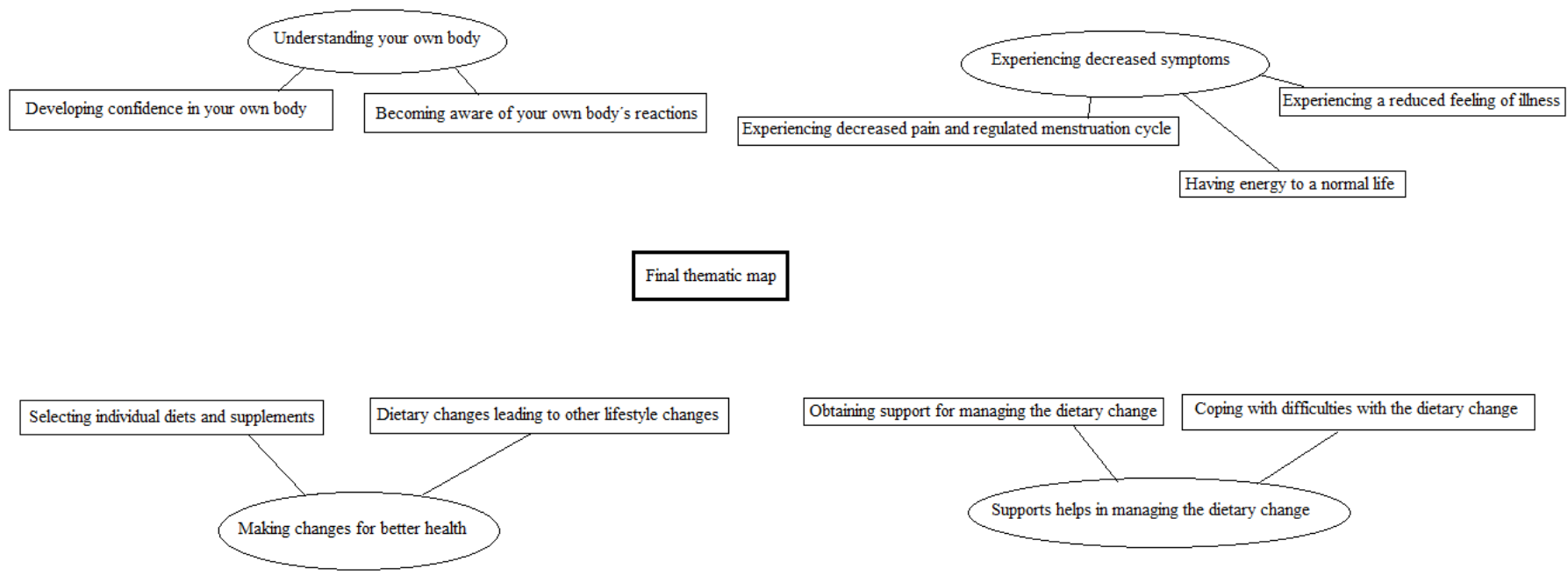
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46



Appendix 3



1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46



SRQR: checklist to BMJ Open

	Page
Title and abstract	
S1 Title Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2 Abstract Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2
Introduction	
S3 Problem formulation Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	5
S4 Purpose or research question Purpose of the study and specific objectives or questions	5
Methods	
S5 Qualitative approach and research paradigm Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale	6-7
S6 Researcher characteristics and reflexivity Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6-7
S7 Context Setting/site and salient contextual factors; rationale	6
S8 Sampling strategy How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	6, 14
S9 Ethical issues pertaining to human subjects Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7, 16
S10 Data collection methods Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, Iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	6-7
S11 Data collection instruments and technologies Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6-7
S12 Units of study Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6-7
S13 Data processing Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	6-7
S14 Data analysis Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	7
S15 Techniques to enhance trustworthiness Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	6-7
Results/findings	
S16 Synthesis and interpretation Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-12
S17 Links to empirical data Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-12
Discussion	
S18 Integration with prior work, implications, transferability, and contribution(s) to the field Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12-15
S19 Limitations Trustworthiness and limitations of findings	14-15
Other	
S20 Conflicts of interest Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	16
S21 Funding Sources of funding and other support; role of funders in data collection, interpretation, and reporting	16

BMJ Open

Experiences of health after dietary changes in endometriosis: A qualitative interview study.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2019-032321.R2
Article Type:	Original research
Date Submitted by the Author:	04-Dec-2019
Complete List of Authors:	Vennberg Karlsson, Jenny; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences; Västra Götalandsregionen, Primary Health Care, Research and Development Unit, Närhälsan Patel, Harshida; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences Premberg, Aasa; University of Gothenburg Sahlgrenska Academy, Institute of Health and Care Sciences; Västra Götalandsregionen, Primary Health Care, Research and Development Unit, Närhälsan
Primary Subject Heading:	Obstetrics and gynaecology
Secondary Subject Heading:	Complementary medicine, Patient-centred medicine, Qualitative research, Reproductive medicine, Sexual health
Keywords:	Endometriosis, dietary changes, QUALITATIVE RESEARCH, NUTRITION & DIETETICS, GYNAECOLOGY

SCHOLARONE™
Manuscripts

1
2
3 **Title:** Experiences of health after dietary changes in endometriosis: A qualitative interview
4 study.
5
6
7

8 **Authors:** Jenny Vennberg Karlsson^{a,b}, Harshida Patel^a, Aasa Premberg^{a,c}
9

10 Jenny Vennberg Karlsson RNM, MSc
11 E-mail: jenny.vennberg-karlsson@vgregion.se
12
13

14 Harshida Patel RN, PhD
15 E-mail: harshida.patel@gu.se
16
17

18 Aasa Premberg RNM, PhD
19 E-mail: asa.premberg@gu.se
20
21

22
23 ^a Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg,
24 Sweden
25

26 ^b Primary Health Care, Research and Development Unit, Närhälsan, Vänersborg, Region
27 Västra Götaland, Sweden
28

29 ^c Primary Health Care, Research and Development Unit, Närhälsan, Gothenburg, Region
30 Västra Götaland, Sweden
31

32
33 Corresponding author: Jenny Vennberg Karlsson
34 Institute of Health and Care Sciences, Sahlgrenska Academy,
35 University of Gothenburg, Arvid Wallgrens Backe, Box 457, S-
36 405 30 Gothenburg, Sweden
37
38 Mobile: +46 763189462
39 E-mail: jenny.vennberg-karlsson@vgregion.se
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Abstract

Objectives

Endometriosis is a chronic disease with no known cure. Persons affected by this disease often use complementary therapies such as dietary changes to reduce their symptoms, and so it is important to investigate whether and how these therapies affect endometriosis symptoms. The aim of this study was to explore how persons with endometriosis experienced their health after dietary changes.

Design

Semi-structured qualitative interviews were conducted with twelve persons with endometriosis who had made individual dietary changes aimed at decreasing their endometriosis symptoms. The interviews were recorded and transcribed verbatim, and analysed using thematic analysis.

Setting

Region Västra Götaland and the eastern part of central Sweden, Sweden.

Participants

Twelve persons with endometriosis aged 28 – 44 were recruited from two Swedish endometriosis support forums on the Internet.

Results

Participants experienced an increase in wellbeing and a decrease in symptoms following their dietary and lifestyle changes. They also felt that the dietary changes led to increased energy levels and a deeper understanding of how they could affect their health by listening to their body's reactions. The participants understood that they could influence their symptoms through lifestyle changes. Support from family and friends was important in implementing and sustaining the dietary changes. However, the participants stressed the lack of support from healthcare professionals.

Conclusions

This study contributes to filling the knowledge gap about dietary strategies in endometriosis and lifestyle change as a method of alleviating suffering and increasing wellbeing. An important finding is that the participants experienced decreased symptoms and increased wellbeing after adopting an individually-adapted diet. Healthcare professionals should take their patients' knowledge and experience into consideration, and allow patients to participate in their own care. Further research is necessary to give evidenced-based dietary advices in endometriosis.

Keywords

Endometriosis, dietary changes, qualitative research, nutrition & dietetics, gynaecology

Strengths and limitations of this study

- To the best of our knowledge, this is the first qualitative study to examine how persons with endometriosis experience health after dietary changes.
- The strategy of recruiting from Internet support forums might be a limitation, since studies conducted with patients from a disease-specific patient organization often reveal a more adverse experience of the disease.
- Although this study is qualitative in nature and direct comparison of dietary changes cannot be made, the experiences from the interview data may facilitate our understanding of using dietary changes to relieve symptoms of endometriosis.

For peer review only

Abbreviations

FODMAPs	Fermentable oligo-, di-, monosaccharides and polyols; a low-FODMAP diet restricts all fermentable carbohydrates.
HCP	Healthcare professional
HRQOL	Health-related quality of life
IBS	Irritable bowel syndrome
PCC	Person-centered care

For peer review only

Introduction

Endometriosis is a benign chronic gynaecological disorder that affects about 1.5 % (population-based studies) to 15 % (clinic-based studies) of the population with internal reproduction organs, such as uteruses and ovaries [1 2]. In this disorder, endometrium-like tissue grows outside the uterus in areas which may include the ovaries, fallopian tubes, and peritoneum. The primary symptoms are pain, dysmenorrhea, pelvic pain, dyschesia, dysuria, and dyspareunia [3]. Fatigue and bowel problems are common, but the disease can also occur without symptoms [4]. Infertility is more frequent among persons with endometriosis (10–15 %) than in the general population (9%) [5]. Endometriosis can affect several aspects of life including health, relationships, and performance, and can have a negative impact on employment and education [6-8]. Every day of life is influenced, with decreased possibilities to perform household tasks such as cooking, shopping, cleaning, and parenting [9].

There is no cure for the endometriosis, but traditionally pain medication, hormone therapy, and surgical treatment are used to decrease endometriosis symptoms [10]. However traditional treatment does not always have the desired effect on symptoms and health [7]. Persons with endometriosis uses a range of self-care activities and complementary therapies in addition to traditional treatment to assist them in managing their symptoms [4 11 12]. These therapies include supplements, yoga/meditation, herbal medicines, transcutaneous electrical nerve stimulation (TENS), dietary changes, exercise, osteopathy, massage, acupuncture, herbalism, and Chinese medicine [4 13]. Several studies have also described the use of dietary and lifestyle changes [14-17], mainly focusing on a healthy diet free from dairy, wheat [14], and caffeine and with high vegetable and fruit content, and containing no high-oestrogen foods [16]. The main source used for information on dietary and lifestyle changes is the Internet [14]. According to an Australian study, self-management strategies and lifestyle interventions are common and important approaches to reduce the symptoms of endometriosis [18]. The use of complementary therapies can affect the experience of pain, improve mood, and increase quality of life [19]. However, there is uncertainty about their efficacy of these therapies, and so they are not usually recommended by healthcare professionals (HCPs). Nevertheless, it is important to acknowledge that some persons with endometriosis may benefit from using complementary therapies may benefit from it [4].

The role of diet in endometriosis has gained more attention in recent years, since it has been observed that diet can affect several processes that are involved in endometriosis, including inflammation, prostaglandin metabolism, and oestrogen activity [13 20]. Still, there are no clear recommendations for dietary changes that can reduce the symptoms of endometriosis [21]. Several studies have explored whether diet increases the risk of being diagnosed with endometriosis, with the results suggesting a link between diet and endometriosis [22-25]. Relevant dietary factors include fat, dairy products, calcium, Vitamins B, C, D and E, coffee, alcohol, and fruit [24 26-34]. For example, a high intake of omega-3 is associated with a significantly lower risk for the diagnosis of endometriosis and a high intake of trans fats and potentially of animal fats is associated with a higher risk of endometriosis [24]. 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]. Nevertheless, there is a lack of studies focusing on dietary changes. This indicates a need to understand how complementary therapies such as dietary changes affect the experience of health among persons with endometriosis. The present study therefore

1
2
3 aimed to explore how persons with endometriosis experienced their health after dietary
4 changes.
5
6
7

8 9 **Methods**

10 11 **Study design**

12 A qualitative approach was considered suitable to study the participants' lived experience
13 of the phenomenon of interest [37].
14
15

16 17 **Participants and setting**

18 Participants were recruited from three Swedish endometriosis support forums on the Internet;
19 two with a connection to diet and one with general topics. Membership of these forums was
20 by application only, and was granted to the first author on request. Initially a general
21 advertisement (Appendix 1) was placed in all three forums, but only a few persons agreed to
22 take part in the study. Next, a direct invitation was sent to fifty randomly selected persons in
23 one of the forums. This forum was chosen as it had a connection to naturally healing and diet.
24 This approach was more successful. The participants who responded to the advertisement all
25 came from the two forums with a connection to diet, the forum with general topics did not
26 generate any participants. The inclusion criteria were being able to speak Swedish, being aged
27 between 18 and 45 years, having a physician-established diagnosis of endometriosis, and
28 having carried out one or more dietary changes. The exclusion criterion was having been
29 diagnosed with diabetes, coeliac disease, or inflammatory bowel diseases (Crohn's disease
30 and ulcerative colitis). Of the 13 participants drawn from the forums, two were excluded from
31 the study because they failed to attend the interview. A pilot interview was also conducted
32 with a person with endometriosis who was known to the interviewer and who had made
33 dietary changes. Since the pilot interview was judged by the authors to be of good quality and
34 content, the data was included in the analysis, giving a total of 12 participants and a rich
35 material for analysis.
36
37
38
39
40

41 42 **Patient and public involvement**

43 There was no patient or public involvement in setting the research agenda.
44

45 46 **Data collection**

47 The participants in this study made individual dietary changes as a complementary therapy.
48 These dietary changes involved either increasing or decreasing their intake of different kinds
49 of foods, or adding or removing foods in their daily diet. In this study we defined dietary
50 change as a change of diet from one's previous diet.
51

52 Data were collected via semi-structured interviews using an interview guide (Appendix 2).
53 The participants were asked about their experiences of individually chosen dietary changes.
54 The opening question was: *Will you please tell me about your experiences of health after the*
55 *dietary change?* The participants answered the question freely in their own words, and
56 follow-up questions were used to clarify any unclear descriptions. Recapitulation was used
57 with individuals who stopped talking; directing them back to previous comments to clarify or
58 elaborate on any descriptions. Credibility was ensured by establishing a trusting and
59 confidential relationship with the participants, and through use of referential adequacy via
60

1
2
3 audio tape-recording [38]. The interviews were performed between November 2016 and June
4 2017 by one of the authors (JVK), with the locations chosen by the participants: in the
5 participant's home (n = 2), at the participant's workplace/school (n = 2), by phone (n = 1),
6 and via online interview with voice and video link (n = 7). The interviews were conducted in
7 Swedish, were digitally recorded, and lasted between 32 and 64 minutes.
8
9

10 **Data analysis**

11 All interviews were transcribed verbatim and analysed using thematic analysis [39]. The
12 research team consisted of two midwives, (JVK and AP) and a registered nurse (HP). The
13 analysis was data-driven, based on the Swedish transcript, and performed inductively by two
14 researchers (JVK and AP) on the basis of the conceptual framework proposed by Braun &
15 Clarke [39]. First, the text from all the interviews was read and reread to understand the depth
16 and breadth of the data. In the next step, meanings units were identified, condensed, and
17 coded. The codes were then compared and sorted into candidate themes in relation to the
18 research question. A thematic map was developed with sub-themes and themes (Appendix 3).
19 The candidate themes were refined and adjusted to cover all meaning patterns in the text and
20 to be coherent, sufficiently distinct from other themes, and internally consistent. In the next
21 step, the whole data set was reviewed, the potential themes were compared in relation to the
22 data, and adjustments were made. Lastly, the final themes were defined and named to
23 correspond to the essential meaning of each theme. Annotations and memos were used to
24 record ideas, reflections, and coding decisions to support trustworthiness [40]. To further
25 establish the trustworthiness of the analysis [41], the third researcher (HP) performed a
26 scrutiny of the results and has made critical revisions of the manuscript together with the
27 other researchers (JVK and AP).
28
29
30
31

32 **Ethical considerations**

33 Ethical approval was obtained from the Regional Ethics Committee of Gothenburg (ref: 889-
34 16). The advertisements on the endometriosis forums were approved in writing by all forum
35 administrators. Participants received oral and written information and were asked for their
36 written consent. To ensure confidentiality, the characteristics of the participants are presented
37 at a group level, and the quotations are labelled with IP1 – IP12 to maintain anonymity.
38
39
40
41

42 **Results**

43
44
45 Twelve persons with endometriosis who had made individual dietary changes were
46 interviewed. Their ages ranged from 28 to 44 years, their time since endometriosis diagnosis
47 from 0.5 to 17 years, and the time since initiating dietary change from 2 months to 3.5 years.
48 Eight of the participants had no hormonal treatment at the time of the interview, two had a
49 hormonal intra uterine device (Mirena), one used progestogen-only pills (Cerazette), and one
50 used natural progesterone. Their education background varied, including secondary school,
51 further education, and university education (Table 1).
52
53
54
55
56
57
58
59
60

Table 1 Demographic data

Pseudonym	Time since diagnosis	Time since dietary change
IP1	3.5 years	3.5 years
IP2	2 years	2 years
IP3	5 years	3 years
IP4	17 years	1 year
IP5	2 years	2 years
IP6	8 years	1 year
IP7	2 years	2 years
IP8	9 years	3 years
IP9	2 months	2 months
IP10	2 years	3 years
IP11	1 year	1 year
IP12	6 years	About 1 year

The thematic analyses of the data identified four main themes and nine subthemes. The four main themes were *Making changes for better health*, *Understanding your own body*, *Experiencing decreased symptoms* and *Support helps in managing the dietary change*.

Making changes for better health

Selecting individual diets and supplements

The participants made individual dietary changes, consisting of excluding or decreasing their intake of different foods. Most of the participants excluded or decreased gluten, dairy products, and carbohydrates. Foods that were considered to stress the body or to affect oestrogen levels or inflammatory processes were eliminated from the diet.

...then I removed everything that stresses the body. All gluten, all dairy products... (IP11)

Foods were also added to their diets; for example, they increased their intake of fruit, vegetables and fish. The participants said that they *'ate far more vegetables'*. Meat and fish could also be excluded from the diet, but some of them who had previously been vegetarian began to eat animal foods again. Meals were cooked from scratch, and they avoided junk food. They also used supplements such as vitamins, minerals, omega3, turmeric, and ginger.

One reason for dietary change was that medical treatment did not result in the desired effect. When the treatment did not work to decrease their endometriosis symptoms, the participants felt that there was no alternative than *'except having to try it [dietary changes] out'*. When a dietary change had a positive impact on health, it became worthwhile to continue with the change. The dietary change was used as an instrument to obtain control over their health.

...It's that I can have control somehow in my own life...being able to do what I want...not being controlled by a disease. (IP11)

Dietary changes leading to other lifestyle changes

The participants described how the positive effect from the dietary changes also aroused their

1
2
3 interest in making other lifestyle changes, for example in their stress level, work situation, and
4 physical activity. The combination of several lifestyle changes amplified the effect of the
5 dietary change and led to increased awareness of how to achieve health.
6

7
8 ...I started to do diet changes and then I also experienced a better
9 effect from the diet changes when I made lifestyle changes too. (IP1)
10

11 Stress was considered to affect health negatively and to decrease the effects of dietary change.
12 They emphasised that stress had a substantial effect on their endometriosis symptoms. Stress
13 could be reduced by resting and not trying to conform to society. Physical activity was also
14 experienced to have a positive impact. They used walking, yoga, mindfulness, meditation, and
15 dancing '*to slow down the stress*'. To minimize hormonal effects, some participants stopped
16 using hormone-disturbing products, such as parabens. Ecological and natural products were
17 preferred, and they wanted to '*get rid of as many chemicals as possible*'.
18
19

20
21 ...I have sometimes noticed that walking or exercising have relieved
22 [the pain] a little bit. (IP4)
23

24 However, although the participants also made other lifestyle changes, they felt that the dietary
25 changes were central to improving health.
26

27 ...the dietary change is central, but other changes are there too...it
28 doesn't matter how well you eat if you don't sleep or exercise. (IP1)
29
30

31 32 **Understanding your own body**

33 34 **Becoming aware of your own body's reactions**

35 Experimenting with dietary changes allowed the participants to become aware of their body's
36 reactions to different kinds of foods, as they removed and reintroduced foods. A deviation
37 could also lead to the detection of positive effects. The participants noticed that if they did not
38 pay attention to the dietary change, '*the endometriosis symptoms came back*'.
39
40

41 They felt that it was safe to try dietary changes because of the lack of side effects, and if these
42 changes did not have a positive effect on their health then they could go back to eating as
43 before. The participants emphasised that reactions to dietary changes were individual.
44
45

46 ...everybody reacts differently to diet...I think that you need to know
47 your body and sense whether something makes you feel good or bad...
48 (IP3)
49
50

51 52 **Developing confidence in your own body**

53 Their participants' experiences of positive and negative bodily responses to dietary changes
54 made them feel that they could trust and believe in the dietary change and their bodies: '*I*
55 *believe in the diet*'. They considered that the body could function more optimally if it was
56 given the right conditions via necessary nutrients in the diet.
57

58 ...I look at my endometriosis...as a symptom of something not
59 working properly in my body, and then make sure I give my body all
60

1
2
3 the conditions to feel as good as possible, so maybe it can...get well
4 on its own. (IP1)
5

6 Deviations from the diet led to more negative symptoms from the endometriosis.
7

8
9 ...began to eat [the person went back to eating as before the dietary
10 changes]...still vegan but sugar, gluten, everything I'd taken away
11 earlier...and in two weeks, I went back to not being able to get out of
12 bed again [painful symptoms re-emerged]. (IP12)
13

14
15 The body's signals were trusted regardless of what the medical results showed. Participants
16 who found that a gluten-free diet decreased their symptoms kept to the diet even if a coeliac
17 test was negative or had not been performed.
18

19
20 ...stop eating gluten and then milk...quite quickly I noticed
21 improvements...in my health...Nah, I don't give a damn about it
22 [coeliac testing]. I don't even care. (IP8)
23
24

25 **Experiencing decreased symptoms**

26 **Experiencing decreased pain and regulated menstruation cycle**

27
28 Before the dietary changes, the pain was described as intense and disabling, but after the
29 changes the participants reported that pain decreased or disappeared. For some participants,
30 menstruation no longer produced the previous symptoms, and arrived '*without any*
31 *premonition*'. The reduced pain was described as ordinary pain, and the use of pain
32 medication decreased. One person said that trying out a general diet low in fermentable oligo-
33 , di-, mono-saccharides and polyols (FODMAPs) did not improve endometriosis symptoms
34 and changed the strategy and started to make own individual dietary changes instead.
35
36
37

38 I could still feel...but it was more like a...normal menstruation. (IP11)
39

40
41 Some participants also experienced a decrease in the amount of bleeding and the number of
42 days of bleeding. The length of their menstruation cycles increased to about 28 days, and
43 menstruation came regularly every month.
44

45 Before...I couldn't use tampons, it only took about an hour for them to
46 fill up, now I use tampons and it works...without leaking....so that's
47 also an...improvement...that I don't bleed as much. (IP5)
48
49

50 **Experiencing a reduced feeling of illness**

51 A general improvement in health was achieved after the dietary changes. The participants felt
52 '*healthier*' even if they still had endometriosis symptoms. Inconveniences from the
53 gastrointestinal tract decreased, and the abdomen felt calmer; normal and less swollen. Gases
54 and the stool were normalised, and the body felt more comfortable when the stomach was
55 '*functioning better*'.
56
57

58 I cut out gluten and noticed a very big difference in my stomach, I
59 became less swollen, less gassy...and then more normal stools. (IP6)
60

1
2
3
4 Dietary changes also affected mood. The pain previously had a negative impact in the form of
5 '[making] *you grumpy*'. After the dietary change the participants became happier, had more
6 patience, and could trust their feelings.
7

8
9 ...my endometriosis has always been in control in a way, but now it
10 has less control when you...[I] can trust [my feelings] a little more,
11 like, OK now I'm angry because I'm angry [not because I'm in pain].
12 (IP4)
13

14
15 Symptoms such as colds, headache, nausea, and fever were reduced, as were allergic and
16 skin reactions. Some of the participants said that their '*allergies disappeared*.' Their sleep
17 improved, and they found it easier to fall asleep.
18

19 **Having the energy to live a normal life**

20 After the dietary changes, the participants experienced a '*higher level of energy*' and were
21 less tired. They were able to cope with work, home, and socializing with friends and family,
22 since they did not experience tiredness in the evening in the same way as before the dietary
23 change. They could perform everyday chores such as cleaning and washing. Their increased
24 energy levels made them function better as a parent, for example by joining their children in
25 activities. Increased energy gave them a feeling of regaining their life and being normal again.
26
27

28
29 Alertness...I feel normal...I can do things without needing a break...
30 (IP 9)
31

32 After the dietary changes, the participants felt able to go back to work, and experienced better
33 functioning when they were there. The number of sick days decreased. They believed that the
34 dietary changes were necessary to allow them to work and live a normal life.
35

36
37 ...[The dietary change] enabled me to actually continue to work
38 and...live a decent normal life... (IP1)
39

40 41 42 **Support helps in managing the dietary change**

43 **Obtaining support for the dietary change**

44 It was important that the participants' families understood and supported the implementation
45 and maintenance of the dietary change.
46

47
48 ...if I hadn't had support from my friends and family, I'd have had it
49 much, much harder. (IP11)
50

51
52 Family members could be supportive by understanding the dietary change, by talking about it,
53 and by helping to explain it to other people. They could also give financial help, for example
54 by paying for expensive supplements. When family members saw positive results from the
55 change, this made them more engaged and they continued to support it. Support also came
56 from co-workers and friends, who adapted to the new circumstances.
57
58
59
60

1
2
3 ...but then we all go somewhere else, or someone has already been
4 there and says that they have other things to eat there too. (IP2)
5
6

7 Another source of support was Internet forums where the participants shared information
8 about dietary changes and received tips and advices. They also sought out information from
9 groups on the Internet. The participants felt that there was increased support in society for
10 different diets, as restaurants and cafes had begun to offer dishes adapted for allergies.
11

12 **Coping with difficulties and lack of support with the dietary change**

13 The dietary change was associated with several difficulties. It could be hard to maintain, for
14 several reasons; for example, meal planning took time and it was exhausting to always have to
15 think about what to eat. It was harder to eat in a '*social context*' with family and friends, and
16 at restaurants. Difficulties were handled by planning meals in advance or bringing their own
17 meal when visiting other people; the easiest way was just to eat at home. They were '*not*
18 '*invited*' to things as often as before. Social norms around food made some of the participants
19 feel odd; from a norm perspective, it would have been easier just to eat in the same way as
20 everybody else. Other participants felt that many people '*eat differently*' and that it did not
21 matter to them what other people thought about their diet. Another difficulty was the weak or
22 non-existent support from HCPs. Although HCPs expressed interest in the dietary change, the
23 participants' experiences were dominated by a lack of interest from HCPs. The participants
24 wanted there to be a '*shorter gap*' between their own desires and knowledge and those of the
25 HCPs.
26
27
28
29

30 ...in the health care systems it's all...I hardly dare to talk about it
31 [dietary changes] anymore, because... you... just get in a sour
32 mood...It's just like meeting a brick wall, you just get a: 'Nah, it's
33 meaningless, just eat what you want'. (IP12)
34
35

36 One reason why the dietary changes were difficult to maintain was that it could take weeks,
37 months, or even years before the change had any positive effect. Positive effects of the dietary
38 changes made it easier to handle the difficulties.
39
40

41 Because I think the diet is a long-term change, it's a process that takes
42 a long time. (IP3)
43
44
45
46
47

48 **Discussion**

49 The results of this study show that the participants experienced decreased symptoms of
50 endometriosis and gained a greater understanding of their bodies after making individual
51 dietary changes. The most important finding is that the participants described reductions in
52 symptoms, specifically pain and fatigue, which led to the positive experience of increased
53 health.
54
55

56 The main dietary changes described by the participants involved excluding or decreasing the
57 amount of gluten and dairy products, adding more vegetables and fruit, and cooking food
58 from scratch with 'clean' ingredients. These results are in line with the findings of other
59
60

1
2
3 studies showing that diet can influence the symptoms of endometriosis [42-44]. One study
4 found that persons with endometriosis who ate a gluten-free diet experienced improvement in
5 painful symptoms, physical function, overall health experience, vitality, social function, and
6 mental health [42]. A study comparing diet treatment, hormonal treatment, and placebo after
7 conservative surgery found that diet and postoperative treatment with hormones were both
8 effective in reducing painful symptoms from endometriosis [43]. Another study showed that
9 an increased intake of antioxidants produced decreased oxidative stress, which affects
10 inflammation [45].
11
12

13 Several studies have reported that pain is a major symptom in endometriosis, and one that
14 affects both health and quality of life [46 47]. Tiredness and fatigue are also common
15 symptoms [4]. Quality of life can be influenced by both physical and psychological factors
16 [48]. The participants in the present study experienced increased health through decreased
17 symptoms from menstruation and the gastrointestinal tract. Decreased symptoms from the
18 gastrointestinal tract can also be explained by the feasible coexistence of endometriosis and
19 irritable bowel syndrome (IBS). Previously studies have demonstrated that symptoms from
20 IBS can be reduced by adapting the diet [49]. An Australian study showed that a low-
21 FODMAP diet could reduce bowel symptoms in people with endometriosis [44].
22 Improvements in clinical status and organ function affect the experience of health and quality
23 of life [48]. The participants in the present study described an increased sensory experience of
24 the body. They achieved an awareness of their own body's reaction to diet, stress, and sleep
25 through listening to the body's reactions to adapting their diet and other lifestyle changes.
26 Persons with endometriosis sometimes feel that pain controls their lives, and they have to
27 arrange everyday life and social events to avoid times when the pain can be severe. The
28 experience of this has been described as the pain is 'taking away their life' [9]. In this study
29 the participants described their pain as intense and disabling before the dietary change. After
30 the change they experienced positive and negative bodily responses which made them feel
31 that they could trust and believe in the dietary change and their bodies. This echoes the
32 findings of earlier research that states that recognizing symptoms and patterns can be one path
33 to taking control and regaining quality of life for persons with endometriosis [50]. Several
34 have described how the use of that complementary therapies has allowed persons with
35 endometriosis to take control of their own symptom management [14 16 50 51].
36
37
38
39
40

41 A person's motor, cognitive, and sensory ability could influence their possibility to live a
42 normal life [48]. After dietary changes, the participants in this study experienced an increased
43 level of energy in the form of improved ability to do household chores, socialize with family
44 and friends, exercise, and perform paid work. This can be interpreted as meaning that their
45 'ability to perform' had increased, which furthermore increased their experience of health, as
46 an increased experience of health can be achieved via an increased ability to perform. Fitness,
47 energy, and wakefulness all influence a person's possibility to make use of their abilities [48].
48 The participants in this study experienced that their mood was also influenced by the dietary
49 changes; they were happier and had more patience. A person's health is likewise affected by
50 how pleasant or unpleasant their health-related mood state is; for example, if they are focused
51 and in harmony or anxious and depressed [48].
52
53
54

55 An important finding in this study is that the participants described that support from family,
56 friends, and society as being important for the implementation and maintenance of their
57 dietary changes. They also described a lack of support from HCPs. This suggests that support
58 from HCPs may make it even easier to continue with dietary changes and maintain health. In
59 this context, person centered care (PCC) may improve these persons' experiences of health
60

1
2
3 and caring. Health-related quality of life (HRQoL) has been shown to increase among persons
4 with endometriosis when HCPs pay attention to continuity, respect, and individual
5 preferences [52]. If HCPs take the patient's pain seriously, the pain becomes legitimate and it
6 is easier for the patient to understand and manage. A review highlighted that it is essential for
7 HCPs to evaluate HRQoL in persons with endometriosis [53]. Listening to the patient
8 enables the development of a partnership which helps them to manage and regain control over
9 pain, and is crucial in empowering them to take an active part in decisions about their own
10 care planning [54]. One study showed that a person-centered approach to patients with
11 fibromyalgia syndrome can expand and strengthen the medical treatment. PPC enhances the
12 patient-physician relationship and helps patients to develop their own treatment plan together
13 with the HCP. HCPs play an important role in empowering the patients to achieve better
14 coping abilities, improved self-management, and control of aggravating factors [55].
15
16
17
18
19
20

21 **Strengths and limitations**

22
23 A qualitative approach is a suitable method for capturing a person's lived experience [56],
24 and qualitative research interviews are frequently used to obtain useful data about another
25 person's lifeworld [57]. The narratives from the participants in this study were broad, the
26 themes were recurrent, and the data from the interviews agreed well.
27
28

29 One limitation of the study might be the number of participants, but although twelve
30 participants may seem to be a low number, it was considered sufficient. Saturation was
31 reached, and no new insights emerged during the last few interviews. One indication that the
32 data has reached saturation and have been thoroughly examined is that no new themes or
33 points in need of further exploration emerge from the recursive process of data collection and
34 analysis [58]. A large study sample is not suited to meet the aim of qualitative studies, since a
35 large set of data will not necessarily strengthen the data analysis [56].
36
37

38 One strength of this study is that the participants varied in age and geographic area (Region
39 Västra Götaland and the eastern part of central Sweden). The aim of this qualitative research
40 was to understand how persons with endometriosis experienced their health after dietary
41 changes. Hence, a small number of participants who maximized the diversity relevant to the
42 research question were selected, with a variation in age and geographic area [59].
43
44

45 The majority of the interviews were performed online with voice and video link, meaning that
46 verbal and non-verbal communication could be mediated in a similar way to what is possible
47 with a face-to-face interview [60]. Online interviews give participants a greater opportunity to
48 choose the time and place of the interview, and they are also cost-effective and
49 environmentally friendly as they remove the need for researchers or participants to travel [61].
50 Such a method allowed participants who lived at a large geographical distance to take part in
51 the study. However, technical hitches during important questions can constrain the
52 development of an intimate feeling during the interview, and may hinder resumption of the
53 interview [62].
54
55

56 A weakness of the study is that it only reflects the experiences of health among persons with
57 endometriosis who had completed tertiary education and who experienced an increased health
58 after dietary changes. The Internet support forums also included members who did not
59 experience any positive advantages from dietary changes, but they were not interested in
60

1
2
3 participating in the study. Persons who choose to participate in a forum concerned with diet
4 might have a more positively attitude towards dietary changes. This was a weakness of the
5 study, since it is unlikely that persons who did not experience any difference from dietary
6 changes would have continued to use the support forum.
7

8
9 The study is also limited by the lack of definition of dietary changes. No scientific definition
10 of this has been found, and so we simply defined dietary change as a change from one's prior
11 diet. Another limitation is also the lack of definition of self-management among persons with
12 endometriosis, as revealed by a systematic review of all the components of self-management
13 in relation to endometriosis [11]. One study defined it as 'steps taken by the participants to
14 alleviate the symptoms of endometriosis', but this definition is more consistent with the
15 definition of 'self-care' than that of self-management [15].
16
17

18 The choice to seek interviewees in Internet forums with a connection to diet was a strength,
19 since such interviewees can typify and shed light on the object of the study. In qualitative
20 sampling, purposiveness is a strategic approach to identify and gain access to those who can
21 teach you the most about your topic [59]. There is growing evidence to suggest that the
22 Internet is a successful recruitment tool, and that health researchers should therefore consider
23 using it. Benefits include reduced cost, shorter recruitment periods, better representation, and
24 improved participant selection. This may spell the end for traditional methods, although
25 currently the minor limitations of the need for Internet access and the over-representation of
26 young white women may make its use inappropriate in some settings [63]. Other researchers
27 have used this method and found it usable within clinical implications in cancer pain [64].
28 Recruiting from Internet forums was considered to be an effective strategy, as the members
29 there had experienced dietary changes in endometriosis. However, this form of recruitment
30 might also be a weakness in comparison to recruiting via an association, since persons
31 participating in the latter might have severe symptoms comparable to those in tertiary care
32 and a longer delay for diagnosis than persons in secondary and tertiary care, and a longer
33 delay for diagnosis than persons in secondary and tertiary care. Women recruited via a
34 patient association reported a larger disease burden, similar to those in tertiary care,
35 emphasizing the need for care when interpreting studies conducted within the sole confines of
36 a disease-specific patient organization [65].
37
38
39
40

41 This study took a qualitative approach, and so was not designed to find any causal
42 relationship between dietary changes and better health, but provides a new understanding in
43 form of participants' descriptions of improved wellbeing and improved symptoms. Several
44 questions still remain unanswered on the current topic, and should become the focus of future
45 research; for example, which dietary changes can be positive for endometriosis symptoms,
46 and whether it is something specific in the dietary change in itself or if it is the self-
47 management and feeling of control that affects the experience of health. Another important
48 issue for future research is the connection between endometriosis and coeliac disease and IBS.
49
50
51

52 **Conclusion**

53
54
55

56 This study contributes to filling the knowledge gap about dietary strategies in endometriosis
57 and lifestyle change as a method of alleviating suffering and increasing wellbeing. An
58 important finding is that the participants experienced decreased symptoms and increased
59 wellbeing after adopting an individually-adapted diet. Healthcare professionals should take
60

1
2
3 their patients' knowledge and experience into consideration, and allow patients to participate
4 in their own care. Further research is necessary to give evidenced-based dietary advices in
5 endometriosis.
6
7
8
9

10 **Acknowledgements**

11
12 We would like to thank the forum administrators who allowed us to advertise this study, and
13 the participants who shared their experiences of health after dietary changes.
14
15
16
17

18 **Contributors**

19
20 All authors contributed to this article, and all have approved the final manuscript. JVK and
21 AP were involved in the design of the study and analysis of the data; JVK performed the
22 recruitment and data collection and drafted the manuscript. HP scrutinised the result and also
23 contributed to the manuscript. All authors (JVK, AP, and HP) took part in the writing process
24 and performed critical revisions of the manuscript.
25
26
27
28
29

30 **Funding**

31
32 This work was supported by the local research and development board for Fyrbodol. This
33 financial partner had no involvement in the preparation of this article, the analysis or
34 interpretation of the data, or the decision to submit this article for publication.
35
36
37
38
39

40 **Competing interests**

41
42 None declared.
43
44
45
46
47

48 **Patient consent for publication**

49
50 Not required.
51

52 **Ethics approval**

53
54 The study was approved by the Regional Ethics Committee of Gothenburg (ref: 889-16).
55
56
57
58
59
60

Data sharing statement

The qualitative interview data used to support the findings of this study have not been made available due to the sensitivity of the subject matter and risk of identifying the participants.

For peer review only

References

1. Morassutto C, Monasta L, Ricci G, et al. Incidence and estimated prevalence of endometriosis and adenomyosis in Northeast Italy: a data linkage study. *PLoS One* 2016;11(4):e0154227.
2. Ballard KD, Seaman HE, de Vries CS, et al. Can symptomatology help in the diagnosis of endometriosis? Findings from a national case-control study – Part 1. *BJOG* 2008;115(11):1382-91.
3. Giudice LC, Kao LC. Endometriosis. *Lancet* 2004;364(9447):1789-99.
4. Dunselman GA, Vermeulen N, Becker C, et al. ESHRE guideline: management of women with endometriosis. *Hum Reprod* 2014;29(3):400-12.
5. Young K, Kirkman M, Holton S, et al. Fertility experiences in women reporting endometriosis: findings from the Understanding Fertility Management in Contemporary Australia survey. *Eur J Contracept Reprod Health Care* 2018;23(6):434-40.
6. Rush G, Misajon R. Examining subjective wellbeing and health-related quality of life in women with endometriosis. *Health Care Women Int* 2018;39(3):303-21.
7. Facchin F, Barbara G, Saita E, et al. Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J Psychosom Obstet Gynaecol* 2015;36(4):135-41.
8. Sperschneider ML, Hengartner MP, Kohl-Schwartz A, et al. Does endometriosis affect professional life? A matched case-control study in Switzerland, Germany and Austria. *BMJ Open* 2019;9(1):e019570.
9. Jones G, Jenkinson C, Kennedy S. The impact of endometriosis upon quality of life: a qualitative analysis. *J Psychosom Obstet Gynaecol* 2004;25(2):123-33.
10. Streuli I, de Ziegler D, Santulli P, et al. An update on the pharmacological management of endometriosis. *Expert Opin Pharmacother* 2013;14(3):291-305.
11. O'Hara R, Rowe H, Fisher J. Self-management in condition-specific health: a systematic review of the evidence among women diagnosed with endometriosis. *BMC Womens Health* 2019;19(1):80.
12. MacKichan F, Paterson C, Henley WE, et al. Self-care in people with long term health problems: a community based survey. *BMC Fam Pract* 2011;12:53.
13. Buggio L, Barbara G, Facchin F, et al. Self-management and psychological-sexological interventions in patients with endometriosis: strategies, outcomes, and integration into clinical care. *Int J Womens Health* 2017;9:281-93.
14. Seear K. The third shift: Health, work and expertise among women with endometriosis. *Health Sociology Review* 2009;18(2):194-206.
15. Roomaney R, Kagee A. Coping strategies employed by women with endometriosis in a public health-care setting. *J Health Psychol* 2016;21(10):2259-68.
16. Huntington A, Gilmour JA. A life shaped by pain: women and endometriosis. *J Clin Nurs* 2005;14(9):1124-32.
17. Moradi M, Parker M, Sneddon A, et al. Impact of endometriosis on women's lives: a qualitative study. *BMC Womens Health* 2014;14:123.
18. Armour M, Sinclair J, Chalmers KJ, et al. Self-management strategies amongst Australian women with endometriosis: a national online survey. *BMC Complement Altern Med* 2019;19(1):17.
19. Pujol LA, Monti DA. Managing cancer pain with nonpharmacologic and complementary therapies. *J Am Osteopath Assoc* 2007;107(12 Suppl 7):ES15-21.

- 1
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10
 - 11
 - 12
 - 13
 - 14
 - 15
 - 16
 - 17
 - 18
 - 19
 - 20
 - 21
 - 22
 - 23
 - 24
 - 25
 - 26
 - 27
 - 28
 - 29
 - 30
 - 31
 - 32
 - 33
 - 34
 - 35
 - 36
 - 37
 - 38
 - 39
 - 40
 - 41
 - 42
 - 43
 - 44
 - 45
 - 46
 - 47
 - 48
 - 49
 - 50
 - 51
 - 52
 - 53
 - 54
 - 55
 - 56
 - 57
 - 58
 - 59
 - 60
20. Saguyod SJU, Kelley AS, Velarde MC, et al. Diet and endometriosis-revisiting the linkages to inflammation. *J Endometriosis Pelvic Pain Disorders* 2018;10(2):51-58.
21. Fjerbaek A, Knudsen UB. Endometriosis, dysmenorrhea and diet--what is the evidence? *Eur J Obstet Gynecol Reprod Biol* 2007;132(2):140-7.
22. Parazzini F, Vigano P, Candiani M, et al. Diet and endometriosis risk: a literature review. *Reprod Biomed Online* 2013;26(4):323-36.
23. Trabert B, Peters U, De Roos AJ, et al. Diet and risk of endometriosis in a population-based case-control study. *Br J Nutr* 2011;105(3):459-67.
24. Missmer SA, Chavarro JE, Malspeis S, et al. A prospective study of dietary fat consumption and endometriosis risk. *Hum Reprod* 2010;25(6):1528-35.
25. Heard ME, Melnyk SB, Simmen FA, et al. High-Fat diet promotion of endometriosis in an immunocompetent mouse model is associated with altered peripheral and ectopic lesion redox and inflammatory status. *Endocrinology* 2016;157(7):2870-82.
26. Trabert B, Peters U, De Roos AJ, et al. Diet and risk of endometriosis in a population-based case-control study. *Br J Nutr* 2011;105(3/4):459-67 9p.
27. arazzini F, Chiaffarino F, Surace M, et al. Selected food intake and risk of endometriosis. *Hum Reprod* 2004;19(8):1755-9.
28. Matalliotakis IM, Cakmak H, Fragouli YG, et al. Epidemiological characteristics in women with and without endometriosis in the Yale series. *Arch Gynecol Obstet* 2008;277(5):389-93.
29. Harris HR, Chavarro JE, Malspeis S, et al. Dairy-food, calcium, magnesium, and vitamin D intake and endometriosis: a prospective cohort study. *Am J Epidemiol* 2013;177(5):420-30.
30. Darling AM, Chavarro JE, Malspeis S, et al. A prospective cohort study of Vitamins B, C, E, and multivitamin intake and endometriosis. *J Endometriosis* 2013;5(1):17-26.
31. Heilier JF, Donnez J, Nackers F, et al. Environmental and host-associated risk factors in endometriosis and deep endometriotic nodules: a matched case-control study. *Environ Res* 2007;103(1):121-9.
32. Covens AL, Christopher P, Casper RF. The effect of dietary supplementation with fish oil fatty acids on surgically induced endometriosis in the rabbit. *Fertil Steril* 1988;49(4):698-703.
33. Berube S, Marcoux S, Maheux R. Characteristics related to the prevalence of minimal or mild endometriosis in infertile women. Canadian Collaborative Group on Endometriosis. *Epidemiology* 1998;9(5):504-10.
34. Grodstein F, Goldman MB, Ryan L, et al. Relation of female infertility to consumption of caffeinated beverages. *Am J Epidemiol* 1993;137(12):1353-60.
35. Savaris AL, do Amaral VF. Nutrient intake, anthropometric data and correlations with the systemic antioxidant capacity of women with pelvic endometriosis. *Eur J Obstet Gynecol Reprod Biol* 2011;158(2):314-8.
36. Hansen SO, Knudsen UB. Endometriosis, dysmenorrhoea and diet. *Eur J Obstet Gynecol Reprod Biol* 2013;169(2):162-71.
37. Marshall C, Rossman GB. *Designing Qualitative Research*. 6th ed. Thousand Oaks, CA: Sage 2016.
38. Denzin NK, Lincoln YS. *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage 1994.
39. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101.
40. Creswell JW, ed. *Research Design : Qualitative, Quantitative, and Mixed Methods approaches*. 2nd ed. Thousand Oaks,CA: Sage 2003.

- 1
- 2
- 3
- 4 41. Noble H, Smith J. Issues of validity and reliability in qualitative research. *Evid Based Nurs* 2015;18(2):34-5.
- 5
- 6 42. Marziali M, VENZA M, Lazzaro S, et al. Gluten-free diet: a new strategy for
- 7 management of painful endometriosis related symptoms? *Minerva Chir*
- 8 2012;67(6):499-504. [
- 9 43. Sesti F, Pietropolli A, Capozzolo T, et al. Hormonal suppression treatment or dietary
- 10 therapy versus placebo in the control of painful symptoms after conservative surgery
- 11 for endometriosis stage III-IV. A randomized comparative trial. *Fertil Steril*
- 12 2007;88(6):1541-7.
- 13 44. Moore JS, Gibson PR, Perry RE, et al. Endometriosis in patients with irritable bowel
- 14 syndrome: specific symptomatic and demographic profile, and response to the low
- 15 FODMAP diet. *Aust N Z J Obstet Gynaecol* 2017;57(2):201-05.
- 16 45. Mier-Cabrera J, Aburto-Soto T, Burrola-Mendez S, et al. Women with endometriosis
- 17 improved their peripheral antioxidant markers after the application of a high
- 18 antioxidant diet. *Reprod Biol Endocrinol* 2009;7:54.
- 19 46. Souza CA, Oliveira LM, Scheffel C, et al. Quality of life associated to chronic pelvic
- 20 pain is independent of endometriosis diagnosis--a cross-sectional survey. *Health Qual*
- 21 *Life Outcomes* 2011;9:41.
- 22 47. Sepulcri Rde P, do Amaral VF. Depressive symptoms, anxiety, and quality of life in
- 23 women with pelvic endometriosis. *Eur J Obstet Gynecol Reprod Biol* 2009;142(1):53-
- 24 6.
- 25 48. Brulde B. On how to define the concept of health: a loose comparative approach. *Med*
- 26 *Health Care Philos* 2000;3(3):305-8.
- 27 49. Bohn L, Storsrud S, Liljebo T, et al. Diet low in FODMAPs reduces symptoms of
- 28 irritable bowel syndrome as well as traditional dietary advice: a randomized controlled
- 29 trial. *Gastroenterology* 2015;149(6):1399-407.e2.
- 30 50. Cox H, Henderson L, Wood R, et al. Learning to take charge: women's experiences of
- 31 living with endometriosis. *Complement Ther Nurs Midwifery* 2003;9(2):62-8.
- 32 51. Cox H, Henderson L, Andersen N, et al. Focus group study of endometriosis: struggle,
- 33 loss and the medical merry-go-round. *Int J Nurs Pract* 2003;9(1):2-9.
- 34 52. Apers S, Dancet EAF, Aarts JWM, et al. The association between experiences with
- 35 patient-centred care and health-related quality of life in women with endometriosis.
- 36 *Reprod Biomed Online* 2018;36(2):197-205.
- 37 53. Bourdel N, Chauvet P, Billone V, et al. Systematic review of quality of life measures
- 38 in patients with endometriosis. *PLoS One* 2019;14(1):e0208464.
- 39 54. Howarth M, Warne T, Haigh C. Pain from the inside: understanding the theoretical
- 40 underpinning of person-centered care delivered by pain teams. *Pain Manag Nurs*
- 41 2014;15(1):340-8.
- 42 55. Masi AT, White KP, Pilcher JJ. Person-centered approach to care, teaching, and
- 43 research in fibromyalgia syndrome: justification from biopsychosocial perspectives in
- 44 populations. *Semin Arthritis Rheum* 2002;32(2):71-93.
- 45 56. Kvale S. Interviews: An Introduction to Qualitative Research interviewing: Thousand
- 46 Oaks, CA: Sage 1996.
- 47 57. Qu SQ, Dumay J. The qualitative research interview". *Qual Res Account Manag*
- 48 2011;8(3):238-64.
- 49 58. Trainor AA, Graue E, eds. Reviewing Qualitative Research in the Social Sciences.
- 50 New York: Routledge 2013.
- 51 59. Ulin PR, Robinson ET, Tolley EE. Qualitative Methods in Public Health : A Field
- 52 Guide for Applied Research. Hoboken, NJ: Wiley 2012.
- 53
- 54
- 55
- 56
- 57
- 58
- 59
- 60

- 1
2
3 60. Sullivan JR. Skype: an appropriate method of data collection for qualitative
4 interviews? *Hilltop Review* 2012;6(1):54-60.
5 61. Iacono V, Symonds P, Brown D. Skype as a tool for qualitative research interviews.
6 *Soc Res Online* 2016;21(2):1-15.
7 62. Seitz S. Pixilated partnerships, overcoming obstacles in qualitative interviews via
8 Skype: a research note. *Qual Res* 2016;16(2):229-35.
9 63. Whitaker C, Stevelink S, Fear N. The use of facebook in recruiting participants for
10 health research purposes: A Systematic Review. *J Med Internet Res* 2017;19(8):e290.
11 64. Im EO, Lee SH, Liu Y, et al. A national online forum on ethnic differences in cancer
12 pain experience. *Nurs Res* 2009;58(2):86-94.
13 65. De Graaff AA, Dirksen CD, Simoens S, et al. Quality of life outcomes in women with
14 endometriosis are highly influenced by recruitment strategies. *Hum Reprod*
15 2015;30(6):1331-41.
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Appendix 1 General Advertisement in the forums

General Advertisement in the forums

ENDOMETRIOSIS STUDY

Request made with the approval of the administrator.

University of Gothenburg
Sahlgrenska Academy
Department of Health Sciences and Health
Box 457
40 503 Gothenburg

The study is about the how persons with endometriosis experienced their health after dietary changes.

Endometriosis, a chronic gynecological disease, affects about 10% of people with female genitalia in childbearing age. The treatment currently available is aimed at reducing symptoms, preventing progression and recurrence of the disease and, if possible, improving fertility. Today's treatment, hormonal and / or surgical treatment is not always effective for all people with endometriosis and many often experience symptoms after completed treatment. The diet and its composition are important for health and can both promote good health and prevent disease. It appears that people with endometriosis use complementary or alternative treatments, for example. dietary changes to improve one's health. This study aims to explore the experience of health following dietary changes in people with endometriosis.

You are hereby invited to this interview study to share how you experience health following dietary changes in endometriosis. To participate you need to be 18 years of age and have the diagnosis of endometriosis prescribed by a doctor. The study is about dietary changes and experience of health in endometriosis and therefore you must not have the diagnoses diabetes, celiac disease or inflammatory bowel disease (Crohn's disease, Ulcerative colitis).

Participation in the study is completely voluntary and you have the opportunity to cancel your participation at any time. Your answers and your results will be processed so that unauthorized persons cannot access them. Research data will be stored for at least 10 years to allow for review of the material, even if you cancel your participation. No financial compensation will be paid.

Jenny Vennberg Karlsson is conducting the study and is a legitimate midwife and works in primary care in Västra Götaland. The interview study is part of my master's thesis / master in reproductive and perinatal health at the University of Gothenburg. The supervisor responsible for the study is my supervisor Åsa Premberg, a qualified midwife and university lecturer.

If you have any further questions regarding this study or are interested in participating in the study, you are most welcome to contact the project manager.

Sincerely

Project manager: Jenny Vennberg Karlsson

Email: gusvennb@student.gu.se

Phone: 0763 189 562

Supervisor / Principal: Åsa Premberg

Email: asa.premberg@gu.se

Phone: 031 786 6087

Appendix 2 Interview guide

Interview guide

The initial interview question was:

Will you please tell me about your experiences of health after the dietary change?

If the subjects below not where mentioned spontaneously, the interview person was asked about:

Information about dietary change

Pain and other symptoms

Menstruation

Health

Work/school

Relationships

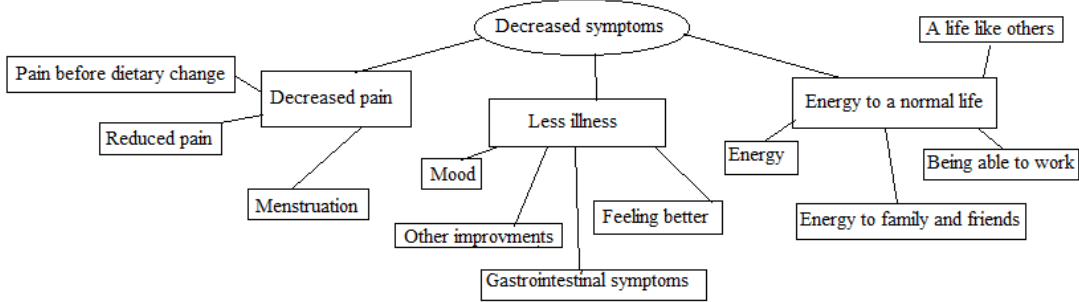
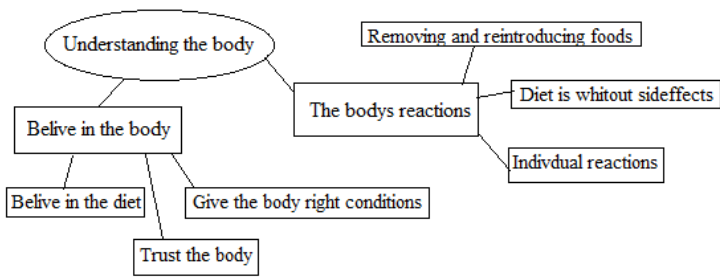
Relationship with a partner

Other changes

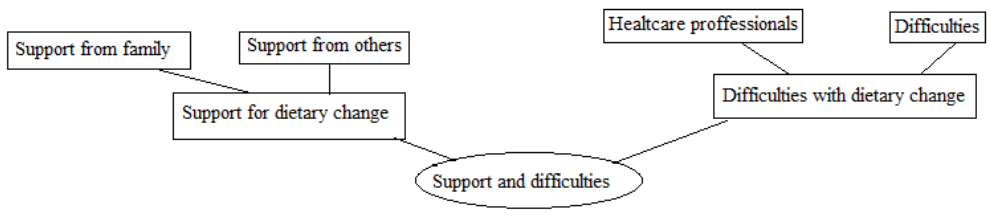
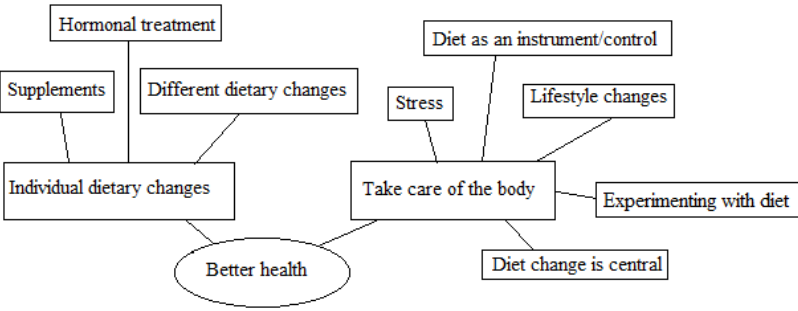
Do you have anything else to add that I did not ask about?

Appendix 3 The thematic maps develop during the thematic analysis based on the conceptual framework proposed by Braun & Clarke

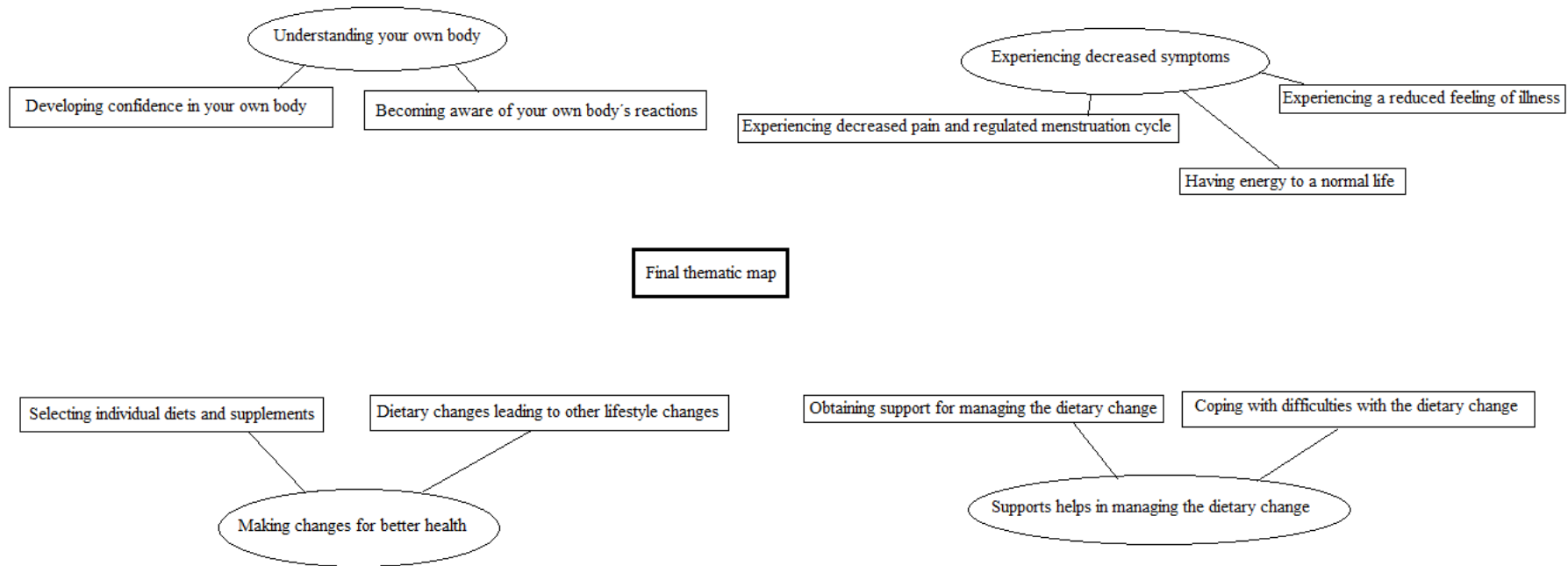
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46



Developed thematic map



Appendix 3 The thematic maps develop during the thematic analysis based on the conceptual framework proposed by Braun & Clarke



SRQR: checklist to BMJ Open

	Page
Title and abstract	
S1 Title Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1
S2 Abstract Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	2
Introduction	
S3 Problem formulation Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	5
S4 Purpose or research question Purpose of the study and specific objectives or questions	5
Methods	
S5 Qualitative approach and research paradigm Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale	6-7
S6 Researcher characteristics and reflexivity Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	6-7
S7 Context Setting/site and salient contextual factors; rationale	6-7
S8 Sampling strategy How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	6, 14
S9 Ethical issues pertaining to human subjects Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7, 17
S10 Data collection methods Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, Iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	6-7
S11 Data collection instruments and technologies Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	6-7
S12 Units of study Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	6-7
S13 Data processing Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	6-7
S14 Data analysis Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	7
S15 Techniques to enhance trustworthiness Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	6-7
Results/findings	
S16 Synthesis and interpretation Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	7-12
S17 Links to empirical data Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	7-12
Discussion	
S18 Integration with prior work, implications, transferability, and contribution(s) to the field Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	12-15
S19 Limitations Trustworthiness and limitations of findings	14-15
Other	
S20 Conflicts of interest Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	16
S21 Funding Sources of funding and other support; role of funders in data collection, interpretation, and reporting	16