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Original Article

Feelings and expectations in endometriosis: Analysis of open comments from a cohort of endometriosis patients

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A R T I C L E   I N F O

A B S T R A C T

Introduction. – Endometriosis symptoms may have a negative effect on health-related quality of life (HRQoL). Analyses of open comments are known to be a key source of information and support. The authors aimed to analyse open comments associated with a validation scale study, in order to ascertain whether the questionnaires allowed an adequate exploration of patient preoccupations and in so doing define important quality of life themes not assessed in HRQoL scales.
Material and methods. – Analysis of open comments, following two questionnaires (SF-36 and EHP-30) as part of a national study evaluating the EHP-30, was performed. Questionnaires were distributed online, via a link to the RedCap Internet platform. The association EndoFrance, a support group for endometriosis patients, notified women of the launching of the study. Women were asked to complete the questionnaire and had the opportunity to comment. Comments were gathered, coded systematically, and categorised by theme.
Results. – Of the 1156 women who responded to the questionnaire, 913 (79.0%) declared having a confirmed surgical diagnosis of endometriosis, and 265 comments were analysed. Comments were classified in 20 themes. Correspondence between the themes and items for both questionnaires and the open comments was investigated for all topics, including those non-addressed by the questionnaires. 8 themes are not mentioned in both questionnaires, 9 themes are covered by EHP-30, two by SF-36 and only one by both.
Conclusion. – Anonymous data collection and subsequent analysis proves to be an effective and practical way of obtaining patient opinion on their pathology. Analysis of comments may provide additional and useful information to the classical HRQoL Scale.

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Introduction

Endometriosis is typically associated with symptoms such as pelvic pain, painful periods and subfertility. Three main types of pain, chronic pelvic pain, dysmenorrhea and dyspareunia are

reported [1], though patients also experience a range of non-clinical symptoms, such as depression, feelings of isolation or lack of energy. All symptoms may potentially have an adverse impact on physical, mental, and social wellbeing [2] and therefore a negative effect on health-related quality of life (HRQoL) [3,4]. HRQoL of women with endometriosis is a growing concern, increasingly voiced by health professionals and patients alike. As part of a recent study of the reliability and validity of the cross-cultural adaptation of the Endometriosis Health Profile-30 instrument including prospective data of 913 women with endometriosis, the authors gathered patient comments relating to the study

and to endometriosis, using open-ended comments questions. Comments collected were analysed and compared to EHP-30 and SF-36 items, to ascertain whether the questionnaires allowed adequate exploration of patient preoccupations. Responses obtained from questionnaires were classified and analysed in relation to quality of life.

Material and methods

Analyses of comments questions following two questionnaires (SF-36 and EHP-30) as part of a national study evaluating the translation of the EHP-30 and its psychometric properties [4] were performed. This cross-sectional online study was conducted in France between July and October 2015. Questionnaires were distributed online, via a secure link to the Research Electronic Data Capture (RedCap) Internet platform. RedCap is a secure, web-based application designed to support data capture for research studies [5]. The association EndoFrance, a support group for endometriosis patients, notified women of the launching of a study on patient HRQoL via its website and social networks. Women were asked to complete a self-administered online questionnaire including demographic information, characteristics of their disease, the EHP-30, a self-reported instrument, and the SF-36, a generic HRQoL instrument recommended for endometriosis. Women who reported no confirmed diagnosis of endometriosis were excluded from the study.

At the end of the questionnaires, respondents were given the opportunity to comment (instruction: "If you have any comments or suggestions, this space is for you"). Comment analysis involved several phases, that can be synthesised in: (1) data consultation, (2) systematic coding and categorisation of data by theme, and (3) interpretation of findings. The analysis was carried out according to the guidelines proposed by Braun and Clarke [6], and in accordance with recommended steps used in others qualitative studies [7–9] (Fig. 1).

Conceptual groupings were created from the data, in line with research into participant comments about endometriosis [10–13].

The analyses began with detailed consultation of all comments, and the identification of 20 different themes, with a similar methodology as in other open comments studies [14]. A coding system was developed and an initial analysis carried out by a gynaecologist (P.C) in collaboration with L.G and C.A (Department of Public Health) and M.C and NB, gynaecologists experts in endometriosis [4,15,16].

The data were then coded (each comment corresponding to one or more theme) and analysed by theme; codes were manually assigned to all comments, with each comment receiving between one and five codes. Each code corresponded to a specific theme. Similarities and differences in women's views and experiences were established by subsequent indepth data analysis by code.

Finally, both codes and the data from the closed questions of the questionnaires were treated as variables in a quantitative analysis. Women who made open comments were compared to women without open comments according, using non-parametric Mann Whitney tests for quantitative characteristics and Chi-squared tests for qualitative characteristics. To investigate correspondence between responses of SF-36 and EHP-30 instruments and themes in the comments, scores of SF-36/EHP-30 items or dimensions related to a theme were compared according the presence of comments or not related to this theme, using non-parametric Mann Whitney tests. Statistical analysis was performed using SAS v9.4 software. P-values <0.05 were considered to be statistically significant.

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Fig. 1. Phases of thematic analysis from Braun et al. (*copyright request in progress*).