

Clinical aspects, natural history and medical consumption in fibromyalgia: a description of a patient group

A.A. KNIPPING, A.C.E. DE BLÉCOURT.

Introduction

When fibromyalgia in the seventies (fibrositis in those years) became known as a syndrome, a series of publications have emerged in which clinical aspects of this syndrome are described. Different criteria sets made a comparison between the patient groups that were described in these studies very difficult. When the ACR 1990 criteria for fibromyalgia (1) were developed, comparison between different patient populations could be made more easily. For a good understanding of fibromyalgia and the relation of this syndrome to other syndromes (e.g. chronic fatigue syndrome, irritable bowel syndrome, myofascial pain syndrome), it is necessary to describe the clinical aspects and its natural history. The latter has been done by Felson and Goldenberg (2). They used interviews and followed 39 patients from an office-based, academic, rheumatology referral practice over a period of 3 years. They concluded that fibromyalgia is a chronic disease, with symptoms that usually persist for at least 3 years after diagnosis. Symptom remissions are rare, and when they occur, are often transitory. Longterm medication use is the rule. Generalization to the total fibromyalgia population is doubtful however. A referral population was studied, which may be a biased sample of those with relatively severe, long-standing symptoms. Hawley et al. assessed 75 fibromyalgia patients at monthly intervals during a 1-year period (3). The symptoms of individual patients and the group as a whole regarding sleep, pain, severity, psychological status, and functional disability were remarkably stable over the 1-year period. The authors noted no global trends toward improvement or worsening, nor seasonal effects.

Pain is the primary characteristic of fibromyalgia. For example, Wolfe et al. (1) found that 97.5% of fibromyalgia patients complained of widespread pain; in comparison, 71.1% of chronic pain controls expressed a similar complaint. Several studies, using visual analogue scales, numerical rating scales and multidimensional approaches to pain, such as the McGill Pain Questionnaire, point out that high levels of pain are perceived by fibromyalgia patients, when compared to other patient groups in which chronic pain is involved (4).

The presence of tender points is another important factor in fibromyalgia, as has been described in chapter 7.

In a description of the clinical features of fibromyalgia Wolfe (5) makes a distinction between core features (present in all patients: generalized pain and widespread tenderness), characteristic features (present in more than 75% of patients: fatigue, non-refreshed or disturbed sleep, morning stiffness), common features (present in more than 25% of patients: irritable bowel syndrome, Raynaud's phenomenon, headache, subjective swelling, paresthesias, psychological abnormality, and functional disability), and coexisting rheumatic conditions, for example arthritis, low back and cervical disorders, tendinitis etcetera, whose symptoms intertwine and overlap with those of fibromyalgia. Generally there are no clinical or laboratory abnormalities in fibromyalgia beyond that what one might expect by chance or when other disorders

are present.

Very little is known about the pattern and amount of medical consumption in fibromyalgia. The wide variety of possible medication types and many different treatment forms make a stock-taking a difficult task.

Henriksson (6) concluded on basis of a study on the longterm effects of fibromyalgia that this syndrome must be regarded as a chronic non-remitting pain syndrome, with considerable social consequences and involvement in all aspects of daily life.

Adaptation seems to be dependent of individual characteristics in the patients.

Successful adaptation from the viewpoint of the patients does not implicate the same from the viewpoint of the society. A great amount of medical consumption may seem a satisfactory way for the patient, but clinicians feel that medication use should be minimized.

Studies have been made of the socioeconomic impact of fibromyalgia (see also chapter 8), but the great differences in social security systems and medical care facilities between countries make a meaningful comparison between studies that are carried out in different countries very difficult.

A description of clinical features in a Dutch population of fibromyalgia patients has not been made yet. The objective of this chapter is to make a description of the clinical features of a Dutch fibromyalgia population. Also a description is made of the pattern and amount of medical consumption in this group. An inquiry, carried out in 1986 by the Dutch patient's organisation for fibromyalgia shows that more than 60% underwent therapy (varying from physical therapy to non-allopathic forms of treatment) for their fibromyalgia complaints, with only moderate effects. For the Dutch health insurance system the high costs of the various forms of treatment and medical supplies without certainty about the necessity or effectiveness form a problem (7).

Methods and subjects

In the years 1989 till 1992 clinical aspects of 161 fibromyalgia patients were charted, serving research aims that are described in chapters 14 (n=100) and 15 (n=61). Also 44 extra fibromyalgia patients were screened solely on medical consumption and natural history, making the total amount of patients that were involved in this study 205. All patients were recruited from the rheumatology outpatient clinic of the University Hospital of Groningen (the Netherlands) in a random selection procedure. All patients were diagnosed by their rheumatologist as having fibromyalgia. The patients first received a letter in which the aims of the research program was explained. Approximately 1-2 weeks later they received a telephone call and were asked to participate.

As part of the measurement procedure, a standardized interview was used to obtain data about the description and development of the complaints, the medical

consumption, and also some sociodemographic variables. Also a physical examination was performed by the physiatrist.

- Duration of complaints was measured with an interview question: "For how long have you had these complaints?" If an estimation by the patient proved to be difficult, the first time a doctor was visited because of their fibromyalgia complaints was taken.
- Perceived onset of complaints was measured with the question "How did your complaints start?", an open end question. The answers given by the patients were scored into one of the six possible categories: following an accident, following an operation, following an illness, after or during a period of overexertion, gradually, without preceding or provoking events, or different answers.
- Perceived natural history over the past year was measured with the open end question "Were there changes in your complaints over the last year?" Answers of the patients were scored in one of the 6 categories: better, no changes, more painful localizations, higher pain intensity (more pain), more painful localization and higher pain intensity, or changing/unclear.
- Patients were also asked to give a description of their complaints ("What are your most important complaints") and a description of their pain ("Can you describe your pain"). Some complaints were asked explicitly, such as sleeping problems, headaches, and irritable bowel syndrome.
- Factors influencing the fibromyalgia complaints were measured with two interview questions: "What worsens your complaints?" and "What makes you have less complaints?"
- Physical examination by the physiatrist included standardized musculoskeletal examination, in which presence or absence of posture abnormalities, problems with joint- or spine mobility, paresis, sensibility problems, abnormal reflexes and skin-fold tenderness were evaluated in a dichotomous way.
- Problems with activities of daily life were evaluated with help of an ADL-checklist, which is a part of the Fibromyalgia Impact Questionnaire (8). Patients had to state whether they could or could not perform a certain activity. The activities that could be performed by the patient were summarized, which yields in a score between 0 (not a single activity possible) to 9 (all activities possible).
- Finally, medical consumption was measured in two ways. The types of treatment were evaluated with the question "What treatment do you get for your fibromyalgia complaints?" The answers were grouped into four categories: no treatment, physical therapy, medication, and non-allopathic treatment (e.g. acupuncture, Reiki etc.). Combinations of the latter three categories were also possible.

If the patients used medication, the type of their medications was asked and then scored into one of the three possible categories: non-steroid anti inflammatory drugs (NSAID's), analgesics, and a category containing benzodiazepines and

antidepressants.

Some of the interview questions were expelled in later stages of the research program, for practical reasons. Total number of patients are given with each variable in the results, described below.

Results

Sociodemographic data

The group of 205 fibromyalgia patients consisted of 100 persons who took part in the research program in which we evaluated the effect of a combined treatment of psychomotor therapy and marital counselling (see also chapter 14), 61 persons who took part in the research program in which we evaluated the effect of psycho-education on a behavioral therapy basis (see also chapter 15), and 44 persons who were screened solely on a set of retrospective variables.

In table 1 some sociodemographic variables of the research group are summarized.

In a study performed by Leavitt et al. (9) the mean age for a group of 50 hospitalized fibromyalgia patients is 45.1 (SD=12.0), with 88% female and 78% married. In the report of the Multicenter criteria committee (1) several groups of fibromyalgia outpatients are described (n=558). The mean age varies from 48.0 (SD=2.0) to 49.1 (SD=12.8) years. Other studies (10) show that fibromyalgia is much more common in woman (76-95% female), and the

Table 1
SOCIODEMOGRAPHIC VARIABLES

Age	mean=44.3 SD=9.4 range 21-66 yrs
% Female	87.8
Marital status	87.3% married or living with partner
	5.9% divorced
	1.0% widowed
	5.4% single
	0.5% living with parents
Level of education	26.3% elementary education (finished or unfinished)
	40.0% low level secondary school
	25.4% medium level secondary school
	8.3% high level secondary school or university
Level of occupation	79.2% unskilled, housewives or unemployed
	17.4% skilled
	3.5% leading position
Disability compensation (Dutch: WAO)	21.5% full compensation
	8.8% partial compensation
	10.2% unknown
	50.7% no compensation

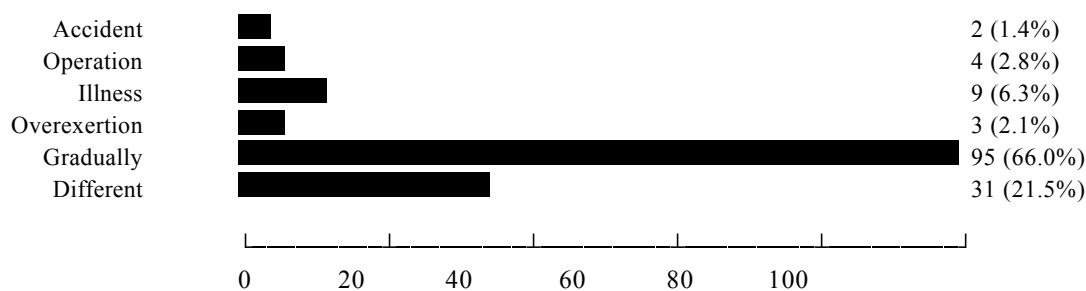
age of onset in clinical series varies from 12 to 45 years. Onset after 60 is rare. In most clinical studies the mean age is between 40 and 55 years. These data are very similar to those of our study.

The sociodemographic data of fibromyalgia patients do not seem to differ much of those of other chronic pain patients, except for the sex ratio. In the study of Reitsma (11) the mean age of a group of 219 chronic pain patients is 48.7 (SD=12.4), with 64.7% female. In his study 74.6% is married or living with a partner and 29.1% receives disability compensation. 61.3% of the chronic pain patients has a low level of education (our study: 26.3 + 40 = 66.3%), 30.1 medium and 8.6 had a high level of education.

Complaints

The mean duration of the complaints is 10.1 year (SD=5.8). Some data about the onset of the complaints (as perceived by the patients) is summarized in figure 1.

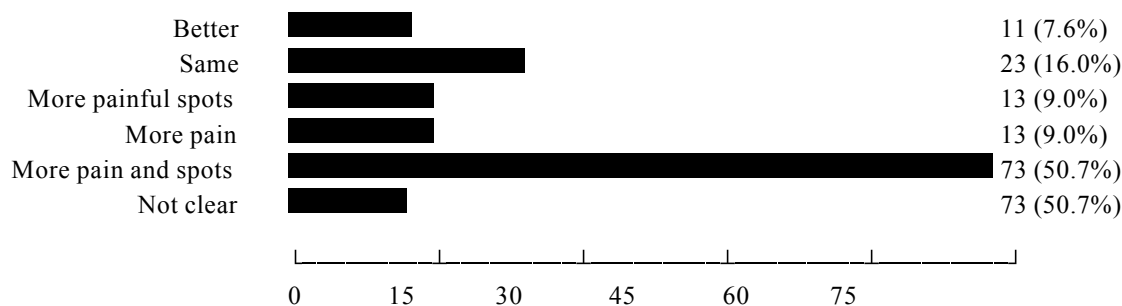
Figure 1
PERCEIVED ONSET OF COMPLAINTS (N=144)



The vast majority (66%) of the group did not indicate a preceding or provoking event and stated that their complaints came spontaneously and gradually. Only 12.5% stated a provoking or preceding event.

The natural history of the complaints in the past year is shown in figure 2.

Figure 2
NATURAL HISTORY OF COMPLAINTS IN PAST YEAR AS PERCEIVED BY THE PATIENTS
(N=144).



Few patients (16%) stated that the situation remained the same as referred to their complaints. Only a small group (7.6%) had the feeling that their complaints were gradually diminishing.

The vast majority (almost 70%) of the group complained about a worsening of their complaints in some way.

In the Swedish study of Henriksson (6), mentioned earlier 50% of the patient group (n=56) reported an increase of their symptoms in the past 5 years, 35% reported no change and approximately 15% reported improvement. The Dutch fibromyalgia patients seem to evaluate the natural history of complaints as being a little more negative.

Pain was present in almost all patients; only one person did not mention pain as part of the subjective complaints. Fatigue was mentioned spontaneous by 58.6% and stiffness by 26.4%

of the patient group.

The most frequent spontaneous descriptions of the pain complaint was "nagging" (Dutch: "zeurend") which was mentioned by 47.9% as the most prominent pain description. Another frequently mentioned description was "stabbing" (30.6%) (Dutch: "stekend").

Patients were also asked about the presence of some frequently reported concomitant complaints. Results are presented in table 2.

Problems with sleeping and a nonrestorative sleep seem to be "normal" in fibromyalgia and headaches and fatigue is reported by almost 60% of the total group.

Table 2
PRESENCE OF SOME CONCOMITANT COMPLAINTS IN FIBROMYALGIA

Sleeping problems	73.6%
Unrefreshing sleep	91.0%
Headaches	59.7%
Irritable Bowel Syndrome	30.3%
Raynaud symptoms	23.2%

Also questions were asked about factors that could have a possible influence on the complaints. The results can be found in table 3.

Table 3:
FACTORS INFLUENCING THE FIBROMYALGIA COMPLAINTS AS PERCEIVED BY THE PATIENTS.

Worse through humidity	49.7%
Worse through cold	42.7%
Worse through stress	44.1%
Worse through physical exercise	83.2%
Better through warmth	66.4%
Better through resting	18.2%
Better through relaxation	12.6%
Better through seeking distraction	15.4%

Fibromyalgia patients can easily tell what worsens their complaints, but apart from warmth (especially hot showers) they perceive their complaints as being fairly uncontrollable. Physical examination as performed by the physiatrist show that clear musculoskeletal abnormalities are rare. In 2.9% structural posture abnormalities were seen. In 10.2% there were problems with joint- or spine mobility. Paresis did not appear as phenomenon. Only 2% showed clear sensibility problems. Absence of reflexes were found in 1% of the patient group.

Skin-fold tenderness was present in 57% of the total group, in 41.4% in both scapular regions, in 13.4% only on the left side and in 2.5% only right.

Results obtained from the ADL-checklist are represented in figure 3.

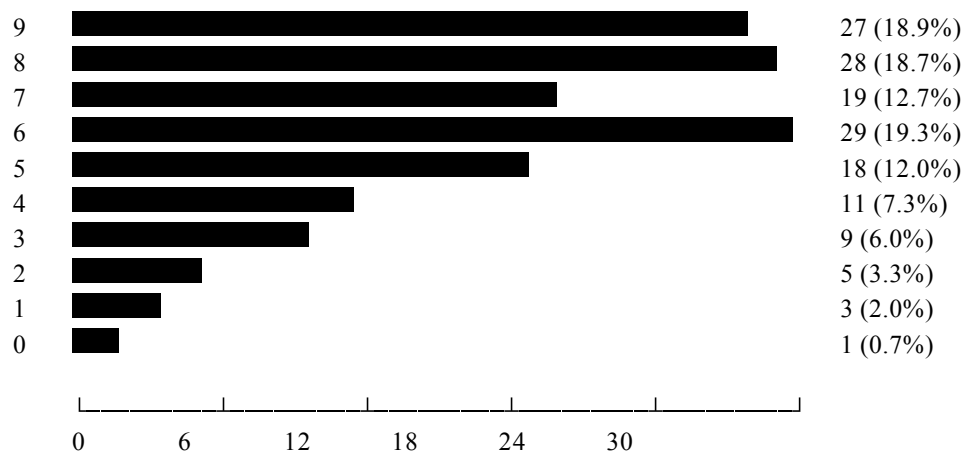
Only 19% of the patients indicate no problems at all with activities of daily life.

Approximately 20% claim to have severe problems in this area (0 to 4 activities possible).

Apparently the patients themselves seem to perceive fibromyalgia as a crippling and debilitating syndrome and they experience several disabilities.

Figure 3

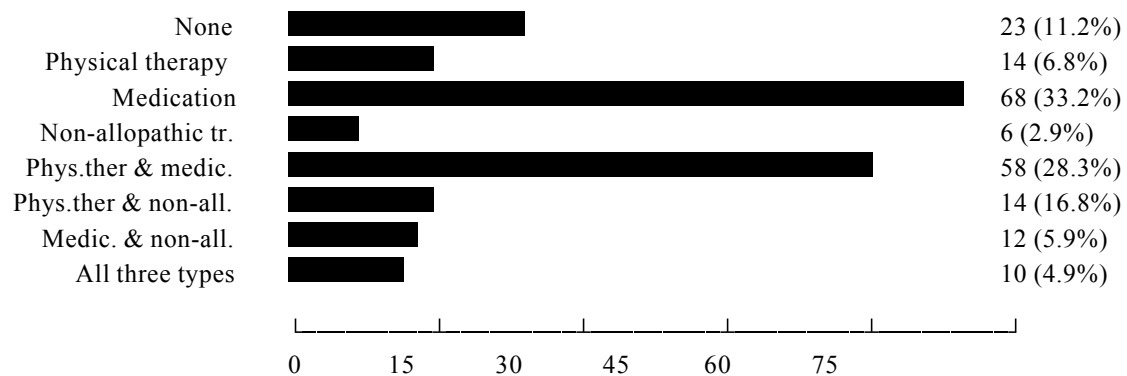
NUMBER OF ADL-ACTIVITIES THAT COULD BE PERFORMED BY FIBROMYALGIA PATIENTS



Medical consumption

Many types of therapy seem to be tried out by fibromyalgia patients. The main described forms of treatment are 1) physical therapy, 2) medication and 3) non-allopathic treatment. Very often combinations of these types can be found. The results of the group that was examined in this study can be found in figure 4.

Figure 4
COMMON TYPES OF TREATMENT IN FIBROMYALGIA (N=205)

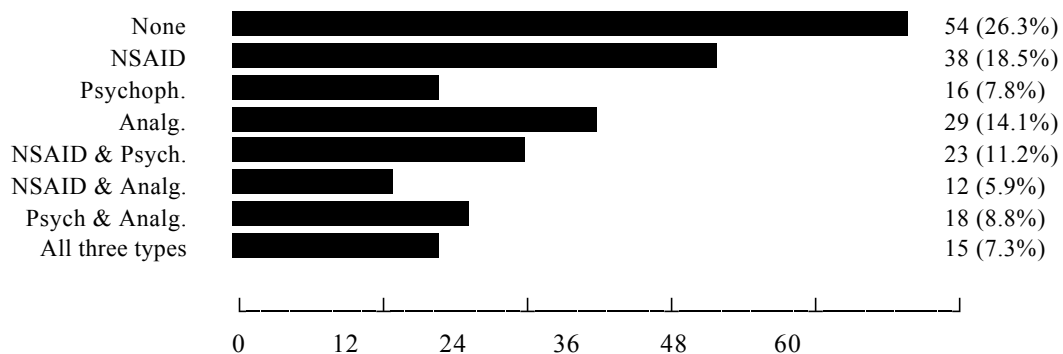


As can be derived from figure 3, medication is the most frequently applied type of treatment in fibromyalgia. All together 72.3% of the patients receive medication. Physical therapy is a less frequently used type of treatment (46.8%). Combination of medication and physical therapy is applied in almost one third (28.3%) of the patient group.

Medication was divided into three categories: 1) the non-steroid anti inflammatory drugs (NSAID's), 2) analgesics and 3) psychopharmacons (tranquillizers, antidepressants and hypnotics).

Results are presented in figure 5.

Figure 5
MEDICATION USE IN FIBROMYALGIA PATIENTS (N=205)



Almost three quarter (73.7%) of the patient group use medication that fit into these three categories. NSAID's are the most frequently prescribed medication (37.0%). Analgesics and psychopharmacons are prescribed in respectively 27.3% and 27.8%.

More than a quarter of the total group (25.9%) use a combination of two medication types and 7.3% even three types.

Discussion

One of the most striking findings found in research on clinical and epidemiological aspects is the high percentage of female patients in fibromyalgia. In spite of extensive research and discussion a good explanation for this still has to be found. Hormonal and sociocultural aspects, or perhaps a combination of these two are likely to be important as explanatory factors. Also in our study the percentage of female patients is high, comparable to the findings in other studies (9).

The fibromyalgia patient group described in this chapter has a duration of complaints of 10.1 ± 5.7 years, which seems to be long. The duration of symptoms in the study of Felson and Goldenberg, mentioned earlier (2) was 4.3 ± 4.7 years. In a study performed by Campbell et al. (12) the mean duration was 7.6 years. Their patient group consisted of 22 patients selected from a general medical outpatient population. Twelve patients (54.5%) identified events which they felt precipitated their fibromyalgia; these included injury (36.4%), illness (13.6%) and emotional stress (4.5%). There seems to be a difference with the Dutch patient group, described in this chapter, in which 66% of the patient state that the fibromyalgia complaints emerged gradually, without a precipitating event. In a controlled study on 113 fibromyalgia patients from an ambulatory clinic, Yunus et al. report a duration complaints of 6.9 ± 7.9 years (13).

Diagnosing fibromyalgia is time-consuming, since the possibility of other diseases (e.g. rheumatoid arthritis) have to be excluded. This may play a role in the strong feelings of uncertainty that are expressed by these patients, even after the diagnosis has been given. The fact that the complaints are worsening over time, as perceived by the patients themselves, is rarely supported by an objective worsening in the view of the doctor, which also contributes to the feelings of uncertainty.

In spite of the fairly neutral outcome of physical examination the patients themselves perceive fibromyalgia as a crippling and debilitating syndrome, which keeps them of a normal pattern of daily activities and work.

Medical consumption seems to be high in fibromyalgia. A typical phenomenon is that many patients state that the beneficial effect of most forms of treatment is insignificant, without a changing of their pattern of medical consumption.

A more detailed analysis of medical consumption is not possible, using only interview questions. Further research on this issue could be based on a registration of the family doctor, in a longitudinal research design. Retrospectively the registration of health-insurance companies can be used also for this purpose.

References

1. WOLFE F, SMYTHE HA, YUNUS MB, BENNET RM, BOMBARDIER C, GOLDENBERG D ET AL. The american college of rheumatology 1990 criteria for the classification of fibromyalgia. *Arthr Rheum* 1990;33:160-172.
2. FELSON DT, GOLDENBERG D. The natural history of fibromyalgia. *Arthr Rheum* 1986;29:1522-1526.
3. HAWLEY DJ, WOLFE F, CATHEY MA. Pain, functional disability and psychological status: A 12-month study in severity of fibromyalgia. *J Rheumatol* 1988;15:1551-1556.
4. BOISSEVAIN MD, MCCAIN GA. Toward an integrated understanding of fibromyalgia syndrome. II. Psychological and phenomenological aspects. *Pain* 1991;45:239-248.
5. WOLFE F. Fibromyalgia: The clinical syndrome. *Rheum Dis Clin N Am* 1989;15:1-18.
6. HENRIKSSON CM Longterm effects of fibromyalgia on everyday life. *Scand J Rheumatol* 1994;23:36-41.
7. ANONYMOUS Hoe staat het met de problemen rond fibromyalgie? *GMD actueel* 1989;12:5-7.
8. BURCKHARDT CS, CLARK SR, BENNET RM. The Fibromyalgia Impact Questionnaire: development and validation. *J. Rheumatol* 1991;18:728-733.
9. LEAVITT F, KATZ RS, GOLDENHE, GLICKMAN PB, LAYFER LF. Comparison of pain properties in fibromyalgia patients an rheumatoid arthritis patients. *Arthr Rheum* 1986; 29:775-781.
10. FELSON DT. Epidemiologic research in fibromyalgia. *J Rheumatol* 1989; (suppl 19)16:7-11.
11. REITSMA B. The end of the line? Evaluation of a multidisciplinary team approach to chronic pain. Dissertation University of Groningen, 1994.
12. CAMPBELL SM, CLARK S, TINDALL EA, FOREHAND ME, BENNET RM. Clinical characteristics of fibrositis. I. A "blinded," controlled study of symptoms and tender points. *Arthr Rheum* 1983;26:817-824.
13. YUNUS MB, MASI AT, ALDAG JC. A controlled study of primary fibromyalgia syndrome: Clinical features and association with other functional syndromes. *J Rheumatol* 1989;16:62-71.