



**Exploring women's experiences of living with endometriosis and its impact;  
development and psychometric properties of a questionnaire to measure  
the impact of endometriosis on women's lives**

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## Abstract

**Background:** Endometriosis is a chronic disease that impacts on many aspects of a woman's life. Recent review studies on the impact of endometriosis recommended additional research in more diverse population and settings. Considering the chronic and recurring nature of endometriosis, many of the impacts of endometriosis could be missed by only looking at the last 4 weeks using existing questionnaires, and therefore developing one with a long-term perspective is necessary.

**Aim:** There were two phases in this study. Phase 1: to explore women's experiences of living with endometriosis and its impact on women's lives; and phase 2: to develop and evaluate the psychometric properties of a questionnaire to measure the impact of endometriosis on women's lives.

**Methods:** In Phase 1, through a qualitative, descriptive design, ten semi-structured focus group discussions were conducted with 35 Australian women with endometriosis (from both hospital and community), in three age groups. All tape-recorded discussions were transcribed verbatim and read line-by-line to extract meaningful codes and categories using NVivo 9 software through a thematic analysis approach. Categories were then clustered into meaningful themes. Phase 2 was a methodological research study. Firstly, items of the Endometriosis Impact Questionnaire (EIQ) were developed based on themes and categories that emerged from phase 1, along with an extensive literature review. Then, the psychometric properties of the questionnaire were evaluated through a cross-sectional survey using SPSS 20.

**Results:** In phase 1, participants were aged 17 to 53 years and had an average delayed diagnosis of 8.1 years. Two main themes emerged with 14 categories. The most highlighted impacts were on marital/sexual relationships, social life, and on physical and psychological aspects in all three age groups, but with different orders of priority. Education was the second most highlighted for the 16-24 years, life opportunities and employment for the 25 -34 years; and financial impact for those 35 years and above. In phase 2, the initial EIQ was developed with 100 items. Fourteen experts and 12 patients assessed content and face validity of the 89-item EIQ. The EIQ had an excellent content validity with S-CVI from the patients' perspective of 0.93 and 0.84 from the experts' point of view. Exploratory factor analysis of the 66-item EIQ was established with 423 responders (surgically diagnosed with endometriosis). The final 63-item EIQ contained six dimensions including: 33-item physical-psychosocial; 3-item fertility; 7-item sexual; 11-item employment; 6-item educational; and 3-item lifestyle. Cronbach's alpha of 0.99 for the 63-item EIQ, and 0.84 to 0.98 for the dimensions suggested a very good reliability. High positive correlations (0.664-0.802,  $n=423$ ,  $P < 0.01$ ) between the EIQ and the EHP-5 (altered recall period) indicated good concurrent validity. High intra-class correlation (0.88-0.99) identified very good test-retest reliability.

**Conclusions:** Endometriosis impacts negatively on different aspects of women's lives. The EIQ was successfully developed and validated to measure the impacts of endometriosis on women's lives with a long-term view. The EIQ will provide a better understanding of the impact of endometriosis to meet the needs of women living with this condition. Further validation of the EIQ in other countries and languages is recommended.

**Keywords:** Endometriosis, questionnaire, psychometrics, quality of life, qualitative research