

A phenomenological study of fibromyalgia. Patient perspectives

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Objective – To describe the way in which the fibromyalgia patients understand the meaning of their illness.

Design – Qualitative, empirical phenomenological psychological method.

Setting – A collaborative transdisciplinary interview study of patients' described experiences of living with fibromyalgia. No therapeutic relationships existed between patients and researchers.

Subjects – Eighteen patients with fibromyalgia were interviewed. Ten of the 18 taped interviews were transcribed and analysed.

Main outcome measures – Patients' narratives, described experiences of living with fibromyalgia.

Results – The patients were intensively involved in efforts to get their self-images as ill persons confirmed. Their experience was that the disease started dramatically, with a variety of capriciously appearing

symptoms of unknown cause that gave rise to the suffering. The fibromyalgia patients seemed to develop strategies to cope with a precarious self-image and find ways to manage the thought of what the future would bring.

Conclusion – The meaning structures revealed in the patients' ways of describing their experiences of living with fibromyalgia seemed to be partially constituted by their efforts to stand forth as afflicted with a disease, which could be a way to help them to manage the demands that they placed upon themselves.

Key words: qualitative study, empirical phenomenological psychological method, meaning structure, fibromyalgia patients.

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Fibromyalgia is a syndrome characterised by generalised chronic muscular pain, pressure hyperalgesia, sleep disturbances, stiffness, fatigue and psychological distress (1). The aetiology is not known. It is more common among women and has been diagnosed in all age groups. The onset is most common from the age of 20–40 years. The prevalence is 2–4% (2). Boissevain and McCain (3) and Wall (4) found no convincing evidence that fibromyalgia is a well-defined disease entity. Henriksson (1) notes that qualitative aspects of the patient's perception of living with fibromyalgia are seldom studied. In general few studies deal with the issue of doctors' perception of illness as opposed to disease. Toombs (5) has made a phenomenological investigation of her own multiple sclerosis and demonstrated the presence in practice of two different conceptual worlds of doctors and patients, the former focussing on the disease aspect and the latter on the illness aspect of expressed ailment. Toombs's philosophical work deals with the kind of meaning where a relatively well-defined disease entity is thought to give rise to a sense of illness. The philosophical setting of our study includes the notion that human individuals' profound drive to remain in a world of meaning (5) may give rise to vaguely

appearing "diseases" conveniently named for instance fibromyalgia or chronic fatigue syndrome by doctors who, perhaps for meaning-connected reasons, perceive illnesses as diseases.

"Human illness is not only a physical condition but a symbolic one as well" (6). The main message in Barnlund's (6) paper on meaning is that an illness and even an organic disorder may be apprehended not so much as a bodily result, but rather as an expression – requiring a response – of an individual's efforts to symbolically come to terms with a threatening sense of fundamental human incoherence.

Judging from qualitative studies, e.g. Henriksson (1), and the literature review by Hilden (7), researchers and clinicians rely on the notion that the fibromyalgia patient *has* something, whose consequences are studied and subjected to managing efforts. When doctors' experiences of meeting patients with fibromyalgia were studied (8) it was found that the doctors hesitated to apply an action-repertoire that was unfamiliar to them. Another often-recurring feature was a feeling of frustration and a tendency to avoid close encounters with the patients (8). Whatever fibromyalgia is, it does not easily let itself be captured by biomedical theory. Perhaps it should not

be apprehended as a disease in a conventional sense of the word (8). The diagnosis sometimes seems to be regarded as a successful therapy in itself, a notion that Hilden (7) questions. Jacobsen (9) suggests that a doctor's aiming to identify a disease might increase the risk of "iatrogenic patient fixation".

Studies on patients' perceptions and coping strategies related to chronic pain and treatment in pain clinics are well represented in the research literature. In much phenomenological research the phenomenon studied is apprehended in advance as either a well-defined condition, e.g. blindness (10), a well-identified disease, e.g. rheumatoid arthritis (11), or a less distinctly recognised disease, e.g. chronic low back pain (12). We did not exclude the idea that fibromyalgia could be understood as a conceptual solution that symbiotically serves both the patients' efforts to manage a sense of threatening incoherence and the doctors' desire to come to terms with what otherwise would challenge their biomedical action-repertoire.

AIM

The aim of the study was to describe the way in which the fibromyalgia patients understand the meaning of their illness.

METHOD

An empirical phenomenological psychological method (8,13) was applied for interviewing fibromyalgia patients and analysing the taped and transcribed texts (13). The interviewer (OH), a GP, who knew none of the patients in advance, was invited to 4 monthly, local fibromyalgia patient group meetings and, thus, had the opportunity to become well-acquainted with the patients. The 48 patients present were asked to fill in a questionnaire on age, family, symptoms, duration of disease, treatment, time of diagnosis and by whom it was made. Judging from what was learnt during the 4 group meetings 20 of the 48 patients (19 women and 1 man) were considered to be those who best could provide us with a multitude of described experiences of living with fibromyalgia. Later they were invited by telephone to take part in the study. All but two accepted. This pre-analytic manoeuvre facilitated our data collection procedure and reduced the volume of texts to be analysed (14). The inclusion criteria were an ability to give a many-faceted account of what it was like to live with fibromyalgia, a preparedness to express a personal opinion of experiences of health care, of doctors, and a willingness to discuss other relevant issues. Further inclusion criteria were duration of illness, having been diagnosed according to certain

criteria (15), and other factors that comprised a rich spectrum of patients' varying notions and experiences of the illness.

The interviews lasted 30–50 min, took place in the patients' homes and were introduced by the request: "Please tell me a little bit about what is it like to live with fibromyalgia". The interviewees were encouraged to choose what experiences they themselves felt most anxious to describe. Thus, the interviewer took steps to comply with the principles of a phenomenological attitude (13) and genuine dialogue (16). The 18 tapes were listened to three times and 10 of the most nuanced, original, interpretable and exhaustive ones were transcribed to be analysed by the research group. The excluded tapes were found not to contribute qualitatively to the eliciting of the studied phenomenon, a legitimate exclusion in line with, for instance, Taylor and Bogdan (14). The collecting of interviews to be analysed was ended when the next interview just confirmed what had already been said (17). The 10 patients whose tapes were included had all been diagnosed by rheumatologists according to current diagnostic criteria (15).

In analysing the texts we followed Karlsson's (13) empirical phenomenological psychological method: 1) reading through each text in order to get a good grasp of its contents; 2) organising the text into separate meaning units; 3) transforming each meaning unit into the researchers' language; 4) synthesising the transformed meaning units into themes, each one with its separate meaning units, and 5) for the sake of comprehensibility finally presenting the themes together with significant quotations from the texts. The applied method is similar to Giorgi's (18), described by for instance Malterud (19).

RESULTS

The results of the analysis will be presented as themes characteristic of the patients' experiences of living with fibromyalgia (Roman numbers refer to the subjects listed in Table I).

Onset

The onset of fibromyalgia was experienced by the patients as temporally well-defined and connected with significant and unpredictable life events, "like a bolt of lightning" (IX). The illness was believed to originate from bodily disorders and other easily recognised events: "When driving my car I was hit from behind" (I). Connections between illness and significant life-events were pointed out: "It started just after I got my second child." (IX).

Table I. Gender, age, marital status and other relevant data in respect of patients whose interviews were included in the final analysis.

| Patient | Gender | Age (years) | Marital status | Number of children | Duration of illness (years) | Duration of diagnosis (years) | Occupation | Disability pension (%) |
|---------|--------|-------------|----------------|--------------------|-----------------------------|-------------------------------|-------------|------------------------|
| I | M | 49 | Married | 1 | 9 | 7 | Store man | 50 |
| II | F | 50 | Com.-law | 2 | 4 | 2 | Saleswoman | 50 |
| III | F | 40 | Single | 1 | 4 | 3 | Staff nurse | 50 |
| IV | F | 38 | Com.-law | 6 | 8 | 7 | Traveller | 50 |
| V | F | 50 | Single | 2 | 18 | 7 | Staff nurse | 75 |
| VI | F | 48 | Married | 2 | 14 | 5 | Saleswoman | 50 |
| VII | F | 55 | Married | 2 | 4 | 3 | Housewife | 100 |
| VIII | F | 32 | Married | 3 | 7 | 6 | Staff nurse | 50 |
| IX | F | 46 | Married | 3 | 6 | 3 | Nurse | 50 |
| X | F | 42 | Married | 1 | 6 | 5 | Secretary | 50 |

Unpredictable, invisible and incapacitating symptoms

If one experiences oneself as afflicted with an illness that appears capriciously, is invisible and makes one look wasted, then one's family and friends always have to be on guard and pay attention to one's present health status.

Unpredictable and capricious: "It's very annoying not to be able to plan anything" (II); "Sometimes I am very alert, sometimes I am totally exhausted; you never know which and when" (VI); "One day you feel like doing something. Then, all of a sudden, bang!...The illness is so fickle, so capricious" (IX). Invisible: As the effects of the experienced disease often could not be seen on the body surface, the patients perhaps tried to communicate their experiences by words and body language: "I can't even remember when I slept last" (VII). Incapacitating: "Sometimes I can't even unscrew the toothpaste tube" (X).

Search for confirmation as an ill person, i.e. as afflicted with a diagnosable disorder

Search for a diagnosis seemed to be important for the patients. However, the essence of fibromyalgia was not easily communicable: "Worst of all was the time before others understood that I really was ill" (I). Also, the diagnosis meant relief from the fear of a malignant disease: "It is a relief to know that one, anyway, doesn't have MS" (II). Sometimes the diagnosis was met with joy: "It was like winning the first prize..." (V). However there were drawbacks: "Once you've got a diagnosis it's more difficult to convince doctors that you also might be suffering from another illness" (VI).

The texts dealt with how the patients managed the feeling of not being believed: "They (the doctors) do not think that it hurts as much as one says" (IX). "If I'd had just one leg or one arm, how much easier wouldn't it have been?" (I).

The patients felt that they easily understood each other: "You always know that you can make yourself understood in the (fibromyalgia patient education) group". Healthy others were confronted with expressions of illness which were difficult to interpret: "Often neighbours and friends say: You don't seem to be ill, you are so active and alert. I can't believe it" (VI). "The only time they (the family members) understood me was when I'd gone through a big gynaecological operation. Then I could not do the dishes and cleaning" (X). Only an ill person understands an ill person: "Now my husband understands me. He has become ill" (X).

Search for a cause of the suffering

The patients seemed to rely upon explanations that

gave the illness and their life situation meaning. "When I was five I had a close-to-death experience" (III). This woman thought that her experience was never recognised, which gave rise to frustration and, in turn, muscular tension. She continued: "Now I can relax. My feeling has been confirmed that such experiences exist" (III).

Troublesome working conditions were apprehended as another cause of the disease: "I constantly had to face customers on the other side of the table. Couldn't massage my neck then...the muscle pain kept getting worse" (I).

The notion that fibromyalgia is of psychological origin was strongly rejected: "I got a horrible feeling that the doctor thought it was mental" (II). However, the suffering was thought to give rise to mental problems: "When it hurts and one has pain and no energy, then one gets sad and this gets on one's nerves" (VI).

Demands placed upon oneself

The patients seemed to suffer from not being able to manage like others, although they displayed high ambitions: "The problem with me is that I demand so enormously much from myself. As soon as I come close to what I really want I immediately raise the demands on myself" (IV). The illness seemed to give meaning to a feeling of inability: "If it wasn't for my illness, I'd certainly have been able to attain my set goals" (V).

The appearance of the illness was also seen as a lucky occurrence: "My fibromyalgia made me stop. It was a way back to life. Before then I'd just been chasing time" (IV); "My involvement in the local fibromyalgia group is my deliverance, a sort of emergency exit...To start with, the illness directed me, but now I have the power to determine what to do, though it has given me a lot of pain" (IV).

The patients seemed to be struggling with reducing the deficit between their ideal and perceived self-image. An experience of insufficiency or even uselessness could be poignantly expressed: "The worst punishment for me as a mother is to be unable to lift and embrace my child who wants to come to me. Indeed, it is unbelievably hard to be in this situation" (IV).

Managing experiences of threatening failure

An irresistible fatigue can be "used" for postponing a decision difficult to make: "I often become unbelievably tired and just want to lie down and cry" (IV). The texts seemed to demonstrate the patients' attempts to connect a feared inability and the existence of an incapacitating illness: "I really want to do things...and then I don't manage...I suffer from a feeling of insufficiency...It makes me so damn

disappointed" (I). It is tempting to imagine that one is afflicted with something physical, which would explain the presence of an undesirable life situation: "You cannot discuss (an intricate conflict with your husband) when you are tired" (VIII).

Avoiding thoughts of the future

A question that it often came natural to ask at the end of the interviews was: "What are your future plans?" The answers, however, seldom dealt with aspects of the future. Instead, the patients talked about different kinds of obstacles brought upon them by the disease: "When I could not manage the job as a nurse I got a disability pension. If not, I would probably still have been a nurse" (VII). To the extent that they did address the future, it was described in a restricted and unappealing way: "I used to have a great number of friends, many parties and guests...Today I have no energy for all this. I really miss it...I want very much more than my body does...It makes me feel so useless not to be able to do all I want to do" (VI).

Holding on to safe, familiar routines was perhaps a way to avoid dealing with issues connected to the future: "If I want my husband to do something, and he replies that he'll do it in a while, I become annoyed. I want things to be done immediately" (VII). All of these quotations were replies to the question about the future.

DISCUSSION

The starting point of the study was to deepen the understanding of the nature of fibromyalgia by interviewing patients and analysing their transcribed tapes. Our analysis indicated that the patients found it important to be confirmed as ill by doctors and significant others, and as having been unpredictably and dramatically afflicted with an invisible, incapacitating and wasting disease. They were involved in finding and communicating explanations of their sufferings in line with a biomedical view of correlations between bodily disorders and symptoms. When analysing the texts and recalling the ways the patients described their efforts to both stand forth as ill and respond to their many obligations, we felt that an important aspect of their communicative actions was the way they were dealing with the experienced discrepancy between ideal and actual capability, a significant health issue thoroughly discussed by Pörn (20). Our findings indicate that the patients might in a way "use" their illness experience to manage the demands they have placed upon themselves. Experienced fatigue, pain and weakness, for instance, could be part of a deliverance strategy,

which would provide a way to avoid actions and demands considered unmanageable. As long as one has not tried to do something one finds desirable, the hope of being able to do it is still intact.

Considering the data more freely, it seems as if the onset of the illness was strongly connected to the patients' experience of inability and tiredness and of being misunderstood. To have the diagnosis recognised by a doctor seemed to be experienced as a relief. This feeling could be existentially interpreted as the effect of being confirmed as genuinely afflicted (1) and/or as one who has re-established the human ability to connect to a common communicative environment (5). One possible interpretation is that the symptoms were meant to manage the human dilemma consisting in the fact that, in the final analysis, each individual is personally responsible for his ability to take up his life as a personal project to be enacted (21). To put a label on suffering gives it meaning. This familiar experience could contribute to an understanding of why the patients tended to repeatedly drive themselves to tell about their illness or present themselves as ill, perhaps hoping to be confirmed as not responsible for their perceived inability to comply with the demands they themselves and others would place upon them. We got the impression that the patients in a way, unintentionally, took advantage of being under the influence of an unpredictable and little understood illness.

A disease can perhaps relieve a patient of her sense of responsibility in the face of an unmanageable life situation. Unwittingly avoiding the thought of the future is another facet of a deliverance strategy. The difficulty of managing a perceived discrepancy between set goals and experienced unattainability may give rise to the bodily tension that then develops into an illness. This may then be conveniently (though unwittingly) exploited by the patient to explain the inability to do anything about the discrepancy. Perhaps it is not always the effects of a bodily disorder that encourage patients' search for meaning. Rather, the need of a sense of coherence (22) may direct their "search for illness".

Even if our principal aim was to increase our understanding of the meaning structure of the patients' experiences of fibromyalgia, their own doctors' behaviour is worth mentioning, being part of the context from which the patients' experiences stem. Instead of seeing fibromyalgia as a possible biomedical anomaly (8) and changing action-repertoire accordingly, the doctor may hold on to his biomedical view and avoid seeing the patient's possible existential dilemma. Perhaps this served one of the patient's short-term purposes: "To have a diagnosis was like winning the first prize in a lottery, like becoming a

millionaire. Gee, can you imagine, there are others like me! I have a disease. I can't even describe the feeling" (V).

CONCLUSIONS

The empirical phenomenological psychological method enabled us to get beyond biomedical and other explanatory models in order to investigate the described experiences of fibromyalgia. Our findings made us wonder if the expressions could represent a specifically human need to remain attached to a common communicative environment. The fibromyalgia patient, usually a woman, seemed to believe that her illness started in connection with a significant life-event. The unpredictable onset of the illness and the capriciously appearing symptoms served the patient's desire to control her environment. Thus, she unwittingly could increase the possibilities of making her family and others confirm her as having been afflicted with something for which she could not be blamed. As a consequence, the significant others could see her as someone who certainly would have been able to exercise her genuine qualities – if it had not been for her illness. A means of reducing the sense of being unable to reach set goals was to overlook the existence of a future and to abandon the human predestination to be a subject. Thus, the interviewed patients tended to look upon themselves as things, as objects of doctors, medicine and illness-producing forces. One practical implication of the study would be that more attention should be paid to teaching students and young doctors how to meet patients' presentation of vague symptoms. Our results indicate that many patients, if better understood, could be assisted not to "choose" illness in order to come to terms with personal life situations difficult to manage.

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REFERENCES

1. Henriksson CM. Living with fibromyalgia. A study of the consequences for daily activities. Linköping University Medical Dissertation No. 445, 1995.
2. Wolfe F. The epidemiology of fibromyalgia. *J Musculoskelet Pain* 1993;1:137–48.
3. Boissevain MD, McCain GA. Toward an integrated understanding of fibromyalgia syndrome. I. Medical and pathological aspects. *Pain* 1991;45:227–38.

4. Wall PD. The mechanisms of fibromyalgia: a critical essay. In: Værøy H, Mersky H, editors. Pain research and clinical management, vol. 6. Amsterdam: Elsevier, 1993:53–9.
5. Toombs SK. The meaning of illness. A phenomenological account of the different perspectives of physician and patient. Dordrecht: Kluwer Academic Publishers, 1992.
6. Barnlund DC. The mystification of meaning. Doctor–patient encounters. *J Med Educ* 1976;51:716–25.
7. Hilden J. Fibromyalgidiagnosen. En kritisk oversigt over nordisk litteratur (The fibromyalgia diagnosis. A critical review of Nordic literature). English summary. *Nord Med* 1996;111:308–12.
8. Hellström O, Bullington J, Karlsson G, Lindqvist P, Mattsson B. Doctors' attitudes to fibromyalgia – a phenomenological study. *Scand J Soc Med* 1998;26:232–7.
9. Jacobsen S. Chronic widespread musculoskeletal pain – the fibromyalgia syndrome (dissertation). København: Lægeforeningens forlag, 1994.
10. Karlsson G. The experience of spatiality for congenitally blind people: A phenomenological-psychological study. *Human Studies* 1996;19:303–30.
11. Ryan S. Living with rheumatoid arthritis: a phenomenological exploration. *Nurs Stand* 1996;10:45–8.
12. Bowman JM. The meaning of chronic low back pain. *AAOHN J* 1991;39:381–4.
13. Karlsson G. Psychological qualitative research from a phenomenological perspective. Stockholm: Almqvist & Wiksell International, 1993.
14. Taylor SJ, Bogdan R. Introduction to qualitative research methods. A phenomenological approach to the social sciences. New York: John Wiley & Sons, 1975.
15. Wolfe F. Fibromyalgia. *Rheum Dis Clin North Am* 1990;16:681–98.
16. Freire P. Pedagogy of the oppressed. New York: Seabury, 1970.
17. Segesten K. Qualitative methods – an alternative road to knowledge (editorial). *Scand J Prim Health Care* 1997;15:161–2.
18. Giorgi A. Sketch of a psychological phenomenological method. In: Giorgi A, editor. Phenomenology and psychological research. Pittsburgh: Duquesne University Press, 1985:8–22.
19. Malterud K. Shared understanding of the qualitative research process. Guidelines for the medical researcher. *Fam Pract* 1993;10:201–6.
20. Pörn I. Health and adaptedness. *Theor Med* 1994;14:295–304.
21. Sartre J-P. Being and nothingness. New York: Washington Square Press Publication of Pocket Books, 1965:33–85.
22. Antonovsky A. Unraveling the mystery of health. San Francisco: Jossey-Bass Inc Publishers, 1987.

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