The ENDOCARE questionnaire guides European endometriosis clinics to improve the patient-centeredness of their care

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STUDY QUESTION: How patient-centered are two included specialized endometriosis clinics relative to each other and how can they improve the patient-centeredness of their care?

SUMMARY ANSWER: The validated ENDOCARE questionnaire (ECQ) reliably concluded that the adjusted overall patient-centeredness did not differ between the clinics, that each clinic was significantly more patient-centered for 2 out of 10 dimensions of patient-centered endometriosis care and that clinics 1 and 2 had to improve 8 and 13 specific care aspects, respectively.

WHAT IS KNOWN ALREADY: Patient-centered endometriosis care is essential to high-quality care and is defined by 10 dimensions. The ECQ was developed, validated and proved to be reliable in a European setting of self-reported endometriosis patients but had not yet been used at a clinic level for quality management.

STUDY DESIGN, SIZE, DURATION: A cross-sectional survey was disseminated in 2011 to all 514 women diagnosed with endometriosis during a laparoscopy indicated for pain and/or infertility during a retrospective 2-year period (2009–2010) in two university clinics from two different European countries.

PARTICIPANTS/MATERIALS, SETTING, METHODS: In total 337 patients completed the ECQ (216 and 121 per clinic). Respondents had a mean age of 34.3 years. Three in four reported a surgical diagnosis of moderate or severe endometriosis and the majority reported surgical treatment by a multidisciplinary team. The ECQ assessed the 10 dimensions of patient-centeredness, more specifically whether the health-care performance, as perceived by patients, measured up to what is important to patients in general.

MAIN RESULTS: The ECQ was completed by 337 respondents (response rate = 65.6%). Reliability and validity of the ECQ for use on clinic level were confirmed. Clinics did not differ in overall mean importance scores; importance rankings of the ECQ dimensions were almost identical. The overall patient-centeredness scores (PCS), adjusted for education level, did not discriminate between the clinics. However, the adjusted PCS for the dimensions ‘clinic staff’ and ‘technical skills’ were significantly better in clinic 1, whereas the dimensions ‘physical comfort’ and ‘access to care’ were significantly better in clinic 2. There were 8 (clinic 1) and 13 (clinic 2) targets identified for joint and cross-clinic improvement.

LIMITATIONS, REASONS FOR CAUTION: Response rates were relatively high. Recall bias was the most important limitation and research in more clinics is needed to define the statistical discriminative value of the ECQ.

WIDER IMPLICATIONS OF THE FINDINGS: European endometriosis clinics can use the validated ECQ for reliable assessment of their ‘patient-centeredness’, for comparison with others and for setting specific targets to improve the patient-centeredness of their endometriosis care, to plan interventions, and to evaluate their effectiveness.

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Key words: patient-centered care / endometriosis / questionnaire
Introduction

Quality management is important to clinics. Quality of care is defined by six dimensions (Corigan et al., 2001). In obstetrics and gynecology most attention has been devoted to the dimensions ‘safety’ and ‘effectiveness’. Another important quality dimension is ‘patient-centeredness’, which depends on being respectful of and responsive to individual patient preferences and needs and on care being guided by patients’ values (Corigan et al., 2001). Important safety and effectiveness quality metrics, such as the use of prophylactic antibiotics for Cesarean delivery (Janakiraman and Ecker, 2010) and live birth per IVF cycle (Nelen et al., 2007), should be complemented by assessing the patient-centeredness of care.

For several reasons, quality management might be especially challenging for endometriosis care. First, the population prevalence is high and has been estimated to vary between 2 and 10% (reviewed by Eskenazi and Warner, 1997, based on Houston et al., 1987; Wheeler, 1989; Vessey et al., 1993; Kjerulf et al., 1996). Endometriosis is even more prevalent in women with infertility or pelvic pain, up to 47% prevalence (Meuleman et al., 2009). Second, endometriosis is an enigmatic disease (Holoch and Lessey, 2010; Kappou et al., 2010; Adamson, 2011). There is no consensus on the etiology of endometriosis (Kappou et al., 2010) and professional discussion on appropriate staging, prognosis and treatment continues (Kappou et al., 2010; Holoch and Lessey, 2010; Adamson, 2011). Third, endometriosis presents with variable physical symptoms (Mounsey et al., 2006) and impairs health-related quality of life, especially in the domains of pain and psychosocial functioning (Gao et al., 2006). Fourth, women with endometriosis rely on different health-care settings, including primary, secondary and tertiary care, and multidisciplinary collaboration is often required.

Recently, ‘Patient-Centered Endometriosis Care’ was conceptualized with 10 dimensions and the valid and reliable ‘ENDOCARE Questionnaire’ (ECQ) was developed for assessment (Dancet et al., 2011a). The ECQ has so far only been used at country level, with recruitment of patients by patients’ associations. Its utility to guide endometriosis the quality management of clinics has not yet been evaluated. More specifically, it is unknown to which extent the ECQ can be used to assess and compare the patient-centeredness of endometriosis care within and between clinics, and to identify specific targets for the improvement of the patient-centeredness of endometriosis care. Furthermore, it has not been explored if and how endometriosis clinic staff can identify targets and learn from other clinics about how to provide and improve patient-centered endometriosis care.

Therefore, the aim of this study was to assess and compare the patient-centeredness of endometriosis care in two European clinics, with the goal to identify clinic-specific targets for patient-centered improvement.

Materials and Methods

A retrospective survey was conducted in two university endometriosis clinics, one in Belgium (Leuven University Hospital) and one in the Netherlands (Radboud University Nijmegen Medical Centre). In Belgium, ethics committee approval was acquired (ML7084). In the Netherlands, the ethics committee judged ethical approval was not required. Data were analyzed with SPSS 19.0 (SPSS Inc., Chicago, IL, USA).

The ECQ

The ECQ was developed according to the consumer quality index (CQI) methodology (Sixma et al., 2008), adapted for international use. ‘Patient-centered endometriosis care’ was conceptualized as care for which health-care performance, as perceived by patients, measures up to what is important to patients in general. Full information on the ECQ can be retrieved from the development and validation paper (Dancet et al., 2011a). Briefly, part one of the ECQ contains 8 demographic and 15 medical questions. Part two contains 38 statements on specific care aspects covering the 10 dimensions of patient-centered endometriosis care (Supplementary data, Table SI). Patients rate these statements on four-point Likert scales for importance and performance. The ECQ generates mean importance scores (MIS; 0–10; the higher, the more important for patients) and percentages of negative performance (PNP; 0–100; the higher, the more often a care aspect is negatively experienced by patients). Patient-centeredness scores (PCS) are computed (MIS* (100 − PNP)/100; 0–10; the higher, the more patient-centered). Measures are generated at three levels: specific care aspects (n = 38), dimensions of patient-centered endometriosis care (n = 10) and the overall score (the latter two are mean sum scores). Finally in part three, patients can comment on the feasibility and content of the ECQ.

Dissemination of the ECQ

All autochthonous, Dutch speaking women, diagnosed with endometriosis during a laparoscopy indicated by pain and/or infertility during a retrospective 2-year period (2009–2010) in two university clinics (Leuven University Center of Reproductive Medicine, Belgium and Nijmegen University Center of Reproductive Medicine, the Netherlands) were considered for inclusion in this study and invited to participate in the beginning of 2011 (n = 514). In the Belgian clinic, surgical diagnosis was confirmed by histology, whereas this histological confirmation was not always performed in the Dutch clinic. Questionnaires were sent by mail, accompanied by an invitation letter, an informed consent form (only for Belgian patients), a refusal form and a stamped return envelope. Non-responders received two reminders. Participation was voluntary and no (financial) compensation was given. Questionnaires were anonymous but coded.

Data analysis

Measures of central tendency and variability were generated for patients’ characteristics and clinics’ samples were compared with independent t-, Fisher exact and χ² tests (statistically significant at P < 0.05).

Confirmatory reliability and validity analysis

Item analysis (identifying statements with extremely skewed answers or high non-response rates) and inter-item analysis were conducted. The reliability of the ECQ was evaluated for each clinic separately, based on importance ratings which have been reported to be more stable than performance ratings (van Campen et al., 1998; Sixma et al., 2000; Hekking et al., 2003), with Cronbach’s alpha coefficients and item total correlations (ITC). The validity of the ECQ for the entire sample was evaluated by confirmatory factor analysis (CFA; i.e. simultaneous component analysis; SAS 9.3 statistical package; Dancet et al., 2011a) and described by (adjusted) goodness of fit indexes (GFI and AGFI) and root mean square error of approximation (RMSEA; Kaariainen et al., 2011).

The face validity of the 10 dimensions of patient-centered endometriosis care was appraised by content analysis of the answers with the open-ended question (Graneheim and Lundman, 2004; Polit and Beck, 2008).
Comparing the importance ratings of the clinics

Mann–Whitney U-tests compared both clinics’ overall MIS. The dimensions’ rankings based on MIS per dimension were considered and Kendall’s coefficient of concordance assessed the level of agreement in rankings per country and for the entire group. Additionally, a Kendall’s coefficient of concordance (ranging from 0: no agreement to 1: complete agreement) between the countries’ overall rankings was calculated.

Case-mix adjusted assessment and comparison of the clinics’ patient-centeredness

The need for case-mix adjustment of the overall PCS for the questioned patient characteristics was evaluated. First, co-linearity between patient characteristics indicated the exclusion of five characteristics, strongly correlating to other more clinically relevant characteristics (Pearson correlation coefficients $\geq 0.71$). Second, univariate linear regression indicated an association ($P < 0.20$) between 11 patient characteristics and the overall PCS. Third, stepwise linear regression models with manual backward elimination concluded case-mix adjustments of the overall PCS were only necessary for education level ($P = 0.001$). More specifically, having a university (college) degree related to lower overall PCS.

Linear regressions concluded that case-mix adjustment of the PCS per dimension for education level was required for five dimensions of patient-centered endometriosis care, namely: ‘physical comfort’ ($P < 0.0001$), ‘emotional support and alleviation of fear and anxiety’ ($P = 0.028$), ‘involvement of significant others’ ($P < 0.0001$), ‘continuity and transition’ ($P = 0.026$) and ‘access to care’ ($P = 0.022$).

Finally, linear regressions generated and compared adjusted overall PCS and PCS per dimension (adjusted if required) for each clinic.

Identifying targets for patient-centered improvement

Specific targets for patient-centered quality improvement projects were identified per clinic with an importance–performance matrix derived from production management (Fig. 1; Slack, 1994). As suggested for CQI feedback reports, scatterplots modeled MIS and PNP (Damman et al., 2009). The axes of the quadrant were set on the overall MIS per clinic and on a PNP of 15% (Damman et al., 2009). The specific targets for improvement appeared in the upper right quadrant of the matrix (Fig. 1).

Potential of clinic staff to identify patient-centered improvement targets

In each clinic, four staff members (midwives or gynecologists) specialized in endometriosis filled out the ECQ by placing themselves in the shoes of their patients. For each clinic, Kappa statistics evaluated the level of agreement between patients and staff in identifying targets for patient-centered improvement with the aid of an importance–performance matrix. Patient-centered improvement targets (appearing in the upper right quadrant of the importance–performance matrix) were considered rightfully identified by staff if they were also identified by patients.

Potential of cross and joint clinic improvement

For the improvement targets identified for one clinic only, differences between the clinics in PNP were examined with $\chi^2$ tests ($P < 0.05$). Targets, for which PNP differed significantly between the clinics, called for international cross-clinic improvement (i.e. the worst performing clinic can learn from the other). For the other targets, international joint improvement is advised.

Results

Respondents

In total 337 patients completed the ECQ ($n = 216$ or 67.5% for clinic 1; $n = 121$ or 62.4% for clinic 2; seven additional questionnaires with less than half of the questions filled out were excluded).

Respondents’ characteristics and significant differences between the clinics are presented in Table I. Respondents had a mean age of 34.3 years (but were older in clinic 2). The majority had a European ethnic background, a high degree of education (more likely for clinic 1), were not a member of a patients’ association (more so for clinic 1) and had an intimate partner. About half of the respondents had been pregnant (more likely in clinic 2), the majority wished to have (more) children and had experienced infertility. Respondents’ first endometriosis’ symptoms occurred at a mean age of 26.8 years, which was on average 8.6 years prior to filling out the ECQ (but was longer for clinic 2). Three in four reported a surgical diagnosis of moderate or severe endometriosis and the majority reported surgical treatment by a multidisciplinary team (more likely in clinic 1). Most respondents had endometriosis symptoms during the last year (more likely in clinic 1).

Figure 1 Importance–performance matrix.
Table 1: Characteristics of participants from each clinic and from both clinics and significance of the difference in samples’ characteristics between the clinics.

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Clinic 1 n (%)</th>
<th>Clinic 2 n (%)</th>
<th>Total n (%)</th>
<th>P-value for difference between clinics*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinic 1</strong></td>
<td>33.8 (4.7) (n = 215)</td>
<td>35.1 (5.2) (n = 120)</td>
<td>34.3 (4.9) (n = 335)</td>
<td><strong>0.019</strong></td>
</tr>
<tr>
<td><strong>Demographic characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age (mean; SD)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>European</td>
<td>153/164 (93.3%)</td>
<td>89/99 (89.9%)</td>
<td>242/263 (92.0%)</td>
<td>0.3253</td>
</tr>
<tr>
<td>Other</td>
<td>11/164 (6.7%)</td>
<td>10/99 (10.1%)</td>
<td>21/263 (8.0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Degree of education</strong></td>
<td></td>
<td></td>
<td></td>
<td><strong>0.0037</strong></td>
</tr>
<tr>
<td>European</td>
<td>143/215 (66.5%)</td>
<td>61/121 (50.4%)</td>
<td>204/336 (60.7%)</td>
<td></td>
</tr>
<tr>
<td>No higher education</td>
<td>72/215 (33.5%)</td>
<td>60/121 (49.6%)</td>
<td>132/336 (39.3%)</td>
<td></td>
</tr>
<tr>
<td>(University) College degree</td>
<td>198/214 (92.5%)</td>
<td>113/121 (93.4%)</td>
<td>311/335 (92.8%)</td>
<td>0.7681</td>
</tr>
<tr>
<td>Currently in an intimate partner relationship</td>
<td>6/215 (2.8%)</td>
<td>23/121 (19.0%)</td>
<td>29/336 (8.6%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Member of a patients’ association for endometriosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-reported child wish details</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometriosis-related pain made it impossible to consider becoming pregnant</td>
<td>36/214 (16.8%)</td>
<td>30/116 (25.9%)</td>
<td>66/330 (20.0%)</td>
<td>0.0500</td>
</tr>
<tr>
<td>Tired for more than 12 months to become pregnant, without result</td>
<td>151/215 (70.2%)</td>
<td>85/118 (72%)</td>
<td>236/333 (70.9%)</td>
<td>0.7293</td>
</tr>
<tr>
<td>Ever been pregnant</td>
<td>106/216 (49.1%)</td>
<td>73/121 (60.3%)</td>
<td>179/337 (53.1%)</td>
<td><strong>0.0470</strong></td>
</tr>
<tr>
<td>Have a wish for (more) children in the future</td>
<td>164/209 (78.5%)</td>
<td>86/113 (76.1%)</td>
<td>250/322 (77.6%)</td>
<td>0.6272</td>
</tr>
<tr>
<td><strong>Self-reported medical characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endometriosis-related symptoms experienced during the past year</td>
<td>161/213 (75.6%)</td>
<td>107/121 (88.4%)</td>
<td>268/334 (80.2%)</td>
<td><strong>0.0046</strong></td>
</tr>
<tr>
<td>Fertility problems</td>
<td>106/136 (77.9%)</td>
<td>83/96 (86.5%)</td>
<td>189/232 (81.5%)</td>
<td>0.1001</td>
</tr>
<tr>
<td>Dysmenorrhea</td>
<td>108/151 (71.5%)</td>
<td>84/100 (84%)</td>
<td>192/251 (76.5%)</td>
<td><strong>0.0225</strong></td>
</tr>
<tr>
<td>Dyspareunia</td>
<td>71/140 (50.7%)</td>
<td>54/82 (65.9%)</td>
<td>125/222 (56.3%)</td>
<td><strong>0.0282</strong></td>
</tr>
<tr>
<td>Lower abdominal pain whilst not menstruating</td>
<td>62/137 (45.3%)</td>
<td>43/76 (56.6%)</td>
<td>105/213 (49.3%)</td>
<td>0.1133</td>
</tr>
<tr>
<td>Age at which first symptoms of endometriosis occurred (mean; SD)</td>
<td>27.1 (6.3) (n = 206)</td>
<td>26.4 (7.8) (n = 115)</td>
<td>26.8 (6.9)</td>
<td>0.453b</td>
</tr>
<tr>
<td>Number of years since first symptoms of endometriosis occurred (mean; SD)</td>
<td>6.6 (5.8) (n = 207)</td>
<td>12.6 (10.2) (n = 103)</td>
<td>8.6 (8.1)</td>
<td>&lt;0.0001b</td>
</tr>
<tr>
<td>Underwent surgical treatment by a multidisciplinary team</td>
<td>139/215 (92.7%)</td>
<td>39/71 (54.9%)</td>
<td>178/221 (80.5%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Moderate–severe degree of endometriosis at first diagnosis</td>
<td>147/207 (71.0%)</td>
<td>92/115 (80.0%)</td>
<td>239/322 (74.2%)</td>
<td>0.0773</td>
</tr>
<tr>
<td><strong>History of health-care history</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of years between first symptoms and search for help (mean; SD)</td>
<td>1.0 (0.2) (n = 192)</td>
<td>1.6 (0.4) (n = 106)</td>
<td>1.2 (2.9) (n = 298)</td>
<td>0.076b</td>
</tr>
<tr>
<td>Number of years between first symptoms and diagnosis (mean; SD)</td>
<td>3.0 (4.8) (n = 201)</td>
<td>3.9 (5.7) (n = 114)</td>
<td>3.4 (5.1) (n = 315)</td>
<td>0.176b</td>
</tr>
<tr>
<td>Amount of consultations with GP, related to endometriosis symptoms, before first being referred to a specialist (mean; SD)</td>
<td>8.7 (73.4) (n = 186)</td>
<td>4.8 (10.9) (n = 106)</td>
<td>7.3 (58.9) (n = 292)</td>
<td>0.489b</td>
</tr>
<tr>
<td>Second opinion of more than one gynecologist</td>
<td>103/215 (47.7%)</td>
<td>57/121 (47.1%)</td>
<td>160/336 (47.6%)</td>
<td>0.8880</td>
</tr>
<tr>
<td>Ever referred to other specialists than current gynecologist for symptoms related to endometriosis</td>
<td>122/212 (57.5%)</td>
<td>80/121 (66.1%)</td>
<td>202/333 (60.7%)</td>
<td>0.1237</td>
</tr>
<tr>
<td>Other gynecologist</td>
<td>92/126 (73.0%)</td>
<td>60/82 (73.2%)</td>
<td>152/208 (73.1%)</td>
<td>0.9804</td>
</tr>
</tbody>
</table>
| Continued
2). After their first symptoms, respondents waited about a year to consult a physician and it took 3.4 years on average to reach a diagnosis. It took respondents a mean of 7.3 general practitioner (GP) consultations to be referred to a specialist. Almost half of the respondents consulted more than one gynecologist for a second opinion. Most respondents (60.7%) had been referred to other specialists than their current gynecologist.

The reliability and validity of the ECQ

There were no questions with extremely skewed answers. For clinic 1, high non-response rates (5.1–14.4%) were found on a minority of statements (5/38 statements for importance; 6/38 for performance). For clinic 2, high non-response rates (6.6–30.6%) were found on at least 50% of the statements (22/38 statements for importance; 19/38 for performance). There were no problematic inter-item correlations ($r \leq 0.7$).

All dimensions of patient-centered endometriosis care, except ‘coordination and integration of care’, could be measured reliably for both clinics based on importance ratings ($\alpha = 0.6–0.9$; ITC $= 0.4–0.7$; Supplementary data, Table SII). The validity of the ECQ was confirmed (GFI $= 0.80$; AGFI $= 0.75$; RMSEA $= 0.0725$; Ka¨a¨ria¨inen et al., 2011).

The face validity of the 10 dimensions of patient-centered endometriosis care was confirmed. Three new specific care aspects suggested by 12 patients were already covered by the 10 dimensions of patient-centered endometriosis care (i.e. information for GPs, information on hospitalization during recovery and on alternative medicine; Supplementary data, Table SI).

Importance ratings

The overall MIS did not differ between the clinics ($P = 0.52$). The countries’ rankings of the 10 dimensions of patient-centered endometriosis care based on MIS per dimension were identical except for the third and fourth dimension switching places ($W = 0.994, P = 0.036$). Agreement on rankings between individuals for clinic 1 and clinic 2 were low (respectively: $W = 0.186, P < 0.0001$; $W = 0.342, P < 0.0001$). Therefore, differences in rankings between individuals were greater than differences in rankings between clinics. Overall, the five most important dimensions of patient-centered endometriosis care (MIS per dimension > overall MIS per clinic) for clinic 1 and 2, respectively, were: ‘respect for patients’ values, preferences and needs’ (8.13; 8.21), ‘technical skills’ (7.65; 7.36), ‘information, communication and education’ (7.38; 7.12), ‘endometriosis clinic staff’ (7.65; 7.36) and ‘continuity and transition’ (7.07; 6.79). The five least important dimensions of patient-centered endometriosis care were: ‘access to care’ (6.51; 6.38), ‘coordination and integration of care’ (6.27; 6.21), ‘involvement of significant others’ (5.50; 5.50), ‘physical comfort’ (4.92; 5.10) and ‘emotional support and alleviation of fear and anxiety’ (4.26; 4.63).

Case-mix adjusted assessment and comparison of the clinics’ patient-centeredness

The case-mix adjusted overall PCS did not differ between the clinics ($P = 0.974$). However, the PCS per dimension, adjusted for education level if indicated, did differ for four dimensions. When compared with clinic 2, clinic 1 was more patient-centered for the dimensions...
‘endometriosis clinic staff’ ($P = 0.021$) and ‘technical skills’ ($P = 0.001$), and less patient-centered for the dimensions ‘physical comfort’ ($P = 0.001$) and ‘access to care’ ($P < 0.0001$).

The PCS per dimension, adjusted if required and ranked downwards, for clinic 1 and clinic 2, respectively, were: 7.50 and 7.53 for ‘respect for patients’ values preferences and needs’ ($P = 0.81$), 7.27 and 6.96 for ‘endometriosis clinic staff’ ($P = 0.021$), 7.25 and 6.79 for ‘technical skills’ ($P = 0.001$), 6.48 and 6.34 for ‘information, communication and education’ ($P = 0.26$), 5.02 and 5.01 for ‘coordination and integration of care’ ($P = 0.92$), 5.59 and 5.75 for ‘continuity and transition’ ($P = 0.56$), 4.84 and 4.79 for ‘involvement of significant others’ ($P = 0.32$), 3.77 and 4.34 for ‘physical comfort’ ($P < 0.0001$), 3.63 and 4.18 for ‘access to care’ ($P < 0.0001$) and 1.83 and 1.93 for ‘emotional support and alleviation of fear and anxiety’ ($P = 0.56$).

**Targets for improvement of patient-centered endometriosis care**

There 8 and 13 improvement targets identified for clinic 1 (Fig. 2) and 2 (Fig. 3), respectively.

The following six improvement targets were identified in both clinics: ‘information provision on self-care before surgery’ and ‘information provision on self-care after surgery’, ‘information provision on post-surgical recovery’, ‘presence of a contact person after surgery’, ‘decreased waiting time between diagnosis and surgery’ and ‘physicians’ continuity’.

Clinic 1 additionally needed to improve opportunities for patients to discuss their daily complaints and the waiting time for the discussion of the results of diagnostic examinations or surgery. For the latter, clinic 2 performed better ($P = 0.002$).

Clinic 2 additionally needed to improve seven specific care aspects. For the following four, both clinics’ performance did not differ: consistency of the information provided by different staff members, information provision on pain medication, physicians’ pro-activity and timely diagnosis. Regarding the three other targets, clinic 1 performed better than clinic 2 for ‘partner involvement during consultations’ ($P < 0.001$) and ‘physicians’ recognition of the level of endometriosis’ complexity’ ($P = 0.0161$) and worse than clinic 2 for ‘availability of specialized staff in case of emergency’ ($P = 0.002$).

**Staff identification of improvement targets**

For clinic 1, only two of the eight patient-centered improvement targets were rightfully identified by staff (i.e. ‘opportunities for patients to discuss their daily complaints’ and ‘waiting time to discuss the results of diagnostic examinations and surgery’). Additionally, one target identified by staff was not identified by patients (i.e. ‘treatment on wards separated from obstetric wards’; $k = 0.28$; Fig. 2).

For clinic 2, only 4 of the 13 patient-centered improvement targets were rightfully identified by staff (i.e. ‘information provision on self-care before the operation’, ‘information provision on self-care after the operation’, ‘the consistency of the information provided by different staff members’ and ‘the waiting time between diagnosis and operation’, $k = 0.37$; Fig. 3).

**Discussion**

This study proved the ECQ’s potential to identify differences between clinics in patient-centeredness and clinic-specific targets for improvement of patient-centered endometriosis care.

To our knowledge, this is the first study assessing and comparing the patient-centeredness of endometriosis clinics. The international context of this study is interesting because European patients will soon be allowed to receive reimbursed healthcare in other member states (http://ec.europa.eu/health/cross_border_care/policy). In other health-care fields, mainly primary care, patients’ surveys served.

![Figure 2](attachment:image.png)
for international benchmarking at the country level, however, not at the clinic level (Grol et al., 2000; Coulter and Cleary, 2001; Wensing et al., 2002; Kerssens et al., 2004; Schoen et al., 2007; Koch et al., 2010).

The methodology used by this study had five strengths.

First, the potential threat of response bias was limited due to: high response rates (higher than response rates of 30 and 50%, considered reasonable for general and satisfaction questionnaires, respectively; Barkley and Furse, 1996; Sitzia and Wood, 1998; Polit and Beck, 2008), limiting social desirability response bias by anonymous dissemination (Polit and Beck, 2008; Donselaar et al., 2010) and by assessing performance and importance instead of satisfaction. Additionally, including more patients with moderate–severe endometriosis was not due to self-selection bias (i.e. responding depends on health state; Sica, 2006), as in the Belgian clinic (this data were not available for the Dutch clinic) response rates did not differ between patients with a surgical diagnosis of minimal–mild endometriosis and patients with a surgical diagnosis of moderate–severe endometriosis (P = 0.572).

Second, the ECQ is a good instrument for measuring patient-centeredness. The previously proved validity and reliability of the ECQ’s for Belgium and the Netherlands for all 10 dimensions except ‘coordination and integration’ (Dancet et al., 2011a) was confirmed for both clinics. Contrary to satisfaction research only implying that patient expectations were met (Cleary and Edgman-Levitan, 1997; Sixma et al., 1998), the ECQ identified specific and actionable targets for future improvement (Cleary and Edgman-Levitan, 1997).

Third, as for benchmarking clinics for safety and effectiveness (e.g. maternal mortality and fertility; Tielemans et al., 2002; Saucedo et al., 2011), case-mix adjustments were made to benchmark for patient-centeredness. Hence, reported differences between clinics cannot be attributed to differences in case-mix. The finding that highly educated women were more negative toward their endometriosis care is in accordance with findings from the related field of infertility (Sabourin et al., 1991; Haagen et al., 2008; van Empel et al., 2010).

Fourth, this study innovatively identified targets for improvement of patient-centered care through the patients’ eyes. Indeed, the staff of both clinics was not good at identifying patient-centered targets, identified by patients themselves, for improvement of endometriosis care. This observation is in line with data from other studies showing that fertility staff undervalue the importance of patient-centeredness (van Empel et al., 2011) and judge their own patient-centeredness inadequately (Aarts et al., 2011). Compared with previous patient interviews identifying needs for improvement (Dancet et al., 2010a; Ross et al., 2006; Nachtigall et al., 2009), this survey included more patients. Compared with the quality improvement-indices used by other similar surveys (MISxPNP/100; Van Campen et al., 1998; van Empel et al., 2010), we have developed an improved method to identify targets with importance–performance scatterplots. Therefore, targets with both high importance and low performance (Slack, 1994) were identified, while quality improvement-indices can be high if only one of the two is measured as extremely high.

Fifth, the novel approach to identify the potential of cross and joint clinic learning based on significant differences in performance can be useful for designing improvement projects. However, five critical remarks need to be made regarding this study’s methodology.

First, the retrospective nature of the study potentially resulted in recall bias (Donselaar et al., 2010). It is possible that by the time patients filled in the questionnaire, they had forgotten certain aspects of their experience or had put it into another perspective as time moved on, a phenomenon known as recall bias. The direction of a possible differential recall is difficult to predict and probably depends on several factors such as patients’ clinical and demographic characteristics (Sica, 2006). Although maternal recall for data such as...
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infant feeding events (up to 18 months later; Launer et al., 1992) and obstetric complications (up to 4 years later; Stewart and Festin, 1995) is reasonably accurate, no data on recall bias are available in endometriosis research.

Second, non-response rates on certain items were higher than in our previous ECQ-study recruiting patients by patients’ associations instead of clinics (Dancet et al., 2011a) and higher in clinic 2 than in clinic 1. This might indicate that the patients included in our current study, especially in clinic 2, had limited motivation or low confidence in anonymity.

Third, the position of the axes of the novel importance–performance matrix is partially subjective and therefore up for discussion, given the lack of a golden standard (Dancet et al., 2010b) and the fact that the position is normatively charged. In our study, we concur with the only similar study (Damman et al., 2009) on the position of the axes for the following explicit reasons. The position of the importance axis implies that the care aspects most important to patients need to be improved first, which is in line with patient-centered principles (Cormgan et al., 2001). The position of the performance axis implies that improvement is required in case 15% of patients reported a negative performance, which was considered reasonable by our research team. Another limitation is the fact that matrices cannot be adjusted for case-mix as they model two different dependent variables. Based on both limitations (the subjective nature of positioning the importance/performance axes, and the inability to adjust matrices for case-mix), the number of improvement targets cannot be used for trustworthy benchmarking.

Fourth, although we found differences in patient-centeredness between two clinics based on case-mix adjusted PCS, more research is needed to statistically define the discriminative value of the ECQ. If at least 20 clinics would be included in our next study, we could calculate the variance of scores due to the difference between clinics and the variance of scores due to differences between patients (and their respective statistical significance levels) and this both for a model including and a model not including case-mix adjustments (Sixma et al., 2008; van Empel et al., 2010).

Fifth, although reporting on patients’ self-reported degree of endometriosis is in line with patient-centered research exploring the patients’ perspective, the self-reported degree of endometriosis differed from the degree noted in the patient records after the last surgery for Belgian patients (P < 0.001; data were not available for Dutch sample). Patients self-reported both more and less severe endometriosis compared with the endometriosis degree noted in their patient records, which is not surprising since the severity of symptoms does not always correlate to severity of disease (Spaczynski and Duleba, 2003) and since several patients had multiple surgeries resulting in being informed on different diagnoses.

The 15 improvement targets identified by this study are not all equally surprising in view of the findings of a recent literature review on the patients’ perspective on endometriosis care (Dancet et al., 2012, submitted) and the rightful identification of 6 of the 15 patient-centered improvement targets by the clinics’ staff in this study.

The improvement potential of four specific patient needs for timely diagnosis and treatment (‘staff’s proactive approach’, ‘timely diagnosis’, ‘waiting times for surgery’ and ‘waiting times for discussions of the results of diagnosis or operation’); the latter two also identified by staff) has also been recognized in other studies (Hirsh et al., 2001; Jones et al., 2004; Denny, 2004a,b; Huntington and Gilmour, 2005; Ballard et al., 2006; Denny and Mann, 2008; Manderson et al., 2008; Greene et al., 2009). The improvement potential of three specific information needs (out of which, two were identified by staff) was not surprising as it is known that patients agree on the important and problematic nature of quality and detail of information (Hirsh et al., 2001; Lemaire, 2004; Huntington and Gilmour, 2005). Preventing inconsistent information was an improvement target expected by staff, but not yet documented in the literature (Dancet et al., 2012, submitted). The improvement potential of ‘discussing daily complaints’ was in line with patient needs to discuss pain issues (Denny, 2004a,b) and was also identified by staff.

We also identified the five following new and interesting targets for patient-centered improvement of endometriosis care: ‘physicians’ continuity’, ‘availability of a contact person’, ‘partner involvement during consultations’ and ‘physicians stating which complexity level of endometriosis they could handle’.

This study represents the first step of a plan—do—study—act cycle as it ‘planned’ targets for improvement (Curtis et al., 2006; Frampton et al., 2008; Quigley et al., 2010). Feedback was necessary to allow improvement of patient-centered care as endometriosis clinic staff did not identify all targets for improvement set by their patients. Hence, clinic staff was given feedback, as previously advised by others (Curtis et al., 2006; Frampton et al., 2008; Main and Bingham, 2008; Delnoij, 2009). Both clinics were advised to inform their patients on the results of this quality control study on their websites. Additional public reporting should be considered, as it stimulates clinics to conduct improvement projects (Fung et al., 2008) in order to attract consumers (Berwick et al., 2003) and as the PCS were reliable and case-mix adjusted (Kelly et al., 2008). However, evidence on the result of public reporting of quality measures on patients’ clinic selection is inconsistent and few studies examine whether public reporting improves patient-centeredness (Fung et al., 2008).

Improving the patient-centeredness of care additionally requires completing the plan—do—study—act cycle (Curtis et al., 2006; Frampton et al., 2008; Main and Bingham, 2008; Delnoij, 2009). First, each clinic should ‘plan’ strategies to address the identified targets (Curtis et al., 2006). Of the six targets that need to be improved in both clinics, three targets considered information and could potentially be tackled by an information brochure (Dancet et al., 2010a) and by training clinical staff in patient-centered consultations (Lewin et al., 2009). The communal targets regarding waiting times for surgery, physician’s continuity and availability of a contact person could be tackled by management decisions affecting these system factors of care (e.g. devoting more surgery time to endometriosis; Dancet et al., 2011b). Second, in the ‘do’ phase, improvement projects should be implemented. Involving clinic staff is advised to create their engagement and project ownership (Picker Institute Europe (PIE), 2009). Third, in the ‘study’ phase, a post-improvement project assessment using the ECQ is crucial to monitor the evolution of patient-centered care (Curtis et al., 2006; Lewin et al., 2009). If a project does not yield improvement, the plan needs to be modified and the plan—do—study—act cycle repeated (Massoud et al., 2001). Fourth, quality improvement is never ending and in the last ‘act’ phase, periodical assessments should ensure that improvement sticks (Quigley et al., 2010). Finally, improvement requires commitment of the entire staff and strong leadership.
Future research should examine the effect of improvement projects on the patient-centeredness of care by comparing ECQ assessment before and after improvement projects. The additional effect of improvement projects on endometriosis patients’ physical and mental health should be examined as, in other fields of medicine, patient-centered care is related to treatment adherence (Robinson et al., 2008; Walsh et al., 2009; Silver et al., 2011).

It would be interesting for future ECQ studies to include more patients with self-reported minimal or mild endometriosis, as recruiting patients whose surgery was indicated by pain or infertility resulted in a smaller proportion of patients with minimal–mild endometriosis than reported for the general population (25.8% instead of 37%; Gylfason et al., 2010).

Furthermore, it is necessary to test the usability of the ECQ, which so far has only been used in Europe, in other continents. It would be especially interesting to examine whether the ECQ can be used in developing countries. Finally, the effect of patient and public reporting of patient-centeredness data on clinic’s quality management and attractiveness to patients could be examined.

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

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E.A.F.D., S.A., T.M.D., J.A.M.K., W.L.D.M.N., K.B.K. and W.S. substantially contributed to the study conception and design, acquisition of data, analysis and interpretation of data, and ED and SA drafted the article. All other authors revised it critically for important intellectual content. All authors finally approved the version to be published.

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Conflict of interest
None declared.

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