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ORIGINAL ARTICLE

A systematic review and secondary analysis of two studies identifying demographic and medical characteristics determining patient-centeredness in endometriosis care as experienced by patients

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STUDY QUESTION: What are the patient-specific determinants associated with patient-centered endometriosis care as measured by the ENDOCARE questionnaire (ECQ)?

SUMMARY ANSWER: 'Overall grade for endometriosis care', 'educational level', 'membership of a patient organization' and 'having seen other specialists for endometriosis complaints' are correlated with overall patient-centeredness scores (PCS).

WHAT IS KNOWN ALREADY: Patient-centeredness of endometriosis care can be evaluated using the validated ECQ. The ECQ leads to an overall PCS and separate PCS for 10 dimensions of endometriosis care. Previously, educational level and quality of life scores were found to be associated with ECQ results.

STUDY DESIGN, SIZE, DURATION: First, a systematic literature review was performed (PROSPERO registration number: CRD42020169872). MEDLINE, Cochrane CENTRAL and EMBASE databases were searched from inception to May 2020 for studies in any language reporting on the results of the ECQ in patients with endometriosis. Two studies were identified. From the two studies, all original data were merged. In total, data from 546 patients were available for analysis. Second, univariate and multivariate regression analyses were performed to identify determinants for patient-centeredness of endometriosis care.

PARTICIPANTS/MATERIALS, SETTING, METHODS: The two included studies evaluated patient-centeredness in four endometriosis care centers in Belgium and the Netherlands. All participants had surgically proven endometriosis. Possible patient-specific determinants were selected from the demographic and medical questions from the first part of the ECQ. These determinants were evaluated using linear regression analysis and all possible determinants with a $P > 0.2$ in the univariate analysis were selected for stepwise multivariate analysis. Separate analyses were performed for overall PCS and each of the 10 dimensions.

MAIN RESULTS AND THE ROLE OF CHANCE: The two included studies provided data from 546 patients. After adjustment for care center, multivariate analysis showed that a higher 'grade for endometriosis care' ($B = 0.66$), a 'lower educational level' ($B = 0.50$), 'being member of a patient organization' ($B = 0.49$) and 'having seen other specialists for endometriosis complaints' ($B = 0.34$) were

independently associated with higher overall PCS ($R^2 = 0.41$). 'Grade for endometriosis care' was a determinant for all dimensions of endometriosis care. 'Having seen other specialists for endometriosis complaints' was positively associated with the care dimensions 'respect for patients' values, preferences and expressed needs', 'continuity and transition' and 'technical skills'. Members of a patient organization showed higher scores on the care dimensions 'emotional support and alleviation of fear and anxiety', 'continuity and transition' and 'endometriosis clinic staff'. Furthermore, we found that having a higher level of education is associated with lower scores in the care dimensions 'physical comfort', 'emotional support and alleviation of fear and anxiety' and 'involvement of significant other'.

LIMITATIONS, REASONS FOR CAUTION: These results delineate the patient-specific determinants of patient-centered care as measured using the Dutch ECQ. Whether results are generalizable to other countries should be investigated in an international study. This requires the ECQ to be validated in other languages first.

WIDER IMPLICATIONS OF THE FINDINGS: The aforementioned determinants of patient-centered care are of value for studies benchmarking clinics for their patient-centeredness. In addition, they help clinicians to determine how to tailor their care to individual patients. At every visit, patients could be asked to grade the endometriosis care (on a scale of 0–10) to easily investigate patient-centeredness. When there is more time, women with endometriosis should be asked to complete the entire ECQ to investigate patient-centeredness in depth.

STUDY FUNDING/COMPETING INTEREST(S): The department of reproductive medicine (involving C.B.L. and V.M.) of the Amsterdam UMC, Vrije Universiteit Amsterdam has received several research and educational grants from Guerbet, Merck and Ferring. The authors have no conflict of interest related to this manuscript.

Key words: endometriosis / quality control / quality of care / patient-centeredness / ENDOCARE questionnaire / psychology

WHAT DOES THIS MEAN FOR PATIENTS?

When a woman with endometriosis visits an endometriosis health care provider, it is important for both parties that the woman with endometriosis feels helped and is satisfied with the care she received. Women with endometriosis that are more satisfied with their endometriosis care, also show better quality of life. The ENDOCARE questionnaire can be used to investigate quality of endometriosis care by questioning women with endometriosis on their experiences. To help the health care providers in improving their care, it is important to understand which women might experience their care as less patient-centered compared to others. In this study, we found multiple factors that are associated with a lower satisfaction of endometriosis care: having a higher educational level, lacking a membership of a patient organization, and not having seen other specialists for endometriosis complaints. In the future health care providers can use this information to reflect and adapt their care when necessary in order to improve satisfaction with endometriosis care. Furthermore, this study will help to standardize care in endometriosis care centers.

Introduction

Endometriosis is a chronic estrogen-dependent gynecologic disease that may cause pain and subfertility and therefore can have a major impact on women's lives. Women with endometriosis report a lower quality of life compared with healthy controls (Marinho et al., 2018). Moreover, health-related limitations in careers have to be taken into account by working women with endometriosis. They are less likely to pursue the career they desire due to frequent sick leaves and loss of productivity (Simoens et al., 2012; Sperschneider et al., 2019). The annual cost of endometriosis is thought to be €9579 per woman (Simoens et al., 2012).

Treatment of endometriosis can be challenging, as to date there still is no definitive cure for the disease. Patients are therefore reliant on long-term hormonal treatments, pain medication, (recurrent) surgery and fertility treatments (Dunselman et al., 2014). This implies multiple visits to the hospital and outpatient clinics and possible long-term use of medication.

Nowadays, the focus in endometriosis research is shifting from pregnancy and pain outcomes to quality of life, patient-centeredness of care and patient preferences (Lukas et al., 2018; Marinho et al., 2018;

Rowe et al., 2019). It is advised to offer new treatment strategies that are based on patients' symptoms and priorities (Chapron et al., 2019). With an increased focus on shared decision-making, it is important to have better insight into women's considerations with respect to endometriosis care. Targeted improvements in endometriosis care can be made by identifying important aspects of patient-centered care. Improvement of care is especially important since better quality of care is also associated with a better quality of life in women with endometriosis (Apers et al., 2018).

For endometriosis patients, the quality of care can be analyzed using the ENDOCARE questionnaire (ECQ), which is a validated and reliable instrument with a focus on patient-centeredness of endometriosis care (Dancet et al., 2011; Dancet et al., 2012). Using the ECQ questionnaire, available in English, Dutch and Italian, the patient-centeredness per participating endometriosis care center can be investigated and specific targets for improvement per center can be identified. These targets for improvement can be used to create specific improvements of care.

In order to tailor care more on an individual level, it is important to know which patients are more at risk of experiencing their endometriosis care as less patient-centered. Previous research identified age,

educational level and health status to be associated with general patient satisfaction in different medical fields (Hall and Dornan, 1990; Cleary et al., 1991; Kane et al., 1997; Young et al., 2000; Hargraves et al., 2001). It is hypothesized that the aforementioned determining factors are also correlated with patient-centeredness of endometriosis care. Furthermore, Comptour et al. (2020) identified determining factors for quality of life in women with endometriosis, such as preoperative chronic pelvic pain and fertility. These factors are also hypothesized to influence patient-centeredness, as quality of life might be correlated with patient-centeredness of endometriosis care (Apers et al., 2018). Identifying patient-specific determinants of patient-centeredness of endometriosis care might raise health care providers' awareness to preserve patient-centeredness and quality of care in patients who are more at risk of experiencing diminished patient-centeredness. Therefore, the aim of this study is to identify patient-specific determinants that are associated with patient-centeredness of endometriosis care using previous usages of the ECQ.

Materials and methods

A systematic review was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (Moher et al., 2009) to identify all possible studies reporting on the use of the ECQ. The protocol of the systematic review was registered on PROSPERO (registration number: CRD42020169872). Additionally, the authors of the selected studies were contacted to share the original data. After merging all databases, determinants for the ECQ were sought by using univariate and multivariate regression analysis.

Information sources and search

The electronic databases EMBASE, MEDLINE and Cochrane Central Register of Controlled Trials (CENTRAL) were searched using the terms expressing 'ENDOCARE' and 'endometriosis' from inception to May 2020. No limitations were used in the search. The MEDLINE search strategy, which is used as a basis for all searches, is available in Supplementary Data.

Study selection

Studies reporting on primary data on patient-centeredness of endometriosis care using the final version of the ECQ, as presented by Dancet et al. (2012), were eligible for inclusion. Two researchers independently performed the search and study selection. References of identified studies were searched for other relevant publications.

Data collection

Authors of the identified studies were contacted after selection to obtain original anonymized datasets. The data included all the answers to the demographic and medical questions of the ECQ as well as the patient-centeredness scores (PCS). Databases were checked for inconsistencies and missing data. Confirmation of medical ethical approval of the original study was obtained.

Questionnaire

The ECQ (Dancet et al., 2011, 2012) consists of two sections: first, demographic and medical questions are asked; second, women are questioned on patient-centeredness of endometriosis care aspects. For analyzing patient-centeredness, statements on importance and performance of 38 care aspects are scored on a 4-point Likert scale. Examples of statements on specific care aspects are 'my complaints were taken seriously' and 'I was able to contact my attending physician'. By calculating the mean importance score (MIS) and percentage of negative performance (PNP) per care aspect, the strengths (high MIS, low PNP) and targets for improvement (high MIS, high PNP) can be identified. The 38 care aspects can be categorized into 10 dimensions of care: respect for patients' values, preferences and needs; coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of significant others; continuity and transition; access to care; technical skills; and endometriosis clinic staff. PCS can be calculated using the MISs and the PNP (PCS = MIS * (100 − PNP)/100). PCS are calculated for all 10 dimensions with 0 being the worst patient-centeredness and 10 the best. The overall PCS can be calculated as an average of the PCS of all 10 dimensions.

Determinants

Potential patient-specific determinants for patient-centeredness were selected from the demographic and medical questions from the first part of the ECQ. These potential determinants were compared to the PCS per care dimension and overall PCS in univariate and multivariable regression analysis. All possible determinants were dichotomous outcomes, except for age, diagnostic delay, patient delay, doctor delay, age at first symptoms and grade for endometriosis care. Cutoff value for the determinant 'amount of consultations with general practitioner before referral to a specialist' was arbitrarily set at 10 visits (90th percentile).

Risk of bias

Quality assessment of the individual studies was carried out using the standard quality assessment for evaluating primary research papers (Kmet et al., 2004). Furthermore, the risk of bias was assessed using the Grading of Recommendation, Assessment, Development and Evaluations (GRADE) approach (Balshem et al., 2011). This approach has four levels of evidence (very low – high) based on five items that can influence evidence: risk of bias; imprecision; inconsistency; indirectness; and publication bias.
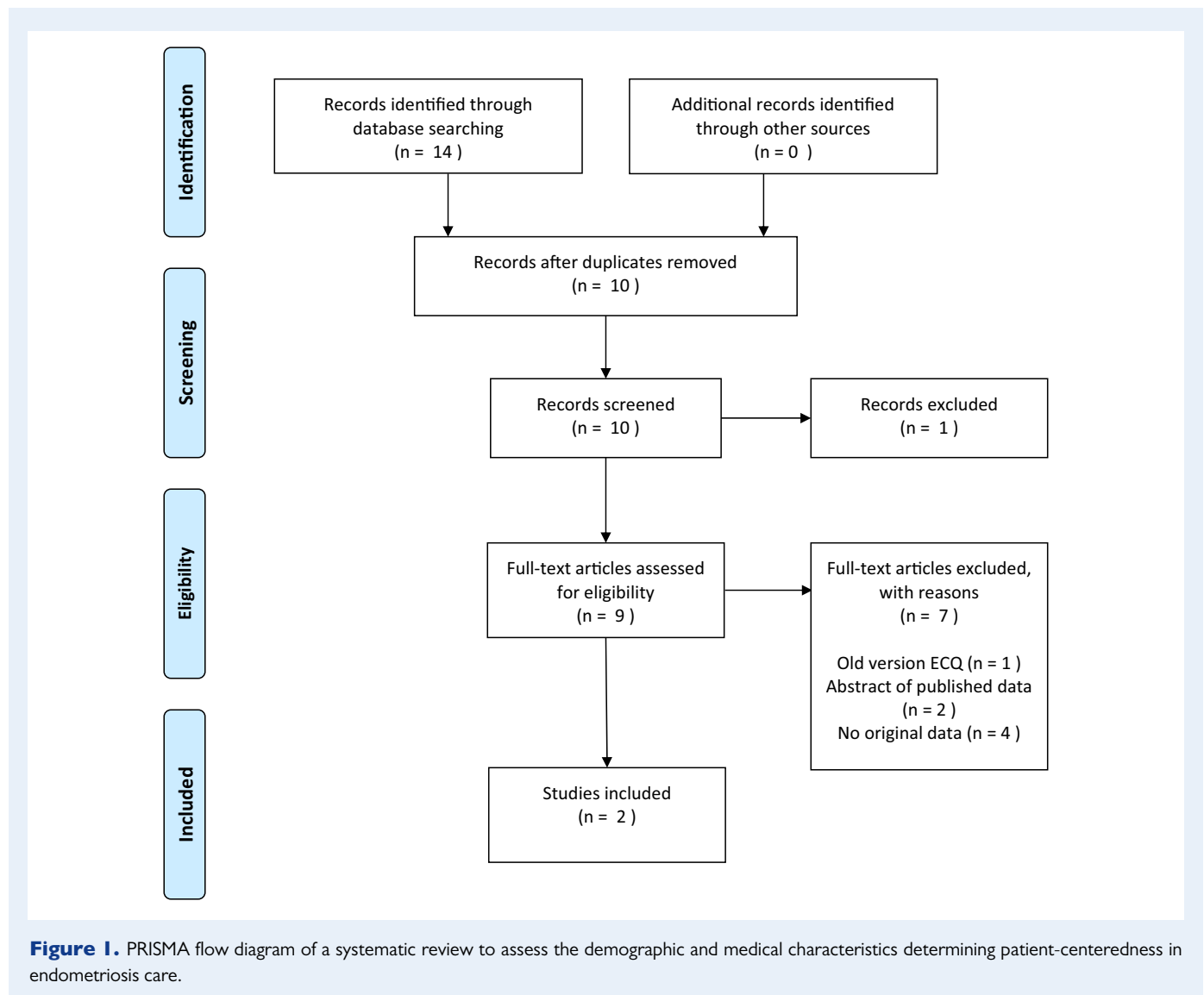
Analysis

Data from all included studies were merged after consulting a data manager. Since only the answers to the ECQ were used, no standardization of the results had to be performed. The ECQ was analyzed as described by Dancet et al. (2012). Univariate and multivariable regression analysis were used to find determinants for patient-centeredness per dimension and for overall PCS. Determinants with a response rate of <75% were excluded from the analysis. Determinants with a $P < 0.2$ in the univariate analysis were further analyzed in multivariable regression analysis with a forward selection procedure after adjustment for each clinic, using dummy variables (van Empel et al., 2010; Apers

et al., 2018). A *P*-value of <0.05 was considered significant in the multivariate regression analysis. The sample size was verified by using the calculation for minimum sample size for multiple regression according to Green (1991) (104 + amount of predictors). Association of determinants and PCS was quantified using regression coefficients, their CI and *P*-value. Explained variance of the multivariate models is quantified by means of adjusted R^2. Regression coefficients (Beta) represent the mean change that one unit increase in the determinant has on the PCS score while keeping all determinants in the model at the same level. Statistical analysis was performed using SPSS statistics (version 22, IBM, USA).

Results

In total, 14 studies were identified for initial assessment. After assessment for eligibility, two datasets were identified that used the ECQ in a total of four endometriosis care centers (Dancet *et al.*, 2012; Schreurs *et al.*, 2020) (Fig. 1). One study used an older version of the questionnaire and was therefore not included (Dancet *et al.*, 2011). All individual participant data related to the ECQ outcomes of the included four endometriosis care centers were pooled. The four centers are (i) University Hospitals Leuven, Leuven, Belgium, (ii) Radboudumc, Nijmegen, the Netherlands, (iii) Isala Clinics, Zwolle, the Netherlands and (iv) Amsterdam UMC, Vrije Universiteit Amsterdam, the Netherlands. In the Netherlands access to care is granted for all citizens with solidarity through medical insurance (which is compulsory for all and available to all). The Belgian health system is also based on equal access and with a compulsory health care insurance, which includes the whole population and has a very broad benefits package. Dancet *et al.* (2012) performed a cross-sectional study in a Dutch and Belgian tertiary care center (center i and ii). All women over the age of 18 years with surgically proven endometriosis that underwent laparoscopy in 2009 or 2010 were asked to complete the ECQ in 2011. The data from Schreurs *et al.* (2020) were obtained likewise by means of a cross-sectional cohort study in a secondary and tertiary endometriosis care center (center iii and iv) in the Netherlands with no overlap in patient population. Similarly, all women over the age of 18 years

Figure 1. PRISMA flow diagram of a systematic review to assess the demographic and medical characteristics determining patient-centeredness in endometriosis care.

with surgically confirmed endometriosis (surgery in 2013 or 2014) were asked to complete the questionnaire in 2015 and 2016. All four clinics are specialized endometriosis care centers and use the same international guideline in diagnosis and treatment of endometriosis (Dunselman et al., 2014).

After merging all original databases, data from 546 patients from four endometriosis care centers were available for analysis. Descriptive data of patient characteristics and potential determinants are shown in Table I. All potential determinants, except for 'surgery by a multidisciplinary team', had a response rate >75% and were included in univariate regression analyses. Table II shows the overall PCS and PCS per dimension for all four care centers.

The importance ratings of the ECQ seem reliable in the four centers for all dimensions except for the dimension 'coordination and integration of care' (Table III). Cronbach's alpha for 'coordination and integration of care' of 0.09–0.53 and Item Total Correlations −0.003 to 0.43 was judged as not reliable.

Risk of bias

Using the standard quality assessment criteria as described by Kmet et al. (2004), summary scores for quality could be calculated for each study separately. A score of 0.68 and 0.77 was calculated for Dancet et al. (2012) and Schreurs et al. (2020), respectively. Overall quality of the evidence was graded as moderate based on the GRADE approach. Since the current study performed a new, secondary evaluation of the previously published data, indirectness was present. Furthermore, the included studies were performed in adjoining countries. On the other hand, all investigated centers show consistent results on patient-centeredness, as shown in Table II. Selection bias is minimized as in both included studies all patients that underwent endometriosis surgery in a specific time frame were asked to participate. Moreover, Schreurs et al. (2020) also compared non-responders with responders and found no differences between the two groups. Both studies report on confounding variables and show adequately adjusted outcomes. Performance bias is minimized as both studies use the same inclusion criteria and the same questionnaire. As both original data sets are used in the current study, confounding is minimized. Publication bias is low as no limitations were used in the literature search. No blinding of the outcomes was performed before analysis, indicating that no blinding of the outcome assessment was performed. Selective outcome reporting and publication bias were minimized as all possible usages of the ECQ were included in the current study.

Determinants of patient-centeredness

Determinants per dimension of patient-centeredness of endometriosis care and for overall PCS are demonstrated in Table IV. In this table, all Beta's are shown per PCS for the determinants that showed a significant association with the PCS in multivariate regression analysis. The 'overall grade for endometriosis care' was found as a determinant for all 10 dimensions. The overall grade was a score between 0 and 10 for overall endometriosis care and was asked for at the end of the ECQ.

Overall PCS was associated with 'overall grade for endometriosis care ($\beta = 0.66$)', 'being higher educated ($\beta = -0.50$)', 'membership of a patient organization ($\beta = 0.49$)' and 'having seen other specialists for endometriosis complaints ($\beta = 0.34$)' (adjusted $R^2 = 0.41$).

Table I Patient characteristics and possible determinants of endometriosis care (N = 546).

Possible determinants	n/N(%) or median(IQR)
Age (years)	34 (32–38)
Ethnic background	
European	404/449 (90.0%)
Other	45/449 (10.0%)
Education	
No higher education	223/544 (41.0%)
(University) College degree	321/544 (59.0%)
Currently in an intimate partner relationship	499/543 (91.9%)
Intimate partner relationship past 5 years	510/538 (94.8%)
Stage of endometriosis (self-reported)	
Minimal/mild	157/527 (29.8%)
Moderate/severe	370/527 (70.2%)
Endometriosis complaints (at diagnosis)	
Infertility	267/543 (49.2%)
Dysmenorrhea	456/543 (84.0%)
Dyspareunia	216/543 (39.8%)
Chronic pelvic pain	213/543 (39.2%)
Endometriosis complaints (past year)	435/542 (90.3%)
Infertility	289/543 (53.2%)
Dysmenorrhea	308/543 (56.7%)
Dyspareunia	218/543 (40.1%)
Chronic pelvic pain	184/543 (33.9%)
Diagnostic delay, years	1 (0–6)
Patients' delay, years	0 (0–1)
Doctors' delay, years	1 (0–3)
Age at first symptoms	27 (20–31)
Amount of GP consultations before referral	2 (0–5)
>10 GP consultations before referral	34/485 (7.0%)
Self-reported characteristics: wish to conceive	
Ever been pregnant	313/545 (57.4%)
Ever tried to conceive >12 months	376/541 (69.5%)
Has one or more child(ren)	212/543 (39.0%)
Hope for (more) children in future	403/525 (76.8%)
Endometriosis pain made it impossible to consider becoming pregnant	101/435 (23.2%)
Second opinion of >1 gynecologist	241/544 (44.3%)
Ever referred to other specialist for endometriosis related symptoms	326/540 (60.4%)
Surgery by multidisciplinary team	233/326 (71.5%)
Member of patients' organization	48/544 (8.8%)
Grade for endometriosis care (scale 0–10)	8.0 (7.0–9.0)
Would recommend care to others	496/528 (93.9%)

GP, general practitioner.

Of the care dimensions, the dimension 'technical skills' had the highest explained variance (adjusted $R^2 = 0.38$). The score on 'Technical skills' was associated with 'grade for endometriosis care ($\beta = 1.10$)', 'being unable to conceive due to endometriosis complaints

Table II Uncorrected patient-centeredness scores per included center.

PCS	Center 1 Leuven (n = 216)	Center 2 Nijmegen (n = 121)	Center 3 Zwolle (n = 76)	Center 4 Amsterdam (n = 133)
Overall PCS	4.8 (3.9–5.9)	4.9 (3.9–6.0)	4.8 (3.9 - 5.7)	4.5 (3.5 - 5.6)
PCS 1: Respect for patients' values, preferences and expressed needs	7.3 (6.0–10.0)	7.3 (6.0–10.0)	7.0 (5.8–8.7)	7.3 (6.0–10.0)
PCS 2: Coordination and integration of care	5.0 (3.3–6.3)	4.9 (3.0–6.3)	4.2 (2.0–6.0)	4.2 (3.0–6.0)
PCS 3: Information, communication and education	6.0 (4.8–8.1)	6.0 (5.1–7.1)	6.0 (4.3–7.1)	6.0 (4.3–7.0)
PCS 4: Physical comfort	3.0 (1.5–4.5)	4.5 (2.6–6.0)	4.5 (3.0–6.0)	3.0 (2.2–6.0)
PCS 5: Emotional support and alleviation of fear and anxiety	0.8 (0.0–2.0)	1.1 (0.0–2.4)	0.9 (0.0–2.0)	0.7 (0.0–2.0)
PCS 6: Involvement of significant others	2.8 (0.0–5.4)	2.5 (0.8–4.5)	2.3 (0.3–4.0)	1.9 (0.4–3.9)
PCS 7: Continuity and transition	4.9 (2.0–7.2)	6.0 (3.0–6.0)	6.0 (4.0–8.3)	4.2 (3.3–6.0)
PCS 8: Access to care	3.4 (2.0–5.4)	4.8 (3.0–6.0)	4.8 (3.2–6.0)	4.3 (3.2–6.0)
PCS 9: Technical skills	6.8 (5.3–9.0)	6.0 (4.0–8.0)	6.0 (4.5–8.0)	6.0 (3.9–8.0)
PCS 10: Endometriosis clinic staff	7.0 (6.0–8.7)	6.0 (5.7–8.3))	6.0 (6.0–8.7)	6.0 (5.0–7.3)

Data are represented as median (IQR).
PCS, patient-centeredness score.

Table III Cronbach's alpha per included center based on importance ratings (range of Item Total Correlations).

Dimension	Center 1 Leuven	Center 2 Nijmegen	Center 3 Zwolle	Center 4 Amsterdam
PCS 1: Respect for patients' values, preferences and expressed needs	0.58 (0.37–0.41)	0.70 (0.50–0.54)	0.65 (0.39–0.58)	0.70 (0.46–0.57)
PCS 2: Coordination and integration of care	0.49 (0.25–0.38)	0.53 (0.32–0.43)	0.48 (0.28–0.35)	0.09 (−0.003–0.11)
PCS 3: Information, communication and education	0.86 (0.55–0.69)	0.87 (0.55–0.70)	0.78 (0.37–0.70)	0.80 (0.40–0.65)
PCS 4: Physical comfort	0.55 (0.38)	0.74 (0.60)	0.69 (0.53)	0.61 (0.43)
PCS 5: Emotional support and alleviation of fear and anxiety	0.74 (0.45–0.60)	0.77 (0.51–0.62)	0.66 (0.30–0.53)	0.85 (0.61–0.76)
PCS 6: Involvement of significant others	0.80 (0.45–0.74)	0.82 (0.60–0.68)	0.59 (0.32–0.47)	0.83 (0.59–0.70)
PCS 7: Continuity and transition	0.74 (0.49–0.60)	0.79 (0.56–0.69)	0.66 (0.44–0.51)	0.67 (0.35–0.57)
PCS 8: Access to care	0.72 (0.40–0.56)	0.77 (0.42–0.63)	0.73 (0.37–0.63)	0.65 (0.27–0.49)
PCS 9: Technical skills	0.80 (0.50–0.65)	0.79 (0.54–0.67)	0.70 (0.43–0.55)	0.77 (0.40–0.66)
PCS 10: Endometriosis clinic staff	0.73 (0.51–0.62)	0.75 (0.56–0.60)	0.81 (0.62–0.71)	0.76 (0.48–0.68)

$(\beta = -0.85)$', 'having seen other specialists for endometriosis complaints $(\beta = 0.71)$' and 'chronic pelvic pain as a first symptom of endometriosis $(\beta = 0.47)$'. For the score on the 'coordination and integration of care' dimension the multivariate model only included 'overall grade for endometriosis care $(\beta = 0.39)$' as a determinant and explained variance was low (adjusted $R^2 = 0.06$).

We found a positive association between PCS and the participant being a member of a patient organization. Members of a patient organization score their care as more patient-centered for the dimensions 'emotional support and alleviation of fear and anxiety' $(\beta = 0.98)$, 'continuity and transition' $(\beta = 0.96)$ and 'endometriosis clinic staff' $(\beta = 0.89)$. On the other hand, it seems that a higher level of education is negatively associated with scores on the PCS dimensions 'involvement of significant others' $(\beta = -1.20)$, 'physical comfort' $(\beta = -0.83)$ and 'emotional support and alleviation of fear and anxiety' $(\beta = -0.60)$. Furthermore, having an intimate partner relationship was found to be negatively associated with scores on the dimension

'respect for patients' values, preferences and expressed needs' $(\beta = -0.83)$ and positively associated with scores on the dimension 'Involvement of significant others' $(\beta = 1.72)$.

Discussion

In this study, we identified different patient-specific determinants for patient-centeredness of endometriosis care in a combined sample containing all the individual participant data from the two studies selected by our systematic review.

'Overall grade for endometriosis care' was found to be associated with scores on all dimensions. This indicates that up to a certain point, 'grade for endometriosis care' can be used as a first indicator for the extent of patient-centeredness of the endometriosis care. This knowledge could provide health care providers with an easy tool for fast assessment of patient-centeredness of care. It is a small burden to ask all

Table IV Determinants of patient-centeredness of endometriosis care per dimension and overall PCS (Beta (95% CI)).

	PCS1: Respect for patients' values, preferences and expressed needs	PCS2: Coordination and integration of care	PCS 3: Information, communication and education	PCS4: Physical comfort	PCS5: Emotional support and alleviation of fear and anxiety	PCS6: Involvement of significant others	PCS7: Continuity and transition	PCS8: Access to care	PCS9: Technical skills	PCS10: Endometriosis clinic staff	Overall PCS
Grade for endometriosis care (+1 grade)	0.56(0.41–0.71)	0.39 (0.25–0.53)	0.64 (0.51–0.76)	0.36 (0.20–0.51)	0.35 (0.22–0.48)	0.54 (0.34–0.74)	0.88 (0.90–1.07)	0.52 (0.38–0.66)	1.10 (0.93–1.26)	0.70 (0.55–0.85)	0.66 (0.58–0.74)
Would recommend clinic to family and friends	1.78(0.85-2.71)										
Currently in an intimate partner relationship	−0.83(−1.50 to −0.17)					1.72 (0.07–3.37)					
Seen other specialist than gynecologist for endometriosis complaints	0.41 (0.05–0.77)						0.65(0.10–1.19)		0.71(0.25–1.18)		0.34(0.11 – 0.57)
Higher educated				−0.83 (−1.30 to −0.37)	−0.60 (−1.00 to −0.20)	−1.20 (−1.81 to −0.59)					−0.50(−0.73 to −0.26)
Member of patients' organization					0.98(0.34–1.61)		0.96(0.05–1.87)			0.89(0.14–1.63)	0.49(0.08–0.91)
>10 GP visits before referral										0.96(0.16–1.75)	
Chronic pelvic pain as first endometriosis symptom					0.38(0.00–0.76)				0.47(0.00–0.93)		
Ever tried to conceive >12 months				0.63(0.16–1.11)							
Unable to conceive due to endometriosis complaints									−0.85(−1.40 to −0.30)		
Adjusted R^2	0.26	0.06	0.20	0.12	0.13	0.15	0.23	0.15	0.38	0.22	0.41

Unstandardized coefficients with 95% CI ($P < 0.05$) are demonstrated.

patients to score their care with a single grade. However, 'grade for endometriosis' alone explains only part of the variation in overall ECQ scores. It is therefore advised to use the ECQ for a thorough assessment of care, allowing identification of the exact targets for improvement. The finding that the overall grade is correlated to all dimensions also confirms that the ECQ investigates what it needs to investigate: how patients experience patient-centeredness of their endometriosis care.

Overall PCS is positively associated with grade for endometriosis care, membership of a patient organization and whether patients have seen other specialists for their endometriosis care and is negatively associated with educational level.

Educational level was previously found to be a determining factor by Dancet *et al.* (2012) and is confirmed as a determinant in our study. It has been observed earlier in the field of fertility care that higher educated women perceive their care as less patient-centered and have more negative experiences with their care (Haagen *et al.*, 2008; van Empel *et al.*, 2010). As around half of the participants in this study suffer from infertility alongside their endometriosis, a similar result was to be expected.

Being a member of a patient organization is positively correlated with different dimensions of endometriosis care. Members are more positive toward the dimensions 'emotional support', 'the clinic staff' and 'continuity and transition'. Previously, de Graaff *et al.* (2015) reported that members of an endometriosis patient organization more often have affected relationships, affected jobs and chronic pelvic pain compared to women recruited from secondary care centers. Next to that they found a lower quality of life in members of a patient organization compared to women selected from a secondary care center. Overall they seem to have a more severe burden of endometriosis on their daily life. This could possibly indicate that they rely more heavily on the medical team and that treatment may have a bigger impact on their current life, therefore rating the care as more patient-centered. An alternative explanation could be that women who are members of a patient organization learn from peers which endometrioses care centers are patient-centered and visit those centers with this information in mind. Expecting to visit a good quality care center might influence the appreciation (Lee and Youn, 2009). Whether women with endometriosis will see their care as more patient-centered after health care providers advise them to become a member should be investigated further.

One possible explanation for the positive association that the determinant 'having seen other specialists for endometriosis complaints' has with several dimensions and the overall score, might be that women finally feel heard. When women have seen different specialists for endometriosis complaints, this might indicate that they were sent to different specialists without receiving the correct diagnosis before getting the diagnosis endometriosis. This hypothesis is supported by the fact that in our study, having seen other specialists for endometriosis complaints was correlated with a 2-year longer doctor delay (data not shown) and more than 1.7-year longer diagnostic delay (data not shown). Likewise, Ghai *et al.* (2020) found that previous misdiagnosis, such as irritable bowel syndrome, is also correlated with a longer diagnostic delay in women with endometriosis.

The dimension 'technical skills' had the highest proportion of explained variance. The dimension encompasses expertise of the physician, pro-activity of physician and the quick time to diagnosis. Where the inability to conceive within 12 months was found to be negatively associated with the dimension 'technical skills', chronic pelvic pain at first symptoms and having seen other specialists for endometriosis complaints were found to be positively associated with this dimension of patient-centeredness. It could be hypothesized that patients with chronic pelvic pain and patients that have seen other specialists for endometriosis finally feel acknowledged when they get treated in one of the four investigated centers with a lot of experience in treating endometriosis.

Having an intimate partner relationship has a positive correlation with the dimension 'involvement of significant others', but a negative correlation with the dimension 'respect for patients' values, preferences and needs'. Previously, Fernandez *et al.* (2006) described that male partners of endometriosis patients can initially, as one of the first stages of grief, express frustration, stress and anger toward the medical profession. This emotional response may negatively influence the score on 'respect for patients' values, preferences and needs' as expressed by our participants. The positive association of having an intimate partner relationship with 'involvement of significant others' could be explained by the possibility that only women with an intimate relationship experience this involvement compared to women without a relationship that cannot experience this.

Strengths and limitations

For this study, we included data from all known usages of the ECQ that were found through our systematic review. By pooling all available patient data, it was possible to optimize the sample size and increase generalizability. Using the formula for minimal sample size in multiple regression analysis of $(104 + 31 = 135)$, the current sample size should be sufficient (Green, 1991). Furthermore, it has to be noted that for both the included studies in this systematic review, some of the current authors were co-authors. Ideally, the ECQ would have been performed in more than two countries with a greater difference in research group, culture, languages and health systems, but at time of writing this is the best available evidence.

Since endometriosis is a chronic disease and care is very dynamic, it is possible that care would be valued differently at different times and at different locations. Even though endometriosis care has changed in the past century, we do not know how this may affect ECQ outcomes, as this has never been investigated. Our data are the best evidence available to date. Furthermore, the aim of this study was to identify patient-specific determinants for patient-centeredness of care. These determinants are supposedly independent of differences over time, and the date of evaluating the patient-centeredness is therefore not expected to influence these outcomes. The identified determinants were found within the Dutch and Belgian health care systems. The two systems are similar and use the same guidelines. Furthermore, culture and language are similar in the two countries. Whether these determinants are generalizable to other countries should be investigated in future research. To be able to achieve this, the ECQ should first be validated in other languages, even though the questionnaire is already available in Italian, English and Dutch (Dancet *et al.*, 2011).

Clinical implications

In this study, we sought to identify patient-specific determinants of care. These demographic and medical aspects are not subjective to

change and can therefore not be altered in order to improve patient-centeredness. By being aware of the association between the determinants and patient-centeredness of care, health care providers can tailor their care. For example, as being unable to conceive owing to endometriosis complaints is associated with lower scores for the dimension technical skills, health care providers could actively pay more attention to this aspect during their consultation. Also, health care providers might consider referring these women to a different care center earlier than they otherwise would.

Conclusion

The aforementioned determinants associated with patient-centered endometriosis care are of value for studies benchmarking clinics for their patient-centeredness. In addition, they help clinicians to determine how to tailor their care to individual patients. As Geukens *et al.* stated (2018), identifying specific patient characteristics influencing patients' experience with quality of care can help caregivers target their improvements. Future studies should focus on improving endometriosis care. The ECQ could be used as a guide to identify targets for improvement and check subsequently whether these targets have in fact been improved. In a subsequent phase, the determinants could be used to refine some of the results of the ECQ.

Supplementary data

Supplementary data are available at *Human Reproduction Open* online.

Authors' roles

The study was designed by W.N., C.L., V.M., L.H. and A.S. The systematic review was performed by L.H. and A.S. Collection of data was performed by E.D., S.A. and A.S. Expertise on the ENDOCARE questionnaire was added by E.D. and A.S. Analysis of the data was performed by M.H., P.V. and A.S. A.S. drafted the manuscript, which was critically revised and approved by all authors.

Funding

Conflict of interest

V.M. and C.B.L. report grants from Guerbet, grants from Merck and grants from Ferring outside the submitted work. All authors declare that they have no competing interests concerning this publication.

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