


# Practices and Attitudes Concerning Endometriosis Among Nurses Specializing in Gynecology

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## Abstract

Endometriosis is a chronic disease affecting approximately 10% of fertile women. These women often have negative health care experiences. This study adds new knowledge about endometriosis care in a hospital setting and nurses' attitudes toward the disease. To explore how the personal attitudes of gynecological nurses, their specialized knowledge, and their clinical experiences influenced the way they conceptualized and cared for women with endometriosis, participant observations and semistructured interviews were conducted. Categorization of patients into certain kinds, with more or less legitimate needs, provided an important framework for practice. Specialized knowledge qualified the nurses' views of their patients and seemed to be conducive to sustained patient involvement. However, the organization of care based solely on medical specialization restricted a holistic approach. An important goal is, therefore, to investigate patients' perspectives of health and illness and to create participatory relationships with patients, regardless of their diagnosis.

## Keywords

illness and disease, interviews, ethnography, caregivers / caregiving, quality of care

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The nursing staff is pivotal to the provision of patient support in a hospital setting (Bloski & Pierson, 2008). In this study, we add to the field by exploring how the personal attitudes of gynecological nurses, their specialized professional knowledge, and their clinical experiences influence the way they conceptualize and care for women undergoing major surgery for endometriosis.

Endometriosis is a chronic disease, presumably caused by retrograde menstruation, where fragments of the endometrium (the mucosal lining of the uterine cavity) implant on the peritoneal surface of the pelvis. This causes local inflammation and can lead to severe dysmenorrhea (menstrual pain), intermenstrual pain, dyspareunia (pain during sexual intercourse), and painful defecation (Giudice, 2010). Further symptoms include fatigue and infertility, and endometriosis has a profound negative influence on quality of life (Ballweg, 2004; Culley et al., 2013; Denny, 2004, 2009; Kaatz, Solari-Twadell, Cameron, & Schultz, 2010; Lovkvist, Bostrom, Edlund, & Olovsson, 2015; Seear, 2009; Toye, Seers, & Barker, 2014). The disease affects up to 10% of fertile women, and annual socioeconomic costs are estimated at 30 billion euros in the EU alone (European Endometriosis Alliance, 2006).

In their encounter with the health care system, women with endometriosis experience stigmatization and delays in diagnosis and treatment (Ballard, Lowton, & Wright, 2006; Ballweg, 2004; Cox, Henderson, Wood, & Cagliarini, 2003; Culley et al., 2013; Denny, 2009; Guo et al., 2009; Husby, Haugen, & Moen, 2003; Seear, 2009; Stratton, 2006; Stratton & Berkley, 2011; Toye et al., 2014). This, we assume, reflects deficient knowledge and unvoiced assumptions among patients as well as their health care professionals.

## Background

Menstrual pain is both a normal part of many women's lives and a principal symptom of endometriosis (Denny, 2009; Whelan, 2003). Women handle menstrual problems by the

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use of certain cultural practices, including silence and discretion, and by following a “menstrual etiquette” (Seear, 2009; Strange, 2001). By disclosing severe menstrual pain to others, a woman therefore risks being perceived as malingering, and women with endometriosis can experience that their pain is normalized, minimized, or trivialized by health care staff in charge of their treatment (Bloski & Pierson, 2008; Bodén, Wendel, & Adolfsson, 2013; Denny, 2004; Huntington & Gilmour, 2005; Seear, 2009; Toye et al., 2014).

In addition, 46% of endometriosis patients need to see five or more doctors before they reach a correct diagnosis (Ballweg, 2004; Cheong & William Stones, 2006; European Endometriosis Alliance, 2006; Mihalyi et al., 2010). This diagnostic delay partly arises out of the behavior of both the women and the health care professionals (Ballard et al., 2006; Ballweg, 1997; Bloski & Pierson, 2008; Huntington & Gilmour, 2005; Husby et al., 2003; Seear, 2009; Stratton, 2006).

Attitudes of health care professionals are influenced by multiple factors, such as gender, age, and personal and professional experiences, and by knowledge of the patient. This phenomenon has previously been documented for pain treatment in cancer (Jeon, Kim, Cleeland, & Wang, 2007), back pain (Daykin & Richardson, 2004), pain treatment in pediatric and medical units (Lui, So, & Fong, 2008; Rieman & Gordon, 2007), and chronic pelvic pain (Ballweg, 1997), and for clinical assessment of postoperative pain behavior (Leung & Chung, 2008).

Chronic pain in endometriosis is characterized by sensitization (Evans, Moalem-Taylor, & Tracey, 2007) with complex changes in the autonomous neuronal function. This involves pathological growth of peripheral nerve endings, enhanced afferent activity, changes in spinal and cerebral processing of signals, and altered and enhanced pain experience (Stratton & Berkley, 2011). Changes in autonomous reflexes, including the development of irritable bowel syndrome and bladder symptoms, seem to represent another important aspect, and a recent study defined a visceral syndrome characteristic of endometriosis-related chronic pain (Hansen, Kesmodel, Baldursson, Kold, & Forman, 2014). Despite the above findings, and although chronic pain conditions are considered as illnesses, they are not yet recognized and dealt with as disease, either in health care or in society in general (Brown, 1995; Good, 1992; Stratton, 2006).

In this study, we understand the concepts of illness and disease according to the theory of the medical anthropologist Arthur Kleinman (1988), where illness represents the culturally formed response by the individual to her symptoms and disabilities, in this case living with endometriosis and pain. In a hospital context, the concept of disease is predominantly referred to as abnormal body functions, often with clearly defined medical solutions. If cure in the medical sense is not possible, as is often seen in the case of endometriosis, a potential conflict might arise (Kleinman, 1988). However, a considerate attitude on the part of health care professionals

can positively influence the patient’s overall illness experience (Toye et al., 2014; Werner, Steihaug, & Malterud, 2003). When shared, illness perspectives can contribute to mutual understanding, cooperation, and development of new knowledge.

In line with other social communities, health care professionals develop a common culture with shared concepts of disease, illness, and patients in addition to their joint mission as professionals (Barth, 1995; Kleinman, 1988). Within this cultural framework, symptoms, diagnoses, and patient identities are negotiated and constructed among the members of the community. Categorization into different kinds of patient with distinct “institutional identities” is a characteristic of hospital social processes (Goffman, 1963; Gubrium & Holstein, 2001; Hojlund, 2002; Mik-Meyer, 2011). These cultural assumptions are represented in both speech and action, but there is not necessarily a strong correlation between them. Therefore, a qualitative investigation of culture should include both aspects. No fixed reality can be identified here, as meaning is subjective and contextual, and is furthermore negotiated with the researcher as part of the research process (Spradley, 1980).

In theory, the nurse–patient relationship is founded on a holistic approach with dialogue and engagement in the encounter, with a view to creating a fundamental trust that allows the patient to actively influence her own care (Martinsen, 2005). This includes a dialectical approach to the disease, the patient’s psychological response to the disease, and her social functioning. This process might be affected by the general comprehension of endometriosis-related symptoms in patients as well as in nurses (Bodén et al., 2013). In addition, most nurses are women and, besides their knowledge of endometriosis, they might have personal and professional experiences of menstrual pain. Awareness of staff attitudes therefore represents a prerequisite for developing and performing high-quality treatment and care. To our knowledge, however, no previous studies have focused on nurses’ attitudes toward women undergoing major surgery for endometriosis and how this affects their care delivery.

## Method

To gain an insight into health care professionals’ attitudes toward endometriosis, we made an anthropological field study among nursing staff members in two inpatient units. From September 2009 until January 2011, we collected data from nurses in two gynecological units in an urban hospital. During the study period, we combined observational data, collected by the first author (FA) in either the role of observing participant or in full participation (Spradley, 1980) with semistructured interviews (Kvale & Brinkmann, 2009). The primary focus was on staff members’ attitudes, which we believed to be recognizable in their actions and speech, and on what appeared to be meaningful to them when they carried out their practice. Through participation in staff member

activities, the FA sought to learn from and understand their point of view (Spradley, 1980). In doing so, the FA had an active role in seeking out the multiple perspectives and cultural assumptions held by the participants. From an anthropological perspective, cultural assumptions are constructed in a process of sense-making, and they are present in both speech and actions. An investigation of culture must include both aspects, as there is not necessarily a correlation between the two. In this approach, no fixed reality can be identified, and multiple perspectives are involved.

### Study Setting

During the study period, the Department of Gynecology consisted of two inpatient units, which included a number of outpatient clinics and an operating theater. In the Danish National Health Service, hospital care is free and organized in five politically driven regions, and ongoing debates on priorities in health care characterize the political agenda. This includes efforts to reduce hospitalization, and the duration of hospital stay is among the lowest in the world. One of the included units specializing in the treatment and care of women with endometriosis (the "Endo-unit") was closed at weekends. The other unit specialized in the treatment of women with gynecological cancer (the "Onco-unit") and was in operation 7 days a week. According to guidelines from the Danish Health and Medicines Authority, the Endo-unit represented one of two national referral centers and the Onco-unit represented one of five, with outpatient clinics attached to both units. Consequently, care was organized so that patients with a postoperative need of prolonged stay had to be transferred from the Endo-unit to the Onco-unit at weekends and on holidays. Patients undergoing major surgery for endometriosis were among those most likely to be transferred, which meant that at weekends they were taken care of by the Onco-unit nurses.

The endometriosis team included three senior gynecologists, one young specialist, and five nurses (including the FA). There is no Danish postgraduate educational program in gynecological care, so the nursing staff members were not formally specialized. However, besides their professional bachelor's degree in nursing, several had further education within other areas and considerable clinical experience; however, their knowledge of the subspecialism was mainly experiential, as it derived from working in a team structure with senior doctors.

### The Field Study

Field studies were conducted to explore and describe the clinical units as a cultural scene, from the shifting perspectives of the field-worker, who was both an insider and an outsider. During the study period, the FA functioned half-time as a nurse in the Endo-unit, performing full participation (Spradley, 1980), and half-time as a researcher, doing

participant observations. During the participant observations, the FA dressed in civilian clothes, and her role was established as "note taker" (Emerson, Fretz, & Shaw, 1995).

The FA had peripheral knowledge of the gynecological staff members, because, previously, she had been responsible for the overall training and documentation of the nursing care in the department. Because she was not familiar with the clinical aspects of gynecological nursing, the FA initially followed introduction procedures for newly recruited nursing staff members.

The FA undertook participant observation by accompanying staff members taking care of patients, during staff meetings, and when working with colleagues and other hospital employees. The observations took place during morning and afternoon shifts, and often involved nurses giving pre- and postoperative care to women undergoing major surgery for endometriosis. Informal conversations with nurses, doctors, and patients took place during the time spent in the setting. The observations sought to capture both verbal and nonverbal communication, concerning perceptions of particular endometriosis patients, how the nurses interpreted the patients' pain, and how they made clinical decisions. Each observation lasted between 1 and 4 hours, and took place on 26 nonconsecutive days, between September 2009 and January 2011.

To exemplify, one focus in the observations was pain. It included everything that took place among the staff members and between patients and staff concerning pain. Primarily, this included not only patients undergoing major surgery for endometriosis but also other patients with pain problems and cancer. In the field notes, we noted what kind of patient the nurse was caring for and talking about. The observations sought to capture questions such as follows: How did the staff members recognize and interpret pain? How were decisions concerning pain made, on what basis and by whom? How did differences appear in the staff's perception of and reactions to pain? Were there any differences in the staff's reactions to different kinds of patients and/or different diagnoses? In this way, we observed how patients with pain were constructed in clinical practice.

During full participation, the FA made field notes immediately after incidents that made a particular impression. Generally, these incidents involved nurses expressing their opinions about patients. The FA transcribed the field notes within 2 days using Microsoft Word. Besides observations, the notes also contained some of the dialogue written verbatim in situ and information on personal reactions during observations. This meant that the FA's preconceptions were systematically identified to promote trustworthiness. Feelings and reactions were therefore monitored and recorded as an integrated element of the field notes. This approach allowed the FA to be conscious of her subjectivity and reflect on it during the study (Bradbury-Jones, 2007; Peshkin, 1988; Simmons, 2007). We considered this especially important because the FA was investigating peers.

**Table 1.** Interview Guide for Staff Interviews.

Topics	Questions
Professional background	<p>What is your job role?</p> <p>How many years of experience in nursing/gynecology?</p> <p>Do you have any special professional interests or experiences?</p> <p>Do you have specific education or training in taking care of patients with pain/endometriosis?</p>
Personal experiences and attitudes	<p>Do you have personal experiences with pain/menstrual pain/chronic pain?</p> <p>Have you been absent from school or work due to pain?</p> <p>How did you learn about dealing with pain as a child?</p> <p>Do you have colleagues who are absent due to pain? What is your personal view on that?</p> <p>In your opinion, is a woman ill if she is having menstrual pain/endometriosis?</p>
Professional experiences and attitudes	<p>How often do you take care of patients with endometriosis?</p> <p>Please share your reflections on endometriosis and the particular patient suffering from it.</p> <p>How will you know if a patient is in pain? How is your experience of mental issues in the case of patients with endometriosis?</p> <p>Do you think your point of view is of any importance for the care you provide?</p> <p>What do you find challenging in caring for patients with endometriosis?</p> <p>Is there anything you would like to add or find important?</p>

## Interviews

The FA conducted formal, semistructured interviews with nine nurses (including one final year student) from the two gynecological units. We identified participants during observations and selected them strategically, based on variation in level of experience and specialization, because staff attitudes might be affected by these factors. The interviews took place in private on the wards, at the end of the day shift. They lasted 30 to 75 minutes and were digitally audio-recorded, and transcribed verbatim using Microsoft Word. Nonverbal expressions, such as laughter, sighs, and pauses, and emphasized words were included. Because of the limited opportunity to conduct field observations among the nurses from the Onco-unit, their perspectives are presented mainly through interviews.

## Overview of Interview Informants

All nine participating nurses were women. Their ages ranged from 24 to 61 and they had between 5 months and 40 years of experience in gynecology nursing. The interviews focused on predetermined topics identified by reviewing the literature concerning endometriosis, women's experiences with endometriosis and pelvic pain, health care staff attitudes concerning patients with pain, and the findings from the field studies. After conducting a pilot interview, an interview guide was developed (see Table 1). The guide and interview technique were refined in cooperation with the second author. We used the guide to systematically investigate the informants' personal and professional experiences and perceptions of pain in general, menstrual pain, endometriosis, patients' needs, previous experiences, and the challenges they encountered in their clinical practice. During the interview process, topics of significance were identified, through discussions with coauthors, and pursued further in interviews. Some of these were pain, the use of a Visual Analogue Scale (VAS) for pain,

body–mind relations in endometriosis, experiences of challenging patients, and illness categorizations.

## Ethical Considerations and Data Protection

Initially, the ward management orally approved the study. In accordance with the rules of the Central Denmark Region's Committees on Biomedical Research Ethics, the study needed no further approval (Law No. 402 of May 28, 2003, para. 7, No. 1). However, substantial ethical considerations were required, both before and during the study ("Ethical Guidelines for Good Research Practice," 2011; International Council of Nurses, 2012).

In relation to the field study, the FA orally informed the nurses in the two units about the study and invited them to participate. In addition, written information for staff members about the study was distributed. None declined to participate. Patients and relatives also received written and oral information about the study, and subsequently the responsible nurse obtained oral consent from them. None refused to participate.

In relation to the interview study, we handed out information letters about participation and obtained individual oral consent from each nurse. One nurse declined to be interviewed. She stated that she knew nothing of endometriosis and had never met a patient with this diagnosis during her 1 year at the Onco-unit.

Names were changed in transcripts. We stored data in a safe password-protected system and accessed the data only to discuss the findings.

## Analysis

Interviews and field notes were transcribed and analyzed using Microsoft Word and handwritten drawings and notes. We performed the data collection and analyses simultaneously. This

allowed for an iterative process, in which we used systematic reflection on previous data to refine and define the process, with a view to increasing our in-depth understanding of the nurses' perspectives and their practice. In this way, various interpretations or assumptions could be tested and adjusted.

During the data collection, we analyzed field notes by conducting domain and taxonomic analyses to promote selected observations that focused on how categorization works, and on actions and interpretations related to pain and endometriosis (Spradley, 1980). We initially read and listened to the interviews in their entirety, and, to gain an overall understanding, informant portraits were drawn up. Subsequently, we coded transcripts openly (Kvale & Brinkmann, 2009), and meaningful and significant units were sought to identify important themes, such as relationships with patients, strategies in managing patient contact, and nurses' views of their duties. The themes were linked to subheadings, which were based on preliminary topics, and included nurses' personal pain experiences and assumptions about endometriosis patients. From this, we identified new themes, such as categorizing patients, causal relationships in endometriosis/illness perceptions, cooperation with patients, patients' competence, and trust and distrust. Finally, we analyzed the themes, drawing on medical anthropological perspectives (Good, 1992) and Goffman's (1963) sociology of stigma. All authors were involved in the analysis and interpretation of the data, and consensus was reached through mutual discussions.

In the following, we present the findings from the field study and the interviews as a whole. The term "patient" is used for women with endometriosis, although it represents a specific perspective, in which the individual is categorized as an object. From the analyses of the empirical findings, the main theme "Knowing About the Disease—Striving to Understand the Illness" emerged. Three subthemes were associated with the main theme: "The History of Pelvic Pain," "You Don't Die From Endometriosis," and "The Nurse–Patient Relationship." Although they are closely interrelated, the subthemes are presented separately for reasons of transparency. To make the number of topics manageable, we intend to deal with findings relating to pain in a subsequent article.

## Findings

### *Knowing About the Disease—Striving to Understand the Illness*

Our main finding was that all the nurses were deeply concerned about taking good care of patients undergoing major surgery for endometriosis and sought to understand them. They recognized that the women were having problems but applied different views of the underlying causes. Consequently, they also held different views of the solutions and of how to care for the patients in the best way possible.

### *The History of Pelvic Pain*

Historically, beliefs about psychosomatic causes of pain have affected views of pelvic pain, a main symptom of endometriosis. During the 1980s, women with pelvic pain began to seek gynecological counseling. They suffered from what, in those days, was believed to be psychosomatic pain, as no physical cause could be found (Leviton, Eibschitz, de Vries, Hakim, & Sharf, 1985). Two nurses told this "history of pelvic pain," as they had experienced it during their more than 15 years of clinical practice in gynecology:

Ten or 12 years ago, or even earlier, there were almost nothing called endometriosis, you know. Those patients were just put in a box labeled psychosomatic pain, and really, we didn't believe there was anything physical causing the pain . . . it was seen as something going on in their heads.

However, the above understanding of pelvic pain as caused or amplified by psychological problems was still expressed by some of the nurses:

When you meet an acute patient who arrives in pain in the middle of the night, whether they have endometriosis I couldn't say . . . but you know they are in that category . . . perhaps psychosocial and somatic pain, right, precisely because you just can't find any obvious reason for their pain.

This understanding could have clinical consequences: One patient, who had been suffering from severe pelvic pain ever since she had her first period, was admitted to the Endo-unit with suspected endometriosis. Previously, she was not examined by a gynecologist until she had undergone psychiatric assessment and was found to be mentally well (field note).

The nurses could change their perspective on endometriosis, in line with a change in their position. One nurse, who moved from the Onco-unit to the Endo-unit, expressed her worries about taking care of women with endometriosis (field note). A few months later, she said,

It's really hard, I think, with endometriosis . . . when you only know a little about it. The more I get to know about it . . . the greater my understanding gets, that it's something physical that makes it mentally difficult. Initially, I thought the opposite.

Another nurse from the Endo-unit suspected that patients could exploit their pelvic pain for their own gain and raised suspicion that, in some cases, there were motives behind pain-related complaints. She apparently distanced herself from patients with endometriosis, and her empathy lay more with the relatives and what they had to endure:

I think as well that I've heard people say how it's always just when there's a lot to be done that she has to lie down because she is in so much pain [laughing] . . . I've often thought to myself . . . that is no mother-in-law's dream . . . I hope my son won't run into a girl like that.

However, there were informants from both units who did express their deep appreciation of the reality of chronic pain and the need for recognition. Based on personal experiences with pain, they had attitudes toward endometriosis that were significantly different from their colleagues, suggesting that personal experience can supersede cultural assumptions.

In the following, we present how patients were perceived and grouped in different ways by the nurses, and how this influenced the quality and extent of care they received.

### *You Don't Die From Endometriosis*

Categorization appeared to be central to the forming of attitudes and patterns of practice. In the Endo-unit, new gynecological patients were categorized according to their type of operation, as a "hysterectomy" or "laparoscopy." However, patients admitted for endometriosis represented an exception, because they were categorized as "Endo-patients," thus underlining this special diagnosis. The patients were further categorized as "easy" patients, "resilient" patients, and "heavy/complex" patients. The meaning attributed to these categories revealed a common understanding of how these patients would present. "Easy" patients would make few demands; they would display confidence, have few requirements concerning pain, and be socially well adapted. A "resilient" patient would demonstrate stoicism in relation to pain and in other ways appear similar to the "easy" patient. Field notes from observations conducted in the Endo-unit staff office during shifts illustrated this:

She is strong. She does a lot herself, like exercise. She's a tough girl. She doesn't let endo rule her life. She can't take on too much, has to sleep or rest after work, but . . . she has a horse, she's tenacious and really wants to . . . She's the type who doesn't talk about it.

In contrast to this, a "heavy" or "complex" patient was characterized by having chronic pain, distrust of the health care system, being demanding of the staff, and by being mentally and socially influenced by her situation. Moreover, she would need extensive support from the staff to restore trust and to handle her complex problems. These patients could be categorized as having a problematic psyche or an inappropriate way of dealing with their disease.

The use of stereotypes seemed to have different functions in categorizing patients. It provided a shorthand way of describing a task to a colleague, but it was also a way of justifying the amount of time the nurse spent with the patient, as it was more acceptable among the staff members to spend a lot of time on "heavy and complex" patients than on so-called "easy" patients. This mechanism was also used in retrospect; if a nurse had spent very little time with a patient during the day shift, she could categorize the patient as an "easy" patient, thus legitimizing the limited engagement. Another consequence of being a "complex" patient was a

high degree of patient involvement in care, in that the nurses spent more time negotiating care with these patients. "Complex" patients were perceived as being competent, and the nurses acted as if partnership with these patients was important. Remarkably, a consequence of being an "easy" patient was less patient involvement, because the nurse took the opportunity to get her job done quickly. These categories were seldom conveyed to patients. An exception was patients who were explicitly recognized as being resilient, as this categorization would often cause the nurse to seek out the patient more often, to look for signs of pain. In these ways, the categorizations influenced clinical practice and the quality of care. If a patient acted surprisingly because her behavior lay outside of the expectations of the assigned category, she could be reassigned to another category. These categorizations were commonly used, especially by the Endo-team members. When the nurses and doctors agreed that a patient was "heavy" or "complex," the team supported and acknowledged each other's efforts to manage the perceived difficult task, and described their practice as challenging, necessary, and important:

I like the combination of the totally practical . . . like helping out the newly operated patient, and then this . . . more psychological side, because many of them have pain issues that have been going on for years, and they feel threatened, not just about their physical well-being, but about issues such as their job, marital relationship, and children as well. The complexity of care really challenges me, because it requires something different from me as a nurse. I have to be present in the encounter with the patient and to be able to communicate.

In the Onco-unit, the nurses usually categorized the patients in other terms, as either "sick/ill" or "not ill/healthy." Women with cancer were referred to as "our sick cancer patients," whereas a "healthy" patient could refer to any other gynecological patient. Consequently, the "not ill" patients would often be patients with endometriosis who were moved to the Onco-unit for the weekend. Accordingly, this transfer between the units implied a change in status and categorization of the patients, because they were suddenly considered to be "healthy" patients instead of "Endo-patients." Thus, a patient who was a special and important case for the Endo-unit nurses could be placed in a two-bed room in the Onco-unit, to share with another patient, instead of having her own private room. However, this change in attitude involved not only the unit and category but also the nurses' attitudes. The patient was expected to do more by herself, not call on the nurse too often, and not show too much distrust of the staff.

When moved to the Onco-unit, some of the women with endometriosis were categorized as "difficult"; however, others were seen as "heavily influenced" by their condition. This could be the case if a patient had developed severe complications, and the nurses would have a higher tolerance for these

patients. Categories were used regardless of the diagnosis, however; these spontaneous utterances were especially frequent with regard to patients with endometriosis. Cancer patients were mainly seen as nondemanding, rarely calling for help, and the staff considered them to be generally grateful. In contrast, a “difficult” patient was one who made higher demands for care than the staff based on her diagnosis found her entitled to. However, these expectations concerning a specific behavior were not necessarily obvious and were never explained to the patients.

Furthermore, categorization seemed essential to the way the nurses formed their professional relationship with the patient. For the Onco-unit nurses, the central question was whether the patient’s life was endangered. In this sense, nothing compared with cancer. This led to the risk of discriminating patients with a perceived less legitimate claim for care, and an apologetic attitude was expressed:

And sometimes it’s really difficult to work with two patient categories that are so different, I mean, in the sense that sometimes it’s really hard to see the point in providing so much help to someone who you think is only marginally ill, you know, because you are sort of contaminated by all that cancer and how ill these patients are . . . at the end of the day, you don’t die from endometriosis.

Consequently, the categories seemed to define the importance and legitimacy of patients’ needs, influenced whether the nurse found it meaningful to provide care, and affected the nurse–patient relationship.

### *The Nurse–Patient Relationship*

According to the Onco-unit nurses, cancer patients had the greatest claim for care and represented their main priority. This assumption influenced their attitude to women with endometriosis, and the legitimacy of their needs was questioned:

I mean, again it’s this long-term chronic disease that comes into play . . . yes, they’ve also undergone major surgery . . . but I see the recovery process as slower for these patients, compared to cancer patients.

In both units, the endometriosis patients were categorized as skeptical and distrustful, but apparently, this constituted a major problem for the Onco-unit nurses. They experienced that endometriosis patients questioned their professional competence and the extent of their knowledge of endometriosis:

They size you up, the patients, and challenges whether you are competent and will respond to their needs in the way they think they need [smiling].

One nurse with 40 years of experience described this routine of moving patients as “catastrophic.” She was prepared

to take care of patients with endometriosis, but expressed that her colleagues sought to avoid them, begging her to do the job. She was the only nurse from the Onco-unit who categorized the endometriosis patients as sick:

It’s actually a much more serious diagnosis compared to how it was considered previously, . . . because it affects so many things in the woman’s life . . . they are ill when they are here, they are in a bad state, many of them.

Although she recognized the patient as ill, she kept at a distance from the patient’s needs and provided care out of a sense of professional duty:

This is something you need to resolve, because you are the nurse allocated to this patient on this shift, right . . . I mean, I might think that, if I had to take care of her during weekdays, I would find that exhausting, or if I had to support her with coping.

Concerning the endometriosis patients, it seemed as if the Onco-unit nurses mainly saw their role as taking care of the physical body and technical aspects of the disease management. However, quite another perception of patients’ needs is present in the following, expressed by an Endo-team nurse:

They challenge me because . . . they often bring complex problems and lots of experience from encounters with the health care system that were to a greater or lesser extent successful. And this often makes them some very well informed patients . . . they often have high expectations . . . when they finally get in touch with the specialized team, which is our unit. And it also challenges me that, as a nurse, I must be able to answer lots of questions, and be able to communicate a lot of knowledge to these patients.

Although all the nurses had similar pathophysiological knowledge about endometriosis, the Endo-team nurses had acquired experiential knowledge of caring for women with endometriosis through daily contact with the women and the team doctors. The creation of a participatory relationship with the patient was central to the work of the Endo-team nurses. Their specialized knowledge contributed to their professional identity as “Endo nurses,” and their attitudes seemed to influence their colleagues in the Endo-unit, leading to positive and accommodating attitudes toward patients with endometriosis.

## **Discussion**

Through the study, we have developed knowledge concerning hospital nurses’ attitudes and provision of care for women with endometriosis, based on their conceptions of illness and disease. In the discussion, we address some methodological considerations and evaluate the findings, which are structured according to analytical categories.

### *Strengths and Limitations*

We found interviews valuable in gaining detailed insights into the nurses' personal experiences. Furthermore, supplementary field observations and informal conversations contributed to the data collection and strengthened the findings.

Because the study took place among peers, the participant observations posed certain ethical challenges for the FA, such as handling conflicts of loyalty, and balancing confidentiality, while maintaining credibility as both a researcher and a colleague (Bloomer, Doman, & Endacott, 2013). As a nurse without prior knowledge of gynecological care, the study provided the FA with an opportunity to enter into and learn about the work culture in the two units. Additional field observations in the Onco-unit might have further added to the data collection. However, the management of the Onco-unit declined permission for to conduct observations, allegedly because of organizational difficulties. Out of respect for the patients' need to rest, the FA did not perform observations during night shifts, which might have added valuable information to the study.

Initially, we analyzed transcripts and field notes for repetition and use of sarcasm, laughter, and verbal excuses by the informants. These were interpreted as signs of an apologetic attitude to what they said or as an attempt to distance themselves from those opinions that were honest and maybe less socially acceptable. For ethical reasons, we disregarded statements dealing with colleagues or other health care professionals in the analyses. When investigating attitudes among community members, it can be a major problem that informants withhold stigmatizing attitudes due to political correctness or social desirability (Yang et al., 2007). However, the ethnographer's long-term stay in the community is stressed by Yang to be a valuable way of getting insight into stigma-related topics. This was confirmed in our findings.

### *Discussion of Main Findings*

Through the findings, we reveal that pelvic pain and endometriosis are phenomena that continue to be associated with psychological problems among health care professionals. During hospitalization, patients are therefore at risk of being labeled as having difficult psyches, psychological conflicts, or ulterior motives, even though the disease has been verified by biopsy.

It was a main finding that the nurses' personal experiences of pain and values concerning professional conduct seemed to influence their professional attitudes toward endometriosis, despite their biomedical knowledge. We found no particular differences between nurses' attitudes as they were expressed through speech and action, respectively. In some cases, they considered that women with endometriosis failed to meet their expectations of a woman, and that they were undesirable as wives or girlfriends. However, they also

recognized other patients for not allowing the disease to "rule their lives." This way of problematizing women's actions and behavior indicated that the identity of the endometriosis patient was construed to be gendered. Holen and Lehn-Christiansen (2010) found gender to play a constitutive role in the hospital setting, creating individualized problems not necessarily connected to the biomedical condition (Holen & Lehn-Christiansen, 2010). Our findings indicated that this might also be the case in relation to endometriosis, which is inextricably linked to female body functions, such as menstruation and concepts of fertility and sexuality.

It is a common experience among women with endometriosis that they are assessed or regarded in psychological terms (Ballweg, 1997; Denny, 2004). It is not unusual to have the cause or validity of one's pain questioned and to be referred for psychiatric instead of gynecological assessment (Ballweg, 1997). Historically, this applied to pelvic pain in general, but other chronic pain patients have similar experiences (Jackson, 1992). Ballweg (1997) stressed that, when physical symptoms are ignored or interpreted as being caused by psychological issues, the problems are personalized, and it becomes easy to "blame the victim." Furthermore, studies by Mik-Meyer and Werner have shown that when the diagnostic choice is between biomedical disease and psychological problems, the latter is more often preferred in the case of women (Mik-Meyer, 2011; Werner et al., 2003).

To summarize, the nurses generally psychologized the health problems of women with endometriosis and attributed individual responsibility for their disease to them. These attitudes reflected a continuum of perspectives influenced by gender, knowledge, and experience. Furthermore, strong values and personal experiences among the nurses seemed to trump their biomedical knowledge. The second main finding was that the nurses' categorization of patients as, for example, "sick," "not sick," or "difficult" had important consequences for their nursing care, because patients' needs and nurses' provision of care were legitimized and interpreted accordingly. Hojlund (2002) has previously shown the impact of categorization based on different diagnoses. She found that the needs and competences of pediatric patients were interpreted differently depending on whether the child had suspected psychosocial problems or other diseases. These different interpretations actually influenced who was protected or acknowledged by the nurses (Hojlund, 2002). In our study, we found that the nurses' perception of the patient's competence changed negatively when the patient was moved from the Endo-unit to the Onco-unit, possibly also connected to different diagnoses, and influenced the nurse-patient relationship, a topic that will be discussed later.

In their interaction with and caring for patients, the nurses seemed to create a range of patient categories, which influenced their own role perception. The nurses expressed frustration about the emotional challenges they faced, and some nurses chose not to actively assist patients in coping with their endometriosis. On this point, the nurses' attitudes



deviated from professionally shared assumptions about holism in nursing care, in which the relationship with the patient is central (Martinsen, 2005; Werner et al., 2003). Denny and Werner have demonstrated the importance of creating participatory relationships when caring for chronically ill patients (Denny, 2004; Werner et al., 2003). However, to recognize the patients' expertise and illness perspective requires a willingness from the nurse to surrender some of her control to the patient. Previous studies have shown that this might pose a significant challenge, especially for the older nurses who had been educated in more hierarchical systems (Goffman, 1963; Macdonald, 2003; Michaelsen, 2012; Trexler, 1996).

Investigating nurses' attitudes and perceptions and taking our point of departure from theoretical concepts of illness narratives, this study provides an insight into health professionals' narratives about illness (Hydén, 1997). Most commonly, when talking about illness narratives, the patient's illness experience is performed as a narrative that gives voice to his or her suffering (Kleinman, 1988). In this study, the emerging health professional illness narratives deal with how to understand the patients' conditions. However, notably, this understanding seems to work not primarily to acquire clinical knowledge or understand the patient's personal perspective but as frameworks for management. Such a narrative framework is generated by a transformation of personal attitudes, collectively shared ideas and clinical knowledge, which are decisive factors in the communication with the study's patient group.

Correspondingly, nurses with different kinds of experiential and specialized clinical knowledge expressed differing attitudes concerning women with endometriosis. Within the microcultures of the two units, the nurses applied various perspectives of their professional duties and the extent of care they felt obliged to deliver. One of the main findings was that different nurses in different units interpreted the needs of individual endometriosis patients differently. The nurses either valued or disregarded the knowledge that the patients possessed. In the latter case, the patient was not given the opportunity to be a competent participant with the capacity to influence her own care.

Another main finding was that the nurse-patient relationship and care delivery were influenced by the individual nurse's attitudes toward women with endometriosis. What was construed as an interesting challenge in the eyes of the Endo-team nurse seemed in some cases to be considered a disturbance to the Onco-unit nurse: She sought to accommodate the needs of the cancer patient as her main priority. The possession of experiential knowledge of endometriosis seemed to be important for quality of care, and the lack of this knowledge led some nurses to question their own competences regarding endometriosis. This suggests that there might be a link between nurses' level of knowledge and clinical competence, and the risk for the patient of being characterized as difficult (Macdonald, 2003; Podrasky &

Sexton, 1988; Trexler, 1996). Michaelsen (2012) found that if patients had certain characteristics or exhibited certain kinds of behavior, for example, "demanding, time consuming, requesting often, calling frequently, being female or uncooperative," or having a different understanding of their illness than the nurse, they were more likely to be perceived as difficult. In our study, we found that some women with endometriosis were seen as having "difficult psyches" and were considered especially difficult to deal with by the nurses. Furthermore, if patients seemed to question the nurses' professional competences, the nurses spoke about them dismissively.

Some nurses experienced that women with endometriosis made excessive demands for care that they neither could nor would meet. In these cases, the nurse might seek to persuade the patient to cooperate, use sarcasm, "say only yes," resort to avoidance, or label the patient as difficult, as a way of distancing herself emotionally. According to labeling theory, such reactions could be classified as "inclusionary and exclusionary reactions" (Michaelsen, 2012; Podrasky & Sexton, 1988; Trexler, 1996). In labeling theory, "surface acting" is used to camouflage the nurse's impermissible emotions. In this way, labeling appeared to be a negative form of the ongoing categorization. The patient's behavior, diagnosis, and the nurses' competence all seemed to cocreate the category assigned to the patient. If a patient was believed to take a position in opposition to her caregivers, she was considered to have violated the unwritten rules of good patient behavior, even though this position could be taken because of her previous bad experiences. This created a clinical atmosphere where trust and support were replaced by suspicion and frustration, and led to the patient becoming at risk of receiving a stigmatizing label as a "problem patient" (Kleinman, 1992). That might be the case for patients with endometriosis who were labeled "heavy" or "difficult." In contrast, a more positive picture was painted of the gynecological cancer patients, who seemed to fit the description of desirable behavior, constituting a so-called "good patient" (Holen & Lehn-Christiansen, 2010; Jahn, 2002; Podrasky & Sexton, 1988; Trexler, 1996). Compared with patients undergoing major surgery for endometriosis, who were viewed by some as "slow to get started," or without the will to get well, the cancer patients were perceived as doing everything they could to get well.

In this way, the specialization that demarcated the units unintentionally seemed to be a limiting factor in the development of quality care, as it seemed to exclude some of the needs of patients from other subspecialties. A narrow focus on certain patients created new forms of subjectivity that supported a diagnostic hierarchy, in which patients with endometriosis were important and needed specialized care during weekdays, but did not receive the specialized care on weekends. This was in contrast to the cancer diagnosis, which had a priority all week. In this way, organizational factors and narrow specialization seemed to restrict a

humanistic approach in the overall care (Cotton, 1997), in the case of our study, by qualifying or de-qualifying the care for women with endometriosis.

To summarize, nurses assigned patients with endometriosis to a range of categories depending on the nurses' specialization and attitudes. The patients risked having the legitimacy of their needs called into question by the nurses. Consequently, a patient whose care, in one context, was considered an "important task" could be construed as being "not sick," "time-consuming," or "difficult" in another context. This had negative consequences for the nurse–patient relationship and, thereby, for the quality and delivery of nursing care.

## Conclusion and Perspectives

Medical specialization in teams can promote clinical development and performances of high-quality nursing care, including establishing participatory relationships with the most affected patients. However, if the organization of care is solely based on medical specialization, it might limit a holistic approach in the care provision as well as in patient involvement—two hallmarks of contemporary nursing care. This is especially the case for those patients who do not fit into the subspecialism. On this basis, we suggest that patient pathways should also be analyzed in the light of nursing theories, and that a patient perspective is furthered in terms of patient involvement.

Gynecological nurses play an important role in providing specialized care and in creating appropriate patient pathways for women undergoing major surgery for endometriosis. For gynecological nurses in a hospital setting, caring for women with endometriosis might represent an emotional challenge. We found that the nurses' attitudes toward patients suffering from endometriosis were influenced by the microculture in which they were working and by medical specialization. Biomedical knowledge, personal assumptions about endometriosis, personal values, and personal pain experiences influenced the nurses' clinical practice. In addition, different levels in the nurses' experiential and professional knowledge significantly influenced their illness and disease perceptions. However, care seemed less influenced by nursing values and ethics. We therefore suggest that nurse leaders implement self-reflection in the clinical setting and systematically promote it in clinical practice, to train and sustain a holistic approach to the patient that goes further than her biomedical diagnosis.

Because culture influenced and legitimized the nurses' decisions about their patient care, the categorization of patients and alignment with a range of institutional identities became crucial to the kind of practice carried out. One major future challenge for clinical nursing practice is to develop a comprehensive understanding of patient care and to enhance the ability to negotiate the organization and provision of care with other health care professions and decision makers.

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