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Crossroad decisions in deep endometriosis treatment options: a qualitative study among patients

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Objective: To study the experiences, considerations, and motivations of patients with endometriosis in the decision-making process for deep endometriosis (DE) treatment options.

Design: Qualitative study using semi-structured in-depth focus group methodology.

Setting: University medical center.

Patient(s): A total of 19 Dutch women diagnosed with DE between 27 and 47 years of age.

Intervention(s): Not applicable.

Main Outcome Measure(s): Focus group topics were disease impact and motives for treatment, expectations of the treatment process, and important factors in the decision process.

Result(s): Women reported that pain, fertility, and strong fear of complications are important decisive factors in the treatment process. The goal of conceiving a child is considered important, however, sometimes doctors emphasize this topic too much. It emerged that complication counseling is frequently about surgical complications, whereas side effects of hormonal treatments are neglected. Shared decision making and information about treatment options, complications, and side effects are not always optimal, making it difficult to make a well-considered choice. Despite negative experiences encountered after surgery, the positive effect of surgery ensures that most women do not regret their choice.

Conclusion(s): In the treatment decision process for patients with DE, pain is almost always the most important decisive factor. The wish to conceive and strong fear of complications can change this choice. Doctors should understand the importance of fertility for the majority of women, but, also, if this is not considered paramount, respect that view. To improve shared decision making, exploration of treatment goals, training of healthcare providers, and better patient information provision are desirable. (Fertil Steril® 2021;115:702–14. ©2020 by American Society for Reproductive Medicine.)

El resumen está disponible en Español al final del artículo.

Key Words: Decision making, focus groups, qualitative research, endometriosis

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Endometriosis is defined as the presence of endometrium-like tissue outside the uterus inducing

chronic inflammation and formation of adhesions (1). Endometriosis is associated with infertility and pain expressed

as dysmenorrhea, dyspareunia, chronic pelvic pain, pain during ovulation, dyschezia, and dysuria (2). The prevalence varies between 2% and 10% among the general female population of reproductive age but increases up to 50% among women with infertility (3, 4). Three distinct types of endometriosis are known: superficial endometriosis, ovarian endometriomas, and, the most aggressive presentation, deep endometriosis (DE). Deep endometriosis is defined as endometriotic lesions penetrating >5 mm under the peritoneum

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and this type affects approximately 20% of all cases (5–7). Despite the benign aspect of this disease, endometriosis-associated symptoms cause a significant reduction of women's quality of life (QoL), social participation (e.g., loss of productivity), and sexual health (8, 9).

Several therapeutic options are available for endometriosis, including conservative treatment (analgesics and/or hormones) and surgical treatment. None of these options achieve a complete cure but aim to reduce pain, increase the QoL, and potentially increase the chance of pregnancy (10).

Available data suggest that both conservative and surgical treatment options are effective in reducing pain (11, 12). The potential benefit of surgery on pregnancy rate remains unclear due to a lack of proper conclusive studies (13). However, DE surgery is associated with significant complication rates up to 14% (14), which include enterotomy, anastomosis leakage, damage of the urinary tract, fistula formation, and even temporary or permanent stoma (14–17). Reasons for the failure of hormonal treatment include the onset of side effects (weight gain, decreased libido, mood swings, and headaches), refusal to take chronic medication, or contraindications to this treatment (e.g., deep venous thrombosis, heart disease, and hormone-sensitive tumors) (12).

Currently, an important quality dimension in healthcare is patient centeredness. This type of care is guided by the values, preferences, and needs of patients (18). A patient-oriented approach is particularly applicable to endometriosis because it compromises both physical and psychological health (8, 9). In patient-centered health care, decisions about treatments preferably are made in consultation between the physician and the patient (19). Therefore, gynecologists need to counsel patients optimally by providing more extensive information on the pros and cons of each treatment option and by supporting the shared decision-making (SDM) process. This is only possible when gynecologists understand which risks and benefits may be important to patients and are trained properly in guiding SDM. In today's literature, there is no thorough understanding of the value attributed by patients and physicians to benefits and risks of the different therapeutic options for endometriosis, which makes SDM difficult. In the absence of conclusive evidence for the superiority of one treatment, preference-sensitive care is most favored to use (20). Therefore, it remains vital to form a therapeutic balance that takes into account risks and benefits and patients' priorities and preferences. Shared decision making has the potential to improve health care (increase patient's knowledge, lower anxiety in the care process, and improve health outcomes), but also to decrease health-care expenses and to provide better alignment of care with a patient's values (21).

Qualitative research on care for patients with endometriosis has focused on information need (22), experiences and lack of support (23–26), dyspareunia (27), psychological health (28), work and social life (29, 30), health-care encounters (31), and QoL (32, 33). The average number of patients in these studies was 34 (range 12–74), and none of these studies

were specifically about patients with DE. From these 12 studies, 7 were from Europe, 3 from Australia/New Zealand, 1 from Brazil, and 1 from South Africa. These studies showed women feel that their symptoms are trivialized and dismissed, and they lack support and understanding of the disease by doctors and family. Furthermore, these studies show endometriosis has a major negative influence on sexual functioning, psychological health, and social life. These factors together result in an overall deterioration of QoL. One important note to these studies is they did not differentiate between DE and endometriosis in general. However, this distinction is extremely important because patients with DE experience very severe pain symptoms, often >95% of the cases (34). Furthermore, they present impairment in different domains of QoL (35), but also have to deal with more complex treatment options. For example, DE surgery is comparable with highly complex oncology surgery, and, therefore, treatment decisions are different compared with a cystectomy in more general endometriosis surgery. A neglected area in the field of qualitative research in DE is the treatment decision-making process. The European Society of Human Reproduction and Embryology guideline for endometriosis (10) mentions that the guideline could assist in the SDM process, however, in the references given, only one qualitative study with patients is mentioned regarding diagnosis delay. This guideline does not refer to any qualitative research about the SDM process, which is essential information. For SDM, insight from both the doctor and patient are needed. To get this understanding in the patient perspective, qualitative studies are needed.

Because patients with DE are confronted frequently with several treatment options, including hormonal and surgical treatment, the choice between these options not only differs by their stage of life (e.g., actual or future wish to conceive) and treatment goal (e.g., pain reduction or fertility improvement), but also by their unique risk-benefit profiles. Therefore, decision making for women with endometriosis may be really challenging and complex.

The aim of this qualitative study was to explore the considerations and motivations of patients with endometriosis in decision making for DE treatment options.

MATERIALS AND METHODS

Study Design

A qualitative study design was used, with a semi-structured in-depth focus group methodology. We chose a qualitative focus group study because this answers questions about experience, meaning, and perspective of patients with DE (36). We did not choose individual interviews because the literature shows that sensitive and personal disclosures are more likely to emerge in focus group than in individual interviews (37). With this qualitative focus group data, doctors can gain better insight into what is important for patients in the SDM process and potentially can better guide patients with DE in making a well-considered treatment choice. This information can be collected by asking patients about their experiences in the SDM process.

Participant Recruitment

Dutch-speaking women between 18 and 65 years of age diagnosed with DE (using ultrasound/magnetic resonance imaging or surgery) were recruited. For recruitment, patients from an endometriosis center specialized in DE and the Leiden University Medical Center were informed by their gynecologist about the study. Patients received oral information from their gynecologist about the study format (discussion group study of 5–8 patients) and the discussion topic (decision making in DE treatment). If women were interested, they contacted the researcher for further information. In addition, women were recruited through a nation-wide appeal on the website of the Dutch Endometriosis Foundation (Dutch patient association). An information sheet was sent to women interested in the study containing information about the study's purpose, inclusion criteria, and format. For this study, we selected and grouped patients with DE facing a therapeutic choice, prior to the decision (focus group 1 [FG1]) and patients after their decision or treatment (focus group 2 [FG2] and focus group 3 [FG3]). For FG1, it was not an exclusion criterion that they had previous surgery; it was only important that they were facing a therapeutic treatment choice for this research. The patients in FG1 were not in contact with the patients from FG 2 and FG 3 to prevent any information (e.g., treatment outcomes) being shared with FG1. Patients in FG1 were recruited between November and December 2017, and FG2 and FG3 were recruited from February to March 2019. For both groups, it was noted specifically that they had to be diagnosed with DE. For patients in FG1, the inclusion criterion was that they were facing a therapeutic choice (before the decision). For FG 2 and FG 3 the inclusion criterion was that patients could only participate if they had already made a choice in the treatment decision process or were already being treated. When patients responded by e-mail, this was verified with all patients before we included them in this study. In line with the literature on focus group size (38), the aim was to include 5–8 patients per group. Patients received a gift voucher for their participation. Ethical approval was given by the Medical Ethics Committee of the Leiden University Medical Center (P18.142).

Data Collection and Procedure

In all focus groups, we used 5–7 general questions (Table 1) to start and guide the discussion, making it a semi-structured in-depth focus group. Our goal was not to restrict the focus group discussion with these questions but to keep the focus on the decision-making process. A pilot validation study was held in 2017 with a group of pre-operative patients receiving information about their upcoming surgical procedure to test whether the patients understood the questions as formulated. From our pilot focus group, we could conclude that all questions were understood, therefore, no changes were needed. For FG1 we used slightly different questions because that group still had to make the decision, whereas FG2 and FG3 had already made the decision. The focus group sessions were conducted at the Leiden University Medical Center, with all focus groups having one small break halfway through the ses-

TABLE 1

Questions for each type of focus group.

Question

Group 1: patients before decision-making.

1. What are the most important symptoms when you think of endometriosis?
2. What is important in endometriosis treatment (e.g., pain relief, fertility)?
3. What do you think about possible complications and side effects?
4. Do you involve family/friends (do you seek help) when making a choice?
5. What is the deciding factor for choosing a treatment?

Groups 2 and 3: patients after decision-making.

1. Which expectations did you have from the different treatment options and how did you finally make your choice?
2. To what extent have you taken people in your near surroundings into account in your decision making?
3. To what extent does your experience with your treatment correspond to your expectations in advance?
4. With the knowledge and experience of today, would you have made the same decision?
5. How do you look back on the period before the diagnosis was made?
6. To what extent did you feel that you had control over your situation during the decision-making process?
7. Looking back at your decision, do you have the feeling that the treatment fit what was most important for you?

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sion. A few months after the focus groups were completed, we asked the participants to fill in a short digital form with additional questions about demographics, treatment, and use of medication. Two researchers led each focus group. Focus group 1 was guided by two medical doctors and one medical student (J.S., J.M., and P.V.), all with experience in endometriosis care; FG2 and FG3 were guided by one doctor and one psychologist (J.M. and S.S.). All interviewers had acquired their interview skills during their (medical) training. They were not involved in the treatment of the women they interviewed. Permission for audio recording and informed consent were obtained before the start of the focus group, whereby confidentiality and anonymity in data processing and reporting were assured.

Sample Characteristics

Nineteen patients participated, divided over three focus groups. Focus group 1 consisted of eight participants, FG2 of five participants, and FG3 of six participants. The average duration of a focus group session was 2 hours and 15 minutes (FG1 1:53 hours; FG2 2:06 hours; FG3 2:48 hours) (Table 2). Baseline characteristics were collected with a questionnaire after the focus group sessions; three women did not respond to this questionnaire resulting in 16 responders. The average age of the participants was 36.7 ± 6.3 years. The average time from symptoms to diagnosis was $9.4 \text{ years} \pm 6.7$. The majority of the participants were postgraduates (44%), all were of Dutch nationality, most of them were working part-time, and 69% was married or had a committed relationship. Fifty-six percent of the participants had fertility problems and

TABLE 2

Baseline characteristics of the focus groups and participants.

Characteristic	Total (N = 16), % ^a	Group 1 (N = 8) ^b	Group 2 (N = 5) ^b	Group 3 (N = 6) ^b
Duration of focus group, h:min	02:15 ^c	01:53	02:06	02:48
Age, y ^d	36.7±6.3	36.4±4.1	36.8±8.7	37.0±8.3
Age diagnose, y ^d	30.7±5.5	29.0±4.3	33.5±6.5	31.0±6.3
Time till diagnose, y ^d	9.4±6.7	7.3±5.5	14.0±8.8	8.8±6.3
Educational level				
Intermediate vocational education	3 (19)	2	0	1
Higher vocational education	6 (38)	3	1	2
Postgraduate	7 (44)	2	3	2
Nationality				
Dutch	16 (100)	7	4	5
Employment				
Full time	7 (44)	3	2	2
Part time	8 (50)	4	1	3
Unemployed	1 (6)	0	1	0
Marital status				
Married, committed relationship	11 (69)	5	3	3
Single	4 (25)	2	1	1
Divorced	1 (6)	0	0	1
Children				
Yes	4 (25)	3	1	0
No	9 (56)	3	2	4
Foster child	1 (6)	0	0	1
Currently pregnant	2 (13)	1	1	0
Fertility problems				
Yes	9 (56)	4	2	3
No	1 (6)	1	0	0
NA	5 (31)	1	2	2
Unknown	1 (6)	1	0	0
Current medication				
No medication	9 (56)	3	3	3
Ethinylestradiol/levonorgestrel	2 (13)	1	0	1
Progesterone only	2 (13)	1	1	0
IUD	1 (6)	0	0	1
GnRH	1 (6)	1	0	0
Other	1 (6)	1	0	0
Ever experienced a complication during surgery				
Yes	7 (44)	4	0	3
No	9 (56)	3	4	2
Satisfaction treatment decision				
Completely satisfied	10 (63)	4	4	2
A little satisfied	4 (25)	1	0	3
Neutral	1 (6)	1	0	0
Not really satisfied	1 (6)	1	0	0
Not satisfied	0 (0)	0	0	0
Shared decision making				
Yes	10 (63)	4	3	3
No	2 (13)	1	0	1
Partially	4 (25)	2	1	1

Note: Data presented as mean ± standard deviation or n (%) unless noted otherwise. GnRH = gonadotropin-releasing hormone; IUD = intrauterine device; NA = not applicable.

^a Three women did not respond to the questionnaire, therefore, the total women in the baseline table is 16 instead of 19.

^b One woman did not respond.

^c Mean.

^d Mean (SD).

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25% had children. Medication use varied from 13% ethinylestradiol/levonorgestrel, 13% progesterone-only, 6% intrauterine device use, 6% gonadotropin-releasing hormone agonist (GnRH) use, 6% other medication, and 56% without medication. Forty-four percent experienced complications during endometriosis surgery, ranging from cystitis to anastomosis

leakage. Finally, 63% were completely satisfied with the treatment decision they made and had the feeling that there was SDM. Looking at the distribution of baseline characteristics, it shows that FG2 did not experience any complications and all participants were completely satisfied with the treatment.

Data Analysis

Important field notes were made during the focus groups and the audiotapes were transcribed verbatim. Thematic analysis is a method to emerge themes and subthemes from essentially recurring subjects in data (39). This method was used to structure and reduce the data with the program QualiCoder (2019, <http://qualicoder.com>). The analysis started with reading the transcripts, formulating common themes, classifying the data by codes, and dividing it into themes and subthemes. This was performed by two researchers (J.M. and S.S.) using a combination of deductive and inductive coding (40). Forty-five codes emerged with open coding. Codes with the same meaning were merged together; codes were deleted or renamed when there was similarity or when they had a low frequency. The results of the thematic analysis were discussed with all the researchers to create consensus, which resulted in a codebook with 31 codes. Three main themes emerged from the codebook which could be divided in subthemes (Table 3). Theme 1 was disease impact and motives for treatment with five subthemes: symptoms, sexuality, impact on relationships, mental well-being, and time to diagnosis. Theme 2 was expectations of the surgical process with three subthemes: treatment expectations, previous experience with surgery in the treatment process, and postsurgical period. Theme 3 was important factors in the decision process with eight subthemes: impact of the social environment (partner, family, and friends) on the decision-making process, importance of information, doctor-patient relationship, it is all about fertility, decisive factor in the treatment decision, feeling of control, SDM, and considerations in the treatment process.

RESULTS

Table 3 shows an overview of the themes and subthemes. For each theme the emerged data is elaborated, summarized, and

TABLE 3

Themes and subthemes that emerged from the focus groups.

1. Disease impact and motives for treatment
 - 1.1 Symptoms
 - 1.2 Sexuality
 - 1.3 Impact on relationships
 - 1.4 Mental well-being
 - 1.5 Time to diagnosis
2. Expectation of the surgical process
 - 2.1 Treatment expectations
 - 2.2 Previous experience with surgery in the treatment process
 - 2.3 Postsurgical period
3. Important factors in decision process
 - 3.1 Impact of the social environment on the decision-making process
 - 3.2 Importance of information
 - 3.3 Doctor-patient relationship
 - 3.4 It is all about fertility
 - 3.5 Decisive factor in the treatment decision
 - 3.6 Feeling of control
 - 3.7 Shared decision making
 - 3.8 Considerations in the treatment process

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enforced and illustrated with quotes (FG1, FG2, and FG3) from the transcripts.

Theme 1: Disease Impact and Motives for Treatment

This main theme represents the wide range of negative effects caused by DE on the diagnosis trajectory (delay), physical (symptoms), psychological (mental well-being), and social aspects (sexuality and relationships) in women with this condition. The common aspects that emerged in this main theme were elaborated in the following five subthemes.

Symptoms. Almost all women described pain and fatigue as the most important symptoms of endometriosis. Pain from DE is an incapacitating factor in everyday functioning, school, work, and QoL. Functioning in a normal way becomes harder and harder, although women try all sorts of things to keep up with society. One woman explains that because of the pain she even fainted sometimes and also missed school days because of that: "For me the complaints started when I was 15, menstrual complaints, a lot of pain, even fainting from the pain, missing 1 or 2 days from school and very heavy bleeding." (FG1).

Almost all women reported in some way that they had to live with the pain, and that their pain tolerance gradually increased. They reported that because of this gradual deterioration, it was difficult to realize how bad it really was: "It is not that you wake up and your intestine is 80 percent obstructed, it goes gradually percent by percent over the years and at some point, it is just normal." (FG2).

Sexuality. Women mentioned that, as a result of the pain, it is hard to have and maintain a sexual relationship. Women reported that they gradually push their limits, because they do not want to hold back on participating in daily activities/life. They reported that there was often a feeling of insecurity and guilt toward their partner: "He probably wants someone who can do anything, someone who is not in pain." (FG1).

This woman reported that because of all the pain, she was not able to have sex as much as her partner wanted it. She claims that this caused her relationship to end: "Being sick and in pain all the time, sex was very important to my partner while I could no longer do anything. The relationship ended because of that." (FG1).

Pushing boundaries and exceeding boundaries was often told by the women in these focus groups. This following quote illustrates very well the point of pushing limits, at the expense of the patient's own health: "Sometimes taking extra pain killers and more than the recommended dose to be able to have sex." (FG1).

Impact on relationships. Besides sexuality, fertility problems and pain also have a huge impact on the relationship. Some of the women with broken relationships explained that endometriosis played a causal part in the breakdown. They tried to be a loving partner, but because of the pain, many everyday things had to be canceled or were just not possible. Some women even said they understand why their partner broke up with them and they did not blame him for this. They felt like they failed as women.

Not only relationships with partners but also social relationships with coworkers, friends, and family were influenced negatively by endometriosis. Women were often not understood about their illness or got negative reactions from coworkers: “When I reported sick on Monday people said, ‘You probably partied too hard at the weekend.’” (FG2).

Women reported that appointments were always difficult to make—one moment they feel good while the next moment they cannot do anything. Friends only accepted appointments being canceled to a certain extent and then they stopped inviting them. To be able to participate in social life, women had to be creative in planning activities around the disease. For example, saving energy for days prior to a social event or planning a longer recovery period afterward.

Mental well-being. Women often mentioned mental issues, for example, depressed feelings and mood swings. They explained them as partly the result of the use of long-term hormonal treatment. Most of the women had used hormonal treatment since their menarche. Women reported that because of this early and extensive use, they had no idea what is their natural emotional state of mind. Some women started to realize who they were after the surgery, when they were able to quit the medication: “For your partner, you are no longer the woman they met at the beginning of the relationship because you changed due to the hormones.” (FG1).

Time to diagnosis. Women reported that not all doctors are familiar with endometriosis, with the consequence of failure to recognize the disease leading to long diagnostic delays: “Very unfortunate that those GPs do not know what endometriosis is.” (FG2).

Almost all women experienced people who told them not to dramatize so much. Because of these experiences, women started to doubt themselves and developed a feeling of being less strong compared with other women: “Even worse than the pain, the doctors said, ‘It is between your ears, girl, just go back to work.’” (FG1).

When the diagnosis was made, there was mostly a feeling of relief, finally knowing what was causing the pain: “That the doctor said, ‘You have endometriosis and you must have gone through a difficult and hard time’, that may have been the most important moment of the entire process, it was such a relief, such an essential moment of recognition in particular.” (FG3).

Later on, a feeling of anger and sadness often took over because of all these years of disbelief. Women wondered how their life would have turned out if the diagnosis was made earlier: “I was particularly angry after the operation when the pain was gone. I thought why didn’t anyone help me before, why did I feel so terrible for so long, why didn’t anyone take it seriously, not even the doctors. I was really angry and thought if I had done that 15 years earlier, then I would have 15 years more quality of life” (FG3); and “I feel better now than I did for the last 30 years, which is a shame.” (FG3).

Theme 2: Expectations of the Surgical Process

Women undergoing surgery for endometriosis had, understandably, certain expectations from this treatment option.

These expectations were influenced and related to previous experiences, counseling, and faith in improvement. Although expectations are extremely important in decision making and are often discussed in the focus groups, we summarized this topic under the second main theme. This main theme could be divided into three subsequent subthemes, namely, treatment expectations, previous experiences, and experiences from the postsurgical period.

Treatment expectations. Most women mentioned the expectations of pain relief, gaining back their energy/physical strength, and improvement of QoL as outcomes of surgical treatment. Most did not expect complete pain relief after surgery, but a significant reduction of the pain symptoms. In response to the question about what to expect from the treatment, one woman reported: “You expect or hope to get rid of the pain after surgery.” (FG2).

The patients expected that together with this pain relief, their QoL automatically would improve and that they would be able to regain a “normal life” again. There was a difference in the expectation of women who were facing their first surgery and women who had already had multiple surgeries in the past. Patients facing their first surgery focused mainly on pain relief and less on possible complications. Patients who had previous surgery relied more on expectations based on previous experiences, and complications in a previous surgery were expected again. Expectations also were strongly dependent on the counseling by the surgeon/gynecologist. Women noticed that the percentages of complications mentioned varied strongly between doctors. Some doctors explained there was a 5% chance of getting a stoma, whereas others indicated that these complications hardly occur.

Previous experience with surgery in the treatment process. Women reported that in repetitive surgery, the decision-making process is based on previously experienced complications, such as internal bleeding, bladder problems, long rehabilitation time, adhesion formation, and serious psychological side effects of medication. The majority of women chose surgery instead of medication because they believed that surgery was a step forward whereas medication was maintaining the same situation: “If I continue hormone therapy, I will keep it under control, but if I ever stop, it will be at the same level.” While during an operation I had the feeling “then I am going forward, then something changes, may come back again, but then at least there is a step forward.” (FG1).

Gonadotropin-releasing hormone agonist treatment was seen as a temporary solution, but not for the long term. Women reported that the decision to opt for surgery was enforced when they believed that surgery would be more effective than continuing medication, and when they feared the possible harm of not removing endometriosis spots (continuing growth and possible ‘silent’ organ damage, e.g., ureter obstruction). Women with previous surgical experience who no longer believed that surgery would be effective reported that they would not choose surgery again: “You know what kind of pain you have now, but you don’t know what kind of pain you will have after the operation and possibly suffer from complications.” (FG1).

If women were determined not to use GnRH treatment for hormonal down-regulation, a surgical procedure was preferred. However, it emerged that this decision was mostly not that clear and due to uncertain outcomes of the surgical treatment, making a considered choice difficult: “If something turns out to be successful, you are willing to go very far, but if it doesn’t help, then negative things will work through because then you will only feel the negative things.” (FG3); and “You have to choose the lesser of two evils: complications if you go for surgery on one hand and the potential progression on the other hand if you leave it.” (FG1).

Postsurgical period. Women reported that most doctors tell you that the recovery will take about 6 weeks, however, not all women agreed with that statement. With the mindset of being up and running in 6 weeks, it was difficult for a patient to accept if she was not recovered after 6 weeks. However, other women agreed with their doctor’s statement and were recovered fully after 6 weeks. There was consensus on the fact that 6 weeks is the average time of recovery and that recovery after surgery remains an individual process depending on many factors.

There was an overall impression in all groups that the pain-free period is long after surgery. Although the recovery took a long time and the positive effect of the surgery took a long time to notice, the general feeling regarding surgery was positive. In response to the question of whether the experience was in line with her expectations, one woman explain: “In advance, you can no longer imagine what it is like to be without pain, so the fact that you are no longer in pain is not as expected, because you just didn’t know any better.” (FG3).

For another woman, the operation exceeded her expectations: “That it has given me so much more energy after the operation; I did not expect that in advance. Because my energy level had gradually decreased, now I am able to notice how bad it really was.” (FG3).

Women who were satisfied with the operation were, without a doubt, willing to have a future surgery if needed. There also were women who experienced a disappointing effect of the surgery: pain and fatigue were reduced, but not as much as expected. These women were reticent when we asked them if they would choose surgery again when needed. Some women who experienced complications reported they would not have surgery anymore due to a loss of confidence in the positive effects of the surgery.

Apart from the experience with the effect of the surgery on the symptoms, many of the experiences had to do with the decision-making process and the treatment process. Even when the effect of the surgery was positive, the entire process was often experienced as difficult mostly due to complications that occurred that the patients had not been counseled about preoperatively: “I am now completely pain-free, so I am very happy with that, but the process has been a lot harder than I had estimated.” (FG3).

Another woman reported that the whole surgical process was traumatic, but she was still satisfied because of the positive effect of the surgery: “I am not yet fully working, my energy is a lot better and I no longer have pain and I don’t

menstruate anymore, so that’s great. I can eat everything again, my bowels are better than in the previous 30 years, but I have experienced everything as traumatic.” (FG3).

Theme 3: Important Factors in the Decision Process

Making a well-considered decision in the treatment process depends on several factors, as illustrated and explained by the women in this study. The data that emerged about these factors are presented under the third main theme, which could be elaborated in the following subthemes about the impact on the social environment, importance of information, doctor-patient relation, fertility, decisive factors, feeling of control, SDM, and treatment considerations.

Impact of the social environment (partner, family, and friends) on the decision-making process. Women reported that potential consequences of their decision on the social environment (e.g., work and relationships) had little to no effect on the decision-making process. However, support from their social group was of great importance. One woman even explained that she would not have chosen surgery if her partner did not support that decision. In general, the support from a partner was considered the most important, however, women themselves made the final decision: “My partner is a kind of extra eyes and ears, nice to talk to your partner afterwards. Very important support.” (FG1).

Importance of information. Women reported that inconsistent and, in their opinion, wrong information was provided in the decision-making process (e.g., different complication rates or recovery time). Eventually, these women found their own ways of extracting information, but it would have been optimal if hospitals had provided unambiguously qualitative information in letters or on their website. That not only applied to general therapy, but also to some more alternative therapies like the endometriosis diet. Women joined Facebook groups or became a member of the Endometriosis Foundation and found support and information from their peers. As illustrated in the following quote, these information sources were important, but not always sufficient: “I have shared many questions on the Facebook group, getting answers is another.” (FG2).

Women reported that the quality of information provided by hospitals should be improved as well, as shown in this quote: “The doctor said, “You can go to the website and download a brochure about colon cancer, that’s what translates to your situation.” (FG2).

Doctor-patient relationship. The feeling that health providers take you seriously was mentioned as enormously important but was not always the case. Women reported that communication, therefore, was not always how it should be. This often started when the diagnosis was made and women were not prepared for the situation: “Madam, it’s endometriosis. You can come back in two weeks and then I will bring you artificially into the menopause. Have a good day.” (FG1).

Even later on in the treatment, women felt that there was not always the possibility to ask questions or get a satisfying answer: “I have asked quite a few questions, but if you get the

same answer every time, “Yes, that varies from person to person,” then at a certain moment you also think, I’ll pose my questions to fellow sufferers because they have experience.” (FG2).

There was little room for questions, especially when it was clear to the doctor what needed to be done. Also, when the time between first diagnosis and the operation was short, quite a number of women still had unanswered questions. Positive experiences were reported with doctors who showed interest in the patient’s situation, listened, and saw the human behind the disease. Women explained that empathic doctors made sure that the patient felt comfortable and had trust in the treatment. One patient reported that her doctor started to introduce the whole operating team to her, took her hand, and explained that during the procedure he had to focus on the screens as well. She was touched by his kindness and him being so thoughtful. These small things were really important to gain trust, which is shown in the following quote from this woman: “... And then I thought, if he already has an eye for those little things, he certainly has an eye for what’s going on in my belly.” (FG3).

It is all about fertility. Important factors related to personal values that emerged during the focus groups were the wish to conceive, physical factors, and mental factors. Women reported that these factors influenced the treatment choice significantly. The wish to have children emerged as important in all three focus groups. There was one difference in the view on this: patients who were diagnosed before there was a child wish and patients with fertility problems who found out that they had endometriosis during the fertility tests. For the first group, the overall experience was that doctors did not anticipate these women feeling that they were not yet ready for having children or were not ready to make a decision about having children. They were often told that it is better to have children now than later, otherwise it might be too late. This was a peculiar message if you were not ready to have children because your relationship was not yet ready for it or you did not even have a partner. All women reported it was important that doctors paid attention to fertility, but the doctors also should bear in mind that not all women want children and that is normal too. Women without a wish to conceive had the feeling that the treatment options focus too much on this:

“When I was there for the first time, the gynecologist said, ‘If you want to have a child, then better now than never.’ At that time I hadn’t figured out whether I wanted children. Now I am convinced that I don’t want children, but then I was almost forced to.” (FG1).

The second group of women, in whom the endometriosis was discovered because of fertility problems, reported that the wish to conceive outweighed pain and fatigue. They reported that there was a risk that the strong wish to conceive took precedence for too long at the expense of the endometriosis treatment: “I think afterward, maybe I would have been better off if that womb had been removed ten years ago.” (FG3).

For the women with a wish to have a child, it became clear that it was important to have clarity about the question of whether in vitro fertilization (IVF) should be performed prior

to surgery or whether first surgery and then IVF should be performed to optimize fertility chances. Women reported that most doctors advised surgery prior to IVF. However, women who first underwent IVF also had doubts as to whether that was a wise decision.

From the focus groups it emerged that fertility influenced so much and was an essential part of the identity of these women. When this identity was at risk, it could cause a variety of problems: “One of the most difficult aspects of the disease is infertility. Your fertility is a very essential part of who you are.” (FG1).

Decisive factor in the treatment decision. For almost all women, reduction of pain was reported as the paramount factor in the decision process and almost always the reason for choosing surgery: “I was in so much pain, I couldn’t function anymore. I thought ‘if I have that pain any longer, then I’m done with it, I don’t want to live like that.’” (FG1).

Regarding hormonal treatment, the women’s experiences showed that the treatment option offered by the doctor was not in line with the patients’ wishes. Women reported that hormonal treatment was advised despite the fact that women reported severe side effects from the hormonal treatment. They feel incomprehension on the part of doctors when they wanted to discuss the fact that long-term hormone use could influence seriously their mental well-being: “If you say, ‘Maybe those hormones make me feel so miserable,’ then you will be declared crazy.” (FG3).

Feeling of control. The feeling of control in a woman’s own treatment emerged as enormously important. Doctors need to counsel the pros and cons of the treatment options, but should not force their patients in one direction: “You don’t want to feel you are being forced to do things they think is needed, while as for yourself, you’re not mentally ready for it.” (FG1).

Throughout the entire treatment process, these women did not always feel in control. Painful examinations before the surgery and not having the courage to say stop are still traumatic experiences for some women as illustrated in the following quote: “I fell for it again, I should have just said no. It is at that moment when I need it the most - to be assertive - and I am not and just let it happen.” (FG3).

An important factor for women was having control, the ability to actually do something themselves, for example, by following the endometriosis diet. Other women chose to give all control to the doctor, but only when they had the feeling that it was an adequate doctor who knew their wishes and needs.

Shared decision making. From the questionnaire, we found that 63% of the patients had the feeling that there was SDM during the treatment process. Women reported in the focus groups that making a decision was experienced as difficult when there were more treatment options. There were positive experiences with doctors who explained clearly the benefits and possible harms of different treatments. Some women did not have a choice and needed an operation (e.g., ureteral obstruction), but even in that situation, some form of participation would have been helpful. In terms of participation, women mentioned, for example, the endometriosis diet,

whereby it felt that they had control and direction. Other women claimed that they did not have much to say with a doctor who stated clearly what needed to be done. In the following quote it is shown how important it was that the final decision was up to the patient, which gave a feeling of control: “It was said to me that we will only do something if you want it ... I was in doubt about cutting into my gut because I thought I am not in pain, so why go cutting into something that is good, I really liked that I had the freedom to do that. With the information they gave me I had the opportunity to choose for myself.” (FG2).

Considerations in the treatment process. All participants mentioned pain as almost always the most important decisive factor for treatment. Even when the consideration between possible surgical complications and pain reduction needed to be made, most of the women choose pain reduction rather than surgical risks. Although it is a difficult choice, most of these women felt that they had a choice, as shown in the following quote, which illustrates the counseling of a woman with her general practitioner: “My GP said, ‘if you have colon cancer, you have no choice, then choose between stoma and death.’ But in this case you have a choice, namely living with pain or a risk of living with a stoma, whether or not temporarily.” (FG2).

After taking all risks into account, this woman chose surgery, because she could not live with the daily heavy pain. However, there were three factors that sometimes outweighed the factor of pain reduction. Fear of complications could be more important, but mostly because of a life-threatening complication in a previous surgery: “I’d rather live in pain than take on the risks of an operation.” (FG1). As a reaction to this, these women will tolerate and live with the pain in the hope it will get better after menopause.

The second factor that sometimes outweighs pain is severe psychological side effects (depression or suicidal thoughts) from hormonal treatment. Some women experienced this as worse than pain: “But of all the hormones I’ve had, I’ve almost wanted to jump off my balcony.” (FG2).

The third factor that sometimes outweighed pain reduction was possible fertility improvement, which was discussed in the section, “It is all about fertility”.

DISCUSSION

In this qualitative study, we explored important aspects for patients in the process of DE treatment decisions. Furthermore, we reported the needs and recommendations women suggest for improving the treatment process for future patients with endometriosis (Table 4).

Regarding the first theme, disease impact and motives for treatment, women reported that pain and fatigue were the most important symptoms of endometriosis, which were mainly responsible for the deterioration in QoL, social participation, and (sexual) relationships. These findings are in line with the results from Verket et al. (41) who also found a decreased QoL in all domains of women with endometriosis. In addition, as a coping strategy, women in our study reported that their pain tolerance gradually increased to continue daily activities. Women in our focus groups also experienced that people did not always understand and believe the severity of the disease because endometriosis is not visible like a broken arm with plaster around it. Research from Mellado et al. (42) demonstrated that lack of acknowledgment and the fact that endometriosis is not visible from the outside leads to feelings of loneliness and social isolation. It is often stated that fertility problems caused by endometriosis place tension on women and their relationships. Fertility is experienced as such an essential part of being a woman that not getting the desired outcome in that aspect has an enormous impact, and not solely on the desire to have children.

In line with a Dutch study (43), our results also reveal the long time to diagnosis. Women report that recognition of the disease is often late because of a lack of awareness of the disease among doctors. This results in multiple doctor consultations from different specialties, which causes insecurity and doubt in the health-care system. This delay in time to diagnosis is very well recognized and multifactorial (44). Women in our study suggested that more awareness and training among health-care providers could potentially benefit earlier recognition of the disease.

Within the second theme, expectation of the surgical process, it emerged that most women expected a significant reduction in pain followed by gradual improvement of QoL and regaining their ability to participate socially. For women with the wish to become pregnant, their expectation was also that surgery would increase their fertility to some extent. Expectations are understandably different in women who never had surgery compared with women with previous surgery. Patients with no surgical history focused mainly on the effect of pain relief after surgery, whereas women with surgical experience took possible complications into account. Complication counseling differed significantly between doctors, and the accent was often put on physical complications, such as the risk of getting a temporary stoma, whereas side effects of hormonal treatments were less frequently discussed. Hormonal treatments were common in endometriosis to control the disease (10), however, according to the women in our study, not all doctors provided adequate information about the side effects of these treatments. In our study, mental side effects were extremely important to women and could have enormous impact on social relations and daily

TABLE 4

Recommendations for deep endometriosis care.

Improvement of information provision

Information about disease, treatment options, complications, and side effects of medication

Preferably digital information (e.g., web site, patient journey apps)

Importance of patient support groups

Shared decision-making training for doctors

Improving communication skills

Creating and providing tools (e.g., decision aid, videos)

Aiming for personalized medicine

Every woman is different and has different wishes/needs

These wishes should be respected, even if this is against guideline advice or the opinion of the doctor

Metzemaekers. Deep endometriosis: a qualitative study. Fertil Steril 2020.

functioning. Women who took hormonal medications for years doubted whether they knew what their natural state of mind was because they could not remember how they functioned before the start of the medication. Some women noticed this difference really clearly: when they were able to stop hormonal medication following surgery, and regained their natural state of mind. Ceasing medication after surgery is not possible for all women, and it is even quite common to prescribe hormonal medication after surgery to control the disease. For the women in our study, the impact of the disease on the social environment, such as the partner, family, and friends, played a limited role in actual decision making, however, support from the social circle during and after the process was of huge importance. This need is in line with Patient-Centered Care principles in endometriosis (45), whereby the involvement of the social environment is of huge importance. Patients do need this support in the decision-making process, surgery, and postsurgical recovery period.

In the third theme, important factors in the decision process, information provision was identified as being of vital importance in making a well-considered decision. However, the patients' experiences were that not all hospitals/doctors provided enough and qualitative satisfactory information. As a result, women sought information from social media or peer groups, however, the quality of these sources can be doubted. Some patients reported that they received a bowel cancer information folder because folders for endometriosis were not available.

In the decision-making process, the majority of women preferred surgery to conservative treatment. The rationale behind this is the belief that surgery is a step forward, whereas pharmacological treatment is maintaining the current situation and suppressing the disease. The majority of women in this study actually did report a long pain-free period after surgery. In line with a study about pain and surgery for recto-vaginal DE (46), a pain-free improvement was shown up to 24 months compared with conservative management (dysmenorrhea [38.9% vs. 24.5%], dyspareunia [72.9% vs. 48.2%], and dyschezia [78.1% vs. 57.4%]). This data indicates that surgery might provide a longer pain-free period after surgery compared with conservative treatment options.

The feeling that health-care providers take you seriously was identified as a very important issue. With patients with endometriosis, trust often is affected negatively due to the long time to diagnosis and their history of not having their symptoms taken seriously. We found that recognition from doctors and the social network enabled women to have a less negative experience of the treatment process. Research from Facchin et al. (28) supports the crucial role doctors play in reducing stress. Also, the feeling of remaining in control during the entire process is important, and can be identified in small issues, for example, the possibility of following the endometriosis diet, which can give a feeling of control. Another factor that can reinforce the feeling of control is the opportunity to ask questions. The women reported that this was not always possible, resulting in unanswered questions, which created uncertainty.

Personal values like the wish to conceive are unanimously important factors. However, women in our focus groups emphasized that doctors should not always regard this factor as the most important issue for women. Some women reported that they were told, while they are in their early 30s and without a partner, that the best thing to do is have children before it is too late. This is remarkable advice if patients are not ready to have children. It also leaves women feeling forced into having children and does not always meet their treatment goal. These statements show that fertility is an important factor for doctors, however, its importance is different for each individual patient. Doctors should not make assumptions, but determine each patient's fertility needs and adapt the treatment advice to this information. Personalized medicine with tailor-made treatment advice would be ideal for these women.

Women reported that in the decision-making process, pain was almost always the most decisive factor. Doctors need to be aware of this because women also can become "blinded" by the pain, and may, as a consequence, consider the possible complications of surgery less carefully. Women with previous complications we understandably more careful in choosing surgery again and were more inclined to choose conservative treatment options.

A different but important result from this study is the importance to talk with peers who understand and deal with the same problems. We evaluated each focus group with the participants and noticed that all women were really relieved and received useful information from their focus group members. This observation is supported with literature that highlights the positive effect of patient support groups in chronic illness (47). Women also were really motivated to explain their (preventable) struggles in the treatment process. They hoped with this research to inform doctors about these problems, and, therefore, indirectly help future patients.

Strengths and Limitations

The strength of this study is that we conducted focus groups with only patients with DE. Almost all the qualitative research includes patients with endometriosis without distinction of DE, and, therefore, does not focus specifically on patients in the more severe endometriosis group. This is important because DE treatments, surgical or pharmacological, have often more severe complications or side effects. Information and insights from our study could benefit the understanding of patients with DE during the decision-making and treatment process.

Regarding limitations of this study, it is important to note that we only conducted one focus group with patients who still had to make the decision and two groups with patients who already made the decision. This could have led to a more dominant influence on the data of women who already made the decision. However, if we look at the Results section, we do not see a dominant contribution from FG2 and FG3. A different limitation is that we only performed a pilot study with focus group methodology and not with individual interviews; it could be expected that different topics would be discussed in one-on-one interviews that would not be discussed

(or less) in focus groups. However, from our pilot focus group, the information that emerged could answer our research questions, and, therefore, we made the decision for focus group methodology.

Conclusion

This qualitative study that focused on patients with DE showed that different factors play a complex role in the complex decision process regarding complications, side effects, pain relief, and wish to conceive. In the treatment decision process for patients with DE, pain was almost always the most important decisive factor in the treatment choice. The wish to conceive and strong fear of complications could change this choice. This process was influenced indirectly by information provision and previous experiences with treatment and doctors. From this study, a few recommendations emerged for (deep) endometriosis care (Table 4). First, the quality of the information about the disease, treatment options, complications, and side effects of medication that is specifically targeted at women with (deep) endometriosis has to be improved. This is needed to empower patients and promote patient-centeredness, which could lead to a better decision-making process and enforces the doctor-patient relationship. This can be achieved by information letters, however, digital information or the use of patient journey apps would be a more up-to-date alternative. Also, SDM training for doctors would be helpful to improve communication skills, leading potentially to better patient understanding and support in the decision-making process. It should be noted that besides SDM training, tools such as patient decision aids also are needed for proper implementation of SDM. Finally, doctors should realize that every woman has her own treatment goal, which should be explored with an open mind. Fertility is important for the majority of women, but not for all, and this also should be respected.

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Decisiones controvertidas sobre las opciones de tratamiento de la endometriosis profunda: estudio cualitativo entre pacientes.

Objetivo: Estudiar las experiencias, consideraciones y motivaciones de las pacientes con endometriosis en el proceso de toma de decisiones para las opciones de tratamiento de la endometriosis profunda (DE).

Diseño: Estudio cualitativo mediante metodología semiestructurada profunda de grupos de referencia.

Entorno: Centro médico universitario.

Paciente (s): Un total de 19 mujeres holandesas diagnosticadas con DE entre los 27 y 47 años de edad.

Intervención (es): No aplica.

Principales medidas de resultado: Los temas de los grupos de referencia fueron el impacto de la enfermedad y los motivos del tratamiento, las expectativas del proceso de tratamiento, y factores importantes en el proceso de tomas de decisión.

Resultado (s): Las mujeres informaron que el dolor, la fertilidad y un gran temor a las complicaciones son factores decisivos importantes en el proceso del tratamiento. El objetivo de concebir un hijo se considera importante, sin embargo, a veces los médicos enfatizan demasiado este tema. El asesoramiento sobre complicaciones se trata frecuentemente de complicaciones quirúrgicas, mientras que se descuidan los efectos secundarios de los tratamientos hormonales. La toma de decisiones compartidas y la información sobre las opciones de tratamiento, las complicaciones y los efectos secundarios no siempre son óptimas, lo que dificulta la una elección idónea. A pesar de las experiencias negativas encontradas después de la cirugía, el efecto positivo de la cirugía asegura que la mayoría las mujeres no se arrepienten de su elección

Conclusión (es): En el proceso de toma de decisión sobre el tratamiento de las pacientes con DE, el dolor es casi siempre el factor decisivo más importante. El deseo de concebir y el fuerte miedo a las complicaciones pueden cambiar esta elección. Los médicos deben entender la importancia de la fertilidad para la mayoría de las mujeres, pero, además, si esto no se considera primordial, respetar ese punto de vista. Para mejorar la toma de decisiones compartida, la exploración de los objetivos del tratamiento, la capacitación de los proveedores de atención médica y una mejor provisión de información al paciente son necesarios.