

Article

The association between experiences with patient-centred care and health-related quality of life in women with endometriosis

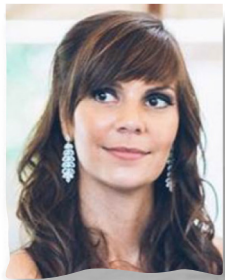
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KEY MESSAGE

It is of paramount importance to find additional ways of improving psychosocial wellbeing in women with endometriosis. Providing patient-centred care could lead to improvements in health-related quality of life of women with endometriosis, especially if paying attention to 'continuity', 'respect' and 'information'. Further large-scale longitudinal research is needed.

ABSTRACT

In this cross-sectional study, we investigated whether patient-centred endometriosis care (PCEC) is associated with health-related quality of life (HRQOL). Dutch-speaking women with endometriosis, treated by laparoscopy in a university clinic between 2009 and 2010, were eligible ($n = 194$). Endometriosis Health Profile-30 and ENDOCARE questionnaire were used to assess HRQOL and PCEC, respectively. Overall and subscale scores were converted to a scale from 0 (best score) to 100 (worst score). Linear regression analyses were conducted while controlling for confounders. Participants ($n = 109$) had a mean age of 35.4 years; 79.6% had moderate-severe endometriosis. Mean scores for overall HRQOL and PCEC were 29.3/100 and 38.0/100, respectively. The PCEC-subscale 'continuity' was significantly associated with overall HRQOL ($P = 0.029$). A significant association was found between overall PCEC and the HRQOL-subscale 'social support' ($P = 0.026$). The PCEC-subscales 'information' and 'continuity' were significantly associated with the HRQOL-subscales 'emotional wellbeing' and 'social support' ($P < 0.05$). The PCEC-subscale 'respect' was significantly associated with the HRQOL-subscale 'emotional wellbeing' ($P = 0.023$). Multivariable regression analyses produced no significant associations, including all subscales of PCEC. Providing PCEC could lead to better HRQOL, especially if paying attention to 'continuity', 'respect' and 'information'. Large-scale longitudinal research is needed.

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Introduction

Endometriosis, or the presence of endometrial-like tissue outside the uterine cavity, is estimated to affect between 3 and 10% of women who are of reproductive age in Europe and the USA (Eskenazi and Warner, 1997; Gylfason et al., 2010). Compared with their healthy counterparts, women with endometriosis score lower on quality of life (Fritzer et al., 2012) and report more anxiety and depressive symptoms (Friedl et al., 2015; Laganà et al., 2015). This can be explained by the negative effect that endometriosis has on women's psychosocial wellbeing (Culley et al., 2013; Jia et al., 2012; Kennedy et al., 2005; Nnoaham et al., 2011; Verhaak et al., 2007) owing to symptoms such as pelvic pain, such as dysmenorrhoea, dyspareunia, dyschezia and dysuria, and infertility (Kennedy et al., 2005).

Medical, surgical treatment, or both, for endometriosis does not always result in adequate pain relief, and this affects patient's psychosocial wellbeing (Vercellini et al., 2009). Hence, it is of paramount importance to find additional ways of improving patients' psychosocial wellbeing (Culley et al., 2013; Rowlands et al., 2016). Quantitative studies in the field of fertility care found that positive experiences with patient-centred care were associated with better health-related quality of life (HRQOL) (Aarts et al., 2012; Gameiro et al., 2013). In the field of endometriosis, quantitative studies have yet to be conducted. Nevertheless, qualitative findings suggest that the HRQOL of women with endometriosis may significantly benefit from more patient-centred care (Cox et al., 2003a; Dancet et al., 2014; Jones et al., 2004), which has been conceptualized into 10 dimensions that are important to patients (Dancet et al., 2011; Gerteis et al., 1993). Qualitative interviews have highlighted, for instance, that a delay in diagnosis, i.e. part of the patient-centred care dimension 'access to care', seemed to be associated with reduced HRQOL, whereas receiving a diagnosis seemed to validate symptoms and empower women (Culley et al., 2013; Dancet et al., 2014; Roomaney and Kagee, 2016). Furthermore, being informed by professionals, i.e. part of the patient-centred care dimension 'information, communication and education', helped interviewed women cope with the burden of their disease (Cox et al., 2003b; Young et al., 2016).

The objective of this study was to examine quantitatively how women's experiences with patient-centred endometriosis care (PCEC) relate to their HRQOL.

Materials and methods

This cross-sectional survey conducted in 2011 included patients who were followed up by a Dutch university clinic (Radboud University Medical Center, Nijmegen, the Netherlands). The study protocol was submitted to the Ethical Review Board of the clinic, which attested that no further formal ethical approval was required according to Dutch legislation. Patients who completed questionnaires after being thoroughly briefed about the study in the invitation letter, were considered for inclusion.

Measurements

Patients completed eight demographic, e.g. educational level, and 15 medical background questions, e.g. endometriosis-related symptoms. Furthermore, their experiences with PCEC and their HRQOL

were assessed with the valid and reliable Dutch translations of the ENDOCARE questionnaire (ECQ) (Dancet et al., 2011, 2012) and the Endometriosis Health Profile-30 (EHP-30), respectively (Jones et al., 2001, 2006; van de Burgt et al., 2011, 2013). The outcomes of both questionnaires were standardized to the same unit of measurement (0–100) and direction (higher scores reflecting worse experiences).

Part two of the ECQ was used and contains 38 statements on experiences with PCEC for which patients are asked to rate on a four-point Likert scale (from agree completely to disagree completely) whether each of the statements applies to the care they received (Dancet et al., 2011). The ratings were transformed into a score ranging from 0 to 100 (scale score = total of raw scores for each item divided by maximum possible raw score multiplied by 100), with 0 indicating the best patient-centred care experience and 100 indicating the worst experience. Besides the overall score, 10 subscale scores can be computed as the 38 statements cover the 10 dimensions of PCEC (Table 1). Detailed information on the ECQ can be obtained from the development and validation papers (Dancet et al., 2011, 2012).

The EHP-30 consists of 30 questions on the extent of experienced ill health to be rated on a five-point Likert scale (from never to always). The ratings were transformed into a score ranging from 0 to 100, where 0 indicates the best HRQOL and 100 indicates the worst HRQOL (scale score = total of raw scores for each item divided by the maximum possible raw score multiplied by 100) (Jones et al., 2001). Besides the overall score, five subscale scores can be computed (Table 1) (Jones et al., 2001, 2006).

Patients and procedure

Patients were eligible if they were diagnosed with, and treated for, endometriosis during a laparoscopy indicated by pain or infertility during a 2-year period (2009–2010) in the Radboud University Medical Centre ($n = 194$). Furthermore, patients had to speak Dutch and live in the Netherlands.

In 2011, the ECQ and the EHP-30 were disseminated simultaneously by surface mail using a three-phase strategy. First, an invitation letter, a set of questionnaires, a refusal form and a stamped return envelope were sent. After that, non-responders received two written reminders with a 3-week interval. Participation was voluntary and no (financial) compensation was given. Questionnaires were coded.

No patients had to be excluded for completing less than 50% of the items on the ECQ or the EHP-30. Only one patient did not complete one EHP-30 item. For the ECQ, 1.8% (respect; physical comfort) to 33.9% (access to care) of patients had missing data, but they all completed at least 50% of the items from each subscale. In line with the ECQ-manual, the limited amount of missing data was accounted for by changing the denominator to the number of answers from that patient, i.e. maximum possible raw score. Hence, no missing answers were interpolated.

Data analysis

SPSS version 23.0 (IBM Corp., Chicago, Illinois, USA) was used for data analysis, and the significance level was set at $P \leq 0.05$. Continuous data are presented as means and \pm SD. Categorical variables are presented as absolute numbers and percentages. As described earlier, all outcomes of the ECQ and the EHP-30 were standardized to the same unit of measurement (0–100) and direction (higher scores reflecting worse experiences). Pearson's correlation coefficients (r)

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