Good pain, bad pain: illness perception and physician attitudes towards rheumatoid arthritis and fibromyalgia patients

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ABSTRACT

Objective. *Rheumatoid arthritis (RA) and fibromyalgia syndrome (FM) are common diagnoses encountered in rheumatology practice, but do not enjoy the same status. We aimed to examine physician's illness perceptions regarding these two rheumatologic disorders and to evaluate how they correlate with their relationship with these patients.*

Methods. *Forty-five rheumatologists were enrolled in the study. Demographic data were registered. Measures collected included the Brief Illness Perception Questionnaire (BIPQ) and the Difficult Doctor- Patient Relation Questionnaire (DDPRQ-10). Both were recorded twice, related to FM and RA. Empathy and burnout were also assessed.*

Results. *Of 45 physicians included in the study, only 53% were willing to accept FM patients. FM was considered a more severe disease than RA (FM-BIPQ mean score 54, SD 5.5 versus RA-BIPQ mean 45.6 SD 6.5, p<0.00) in terms of treatment control, understanding and emotional response generated by the disease. Doctor-patient relationship was perceived more difficult with FM patients compared to RA patients (FM-DDPRQ mean score 35.1, SD 9.2 versus RA-DDPRQ mean 19.6, SD 7.1, p<0.00), and was significantly correlated to the patient's concern about the illness (p<0.034) and patient's emotional response (p<0.036). Resistance to accept FM patients was largely influenced by difficult doctor-patient relationship. Higher levels of empathy were found in physicians experiencing less difficulty with FM patients.*

Conclusion. *FM patients were perceived as more difficult than RA patients, with a high level of concern and emotional response. A high proportion of physicians were reluctant to accept them because they feel emotional/psychological difficulties meeting and coping with these patients.*

Introduction

Rheumatoid arthritis (RA) is a well-defined systemic auto-immune disease affecting up to 1% of the population, with clear clinical features, well-understood pathogenesis, and a constantly growing effective therapeutic arsenal (1).

Fibromyalgia (FM) is a complex set of disabling symptoms including widespread chronic pain, disturbed sleep, fatigue, as well as functional complaints, anxiety, and depression. Its prevalence ranges from 2 to 8% of the adult population, affecting all ages. Despite increasing research, pathogenesis is still not well-understood, and treatment remains both challenging and non-specific (2). The complex nature of this syndrome, with a high burden of symptoms, affecting both physical and mental health (3) along with poor understanding of pathophysiology and few effective therapeutic tools, may engender a sceptic and suspicious approach on the part of healthcare professionals, some of whom persist in regarding FM as a contentious illness, while others may suspect patients are actually malingering (4).

Both diseases represent a large part of common rheumatology practice, although patients' profile and medical encounter experiences differ greatly. FM patients experience more somatic symptoms, which are more severe, continuous and life-disturbing, leading to significant functional impairment and reduced quality of life, when compared to RA patients (5, 6). Higher depression scores, greater perceived distress and more frequent unsupportive relationships have been observed in FM patients compared to those with auto-immune disorders such as lupus or RA (7).

These disparities between FM and RA patients largely influence the nature of the medical encounter, which is the most important event in clinical

activity, extending beyond scientific knowledge and technological implementations. This interpersonal communicational process remains critical for the establishment of a therapeutic relationship and carries great significance regarding future quality of care; thus, early physician-patient rapport has the potential to affect illness trajectories and to regulate future treatment behaviour. Both patients and physicians may experience difficulties during this encounter. On the one hand, patients with unexplained medical conditions, and especially chronic pain and FM, have reported negative experiences during medical encounters, facing scepticism and lack of comprehension, feeling rejected, ignored, and even being blamed for their condition, and have to struggle for their own credibility. Due to the transparency of pain, the main symptom of FM, they have to struggle in order to make the symptoms socially visible, "real", and substantive when consulting a doctor (8). On the other hand, physicians also experience difficulties in treating these patients. Unfamiliarity with the aetiology and frustration about not being able to handle the problem may lead doctors to develop dismissive attitudes and aversion toward these patients. Regarding the well-defined and easily visible condition of RA, medical encounters are quite different.

In this context, we aimed to understand factors that may influence the doctor-patient relationship, and the willingness to take care of patients perceived as difficult. Illness perception represents the cognitive and emotional self-interpretation of patients regarding their condition, culminating in the development of a comprehensive picture of the illness threat and leading to the development and formulation of coping strategies (9).

It is a five-component construct including identity, causes, timeline, consequences, curability and controllability. The physician's perception of an illness consists of the same dimensions of representation, integrated with academic knowledge and clinical experience. It is reasonable to assume that a physician's interpretation of illness will influence his or her relationship with a patient suffering from this disease. Burnout, as a result of prolonged work in rheumatology clinics treating chronic patients with high clinical and emotional demand, is another factor potentially affecting physician-patient encounters (10). Empathy, one of physician's most important skills, may protect physician's wellbeing from burnout symptoms. Empathy has been shown to improve therapeutic outcomes in a wide range of clinical settings and is a crucial component of the physician-patient therapeutic relationship. (11).

The aim of the current study was to examine physician's illness perceptions regarding these two rheumatologic disorders (FM and RA) and to evaluate how they correlate with their relationship with these patients, as well as with the willingness/resistance to accept them for treatment. We also aimed to determine whether factors such as physician's empathy and burnout influence illness perceptions and doctor- patient relationship.

Methods

Participants in this study were rheumatologists who attended a national rheumatology conference of the Israeli Society of Rheumatology in 2019, where a study research-assistant distributed a paper print version of the questionnaires and asked to sign an informed consent. From the 83 physicians who accepted the questionnaires, 52 returned them, but only 45 were fully answered forms, with all the answers marked in each questionnaire. The study was approved by the ethics committee of the Academic College of Tel-Aviv Yaffo, Israel.

Study tools consisted of five different questionnaires: The Brief Illness perception Questionnaire (B-IPQ) and Difficult Doctor-Patient Relation Questionnaire (DDPRQ-10), which were presented twice, one version addressing FM and the other RA, the Jefferson scale of physician empathy (JSPE), the Shirom-Melamed Vigor Measure (SMVM) and Shirom-Melamed Burnout Measure (SMBM). Demographic variables (gender, age, years and place of practice, personal relationship to FM or RA patients) were obtained through an additional questionnaire. All participants were also asked about their willingness to accept FM and RA patients, and in case of negative response, to fill one reason from a given list.

Questionnaires

The Brief Illness Perception Questionnaire

The Brief Illness Perception Questionnaire (B-IPQ) contains 9 items answered on a 11-point Likert scale ranging from 0-10 and was constructed in order to rapidly assess the cognitive and emotional representations of an illness. The B-IPQ was presented twice, once for each of the addressed conditions in this study. This instrument measures eight different aspects of illness perception (12); consequences - the individual's beliefs about the consequences of the condition, physically and socially (item 1) , timeline - the predictive belief about the length of the condition (item 2), personal control: the degree to which the individual takes part in the treatment (item 3), treatment control - the beliefs about whether the condition is curable or manageable (item 4) and identity- the label or name given to the condition, (item 5). All five items assess cognitive representations of the illness. Illness comprehensibility (item 7) and concern and emotions (items 6 and 8) assess emotional representation of the disease. Assessment of the causal representation (item 9) (the individual's ideas about the perceived cause of the condition) is measured by an open-ended response which asks physicians to list the three most important causal factors that can causes FM or RA. These open answers were further categorised into internal and environmental factors.

In this study, the BIPQ was modified from the patients to the physician's point of view.

Difficult Doctor-Patient Relation Questionnaire

The Difficult Doctor-Patient Relation Questionnaire (DDPRQ-10) is a 10-item questionnaire answered by a 6-point Likert scale (13). This questionnaire was also presented twice, once for FMS and once for RA, with

values ranging from 1 ("Not at all") to 6 ("A great deal"). Higher scores indicate greater difficulty in the physician's experience of the relationship.

In order to dichotomise the answers into difficult patients/non-difficult patients, we used the score of 30 as a cut-off point. A total score of 30 and above points indicates that the physicians consider the patients as difficult (14).

Jefferson scale of physician empathy

The Jefferson scale of physician empathy (JSPE) is a universally used instrument developed to measure empathy in the context of health professions education and patient care (15). This instrument consists of 20 items answered on a 7-point Likert scale ranging from 1-7 (strongly disagree - strongly agree, respectively). A higher score in JSPE indicating greater empathy.

Shirom-Melamed Vigor Measure

The Shirom-Melamed Vigor Measure (SMVM) consists of 12-items and is divided to three subscales; Physical strength (PHY, 5 items); emotional energy (EE, 4 items); and cognitive liveliness (CL, 3 items). Responses are given on a 7-point scale from 1(never) to 7 (always). A global vigor score can be calculated by averaging item scores across each of the three subscales. Scores above mean refer to a measure of vigour (16).

Shirom-Melamed Burnout Measure

The Shirom-Melamed Burnout Measure (SMBM) consists of 14-item and is divided into three subscales: physical fatigue (6 items) cognitive weariness (5 items), and emotional exhaustion (3 items). Responses are given on a 7-point scale from 1(never) to 7 (always). A global burnout score can be calculated by averaging item scores. Score above mean refer to a measure of burnout (17).

Results

The Sample consisted of 45 physicians (19 males, 16 female and 10 who did not identify their gender) between the ages of 31-76. The mean years of practice was 14.4 (SD=10), with 39.5 mean working hours per week of (SD=10.87), All participants reported having moder-

Table I. Rheumatologists demographic characteristics.

Age (Mean, SD)	49 (10.46)
Years of practice (Mean, SD)	14.42 (10.11)
Working hours per week (Mean, SD)	39.53 (10.87)
Fibromyalgia familiarity	
some familiarity	2%
moderate familiarity	18%
strong familiarity	80%
Rheumatoid arthritis familiarity	
some familiarity	2%
moderate familiarity	13%
strong familiarity	85%
Place of practice	
Hospital	48.90%
Public clinic	8.90%
Hospital & public clinic	13.30%
Hospital, public clinic & private practice	28.90%
Questionnaire Score (Mean, SD)	
Jefferson scale of physician empathy	**85.93 (9.24)**
Shirom-Melamed vigor measure	**5.25 (0.93)**
Subscales: physical strength	5.12 (1.18)
cognitive liveliness	5.17 (0.89)
emotional energy	5.47 (1.02)
Shirom-Melamed burnout measure	**2.43 (0.79)**
Subscales: physical fatigue	2.66 (0.98)
cognitive weariness	2.4 (1.01)
emotional exhaustion	2.08 (0.83)

Table II. Physician's illness perception (B-IPQ).

**B-IPQ Questions ranked 0-10 (r - reverse scale)	Considering fibromyalgia n=45 Mean (SD)	Considering rheumatoid arthritis n=45 Mean (SD)	*p*
Consequences: How much does illness affect the patient's life?	9.33 (1.2)	8.6 (1.4)	0.005
Timeline: How long do you think the illness will continue?	8.89 (1.19)	8.82 (1.21)	0.806
Personal control (r): In general, how much control do you think patients have over their illness in general?	4.04 (2.42)	4.73 (2.39)	0.140
Treatment control (r): How much do you think general treatment can help the patient's illness?	5.04 (2.46)	1.58 (1.91)	0.000
Identity: How much do patients experience symptoms from their illness?	8.44 (1.17)	8.33 (1.56)	0.803
Concern: In general, how much are patients concerned about their illness?	8.84 (1.18)	7.98 (1.66)	0.001
Understanding (r): In general, how much do you feel patients understand about their illness?	4.58 (2.12)	3.09 (1.6)	0.000
Emotional response: In general, how much does fibromyalgia affect patients emotionally? (*e.g.* anger, fear, confusion depression))	8.87 (1.45)	7.16 (1.9)	0.000
**Causal factors: Please list the three most important factors you believe to be the cause of the patient's illness			
Internal	53%	0%	
Environmental	3%	75%	
Internal and environmental	44%	25%	

*Brief Illness Perception questionnaire was presented twice, once referring to fibromyalgia and once to rheumatoid arthritis. The questions above are written for one condition for easy reading but represent the two versions we used.

**Item 9 - Answers were categorised in two groups for analysis.

ate-to-strong familiarity with FM and RA (Table I).

The Brief Illness Perception Questionnaire

A paired sample t-test analysis was conducted for differences in B-IPQ total scores between FM and RA (Table II). A significant difference in B-IPQ total scores was observed between the two conditions [t (43) = 5.584, $p<0.00$)], with a higher score for FMS [54 (7.33)] compared to RA [45.68 (6.34)] (Fig.1). Physicians perceived FM as a more severe condition than RA; the main reason cited for this perception included the lack of effective therapeutic control over the disease, a greater emotional burden, a higher degree of concern, and an overall higher impact of disease on daily life of FM patients.

None of the physicians attributed RA to internal factors while 53% of them consider FM to be due exclusively to internal factors such as mental state, personality traits or personality disorders, depression, anxiety, childhood trauma, sexual abuse and secondary gain. Forty- four percent thought that a combination of internal and environmental factors causes FM.

Difficult Doctor-Patient Relation Questionnaire

In order to compare the difficulty of the relationship between physicians and their patients in both groups, a paired sample t-test analysis for differences in DDPRQ total scores between FM and RA was performed (Table III).

A significant difference was found (t (43) = 6.044, $p<0.00$) in DDPRQ total scores, with higher scores for FM [35.48 (10.58)] compared to RA [19.66 (10)] (Fig. 1).

Physicians experienced the encounters with FM patients as more frustrating, with vague complaints and difficult communication. FM patients were considered more manipulative and self-distractive. Physicians were significantly less enthusiastic to take care of a patient with FM than a patient with RA ($p<0.00$).

Willingness to accept patients

53% of the physicians were willing to accept FM patients, whereas 98% were willing to accept RA patients. All participants filled reasons for rejection when they chose 'not willing to accept' (Table IV), most of them thought that "it is better to consult a specialist in FM" (27.8%).

In order to check if the doctor-patient relationship or the physician's illness perception can explain part of the physician's willingness to accept or not FM patients, we first conducted an Eta test with DDPRQ total score as an independent factor and willingness to ac-

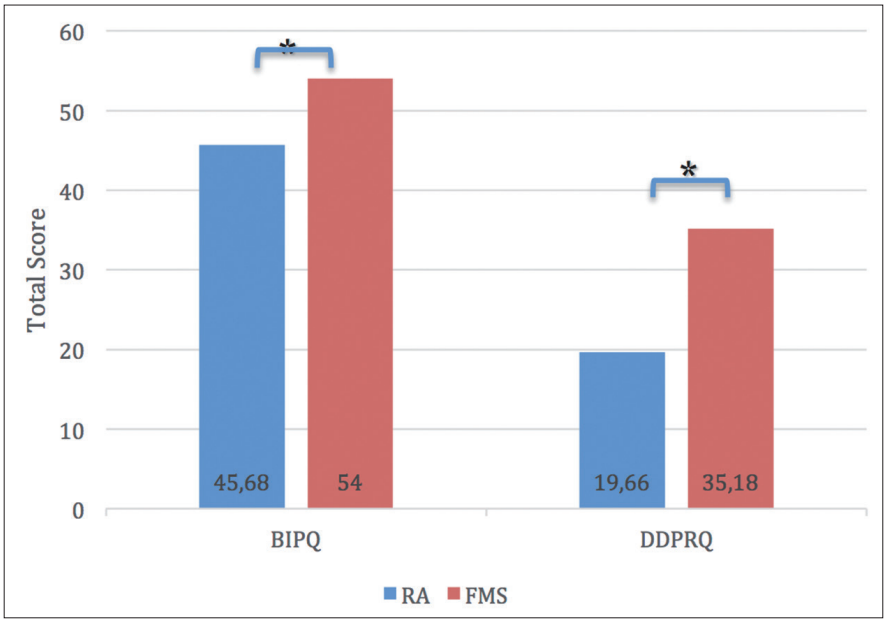

Fig. 1. Differences in physician's illness perception and doctor-patient relationship for FM and RA patients.
*Significant difference. $p<0.00$. BIPQ: brief illness perception questionnaire; DDPQR: difficult doctor-patient relationship questionnaire.

Table III. Difficult Doctor Patient Relation Questionnaire (DDPRQ).

**DDPRQ Questions ranked 0-6 (r - reverse scale)	Considering fibromyalgia n=45 Mean (SD)	Considering rheumatoid arthritis n=45 Mean (SD)	*p*
How much are you looking forward to a fibromyalgia patient next visit? (r)	4.36 (1.54)	2.25 (1.51)	0.000
How "frustrating" you find a fibromyalgia patient?	4.07 (1.5)	1.84 (1.61)	0.000
How manipulative you find a fibromyalgia patient?	2.73 (1.51)	1.27 (1.06)	0.000
To what extent are you frustrated by fibromyalgia patient's vague complaints?	3.52 (1.75)	2.75 (1.72)	0.012
How self-distractive is fibromyalgia patient?	2.59 (1.83)	1.3 (1.09)	0.000
Do you find yourself secretly hoping a fibromyalgia patient will not return?	3.32 (1.96)	0.98 (1.47)	0.000
How at ease you feel with fibromyalgia patients? (r)	2.41 (1.68)	1.2 (1.32)	0.001
How time consuming is caring for a fibromyalgia patient?	4.68 (1.27)	3.82 (1.12)	0.001
How enthusiastic do you feel about caring about a fibromyalgia patient? (r)	4.66 (1.43)	2.61 (1.15)	0.000
How difficult is it to communicate with a fibromyalgia patient?	3.14 (1.76)	1.64 (1.48)	0.000

**Difficult Doctor Patient Relation Questionnaire was presented twice, once referring to fibromyalgia and once to rheumatoid arthritis patients. The questions above are written for one condition for easy reading, but represent the two versions we used.

cept FM patient as a dependent factor. The results showed a strong association between the two factors (η= 0.87), showing that the DDPRQ total score explains a great part of the variance in the physician's willingness to accept FM patients (η^2= 0.756).

The same analysis performed with B-IPQ as an independent factor showed a moderate association between the B-IPQ total score and willingness to accept FM patients (η= 0.654), so that physician's illness perception explains a small part of the variance in the willingness to accept FM patients (η^2= 0.428).

Factors associated to difficult encounters with FM patients

We dichotomised physicians' responses on the DDPRQ for FM patients into two groups: difficult relationship (total score above 30) and non-difficult relationship, and checked for correlation with empathy, burnout and vigour feelings. We found a significantly higher JSPE total score in the group of physicians with non-difficult relationship [91.31 (7.65), n=13] than in the difficult relationship group [84.53 (7.38], n=30) [p<0.013], indicating that physicians with a higher degree of empathy experienced less difficulty with FMS patients (Fig. 2).

No significant differences were found between the two groups in terms of burnout feeling (p<0.15) or vigour feeling (p<0.767).

Correlation between physician's illness perception and difficult doctor-patient relationship with FM patients

Pearson correlation analysis yield significant positive correlation between BIPQ total score and DDPRQ total score (r=0.42, p<0.004). The more severe the illness perception, the more difficult the relationship with the patient. Specifically, a significant correlation was found between FM-DDPRQ total score and BIPQ question 6 - patient's concern about the illness [r=0.324, p<0.034)] and question 8 – patient's emotional response [r=0.321, p<0.036)].

These results indicate the negative impact of emotional aspects of FM on physicians.

Table IV. Willingness to accept patients with FM.

	n	%
Does not want to accept FM patients	**18**	**47**
Reason for rejection (FM)		
It is better to consult a specialist in FM	5	27.8
FM is a psychiatric disorder	2	11.1
It takes a lot of time to treat patients with FM	1	5.6
I am not sure about the treatment	3	16.7
I have doubt about the illness concept	2	11.1
This is not my specialty	2	11.1
Other	3	16.7

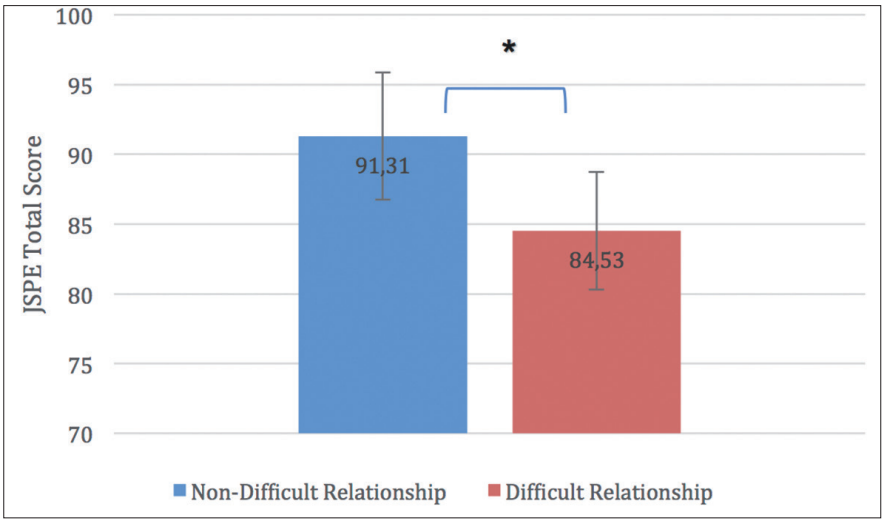

Fig. 2. Physician's empathy and difficult doctor-patient relationship with FM patients.
*Significant difference.
p<0.05. JSPE: Jefferson scale of physician empathy.

Discussion

In the current study, only 53% of rheumatologists stated they were willing to accept FM patients, whereas 98% of physicians were willing to accept RA patients.

Physicians considered FM as a significantly more severe condition than RA, with differences found across most aspects of the illness perception, mainly due to lack of effective treatment, lack of illness -understanding and a high degree of concern and emotional response among FM patients. Doctor-patient relationship was also perceived to be much more difficult with FM patients than with RA patients, in all aspects, and was correlated with the perceived severity of disease. The more severe the rheumatologist considered the disease, the more difficult the relationship.

These results are in line with a previous study among Japanese physicians that revealed the same high score of DDPRQ (18), indicating that the degree of frustration experienced by physicians when treating FM patients is probably trans-cultural. Patient's concerns and emotional responses were the most significant factors contributing to rheumatologist's feelings of difficult encounter when facing an FM patient, highlighting how difficult it is for physicians to deal with patient's emotional demands. This issue was previously raised in an anthropological study of rheumatologists stating that they were reluctant to see FM patients because of their special emotional needs, and due to the lack of training on the part of rheumatologists regarding ways to deal with emotional problems. (19).

Finally, this perceived difficult relationship with FM patients contributes greatly to the willingness of accepting patients while the illness perception has less impact.

In our study, we also found a signifi-

cant correlation between a higher score of empathy and a less difficult doctor-patient relationship. Empathy has cognitive, affective and behavioural dimensions, including the ability to understand the patient's experience, to feel "emotional resonance" with him, and be able to communicate this understanding. It also encompasses respect and a non-judgmental approach towards the patient (20). This essential medical skill is particularly of value in the field of chronic pain: when treatment options are scarce, the empathic process itself has therapeutic benefit, allowing the patient to feel understood and recognised, and receiving validation for his condition. This process also benefits physicians, as higher empathy capabilities enable a better containment of the patient's medical and emotional demands, leading to a better, less difficult encounter experience, as seen in our study (21).

Causal attributions of disease are an important factor influencing illness perception and doctor-patient relationship. In this study, almost all physicians attribute FM to internal/psychological factors, while RA was mostly attributed to environmental factors. When no clear pathogenic factors are known, and the disease is not "visible", physicians may tend to blame and stigmatise patients for their disease, which in turn limits their empathic abilities. Seeing patients who are blamed for their illness may remind the physician of his or her own vulnerability (22), especially when facing a condition whose symptomatic visibility is low and can blur the clear distinction between the sick and the healthy.

In this regard, Homma *et al*. have demonstrated a decrease in physician's resistance to accept FM patients when they consider external biomedical risk factors as causes of FM (18). In our study, no correlation was found between causal attributes and willingness to accept FM patients, but only 75% of the physicians filled the causal attribute part in B-IPQ questionnaire (Question 9), which could affect Chi Square test results, and may also emphasise the lack of understanding of FM.

Pain visibility may also play a role in caregivers' behaviours. In a study of 42 physicians and nurses that evaluated attitudes towards chronic pain patients, patient-centered care and empathetic behaviours were significantly higher for patients who had visible signs of pain (RA and chronic regional pain syndrome) than for those who had no visible signs such as FM and Ehlers-Danlos patients (23).

Enhancing emotional competencies of healthcare providers may help changing illness perception of FM and lead to a better encounter experience with FM patients. Such changes will not only affect treatment outcomes of patients, but may also diminish feelings of burnout, improving quality of life for physicians and patients alike.

There are some limitations to this study. First, the relatively small number of participants obviously constitutes a limitation; however, the study sample nonetheless included a significant percentage of the relatively small Israeli rheumatologic community. Another bias may be caused by the tendency of rheumatologists holding a relatively strong opinion (either "in favour" or "against" caring for FM patients) to be more keen on participating and filling out the study questionnaires, while those with a less clear opinion may be more reluctant to comply.

Conclusion

FM patients were perceived as more difficult than RA patients, with a high level of concern and emotional response and a lack of control on their disease. A high proportion of physicians were reluctant to accept them because they feel emotional/psychological difficulties when faced with meeting and coping with these patients. Physician's empathy had a positive role on doctor-patient relationship. Improving illness understanding and providing coping skills to rheumatologists may improve the consultation experience for both doctors and patients when coping with chronic conditions such as FM.

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