


“Can Someone as Young as You Really Feel That Much Pain?” – A Survey on How People With Fibromyalgia Experience Healthcare in Sweden

SAGE Open Nursing
Volume 7: 1–10
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DOI: 10.1177/23779608211026145
journals.sagepub.com/home/son


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Abstract

Background: Research show that fibromyalgia has low credibility in healthcare, leading to poor treatment, lack of knowledge and disinterest. Therefore, people with fibromyalgia feel frustration, fear, anxiety and disappointment.

Objective: The aim of this study was to explore the experiences of people with fibromyalgia in their encounters with healthcare personnel in Sweden.

Method: A cross-sectional design, where 409 people with fibromyalgia answered an anonymous online patient-reported experience measure, developed specific for the study, with six closed questions and one open-ended question. Descriptive statistics were analysed by response frequencies. Correlation analysis were performed between demographic and clinical variables with the answers from the closed questions. Free-text answers were analysed with content analysis.

Results: A third experienced the treatment as bad (34%) and that they were not being taken seriously (30.5%). Almost half (47%) always or mostly felt fear of seeking healthcare related to fibromyalgia and that the health care personnel did not understand their diagnosis (46%). The majority (54%) experienced that the health care personnel did not understand how fibromyalgia affected them or how they could help them. The findings were confirmed in the free-text answers that were categorized into: Scepticism and disregard, Ignorance and disinterest and Professionalism and empathy. There were positive significant correlations between age and five of the questions ($\rho = .105-.181$, $p < .05-p < .01$), indicating that lower age is correlated with a worse experience. Furthermore, the duration of fibromyalgia showed a significant correlation with feeling afraid of seeking healthcare because of fibromyalgia ($\rho = .144$, $p < .01$), the shorter duration, the greater was the fear of seeking healthcare.

Conclusion: As a third of patients with fibromyalgia had bad experiences with healthcare, especially younger patients, knowledge about fibromyalgia needs to be increased and the patients should be taken seriously and treated respectfully, as well as given adequate support.

Keywords

fibromyalgia, healthcare, patient-reported experience, professional patient-relation

Received 26 February 2021; accepted 28 May 2021

Introduction

People with fibromyalgia describe a great lack of understanding and knowledge from healthcare (Diviney & Dowling, 2015; Longley, 2006; Reibel & Pearson, 2017; Söderberg et al., 1999). As a disease, it is found to have low credibility (Cunningham & Jillings, 2006; Reibel & Pearson, 2017). Research has shown (Cunningham & Jillings, 2006; Longley, 2006) that healthcare

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professionals denied fibromyalgia as a disease and expressed that it was just laziness and imagination. Mistrust from healthcare professionals, as well as suggestions that fibromyalgia was just a mental illness and not a real illness, left the persons feeling frustrated, afraid, anxious, and disappointed. Furthermore, fibromyalgia is an invisible disease and living with it can be a new experience each day as the pain is constantly changing. The pain can become worse or be relieved for periods. The condition is complex, difficult to manage, as well as difficult to understand for friends, family and healthcare professionals (Cunningham & Jillings, 2006; Reibel & Pearson, 2017). People with fibromyalgia also claimed that the illness not only has low credibility, but is also of low interest among healthcare staff, leading to poor treatment and lack of interest in them as patients. In addition, they experienced disinterest from the healthcare staff regarding diagnosis and treatment of other symptoms not connected to the fibromyalgia (Cunningham & Jillings, 2006). The prevalence of fibromyalgia is about 1.8 percent in the general population, but higher in women (3,98%) than in men (0.01%) (Heidari et al., 2017). Research has shown that fibromyalgia is primarily regarded as a women's disease and could be subject to a gender bias. Research indicates that the health care professionals' stereotypical perception of the patient is of a complaining woman and, therefore, not recognizing fibromyalgia as a severe disease (Briones-Vozmediano et al., 2018).

Symptoms, associated with fibromyalgia are pain, sleep disturbance, severe disability, and anxiety. The diagnosis should be based on medical history and physical examination such as radiological exams, laboratory exams and specialists counsel (Macfarlane et al., 2017; Suresh, 2015). A recent study described that glial cells are activated in patients with fibromyalgia, leading to inflammation of the brain. One could also find evidence that, depending on how much of the glial cells were affected, they could be linked to patients' fatigue. All data collected support a theory of a new treatment method through glial modulation, as a possible therapeutic treatment strategy for fibromyalgia (Albrecht et al., 2019). The European League Against Rheumatism (EULAR) have updated their recommendation in 2016 about the treatment for fibromyalgia; this was done to increase the evidence around the treatment, but more research is needed to increase good outcomes for successful treatment for people with fibromyalgia (Macfarlane et al., 2017).

Providing person-centered care has become increasingly important and involves the patient as an active participant in their care and decision-making (Ekman et al., 2011).

Person-centered care and empathetic behaviours from health care personnel have been shown to be

significantly lower for patients with no visible signs of pain, such as in fibromyalgia, compared to patients who have visible signs of pain such as in rheumatoid arthritis (Paul-Savoie et al., 2018). To our knowledge there are no recent studies from a patient-perspective for patients with fibromyalgia on how they specifically experience encounters with health care personnel in a Swedish context, which is surprising given that person-centered care has become increasingly acknowledged in healthcare in recent years. The overall aim of this study was, therefore, to explore the experiences of people with fibromyalgia in their encounters with healthcare personnel in Sweden.

Methods

Study Design

The study has a cross-sectional research design. A study specific questionnaire, PREM, was used for data collection in order to explore experiences of healthcare of people with fibromyalgia. The questionnaire was developed by the researchers and contained two sections, the first focused on demographic data, while section two related to questions about encounters with healthcare, of people with fibromyalgia, and the specific objectives of the study.

Broad Objective

- To determine experience of encounters with healthcare of people with fibromyalgia in Sweden.

Specific Objective

- To determine the association between age, gender, duration of fibromyalgia, and number of times seeking healthcare in the last 12 months, with experience of encounters in healthcare.

Study Setting

Participants were recruited from the Fibromyalgia Association in Sweden with a total number of members of 3000. Permission was given by the Association for the researchers to contact their members regarding participation in the present study, through the administrator of the Fibromyalgia Association. A closed Facebook group for people with a Fibromyalgia diagnosis was also contacted through their group administrator.

Participants

Eligibility Criteria. Patients, with fibromyalgia who were members of the Fibromyalgia Association in Sweden or members of a closed Facebook group for people diagnosed with fibromyalgia, who answered the PREM during a period of four days.

Inclusion Criteria. Women and men between 18 to 65 years of age with a fibromyalgia diagnosis. The age span was chosen in order to recruit participants of working age.

Sample Size

Due to the shortage of studies regarding experiences of encounters in healthcare of people suffering from fibromyalgia, we based an assumption from a population study in Sweden where 21% of the participants had negative experience of encounters in healthcare (Månsson et al., 2019). We therefore estimated the frequency of negative experience to be 21%.

Sample Size Calculation.

$$n = (z)^2 p(1-p)/d^2$$

n = sample size

z = level of confidence 95% (1.96)

p = expected prevalence of bad experience 21% (0.21)

d = tolerated margin of error 5% (0.05)

add 10% for missing data

Calculation of the Number of Participants.

$$n = (1.96)^2 \times 0.21 \times (1-0.21) / 0.05^2$$

$$n = 255 + 25 = 280$$

According to the calculation, this study's sample size should be at least 280 participants with extra margin for missing data of 10%. Since the calculation is based on previous prevalence of bad experience of healthcare, we decided, however, to include at least 300 participants in the study.

Data Collection

Patient Reported Experience Measure (PREM). Data was collected via a study-specific online questionnaire which consisted of four demographic and clinical questions and a seven-item PREM. The PREM was developed

specifically for this study, by the research group through discussions. A validation of the PREM by face validity was assessed as good by the research group. The PREM consisted of questions mainly focusing on the experiences of encounters with health care personnel such as the treatment from and understanding from the health care personnel. Six of the questions were closed questions with a five-point Likert scale. The last question was a free-text answer question. Table 1 provides a detailed description of the PREM. The functionality of the web based PREM was pre-tested by the researchers.

Data Collection Procedure. An information letter with a link to the PREM was sent, via the Fibromyalgia Association, to all its members and to members in a closed Facebook group for persons with a fibromyalgia diagnosis, via the administrator who shared the link and information letter. If a person received the link through both forums, they were instructed to reply on only one of the links. The link to the survey was sent out at the end of January 2019 and was open for four days. After that, the research group decided to close the link as the required number of participants was reached with a great margin. According to the sample size calculation, a total of 280 participants should be included, but after four days the number of participants had reach 409, which is why the research group decided to close the link to the PREM.

Data-Analysis

Descriptive statistics were analysed with IBM SPSS statistics 26.0 by response frequencies. In order to detect any significant differences in clinical and demographic data between the group that was sampled via the Fibromyalgia Association and the closed Facebook group for people with fibromyalgia, Chi-square test and Fisher's exact test, when the expected count was less than five, were performed. Data was screened for departure from normal distribution and the items in the questionnaire all showed acceptable values for

Table 1. Patient-Reported Experience Measure for Persons With Fibromyalgia.

• On a scale from always to never, how often do you feel afraid of seeking healthcare because of your fibromyalgia?				
Always	Mostly	Sometimes	Seldom	Never
• On a scale from very bad to very good, how do you experience that health care personnel treat you?				
Very bad	Bad	Fairly good	Good	Very good
• On a scale from never to always, how often do you experience that health care personnel take you seriously?				
Never	Seldom	Sometimes	Mostly	Always
• On a scale from never to always, how often do you experience that health care personnel understand your fibromyalgia diagnosis?				
Never	Seldom	Sometimes	Mostly	Always
• On a scale from never to always, how often do you experience that health care personnel understand how fibromyalgia affects you?				
Never	Seldom	Sometimes	Mostly	Always
• On a scale from never to always, how often do you experience that health care personnel help you with your diagnosis?				
Never	Seldom	Sometimes	Mostly	Always
• Briefly, how would you describe the way healthcare treats you?				

skewness and kurtosis (skewness ranging from $-.172$ to $.405$ and kurtosis ranging from $-.907$ to $-.421$). To explore any differences between gender and the outcome on the PREM, Mann-Whitney U-test was performed. Furthermore, to examine associations between age, duration of fibromyalgia diagnosis and number of times seeking healthcare in the last year with items in the PREM, Spearman correlation analyses were carried out.

A content analysis, inspired by Elo and Kyngäs (2008), was adopted regarding the free text answers. All the free text answers were read through and meaning units were derived and coded into ten sub-categories. The sub-categories were thereafter sorted into three main categories. Two of the researchers were initially part of this process but the results were discussed in the whole research group. Consensus was reached through discussions. In total, there were $n = 377$ free text answers.

Ethical Consideration

The study follows the ethical guidelines of the Swedish Red Cross University College. The online questionnaire was anonymous, and no personal identifying data was collected. The information letter provided information about the study and explained that participation was voluntary. The questionnaire was designed to ensure confidentiality and all participants were anonymous. If a participant started to respond but changed his/her mind, the link could be closed, and no information would be saved.

Results

In total, $n = 409$ persons answered the questionnaire, where $n = 371$ answered on the link via the Fibromyalgia Association and $n = 38$ via the closed Facebook group for people with fibromyalgia. Cronbach's alpha for the PREM was 0.91 which shows a very good internal consistency. Table 2 displays demographic and clinical data. There were no significant differences in demographic and clinical data between the two sampled groups.

The results from the closed questions showed that almost half (47%) always, or mostly, felt fear of seeking healthcare related to fibromyalgia. The majority of the participants (66%) experienced the treatment from the health care personnel to be fairly good to very good, but a third (34%) experienced the treatment to be bad.

The experience of being taken seriously by the health care personnel was divided among the participants, 30.5% were never or seldom felt they were being taken seriously, 28.5% sometimes and 41% mostly or always. Almost half (46%) of the participants experienced that health care personnel never or seldom understood their fibromyalgia diagnosis. Furthermore, the majority (54%) experienced that health care personnel never or

Table 2. Demographic and Clinical Variables of the Participants.

Gender	n	(%)
Women	394	(96.3)
Men	15	(3.7)
Age		
18–30	24	(5.9)
31–50	198	(48.4)
51–65	187	(45.7)
Duration of fibromyalgia diagnosis		
1–6 months	10	(2.4)
6–12 months	13	(3.2)
1–3 years	58	(14.2)
4–6 years	63	(15.4)
7–10 years	65	(15.9)
>10 years	197	(48.2)
Number of times seeking healthcare in the latest year		
1–3 times	219	(53.5)
4–6 times	101	(24.7)
7–10 times	44	(10.8)
>10 times	41	(10.0)

seldom understood how the fibromyalgia affected them. The majority (54%) also experienced that health care personnel never or seldom helped them with their fibromyalgia. Table 3 displays the response frequencies.

There were no significant differences in gender with respect to the items in the PREM. However, age had a positive correlation and was significantly associated with all items in the PREM except for one (see Table 4).

Duration of fibromyalgia showed a significant correlation with feeling afraid of seeking healthcare because of fibromyalgia ($\rho = .144$, $p < .01$), meaning that the shorter duration of fibromyalgia the greater was the fear of seeking healthcare. The number of times seeking healthcare in the last year had no significant correlations with any of the items in the PREM.

Free Text Answers

In total, there were $n = 377$ free text answers to the open question:

“Briefly, how would you describe the way healthcare treats you?”

The number of free text answers gives a response rate of 92%. The comments were read through, analysed, and sorted into sub-categories and three categories. The three main categories were 1) *Scepticism and disregard*, 2) *Ignorance and disinterest* and 3) *Professionalism and empathy*. In Table 5, the categories are displayed together with an example of the analysis, with sub-categories and meaning units. The number of comments in each main category, is also displayed.

Table 3. Response Frequencies of the Closed Questions in the Study PREM.

		n	%
On a scale from always to never, how often do you feel afraid of seeking healthcare because of your fibromyalgia? n = 408	Always	74	18.1
	Mostly	119	29.2
	Sometimes	104	25.5
	Seldom	55	13.5
	Never	56	13.7
On a scale from very bad to very good, how do you experience that health care personnel treat you? n = 408	Very bad	28	6.9
	Bad	111	27.2
	Fairly good	156	38.2
	Good	67	16.4
	Very good	46	11.3
On a scale from never to always, how often do you experience that health care personnel take you seriously? n = 407	Never	30	7.4
	Seldom	94	23.1
	Sometimes	116	28.5
	Mostly	131	32.2
	Always	36	8.8
On a scale from never to always, how often do you experience that health care personnel understand your fibromyalgia diagnosis? n = 408	Never	46	11.3
	Seldom	142	34.8
	Sometimes	131	32.1
	Mostly	73	17.9
	Always	16	3.9
On a scale from never to always, how often do you experience that health care personnel understand how fibromyalgia affects you? n = 407	Never	66	16.2
	Seldom	154	37.8
	Sometimes	113	27.8
	Mostly	60	14.7
	Always	14	3.4
On a scale from never to always, how often do you experience that health care personnel help you with your diagnosis? n = 405	Never	67	16.5
	Seldom	152	37.5
	Sometimes	114	28.1
	Mostly	57	14.1
	Always	15	3.7

Table 4. Correlations Between Items in the PREM With Age.

Spearman ρ						
Item in the PREM	On a scale from always to never, how often do you feel afraid of seeking healthcare because of your fibromyalgia?	On a scale from very bad to very good, how do you experience that health care personnel treat you?	On a scale from never to always, how often do you experience that health care personnel take you seriously?	On a scale from never to always, how often do you experience that health care personnel understand your fibromyalgia diagnosis?	On a scale from never to always, how often do you experience that health care personnel understand how fibromyalgia affects you?	On a scale from never to always, how often do you experience that health care personnel help you with your diagnosis?
Age	.169**	.105*	.134**	.181**	.110*	.048

The coefficients in the table denote Spearman ρ .

* $p < .05$, ** $p < .01$

Scepticism and Disregard. Many of the participants had experiences of being neglected, disregarded, met with scepticism and even rudeness. They felt that they were not listened to or taken seriously, that the doctor was minimizing their symptoms or insinuated that the fibromyalgia only was in their head. In this category there

were 154 comments. Below two comments are displayed to illustrate the category.

"No matter what I am suffering from, they only see the fibromyalgia diagnosis and don't do other tests. Therefore, I don't seek healthcare, as they don't recognize me as a

Table 5. Free Text Answer Categories, Sub-Categories and Examples of Meaning Units.

Meaning unit	Sub-category	Category
Skeptical, like one makes the symptoms up. One doctor told me: it is all in the head Like a whining cow who blames everything on the fibromyalgia. You have fibro, so live with it	Doubtful Ignored Questioned Treated badly There is no help Live with it	Skepticism and disregard N=154
Nicely, but with great ignorance of how the fibromyalgia really affects everything. A lot of ignorance about the illness and they only through medicine after you and go on about exercising. With hesitation, uninterest and an idea that fibromyalgia is impossible to manage.	Lack of knowledge With hesitation Uninterested Indifferent Blame everything on the fibromyalgia Other	Ignorance and disinterest N=119
Have a good doctor nowadays who listens, but it has not always been like that. They have always treated me fine. Fairly good	Good treatment Enhanced understanding nowadays	Professionalism and empathy N=104

human being, rather a diagnosis which shouldn't be taken seriously".

"Disregarded, as I would make the symptoms up".

Ignorance and Disinterest. Many of the participants made comments about lack of knowledge among healthcare staff, in particular among doctors. The ignorance had led to mistreatment of the fibromyalgia. Some participants experienced that everything was blamed on the fibromyalgia, so other problems were not correctly diagnosed. There was disinterest from the healthcare staff, and some wrote that they had to tell the doctor what to do. In this category there were 119 comments. Below two comments are displayed to illustrate the category.

"One doctor said: -I don't know anything about this. It would have been much easier if you have had a broken leg. Another one said: - Sweetie, sometimes it hurts and in a couple of years it will pass". I have no confidence in the doctors. Want to go to someone that knows what fibromyalgia is and how it works."

Most doctors are ignorant about fibromyalgia, so you have to tell them, as a patient, what to do."

Professionalism and Empathy. The participants expressed that nowadays they were treated with more respect and very professional, but it differed based on where they went. In some healthcare centres, the staff had knowledge about fibromyalgia and the staff treated them warmly, listened to them, and tried to treat their symptoms, but in other places this was not the case. Overall,

they recently experienced more empathy. In this category there were 104 comments. Below, two comments are displayed to illustrate the category.

"I have been lucky to be treated very professional in healthcare. Mostly, due to the general practitioner at the private primary care and pain clinic in the region".

"Nowadays, very good".

Discussion

The purpose of the study was to explore the experiences of people with fibromyalgia in their encounters with health care personnel in Sweden. Our results showed that experiences varied between the participants. Whereas the majority had experienced good treatment there was still about a third that experienced poor treatment. This is a larger percentage than experienced in sickness absentees with various diagnoses, including musculoskeletal disorders, in a large population study in Sweden, where 21% experienced bad encounters (Månsson et al., 2017). Furthermore, a third thought they were not taken seriously by the health care personnel. About half of the participants experienced that health care personnel did not understand their fibromyalgia diagnosis or how the fibromyalgia affected them and did not help them with their condition. However, free text answers showed that two third of the participants had bad experiences of encounters in healthcare but, recently, attitudes and understanding from healthcare staff has improved, which could explain the diversity in the answers. There is also a general increase in knowledge of fibromyalgia in society that can lead to a

better treatment. On the other hand, some participants expressed that they never discussed the diagnosis with the doctors because of a fear of being neglected. These results are in line with other studies that show lack of understanding and mistrust from health care personnel, as well as the authenticity of the fibromyalgia being contested (Ashe et al., 2017). A study from 1995 (Henriksson, 1995) showed similar results in encounters with the healthcare system in a sample from Sweden and the US. The patients experienced lack of interest or empathy and disbelief. Our results indicate that the same problems are still occurring several decades later. Research has shown that women experience stigma in relation to their diagnosis. Mainly prior to being diagnosed, they were questioned or neglected since they had no visible external symptoms and that their health problems were being psychologized (Åsbring & Närvänen, 2002, 2003). These experiences are also confirmed from the health care personnel's perspective, as research shows that general practitioners report insufficient knowledge and skills to diagnose fibromyalgia, as well as treating it (Hayes et al., 2010; Perrot et al., 2012). Even amongst specialists 1 out of 10 described patients with fibromyalgia as malingerers (Hayes et al., 2010). Physicians had difficulty with the discrepancy of how the patients describe themselves and the physician's view of how a sick person is expected to look and behave (Åsbring & Närvänen, 2003). A large survey found that 64% of physicians across specialties considered that the patients had difficulties in communicating their symptoms of fibromyalgia (Perrot et al., 2012). Physicians felt frustrated and that the frustration was more likely to occur when they thought the fibromyalgia was caused by internal/psychological factors. If biomedical risk factors and uncontrollable external factors were considered as causes the frustration was, however, less (Homma et al., 2016). The healthcare professional and patient relationship has been described as tense and problematic where the patients are dissatisfied with the way they are treated whereas professionals feel they are being challenged in their professionalism (Briones-Vozmediano et al., 2013).

In the correlation analyses of the present study, age was significantly correlated to almost all the items in the PREM. The younger the patient was, the more likely he or she was to experience fear of seeking healthcare, experience bad encounters with healthcare and experience lack of understanding, which is also supported by the free text answers. This is, to our knowledge, a novel finding. Research has found that younger people with fibromyalgia displayed worse health-related quality of life and fibromyalgia symptoms than older people with fibromyalgia (Jiao et al., 2014). Furthermore, our study indicates that the shorter duration of fibromyalgia, the greater the fear of seeking healthcare. The findings

suggest that younger people with fibromyalgia and those newly diagnosed need greater support. There were no significant differences in gender, with respect to how they experienced encounters with health care personnel. The majority of the participants were women and only 3,7% of the sample were men. The prevalence of diagnosed fibromyalgia is known to have a female dominance (Heidari et al., 2017; Haviland et al., 2011) so the low percentage of men in the sample is not surprising. However, there is research indicating that the assessment of fibromyalgia is biased so that men are underdiagnosed (Wolfe et al., 2018). There is one Swedish study that has specifically investigated how men with fibromyalgia experience the healthcare system. It revealed that men were afraid to be looked upon as a whiner and that it was difficult to find a receptive listener. Furthermore, men felt neglected (Paulson et al., 2002), which is similar to women's experience of fibromyalgia (Åsbring & Närvänen, 2003). The number of times seeking healthcare in the past year had no significant correlations with any of the items in the PREM. This result is to some extent contradictory to other research, that has shown that patients with fibromyalgia, who feel discounted by the medical profession, attended healthcare more often. However, the study also revealed that lack of understanding from the healthcare system had no significant correlation with hospital visits which is in line with our results (Homma et al., 2016). Patients, who experience lack of understanding and being discounted report higher dissatisfaction with their physician (Homma et al., 2018).

The free text answers in the present study showed that there is still considerable ignorance about fibromyalgia among healthcare staff in Sweden, however, knowledge is slowly improving. In order to improve knowledge of fibromyalgia an educational toolkit could help physicians feel more confident in managing patients with this condition (Gannon et al., 2011).

A patient-centered approach could be beneficial for patients with fibromyalgia when it comes to reducing pain and dysfunction (Peilot et al., 2018), however, the experience of encounters with the healthcare with a patient-centered approach remains to be investigated. Using patient-reported measures of patients' experiences, PREM, could be one method of incorporating the patient perspective in the evaluation of structure, process and satisfaction of such research (Nilsson et al., 2016). This study used a PREM to evaluate the patients' experiences of encounters with the healthcare. PREMs are becoming increasingly incorporated in the Swedish National Quality Registers (Nilsson et al., 2016). A review has summarized which care preferences patients with fibromyalgia have and they included patient-centered communication styles such as shared decision-making about care, reciprocal information

sharing and increased mutual understanding (Doebel et al., 2020). Furthermore, the study presented ideas from patients on how health care personnel could improve their care such as; allow patients experiences and expertise to be heard, acknowledge fibromyalgia as a condition in need of healthcare, increase knowledge about fibromyalgia and giving appropriate support (Doebel et al., 2020). A Swedish study has found that people with fibromyalgia find support in fibromyalgia associations, where they could get confirmation, understanding and information from each other that the health care personnel could not satisfy (Juuso et al., 2014). The participants in the current study were recruited from the Fibromyalgia Association and a closed Facebook group in Sweden and, since the result showed there could be improvements in the way patients with fibromyalgia are treated, they could potentially find support from each other.

Strengths and Limitations

Since the recruitment of participants was made via the Fibromyalgia Association and a closed Facebook group, it enabled a nationwide geographic spread. In combination with a fairly large sample size, the sample could be considered representative and enhance the external validity. The upper limit of 65 years might be a limitation as we did not retrieve information from older patients.

The internal consistency of the PREM was very good, indicating a high reliability. The validity was only estimated by face value as it was considered sufficient for this study but could be seen as a limitation. The web based PREM was only open for four days which might have limited the number of participants. However, during the short time period 371 out of 3000 members of the Fibromyalgia Association answered the PREM which shows that the questions raised are of interest and importance to them. After three days there was a drop in the web-based responses and since this study is considered to be a pilot-study, and not an epidemiological study, we decided to close the survey. A total of 409 responses is considered a sufficient sample size according to our power calculation. The response rate on the closed Facebook group was quite low compared to the response rate on the Fibromyalgia Association. A possible explanation for this could be that they were members in both groups that answered primarily via the Fibromyalgia Association. It is difficult to estimate a correct response rate as we have no information how many members fulfilled our inclusion criteria in the two forums.

Although it was informed that only people with fibromyalgia were eligible to answer the questionnaire, the fibromyalgia diagnosis could not be validated as the study was anonymous. However, 99,3% had given a duration time for their fibromyalgia diagnosis indicating

that they have the diagnosis. This is a limitation, but the anonymity enabled the participants to answer freely without being afraid of being recognized. This enhanced the trustworthiness of the study. The trustworthiness of the results from the qualitative data was enhanced by including more than one researcher in the analysis, including quotes in the result text and giving examples of the analytic process in a table.

Conclusion

Patients with fibromyalgia experienced both good and bad encounters with the healthcare system and the majority experienced that knowledge of fibromyalgia is low. The younger the patient, the more likely they were to have a bad experience and feel fear of seeking healthcare. The results of the study reveal that there is much left for health care personnel to work on, in order to improve their encounters towards people with fibromyalgia.

Implication for Clinical Practice

This study gives valuable information on how people with fibromyalgia experience encounters with healthcare. It points out, that in clinical practice, knowledge about fibromyalgia needs to be increased and the patients should be taken seriously and treated respectfully, as well as given adequate support. More research on how to improve the encounters with, for example, a person-centered approach, is required.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article:: The authors received funding for publication from The Swedish Red Cross University College.

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