

# Supporting and Inhibiting Factors When Coping with Endometriosis From the Patients' Perspective

## Unterstützende und hemmende Faktoren im Umgang mit der Endometriose aus Sicht der Patientinnen

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- dyspareunia
- endometriosis
- epidemiology
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### Abstract



**Aim:** Endometriosis is a chronic gynaecological disorder with manifold symptoms and psychosocial effects on the lives of affected women. The prevalence of endometriosis is estimated to be up to ten percent of women of reproductive age. As a result of its unclear aetiology, only limited treatment options are available. The treatment and care of affected women is therefore a challenge for their doctors. There is a need for healthcare services to provide affected women with support to cope with the disorder better. The aim of the study was to identify supporting and inhibiting factors on disease management to develop new support ideas.

**Materials and Methods:** The results are based on a content analysis evaluation of text responses from 135 women with confirmed endometriosis. Open questions about disease management were posed in a patient questionnaire. A classification system was developed according to Mayrings Qualitative Content Analysis, which allowed the main topics to be identified and summarised qualitatively using a quantitative intermediate step.

**Results:** Social support, treatment, as well as professional and healthcare system performance were found to be particularly supportive by patients. However, when questioned about inhibiting factors, healthcare system professionals and their performance were most commonly criticised. Just over 50% of women expressed their criticism of doctors. Quality of care and empathy towards the patients were especially criticised. There is also a need for improvement with regard to communication and general support from doctors. The results illustrate the importance of doctors for women affected by endometriosis, but make it clear that there is a great need for improvement with regard to the profession.

### Zusammenfassung



**Fragestellung:** Endometriose ist eine chronische gynäkologische Erkrankung mit vielfältigen Symptomen und psychosozialen Auswirkungen auf das Leben betroffener Frauen. Die Prävalenz von Endometriose wird auf bis zu 10 Prozent der Frauen in der reproduktiven Lebensphase geschätzt. Durch ihre unklare Ätiologie bestehen allerdings nur limitierte therapeutische Optionen. Die Behandlung und Betreuung erkrankter Frauen wird somit zur Herausforderung für behandelnde Ärzte. Es besteht Bedarf an Versorgungsangeboten, die betroffenen Frauen Hilfestellungen zu einem verbesserten Umgang mit der Erkrankung geben. Untersuchungsziel war die Identifikation von unterstützenden und hemmenden Faktoren auf die Krankheitsbewältigung bei Endometriose, um neue Ideen zur Unterstützung zu generieren.

**Material und Methode:** Die Ergebnisse beruhen auf einer inhaltsanalytischen Auswertung der Textantworten von 135 Frauen mit nachgewiesener Endometriose. In einem Patientenfragebogen wurden offene Fragen zur Krankheitsbewältigung gestellt. In Anlehnung an Mayrings Qualitative Inhaltsanalyse wurde ein Kategoriensystem erstellt, mit dessen Hilfe durch einen quantitativen Zwischenschritt Themenschwerpunkte erkannt und anschließend qualitativ zusammengefasst werden konnten.

**Ergebnisse:** Es zeigte sich, dass soziale Unterstützung, Therapie sowie Akteure und Leistungen des Gesundheitssystems als besonders unterstützend von den Patientinnen empfunden werden. Bei der Frage nach hemmenden Faktoren wurden jedoch die Akteure des Gesundheitssystems und ihre Leistungen auch am häufigsten kritisiert. Knapp über 50% der Frauen äußerten sich kritisch zu Ärzten. Besonders wurden die Qualität der Versorgung sowie die Empathie gegenüber den Patientinnen kritisiert. Ebenfalls bestand hinsicht-

**Conclusion:** The results provide the first indication of problem areas in the management of endometriosis from which approaches could be developed to improve care. However, it must be pointed out that the perspective of affected women was solely investigated. For a comprehensive analysis, it would be necessary to include the perspective of care providers and the influence of society as well as the healthcare system.

## Introduction

Endometriosis is an estrogen-dependent, commonly chronic gynaecological disorder which is characterised by the presence of endometrium-like tissue outside its physiological localisation in the uterus [1,2].

The epidemiological data on endometriosis available up to now predominantly refers to very selective approaches [3–7] and is therefore not very representative. A German study by Abbas et al., based on health insurance data from 2007 using the ICD-10 classification system, appears to provide the most reliable information. The data showed prevalences of 8.1% of women being affected and 5.7% of women requiring treatment in their reproductive phase of life [8].

Women of reproductive age usually develop the disorder, i.e. in the time between their first (menarche) and last menstrual bleed (menopause). However, in their “lifecycle approach”, Brosens et al. showed that a woman’s entire life cycle can be affected [9]. From a sociomedical perspective it should be emphasised that the women are not only affected in their reproductive phase, but also in an important productive phase for their career development. The disorder is accompanied by significant costs [10–12].

The causes and mechanisms which play a role in the development of endometriosis are not completely clear. A multifactorial genesis of the disorder is currently being discussed amongst other things, the research focus being on endometrial cell clusters. Genetic, molecular and immunological defects and aberrations, as well as environmental endocrinological factors, appear to play a role in promoting the settlement of endometrial cells in unphysiological localisations and overriding the designated immune response [1,13,14].

Endometriosis is not associated with a consistent clinical appearance. A reason for this is the various sites of endometrial settlement, which lead to the various problems and symptoms experienced by affected women [15]. Pain during menstrual bleeding (dysmenorrhoea) and infertility are typical complaints in women affected by endometriosis [16]. Tiredness and exhaustion, gastrointestinal disorders (e.g. diarrhoea, bloating, intestinal colic, nausea and stomach ache), heavy or irregular menstrual bleeding, pain during sexual intercourse (dyspareunia) or afterwards and also dizziness and headache have been attributed to endometriosis [17]. In isolated cases, endometriosis can also be associated with serious complications. The symptoms and consequences of endometriosis can significantly affect the quality of life of af-

fecting the communication and the general support by doctors. Improvement is needed. The results obtained clarify the importance of doctors for women with endometriosis, but also clearly show that, in this professional group, there is a great need for improvement.

**Schlussfolgerung:** Die vorliegenden Ergebnisse können erste Hinweise auf Problembereiche im Umgang mit der Erkrankung Endometriose geben, aus denen Ansätze zur Verbesserung der Versorgung abgeleitet werden können. Einschränkend muss darauf hingewiesen werden, dass hier ausschließlich die Perspektive der erkrankten Frauen untersucht wurde. Für eine umfassende Analyse wird es erforderlich sein, auch die Perspektive der Leistungserbringer einzubeziehen und die Einflüsse der Gesellschaft sowie des Gesundheitssystems zu erfassen.

affected women in many areas. Pain and other physical symptoms can particularly hinder coping with professional and personal daily life [11,18]. Depression and anxiety disorders can occur as a consequence of endometriosis [19].

Diagnosis is a particular challenge and includes non-invasive and invasive techniques. Laparoscopy is the central element for diagnosis and, depending on the results and symptoms, also for treatment. It should be used with the aim of achieving histological confirmation of the diagnosis [20]. The aim of making an early diagnosis has not yet been achieved either in Germany or internationally [17]. The duration from occurrence of the first symptoms to diagnosis ranges from 6 to 12 years [21–23].

A range of surgical and drug treatment options are available; however, they cannot offer a cure. Because of the complexity of the disorder, an individual treatment concept has to be developed for each patient which is tailored to their symptoms, site and severity of symptoms, as well as to their personal circumstances [24,25]. The still unexplained aetiology, the chronic and variable course of the disorder, distressing treatment with many side-effects as well as a high tendency of relapse are a great challenge for doctors as well as for the patients. The focus of medical assistance up to now was the treatment of physical symptoms. Affected patients – despite their young age – often receive little support in coping with the disorder and the topic has also found little resonance in scientific journals [26].

The outcome of this is the subject of the present study. Based on original data from a survey using open questions, we investigated which inhibiting and supporting factors the study participants listed when coping with disorder to develop recommendations for better care.

## Materials and Methods

### Data collection

The investigation was carried out as part of a study sponsored by the Federal Ministry for Education and Research (Bundesministerium für Bildung und Forschung, BMBF) to evaluate a training programme for women with endometriosis [39]. To improve understanding of how patients cope with endometriosis, the patient questionnaire used to evaluate the training programme was supplemented with open questions about coping with the disorder (“What has helped you to cope with the disorder the most?” and “What has been lacking in the management of the disorder and what could be improved?”). On a sheet of DIN A4 paper, 12

to 14 lines were available to the study participants to answer these questions. The questionnaire was sent to the participants for them to complete before they took part in the training programme. All questionnaires which were received by the Institute for Epidemiology, Social Medicine and Health System Research at Hannover Medical School by October 2009 were included in the present analysis. The topic of coping with the disorder was used as part of a dissertation [40] due to the unexpectedly detailed and comprehensive answers.

### Development of a classification system

The data basis was the written answers to the open questions in the patient questionnaire. Data evaluation was performed as a “quasi qualitative” summary of the content analysis according to Mayring und Kuckartz, including quantitative intermediate steps [27,28]. Categories were generated from the written material by the inductive formation of categories and depicted in the form of category systems. The main topics of the answers were identified and investigated quantitatively by coding of the written material and subsequent frequency analysis. The open questions used were deliberately worded in a very broad sense to encourage a wide variety of answers. The intention of the analysis was to identify these topics with regard to the aims of the project, i.e. to identify the relevant support needs and – where possible – to attain an impression of their importance.

### Random sample

Recruitment of patients for the study took place through easy access routes such as newspaper and internet adverts as well as the distribution of flyers in gynaecological practices. A confirmed diagnosis of endometriosis, age 18 years or over and, because of the style of data collection, sufficient understanding of the German language were stated as inclusion criteria. The study participants were therefore composed of 135 women who completed the declaration of consent.

## Results



### Demographics of the study participants

The mean age of the study participants was 38.4 years (SD  $\pm$  8.0 years) and the main focus lay in the 31–45 year age group. At the time of questioning, 66 women were married (48.9%), 27 (20.0%) were cohabiting and 35 participants (25.9%) stated that they were single, separated or widowed. At the time of questioning, 68 women (50.4%) had achieved university entrance and a further 15 (11.1%) technical college entrance. 40 study participants (29.6%) ended their schooling with a secondary school level I certificate (GCSEs) and 8 women (5.9%) with a primary school or secondary general school certificate. Three women stated that they had graduated from a polytechnic secondary school and one participant was still at school.

### Delay in diagnosis and duration of illness of the study participants

102 participants were able to state when their symptoms first occurred and when the final diagnosis of endometriosis was made. A mean delay in diagnosis of 7.8 years ( $n = 102$ , SD  $\pm$  9.9 years) was found in the study population and, based on information given about the diagnosis, the mean duration of illness was found to be 7.9 years ( $n = 132$ , SD  $\pm$  6.9 years) at the time of data collection. The delay in diagnosis was not taken into account here.

### Coping with the disorder from the perspective of the programme participants – overview

The supporting and inhibiting factors when coping with the disorder, as well as the factors that were determined as main categories in the analysis, were initially listed in synopses. 120 women gave a written answer to the question: “What has helped you to cope with your disorder the most?”. **Fig. 1** further shows how many women commented on each of the individual categories. No fixed response options were set out in the questionnaire; the entries are based on the participants’ written answers.

The statements included in the women’s written answers could be thematically assigned to 12 main categories which were then further divided into sub-categories. Due to the scope and complexity of the classification system, all the sub-categories are not presented in addition. However, for better understanding, it should be noted that the main categories were deliberately separated into “professionals” and “professionals and their performance” based on the patients’ information about their social environment and the health system. Many women named precise people, professions (e.g., relatives, friends, doctors, psychotherapists etc.) or institutions (e.g. hospitals) in direct association with their performance, characteristics and behaviour (e.g. “discussion with my doctor” or “a doctor who takes my problems seriously”), which had a supportive effect on their disorder management from their point of view. By differentiation and classification into further subcategories, specific indicators could be gathered about which professionals and which areas of their performance are of particular importance from the patients’ point of view when dealing with the disorder.

In **Fig. 1**, it is clear for the first time that the members of the social environment are ranked as being on a par with the treatment ( $n = 58$ ) as being the most important factors when coping with the disorder by with women who were questioned, followed by the social environment ( $n = 50$ ), healthcare system professionals ( $n = 49$ ) and self-management ( $n = 44$ ).

**Fig. 2** shows the responses to the question, “What has been lacking in the management of the disorder and what could be improved?” from 115 of the 135 women.

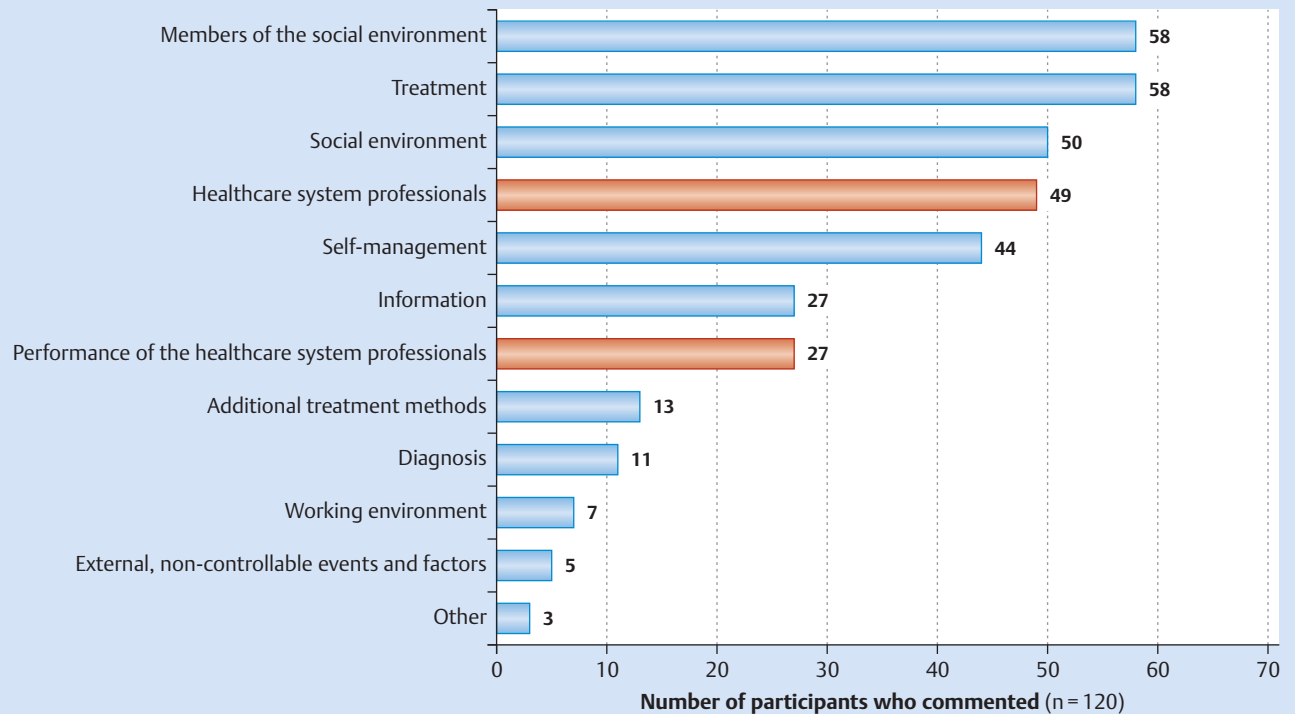
A total of 64 participants saw room for improvement which could be assigned to the “healthcare system professionals” category, followed by performance of the healthcare system professionals ( $n = 56$ ) as well as the treatment ( $n = 53$ ). According to the study participants, the greatest need for action in the management of endometriosis lies in these three main categories.

### Professional and healthcare system performance

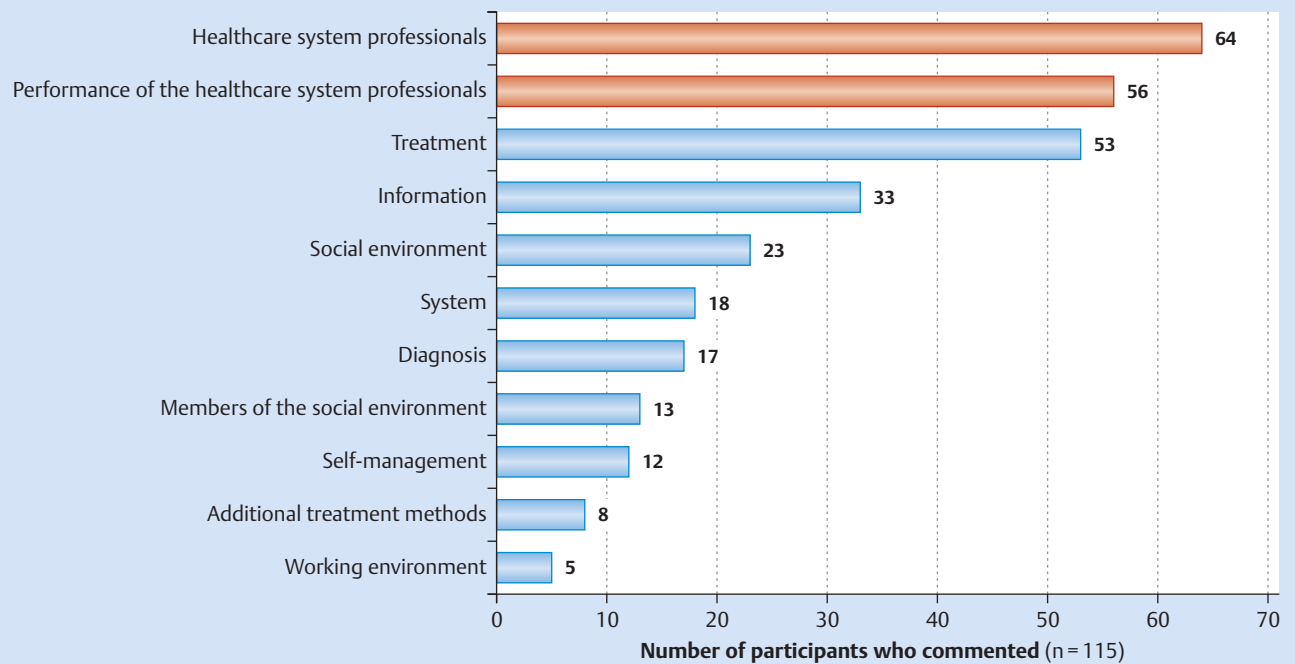
Corresponding with the number of mentions, the results of the quantitative-qualitative analyses on supporting and inhibiting factors relating to the healthcare system professionals (all professional care providers and healthcare insurance providers as well as self-help groups and facilities and their performance) are presented in the following sections. Presentation of the results, especially factors identified as part of the study, is outside the scope of this publication.

### Supporting aspects

In response to the question about what had helped affected women to deal with endometriosis the most, 49 of the 120 women (40.8%) mentioned healthcare system professionals. Doctors were most commonly named in this main category (61.2%,  $n = 30$ ). This was followed by 14.2% ( $n = 7$ ) of women who rated self-help groups or the nationally active German Endometriosis



**Fig. 1** Supporting factors in disorder management from the perspective of the study participants.



**Fig. 2** Inhibiting factors when coping with the disorder from the perspective of the study participants.

Union (Endometriose-Vereinigung Deutschland e.V.) and its offers and services as being helpful. Further support services were found by 6 women via internet forums (12.2%), which serve as virtual exchange platforms for communication and consultation

purposes. Hospitals were named by 10.2% of participants ( $n=5$ ) and 3 women mentioned an alternative practitioner. A psychotherapist, a therapist (without further description), the Endome-

**Table 1** Summary of the comments on the performance of the healthcare system professionals – supporting influences.

Sub-category	“What helped me the most ...”
Quality	<ul style="list-style-type: none"> <li>▶ Professionally competent and qualified doctors, gynaecologists, hospitals and contact persons</li> <li>▶ The belief and the feeling of being in good hands during treatment and in hospital</li> <li>▶ Doctors who give me the feeling that they know what they are doing</li> <li>▶ Doctors who are informed about and skilled in endometriosis</li> <li>▶ A good gynaecologist</li> <li>▶ The right clinic and their right assisted conception centre</li> </ul>
Empathy	<ul style="list-style-type: none"> <li>▶ Doctors who take me and my symptoms seriously and believe me</li> <li>▶ Understanding and sympathy from doctors and gynaecologists</li> </ul>
Communication	<ul style="list-style-type: none"> <li>▶ Discussion with my treating doctor, doctors and</li> <li>▶ Discussion with various doctors</li> <li>▶ Discussion with doctors from an endometriosis centre</li> <li>▶ Postoperative discussion with the surgeon</li> <li>▶ Discussion with a psychotherapist who is also a gynaecologist</li> </ul>

triosis League and Women’s Health Centres were each named by one of those affected, respectively.

Professionals were commonly described in direct association with their respective features and performance. The category “performance of the healthcare system professionals” was created to record this and contained the statements from a total of 27 patients. This main category included features and performance of the professionals which underwent further differentiation into sub-categories such as quality, empathy and communication.

► **Table 1** provides an overview of the participants’ comments on the sub-categories. The individual comments are summarised and shown ranked in descending order of relevance. The most commonly named feature or performance which helped patients to cope with the disorder is listed first each time.

Altogether, the responses of 11 participants were assigned to the sub-category quality and the participants commented positively on quality, competence, awareness, reliability of the professional or the quality of care. A typical comment can be described using the following quote: “a doctor who knows what he is doing”. An empathetic and sensitive approach, especially from the doctors towards the patients and their problems when dealing with the disorder (e.g. “compassion from the doctor”, understanding from doctors”), was described by a further 11 study participants. In the subcategories, communication with healthcare system professionals was mentioned by 9 participants who found communicative interaction helpful (e.g. “discussions with doctors“ and “discussion in internet forums”).

### Inhibiting aspects

Although the comments about helpful influences from over one third of the study participants could be assigned to healthcare system professionals, 56% of the women questioned referred to aspects which were lacking or in need of improvement in connection with healthcare system professionals.

In addition to criticism of medical institutions such as hospitals and health insurance companies – 5 and 4 women remarked on

**Table 2** Summary of the comments on the performance of the healthcare system professionals – inhibiting influences.

Sub-category	“What was lacking, what could be improved ...”
Quality	<ul style="list-style-type: none"> <li>▶ Informed, well trained and competent gynaecologists and doctors in other disciplines</li> <li>▶ Ignorance and poorly informed gynaecologists and doctors</li> <li>▶ Training, education and further education for gynaecologists and doctors in other disciplines as well as general and improved education of these doctors</li> <li>▶ Better pre/postoperative care in the clinic and from doctors</li> <li>▶ Interdisciplinary teamwork between doctors from various specialities and multidisciplinary knowledge in doctors from other specialities</li> </ul>
Empathy	<ul style="list-style-type: none"> <li>▶ To be taken seriously by gynaecologists and doctors</li> <li>▶ Doctors who take those affected and their symptoms seriously</li> <li>▶ General recognition of the disorder and recognition by doctors, health insurance companies and social security authorities</li> <li>▶ Sensitivity and empathy from doctors</li> <li>▶ Understanding from doctors, health insurance companies, pension schemes and assessors</li> <li>▶ To be taken seriously by doctors</li> </ul>
Support	<ul style="list-style-type: none"> <li>▶ General support and offers of help from doctors</li> <li>▶ Financial support and relief during acute phases of the disorder</li> <li>▶ Coverage of the costs of drugs, rehabilitation measures and alternative therapies</li> <li>▶ Generally more support from health insurance companies</li> </ul>
Communication	<ul style="list-style-type: none"> <li>▶ General discussion and someone to talk to</li> <li>▶ Discussion with the surgeon</li> <li>▶ Final discussion after the operation</li> <li>▶ Discussion with the gynaecologist</li> <li>▶ Professional, honest communication</li> </ul>

these respectively – it was almost exclusively the medical profession that was viewed critically in this category. 59 of the 64 participants (92.2%) who expressed deficits recommendations relating to healthcare system professionals based the criticism on the medical profession.

A category for healthcare system professionals was also created for inhibiting aspects. This included the subcategories quality, empathy, support and communication.

The results of the qualitative analysis of the individual subcategories are shown in ► **Table 2** and are listed as a summary of the participants’ main statements.

The responses of 56 women could be allocated to this area. 52 participants also named the professional(s) whose performance they criticised.

Critical comments about the quality of the healthcare system professionals were made by 34 women (60.7%). These included aspects such as competence, awareness and reliability as well as the quality of care. The study participants often criticised that the doctors were not informed about the disorder, that they weren’t familiar with it and that they do not have adequate skills in the field of endometriosis. Some women highlighted the ignorance of doctors in the field of endometriosis, which one study participant described as “a catastrophic medical situation [–] no one knows!”. From the responses of individual women, it became clear that they see the doctors’ poor level of information as the reason that their symptoms are not promptly recognised and diagnoses are made late. It was also assumed that the lacking famil-



ilarity of many doctors with the disorder is the reason that patients' problems are not taken seriously. The criticism is not only directed at specialists in gynaecology, but also doctors from other disciplines who are also poorly informed. Multidisciplinary knowledge was called for. In response to the question about what was lacking in the management of the disorder or what could be improved, education and training of doctors was commonly mentioned. One participant demanded "regular training and education for gynaecologists, urologists, internists, general practitioners, psychologists etc."

In the subcategory "empathy", 26 women (46.4%) regarded the manner and perceived attitude of the healthcare system professional towards the patient as being in need of improvement. Comments were especially summarised here which reflect the women's assessment of their perception by the doctors/professionals. Most commonly criticised was that doctors "do not take [affected women and their problems] seriously". Some women describe situations that they have experienced with doctors. A typical statement in this category can be quoted from one participant in the following sentence: "My many years of pain, especially during menstruation, were not taken seriously by any of my gynaecologists, but were always just treated with painkillers". Another patient reported a statement from her doctor, saying that as a woman, she would just have to put up with pain. These and other similar experiences have prompted the study participants to demand that pain and discomfort should be viewed as a pathological event by doctors and they should recognise the burden of the disorder. This criticism and the resulting demands are mainly aimed at doctors. A lack of empathy on the part of the health insurance company and social security authorities were also mentioned by one woman, respectively.

The two subcategories presented represent the most commonly named areas in performance of the healthcare system professionals. Furthermore, 12 participants (21.4%) demanded (more) support from healthcare system professionals and 7 participants (12.5%) complained about communication with them.

## Discussion



To ensure the widest possible spectrum of responses, a research design was chosen which allowed for open questions about coping with the disorder in the patient survey. The aim of the study was to find initial of how the disease management of endometriosis patients can be supported and improved. These findings have gone into the development of a training programme for women with endometriosis in which the subject of coping with the disorder (aspects of the healthcare system, doctor-patient relationship, social support) has gained significantly more room than originally planned.

### Critical appraisal of the study design and limitations of the research method

A fundamental problem in connection with the questionnaire is that the questions posed with the terminology used could not be further explained to the participants. It therefore remains unclear to what extent the questions were understood as defined by the research team. However, a pretest did not uncover any comprehension problems and no obvious misunderstandings were detected from the available responses. It should also be considered that the influence of social desirability on the response bias cannot be excluded. Several study participants wrote

answers about experiences in their medical history which were beyond the actual question. With regard to the study results, it should always be considered that response styles and response trends are influenced by motivation and intention of the participant, as well other factors such as the point in time of the answer. Since no possible answers were provided, it can be assumed that the present answers do not represent all topics and that the frequency representations are subject to bias.

### Patient selection

As a result of voluntary participation in the study, a selection effect can be assumed. It cannot be excluded that increased distress and high motivation have an affect on this study.

With regard to the socio-demographic factors of the subsample, it is striking that an above-average number of women have a high level of education. Regarding marital status, almost 70% (n = 93) of the women were married or cohabiting. The influence of education and social support on coping behaviour has been proven in various studies on other illnesses. Therefore, it cannot be excluded that the results obtained in this study may be especially relevant for socially well-integrated women who are highly educated and who differ from those with poor social support and poorer education. For this reason, the problems encountered here in dealing with endometriosis may possibly have been underestimated.

The results obtained in this work should be viewed as the first indications of possible problem areas when dealing with the disorder.

### The role of doctors in the management of endometriosis

Assuming that the number of women who express their views on a particular topic is an indication of the importance of this aspect, it can be seen that social support in particular together with the treatment of endometriosis are of the greatest importance for the study participants. In this context, the healthcare system professionals only play a minor role when coping with the disease.

Since the influence on the social environment is often limited, healthcare systems professionals should take action to improve coping strategies. The presented results suggest that the performance of the professionals does not always meet the needs and expectations of the women questioned. Just over 50% of the answers to the question about what was lacking in the management of the disorder and what could be improved related to doctors. The importance of the doctor for a woman affected by endometriosis was hereby made clear on the one hand; on the other hand the figures make it completely clear that there is a great need for improvement regarding this profession. In particular, appropriate ("empathetic") explanation and counselling is expected from doctors. In contrast, empathy and communication were indicated as being an important supporting factor in the social environment, so a compensation for the medical deficits may occur here.

Doctors who helped to cope with the disease from the women's perspective are characterised by competence and qualification. Furthermore, according to their own statements, women benefit from doctors who are understanding towards them and show them compassion. Therefore, doctors do not only have a role as a medical expert, but also as a personal contact. In 1996, Muthny expressed the view that doctors play a particularly important role when coping with an illness. Through professional diagnosis and treatment, they create the conditions for coping which they can guide in the right direction by discussions, understanding

and compassion based on a trusting doctor-patient relationship [33]. The women questioned very clearly described what is important to them in terms of coping with the disorder. Proper communication with the doctors (“discussions with doctors”) is experienced as being helpful. These statements support the call for a re-evaluation of “talking medicine”, which is also being increasingly demanded by other healthcare system professionals [29, 30]. The complexity of the disorder requires much time spent as an out-patient as well as an in-patient. To what extent the current remuneration structures or other aspects of the healthcare system influence the care of endometriosis should be investigated as part of further studies [31, 32].

A special feature in connection with endometriosis seems to be that women complain most frequently about a “normalisation” of their condition and that they and their condition are “... not taken seriously...” by the doctors. In a larger study of endometriosis patients, Green et al. were able to show that these are not just isolated cases. In this study, more than half the respondents (59.6%) said that they had not been taken seriously by doctors or were told that everything was fine [34]. These results are consistent with those of other studies (e.g. [17, 35, 36]). As part of other studies, it will have to be clarified to what extent this is – at the societal level – a manifested misinterpretation on the part of doctors or a problem in the area of doctor-patient communication, in order to then develop and implement appropriate action.

A further aspect of the doctor-patient relationship was broached in Ballard’s study to investigate the causes of diagnostic delays and their impact. Ballard believes that the medical attitude of not taking patients seriously and trivialising their condition is a reason that diagnoses are somewhat delayed. However diagnosis is a liberating moment, especially for women who have suffered with pain and other problems for many years [37]. The delay in diagnosis identified in this study was 7.8 years on average, and responses from 17 women who call for quicker diagnosis confirmed the assumption that women must still suffer from their symptoms for a long time before their illness is recognised. It can also be seen from the results that some of the patients hold the ignorance of the doctors responsible for their late diagnosis. In this context, demand for quicker referral to suitable doctors and for more specialists can be derived from the study material. As a consequence, Hudelist et al. and Ebert et al. see a need to intensify the events within the framework of training and continuing education on endometriosis in order to improve the care of women suffering from the disorder [21, 38]. Gynaecologists especially, and also doctors from general medicine, gastroenterology and urology, who come into contact with patients suffering from endometriosis because of their symptoms should be considered here [38]. In addition to teaching diagnostic and therapeutic possibilities, the main objective would be to raise awareness among physicians to actually consider endometriosis as a differential diagnosis. The development of a good doctor-patient relationship requires far more than just treatment, patient education and counselling by doctors. Doctors should understand the impact of a disease on the lives of their patients in order to jointly develop a customized treatment plan with them. Additive or alternative therapies (TCM, acupuncture, homeopathy, etc.) should also be offered, as it has been shown that these are in demand by those affected and providing alternatives to conventional medicine can be used to improve the doctor-patient relationship.

## Conclusion for Clinical Practice

▼ Endometriosis is a difficult and complex disorder which affects all areas of a woman’s life. In terms of coping with the disorder, endometriosis is distinctive as women have to deal with a high degree of taboos and prejudices as well as a lack of knowledge in society. For this very reason, the doctor-patient relationship, the interaction with patients and the subject of coping with the disorder should return to the centre of attention in clinical settings. Knowledge of mechanisms, forms and influencing factors on coping with the disorder are essential. This could not only guarantee better healthcare, increased patient satisfaction, prevention of misunderstandings between doctor and patient and promotion of patient compliance, but improvements from an economic perspective could also be achieved. The establishment of these topics has already taken place at medical school, and information events regarding this should be offered for practising doctors.

## Conflict of Interest

▼ None.

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