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Medication and the patient–doctor relationship: a qualitative study with patients suffering from fibromyalgia

Christine Durif-Bruckert PhD,* Pauline Roux PhD† and Hugues Rousset PhD‡

*Associate Professor, †PhD, Social Psychology Research Group, EA 4163, Psychology Department, University of Lyon (Lyon 2), Bron, ‡Professor Emeritus, Lyon – Internal Medicine, Claude Bernard University, University Hospital of Lyon South, Lyon, France

Correspondence
Christine Durif-Bruckert, PhD
Associate Professor
Social Psychology Research Group, EA 4163, (GRePS)
University of Lyon (Lyon 2)
5 avenue Pierre Mendès France
69500, Bron
France
E-mail: christine.durif@univ-lyon2.fr

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Abstract

Background Fibromyalgia is characterized by a diffuse and predominantly axial and chronic pain, for which there is no explicit rationale for treatment options.

Objective This qualitative study aims to understand the medication experience of patients with fibromyalgia and their relationship with the doctors derived from treatment negotiation.

Design A qualitative approach was used, based on interviews with patients.

Setting and participants Semi-structured interviews were held in a public hospital, with 35 patients diagnosed with fibromyalgia. Qualitative content analysis was performed.

Results The first axis is centred on the unsuccessful quest for an effective treatment for pain and the feeling of dismissal of patients, who are in search of validation and recognition. The second part of the accounts explains the medication adjustments and the search for collaboration. Developing a model of partnership with the doctor enables the patients to shape their own illness, through the medication.

Discussion It is by mediating their relationship with medication that patients gain access to this state of co-expertise and that they put sense into the collaboration they develop with their doctors. Through this collaboration, useful drugs are identified and adjusted to treat the pain.

Introduction

Fibromyalgia is characterized by a general, chronic pain and fatigue; these are symptoms that are always associated with others, such as sleeping disorders and cognitive dysfunctions.[1–3] Pain is poorly perceived externally: no instruments can measure or show it through analyses, X-rays or scans.[3] The diagnosis of fibromyalgia is thus uncertain, for medical experts as much as for the patients. Because fibromyalgia is diagnosed by exclusion, many physicians remain sceptical of the diagnosis and of the real nature of pain and complaints. Many studies have focused on the doubt and on the distress of patients who are not benefiting from medical assistance, as well as on their search for legitimacy and on their resistance to psychological explanations of pain and suffering.[4–7] Extensive researches have also been done on 'patient nomadism' and stigmatisation, as well as on the ambiguities and difficulties involved in doctor/patient interaction.[8–16]

Patients take a substantial amount of medication daily: antidepressants, anti-inflammatory medication, painkillers, sedatives, etc. Since the establishment of the American College of Rheumatology (ACR) criteria in 1990, the treatment protocol for fibromyalgia has been a symptomatic approach. Patients are frequently given a prescription medication for each of their numerous symptoms, and treatment outcomes are generally poor.[17] There are new medicines used for fibromyalgia as Lyrica or Pregabalin, whose effectiveness is questioned.[18] The definition of a significant response to the treatment is not consensual.[19] Fibromyalgia requires the establishment of a multimodal and multidisciplinary therapy.[20]

The drug's approval gives credibility to the notion that fibromyalgia is a disease with discrete biological causes, rather than a collection of disparate symptoms that are poorly managed with a muddle of existing medications. Méadel and Akrich have shown that medication is a way for patients who have been diagnosed with fibromyalgia to construct their illness.[21] The subjective experience of illness is essentially structured around the patient's relationship with medication. Furthermore, Méadel and Akrich argue that it is the only hold that patients with fibromyalgia have on their illness. Regarding the pharmaceutical firms and their influence on patient's experiences, Barker showed how an officially approved prescription medication for fibromyalgia lends support to the biomedical existence of the condition itself.[22] Barker refers to this as pharmaceutical determinism and argues that it represents an important new phase in the proliferation of contested illness diagnoses.

Prescription is a doctor's legitimate tool, and for the patient, acquiring a medical understanding of medication is experienced as a way of sharing sensitivity and emotional and social skills, as well as biomedical skills. Finally, medication, which in the case of fibromyalgia is very changeable with no explicit target,* tends to be a space onto which the patients project the unexplained, invisible, and unknown dimensions of their illness, where the doctor's doubts and uncertainties and the patient's convictions and discouragement meet.

This qualitative study aimed to understand the experience of medication of patients with fibromyalgia and their relationship with the doctors derived from treatment negotiation, in the absence of an explicit rationale for treatment options.

The aim of the present study is to understand the medication experience of patients with fibromyalgia and their relationship with the doctors derived from treatment negotiation, as described at the interface of lay expertise and medical expertise, between embodied experiences and biomedical and technical references.[21] We refer to the anthropological and psychosocial perspectives that integrate the patient's sociocultural system into the model analysis of his/her participation in healthcare. More precisely, we refer to the concepts of lay knowledge and representations elaborated by patients and negotiated within the therapeutic relationship.[23,24] The management of treatment in this context provides a space not only for medical expertise to impose itself, but also for confrontation between explanatory models and modes of perception of the disease, which diverge and requires negotiations, compromises and agreements between the patient and his/her physician.[23–25]

Method

A qualitative approach was adopted. Information on patients' experiences of medicines

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*These are medicines used both in rheumatology and in psychiatry, as well as in pain management centres.

was collected using semi-structured interviews with patients who have been diagnosed with fibromyalgia.

Sample and procedures

This research took place in a university hospital in France, in 2008, in two units where patients diagnosed with fibromyalgia were treated: the internal medicine department and the rheumatology department. Doctors in these departments (an internist and a rheumatologist) offered their patients the possibility to participate in the research project. Ethical approval was obtained from the hospital institution. Patients diagnosed with fibromyalgia were systematically invited to participate. All solicited patients, in this medical context, accepted to participate in the study. This 100% level of acceptation may be due to the fact that they were invited to participate by medical doctors who are familiar and influential figures for patients. On the other hand, patients may have perceived the interview as an opportunity to freely express their disease experience, as the interviewer did not express any specific expectation about information given by the patient. Patients gave their verbal agreement to the doctor, who then transmitted their contacts to the researchers. Patients were thus informed twice, by their doctor first and the researcher later. On both occasions, they were given the possibility to withdraw their agreement to participation. Patients who accepted to participate gave verbal agreement to researchers. A total of 35 patients participated: 32 women and three men (Table 1). The average age of the interviewed patients was 49. The youngest participant was 25 and the oldest one was 70. We did not limit the sample to a specific range of age. All interviewed patients were diagnosed with fibromyalgia, on average about 3 years before the interviews. A minority of them had only been diagnosed a short time before meeting with us. One patient was diagnosed 15 years before. Every patient, even those who had just been diagnosed, had a past experience of symptoms (of 5 years on average). The

Table 1 Patients' characteristics

Informants	Gender	Age	Length of time since the onset of the symptoms	Length of time since the FM diagnosis
1	Woman	45	4 and a half years	4 years
2	Woman	51	1 and a half years	1 and a half years
3	Woman	55	15 months	8 months
4	Woman	46	8 years	7 years
5	Woman	46	2 years	2 years
6	Woman	50	1 and a half years	1 year
7	Woman	51	8 years	5 years
8	Woman	65	2 years	1 and a half years
9	Woman	38	3 years	1 month
10	Woman	65	30 years	15 years
11	Woman	52	2 years	2 years
12	Woman	27	4 years	3 years
13	Woman	35	4 years	1 and a half years
14	Woman	39	5 years	3 years
15	Woman	54	8 years	2 years
16	Woman	43	2 years	1 and a half years
17	Woman	28	2 years	1 and a half years
18	Woman	65	20 years	10 years
19	Woman	70	7 years	3 years
20	Woman	68	4 years	2 and a half years
21	Woman	25	3 and a half years	2 years
22	Woman	43	4 years	1 and a half years
23	Woman	42	2 years	1 day
24	Woman	31	2 years	2 years
25	Woman	38	1 year	6 months
26	Woman	61	6 months	2 days
27	Woman	62	5 years	1 day
28	Man	42	8 years	7 years
29	Man	66	8 years	6 years
30	Man	58	8 years	3 years
31	Woman	49	1 year	6 months
32	Woman	57	3 years	1 year
33	Woman	56	4 years	2 months
34	Woman	43	2 years	1 week
35	Woman	53	1 and a half years	2 days

criteria for diagnosis are those elaborated by the ACR in 1990.[1] The comorbidities reported by patients had variable forms (irritable bowel syndrome, depressive disorders, thyroid disorders). Data collection ended when we obtained data saturation, meaning when no new data appeared during interviews.[26]

At the beginning of every interview, we detailed the study to participating patients and answered every question they had. The semi-structured interview schedule consisted of open-ended questions exploring patient's experience of fibromyalgia and of its treatment. Respondents were invited to describe the chain of events characterizing their experience of the disease and that took place at an individual, social, professional level and during their exchanges with doctors.

The initial instruction invited patients to speak about their path since the beginning of their health issues. We did not ask direct questions about the diagnosis of fibromyalgia and its treatment, to give patients the possibility to discuss these themes spontaneously. The researchers participated then in the unfolding of the interviews by sustaining the spontaneous narration of patients, which principally focused on their experience of pain and its physical manifestations, on the health-care relation and on their perception of the treatments. Interviews were not limited in time, and were concluded when information saturation was reached or when the participant said that he/she had nothing to add. They lasted one hour on average.

They took place in the concerned departments, in a medical consultation room or in an office of the secretariat. Hospitalised patients were visited in their room.

Given the medical context, we specified to the patients that we were social science researchers with no medical background. We insisted on the independence of our research from the doctors and on the fact that the collected data would not be shared with them.

Data analysis

Both authors of the present article have carried out interviews and analysed the contents. All interviews were digitally recorded and transcribed. They were analysed using a qualitative content analysis.[27] Categories and subcategories were defined and organized in tables while reading the interviews. Codification of categories and subcategories was then further refined, taking into account the frequency of emerging elements within each interview. A transversal analysis of the interviews was then conducted to identify the main argumentation axes developed by the interviewees.

Interviews were conducted in French. Parts where medication was discussed were selected for quotation, to illustrate the range of patients' experiences, and translated with the help of an English expert in human and social sciences.

Results

Two argumentation axes organising the discourse about the treatment emerge from the corpus, consisting of interviews with 32 women and 3 men.[28]

Unsuccessful quest for an effective treatment for pain and patient's feeling of dismissal

The first axis that emerged during the interviews related to the uncertainty of the treatment and its consequences on the patient-physician relationship. It resulted in a real story of twists and turns, drawing out over time, seeking a relieving treatment as much as the recognition of the biological reality of their disease and the seriousness of its symptoms.

> The pain and fatigue got worse, and from there I guess I can say I began the obstacle course, as I always say, where I started seeing specialists who offered a whole lot of diagnoses: tendinitis, sciatic,... Even really weird ones were considered – Prof. P. thought I had a back sprain. I tried all sorts of treatments: mesotherapy, anti-inflammatory drugs, homeopathy, acupuncture (Informant 7).

Narrating this never-ending path, characterized by multiple meetings with different physicians, patients reported their conversations with physicians about their prescriptions. This path is characterized by a strong feeling of disappointment, rejection and incompetence (very often involving shame and humiliation), regardless of the status of the doctor the patient has consulted, general practitioners or well-known specialists. Patients spoke about consultations during which physicians shrugged off the diagnosis of fibromyalgia and its treatment. They described the ways doctors can dismiss the diagnosis and its treatment, through three main types of argument concerning medication.

A first argument relates to doctors' lack of knowledge about this diagnosis: the doctor does not know the illness or the ways of treating it. Fibromyalgia is then reframed as a closed entity, unrecognisable in its compact form, from which it is inconceivable to draw a few explanatory threads. Patients recalled episodes where the doctors they successively consulted confessed their lack of knowledge and even their powerlessness faced with this diagnosis.

> Eventually, I found myself unable to stand Laroxyl or antalgics anymore so I went to see my regular practitioner who said to me: "what do you want me to do?" (Informant 1).

The second argument had to do with doctors questioning the symptoms described, thus making it difficult for the patient to benefit from medical aid. Patients felt suspected of being 'imaginary patients' when doctors gave them prescriptions for treatments that were not explicitly recognized by the medical world.

> So, he explained to me that there isn't a valid treatment, yet, for fibromyalgia, and that the only thing he was going to prescribe me was psychotherapy and balneotherapy. So then, it's true, I left happy that there was a name for my illness as until then they seemed to be telling me that it was in my head. But at the same time I was very uncomfortable, not upset but hurt that he announced it like that and prescribed me psychotherapy and balneotherapy; it made me think that he wasn't taking me seriously (Informant 1).

Finally, the third argument emphasized the risks linked to these confused and uncontrolled trajectories through medication. Unlike the second type, here the patients are the ones who are sceptical concerning the doctors and their prescriptions. Many drug assortments were questioned by the patients, namely because of their iatrogenic effects: giant hives, serious allergic reactions, 'heartburn', gastric ulcers, incapacitating muscular reactions and 'filling up the body' with abundant medication:

> 'We're walking chemists' (Informant 13).

> Sleeping disorders are also associated with fibromyalgia, so one could tell you 'take those sleeping pills'. But they are not a panacea; we know that they can cause addiction. And afterwards, one isn't enough anymore, you need to take two, three. So I didn't take any. And speaking about analgesics! I could have been stoned with morphine! He gave it to me: Now I have a whole medicine cupboard filled with morphine. I could poison the whole city, but I don't see the point of being a zombie. You can't go out, you can't walk… (Informant 33).

In summary, patients argue the uncertainty of the treatment on the basis of three aspects: (i) physicians do not know the medications, (ii) they do not recognize fibromyalgia as a legitimate illness and (iii) prescriptions are perceived by patients as being potentially harmful and risky as they are too uncertain. Facing these different disappointments, which were a recurrent theme during the interviews, patients ask themselves what role to adopt to defend their disease and, additionally, to 'force' their way to medical recognition, to capture the interest of a physician.

Seeking partnership and medication adjustment

A second axis shows how, during the process of trying to find the right medication, patients adopt different strategies to establish themselves as partners and actors in managing the illness and, essentially, the pain. Patients adopt different strategies: they build a repertory of medicines the effects of which on pain have been tested and validated, they negotiate the prescription of a new medicine with physicians and finally they create a partnership with the physician for the management of the illness.

The patients described themselves as being particularly attentive to the functioning and effects of the different medicines:

> And for it to work you need to go up to 200 mg. Because I've done tests! (laughs) I've done a test last time he reduced the dosage. I'd gone up to 200. I asked him if it wouldn't have repercussions in the future so he put me down to 150 and I took it for 1 day, I stopped, I took it again for 1 day, and it wasn't better so I have to take it every day if I want to live a normal life, without suffering (Informant 16).

Likewise, they monitor the level of pain, evaluated from moderate to acute, and at the same time suggest ways of readjusting the dosages and composing various combinations of medications:

> So it's true that Laroxyl is great for pain. Lyrica is also a new molecule. I haven't been taking it for very long. I take 100 mg in the morning, 150 in the evening so it's still a lot and so when I'm in intense pain a Bi-profenid, an anti-inflammatory, or simply some Daffalgan can easily relieve me for a while, get me out of an acute phase (Informant 8).

Thus, they identify the mechanisms that can explain why and under which circumstances the respective medicines work: specific molecules have an impact on specific pain. Each patient follows the contours of the pain, comes to terms with them, anticipates surprises, detects areas of resistance. In this way, they discover its specificities, its consequences, the acceptable thresholds, the limits of what is bearable. This work of shared medication serves crucial purposes for appropriating and overcoming the different forms of pain. It helps to construct a coherent map of the pain, and its atypical and therefore strange character that contributes to organize representations of a new body shaped by fibromyalgia. The medicinal trials described extensively in the patients' accounts show partnership following the pattern of trial/assessing the benefits and outcomes/validating or ruling out/co-adjusting.

In the negotiation and collaboration with their physician, patients find the right compromise between beneficial effects and perceived disadvantages. And even if they voluntarily submit themselves to this construction, which represents for them a forced but desirable entry into the medical domain, some interviewees admitted allowing themselves a few personal decisions:

> I lowered the dose, I'd taken too much of it (Informant 30).

Through this process, they efficiently interiorize the breathing space granted to them:

> He said to me: 'listen, you try this and you let me know' (Informant 2).

They also explained how they managed to arouse and stimulate the doctor's interest, even to get ahead of him and to lead him:

> Doctors don't always explain well, because they don't know so much. It's up to you to ask the right questions [...] It's difficult for them, because they don't know what to give you (Informant 3).

Many of them have gone so far as to establish priority of their own expertise over the doctor's, who they consider ignorant:

> Today I get the impression that it's more me teaching them something than the other way round. It's quite simple, I feel like I'm the one writing the prescriptions (Informant 28).

Patients adopt the role of researcher and informer of their doctor by identifying, targeting and assessing the thresholds of pain: diaries that map out the level of intensity of the pain throughout the day; notebooks that record what proves to be effective or toxic and even graphs that they patiently realized.

> I built an Excel spread sheet with several levels of pain: green, orange, red, black. So green was very bearable, orange a bit less with numerous pains, red I couldn't leave home but I could still get up and walk around my house, and black I was totally paralysed so I couldn't leave home but I couldn't even move around either (Informant 28).

The success of the partnership – as stressed by the narrators – depends on two conditions.

On the one hand, patients shall not try to take their physicians' place.

> I discussed it with my GP, we'd discuss it regularly and we'd see where my illness was at. I'd tell her I'd read something and she paid good attention to me, we'd try; the last anti-depressor I tried was with her (Informant 14).

On the other hand, the patients interviewed insisted that this partnership can only work if doctors agree to share their expertise:

> He's a good doctor because he's willing to try out things, he's willing to give it a go (Informant 14).

'Willing to give it a go' and to take into account the dimensions of pain that he cannot access, precisely because they stem from the patient's perception: the surprising trajectories, the insidious rhythms, the fluctuations and variables that trigger this perception, all give the doctor other clues. He/she can only discover these through the patient.

Discussion

We would like to discuss these two argumentation axes and specifically patients' strategies to deal with their dissatisfaction with the treatments against pain.

This first argumentation axis, which provides evidence of patients' dissatisfaction and uncertainty, is also documented by past studies, such as the one carried out by Briones-Vozmediano *et al.* [29], in Spain: patients, as well as professionals, expressed dissatisfaction with the delay in reaching a diagnosis and obtaining effective treatment. In the same register, in Canadian context, Hayes *et al.* [30] show that general practitioners reported insufficient knowledge and skill in diagnosing fibromyalgia, with not all believing it to be a diagnosable condition. This study also reports feeling of helplessness experienced by physicians confronted to fibromyalgia. In this context of dissatisfaction and questioning of the mutual trust, our study shows that the pain is amplified, as we could observe in the patients' description of the overinvestment of pain and physical hyper-sensibility. The search for treatment is then concomitant to the search for a medication relationship based on mutual trust and goodwill. As shown by van der Geest, Whyte and Hardon, a prescription shows 'the interest of the physician and the right to access therapeutics'.[31]

The second identified argumentation axis works, through the medicine, as a framework for partnership with the physician and for formatting the disease. Through their relation to the medicine, patients can access a status of co-expertise.

Medicines as mediation and as a definition of a partnership based on separate roles for the patient and the physician

The collaboration that develops between patients and doctors only acquires meaning through the medication that collaboration serves to define.

The medication is a tool, a sort of ingredient which belongs to both actors, and which becomes, between them, a sort of active substance that produces relations, actions and representations. On the one hand, the mechanisms through which the medication acquires an active force are underpinned by what unifies the molecular materiality of medicines and their social and emotional dimensions: 'on its cold and neutral substance, the doctor's energy and the patient's trust condense together'.[†] [32] On the other hand, the idea of the medication as a central object between the doctor and the patient signifies a change in the usual representations of the therapeutic scheme and the doctor–patient relationship. It works as a transitional and transactional space, and as the object of the actors' projections. Our results show that it is precisely because the medication presents itself and acts as an echo between themselves and the doctor that patients gain

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[†] French citation: 'Sur sa substance neutre et froide se condensent et l'énergie du médecin et la confiance du malade' (p. 16).[32]

access to a state of co-expertise. This is precisely what the patients understand as a sign of effectiveness and a way of comprehending and appropriating the illness. In this context, medication is the guarantee of this common space that is built on a variety of negotiations, divergences and adjustments.

The alliances thus organized between doctor and patient to develop this space of treatment and make it operational support the co-construction and finalization of medication. The framework of medication, the diagnostic process and the therapeutic act co-determine one another. But medication also allows for new ways of representing the sick body.

Negotiating and appropriating knowledge

Medication acts as a guiding principle for the organization of the different forms of pain and the representation of fibromyalgia afflicted body. The interviews thus recall a series of negotiations and compromises between the legitimacy of medical knowledge (prescriptions, expertise on biochemical effects, etc.) and the sensitive understanding of how medicines work. The significance of these compromises is emphasized through the discourse of the patient taking on an active role, as a fully-fledged actor in the process of research and treatment – which the patients interviewed saw as inseparable. The patients take over the tools that serve to emphasize the doctors' own competences, and build their own grids and categories of representation to provide the doctors with a schema of their sick bodies, re-adapting terms and logic from the medical discourse.

The patient adopts a private language that tends to give substance, movement and structure to the body: through their accounts, they create sensitive spaces for the use and effects of medication. The medication makes its way through the body, brings back functions that had been blocked, and locates the malfunctioning areas and mechanisms. This shared medication plays an essential role for pain appropriation and control. It contributes to construct a coherent view of pain and to organize a new representation of a body shaped by fibromyalgia.

As Fainzang puts it, the patients' behaviour and discourse in relation to medication reveal their ways of understanding their bodies, of analysing the illness and of relating to the prescribing doctors.[33] In the context of fibromyalgia, these processes have been described and analysed in an article about the ways in which patients, diagnosed with fibromyalgia, categorize different medications on the basis of their route and mode of action in the organism and of their effects on painful symptoms.[34] Based more precisely on the approaches to common/ordinary knowledge about the body and the physiological functions, this article analyse how fibromyalgia is constructed on the basis of lay-knowledge concerning physiological functioning, as described by past research by Durif-Bruckert.[23,24]

In this process, the doctor is portrayed as a technician who not only provides support for but also embodies 'the patient's illness',[‡] according to his/her own way of giving sense to things and through specialised vocabulary.

Acquiring control over disease

These mechanisms underlying the therapeutic project provide new understandings of the doctor/patient relationship. First, they trigger shifts in the links and content of what is transmitted between the prescriber and the receiver: medication, as well as information, knowledge and values. The patient learns to control the effects of medication, while the doctor learns to step back from his/her own expertise and to depend on the patient, at least partly.

This control of medication adds to the strategies described by patients in other studies, as in the work of Åsbring and Närvänen: the patients try to gain control over their situation by acquiring knowledge about their illness.[36] Patients also describe various power strategies

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[‡] The expression 'la maladie du malade' ('the patient's illness') was coined by pain surgeon Leriche, and used as a concept by Canguilhem[35].

they use in their interaction with the caregivers to take command of their situation, namely exiting, non-compliance, confrontation, persuasion/insistence, making demands and demonstrative distancing.

In studies dealing with patients with chronic unexplained pain, a disengagement from medical care has been observed.[37] In our study, patients with fibromyalgia describe how they enter into a form of collaboration with the doctors. Patients develop new forms of medication by using medicines as an intermediary space for action between experienced signs of illness (pains, spasms) and the medical system (relationship to doctors, redistribution of the patient/doctor roles), and as a way of understanding, explaining and mapping the illness.

Our results highlight how patients diagnosed with fibromyalgia use the interview to translate their experience concerning the medication. This is to be analysed as indissociable from the appropriation of the disease, within the partnership with the doctor and the medication. Recounting their experience, patients express both their distress and the feeling that they are participating; the one making the other possible. And in this domain of FM, and more generally of those illnesses which remain medically unexplained, patients understand how they could situate themselves in the health-care system by describing their experience of uncertainty and by questioning the lack of medical knowledge about their situation.[38] This is why the meaning of the illness is at the centre of the consideration physicians have for patient's competences and abilities to deal with the disease. Such a way of dealing with the diseases is re-created with the physician (with reference to his point of view and his authority) within the health-care system and complementarily to it.

This study has surfaced some issues that merit further consideration. Our analysis does not take into account variations linked to gender, age and socio-professional levels. Moreover, interviews were carried out at the hospital. Although patients were informed that their interviews would be confidential, we suppose that they were not entirely convinced, as interviews was made in the hospital environment.

Considering the discussed points of view, it is interesting to create guidelines for the employment of patients' expertise and analysis in the care and the treatment of their illness. In the field of medically unexplained illnesses, patients question the very limits of medical knowledge and seek to be counted in the healthcare system, and more precisely in the medication process. In this context, taking patients' representations into account constitutes a level, a tool for rehabilitation.[39,40] Making illness meaningful is crucial in taking the patient's competences into account and hence crucial to his/her capacity to confront the illness. These fundamental patient's competences must be reinstated to enable physicians to be more professionally effective. In this sense, Alamo, Moral and Pérula de Torres demonstrate that the patient-centred approach with patients suffering from benign chronic musculo-skeletal pain and fibromyalgia showed greater improvement in terms of psychological distress than in conventional approach.[41] It is important to explore how this expertise and analysis could be functional, in the case of medically unexplained illnesses involving pain (especially for fibromyalgia) for which the aetiology is unknown, the symptoms non-specific and treatments not standardized.

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