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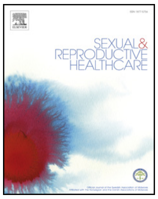

# Living with painful endometriosis – A struggle for coherence. A qualitative study

A. Hållstam[a,*], BM. Stålnacke[b,c], C. Svensén[a,d], M. Löfgren[c]

[a] Department of Clinical Science and Education, Södersjukhuset, Karolinska Institutet, and Anesthesiology and Intensive Care Unit, Södersjukhuset, SE-118 83 Stockholm, Sweden
[b] Department of Community Medicine and Rehabilitation, Rehabilitation Medicine, Umeå University, SE- 901 85 Umeå, Sweden
[c] Department of Clinical Sciences, Karolinska Institutet, and Department of Rehabilitation Medicine, Danderyd Hospital, SE-182 88 Stockholm, Sweden
[d] University of Texas Medical Branch at Galveston, UTMB Health, Department of Anesthesiology, Galveston, TX, USA

## ARTICLE INFO

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## ABSTRACT

*Objectives:* The study sought to examine women's experience of painful endometriosis including long-term aspects, social consequences, impact of treatment and development of own coping strategies.

*Study design:* This qualitative study was based on 16 individual interviews analyzed according to grounded theory. The thirteen women (age 24–48) were recruited at a pain clinic in Stockholm, Sweden.

*Results:* A theory illustrating women's experience of living with painful endometriosis was developed with three categories and one core category. Bidirectional interactions between the categories and with the core category were found. Endometriosis influenced the women's sensations, feelings and reactions, creating a sense of difference from other women (category: *Woman with painful endometriosis*). The condition led to either helpful or harmful encounters with health care and significant others (category: *Dependence)*. It also had overall physical, social and existential consequences (category: *A ruined life)*. To cope, the women had to struggle for coherence by searching for understanding, coping and meaning (core category: *Living with painful endometriosis*).

*Conclusions:* Living with severe painful endometriosis signified a struggle for coherence. The women needed to deal with feelings of difference, dependence and a ruined life and thus struggled for understanding, coping and meaning. Health-care providers should promote the struggle for coherence by explaining the feeling of difference, minimizing dependence and supporting the process of disease-related grief.

## Introduction

Endometriosis is a chronic inflammatory condition. It occurs in about 10% of females, predominantly during the fertile period [1]. Endometriosis is found in many diverse forms, from limited superficial endometrial implants to severe conditions infiltrating different organs and inducing pain and infertility as main problems. Disease-specific hormonal or surgical treatment to minimize pain and bleeding is the recommended treatment but many women have continuous problems [2]. Chronic and recurrent pain such as dysmenorrhea, non-menstrual pelvic pain, dyspareunia and dyschezia occurs in about 80% of cases, influencing quality of live and mental health [3]. Central sensitization and myofascial trigger points aggravate the pain problem [4]. Further nausea, diarrhea, sleep disturbance and fatigue can be associated with endometriosis [5,6].

The extensive effects of endometriosis on women's lives are illustrated in quantitative and qualitative studies. Consequences for daily activity, intimate relationships and uncertainty about having children as well as educational, work-related and financial issues are described [5,7–10]. Reports of insufficiency in health services include delayed diagnosis [6,7,9] and unsatisfactory communication with health-care providers [11–13]. To relieve this complex bio-psychosocial problem a multidimensional treatment approach is needed, requiring multidisciplinary organizations [14,15].

Earlier studies have commonly investigated women's experience of endometriosis when treated in specialized clinics such as reproductive healthcare clinics, or sampled by support groups [7,9]. There is a lack of studies of patients with endometriosis treated at specialized pain clinics that have covered bio-psychosocial aspects of pain in an overall perspective. Thus, our aim was to explore women's experience of severe

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*Abbreviations:* ACT, Acceptance and Commitment Therapy; ICD-10, International Statistical Classification of Diseases and Related Health Problems 2009; TENS, Transcutaneous Electrical Nerve Stimulation

[*] Corresponding author at: Department of Clinical Sciences, Karolinska Institutet, and Department of Rehabilitation Medicine, Danderyd Hospital, SE-182 88 Stockholm, Sweden.

*E-mail addresses:* andrea.hallstam@ki.se (A. Hållstam), britt-marie.stalnacke@umu.se (B. Stålnacke), christer.svensen@ki.se, chsvense@utmb.edu (C. Svensén), monika.lofgren@ki.se (M. Löfgren).

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painful endometriosis and its treatment including long-term aspects, social consequences, impact of treatment and development of own coping strategies.

## Material and methods

A qualitative approach according to grounded theory was chosen [16]. Following emergent design, our parallel data collection and analysis allowed us to adapt the interview guide. The initial purposive sampling was supplemented by theoretical sampling in the later data collection and analysis.

### *Setting and treatment*

The study was performed at the specialized pain clinic of a tertiary center in Stockholm. An endometriosis team of various clinical specialists met to facilitate joint understanding of the treatment for the condition. Patients with severe pain problems were referred to the pain clinic by gynecology specialists. There, the patients met a physician specialized in pain medicine and anesthesiology and a physiotherapist trained in acceptance and commitment therapy (ACT). The treatment was pharmacology-based combined with transcutaneous electrical nerve stimulation (TENS), ACT, and physical training.

### *Participants and inclusion*

From a sample of patients included in a follow-up study after treatment for chronic pain at the clinic [17] twenty-nine women were identified as having endometriosis with an ICD10 code of N 801, 803, 808 or 809. By purposive sampling 23 were invited by letter to participate. Sixteen of the 23 were reached by telephone, where of two declined due to lack of time or dissatisfaction with the clinic, two cancelled the interview and one did not attend, leaving 11 participants. To obtain deeper information about pain treatment, two more women currently being treated at the clinic were included. Thus, 13 women were interviewed. Three follow-up interviews were performed one year later to explore women's experience of clearly positive or negative conditions, this in accordance with theoretical sampling [16]. These women belonged to the sample of the questionnaire study. For all participant's details and background see Table 1.

**Table 1**
Background data for the 13 participants.

| **Age** years | **Mean (min-max)** |
|---|---|
| when diagnosed with endometriosis | 27 (20–35) |
| when interviewed* | 36 (24–48) |
| **Time** since first visit to pain clinic, months * | 34 (9–47) |
| **Country of origin** | **n** |
| Sweden | 12 |
| Europe | 1 |
| **Education** | |
| University | 8 |
| Secondary school** | 4 |
| Primary school*** | 1 |
| **Family status** * | |
| Married/cohabiting | 4 |
| Single/divorced | 5 |
| Boyfriend | 4 |
| **Parity** | |
| Para 0 | 9 |
| Para 1 | 1 |
| Para ≥ 2 | 3 |

* At first interview.
** 11–12 years of school.
*** 9 years of school.

**Table 2**
Interview guide.

| | |
|---|---|
| Initial question areas | Present lifestyle: activity, participation<br>Experience of pain and pain treatment<br>Endometriosis diagnosis: when, by whom<br>Hormonal treatments<br>Relationships: partner, significant others<br>Feeling of self<br>Something to add |
| Emerging question areas | Experience of gynecological examinations<br>Thoughts about future |
| Question areas in follow-up interviews | Your last year<br>New possibilities |
| Examples of follow-up questions | Describe everyday life, your social and working situation.<br>Describe a situation when you are in pain.<br>What kind of pain treatment did you get?<br>Tell me about your partner's and significant others' reactions to your pain.<br>Tell me about how you feel when meeting health-care people.<br>What kind of feelings and thoughts do you have for the future? |

### *Data collection*

The data were collected between February 2015 and March 2016. Written consent was obtained before the semi-structured interviews. Most interviews took place in a secluded place at the hospital, three in patients' homes, one at a workplace and one in a public library. The interviews lasted between 43 and 82 min (mean 59 min). The first author (AH) led 15 interviews and the last author (ML) one. No authors were involved in the care of the women. The interviews were recorded and transcribed verbatim. The interview guide was tested in a pilot interview and supplemented after five interviews. With the data emerging from the interviews, the guide was adjusted again after eight and 11 interviews as well as for the follow-up interviews (Table 2).

### *Data analysis*

The analysis started after two interviews (including the pilot interview) when the transcripts were coded by AH and ML independently, using the Open Code computer software program [18]. The codes were then discussed until agreement was reached, and clustered by AH and ML into 24 preliminary subcategories. Data collection and analysis continued in parallel. After eight interviews the subcategories were discussed by all authors and formed into six categories, and a preliminary theory was developed. AH continued with the data collection and coding and continued the analysis together with ML. All the authors met regularly to discuss the emerging result. During the analysis, memos and constant comparison were used to compare codes, sub-categories and categories with each other and the emerging theory. The theory was continuously refined with new data and in discussions between the first author and health-care peers with relevant experience. Conceptual saturation was reached after 14 interviews (including one follow-up interview) and the last two follow-up interviews confirmed earlier findings. The core category was further defined, and connections to, and interactions with, the other categories were explored. The final categories are presented in Table 3.

## Ethical considerations

The study was approved by the Stockholm Regional Ethical Review Board, (Registration no. 2010/1903-31/5), with a supplementary application (Registration no. 2012/75-32).