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Research Paper

Illness perceptions and negative responses from medical professionals in patients with fibromyalgia: Association with patient satisfaction and number of hospital visits

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ABSTRACT

Objective: To examine whether illness perceptions among patients with fibromyalgia and negative responses from medical professionals correlate with their satisfaction with their physicians or with their number of hospital visits.

Methods: Questionnaires were sent by post to members of the Japan Fibromyalgia Support Association. Measures collected included, as independent variables, the Brief Illness Perception Questionnaire and the Illness Invalidation Inventory; and as outcomes, the Patient Satisfaction Consultation Questionnaire and the number of hospital visits.

Results: We analyzed data from 304 patients. Multiple logistic regressions showed that perception of poor treatment control and the experience of being discounted and misunderstood by medical professionals were strongly correlated with dissatisfaction with attending physicians. Patients who perceived poor treatment control visited the hospital fewer times, while patients who reported being discounted by medical professionals visited more times. Patients' negative emotions correlated neither with patient satisfaction nor with the number of hospital visits.

Conclusion: Treatment effectiveness and the respect accorded to patients were the key factors significantly correlated both with patient satisfaction and the number of hospital visits.

Practice implications: Physicians should not emphasize only patients' negative psychological status but also should convey a respectful attitude and help patients understand their current treatment is useful. © 2017 Elsevier B.V. All rights reserved.

1. Introduction

Fibromyalgia (FM) is a disorder of unknown origin characterized by widespread pain and a wide range of concomitant symptoms. FM is diagnosed using the 1990 diagnostic criteria established by the American College of Rheumatology [1], although there is controversy about the objectivity of these criteria [2]. This leeway for subjectivity in application and interpretation can lead to communication problems between patients with FM and their physicians. Physicians tend to doubt the legitimacy of the FM diagnosis and hence about their patients' experiences [3-5]. This characteristic difficulty in medically unexplained symptoms (MUS) is potentially an important factor influencing other variables. Thus, interpretation of the illness is an important factor because it can affect patient satisfaction and

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http://dx.doi.org/10.1016/j.pec.2017.08.014 0738-3991/© 2017 Elsevier B.V. All rights reserved. consultation behavior, such as hospital visits. At the same time, considering patients' negative experiences in clinical encounters is also important, especially in controversial diseases such as FM.

To understand patient interpretation of illness, the concept of illness perception is useful. The basis of this concept derives from Leventhal's Self-Regulation Model of Illness [6,7]. Affected individuals form cognitive and emotional representations of their illness, and these representations become the basis of subsequent coping behavior such as hospital consultation or self-evaluation. Both qualitative and quantitative scales to measure illness perception have been developed [8]. One of the most popular is the Illness Perception Questionnaire (IPQ) [9]. The original version of the IPQ comprised five components that measure cognitive representations people form when facing health threats: "illness identity" (the label the patient uses to describe the illness); "consequences" (the expected effects or outcomes of the illness); "timeline" (how long the patient believes the illness will last); "cure or control" (the extent the patient believes that they can recover from or control the illness); and "cause" (personal ideas

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about the cause of the illness). Subsequently, an extended version (IPQ-R) [10] was developed, which adds three more dimensions (cyclical timeline, illness coherence, and emotional representation).

Using the IPQ, studies have examined the illness perceptions among patients with various medical conditions [11]. For patients with FM, there are some descriptive studies on illness perception [12–16]. Their common findings were: patients with FM perceive their illness as chronic and persistent, having a substantial effect on their lives, and caused by stress or an abnormal immune system.

Illness perception among patients with FM appears correlated with outcomes such as physical status and symptoms or quality of life [13,15,16], and is different between cultures [17]. A few studies using the IPQ examine the relationship between illness perception and patient satisfaction [18] or medical cost [19]. Studies by Frostholm et al. surveyed patients with MUS who visited primary care providers [20,21]. They found that illness perception correlated with patients' satisfaction with consultation. In particular, "uncertainty" (patient not knowing what is wrong) and the "emotional representations" (the symptoms making the patient feel worried, depressed, helpless, afraid, hopeless) predicted their dissatisfaction. They concluded that patients' negative interpretation of the illness has a stronger effect on their dissatisfaction with consultation than their general mental stress [20]. They also investigated the correlation between illness perception and medical usage cost [21]. Their results indicated that patients who attributed the cause of their illness to psychosocial factors, stress, or lifestyle indicated a higher past usage of medical resources. They also reported that the factors that correlated with higher medical usage were: number of reported symptoms, anxiety about the illness, recognition of a long disease course, impact on life, and emotional representation. Another survey in eight countries [22], although it did not measure illness perception, reported that the factors correlated with FM patients' satisfaction were: number of recognized symptoms, pain severity, and number of treatments taken and doctors seen before

Negative attitudes in the social environment is another important factor. The attitudes of physicians in particular impair patients' dignity [23] and when sufficiently serious, lead some FM patients to attempt suicide [24]. Patients experience rejection, disbelief, and a lack of understanding from other people, which is typical in invisible diseases such as FM. [25] named this experience "invalidation". Using a standardized scale of invalidation, recent studies have shown that invalidation was negatively correlated with QOL [26] and physical status [27]. Invalidation can also lead to strong dissatisfaction with medical professionals, which could result in "doctor shopping" behavior [28] to find good doctors and effective treatment. Consequently, the physician–patient relationship is undermined and the consumption of medical resources is increased at the societal level.

From these empirical study results, we predict that illness perceptions or negative responses from medical professionals would correlate with satisfaction in consultation or with frequency of hospital visits for FM. However, no such study has yet been conducted. Therefore, the purpose of this explanatory study was to show whether illness perceptions and invalidation from medical professionals in patients with FM correlate with their satisfaction with their physicians or their number of hospital visits.

2. Methods

2.1. Participants

The participants of this study were members of the Japanese Fibromyalgia Support Association (JFSA). JSFA staff randomly

selected patients over 20 years old from a list of 1300 JFSA members (Dec. 2012). The first author (M.H.) generated random numbers using spreadsheet software, and the JSFA selected patients who had a corresponding membership number.

2.2. Survey procedures

A preliminary survey targeting 100 randomly selected members of the JFSA from the aforementioned list was conducted in December 2011. This enabled assessment of the response rate and of the validity and credibility of the measurements, which had been translated into Japanese.

The main survey was conducted in March 2012. We mailed survey questionnaires to 500 patients randomly selected from the aforementioned list. Three hundred and sixty-seven completed questionnaires were returned for a response rate of 72.6%. Fifty-nine questionnaires were then excluded owing to missing patient demographics; the data of 304 participants were included for analysis. All questionnaires were returned anonymously so that we could not identify any individual patients. This study was approved by the medical ethics committee at The University of Tokyo Hospital.

2.3. Measures

The questionnaire was written in Japanese. The measures used in the questionnaires (BIPQ, IPQ-R, 3*I and PSCQ-7) were originally written in a foreign language, and we followed the process recommended for translating patient-reported outcomes to assure language validity [29]. We first created a sample of the questionnaire and distributed it to 100 randomly selected preliminary patients to gain feedback.

2.3.1. Illness perceptions

We used the Brief Illness Perception Questionnaire (BIPQ) to evaluate illness perceptions [30]. This is the short version of the IPQ [9] and the IPQ-R [10], publically available on the University of Bergen website [31]. Items (see Table 3) are rated using a 0 to 10-point response scale; a higher score indicates recognition of the illness as more threatening. For instance, for the question "How much does your illness affect your life?", respondents choose 0 (no effect at all) to 10 (severely affects my life). The scale comprises eight dimensions, which contain one question each: Consequences, Timeline, Personal control, Treatment control, Identity, Concern, Coherence, and Emotional response. "Concern" and "Emotional response" assess emotional representations of the illness, and "Coherence" assesses comprehension of the illness, while other five items assess cognitive illness representations. Each BIPQ item assesses one dimension of illness perception.

2.3.2. Causal attribution

Causal attribution is one part of the Illness Perception Questionnaire. Based on the feedback from patients that the free description style of the BIPQ version made it difficult to answer, we employed the IPQ-R version for chronic pain patients [10], which proved easier to answer. In the IPQ-R, a list of 18 possible causes of FM was presented (see Table 3). Participants were asked to rate each causal item on a 5-point scale from "strongly disagree" to "strongly agree." Participants rated the extent to which they considered each item to be a possible cause of FM irrespective of textbook descriptions or general information. Based on previous studies [10,20,21], we performed a principal components factor analysis to create subgroups of the 18 causal items. Varimax rotation produced five subscales: Patient's internal/psychological factors, Biomedical risk factors, Stress, Lifestyle factors, and

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