Translation, Cross-Cultural Adaptation, and Psychometric Evaluation of the Swedish Version of ENDOCARE: An Instrument to Measure Patient Centeredness of Endometriosis Care

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Keywords
Endometriosis · ENDOCARE · Patient centeredness · ENDOCARE questionnaire · Validity

Abstract
Objectives: The need for quality improvement within endometriosis healthcare is widely acknowledged. The ENDOCARE questionnaire (ECQ) measures patient centeredness of endometriosis care. The aims of this study were (1) to translate and culturally adapt ECQ into Swedish, (2) to evaluate validity (construct validity), and (3) to measure reliability (internal consistency and test-retest reliability). Design: This is a cross-sectional randomized study. Participants, Setting, and Methods: ECQ was first translated according to a well-established guideline and was thereafter sent to 500 randomly selected women with endometriosis, who had visited participating clinics during the past 3 years. The first 150 women who returned their questionnaires were immediately sent the same questionnaire again. The ECQ consists of 3 parts. The first part contains demographic and clinical questions, while part II has 38 items that are answered according to 2 aspects: percentage of negative experience of care and mean personal importance. A patient-centeredness score (PCS) is calculated based on these 2 aspects. The items are also divided into 10 dimensions of care. Part III is a grading of overall experience and an open-ended question on any missing aspect in the questionnaire. Results: A total of 187 native Swedish-speaking women participated. Data completeness was high (>90%). The overall PCS median was 3.5. The highest median PCS was found in the dimension regarding endometriosis clinic staff and the lowest in emotional support and alleviation of fear and anxiety and the involvement of significant others. Factor analysis could roughly confirm 2 of the 10 dimensions. The Cronbach’s $\alpha$ coefficient for PCS ranged from 0.35 to 0.73. The test-retest analysis showed acceptable reliability. Limitations: The most important limitation was the relatively low participation rate and the risk of recall bias. It is likely that women gave their answers based on their most recent experiences. Conclusions: Overall, our results indicate that the Swedish version of the ECQ is a usable instrument to measure patient centeredness in endometriosis care, but due to the unstable factor analysis, conclusions based on the dimensions should be made with caution.

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Introduction

Endometriosis is a chronic gynecological disease affecting around 10% of women of fertile age [1]. It is defined as the presence of endometrial-like tissue growing outside the uterus where it induces an inflammatory reaction, often leading to pain such as dysmenorrhea, pelvic pain, and dyspareunia [2]. Many women also suffer from weariness and poor mental health [3]. Living with the disease often has a negative effect on health-related quality of life and affects women’s daily life, including work, relationships, and fertility [4–7]. Receiving a diagnosis often takes years and usually requires many visits to different healthcare professionals [6, 8]. Diagnostic delay is reported to be 4–10 years [9–14]. Many women are discontented with the care they receive, and normalization and trivialization from healthcare professionals are common experiences [4, 6, 15].

During recent years, the need for improved endometriosis healthcare has been acknowledged [16–18]. One aspect of healthcare quality is patient centeredness, a concept that is promoted at legislative and healthcare regulatory levels in Europe and North America. Within the field of endometriosis, patient centeredness has been defined as a combination of understanding the burden of illness and treatment from patients’ points of view while still relying on scientific knowledge [19]. A review from 2014 concluded that patient-centered endometriosis care may be organized into 10 dimensions [20].

The ENDOCARE questionnaire (ECQ) was designed to measure patient centeredness of endometriosis care (PCEC). The questionnaire has been tested for validity and reliability in Belgium, the Netherlands, the UK, and Italy, with satisfactory results [21]. The use of ECQ provides an opportunity to assess PCEC and to compare different clinics nationally and internationally [22]. Data obtained from ECQ may also form a basis for designing and evaluating improvement projects. The aims of this study were (1) to translate and culturally adapt ECQ into Swedish, (2) to evaluate validity (construct validity), and (3) to measure reliability (internal consistency and test-retest reliability).

Materials and Methods

The ENDOCARE Instrument

The instrument comprises 3 parts. The first part consists of 27 demographic and clinical questions. The second part contains 38 statements regarding different aspects of care. Each of these statements is scored on a 4-point Likert scale on 2 dimensions (experience of the aspect and personal importance of the aspect). The third part is a scale (0–10) concerning the overall experience of endometriosis care, a 4-point question on whether women would recommend their endometriosis clinic to family and friends, and an open-ended question on important aspects not covered by the instrument.

In the analyses, the 38 statements in part II are divided into 10 dimensions of PCEC (Table 1). ECQ generates 3 outcome measures on each of the 10 dimensions:

1. Percentage of negative experiences (PNP) are presented on a 0–100 scale, where higher scores indicate worse performance. The answers are coded as 1 = disagree completely, 1 = disagree, 0 = agree, and 0 = agree completely.
2. Mean important scores (MIS) are presented on a scale from 0 to 10. Higher scores indicate greater importance. Answers are recoded as 0 = not important, 3 = fairly important, 6 = important, and 10 = of the utmost importance.
3. Patient-centeredness scores (PCS) are presented on a scale from 0 to 10, with higher scores indicating higher PCEC. PCS weights the performance on each dimension relating to the importance of that dimension.

Table 1. The 10 dimensions of PCEC and their related statements

| Dimension of PCEC | Statements related to the dimension |
|-------------------|-----------------------------------|
| 1. Respect for patient’s values, preferences, and needs | S1, S2, S3 |
| 2. Coordination and integration of care | S4, S5, S13 |
| 3. Information, communication, and education | S6, S7, S8, S9, S10, S11, S12 |
| 4. Physical comfort | S14, S28 |
| 5. Emotional support and alleviation of fear and anxiety | S15, S16, S17, S24 |
| 6. Involvement of significant others | S20, S21, S22, S23 |
| 7. Continuity and transition | S25, S26, S27 |
| 8. Access to care | S29, S30, S31, S32, S33 |
| 9. Technical skills | S34, S35, S36, S37 |
| 10. Endometriosis clinic staff | S18, S19, S38 |

PCEC, patient centeredness of endometriosis care.
Table 2. Background characteristics of study participants (n = 187)

| Characteristic | N (%)/ mean ± SD |
|---------------|------------------|
| Age, years    | 37.2±9           |
| Has one or more child(ren) | 104 (56) |
| Highest level of education | Compulsory school 11 (6) Secondary education 71 (38) University education 105 (56) |
| Occupation | Working/studying full-time 111 (60) Working/studying part-time 41 (22) On sick-leave 17 (9) Others 18 (10) |
| Currently in an intimate partner relationship | 145 (78) |
| Endometriosis-related symptoms during the past year | Infertility 34 (18) Dysmenorrhea 100 (54) Dyspareunia 101 (54) Lower abdominal pain whilst not menstruating 137 (73) Others 122 (65) |
| Years between first symptoms and search for help (patient’s delay) | 3.0±5 |
| Years between first symptoms and diagnosis (doctor’s delay) | 5.1±6 |
| Years between first symptoms and diagnosis (diagnostic delay) | 8.4±8 |
| GP consultations before referral | 7.7±15 |
| Second opinion of >1 specialist | 75 (40) |
| Surgery by multidisciplinary team | 11 (6) |
| Membership of endometriosis patient association | 29 (16) |

GP, general practitioner.

Translation and Cross-Cultural Adaptation of the ECQ

Permission for translation was obtained from the developer of ECQ in March 2019. The translation and cross-cultural adaptation was conducted according to established guidelines [23]. The translation was performed in several steps: (a) forward translation by 2 individuals outside the research group, who were native Swedish speakers and whose second language was English; (b) reconciliation within the research group; (c) backward translation to English by one native English speaker with Swedish as her second language and by a professional translator; (d) the backtranslations were reviewed and compared with the original English-version ECQ; (e) cognitive debriefing of the new translation. Debriefing was performed by face-to-face interviews with 6 native Swedish-speaking women aged 22–44 years with a biopsy-confirmed endometriosis; and (f) the women’s responses and comments regarding the questionnaire were summarized, reviewed, and discussed before the translation was proofread and finalized.

Study Design and Data Collection

The final version of ECQ was sent by regular mail to 500 randomly selected women with laparoscopy-verified endometriosis who had visited 2 clinics in Sweden during the years 2017–2019. The questionnaires were sent in February 2020, and a reminder was sent if no answer was received within 3 weeks. The first 150 native Swedish-speaking women who returned their questionnaires were immediately sent another questionnaire.

The determination of sample size was based on the recommendations of a minimum number of 100 participants and an item:subject ratio of at least 1:4 to confirm stability of the factor analysis [24]. In this study, a minimum sample size of 160 was required. Assuming a response rate of approximately 40%, we invited 500 women to participate. For the test-retest reliability, the recommendation is at least 50 participants [24].

Psychometric Evaluation

a. Data completeness, score distributions, and floor and ceiling effects: to determine the acceptance of ECQ, response rates were calculated. Median, 25th and 75th quartiles, and coefficient of skewness were used to present descriptive data. If >15% of respondents achieved the lowest or highest possible score, floor or ceiling effects were considered to be present [24].

b. Construct validity: to assess the underlying structure of ECQ, principal component analysis was performed using varimax rotation [24]. Loadings ≥0.40 were considered in the following analysis. Lower values indicate such low levels of association that these are effectively disregarded [24].

c. Reliability: to evaluate internal consistency, Cronbach’s coefficient was used, and values >0.70 indicated satisfactory internal consistency [25]. Intraclass correlation was used to assess test-retest reliability over time, that is, measuring the consistency of the results when expecting them to stay constant. Estimated coefficients below 0.75 have been interpreted as poor reliability [26].

All analyses were conducted using R.3.6.1.

Results

A total of 206 women answered the questionnaire (41%), of whom 187 were native Swedish speakers and were included in the analysis (37%). Participants’ demographic characteristics are presented in Table 2.

Data Completeness, Score Distributions, and Floor and Ceiling Effects

The data completeness for parts I and II was and 97 and 91%, respectively. The most frequent missing answers were found in statements 20–24 in part II. However, in statement 20, participants were explicitly asked to continue on to statement 25 if they did not have a partner.

The highest median score for PNP, 100%, was found in dimension (Dim) 5: emotional support and alleviation of fear and anxiety (Em Supp) and in Dim 6: involvement of significant others (Inv Sign). The least negative median
performance score (0%) was reported for Dim 4: physical comfort (Phys Comf). For MIS, the following 4 dimensions had the highest median score (median 10): Dim 1, respect for patient’s values, preferences, and needs (Respect); Dim 7, continuity and transition (Cont); Dim 9, technical skills (Techn); and Dim 10, endometriosis clinic staff (Staff). Dim 4 Phys Comf and Dim 6 Inv Sign were the least important dimensions with median scores of 6.0.

The highest median PCS (5.3) was found in Dim 10 Staff and the lowest in Dim 5 Em Supp (median 0) and Dim 6 Inv Sign (median 0). The overall PCS median was 3.5.

Table 3. Median score distributions, skewness, floor and ceiling effect, and internal consistency of the Swedish version of ECQ (n = 187)

| Subscale of ECQ                        | Median | 25th percentile | 75th percentile | Coefficient of skewness | Floor effect | Ceiling effect | Cronbach’s alpha |
|----------------------------------------|--------|-----------------|-----------------|-------------------------|--------------|----------------|-----------------|
| 1. Respect for patients’ values, preferences, and needs |        |                 |                 |                         |              |                |                 |
| PNP                                    | 33.3   | 0.0             | 100.0           | 0.16                    | 0.36         | 0.25           | 0.74            |
| MIS                                    | 10.0   | 8.7             | 10.0            | −1.38                   | 0.00         | 0.63           | 0.68            |
| PCS                                    | 4.6    | 0.5             | 9.7             | 0.03                    | 0.25         | 0.25           | 0.56            |
| 2. Coordination and integration of care |        |                 |                 |                         |              |                |                 |
| PNP                                    | 50.0   | 33.3            | 66.7            | −0.08                   | 0.20         | 0.24           | 0.42            |
| MIS                                    | 6.3    | 5.0             | 8.7             | −0.23                   | 0.01         | 0.17           | 0.54            |
| PCS                                    | 2.4    | 0.7             | 4.9             | 0.74                    | 0.24         | 0.04           | 0.35            |
| 3. Information, communication, and education |        |                 |                 |                         |              |                |                 |
| PNP                                    | 42.9   | 14.3            | 71.4            | 0.24                    | 0.13         | 0.07           | 0.75            |
| MIS                                    | 8.9    | 7.1             | 10.0            | −0.69                   | 0.00         | 0.32           | 0.84            |
| PCS                                    | 4.7    | 2.7             | 7.1             | 0.18                    | 0.07         | 0.09           | 0.72            |
| 4. Physical comfort                    |        |                 |                 |                         |              |                |                 |
| PNP                                    | 0.0    | 0.0             | 50.0            | 0.81                    | 0.58         | 0.18           | 0.66            |
| MIS                                    | 6.0    | 3.0             | 6.5             | 0.23                    | 0.02         | 0.12           | 0.60            |
| PCS                                    | 3.0    | 1.5             | 6.0             | 0.43                    | 0.20         | 0.05           | 0.58            |
| 5. Emotional support and alleviation of fear and anxiety |        |                 |                 |                         |              |                |                 |
| PNP                                    | 100.0  | 75.0            | 100.0           | −1.45                   | 0.00         | 0.66           | 0.31            |
| MIS                                    | 7.0    | 4.8             | 8.7             | −0.46                   | 0.02         | 0.14           | 0.82            |
| PCS                                    | 0.0    | 0.0             | 1.3             | 1.88                    | 0.67         | 0.00           | 0.58            |
| 6. Involvement of significant others   |        |                 |                 |                         |              |                |                 |
| PNP                                    | 100.0  | 75.0            | 100.0           | −1.75                   | 0.04         | 0.63           | 0.68            |
| MIS                                    | 6.0    | 4.5             | 8.0             | −0.26                   | 0.01         | 0.19           | 0.82            |
| PCS                                    | 0.0    | 0.0             | 1.4             | 2.74                    | 0.65         | 0.01           | 0.64            |
| 7. Continuity and transition           |        |                 |                 |                         |              |                |                 |
| PNP                                    | 66.7   | 33.3            | 100.0           | −0.04                   | 0.25         | 0.26           | 0.57            |
| MIS                                    | 10.0   | 7.3             | 10.0            | −1.06                   | 0.00         | 0.51           | 0.60            |
| PCS                                    | 3.3    | 0.0             | 6.7             | 0.27                    | 0.27         | 0.12           | 0.73            |
| 8. Access to care                      |        |                 |                 |                         |              |                |                 |
| PNP                                    | 40.0   | 20.0            | 63.3            | 0.13                    | 0.21         | 0.13           | 0.68            |
| MIS                                    | 8.4    | 7.0             | 10.0            | −0.78                   | 0.00         | 0.29           | 0.79            |
| PCS                                    | 4.0    | 2.1             | 6.1             | 0.15                    | 0.13         | 0.05           | 0.73            |
| 9. Technical skills                    |        |                 |                 |                         |              |                |                 |
| PNP                                    | 50.0   | 25.0            | 100.0           | −0.12                   | 0.21         | 0.26           | 0.73            |
| MIS                                    | 10.0   | 8.0             | 10.0            | −1.20                   | 0.00         | 0.51           | 0.77            |
| PCS                                    | 4.0    | 1.9             | 6.0             | 0.32                    | 0.21         | 0.08           | 0.73            |
| 10. Endometriosis clinic staff         |        |                 |                 |                         |              |                |                 |
| PNP                                    | 33.3   | 0.0             | 66.7            | 0.34                    | 0.40         | 0.18           | 0.72            |
| MIS                                    | 10.0   | 8.0             | 10.0            | −1.25                   | 0.00         | 0.55           | 0.73            |
| PCS                                    | 5.3    | 0.5             | 8.7             | −0.08                   | 0.18         | 0.21           | 0.64            |
| Overall PCS                           | 3.6    | 2.2             | 4.8             | 0.31                    | 0.02         | 0.00           | 0.93            |

ECQ, ENDOCARE questionnaire; PNP, percentage of negative experiences; MIS, mean important scores; PCS, patient-centeredness scores.
**Table 4. Factor analysis**

| Item                                                                 | Theory-driven dimension | LF 01 | LF 02 | LF 03 | LF 04 | LF 05 | LF 06 | LF 07 | LF 08 | LF 09 | LF 10 |
|----------------------------------------------------------------------|------------------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| 1. My complaints were taken seriously                               | Respect                | 0.22  | 0.04  | 0.24  | 0.24  | 0.01  | 0.10  | 0.05  | <0.01 | <0.01 | 0.49* |
| 2. I was given the opportunity to take part in the decision after I had received all the information | Respect                | 0.17  | 0.08  | <0.01 | 0.21  | 0.19  | <0.01 | 0.13  | 0.04  | <0.01 | 0.52* |
| 3. I was treated like a person and not like a number                 | Respect                | 0.18  | 0.18  | 0.28  | 0.27  | 0.33  | 0.04  | 0.08  | <0.01 | 0.06  | 0.67* |
| 4. The information regarding my health problem was distributed among the caregivers involved | Coordination and integration of care | 0.07  | 0.03  | 0.12  | 0.08  | 0.1   | <0.01 | 0.08  | 0.05  | 0.65* | 0.14  |
| 5. Care was taken to plan examinations and treatments on 1 day       | Coordination and integration of care | 0.25  | 0.19  | 0.02  | 0.20  | 0.44* | <0.01 | 0.52* | 0.16  | 0.18  | 0.24  |
| 6. Everything necessary was done so that I would understand the information | Information, communication, and education | 0.01  | 0.08  | 0.15  | 0.17  | <0.01 | <0.01 | 0.13  | 0.26  | 0.09  | 0.49* |
| 7. I received the information on the course of treatment and the various stages in advance so that I knew what to expect | Information, communication, and education | 0.16  | 0.29  | 0.02  | <0.01 | 0.24  | <0.01 | 0.04  | 0.18  | 0.08  | 0.66* |
| 8. I received practical information and advice on self-care before the operation | Information, communication, and education | 0.04  | 0.17  | 0.74* | 0.11  | 0.25  | <0.01 | 0.05  | 0.06  | 0.01  | 0.11  |
| 9. I received practical information and advice on self-care after the operation | Information, communication, and education | 0.17  | <0.01 | 0.27  | 0.24  | 0.03  | <0.01 | 0.05  | 0.74* | 0.07  | 0.13  |
| 10. The information given to me by the various caregivers was uniform | Information, communication, and education | <0.01 | 0.25  | 0.39  | 0.02  | 0.12  | <0.01 | 0.33* | <0.01 | 0.11  | 0.18  |
| 11. I was given the opportunity to discuss my daily complaints with the caregivers | Information, communication, and education | 0.34  | 0.09  | 0.11  | 0.19  | <0.01 | 0.14  | <0.01 | 0.04  | 0.44* | 0.37  |
| 12. I received information on the medication that I could take to achieve my pain | Information, communication, and education | 0.2   | 0.13  | 0.02  | 0.39  | 0.2   | <0.01 | 0.06  | 0.18  | <0.01 | 0.24  |
| 13. I was treated on wards that were separated from the maternity, obstetrics, and per/postnatal wards | Coordination and integration of care | 0.34  | <0.01 | 0.18  | 0.08  | 0.01  | <0.01 | 0.04  | 0.61* | 0.28  | 0.05  |
| 14. The consultation waiting room is comfortable                     | Physical comfort        | 0.74* | 0.23  | 0.10  | 0.13  | 0.03  | <0.01 | 0.09  | 0.12  | 0.14  | 0.03  |
| 15. I was informed as to the psychological impact of endometriosis   | Emotional support and alleviation of fear/anxiety | <0.01 | 0.12  | 0.04  | 0.15  | 0.66* | <0.01 | 0.11  | <0.01 | <0.01 |
| 16. I was given the opportunity to consult a counselor who was familiar with problems connected with endometriosis | Emotional support and alleviation of fear/anxiety | 0.05  | <0.01 | <0.01 | <0.01 | 0.32  | 0.38  | <0.01 | 0.14  | 0.37  | 0.11 |
| 17. I received information on a patients’ organization (for endometriosis) | Emotional support and alleviation of fear/anxiety | 0.21  | 0.22  | <0.01 | <0.01 | 0.09  | 0.19  | 0.12  | 0.02  | 0.50* | <0.01 |
| 18. The caregivers were understanding and concerned during my treatment | Endometriosis clinic staff | 0.54* | 0.07  | 0.09  | <0.01 | <0.01 | 0.1   | 0.09  | 0.09  | 0.05  | 0.39  |
| 19. I was reassured whenever necessary                               | Endometriosis clinic staff | 0.19  | 0.28  | 0.24  | 0.39  | 0.1   | 0.34  | 0.22  | 0.33  | 0.06  | 0.22  |
| 20. Support was available for myself and my partner                 | Involvement of significant others | 0.14  | 0.03  | 0.08  | 0.24  | 0.08  | 0.66* | 0.19  | 0.29  | <0.01 | 0.16  |
| 21. There were efforts to involve my partner during consultations    | Involvement of significant others | 0.02  | 0.71* | <0.01 | 0.12  | 0.06  | 0.11  | 0.08  | <0.01 | 0.03  | 0.14  |
| 22. My partner was encouraged to be present at the consultations     | Involvement of significant others | 0.08  | 0.65* | 0.03  | 0.02  | 0.04  | <0.01 | 0.05  | 0.12  | 0.04  | 0.08  |
| 23. The consequences of endometriosis and the treatment for my (future) sexual relationship(s) were discussed | Involvement of significant others | 0.13  | 0.72* | 0.02  | 0.06  | <0.01 | <0.01 | 0.28  | 0.04  | 0.09  | 0.11  |
| 24. My partner and/or family members were provided with an information brochure | Emotional support and alleviation of fear/anxiety | 0.16  | 0.71* | 0.15  | <0.01 | <0.01 | <0.01 | 0.19  | 0.1   | 0.03  | <0.01 |
| 25. I received sufficient information regarding recovery after the operation | Continuity | 0.15  | <0.01 | 0.80* | <0.01 | 0.14  | 0.12  | <0.01 | <0.01 | 0.1   | <0.01 |
| Item | Theory-driven dimension | LF 01 | LF 02 | LF 03 | LF 04 | LF 05 | LF 06 | LF 07 | LF 08 | LF 09 | LF 10 |
|------|-------------------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
| 26. It was clear which caregiver I could turn to with questions and/or complaints after the operation | Continuity | 0.28  | 0.13  | 0.74* | <0.01 | 0.27  | 0.05  | 0.03  | 0.06  | <0.01 | 0.15  |
| 27. The physician who is treating me really follows up my case personally | Continuity | 0.09  | 0.08  | <0.01 | 0.49* | 0.52* | 0.18  | 0.17  | 0.12  | 0.03  | 0.09  |
| 28. The waiting time in the consultation waiting room was acceptable | Physical comfort | 0.76* | 0.23  | 0.25  | 0.16  | <0.01 | <0.01 | 0.03  | 0.15  | <0.01 | 0.28  |
| 29. The waiting time between the diagnostic examinations and the operation was acceptable | Access to care | 0.2   | 0.29  | 0.49* | 0.49* | <0.01 | <0.01 | 0.15  | 0.43* | <0.01 | 0.05  |
| 30. I was able to contact the hospital with my questions between the consultations/examinations via clearly specified telephone numbers and at clearly specified times | Access to care | 0.47* | 0.09  | 0.08  | <0.01 | 0.43* | <0.01 | 0.1   | 0.02  | <0.01 | 0.24  |
| 31. I was able to contact my attending physician | Access to care | 0.14  | 0.11  | 0.05  | <0.01 | 0.70* | 0.02  | 0.12  | 0.05  | 0.19  | 0.3   |
| 32. I was able to contact a caregiver with specific knowledge of endometriosis in urgent cases | Access to care | 0.44* | 0.03  | 0.24  | 0.36  | <0.01 | 0.18  | <0.01 | 0.11  | 0.02  | 0.04  |
| 33. The waiting time between the diagnostic examinations and/or the operation and the discussion of the result was acceptable | Access to care | 0.12  | 0.21  | 0.47* | 0.1   | <0.01 | <0.01 | 0.44* | 0.06  | <0.01 | 0.3   |
| 34. I was able to rely on the expertise of the caregivers | Technical skills | 0.23  | 0.25  | 0.17  | 0.05  | 0.09  | 0.17  | 0.15  | 0.52* | 0.32  | 0.23  |
| 35. 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 center | Technical skills | 0.26  | 0.3   | 0.05  | 0.22  | <0.01 | <0.01 | 0.74* | 0.12  | 0.17  | 0.13  |
| 36. My physicians were proactive; they did not adopt a wait-and-see approach | Technical skills | 0.29  | 0.09  | 0.05  | 0.30  | 0.26  | <0.01 | 0.51* | 0.21  | <0.01 | 0.33  |
| 37. I received a correct diagnosis within a short space of time: the endometriosis problem was recognized as such within a short time | Technical skills | 0.08  | 0.25  | 0.11  | 0.74* | 0.08  | 0.11  | <0.01 | 0.03  | <0.01 | 0.04  |
| 38. The professional caregivers were friendly | Endometriosis clinic staff | 0.33  | 0.24  | 0.16  | 0.01  | 0.16  | <0.01 | 0.1   | <0.01 | <0.01 | 0.58* |

Factor loadings for ECQ. Loadings ≥0.40 are marked with an asterisk.
For PNP, positively skewed distributions, towards bad performance, were found in 5 dimensions. PNP Dim 4 Phys Comf had the most positive distribution (0.81), while PNP Dim 6 Inv Sign had the most negative (−1.75). For MIS, negatively skewed distributions towards less importance were found in all dimensions except for Dim 4 Phys Comf (0.23). On the other hand, all dimensions for PCS were positively skewed, except for Dim 10 Staff, which was slightly negatively skewed (0.08). Notable floor and/or ceiling effects were found in most dimensions (Table 3).

**Construct Validity**

Factor analysis was performed on PCS. Analysis of statements 20–23 was only performed on participants with a partner. Our factor analysis had a poor correlation with the theory-driven underlying dimensions of PCEC in the original article. The only 2 dimensions that were confirmed in our data were Dim 4 Phys Comf (0.23). On the other hand, all dimensions for PCS were positively skewed, except for Dim 10 Staff, which was slightly negatively skewed (0.08). Notable floor and/or ceiling effects were found in most dimensions (Table 3).

**Reliability**

In the internal consistency test, Cronbach’s α coefficient for PNP ranged from 0.31 to 0.75 (Table 3). Four dimensions had an α coefficient >0.70. For MIS, Cronbach’s α coefficient ranged from 0.60 to 0.84, with 6 dimensions above 0.70, and for PCS, Cronbach’s α coefficient ranged from 0.35 to 0.73, with 4 dimensions above 0.70 (Table 3).

The test-retest reliability was acceptable based on the intraclass correlation for agreement between 0.64 and 0.90, calculated from the PCS. There were no statistically significant differences between PCS in the first and second questionnaires (Table 5). Response rate for the second questionnaire was 38% (n = 59), and it was answered 6–55 days after the first one.

**Analysis of the Answers to the Open-Ended Question (Part III)**

In total, 117 women provided comments in part III. A majority of the comments (84%) were related to the difficulty in answering questions based on all their experiences. Most had experienced both positive and negative performances from healthcare. They reported that it had taken years to get a proper care and treatment, but most were satisfied with the current care. Other comments were that there was a lack of certain aspects of care in part II of ECQ (e.g., lifestyle changes) and missing symptoms in part I (e.g., pain during defecation and pain after orgasm).

**Discussion**

Our study involved the translation, cross-cultural adaptation, and psychometric evaluation of the Swedish version of the ECQ. To the best of our knowledge, the ECQ is the first and only endometriosis-specific instrument available for measuring patient centeredness, and it is an important step towards evaluating and improving endometriosis care [21].

For the translation process, we strictly followed well-established guidelines for cross-cultural adaptation of pa-
tient-reported outcomes [23]. During this process, some cultural aspects were considered. For example, the question on ethnic origin may be provocative in Sweden and was therefore omitted. All 6 of the interviewed women found it difficult to give an overall rating of their healthcare experiences on the PNP. They wanted to have the possibility of selecting a response somewhere between agree/disagree. Half of the women thought that the instrument was too long. However, they all expressed gratitude for the study.

Our results suggest that ECQ is understandable and accessible based on the high data completeness (97% for part I and 91% for part II). Demographics show 56% of responders had a university degree, which is higher than the average Swedish population (28%) [27]. In the validation of the original version, 68% had a higher degree [21], which may have affected language aspects of instructions and questions.

The high floor and ceiling effects in PNP could be explained by the dichotomizing of answers in the coding of data. This is a necessity to calculate a percentage score, but it also limits the sensitivity of the answers. The high rate of ceiling effects in MIS could be related to patients’ willingness to report the importance of care; as they were not instructed to rank the importance of different aspects, they may have rated most questions as “of the utmost importance.”

Internal consistency varied between low and excellent (min 0.31 for PNP Dim 5–max 0.84 for MIS Dim 3) and was higher for MIS than for PNP in most dimensions. Our Cronbach’s alphas are comparable with those in the original version [21].

Test-retest reliability was acceptable for half of the dimensions, and the differences between the measurements were neither statistically significant nor clinically relevant. The differences between the first and second questionnaire could be related to recall bias, as the women were instructed to answer the questionnaire based on the care they had received since the start of their endometriosis-related complaints, which may have been a long time ago.

In the factor analysis, we were able to confirm 2 of the theory-driven dimensions presented in the original article and no other data-driven pattern. This may have several reasons. Firstly, this can be the consequence of cultural differences, leading to different interpretations of the questions. Secondly, the structure and conditions of endometriosis care probably differ between Belgium and Sweden. Furthermore, the original classification into 10 dimensions may be highly correlated with the data in the original version and not generalizable to other healthcare settings. In the development of the original version, both theory-driven and data-driven dimensions were presented, and adaptations were made to the original theory-driven dimensions [21]. The unstableness of the factor analysis of the theory-driven dimensions is important to consider when interpreting dimension results. Therefore, in the Swedish version of the ECQ, the items and the overall PCS may serve as indications for PCEC, but conclusions based on the dimensions should be made with caution.

The most negative median performances (highest PNP) were reported for Dim 5 Em Supp and Dim 6 Inv Sign. These negative performances are concordant with previous studies, where lack of emotional support from health professionals is often reported among women with endometriosis [4, 6]. When it comes to the impact of endometriosis on partners, the subject is not widely explored. A recent review found a few studies on male partners and concluded that partners were affected by the disease in terms of worse emotional wellbeing and lower quality of life [28].

The 2 dimensions rated as the most important all related to different capabilities of the healthcare professionals (Dim 1, 7, 9, and 10). Women valued being respected, having continuity of care, and being cared for by skilled and understanding doctors and nurses. Looking at the PCS, it is encouraging to see that the most important dimensions reached some of the highest scores. A few studies have used ECQ previously [20, 21, 28, 29], but comparable data are only presented by Schreurs et al. [30]. They reported a higher overall PCS, median 4.8 for a secondary care center, and median 4.5 for a tertiary care center [30], compared with our median 3.6. The low PCS suggests a need to strengthen PCEC, and ECQ may be used for designing and evaluating improvement projects. ECQ may also enable more research on the determination of specific patient characteristics that may have critical effects on the outcome of PCEC [30]. The properties of ECQ enable measurements of patient centeredness both at clinical and national levels, depending on the aim of the study [21].

There are some critical considerations related to this study. There was a relatively low participation rate. Despite this, we had enough data to perform factor and reliability analyses. Another issue was that women found it difficult to answer the ECQ properly as they had different experiences over time. Giving an overall assessment of the endometriosis care received during a lifetime is probably influenced by recall bias. It is thus likely that women gave their answers based on their more recent experiences.
Conclusion

In summary, the Swedish version of the ECQ is a valid, reliable, understandable, acceptable, and usable instrument. However, we suggest that the dimension scores are interpreted with caution. As ECQ is the only validated and internationally used specific instrument assessing PCEC, we recommend ECQ for use in daily clinical practice and for research purposes. Further research could include a national sample and explore possible correlations between experiences of patient centeredness and demographic and clinical characteristics. To overcome the problem of recall bias, we suggest that further studies are based on women’s experiences from their current clinic.

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