

Fears and Concerns of Patients with Uterine Fibroids – a Survey of 807 Women

Ängste und Befürchtungen von Myompatientinnen – Ergebnisse einer Befragung von 807 Patientinnen

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ABSTRACT

Study questions What specific fears and concerns do patients with uterine fibroids have? How are these influenced by sociodemographic factors, duration of condition and level of knowledge among these women?

Methods Between January 2016 and January 2017 807 patients were consecutively surveyed at a university hospital speciality fibroid clinic using a two page locally developed and validated questionnaire focusing on fibroid-associated fears and concerns.

Results The questionnaire was completed by 730 women (90.5%) the majority of whom reported fears/concerns mainly with regards to treatment (need to treat/side-effects/hysterectomy) and the fibroids themselves (increasing size and number). Various parameters influenced the type and severity of fears: Young patients (<40 years) had concerns particularly with regard to pregnancy/birthing while older patients (>40 years) were more concerned about general health and significant blood loss. Time interval since diagnosis also affected fears with different concerns between patients with shorter duration of diagnosis (<12 months) vs. longer duration (>12 months). Overall only slight differences could be attributed to immigrant background. Higher level of education correlated with less anxiety. Proper information about fibroids relieved fears of malignant change in particular. Doctors and the internet were the most important sources of patient information.

Conclusions Due to the benign nature of uterine fibroids and their good treatability, fibroid-associated fears are generally unfounded. Precise knowledge of patient fears and concerns should be integrated into clinical care with targeted psychological support to help patients better understand their condition.

ZUSAMMENFASSUNG

Fragestellungen Welche konkreten Ängste und Befürchtungen haben Myompatientinnen? Welchen Einfluss haben soziodemografische Daten, Erkrankungsdauer und Informiertheit der Frauen?

Methodik Konsekutiv wurden 807 Patientinnen in einer universitären Klinikmyomsprechstunde mit einem 2-seitigen selbstentwickelten validierten Fragebogen im Zeitraum Januar 2016 bis Januar 2017 mit dem Fokus auf myomassozierte Ängste und Befürchtungen befragt.

Ergebnisse Der Fragebogen wurde von 730 Frauen (90,5%) beantwortet und die Mehrzahl der Patientinnen äußerte Ängste. Dabei lag der Schwerpunkt auf der Therapie (Notwendigkeit/Nebenwirkungen/Hysterektomie) und dem Myom an sich (Größen-/Anzahlzunahme). Es zeigte sich, dass die Aus-

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prägung und Art der Ängste durch verschiedene Parameter beeinflusst wird. Junge Patientinnen (<40 Jahre) geben besonders Ängste über Schwangerschaft/Geburt an, ältere (>40 Jahre) eher in Bezug auf die allgemeine Gesundheit und großen Blutverlust. Auch die Zeitdauer seit Diagnosestellung verändert die Ängste bei kurzer (< 12 Monate) vs. langer Erkrankungsdauer (> 12 Monate). Insgesamt konnten nur geringe Unterschiede bei einem Migrationshintergrund gezeigt werden. Per se korreliert ein höherer Bildungsstand mit weniger Ängsten. Eine gute Informiertheit über Myome wirkt be-

sonders bei der Angst vor maligner Entartung entlastend. Der Arzt und das Internet sind insgesamt die wichtigsten Informationsquellen für die Patientinnen.

Schlussfolgerungen Mit der genauen Kenntnis der Ängste und Befürchtungen können diese in die Behandlung von Myompatientinnen integriert werden, den Frauen kann gezielt auf der psychischen Ebene geholfen und eine bessere Einschätzung der Erkrankung vermittelt werden. Durch die Benignität und die gute Behandelbarkeit sind die myomassoziierten Ängste nämlich letztlich unbegründet.

Introduction

With an incidence of 20 to 40%, uterine fibroids are the most common solid benign tumours in women of reproductive age [1]. Prevalence among African-American women is 80% at the age of 50 years and among so-called Caucasian women 70% [2]. Symptoms vary according to fibroid size, number and location and include hypermenorrhoea with secondary anaemia, bleeding disorders, dysmenorrhoea, lower abdominal pain and/or pressure in the bladder region, infertility and miscarriage. A large proportion of affected women is asymptomatic [3, 4]. To date few studies of the mental health of women affected by uterine myomatosis have been conducted. Spies et al. (2002) showed that symptomatic uterine fibroids can have a negative impact on health related quality of life (HRQL) through impairment of daily activities and anxiety, which may develop before and after diagnosis [5]. A European comparative study states that uterine fibroids impair HRQL to a higher degree than other chronic diseases such as asthma, gastro-oesophageal reflux and irritable bowel syndrome [6]. Patients report psychological distress, helplessness in dealing with the diagnosis and treatment options, negative body image, effects on sexuality and a lack of support. They worry about appearing pregnant or overweight due to visible abdominal enlargement [7]. In a Brazilian study anxiety, particularly with regards to heavy bleeding and pelvic pain, is described as one of the major stressors of fibroid patients [8]. In addition, patients report fearing loss of control and unpredictability of menstruation [9]. Downes et al. (2010) also highlight that in addition to physical effects, negative effects on emotional and mental health are evident in women with fibroids [6]. In 2005 Gallachio et al. showed that in their questionnaire study collective of American women, almost 80% of patients having a hysterectomy with a preoperative diagnosis of uterine fibroids reported fear of malignancy as the reason for their decision to undergo surgery [9].

In view of the benign nature and good treatability of this condition most of these patient concerns are in actual fact unfounded. Thus, if the fundamental fears and individual anxieties of fibroid patients are known, through targeted counselling it should be possible to allay these concerns and allow women an improved understanding of their condition. No study focusing on patient concerns has yet been conducted in Germany. The aim of this survey was to define possible fears and concerns in fibroid patients, describing their severity and any possible correlation with

sociodemographic parameters such as age, level of patient information/knowledge and immigrant status.

Patients and Methods

Data acquisition

Between January 2016 and January 2017 807 new patients attending a university hospital fibroid clinic were surveyed consecutively, before doctor-patient consultation, using a two page, internally developed questionnaire.

On page 1 of the questionnaire “Fears/Concerns of Patients with Fibroids” various sociodemographic data were recorded (age, country of birth, level of schooling, employment, source of information and self-assessed level of knowledge about fibroids, duration of diagnosis). These person specific data served to categorise study participants into groups.

The second page listed 20 possible fears and concerns with respect to health related consequences, treatment and outcome of fibroids (► Fig. 1). These 20 items – chosen in view of their repeatedly being mentioned by fibroid clinic patients – were presented in tabular form with the choice of three possible answer categories: “not applicable”, “partially applicable” or “definitely applicable” (multiple answers possible). The questionnaire also allowed ample space for free additional comment. The two-page questionnaire was filled in by patients before doctor-patient consultation and deposited in a designated post box.

Women who provided incomplete sociodemographic data or who did not answer the questions on fears and concerns were regarded as non-responders.

The study was conducted after extensive consultation and with the consent of the institutional board; it complies with the Charité’s charter on assurance of good scientific practice and the Berlin data protection act.

Statistical analysis

Data were analysed using IBM SPSS 24. For an initial overview, after extensive descriptive analysis, the 20 listed fears were divided into five groups (with respect to the fibroids themselves, treatment, general health, pregnancy and the body) and the three possible answers analysed for frequency of occurrence. In the further analysis of possible sociodemographic influences the answers “definitely applicable” and “partially applicable” were combined as the single characteristic “concern present”. Similarly in the pa-

Below you will find a list of statements relating to your fibroids and *any possible concerns you may have*. For every statement please mark or tick the answer that is most true or applies best to you. You can choose one of three answers: “not applicable”, “partially applicable”, “definitely applicable”.

| My concerns are: | not applicable | partially applicable | definitely applicable |
|--------------------------------------------------------------|--------------------------|--------------------------|--------------------------|
| 1. Having no control over the fibroids. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Being psychologically stressed by the fibroids. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. To lose large amounts of blood due to the fibroids. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. The fibroids could become malignant. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. My quality of life could deteriorate. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. The fibroids might grow bigger. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Having a miscarriage or premature birth. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. No longer being able to fall pregnant. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. The fibroids may increase in number. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. I may pass fibroids on to my children. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Negative effects on sexuality. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Having a foreign body inside of me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. About the need for treatment. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Negative effects on my general health. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Side-effects of treatment. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Gaining weight because of the fibroids. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Having (continuing to have) pain from the fibroids. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Being negatively stressed from the fibroids. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. To lose my womb. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 20. Missing something serious (by not undergoing treatment). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other: | | | |

► Fig. 1 Fears and concerns listed in the questionnaire.

tient assessment of their own level of knowledge the answers “knowledge level good” and “knowledge level moderate” were pooled to “well-informed”. Extensive analysis of the correlation between sociodemographic factors and stated fears was performed. Correlation was tested using Fisher’s exact test (two-tailed). Significance level was set at $p < 0.05$. In view of the explorative nature of the study no adjustment for multiple tests was performed.

Results

Descriptive analysis

The questionnaire was distributed to a total of 807 patients attending the fibroid clinic (return rate 90.5% = 730/807 patients, of whom 168 were born outside of Germany and 554 in Germany;

birth data missing for 8 patients). Significant sociodemographic data from the study population are summarised in ► **Table 1**.

Patient information and level of knowledge

Most patients had informed themselves about their condition before their fibroid clinic appointment and regarded their level of knowledge as good (27%) or a moderate (50%). The most commonly stated sources of information were a doctor (72%) and the internet (67%). 2% of participants had not yet sought to inform themselves.

Incidence of stated fears/concerns

The questionnaire presented patients with 20 possible fears and concerns that could be answered with either “not applicable”, “partially applicable” or “definitely applicable”. ► **Fig. 2** shows the incidence of fibroid-associated concerns for the entire study

► **Table 1** Sociodemographic data of the study population (percentages rounded to whole numbers or * means with range).

| Parameter | n/% | |
|--------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------|
| Responders | 730 patients | |
| <ul style="list-style-type: none"> Responders born abroad = first-generation immigrants | 168 patients (23%) from 61 different countries | |
| Age | 42 years* (23–82 years) | |
| Time interval since fibroids diagnosed (according to patient) | 5 years* (1 month – 46 years) | |
| Level of schooling | 70% matriculation | |
| | 29% other school leaving certificate | |
| | 1% no school leaving certificate | |
| Employment (pooled) | 48% employed | |
| | 17% self-employed | |
| | 9% health sector | |
| | 6% civil servant | |
| | 20% other | |
| | <ul style="list-style-type: none"> 6% unemployed 5% housewife 5% scholar/apprentice/student 3% pensioner 1% receiving social support | |
| | Level of knowledge about fibroids (self-estimation) | 27% good 50% moderate 23% poor |
| | Source of information on fibroids and their treatment (multiple answers allowed) | 72% doctor |
| | | 67% the internet |
| 42% other | | |
| 2% none | | |

population, the answers “definitely” and “partially applicable” counted together.

In order to further characterise the response behaviour of the patients ► **Fig. 3** shows the fears and concerns grouped together. It can be seen that concerns about treatment and the fibroids themselves are reported most often for both “definitely applicable” answers and overall (concern “definitely” or “partially applicable”).

Relationship between fears/concerns and level of knowledge: Four of the listed anxieties showed significant correlation in terms of severity with patient level of knowledge. Women who rated their knowledge as poor reported fear of malignancy ($n = 652$, $p < 0.001$) and passing fibroids on to their children ($n = 625$, $p = 0.014$) significantly more often. Well-informed women reported fearing “quality of life restrictions” ($n = 660$, $p = 0.012$) and “loss of the uterus” ($n = 673$, $p = 0.041$) significantly more often than the poorly informed (► **Fig. 4**).

Women whose only source of information was their doctor reported fear of negative effects on sexuality ($n = 249$, $p = 0.038$), foreign body sensation ($n = 241$, $p = 0.029$) and “consequences of non-action” ($n = 244$, $p = 0.012$) significantly less often. They only reported fear of miscarriage/premature birth ($n = 234$, $p = 0.026$) more frequently.

Relationships between fears/concerns and patient age, duration of diagnosis, level of schooling and employment: Young patients (age ≤ 40 years) more often mentioned concerns with respect to birth/pregnancy and increasing number of fibroids ($n = 670$, $p = 0.009$). Patients over 40 years of age on the other hand more often feared significant blood loss ($n = 683$, $p = 0.012$) and negative effects on general health ($n = 677$, $p = 0.031$) (► **Fig. 5**).

Patients with shorter duration of diagnosis (≤ 12 months) also mostly reported concerns around birth/pregnancy and a foreign body sensation ($n = 605$, $p = 0.045$). Among women with duration of diagnosis > 12 months concerns were focussed on the need for treatment significantly more often ($n = 611$, $p = 0.009$) (► **Fig. 6**).

Patients with general qualification for university entrance had less concerns overall than patients with other or no school-leaving qualifications. Only fear of miscarriage/premature birth ($n = 635$, $p < 0.001$) and of not being able to fall pregnant ($n = 641$, $p < 0.001$) were reported significantly more often in this group.

Data did not confirm the hypothesis that women working in the health sector have less anxiety than those working in other sectors.

Fears and concerns among immigrants: Possible influences of immigration were also studied with only few differences in the incidence of the above-mentioned fears and concerns being found between patients with vs. without immigrant background. Significant correlation was however found for the following concerns: For women *without* immigrant background: further tumour growth ($p = 0.012$) and negative effects on sexuality ($p = 0.006$); for immigrants: miscarriage or prematurity ($p = 0.001$) and weight gain ($p = 0.03$).

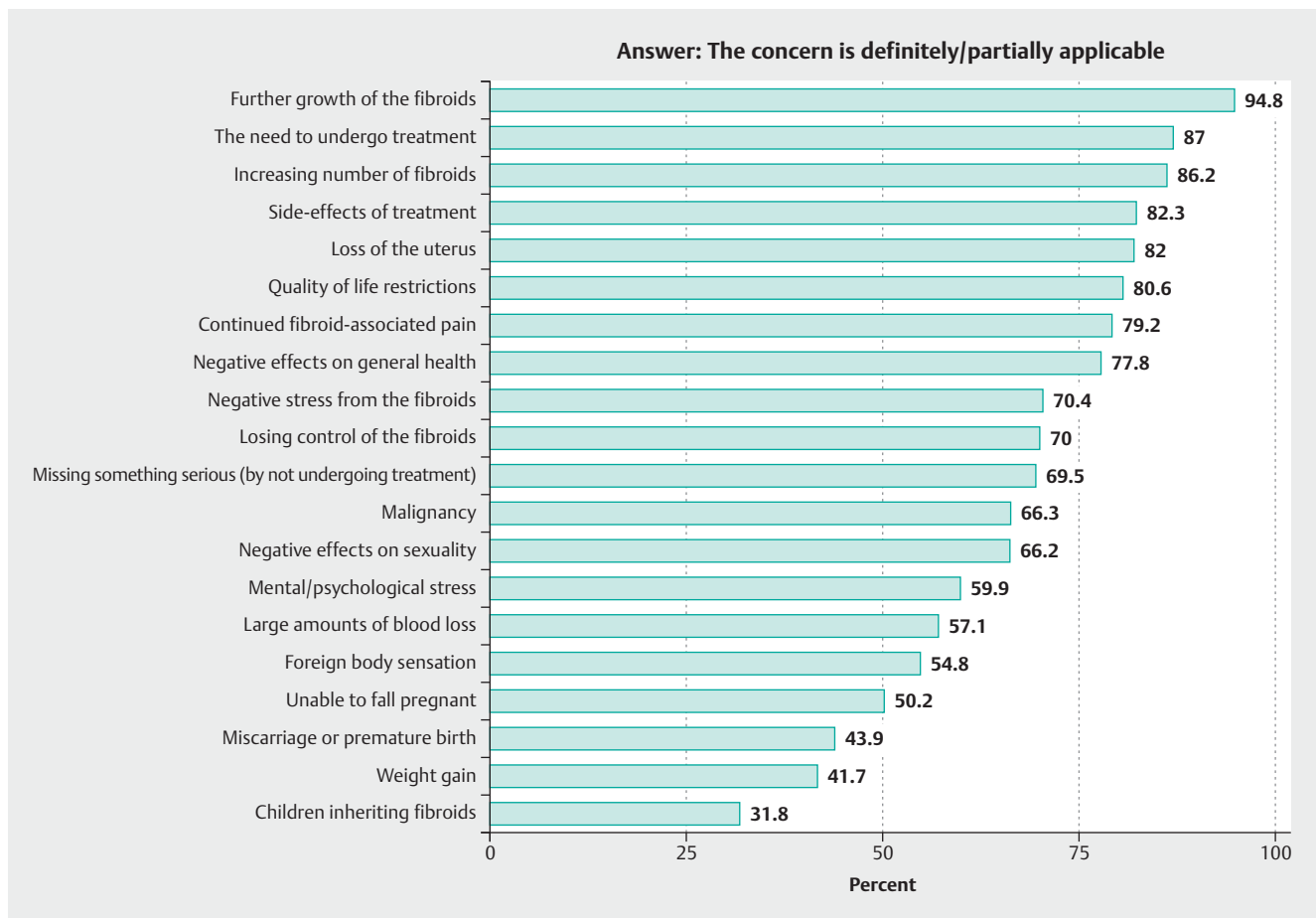
Discussion

This first large study focusing explicitly on fears and concerns among patients with uterine fibroids shows that some affected women have high levels of disease-related anxiety despite the benign nature and good treatability of the condition. Their concerns relate mostly to increasing size and number of fibroids, to the need for treatment and possible side-effects of treatment. Concerns differ according to patient age and duration of diagnosis.

Some of these concerns can be alleviated by the treating doctor through improved levels of patient information. A high level of education seems to be preventive.

Our data confirm statements by Ghant et al. (2015) to the effect that fibroids constitute a significant emotional burden for affected women [7], and they describe specific fibroid-associated fears in the various phases of a woman’s life.

Numerous gynaecological studies have shown that most patients have a need for information about their condition to reduce fears and feelings of uncertainty [10–12]. Utz-Billing et al. (2006) also described that counselling about treatment options (opera-



► **Fig. 2** Incidence of fibroid-associated concerns for the entire study population (Questionnaire answer: “definitely” or “partially applicable”; multiple answers possible).

tive and nonoperative) by the responsible gynaecologists can reduce patient concerns [13].

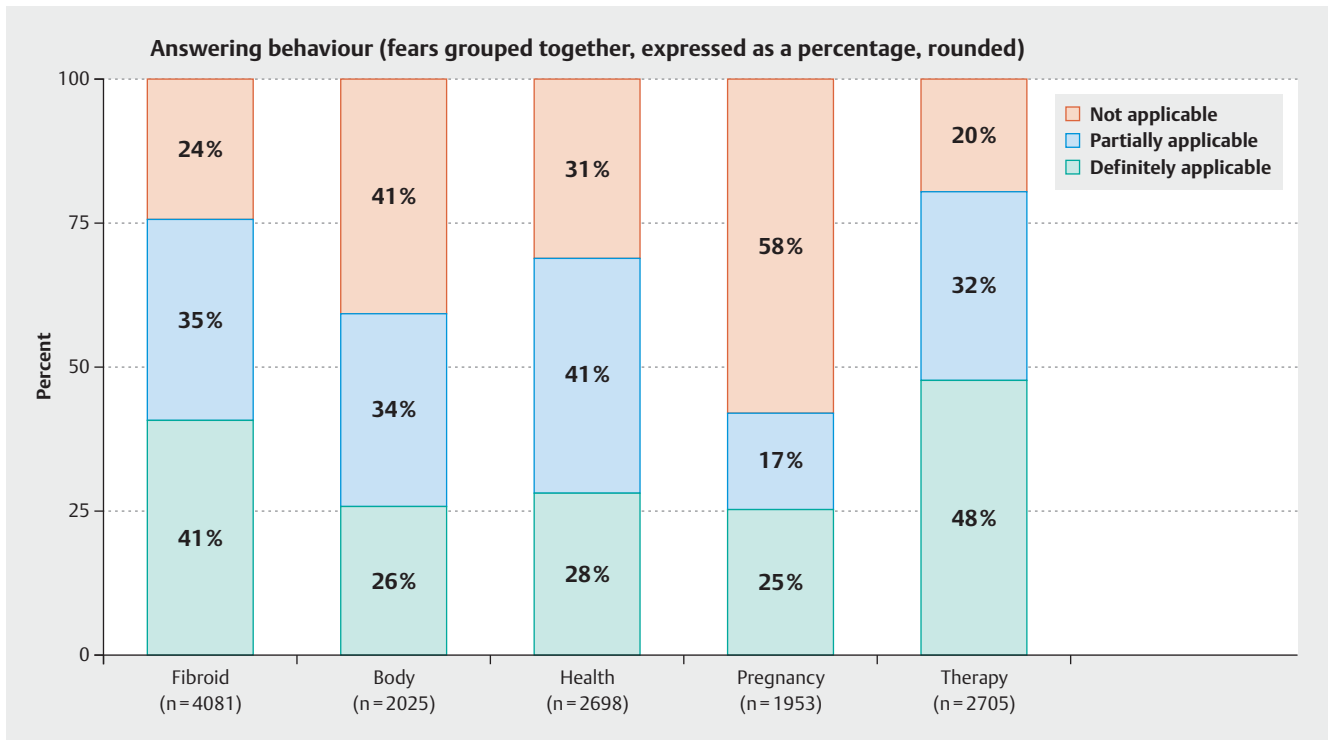
However in the current study, patients who rated themselves as well-informed reported fear of the need for possible hysterectomy and concerns about reduced quality of life significantly more often. Although hysterectomy is the only completely curative treatment available for fibroids, in many cases it is unnecessary [14]. It is however questionable whether these women who judged themselves as well-informed were in fact well-informed enough about uterus sparing treatment options. This question was not covered in the survey. On this point, a study from 2006 found that 38% of gynaecologists gave their patients no information about – and 13% of patients were advised against – nonoperative treatment methods [13]. In our study collective well-informed patients reported fear of reduced quality of life more often. Other studies have however shown that HRQOL in fact improves after treatment [15, 16].

In our collective patients with lower levels of schooling reported more fears. The Norwegian HUNT study highlighted the fact that a higher level of education is generally protective against the development of fears and also protects against depression [17]. Another survey of concerns among pregnant women dem-

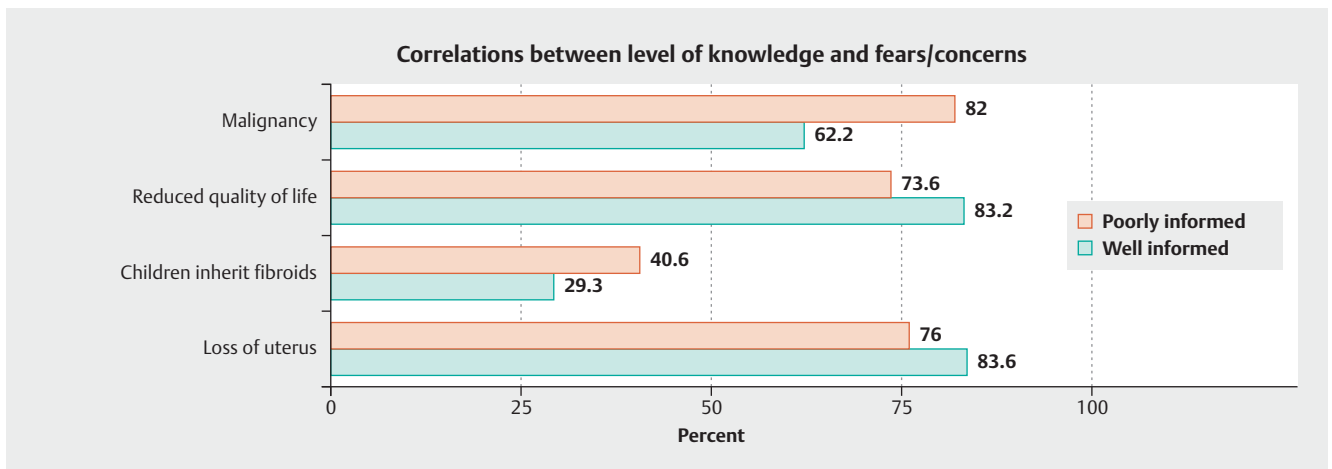
onstrated the same relationship, with education described as the primary determinant of stable personality-inherent anxiety (State Trait Anxiety Inventory) [18].

In 2008 Divakar described asymptomatic fibroids in women finding that the mere diagnosis was a cause of anxiety. Various general fears also found in our study were described: malignancy, hysterectomy, reduced fertility/problems in pregnancy, increasing tumour size and associated treatment options as well as possible negative consequences of “waiting and watching” [14]. Ghant et al. (2015) described the progression of fears in patients with symptomatic fibroids. They found that before diagnosis patients were distressed and anxious through lack of knowledge and uncertainty about the cause of their symptoms. Following diagnosis on the one hand patients were relieved about the benign nature of their condition, but on the other hand continued to be concerned about possible complications and consequences of their fibroids [7].

The often cited fear of malignancy [8, 9, 14] ranked number 12 of 20 possible fears and concerns in our patient collective. Two thirds of participants mentioned this concern, poorly informed women more often than well-informed.



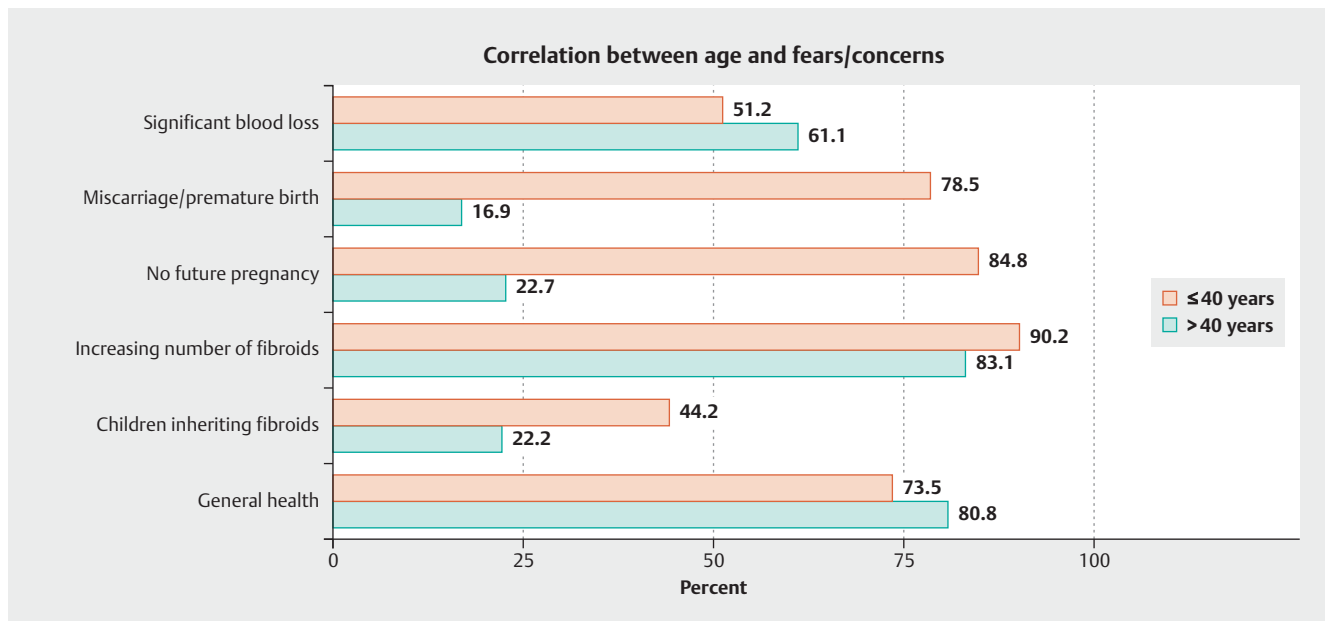
► **Fig. 3** Fears and concerns are grouped according to themes as follows: **Fibroid**: loss of control, blood loss, malignancy, increasing size, increasing number, pain. **Body**: quality of life, foreign body sensation, weight gain. **Health**: mental state, general health, sexuality, stress. **Pregnancy**: miscarriage/premature birth, unable to fall pregnant, passing on to own children. **Therapy**: necessity for treatments and their side-effects, hysterectomy, consequences of nonaction. Analysis according to answers stated.



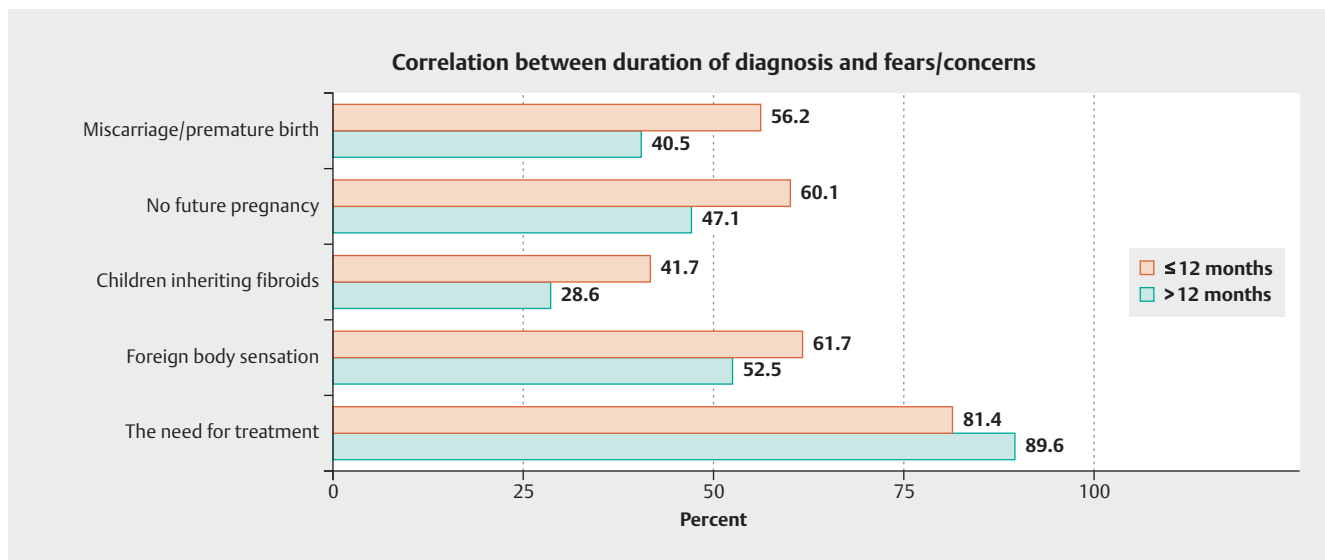
► **Fig. 4** Significant correlation between patient level of knowledge and fears/concerns (Answers “definitely/partially applicable” combined to “anxiety present”; multiple answers possible; the answers “knowledge level good” and “knowledge level moderate” were pooled to “well-informed”).

Various correlations between fears and symptoms are described in the literature. Sepulcri et al. (2009) found a relationship between current pain intensity and degree of fear/anxiety in endometriosis patients [19]. Studies of patients with fibroids highlight the development of anxiety for unpredictable pelvic pain and significant blood loss [8] as well as unpredictable menstruation [5]. The perception of fibroids as part of one’s own body and

not as a foreign body is a preventive factor against the development of anxiety and distress [20]. In our study 54.8% of patients reported anxiety due to foreign body sensation, more commonly women with shorter duration of diagnosis. For this fear in particular the doctor, as a source of information, can reduce anxiety through appropriate counselling.



► **Fig. 5** Significant correlation between age and fears/concerns (Answers “definitely/partially applicable” combined to “anxiety present”; multiple answers possible).



► **Fig. 6** Significant correlation between duration of diagnosis and fears/concerns (Answers “definitely/partially applicable” combined to “anxiety present”; multiple answers possible).

Friedl et al. (2015) note that in endometriosis patients symptoms of anxiety decrease with increasing age [21]. Reasons for this are thought to be the better integration of the condition into everyday life and consequently less stress and less development of affective symptoms [22]. This progression may also be true for women affected by fibroids, though long term studies are lacking. In our study patients aged over 40 years mostly had fears about general health and significant blood loss.

The following are possible *limitations of our study*:

1. The fears and concerns were prescribed.
2. Our study collective was not representative of the German population. The proportion of participants with matriculation is above average (Germany 29.5% [23]) and the proportion of immigrants relatively small (Berlin 27.7% [24]).
3. Estimation of knowledge level and duration of diagnosis were self-assessed by patients.

4. The group of women with immigrant background only included those of the so-called first generation (with personal immigration experience).
5. Severity of symptoms that may have influenced individual concerns was not recorded by the questionnaire.

Clinical Bottom Line

Most fibroid patients demonstrate fears and concerns to varying degrees. Individual life circumstances influence which fears feature most prominently (e.g. fear of miscarriage among young women, fears about general health consequences among older women). Treating doctors should address these fears in a targeted manner in order to reduce unnecessary/unfounded anxiety. To this purpose clear and understandable information handouts that specifically address the fears and concerns highlighted in our study could be helpful.

Conflict of Interest

The authors declare that they have no conflict of interest.

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