

BMJ Open Experiences of health after dietary changes in endometriosis: a qualitative interview study

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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 12 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 to 44 were recruited from two Swedish endometriosis support forums on the Internet.

Results Participants experienced an increase in well-being 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 well-being. An important finding is that the participants experienced decreased symptoms and increased well-being 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.

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

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 organisation 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.

reproduction organs, such as uterus 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, dysmenorrhoea, 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% to 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, 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 focussing on a healthy diet free from dairy, wheat¹⁴ 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 focussing 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 participants' lived experience of the phenomenon of interest.³⁷

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. Membership of these forums was by application only, and was granted to the first author on request. Initially a general advertisement (online supplementary appendix 1) was placed in all three forums, but only a few persons agreed to take part in the study. Next, a direct invitation was sent to 50 randomly selected 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. The participants who responded to the advertisement all came from the two forums with a connection to diet, the forum with general topics did not generate any participants. 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 more 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 participants drawn from the forums, two were excluded from the study because they failed to attend the interview. A pilot interview was also conducted with a person with endometriosis who was known to the interviewer and who had made dietary changes. 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 and 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 their intake of different kinds of foods, or adding or removing foods in their daily diet. In this study we defined dietary change as a change of diet from one's previous diet.

Data were collected via semi-structured interviews using an interview guide (online supplementary 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 in their own words, and follow-up questions were used to clarify any unclear descriptions. Recapitulation was used with individuals who stopped talking; directing them back to previous comments to clarify or elaborate on any descriptions. Credibility was ensured by establishing a trusting and confidential relationship with the participants, and through use of referential adequacy via audio tape-recording.³⁸ The interviews were performed between November 2016 and June 2017 by one of the authors (JVK), with the locations chosen by the participants: in the participant's home (n=2), at the participant's workplace/school (n=2), by phone (n=1) and via online interview with voice and video link (n=7).

The interviews were conducted in Swedish, were digitally recorded and lasted between 32 and 64 min.

Data analysis

All interviews were transcribed verbatim and analysed using thematic analysis.³⁹ The research team consisted of two midwives, (JVK and AP) and a registered nurse (HP). The analysis was data-driven, based on the Swedish transcript and performed inductively by two researchers (JVK and AP) on the basis of the conceptual framework proposed by Braun and Clarke.³⁹ 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 subthemes and themes (online supplementary appendix 3). 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, 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 essential meaning of each theme. Annotations and memos were used to record ideas, reflections and coding decisions to support trustworthiness.⁴⁰ To further establish the trustworthiness of the analysis,⁴¹ the third researcher (HP) performed a scrutiny of the results and has made critical revisions of the manuscript together with the other researchers (JVK and AP).

Ethical considerations

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

RESULTS

Twelve persons with endometriosis who had made individual dietary changes were interviewed. Their ages ranged from 28 to 44 years, their time since endometriosis diagnosis from 0.5 to 17 years and the time since initiating dietary change from 2 months to 3.5 years. Eight of the participants had no hormonal treatment at the time of the interview, two had a hormonal intrauterine device (Mirena), one used progestogen-only pills (Cerazette) and one used natural progesterone. Their education background varied, including secondary school, further education and university education (table 1).

The thematic analyses of the data identified four main themes and nine subthemes. The four main themes were

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

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, omega-3, 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 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 also experienced a better effect from the diet changes when I made lifestyle changes too. (IP1)

Stress was considered to affect health negatively and to decrease the effects of dietary change. They emphasised that stress had a substantial effect on their 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 the stress'. To minimise hormonal effects, some participants stopped using hormone-disturbing products, such as parabens. Ecological and natural products were preferred, and they wanted to 'get rid of as many chemicals as possible'.

...I have sometimes noticed that walking or exercising have relieved (the pain) a little bit. (IP4)

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

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

Understanding your own body

Becoming aware of your own body's reactions

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

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

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

Developing confidence in your own body

The participants' experiences of positive and negative bodily responses to dietary changes made them feel that they could trust and believe in the dietary change and their bodies: 'I believe in the diet'. They considered that

the body could function more optimally if it was given the right conditions via necessary nutrients in the diet.

...I look at my endometriosis...as a symptom of something not working properly in my body, and then make sure I give my body all the conditions to feel as good as possible, so maybe it can...get well on its own. (IP1)

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

...began to eat (the person went back to eating as before the dietary changes)...still vegan but sugar, gluten, everything I'd taken away earlier...and in 2 weeks, I went back to not being able to get out of bed again (painful symptoms re-emerged). (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 participants reported that pain decreased or disappeared. For some participants, menstruation no longer produced the previous symptoms, and arrived 'without any premonition'. The reduced pain was described as ordinary pain, and the use of pain medication decreased. One person said that trying out a general diet low in fermentable oligo-, di-, mono-saccharides and polyols (FODMAPs) did not improve endometriosis symptoms and changed the strategy and started to make own individual dietary changes instead.

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, and menstruation came regularly every month.

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 in 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 normalised, and the body felt more comfortable when the stomach was 'functioning better'.

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

Dietary changes also affected mood. The pain previously had a negative impact in the form of '(making) you grumpy'. After the dietary change the participants became happier, had more patience and could trust their feelings.

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

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

Having the energy to live a normal life

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

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

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

...(The dietary change) enabled me to actually continue to work and...live a decent normal life... (IP1)

Support helps in managing the dietary change

Obtaining support for the dietary change

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

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

Family members could be supportive by understanding the dietary change, by talking about it and by helping to explain it to other people. They could also give financial help, for example by paying for expensive supplements.

When family members saw positive results from the change, this made them more engaged and they continued to support it. Support also came from co-workers and friends, who adapted to the new circumstances.

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

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

Coping with difficulties and lack of support 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 in a 'social context' 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 way was just to eat at home. They were 'not invited' to things as often as before. Social norms around food made some of the participants feel odd; from a norm perspective, it would have been easier just to eat in the same way as everybody else. Other participants felt that many people 'eat differently' and that it did not matter to them what other people thought about their diet. Another difficulty was the weak or non-existent support from HCPs. Although HCPs expressed interest in the dietary change, the participants' experiences were dominated by a lack of interest from HCPs. The participants wanted there to be a 'shorter gap' between their own desires and knowledge and those of the HCPs.

...in the healthcare systems 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 effects of 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 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 scratch with 'clean' ingredients. These results are in line with the findings of other studies showing that diet can influence the symptoms of endometriosis.^{42–44} 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.⁴² A study comparing diet treatment, hormonal treatment and placebo after conservative surgery found that diet and postoperative treatment with hormones were both effective in reducing painful symptoms from endometriosis.⁴³ Another study showed that an increased intake of antioxidants produced decreased oxidative stress, which affects inflammation.⁴⁵

Several studies have reported that pain is a major symptom in endometriosis, and one that affects both health and quality of life.^{46 47} Tiredness and fatigue are also common symptoms.⁴ Quality of life can be influenced by both physical and psychological factors.⁴⁸ 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.⁴⁹ An Australian study showed that a low-FODMAP diet could reduce bowel symptoms in people with endometriosis.⁴⁴ Improvements in clinical status and organ function affect the experience of health and quality of life.⁴⁸ 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 the pain can be severe. The experience of this has been described as the pain is 'taking away their life'.⁹ In this study the participants described their pain as intense and disabling before the dietary change. After the change they experienced positive and negative bodily responses which made them feel that they could trust and believe in the dietary change and their bodies. This echoes the findings of earlier research that states that recognising symptoms and patterns can be one path to taking control and regaining quality of life for persons with endometriosis.⁵⁰ Several have described how the use of that complementary therapies has allowed persons with endometriosis to take control of their own symptom management.^{14 16 50 51}

A person's motor, cognitive and sensory ability could influence their possibility to live a normal life.⁴⁸ After dietary changes, the participants in this study experienced an increased level of energy in the form of improved ability to do household chores, socialise 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, as an increased experience of health can be achieved via an increased ability to perform. Fitness, energy and wakefulness all influence a person's possibility to make use of their abilities.⁴⁸ 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.⁴⁸

An important finding in this study is that the participants described that support from family, friends and society as being important for the implementation and maintenance of their dietary changes. They also described a lack of support from HCPs. This suggests that support from HCPs may make it even easier to continue with dietary changes and maintain health. In this context, person-centred 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 HCPs pay attention to continuity, respect and individual preferences.⁵² If HCPs 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 HCPs to evaluate HRQoL in persons with endometriosis.⁵³ Listening to the patient enables the development of a partnership which helps them to manage and regain control over pain, and is crucial in empowering them to take an active part in decisions about their own care planning.⁵⁴ One study showed that a person-centred 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. HCPs play an important role in empowering the patients to achieve better coping abilities, improved self-management and control of aggravating factors.⁵⁵

Strengths and limitations

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

One limitation of the study might be the number of participants, but although 12 participants may seem to be a low number, it was considered sufficient. Saturation was reached, and no new insights emerged during the last

few interviews. One indication that the data has reached saturation and have been thoroughly examined is that no new themes or points in need of further exploration emerge from the recursive process of data collection and analysis.⁵⁸ A large study sample is not suited to meet the aim of qualitative studies, since a large set of data will not necessarily strengthen the data analysis.⁵⁶

One strength of this study is that the participants varied in age and geographical area (Region Västra Götaland and the eastern part of Central Sweden). The aim of this qualitative research was to understand how persons with endometriosis experienced their health after dietary changes. Hence, a small number of participants who maximised the diversity relevant to the research question were selected, with a variation in age and geographical area.⁵⁹

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

A weakness of the study is that it only reflects the experiences of health among persons with endometriosis who had completed tertiary education and who experienced an increased health after dietary changes. The Internet support forums also included members who did not experience any positive advantages from dietary changes, but they were not interested in participating in the study. Persons who choose to participate in a forum concerned with diet might have a more positive attitude towards dietary changes. This was a weakness of the study, since it is unlikely that persons who did not experience any difference from dietary changes would have continued to use the support forum.

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

The choice to seek interviewees in Internet forums with a connection to diet was a strength, since such interviewees can typify and shed light on the object of the study. In qualitative sampling, purposiveness is a strategic approach to identify and gain access to those who can teach you the most about your topic.⁵⁹ There is growing evidence to suggest that the Internet is a successful

recruitment tool, and that health researchers should therefore consider using it. Benefits include reduced cost, shorter recruitment periods, better representation and improved participant selection. This may spell the end for traditional methods, although currently the minor limitations of the need for Internet access and the over-representation of young white women may make its use inappropriate in some settings.⁶³ Other researchers have used this method and found it usable within clinical implications in cancer pain.⁶⁴ Recruiting from Internet forums was considered to be an effective strategy, as the members there had experienced dietary changes in endometriosis. However, this form of recruitment might also be a weakness in comparison to recruiting via an association, since persons participating in the latter might have severe symptoms comparable to those in tertiary care and a longer delay for diagnosis than persons in secondary and tertiary care. Women recruited via a patient association reported a larger disease burden, similar to those in tertiary care, emphasising the need for care when interpreting studies conducted within the sole confines of a disease-specific patient organisation.⁶⁵

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

CONCLUSION

This study contributes to filling the knowledge gap about dietary strategies in endometriosis and lifestyle change as a method of alleviating suffering and increasing well-being. An important finding is that the participants experienced decreased symptoms and increased well-being 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.

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Contributors All authors contributed to this article, and all have approved the final manuscript. JVK and AP were involved in the design of the study and analysis of the data; JVK performed the recruitment and data collection and drafted the manuscript. HP scrutinised the result and also contributed to the manuscript. All authors (JVK, AP and HP) took part in the writing process and performed critical revisions of the manuscript.

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Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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ORCID iDs

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