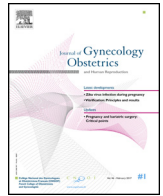




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## Original Article

# A self-administered questionnaire to measure the painful symptoms of endometriosis: Results of a modified DELPHI survey of patients and physicians



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## ABSTRACT

**Purpose.** – To develop a questionnaire based on patients' verbal descriptors, to measure the painful symptoms of endometriosis.

**Methods.** – We performed a two-round modified DELPHI procedure mixing endometriosis patients and physicians to select a set of statements to describe the painful symptoms of endometriosis. Each panelist rated each statement based on diagnosis validity and clarity. The clinicians were experts in endometriosis management selected from various geographic regions in France. Patients were women with surgically confirmed endometriosis who volunteered from a patient association and from the recruitment of the participating physicians. The first round questions were derived from words and phrases in narratives of pain by endometriosis patients.

**Results.** – Overall, 76 experts were invited, and of these 56 (74%), comprising 33 patients and 23 gynecologists, responded to the first round questionnaire, and 40 (71.4%) to the second round. Among the 48 statements assessed in the first-round questionnaire, 11 were selected after completion of the two round DELPHI procedure. After discussion and rewording of some items, a total of 21 questions were selected during a final face-to-face meeting. The content of the final questionnaire is organized according to four dimensions: (i) spontaneous pelvic pain and dysmenorrhea, (ii) dyspareunia, (iii) painful bowel symptoms, (iv) and other symptoms. We also provide an English (UK) version produced using several steps of translation and back-translation.

**Conclusions.** – The questionnaire has content validity to measure the subjective experiences of patients with painful endometriosis and can provide a solid basis on which to develop an efficient patient-centered outcome to measure the painful symptoms in therapeutic or in diagnostic studies of endometriosis.

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## Introduction

Endometriosis is a painful chronic disease affecting about 10% of women in Organisation for economic co-operation and development (OCDE) countries [1]. Endometriosis is responsible

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for various pelvic pain symptoms [2] that can have a great impact on all aspects of the life of endometriosis patients [3].

Measuring pain symptoms and Health-related quality of life (HrQoL) in endometriosis patients was useful to assess treatment outcome in clinical trials including medical therapy, or surgery [4,5]. Various methods of pain assessment are available in the context of endometriosis, some of which have been validated with a high level of evidence. The visual analog scale (VAS) and the numerical rating scale (NRS) are the most frequently used pain scales to assess each type of typical pain related to endometriosis (dysmenorrhea, deep dyspareunia and non-menstrual chronic pelvic pain). Although these scales are appropriate for the measurement of the individual pain symptoms [6], they do not take into account the heterogeneity of the painful symptoms of endometriosis. Furthermore, each of the pain symptoms that may relate to endometriosis involves numerous distinct descriptors and there was considerable variability in symptom description and interpretation by patients and by physicians [7].

Therefore, there is a need for reliable and well-defined patient-reported outcome measures (PRO's) that can be used to determine the clinical benefit of medical interventions and/or promote early diagnosis of endometriosis [8]. Important efforts have been made to develop and validate HrQoL questionnaire in the context of endometriosis, see for example SF-36 [9], or The "Endometriosis Health Profile 30" (EHP-30), specially developed to capture the impact of endometriosis on specific domains of HrQoL [10]. Although endometriosis symptom questionnaires have already been used in an epidemiological surveys [11] and in clinical studies [12], to the best of our knowledge, the various existing pain questionnaires and pain scales to assess symptoms related to endometriosis were primarily developed on the basis of clinician input. Currently, there are few data on the patients' descriptions of symptoms and at the present time, no questionnaire is available to obtain data from patients.

In a previous study, by analyzing in-depth interviews with endometriosis patients, we identified numerous verbal descriptors representing the patients' experience [7]. Here, we describe a first-step questionnaire development based on these verbal descriptors to measure the chronic pain symptoms of endometriosis using a PRO's approach. To achieve this, consensus needs to be reached among the various stakeholders involved in the care of women with endometriosis as well as patient representatives. The aim was to select a set of relevant statements based on patients' perception of painful symptoms to construct a short, standardized self-administered questionnaire.

## Methods

We conducted a two-round modified DELPHI survey among a multidisciplinary expert panel comprising endometriosis patients and physicians, whether gynecologists or not, involved in the diagnosis and treatment of endometriosis. The Delphi method is a practical and structured method to achieve a convergence of opinion and a general consensus on a particular topic from a large number of individuals. It has been used to develop medical recommendations clinical guidelines, questionnaire or clinical indicators such as indicators reflecting patient and general practitioner perceptions of chronic illness. The participants take part anonymously in sequential questionnaires that constitute different rounds [13]. The panellists rate the statements, and statements made by participants at each round of the process can be used to formulate the next round of questions. For the purpose of the present study, we used a modified Delphi technique in which questionnaire rounds were followed by a physical meeting of the

panellists, to enhance the complex decision-making process and to clarify the language used to describe each statement [14].

### Pre-selection of statements

First round questionnaire statements were developed from previous qualitative research [7]: The statements were based on the fully-comprehensive descriptions of painful symptoms obtained by qualitative, interview-based study and analyzed using Colaizzi's method [15], with endometriosis patients selected to represent different types of endometriosis (i.e. superficial endometriosis, ovarian endometriosis, or deeply infiltrating endometriosis [DIE]). To ensure a proper formulation of the first round statements, we first designed an in-person focus group discussions with eight subjects with endometriosis and interested in describing the word of pain (these subjects were not further involved in the DELPHI). The discussion was centered on the meaning of the words and sentences used to describe endometriosis pain related symptoms in order to reformulate some of the items and to clarify some of the sentences used. No physician was present at the time of the focus group discussion. The participating women also recommended to add two themes "fears from sexual intercourse because of the pain" #26 and "difficulties to get pregnant". In total, 48 statements were identified and were used for the first round questionnaire. These statements fall into five general categories:

- severe pelvic pain and dysmenorrhea ( $n = 21$ );
- dyspareunia ( $n = 6$ );
- gastro-intestinal symptoms ( $n = 8$ );
- painful urinary tract signs ( $n = 6$ );
- other symptoms ( $n = 7$ ).

### Panel members

To form a representative expert panel, the aim was to gather a heterogeneous group in order to ensure that the broadest spectrum of opinion was obtained. The clinicians were recognized French-speaking experts in endometriosis including gynecologist surgeons, specialists in reproductive medicine and specialists in pelvic imaging. They were selected from various geographic regions within France and Belgium, and were in practice in university teaching hospitals, general hospitals or in private centers to ensure that they represented a wide array of clinical approaches, backgrounds and practices. The panelists were also selected to represent a broad range of age and experience levels. Endometriosis patients were volunteers diagnosed with endometriosis by surgery; the patients came from a French association of patients with endometriosis (Endofrance, <http://www.endofrance.org/>) and from the recruitment of the participating physicians. We planned to include about 30 panelists by stakeholder category (i.e. physicians and patients).

### First round

The panelists who agreed to participate received the first questionnaire by e-mail. Non-responders were re-contacted by e-mail and telephone. Each panelist was invited to rate the 48 statements for two aspects:

- diagnosis validity, i.e. the statement had the appropriate characteristics to effectively diagnose endometriosis, it appeared to be sufficiently sensitive and/or specific to help detect endometriosis patients from patients with other diseases or free of any pathology;

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