

ARTICLE

A better quality of life could be achieved by applying the endometriosis diet: a cross-sectional study in Dutch endometriosis patients



BIOGRAPHY

Annelotte van Haaps is a PhD candidate at the Amsterdam UMC, the Netherlands. Annelotte is dedicated to performing research in the field of benign gynaecology and reproductive medicine. Her research focuses on pain management in chronic endometriosis and during fertility treatment.

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KEY MESSAGE

Women with self-reported endometriosis adhering to the endometriosis diet reported higher quality of life scores. This effect was even higher when strict adherence to the endometriosis diet was reported. Future studies should aim to identify the facilitators and barriers to dietary adjustments in endometriosis patients.

ABSTRACT

Research question: Does the endometriosis diet positively affect quality of life (QoL) in women diagnosed with endometriosis?

Design: A cross-sectional study was performed, recruiting women using the website and online peer platforms from the Dutch Endometriosis Society. In total, 211 women with a self-reported diagnosis of endometriosis were included in the study. They completed a questionnaire on the six QoL domains based on the conversation tool 'My Positive Health'. Women who adhered to the endometriosis diet were compared with women who did not. A distinction was made between strict (score ≥ 8 on a scale of 0–10) and less strict adherence to the diet.

Results: A significantly higher score was seen in all six QoL domains in women who adhered to the endometriosis diet ($n = 90$) compared with women who did not ($n = 121$) (range $P < 0.001$ to $P = 0.043$). Furthermore, women with strict adherence ($n = 48$) compared to less strict adherence ($n = 42$) reported significantly higher scores in all six QoL domains (range $P = 0.005$ to 0.05). Women diagnosed with endometriosis more than 10 years ago ($n = 13$) adhered to the endometriosis diet significantly less often than women that were diagnosed more recently ($n = 163$; range $P = 0.005$ to 0.046).

Conclusion: The endometriosis diet was associated with a better QoL in Dutch women with endometriosis. Strict adherence showed higher QoL scores compared with less strict adherence. Therefore, more research is needed to clarify the mechanism of this beneficial effect and to identify facilitators and barriers to dietary adjustments in patients with endometriosis.

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KEYWORDS

Diet
Endometriosis
Quality of life

INTRODUCTION

Endometriosis is a chronic condition, affecting up to 10% of women of reproductive age worldwide (Dunselman *et al.*, 2014; Zondervan *et al.*, 2020). It is associated with cyclical symptoms such as dysmenorrhoea, dyschezia and dysuria and non-cyclical symptoms such as deep dyspareunia, chronic pelvic pain and infertility (Dunselman *et al.*, 2014). Furthermore, less specific symptoms can occur such as bloating, back pain and fatigue, which have an overlap with irritable bowel syndrome (Dunselman *et al.*, 2014; Moore *et al.*, 2017). The symptoms can have a negative effect on several aspects of a patient's quality of life (QoL) and psychosocial functioning (De Graaff *et al.*, 2013). Previous cross-sectional research by these authors found that 51% of participants reported a negative effect of endometriosis on their work and career, 50% on their personal relationships and 16% on their education (De Graaff *et al.*, 2013). Additionally, endometriosis can negatively impact the patient's self-image, and contribute to feelings of powerlessness and frustration (Jones *et al.*, 2004).

There is no definitive cure for endometriosis, therefore providing adequate treatment can be challenging (Becker *et al.*, 2022). Treatment of endometriosis is based on three important principles: the reduction of pain symptoms, improvement in QoL, and prevention of disease progression and/or recurrence (Becker *et al.*, 2022; Dunselman *et al.*, 2014). Treatment usually includes adequate pain management, hormonal suppression therapy and/or surgery. In addition, women suffering from endometriosis-related infertility can undergo treatment with assisted reproductive techniques (Dunselman *et al.*, 2014). However, these treatment options are not always sufficient to reduce symptoms and can fail to optimize a patient's QoL. Also, a proportion of women experience side effects of medical treatment that may lower long-term compliance. Therefore, women with endometriosis are often searching for ways to increase their self-sufficiency. Alternative treatment methods, such as dietary interventions, are gaining interest and have been increasingly researched in recent years (Huijs and Nap, 2020).

It is postulated that certain dietary supplements might have a synergistic

effect, functioning as an anti-inflammatory, antioxidant, anti-proliferative and immunomodulatory agent. This can result in the suppression of endometriosis and its associated symptoms (Huijs and Nap, 2020; Yalcin Bahat *et al.*, 2022). Several dietary interventions have been shown to be efficient in the reduction of endometriosis symptoms such as the low FODMAP (fermentable oligo-, di-, monosaccharides and polyols) diet, the endometriosis diet, or a gluten- or lactose free diet (Armour *et al.*, 2019; Marziali *et al.*, 2012; Moore *et al.*, 2017). In 2020, a large systematic review by Nap *et al.* found that both the addition (such as omega-3 and -6, several vitamins and minerals) and the avoidance of certain nutrients (gluten, soy) was associated with a reduction of endometriosis-related symptoms (Huijs and Nap, 2020). These findings were confirmed by the systematic review by Yalcin Bahat *et al.* (2022). In addition, Marziali *et al.* (2012) found that adherence to a gluten-free diet significantly improved QoL. Finally, by adhering to a dietary intervention, with the aim of reducing symptoms, women can feel more self-sufficient and in control of their symptoms, resulting in a significantly higher reported QoL (O'Hara *et al.*, 2021; Vennberg Karlsson *et al.*, 2020).

A diet frequently applied by Dutch women experiencing endometriosis-related pain is the endometriosis diet (Krabbenborg *et al.*, 2021). This diet was developed by women diagnosed with endometriosis and is based on the avoidance of nutrients (e.g. red meat, caffeine, sugar) they noticed provoked or aggravated their symptoms. However, several variations of the diet exist and there are currently no guidelines available on its exact implementation. In this study, the objective was to determine the impact of the endometriosis diet, as recommended by the Dutch Endometriosis Society and applied by Dutch women suffering from endometriosis, on their QoL.

MATERIALS AND METHODS

Study design

A cross-sectional study was performed that included women with a self-reported diagnosis of endometriosis. Women currently adhering to the endometriosis diet were compared to women not adhering to the endometriosis diet. Women based the diet on two sources, both recommended by the Dutch

Endometriosis Society (Endometriose Stichting; the Dutch patient organization): www.endometriosedieet.nl and www.endometriosetelijf.nl. The study was initiated at the Hague University of Applied Sciences. Because there was no Medical Ethics Committee at the Hague University at the start of this study, no ethical approval could be granted.

Study population

Women were recruited from the website of the Dutch Endometriosis Society (www.endometriose.nl) and online peer platforms connected to the Dutch Endometriosis Society (Endometriosestichting 2023). Women were included in the study if they were 18 years and older. Non-Dutch speaking women were excluded from participation.

Study procedure

After women confirmed their willingness to participate in the study, they were asked to complete a digital questionnaire that was distributed using the online survey program GoogleForms[®], part of Google Workspace[®]. Basic demographics, specifics on the use of the endometriosis diet (including reasons to start or discontinue the diet and difficulties encountered when adhering to it) and the participant's QoL were assessed. Furthermore, women were asked how strict their adherence was to the endometriosis diet. They could rate themselves between 'no strict adherence at all' ('0') and 'very strict adherence' ('10'). An 11-point rating scale is considered an appropriate and validated response scale option; it is more normally distributed than a shorter response scale. Participants can discriminate well between the meanings behind 0 and 10 (Gries *et al.*, 2017).

Based on the median, a cut-off value of 8 was used to distinguish between strict and non-strict adherence to the diet. Finally, to assess QoL, the conversation tool 'My Positive Health' was incorporated into the questionnaire, consisting of 42 questions divided into six domains: physical functioning, psychological functioning, spiritual functioning, quality of life, social participation and daily functioning (Huber, 2019; Huber *et al.*, 2016; Prinsen and Terwee, 2019). Women were asked to score these six domains of their QoL, and rate them on an 11-point Likert scale. The detailed questionnaire can be found in the Supplementary Appendix.

TABLE 1 AVOIDANCE OF NUTRIENTS CONSIDERED PART OF THE ENDOMETRIOSIS DIET

Nutrient group	Examples
Red meat	Beef, pork, lamb, mutton, veal, horse, liver
Gluten	(Khorasan) wheat, rye, spelt, barley
Lactose	A sugar found in, for example, milk, cheese spreads, whey-based soft drinks, ice cream
Sugars	All added sugars; refined sugars (cane sugar, caster sugar), natural sugars (honey, palm sugar) and sweeteners (aspartame, polyols)
Nutrients high in oestrogen	Soy (soymilk, tofu, soya sprout, miso, tempeh, soy sauce, natto), linseed, sesame seeds, black beans

The endometriosis diet

The endometriosis diet is based on patient experiences, with a considerable variation in how women apply it. Avoidance of nutrients considered by the researchers as part of the endometriosis diet, was mentioned at the beginning of the questionnaire. If women felt that this specific explanation of the endometriosis diet fitted their diet, they were prompted to complete the questionnaire. The nutrients avoided as part of the endometriosis diet are shown in [TABLE 1](#).

Outcome measures

The primary outcome focused on the effect of the endometriosis diet on women’s QoL. Secondary outcomes focused on the influence of strict or less strict adherence to the endometriosis diet on QoL, the influence of time since diagnosis of endometriosis on adherence to the diet, and reasons to discontinue the endometriosis diet.

Statistical analysis

Data analysis was performed using SPSS Statistics for Windows, Version 26.0 (IBM Corp., Armonk, NY, USA). Baseline characteristics are expressed as mean values with SD or numbers with percentages. Differences in baseline characteristics were calculated using the chi-squared test. The difference between the two groups (diet versus no diet) was calculated using a linear regression. To differentiate between once adhering, never adhering and currently adhering to the endometriosis diet, dummy variables were created and analysed using a linear regression. To analyse the duration of diagnosis and the efficacy of the endometriosis diet, a logistic regression was used. Data were corrected for the following confounders: the participant’s age, severity (grade) of endometriosis and duration of diet adherence. A P-value of ≤ 0.05 was considered statistically significant.

RESULTS

Between 9 April and 22 April 2019, a total of 212 questionnaires were collected. However, one participant completed the questionnaire twice and so a total of 211 participants were included in the study. Participant recruitment is shown in [FIGURE 1](#).

Ninety out of 211 participants adhered to the endometriosis diet. Of the 121 participants that currently did not adhere to the endometriosis diet, 27 women previously had done. No statistically significant differences were seen in baseline characteristics of the diet users versus the non-users. All patient characteristics are presented in [TABLE 2](#).

Participants were asked to score the six domains of their QoL. Participants who applied the endometriosis diet scored significantly higher on all QoL domains (range $P < 0.001$ to $P = 0.043$) than participants who did not apply the diet ([TABLE 3](#)).

Women once adhering to the diet but that had discontinued it previously, and women currently adhering to the diet, were compared to women who never adhered to the endometriosis diet. Only women currently adhering to the diet reported significantly higher scores in the six QoL domains (range $P < 0.000$ to $P = 0.040$), compared to women that had never used the diet. There was no significant difference between women once adhering to the diet and women that had never adhered to the diet ([TABLE 4](#)).

Participants with strict adherence to the diet (based on the median value with a cut-off score ≥ 8) reported a significantly higher score in all six domains of their QoL (range $P = 0.005$ to 0.050) compared to participants with less strict adherence to the diet ([TABLE 5](#)).

Compared to women that were diagnosed with endometriosis more than 10 years ago, women that were diagnosed less than a year ago ($P = 0.046$), 1.1 to 5 years ($P = 0.025$) or 5.1 to 10 years ago ($P = 0.005$) adhered to the endometriosis diet significantly more often ([TABLE 6](#)).

Finally, relevant results were found from the open-ended questions. When asking participants that did not adhere to the endometriosis diet why they did not, they most frequently reported that they were unfamiliar with the diet (39%) or that the

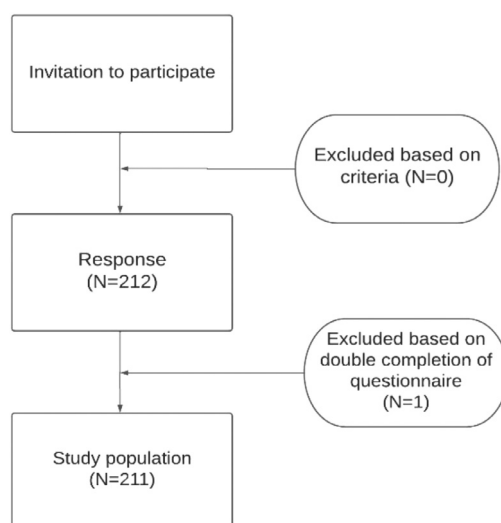


FIGURE 1 Patient recruitment.

TABLE 2 BASELINE CHARACTERISTICS IN ENDOMETRIOSIS DIET USERS COMPARED WITH NON-USERS

Patient characteristic	Endometriosis diet (n = 90)	No endometriosis diet (n = 121)	Total (n = 211)	P-value
Age in years, mean (SD)	35.9 (6.88)	35.8 (7.64)	35.9 (7.31)	0.90
Adherence to diet (score 1–10)				
Score 1–7	42 (46.7)	–	–	
Score 8–10	48 (53.3)	–	–	
Previous adherence to the diet	0 (0)	27 (22.3)	27 (12.8)	
Years since diagnosis				
0–1	16 (17.8)	20 (16.5)	36 (17.1)	0.067
1.1–5	34 (37.8)	42 (34.7)	76 (36.0)	
5.1–10	27 (30)	24 (19.8)	51 (24.2)	
>10	13 (14.4)	35 (28.9)	48 (22.7)	
Grade of endometriosis				
ASRM grade I	6 (6.7)	4 (3.3)	10 (4.7)	0.79
ASRM grade II	3 (3.3)	3 (2.5)	6 (2.8)	
ASRM grade III	10 (11.1)	14 (11.6)	24 (11.4)	
ASRM grade IV	41 (45.6)	54 (44.6)	95 (45.0)	
Unknown	30 (33.3)	46 (38.0)	76 (36.0)	

Data are presented as n (%) unless otherwise stated.

complexity (31%) played an important role in not implementing the endometriosis diet (FIGURE 2). Participants that had adhered to the diet in the past often discontinued the diet because they experienced no positive results (56%) or found it too complex to use (22%) (FIGURE 3).

DISCUSSION

This study provides an assessment of the impact of the endometriosis diet on QoL in Dutch women with endometriosis. It was found that using the endometriosis diet as a self-management strategy had a beneficial effect on the QoL in women diagnosed with endometriosis. This

positive effect was even stronger when there was strict adherence to the diet. This is in line with the finding by *Marziali et al. (2012)* that the use of a gluten-free diet in women with endometriosis resulted in significantly higher scores in all QoL domains. The effectiveness of both diets can possibly be explained by the fact that they influence endometriosis by causing an anti-inflammatory, antioxidant and anti-oestrogenic effect. This is especially achieved by the removal of gluten, dairy or soy, as well as the addition of vegetables, which are all associated with a decrease in endometriosis-related pain symptoms (*Huijs and Nap, 2020*).

In contrast to the current results, *Krabbenborg et al. (2021)* reported no

significant impact of various dietary interventions (i.e. the endometriosis diet, Low FODMAP diet, a gluten-free diet and a low-carbohydrate diet) on QoL in women diagnosed with endometriosis. However, 71.3% of their studied dietary adjustments were reported by women to contribute to the reduction of their chronic endometriosis symptoms (*Krabbenborg et al., 2021*). An explanation might be that experiencing more control over endometriosis symptoms through self-management can be a contributing factor to the effectiveness of the endometriosis diet.

The need for self-management is fuelled by the severity of endometriosis, the lack of curative treatment and its impact on

TABLE 3 SCORES IN THE SIX DOMAINS OF QUALITY OF LIFE (QOL) FOR ENDOMETRIOSIS DIET USERS COMPARED WITH NON-USERS

QoL domain	Mean scores in the six QoL domains		Average difference (diet versus no diet) with 95% confidence interval	Significance P-value ^a
	Endometriosis diet (n = 90)	No diet (n = 121)		
Physical functioning	6.33	5.27	1.06 (0.60–1.53)	<0.001
Psychological functioning	7.36	6.74	0.63 (0.27–0.98)	0.001
Spiritual functioning	7.68	7.14	0.55 (0.15–0.94)	0.007
Quality of life	7.47	7.07	0.40 (0.01–0.78)	0.043
Social participation	8.29	7.63	0.66 (0.25–1.06)	0.002
Daily functioning	8.11	7.42	0.70 (0.30–1.09)	0.001

^a Calculated using linear regression. Scale 0–10.

TABLE 4 SCORES IN THE SIX DOMAINS OF QUALITY OF LIFE (QOL) FOR WOMEN ONCE ADHERING TO THE DIET (N = 27) AND WOMEN CURRENTLY ADHERING TO THE ENDOMETRIOSIS DIET (N = 90) COMPARED TO WOMEN NEVER ADHERING TO THE DIET (N = 94)

QoL domain	Average difference ^a		95% confidence interval (lower bound – upper bound)		Significance	
	Never diet ^b versus once diet	Never diet ^b versus now diet	Never diet ^b versus once diet	Never diet ^b versus now diet	Never diet ^b versus once diet	Never diet ^b versus now diet
Physical functioning	0.20	1.11	–0.53–0.93	0.62–1.60	0.59	<0.000
Psychological functioning	0.13	0.65	–0.44–0.69	0.27–1.03	0.66	0.001
Spiritual functioning	0.31	0.61	–0.31–0.92	0.20–1.03	0.33	0.004
Quality of life	0.16	0.43	–0.44–0.76	0.03–0.84	0.60	0.040
Social participation	–0.18	0.62	–0.82–0.47	0.18–1.05	0.59	0.005
Daily functioning	–0.34	0.62	–0.95–0.28	0.20–1.03	0.28	0.004

^a Scale 0–10.

^b Reference value. All groups were compared to this reference value.

TABLE 5 SCORES IN THE SIX DOMAINS OF QUALITY OF LIFE (QOL) IN WOMEN WITH STRICT ADHERENCE TO THE DIET COMPARED TO NO STRICT ADHERENCE

QoL domain	Mean scores in the six QoL domains		Average difference ^b (strict ^a versus no strict adherence) with 95% confidence interval	Significance P-value
	Strict adherence (n = 48)	No strict adherence (n = 42)		
Physical functioning	6.63	5.99	0.71 (0.02–1.40)	0.044
Psychological functioning	7.62	7.06	0.59 (0.10–1.08)	0.019
Spiritual functioning	7.93	7.39	0.64 (0.11–1.17)	0.018
Quality of life	7.76	7.13	0.72 (0.19–1.25)	0.009
Social participation	8.60	7.93	0.77 (0.24–1.29)	0.005
Daily functioning	8.39	7.79	0.55 (0.00–1.10)	0.050

^a Median score of strictness ≥ 8 (scale 0–10).

^b Calculated using a linear regression. Scale 0–10.

women's QoL. This has also been observed in a recent Australian survey by [Armour et al. \(2019\)](#), where 76% of endometriosis patients used self-management strategies. Of their participants, 44% used dietary adjustments in order to complement their endometriosis treatment. Moreover, a recent cross-sectional online survey showed that endometriosis patients may

experience a higher physical and mental QoL and are able to manage their chronic pain better when they apply these self-management strategies ([O'Hara et al., 2021](#)).

The current study found that women diagnosed with endometriosis up to 10 years ago, compared to women

diagnosed more than 10 years ago, significantly more often adhered to the endometriosis diet. This may be attributed to the fact that a dietary intervention as an addition to standard endometriosis treatment is a relatively new development. Women diagnosed with endometriosis more recently may have a greater need for information about the disease and its

TABLE 6 COMPARISON OF NUMBER OF WOMEN ADHERING TO THE ENDOMETRIOSIS DIET ACCORDING TO TIME SINCE DIAGNOSIS

Years since diagnosis	Average difference (number of women adhering to the diet and years since diagnosis)	95% confidence interval (lower bound – upper bound)	Significance P-value
0–1 (n = 36)	1.06	1.02–8.17	0.046
1.1–5 (n = 76)	0.98	1.13–6.22	0.025
5.1–10 (n = 51)	1.24	1.44–8.28	0.005
>10 (n = 48) ^a	1.00	–	–

^a Reference value. All time intervals were compared to the reference value.

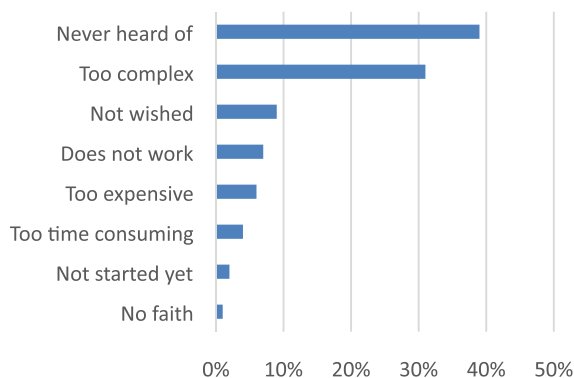


FIGURE 2 Reasons not to adhere to the endometriosis diet (n = 121).

possible treatments and are therefore more likely to encounter dietary interventions such as the endometriosis diet when visiting online platforms. Women diagnosed longer ago may consider themselves more knowledgeable about endometriosis and may not search for information or be in less need of it. This can result in them not encountering information on dietary interventions.

This study investigated a subset of women about reasons for discontinuing the diet. The majority of women stopped the diet due to the lack of a beneficial effect. The diet being too complex and time-consuming were other reasons for women to discontinue the endometriosis diet. This may indicate that consulting a dietician could be of added value for women with endometriosis considering use of the endometriosis diet. Moreover, dieticians can make sure that a balanced diet is used, avoiding nutritional deficiencies that may arise when patients eliminate important nutrients on their own initiative, without attention to the correct dietary replacement (*Huijs and Nap, 2020*).

The additional costs of the endometriosis diet have not yet been studied. However, *Saulle et al. (2013)* studied the additional costs when adhering to the Mediterranean diet. Because the two diets are similar, the costs are expected to be comparable. Adherence to the Mediterranean diet cost an additional €0.71 per 1000 kcals, compared to a standard diet (*Saulle et al. 2013*). In addition, costs for guidance by a dietician varies in the Netherlands, between €63 and €73 per hour. However, the Dutch tax authorities allow women adhering to a dietary intervention to deduct part of these costs, up to €1350 annually, from their tax return. Total costs of adherence to the endometriosis diet are thereby reduced considerably.

The strengths of the current study include the large sample size and the recruitment strategy. The sample size of 211 participants is sufficient to provide reliable results. By recruiting participants through the online platform of the patients' association (the Dutch Endometriosis Society), a population representative of the Dutch population of women with endometriosis

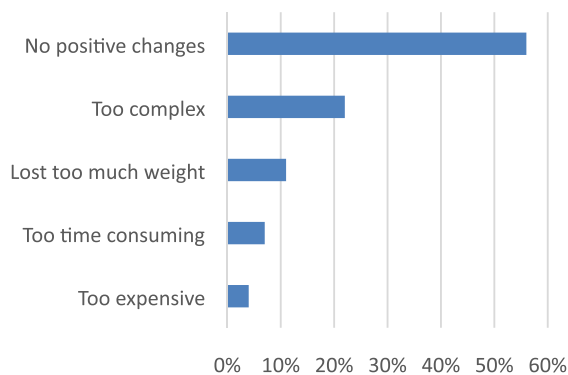


FIGURE 3 Reasons for discontinuing the endometriosis diet reported by 27 participants who had previously adhered to the diet but did not currently adhere to it.

was obtained. The study also has several limitations. First, as it has a cross-sectional design it may not provide definite information about cause-and-effect relationships. Therefore, the observed effect on the QoL cannot be attributed with complete certainty to the endometriosis diet itself. Furthermore, no possible confounders for QoL were studied, such as body mass index, possible stress experienced by the participants in their daily life, their current treatment method and social support. Second, the diagnosis of endometriosis was self-reported. To improve reliability, a diagnosis confirmed by radiological imaging and/or surgery would have been preferable. However, a large study that compared four international cohorts found that women were able to self-report their endometriosis diagnosis accurately, with an overall confirmation proportion of 84% (*Shafir et al., 2021*). Moreover, because the questionnaire was distributed through the Dutch patient organization for endometriosis, it is considered that the probability that women were actually diagnosed with endometriosis to be high.

Although some of the participants did not know the severity of their disease, it is debatable whether this information is important. Incoherency is often seen between severity of disease and severity of endometriosis symptoms and the impact on QoL. As found in a recent study, only dyspareunia seems to be associated with severity of disease. There was no significant association between severity in other endometriosis-related symptoms and severity of disease (*Kor et al., 2020*).

The endometriosis diet is developed by endometriosis patients, based on their experiences and thoughts. Therefore, it lacks standardization and needs to be validated in future research. This study also applied a cut-off value of ≥ 8 for strict adherence to the diet; this was based on the median and not on the outcome of previous studies, as they were not available. No detailed follow-up questions were asked on their strictness, such as adherence during social events or holidays, or number of days they adhered to the diet during the week or month. This limits the details obtained on diet adherence and strictness of the participants. Finally, the conversation tool 'My Positive Health' is not a validated questionnaire to assess QoL in endometriosis patients, whereas the EHP-30 questionnaire is validated for this assessment (*Huber, 2019; Huber et al.,*

2016; Prinsen and Terwee, 2019; van de Burgt et al., 2011). Nevertheless, the 'My Positive Health' questionnaire is a frequently used tool in the setting of general practitioners to measure QoL (Huber, 2019; Huber et al., 2016).

Despite the limitations, these results provide an intriguing picture of women's experiences with the use of the endometriosis diet and emphasizes the importance of more research in order to clarify the mechanism of this beneficial effect and to identify facilitators and barriers of dietary adjustments in patients with endometriosis.

In conclusion, this study found that women diagnosed with endometriosis and adhering to the endometriosis diet reported a significantly better QoL compared to women who did not adhere to the diet. Women reported an even higher QoL when strictly adhering to the diet. It is important to increase knowledge regarding the contribution of a dietary intervention on the improvement of endometriosis-related symptoms, and thus the QoL. Therefore, future research should focus on broadening the knowledge on frequently applied dietary interventions such as the endometriosis diet and low FODMAP diet. Finally, it is important to develop a guideline with regard to dietary interventions, so that they can be applied as homogeneously as possible in the future.

AUTHOR ROLES

AH, JW, AS, VM contributed to the study conception and design. JW recruited participants and acquired data. AH performed the statistical analyses. AH, JW, AS and VM contributed to the interpretation of data. AH prepared the manuscript. AS and VM critically revised the paper. All authors approved the final version of the article.

DATA AVAILABILITY

Data will be made available on request.

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SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.rbmo.2022.12.010](https://doi.org/10.1016/j.rbmo.2022.12.010).

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