

The ENDOCARE questionnaire (ECQ): a valid and reliable instrument to measure the patient-centeredness of endometriosis care in Europe

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BACKGROUND: Endometriosis is prevalent and women need high-quality care, which should be patient-centered. This study aimed to develop a valid and reliable patient-centeredness questionnaire, based on a defined concept of patient-centered endometriosis care (PCEC).

METHODS: A literature review, focus groups (FGs) with patients and an expert panel defined PCEC with 10 dimensions. The ENDOCARE questionnaire (ECQ) was developed. FGs resulted in 43 specific statements covering the 10 dimensions of PCEC, for which the ECQ measured 'importance' and 'performance'. Medical and demographic questions and an open question were added. The Dutch ECQ questionnaire was piloted and reciprocally translated into English and Italian. Patients with endometriosis from Belgium, The Netherlands, Italy and the UK were invited to complete the ECQ online. Item analysis, inter-item analysis and confirmatory and exploratory factor analyses (EFA) and reliability analysis were performed. The theory-driven dimensions were adapted.

RESULTS: The ECQ was completed by 541 patients. Based on item analysis, five statements were deleted. Factor analysis was performed on 322 questionnaires (only from respondents with a partner). Insights from the data-driven EFA suggested adaptations of the theory-driven dimensions. The reliability statistics of 9/10 adapted theory-driven dimensions were satisfactory and the root mean square error of approximation was good.

CONCLUSIONS: This study resulted in a valid and reliable instrument to measure PCEC. For data presentation, the adapted theory-driven dimensions of PCEC are preferred over the data-driven factors. The ECQ may serve to benchmark patient-centeredness, conduct cross-cultural European research and set targets for improvement.

Key words: endometriosis / quality control / patient-centered care / patient-reported outcome / quality of health care

Introduction

Endometriosis is defined as the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction (Kennedy *et al.*, 2005). As endometriosis can only be diagnosed by laparoscopy, the true prevalence in the general population is

unknown, but has been estimated to vary between 2 and 10% (reviewed by Eskenazi and Warner, 1997, based on original papers by Houston *et al.*, 1987; Wheeler, 1989; Vessey *et al.*, 1993; Kjerulff *et al.*, 1996). This prevalence can rise to 30–45% in women with infertility and/or pain (Gruppo Italiana per lo studio dell'endometriosi, 1994; D'Hooghe *et al.*, 2003). Population-based studies estimated

the annual incidence of endometriosis to be between 0.1% (Gylfason *et al.*, 2010) and 0.3% (Moen and Shei, 1997).

Endometriosis has variable physical symptoms comprising chronic pelvic pain, dysmenorrhea, dyspareunia, dyschezia, dysuria, low back pain and fertility problems (Mounsey *et al.*, 2006). Additionally, endometriosis has an impact on women's emotional well-being, quality of life and interferes with daily life and work activities (Mathias *et al.*, 1996; Wingfield *et al.*, 1997; Siedentopf *et al.*, 2008; Sepulcri Rde and do Amaral, 2009; Fourquet *et al.*, 2010).

In order to meet all physical, emotional and social needs of patients, it is important to gather information on the dimension of the quality of care—'patient-centeredness'—(Corrigan *et al.*, 2001) by evaluating the quality of care from the patients' perspective. Chronically ill patients are considered experts in judging the quality of care (Van Campen *et al.*, 1995). Looking at the quality of care from the patients' viewpoint could expand the view of clinic staff to all aspects of care important to patients, including care aspects that were previously neglected and/or that are considered as additional to curing a medical condition. It would also be important for clinics to set targets for quality improvement based on the patients' perspective on care. All consumers are known to want information from 'people like them' (Edgman-Levitan and Cleary, 1996). In the future, European patients might even want information on the patient-centeredness of health care all across Europe. A directive has recently (February 2011) been approved by the European Union (EU) Council of European Ministers, which allows European patients to receive reimbursed health care in another member state, upon certain conditions (http://ec.europa.eu/health/cross_border_care/policy).

In the past, patients' views on the quality of care were assessed with satisfaction questionnaires, but the results received little attention, as the inadequate 'umbrella' concept satisfaction (Sixma *et al.*, 1998) only implies that expectations were met (Cleary and Edgman-Levitan, 1997). Additionally, satisfaction questionnaires had numerous methodological problems (Van Campen *et al.*, 1995; Dancet *et al.*, 2010a) and new methods were needed. The method 'quality of care through the patients' eyes' (QUOTE; Sixma *et al.*, 1998, 2008) has proved to be highly useful to patient-centered quality assurance and improvement in several fields of health care such as rheumatoid arthritis (Van Campen *et al.*, 1998); inflammatory bowel disease (van der Eijk *et al.*, 2001; Stubbe *et al.*, 2007), liver disease (Gutteling *et al.*, 2008), HIV (Hekkink *et al.*, 2003), cataract (Nijkamp *et al.*, 2002), breast care (Damman *et al.*, 2009), infertility (van Empel *et al.*, 2010), care for the elderly (Sixma *et al.*, 2000) and lower limb prosthesis (Van der Linde *et al.*, 2007). Until now, this methodology has not been used in endometriosis research. Only qualitative interviews (Grace, 1995; Hirsh *et al.*, 2001; Cox *et al.*, 2003a,b; Denny, 2004a,b; Huntington and Gilmour, 2005; Denny and Mann, 2008; Manderson *et al.*, 2008; Seear, 2009), qualitative questionnaires (Whitney, 1998; Greene *et al.*, 2009), non-endometriosis-specific questionnaires (Lemaire, 2004; Barnack and Christler, 2007) and self-developed non-validated experience or satisfaction questionnaires (Wingfield *et al.*, 1997; Cox *et al.*, 2003c) have been used to evaluate the patients' perspective on endometriosis care.

The aim of this study was to develop a valid and reliable instrument to measure the patient-centeredness of endometriosis care in Europe, based on a defined concept of patient-centered endometriosis care (PCEC).

Methods

The ENDOCARE questionnaire (ECQ) was developed and was validated using an international cross-sectional web-based survey.

Ethical approval was obtained from the Ethical Committee of the Leuven University Hospital on 23 September 2009.

Development of the questionnaire

'Patient-centered care' was defined as a measurable concept. Care can be considered 'patient-centered' if the health-care performance perceived by patients measures up to what is important to patients in general. The ECQ was developed according to the QUOTE methodology (Sixma *et al.*, 1998, 2008), adapted for international research.

First, patient information, a consent form and a set of 5 demographic and 10 medical questions (all self-reported by the patients) were developed (Part I of the ECQ) based on reviewing the literature on determinants of QUOTE questionnaires.

Secondly, PCEC was conceptualized and a set of statements on PCEC was developed (Part II of the ECQ). The literature was searched for articles on the patients' perspective on endometriosis care and care aspects important to patients were extracted. An expert panel, including three gynecologists and three nurses experienced in endometriosis care, suggested care aspects important to patients. Additionally, 15 women diagnosed with endometriosis in a Belgian University Hospital were contacted in the summer of 2009 using purposive sampling and grouped into two patient focus groups (FGs). Ten women, who differed in stage of endometriosis (rAFS I or II, $n = 5$; rAFS III or IV, $n = 5$), agreed to participate. Most participants were in pain ($n = 8$) and had a wish to conceive ($n = 8$). The FGs were organized as moderated brainstorm sessions (Kitzinger, 1995), structured around the eight dimensions of patient-centered care for medical and surgical patients (Table I; Gerteis *et al.*, 1993). Each dimension (e.g. 'Information, communication and education') was explored by encouraging the women to think of specific important aspects of endometriosis care. Next, the women were asked to identify important aspects of endometriosis care that could not be placed in the eight dimensions framework. This led to two additional dimensions, 'technical skills' and 'endometriosis clinic staff' as recently proposed by a literature review on the patients' perspective on fertility care (Dancet *et al.*, 2010a). The women shared that some care aspects could be part of two dimensions. FGs lasted about 2 h, were recorded digitally, transcribed verbatim and analyzed with content analysis (Graneheim and Lundman, 2004) by two researchers independently.

Finally, 43 specific statements organized according to the 10 dimensions' framework of patient-centered fertility care (Dancet *et al.*, 2010a) were formulated, relying on the wordings of the FG participants. Table I contains the statements and their rationale for inclusion. Statements were derived from one ($n = 14$) or two ($n = 29$) FGs (Table I). All dimensions of 'PCEC' were discussed in the literature and named by the experts, except for 'involvement of family and friends', which was not discussed in the literature (Table I).

In the ECQ, each statement was provided with two 4-point Likert response scales. First, a 'performance' scale measures whether the statement applies to the received care. After dichotomization, this scale results in a 'percentage of positive performance' (PPP; 0–100; agree; agree completely) and a 'percentage of negative performance' (PNP; 0–100; disagree; disagree completely). Secondly, an 'importance'—scale measuring the importance of the statement and resulting in 'mean importance scores' (MIS; 0–10; 0: not important, 3: fairly important, 6: important and 10: of the utmost importance; Sixma *et al.*, 1998). Combining both scales resulted in 'patient-centeredness scores' unique to this study (PCS; MIS × PPP; 0–1000; the higher the score, the more the statement

Table I Development of the ECQ.

| Dimensions of PCEC | Literature on the patients' perspective on endometriosis care supporting the inclusion of the dimension of PCEC | Experts' opinion on importance to patients | Statements as included in the final questionnaire organized according to the adapted dimensions of PCEC | | |
|---|--|--|---|--|------|
| | | | No. | Statement | FG's |
| Dimensions of patient-centered care (<i>Gerteis et al., 1993</i>) | | | | | |
| Respect for patients' values, preferences and expressed needs | <i>Grace (1995); Whitney (1998); Cox et al. (2003a,b,c); Denny (2004a,b); Barnack and Chrisler (2007); Denny and Mann (2008); Manderson et al. (2008); Greene et al. (2009); Seear (2009)</i> | Important | S1 | My complaints were taken seriously. | 1, 2 |
| | | | S2 | I was given the opportunity to take part in the decision after I had received all the information. | 1, 2 |
| | | | S3 | I was treated like a person and not like a number. | 1, 2 |
| Coordination and integration of care | <i>Hirsh et al. (2001)</i> | Important | S4 | The information regarding my health problem was distributed among the caregivers involved. | 1, 2 |
| | | | S5 ^a | It was possible to perform my operation (where this was necessary) by a multidisciplinary team (gynecologist, urologist, abdominal surgeon) on one day | 1, 2 |
| | | | S6 | Care was taken to plan examinations and treatments on one day. | 1, 2 |
| | | | S14 ^b | I was treated on wards that were separated from the maternity, obstetrics and peri/post-natal wards. | 1, 2 |
| Information communication and education | <i>Grace (1995); Whitney (1998); Hirsh et al. (2001); Cox et al. (2003b,c); Denny (2004a,b); Lemaire (2004); Huntington and Gilmour (2005); Denny and Mann (2008); Manderson et al. (2008); Seear (2009)</i> | Important | S7 | Everything necessary was done so that I would understand the information given (time, image material, use of language, etc.). | 1, 2 |
| | | | S8 | I received the information on the course of treatment and the various stages in advance so that I knew what to expect. | 1, 2 |
| | | | S9 | I received practical information and advice on self-care before the operation. | 1, 2 |
| | | | S10 | I received practical information and advice on self-care after the operation. | 1, 2 |
| | | | S11 | The information given to me by the various caregivers was uniform. | 2 |
| | | | S12 | I was given the opportunity to discuss my daily complaints with the caregivers. | 1 |
| | | | S13 ^b | I received information on the medication that I could take to relieve my pain. | 1, 2 |
| Physical comfort | <i>Cox et al. (2003a); Denny (2004a,b)</i> | Important | S15 ^a | I could have stayed in a private room during my stay in hospital if I paid a supplement. | 1 |
| | | | S16 | The consultation waiting room is comfortable. | 1 |
| | | | S30 ^b | The waiting time in the consultation waiting room was acceptable. | 1, 2 |
| | | | S17 | I was informed as to the psychological impact of endometriosis. | 1, 2 |
| Emotional support and alleviation of fear and anxiety | <i>Grace (1995); Whitney (1998); Hirsh et al. (2001); Cox et al. (2003a,b); Denny (2004a,b); Barnack and Chrisler (2007); Denny and Mann (2008); Greene et al. (2009); Seear (2009)</i> | Important | S18 | I was given the opportunity to consult a counselor who was familiar with problems connected with endometriosis. | 1, 2 |
| | | | S19 | I received information on a patients' organization (for endometriosis). | 1, 2 |
| | | | S26 ^b | My partner and/or family members were provided with an information brochure. | 1, 2 |
| | | | S22 ^b | Support was available for myself and my partner. | 2 |
| Involvement of family and friends | | Important | S23 | There were efforts to involve my partner during consultations. | 2 |
| | | | S24 | My partner was encouraged to be present at the consultations (by providing an absentee certificate for the employer). | 2 |
| | | | S25 | The consequences of endometriosis and the treatment for my (future) sexual relationship(s) were discussed. | 2 |
| | | | | | |

| | | | | | |
|--|---|-----------|------------------|---|------|
| Continuity and transition | Grace (1995); Hirsh <i>et al.</i> , 2001); Cox <i>et al.</i> (2003b); Denny and Mann (2008) | Important | S27 | I received sufficient information regarding recovery after the operation (the duration, the necessary care and what was to be expected). | 1, 2 |
| | | | S28 | It was clear which caregiver I could turn to with questions and/or complaints after the operation. | 1, 2 |
| | | | S29 | The physician who is treating me really follows up my case personally. | 2 |
| Access to care | Wingfield <i>et al.</i> , 1997); Hirsh <i>et al.</i> (2001); Cox <i>et al.</i> (2003a,c); Denny (2004a,b); Huntington and Gilmour (2005); Barnack and Chrisler (2007); Denny and Mann (2008); Manderson <i>et al.</i> (2008); Greene <i>et al.</i> (2009) | Important | S31 | The waiting time between the diagnostic examinations and the operation was acceptable. | 1, 2 |
| | | | S32 | I was able to contact the hospital with my questions between the consultations/ examinations via clearly specified telephone numbers and at clearly specified times | 1, 2 |
| | | | S33 | I was able to contact my attending physician. | 1, 2 |
| | | | S34 | I was able to contact a caregiver with specific knowledge of endometriosis in urgent cases (after the operation or in the event of acute pain). | 1, 2 |
| | | | S35 | The waiting time between the diagnostic examinations and/or the operation and the discussion of the result was acceptable. | 1, 2 |
| | | | S36 ^a | Patients who urgently required surgery on medical grounds were given priority. | 1 |
| | | | S37 ^a | It was possible to attend consultations outside working hours. | 1 |
| | | | S38 ^a | An estimate of the costs of the consultations, the examinations and the treatment was given in advance. | 2 |
| Dimensions of patient-centered care added based on the FGs and the 'dimensions of patient-centered fertility care' (Dancet <i>et al.</i> , 2010) | | | | | |
| Technical skills | Hirsh <i>et al.</i> , 2001); Cox <i>et al.</i> (2003b,c); Denny (2004b); Huntington and Gilmour (2005); Barnack and Chrisler (2007); Denny and Mann, 2008) | Important | S39 | I was able to rely on the expertise of the caregivers. | 1, 2 |
| | | | S40 | My physician clearly stated what complexity level of endometriosis he/she was able to treat; where necessary I was referred in good time to a specialist centre. | 1, 2 |
| | | | S41 | My physicians were proactive; they did not adopt a wait-and-see approach. | 2 |
| | | | S42 | I received a correct diagnosis within a short space of time: the endometriosis problem was recognized as such within a short time. | 2 |
| Endometriosis clinic staff | Grace (1995); Cox <i>et al.</i> (2003a,b); Denny (2004b); Huntington and Gilmour (2005); Greene <i>et al.</i> (2009) | Important | S43 | The professional caregivers were friendly. | 1, 2 |
| | | | S20 ^b | The caregivers were understanding and concerned during my treatment. | 1, 2 |
| | | | S21 ^b | I was reassured whenever necessary. | 1, 2 |

^aStatements excluded from final version of the questionnaire based on validation and reliability analysis.

^bStatements that belonged to another dimension in the original theory-driven dimensions of PCEC compared with these adapted theory-driven dimensions of PCEC.

contributes to the patient-centeredness of care) and 'quality impact indices' (MIS \times PNP; 0–1000; the higher the score, the more the statement calls for a patient-centered improvement project; Van Campen et al., 1998).

For the European ECQ, statements with two response scales (one for importance and one for performance) were preferred over the classic method for national QUOTE questionnaires (Sixma et al., 2008). Classically, two separate questions are asked for importance and performance during questionnaire validation and only the performance question is used for routine assessments after questionnaire validation (Sixma et al., 2008). In contrast with national questionnaires, the European ECQ will also address importance, because importance ratings might vary across Europe (Groenewegen et al., 2005).

Thirdly, one open-ended question addressed important aspects of endometriosis care that might have been overlooked (Part III of the ECQ).

Fourthly, the ECQ was pilot tested by four interviews with endometriosis patients.

Finally, the Dutch ECQ was translated into English and Italian according to the 'iterative forward–backward translation sequence' (Fumimoto et al., 2001).

Dissemination of the questionnaire

The ECQ was launched online from 25 November 2009 until 11 December 2009. Patients from four European countries (Italy, the UK, the Netherlands and Belgium) self-reported as surgically diagnosed with endometriosis were eligible to complete the questionnaire online anonymously. Patients were invited by tertiary endometriosis clinics disseminating information sheets and by patients' association sending emails to their members and posting a link to the ECQ on their website.

Validation of the questionnaire

Item analysis deleted statements with extremely skewed answers to the performance scale (i.e. $>90\%$ chose the most positive or most negative response category). Statements with non-response rates $>5\%$ were also considered for deletion. Inter-item correlations (Pearson correlation coefficients) needed to be <0.70 .

As advised by the QUOTE methodology, both a theory-driven confirmatory factor analysis (CFA; more specifically a simultaneous component analysis) and a data-driven exploratory factor analysis (EFA; more specifically a principal component factor analysis with an oblique rotation) were performed on respondents' performance ratings (Sixma et al., 2008) with the aid of software the SAS 9.2.

The suitability of the data set for factor analysis was assessed by considering the sample size (>300 cases; Tabachnick and Fidell, 2001) and the strength of the relationship among variables [Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy >0.60 ; a significant Bartlett's test of sphericity; Pallant, 2005; Sixma et al., 2008].

The theory-driven CFA was first based on the original 10 dimensions of PCEC. Secondly, the possibility to improve the psychometric characteristics of the ECQ by transferring statements from one dimension to another was explored. Statements that could have been part of two dimensions according to FG participants were transferred to another dimension based on insights from the factor structure of the data-driven EFA if this transfer improved the psychometric characteristics of the ECQ. The 'root mean square error of approximation' (RMSEA), 'goodness-of-fit index' (GFI) and 'adjusted goodness-of-fit index' (AGFI) of both the original and the adapted dimensions of PCEC were calculated and compared. For the data-driven EFA, the allowed number of factors was calculated. To be part of the factor, the factor loading on a statement needed to be >0.3 . Statements with high-factor loadings on more than one factor were allocated to the factor with the highest loading. Statements with a difference between the two highest loadings of <0.05

were carefully considered. Inter-factor correlations needed to be >0.70 . Finally, the data-driven factors were interpreted and named.

Reliability analysis of the original and the adapted theory-driven dimensions of PCEC and the data-driven factors

Cronbach's alpha' (α) statistic (>0.70 : reliable; 0.60 – 0.70 : moderately reliable) evaluated the internal consistency of the ECQ. Item-total correlation (ITC >0.40) evaluated whether a statement was part of a dimension/factor. The reliability measures based on respondents' importance ratings were reported in addition to those based on the performance ratings.

Analysis of the answers to the open-ended question

The answers to the open-ended question were analyzed independently through content analysis (Graneheim and Lundman, 2004) by two (or one for Italian data) researchers discussing regularly. The need for a new dimension of PCEC was evaluated.

Adaptation of the questionnaire

The first version of the ECQ was adapted through removal of redundant statements, adaptation of demographic and medical questions and removal of the open-ended question.

Results

Respondents

The ECQ was completed by 541 respondents. Respondents' characteristics are presented in Table II. Respondents had a mean age of 34 years and lived in the UK (50%), The Netherlands (29%), Italy (12%) and Belgium (9%). The majority had a European ethnic background (79%), a higher education (68%) and a membership of a patients' association (63%). Respondents' first endometriosis symptoms occurred at a mean age of 23 years (i.e. on average 12 years prior to completion of the questionnaire). Respondents waited on average 2 years to seek medical advice and received a surgical diagnosis on average 5 years after their first endometriosis symptoms occurred. Respondents had consulted their general practitioner to discuss their endometriosis symptoms about five times (median) before being referred to a specialist. Most respondents (67%) had contacted other specialists besides their current gynecologist and reported moderate-or-severe endometriosis (73%). One year prior to this study, respondents suffered from dysmenorrhea (78%), lower abdominal pain whilst not menstruating (72%), dyspareunia (66%) and/or fertility problems (47%).

Validation of the questionnaire

None of the items was extremely skewed. Eight statements had high non-response rates ($>5\%$). Statements S22, S23 and S24 had high non-response rates (15–17%) because they were only relevant to patients with a partner. These statements were not deleted but factor analysis was limited to the questionnaires of patients with a partner ($n = 322$). The high non-response rate (39%) on statement S5 (Table I) can be explained by its complexity, answering it requires insight into both the medical data and the clinic's organization. Therefore, it was excluded from the factor analysis and translated into a medical background question, to be included in Part I of the final ECQ.

Table II Self-reported participants' characteristics (n = 541).

| Characteristic ^a | n (%) |
|--|----------|
| Age (mean ± SD) | 34 (±7) |
| Country of residence | |
| The UK | 271 (50) |
| The Netherlands | 158 (29) |
| Italy | 63 (12) |
| Belgium | 47 (9) |
| Ethnic background | |
| North-West European | 415 (79) |
| Other Caucasian | 69 (13) |
| Other | 39 (7) |
| Highest degree of education | |
| Primary school | 2 (<1) |
| Lower secondary school (up to age of 16 years) | 27 (5) |
| Upper secondary school (up to age of 17/18 years) | 68 (13) |
| Junior or senior secondary vocational education | 77 (14) |
| Higher education or university | 284 (53) |
| Postgraduate education | 83 (15) |
| Member of a patient association for endometriosis | 339 (63) |
| Age at which first symptoms of endometriosis occurred (mean ± SD) | 23 ± 8 |
| Time since first symptoms of endometriosis occurred (mean ± SD) | 12 ± 8 |
| Degree of endometriosis at first diagnosis according to gynecologist | |
| Minimal–mild endometriosis | 146 (27) |
| Moderate–severe endometriosis | 387 (73) |
| Symptoms related to endometriosis experienced during last year | |
| Reduced fertility | 254 (47) |
| Painful menstruation | 420 (78) |
| Pain during sexual intercourse | 354 (66) |
| Lower abdominal pain whilst not menstruating | 389 (72) |
| Tried more than 12 months to become pregnant, without result | 264 (49) |
| Contacted other specialists than current gynecologist for symptoms related to endometriosis | 363 (67) |
| Other gynecologist | 216 (40) |
| Gastro-enterologist | 156 (29) |
| Urologist | 82 (15) |
| STD clinic | 41 (8) |
| Physiotherapist | 0 (0) |
| Other | 78 (14) |
| Time lapse between first symptoms and search for help (mean ± SD) | 2 ± 4 |
| Time lapse between first symptoms and surgical diagnosis (mean ± SD) | 5 ± 6 |
| Number of consultations with GP, related to endometriosis symptoms, before first being referred to a specialist (Median) | 5 |
| 0–2 | 156 (31) |
| 3–5 | 119 (22) |
| 6–9 | 67 (11) |
| ≥ 10 | 189 (36) |

^aNumber of missing values per characteristic: 1–40.

The other four statements (S15, S36, S37 and S38; Table I) with non-response rates ranging from 5% (S37) to 16% (S38) were deleted.

The inter-item analysis did not result in the deletion of items; the highest Pearson correlation coefficient was 0.66 (between S7 and S8), whilst all other correlation coefficients were <0.60.

Table III Respective statements and reliability measures of the original theory-driven dimensions of PCEC, the adapted theory-driven dimensions of PCEC and the data-driven factors.

| Dimensions of PCEC/factor | Statements (total) | Cronbach's alpha ^b | Range of item-total correlations ^b |
|---|---|-------------------------------|---|
| Original and adapted theory-driven dimensions of PCEC | | | |
| Respect for patients' values, preferences and expressed needs | Original: S1, S2, S3 (n = 3) | P: 0.74 I: 0.66 | P: 0.54–0.60 I: 0.44–0.51 |
| | Coordination and integration of care | Original: S4, S6 (n = 2) | P: 0.50 I: 0.42 |
| Information, communication and education | Adapted: S4, S6, S14 ^a (n = 3) | P: 0.49 I: 0.44 | P: 0.25–0.35 I: 0.22–0.32 |
| | Original: S7, S8, S9, S10, S11, S12 (n = 6) | P: 0.83 I: 0.84 | P: 0.55–0.69 I: 0.52–0.67 |
| Physical comfort | Adapted: S7, S8, S9, S10, S11, S12, S13 ^a (n = 8) | P: 0.85 I: 0.85 | P: 0.53–0.69 I: 0.54–0.66 |
| | Original: S13 ^a , S14 ^a , S16 (n = 3) | P: 0.31 I: 0.47 | P: 0.13–0.25 I: 0.25–0.32 |
| Emotional support and alleviation of fear and anxiety | Adapted: S16, S30 ^a (n = 2) | P: 0.61 I: 0.58 | P: 0.44 I: 0.41 |
| | Original: S17, S18, S19, S20 ^a , S21 ^a , S22 ^a (n = 6) | P: 0.80 I: 0.81 | P: 0.45–0.62 I: 0.50–0.62 |
| Involvement of family and friends | Adapted: S17, S18, S19, S26 ^a (n = 4) | P: 0.76 I: 0.80 | P: 0.51–0.63 I: 0.53–0.66 |
| | Original: S23, S24, S25, S26 ^a (n = 4) | P: 0.74 I: 0.81 | P: 0.50–0.60 I: 0.54–0.70 |
| Continuity and transition | Adapted: S22 ^a , S23, S24, S25 (n = 4) | P: 0.78 I: 0.81 | P: 0.50–0.62 I: 0.52–0.69 |
| | Original: S27, S28, S29 (n = 3) | P: 0.71 I: 0.77 | P: 0.45–0.65 I: 0.54–0.64 |
| Access to care | Original: S30 ^a , S31, S32, S33, S34, S35 (n = 6) | P: 0.75 I: 0.78 | P: 0.35–0.56 I: 0.38–0.61 |
| | Adapted: S31, S32, S33, S34, S35 (n = 5) | P: 0.75 I: 0.79 | P: 0.41–0.55 I: 0.49–0.59 |
| Technical skills | Original: S39, S40, S41, S42 (n = 4) | P: 0.76 I: 0.75 | P: 0.45–0.64 I: 0.46–0.64 |
| Endometriosis clinic staff | Original: S43 (n = 1) | — | — |
| | Adapted: S20 ^a , S21 ^a , S43 (n = 3) | P: 0.80 I: 0.73 | P: 0.57–0.71 I: 0.52–0.57 |
| Data-driven factors | | | |
| Staff | S7, S11, S12, S20, S21, S39, S40, S43 (n = 8) | P: 0.89 I: 0.87 | P: 0.55–0.67 I: 0.46–0.61 |
| Information | S8, S9, S10, S13, S27, S28 (n = 6) | P: 0.85 I: 0.85 | P: 0.54–0.68 I: 0.51–0.68 |
| Partner involvement | S22, S23, S24, S25 (n = 4) | P: 0.78 I: 0.81 | P: 0.50–0.62 I: 0.52–0.69 |
| Personalized care and timeliness | S1, S2, S3, S4, S31, S35, S41, S42 (n = 8) | P: 0.81 I: 0.74 | P: 0.51–0.65 I: 0.41–0.52 |
| Emotional support | S17, S18, S19, S26 (n = 4) | P: 0.76 I: 0.80 | P: 0.51–0.63 I: 0.53–0.66 |
| Waiting | S16, S30 (n = 2) | P: 0.61 I: 0.58 | P: 0.44 I: 0.40 |
| Organization of care | S6, S14 (n = 2) | P: 0.35 I: 0.36 | P: 0.21 I: 0.22 |
| Case management | S29, S32, S33, S34 (n = 4) | P: 0.73 I: 0.66 | P: 0.57 I: 0.49 |

^aStatements that belong to another dimension in the adapted theory-driven dimensions of PCEC compared with the original theory-driven dimensions of PCEC.^bBased on both performance ratings (P) and importance ratings (I).

The data set included in our study was suitable for factor analysis: the sample size was sufficient ($n = 322$), the Kaiser–Meyer–Olkin measure of sampling was high enough (0.926) and the Bartlett's test of sphericity was significant ($P < 0.001$). Factor analysis was based on data from 322 respondents.

For both performance (P) and importance (I) ratings, the original theory-driven CFA indicated a slightly low but acceptable score for developing theories such as GFI (0.80 for P ; 0.83 for I) and AGFI (0.75 for P ; 0.79 for I ; Kääriäinen *et al.*, 2011). The RMSEA for performance (0.068) was acceptable and the RMSEA for importance (0.058) was good (< 0.06 ; Kääriäinen *et al.*, 2011).

In the adapted theory-driven CFA, seven statements (Table III) were transferred from one dimension to another. This resulted, for both performance (P) and importance (I) ratings, in an improved GFI (0.83 for P ; 0.85 for I), AGFI (0.79 for P ; 0.82 for I) and RMSEA (0.059 for P ; 0.050 for I).

The data-driven EFA resulted in eight factors (Table III), while six (Scree test) to eight factors (Kaiser criterion; amount of statements with an 'eigenvalue' > 1.0 ; Supplementary data, Appendix II) were allowed. All statements had at least one factor loading > 0.39 (Supplementary data, Appendix II). For statements S4, S17, S28, S34, S35 and S40 the difference between the two highest loadings was < 0.05 (Supplementary data, Appendix II). After discussion, the research team decided to preserve these statements. Statement S4 had the smallest (0.006) difference between its highest factor loadings. Based on its content, an exception was made and it was allocated to the factor with the second highest factor loading. All inter-factor correlations were > 0.36 (Supplementary data, Appendix III). The eight factors with their respective statements are presented in Table III and interpreted as follows: 'information', 'partner involvement', 'personalized care and timeliness', 'staff', 'emotional support', 'case management', 'waiting' and 'organization of care'. The factor 'staff' included staff communication skills, daily patient support and competence.

Reliability analysis of the original and the adapted theory-driven dimensions of PCEC, and the data-driven factors

Seven out of 10 original theory-driven dimensions of PCEC could be measured reliably. For the dimensions 'coordination and integration of care' and 'physical comfort' Cronbach's alpha's and ITC's (Table III) were too low. The dimension 'endometriosis clinic staff' was addressed by only one statement.

Nine out of 10 adapted theory-driven dimensions of PCEC could be measured reliably. For the dimension 'coordination and integration of care', Cronbach's alpha's and ITC's (Table III) remained too low.

All factors generated by the data-driven EFA, except 'organization of care' (Cronbach's alpha's and ITC's were too low), could be measured reliably (Table III).

Analysis of the answers to the open-ended question

In total, 268 respondents provided 606 comments.

Most comments ($n = 452$, 75%) referred to questionnaire statements (most frequently S1; $n = 80$). Patients described their experience or their reason for the attached importance in detail.

There were 37 comments suggesting 9 new care aspects not yet specifically addressed by the statements. Whereas 7 aspects were only suggested 1–3 times, 2 aspects (provision of information on alternatives to medical treatment and provision of information on fertility) were suggested 18 and 9 times, respectively. However, these nine new care aspects are covered by the 10 dimensions of PCEC, requiring no new dimensions.

In 57 comments, respondents expressed their experience of illness and suffering. In 14 comments, respondents described their general satisfaction: satisfied ($n = 3$), dissatisfied ($n = 5$) and mixed ($n = 6$).

Comments on the questionnaire were also made ($n = 35$). Most respondents ($n = 11$) expressed their gratefulness for the study or shared that it was difficult to answer the questionnaire if care had been provided by several clinics ($n = 6$). Other comments were made by no more than three respondents.

The final ECQ

The final ECQ is presented in Supplementary data, Appendix I. Statements S15, S36, S37 and S38 were deleted based on high non-response rates. Statement S5 was rephrased and transferred to Part I of the questionnaire. Additionally, two questions on partnership (Q18, Q19) and four questions on fertility (Q13–Q17) were added to Part I of the final ECQ. Part III of the questionnaire was deleted. Finally, Part I includes 21 questions and Part II includes 38 statements.

Discussion

In this paper, the conceptualization of the quality dimension 'patient-centeredness' for endometriosis care using systematic literature review data, expert panel opinion and patient FGs resulted in 10 dimensions of PCEC. All 10 dimensions were included in the newly designed ECQ. The instrument was validated after testing in four different countries by both theory-driven CFA and data-driven EFA, and adaptations were made to the original theory-driven dimensions. The ECQ proved to measure 9 out of 10 adapted theory-driven dimensions of PCEC reliably. This ECQ will contribute to an overall view on the quality of endometriosis care (together with information on effectiveness, efficiency, safety, equity, timeliness; Corrigan *et al.*, 2001) and can be used for benchmarking in Europe. The novelty of our approach is based on the conceptualization of 'patient-centeredness' specifically for endometriosis care, on the development of a valid and reliable instrument to assess this PCEC and on the international dimension of the validation steps.

The ECQ is the only validated and reliable instrument to evaluate the patient-centeredness of endometriosis care. However, endometriosis specific, validated and reliable instruments exist for patient-reported outcomes (PRO's) other than patient-centeredness, including health-related quality of life (Endometriosis Health Profile (EHP)-30; Jones *et al.* 2001; and an endometriosis-specific questionnaire to add to the Short Form 36; Bodner *et al.*, 1997), patient satisfaction with symptom improvement after endometriosis treatment (Endometriosis Treatment Satisfaction Questionnaire; ETSQ; Deal *et al.*, 2010b) and treatment-related changes in endometriosis symptoms (Endometriosis Pain and Bleeding Diary; EPBD; Deal *et al.*, 2010a).

The concept PCEC is multidimensional. The two dimensions ('technical skills' and 'endometriosis clinic staff') that had to be added to the

eight dimensions framework of patient-centered care (Gerteis et al., 1993) were similar for endometriosis care and for fertility care (Dancet et al., 2010a). This is not surprising since infertility and endometriosis often co-exist and a causal relationship is presumed (D'Hooghe et al., 2003; Meuleman et al., 2009). The multidimensional aspect of PCEC is also shown by the incorporation of human factors (e.g. emotional support and alleviation of fear and anxiety) besides system factors (e.g. access to care; Dancet, et al., 2011). All dimensions of PCEC, also those that are less obvious than 'technical skills', should receive attention in daily care.

Development and validation of the ECQ in an international setting is a challenge. All other endometriosis-specific PRO instruments were first developed and validated in a mono-country setting in one language only. Some, like the EHP-30, were translated and validated for other countries in a second phase (Jenkinson et al., 2008; Mengarda et al., 2008; van de Burgt et al., 2011). Only one other study (van der Eijk et al., 2001) used the QUOTE methodology in an international setting (in the field of 'Inflammatory Bowel Disease'). The qualitative research for the development of their questionnaire was international, but statistical validation was conducted in one country only. For the ECQ, the qualitative research was conducted in one country only but the validation and reliability were assessed in an international setting. Conducting both the qualitative research and statistical validation internationally would be ideal, but has not yet been done. In our study, the lack of international qualitative research during questionnaire development was compensated for by a review of the international literature and qualitative analysis of answers of patients from four European countries to an open-ended question. Consequently, the ECQ is certainly reliable for the respective four European countries. Confirmatory validity and reliability testing in other European countries would be very interesting. However, due to the international dimension of the current study, the questionnaire is likely to be reliable for other European countries. The fact that the questionnaire serves for international benchmarking is very interesting in view of the increasing mobility of European patients within the EU.

Our study is characterized by a number of strengths. First, the PCEC concept and the ECQ were developed based on a combination of a literature review, an expert panel, and patient FGs. This scientific basis ensured that all care dimensions relevant to patients are covered. Secondly, the PCS, the main outcome of the questionnaire, takes possible cultural differences into account by weighing performance for patient importance, and therefore the ECQ is very applicable to international research. Thirdly, the disease stage distribution of the population studied, containing approximately one-third of women with self-reported minimal–mild endometriosis, was similar to that among women with medically verified surgical diagnoses of endometriosis when sampled from the general population (Gylfason et al., 2010). Fourthly, the ECQ meets the quality criteria set for instruments assessing the quality of care from the patients' perspective (Van Campen et al., 1995). Fifthly, the ECQ has advantages over satisfaction research. Finally, both the theory-driven CFA and the EFA were performed for validation. The latter three strengths are discussed below.

The ECQ meets the six criteria for instruments assessing the quality of care from the patients' perspective (Van Campen et al., 1995). First, it is theory based with the concept 'patient-centered care' explicitly operationalized, whilst the published QUOTE methodology was followed. Secondly, the ECQ is structured around subscales (i.e. 10 dimensions

of PCEC) between which the questionnaire discriminates. Thirdly, the ECQ is valid and reliable. The validity and reliability of instruments are major criteria for assessing its quality, adequacy and trustworthiness (Polit and Beck, 2004). The instrument's validity refers to whether the instrument assesses what it intends to measure and an instrument's reliability refers to its measurement consistency. The face-validity and content validity of the ECQ are ensured by the use of patient FGs, an additional open question in the questionnaire and a pilot test of the questionnaire (Damman et al., 2009; Rothman et al., 2009). The factors and dimensions of the ECQ are internally consistent and nearly all can be reliably measured. Fourthly, the ECQ is feasible. Efforts were made to shorten the questionnaire. As advised based on cost-effectiveness and response rates, an online or 'paper and pencil approach' was preferred to a personal approach (Van Campen et al., 1998). Furthermore, the online provision of the questionnaire proved to be feasible. Based on insights from similar research with rheumatic patients (Van Campen et al., 1998), it is unlikely that including mainly members of patients' associations influenced our results. Fifthly, patient participation was ensured during questionnaire development and validation. Sixthly, the ECQ is endometriosis specific.

The ECQ has three advantages over satisfaction research. It examines the clearly conceptualized PCEC, and patient-centeredness was operationalized in care performance matching what's important to patients, instead of evaluating the 'umbrella' concept satisfaction (Sixma et al., 1998). Moreover, compared with the evaluation questions of satisfaction research, the ECQ included report-type performance questions that are more appropriate to reflect the quality of care and are easier to interpret and to action for quality improvement purposes (Cleary et al., 1991; Cleary and Edgman-Levitan, 1997). Finally, the 'patient-centeredness scores' (PCS) of the ECQ offer an advantage over satisfaction research in that the performances are weighted by their importance to patients (Van Campen et al., 1998).

Both a CFA and an EFA were performed as advised by methodological QUOTE experts (Sixma et al., 2008). Most QUOTE questionnaires only report an EFA. The two studies that used a CFA did so based on the theoretic taxonomy differentiating structure from process items (Van Campen et al., 1998; Sixma et al., 2000). In our study, insights from the data-driven EFA resulted in an adaptation of the theory-driven dimensions, which lead to an improvement in the psychometric characteristics of the instrument. Our group prefers reporting on the adapted theory-driven dimensions over reporting on the data-driven factors because: (i) basing questionnaire development on sound multidimensional taxonomies is important (Van Campen et al., 1995) and adhering to these dimensions for factor analysis is consistent; (ii) theoretical dimensions are easier to interpret and easier to communicate; and (iii) the psychometric characteristics of the data-driven factors are comparable with those of the adapted theory-driven dimensions.

Four critical considerations need to be made. It was difficult for respondents to answer the ECQ properly if care had been provided by different clinics. This is not surprising, since defining the time frame for consumers' quality measures (Cleary and Edgman-Levitan, 1997) and specifying the type of professional are known challenges (Sixma et al., 1998). In this study, we searched for national measures of patient-centeredness. However, if the ECQ is used on a clinic level, this can be prevented by clearly asking to answers the questions in the light of care received in the evaluated clinic.

Additionally, bias could have occurred. The threat of recall bias is due to the retrospective nature of the study (Coughlin, 1990). The possible threat of memory bias (Coles and Heimberg, 2002) is due to the long term, insidious and non-fatal nature of endometriosis and the fact that patients often visit several medical services. Patients could have relied on more recent or more remarkable experiences that were freshest in their memory when answering the questionnaire.

It is also important to note that the ECQ measures the aspects of care most important to the majority of patients and that the results of the ECQ will report on the overall patient-centeredness. It remains crucial for PCEC to tailor care to the needs of individual patients.

Lastly, factor analysis was performed based on performance scores, as advised by methodological QUOTE experts (Sixma *et al.*, 2008). Many other QUOTE instruments based their factor analysis on importance scores because they are more stable (i.e. less skewed, less situation dependent; Van Campen *et al.*, 1998; Sixma *et al.*, 2000; Nijkamp *et al.*, 2002; Hekkink *et al.*, 2003; Gutteling *et al.*, 2008). However, performance scores were not skewed in our data set. Additionally, we report on the reliability measures for both the performance and the importance scores.

The conceptualization of PCEC and the development and validation of the ECQ for Europe are an important first step in evaluating and improving the patient-centeredness of endometriosis care in Europe. However, several challenges remain for future patient-centeredness research in the field of endometriosis.

For researchers using the ECQ, it will be interesting to do so both on the clinic and on the country levels, resulting in clinic- and country-specific measures, respectively. Researchers using the ECQ will be able to report on the six interesting opportunities offered by the ECQ. First, the ECQ can validly and reliably measure the patient-centeredness of endometriosis care across Europe. Secondly, the importance ratings of the ECQ can be used to compare the European patients' perspective on endometriosis care regionally. Thirdly, the performance ratings of the ECQ can serve to compare the performance of countries and clinics. Fourthly, the ECQ can generate information on specific strengths (statements and factors) contributing most to the patient-centeredness of care, based on the 'PCS'. Fifthly, the ECQ can be used to set targets for patient-centered improvement projects, thanks to the 'quality improvement indices'. However, designing improvement projects to attain these targets might require more research (e.g. qualitative; Dancet *et al.*, 2010b). Sixthly, the ECQ can serve to benchmark European countries for patient-centeredness, based on the 'PCS'.

For researchers evaluating the features of the ECQ several challenges remain. Future ECQ research should compare the perspectives of patients from different subgroups, evaluate the need to make case-mix adjustments and document the discriminative power of the questionnaire. Furthermore, in infertility care, Aarts *et al.* (2011) showed that professionals cannot adequately evaluate the patient-centeredness of their clinic and do not agree with patients on improvement targets. It would be interesting to use the ECQ to assess this for endometriosis care. However, reaching an adequate sample size of professionals for this study would be challenging (Aarts *et al.*, 2011). In addition, it would be interesting to examine the relationship between PCEC and other endometriosis-specific PRO's assessed with validated instruments. Lastly, it would be interesting to conduct pre- and post-assessments

of the patient-centeredness of endometriosis care for patient-centered improvement projects.

Supplementary data

Supplementary data are available at <http://humrep.oxfordjournals.org/>.

Authors' roles

E.A.F.D., W.S., M.W. and T.D. conducted the literature review and qualitative study to design the questionnaire. E.A.F.D., M.W. and L.A. developed and managed the main database. E.A.F.D., L.A. and D.T. conducted data-analysis. E.A.F.D., L.A., D.T., W.S., M.W. and T.D. interpreted the data and drafted the paper. K.T.Z., C.T.C., W.N. and J.A.M.K. contributed to the conception, design. L.T., B.D.B., J.V., H.V.H. contributed to conception and patient recruitment. All authors reviewed successive drafts of the paper.

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