

EVALUATION OF FOUR OUTPATIENT EDUCATIONAL PROGRAMMES FOR PATIENTS WITH LONGSTANDING FIBROMYALGIA

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Objective: Four programmes based on educational and cognitive principles but with a variation in total length and number of staff/patient contact hours were compared in order to gain further insight into the importance of the format of the programme for the final outcome.

Design: A prospective non-randomized intervention study with 191 persons with fibromyalgia. Data were collected before, after and at 1-year follow-up. Participants served as their own controls. Results within and between the programmes were calculated.

Methods: Clinical investigations before and after intervention. Questionnaires were answered before, after and at 1-year follow-up.

Results: Most instruments showed no significant improvements after the programme. However, some improvements were found in important variables such as attitudes, self-efficacy, vitality and “days feeling well”. Results were unchanged at the 1-year follow-up and 16 persons had started working. Seven had ceased working. Participants reported frequent use of coping strategies in everyday life. No major differences could be found between the programmes.

Conclusions: More comprehensive programmes did not produce better results at group level. Also short and less costly interventions based on educational and cognitive principles were valuable for persons with longstanding fibromyalgia. More attention must be given to evaluating the clinical effect of programmes.

Key words: fibromyalgia, patient education, evaluation programme, rehabilitation, pain clinics.

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INTRODUCTION

Patients with chronic pain conditions such as fibromyalgia report limitations in their capacity to perform daily activities. The pain influences work (1–3), family roles and leisure (4, 5). Medical treatments may reduce some symptoms, but the pain is more or less persistent, and the patients need support in adjusting to a life

with pain. Multidisciplinary programmes have been reported successfully to support patients with pain syndromes in their rehabilitation (6–10). Many programmes for people with fibromyalgia have included aerobics, physical exercise and relaxation, and practical exercises in daily activities (7–9, 11–14). The results reported from these programmes show some improvements in symptoms and are generally reported to increase global health, self-efficacy and a positive attitude, and to decrease helplessness and anxiety. Previous studies have shown that the attitude of the patient and the meaning assigned to the pain experience will influence the way the patient is able to cope with the pain and the problems associated with the pain. Group sessions have proven to be of special importance for patients with chronic conditions. These programmes are usually based on education and include cognitive behavioural principles (16–21) of varying length, programmes sometimes extend over many weeks, and the patients are admitted to full-time programmes in rehabilitation centres. Others are part-time or short-session programmes, where participants attend as out-patients. Further and more detailed studies are needed on the importance of the length, content and design of these programmes in relation to the results obtained.

The aim of this study was to compare and evaluate 4 programmes based on educational and cognitive principles but with a variation in total length and the number of staff/patient contact hours in order to gain further insight into the importance of the format of the programme for the final outcome. All the programmes in this study were based on the philosophy that a better understanding of the condition would increase the self-confidence of the patient and enhance self-efficacy. The programmes were designed to supply patients with information and offer opportunities to gain further self-knowledge through group discussions, to discuss different reactions to pain, and how to cope with the consequences of pain in ordinary life.

MATERIALS AND METHODS

Programmes

The study was performed between 1997 and 1999. Four programmes at 3 hospitals in different parts of Sweden were included in the study. The rehabilitation staff from the 4 programmes met twice before the project started in order to discuss and co-ordinate philosophy, treatment principles and diagnostic criteria. The length of the programmes varied from 3 to 6 months and were all given at specialist rheumatology or pain rehabilitation units. The scheduled staff/participant contact hours ranged from about 18–70 hours (Table I). The resources in number of professional hours varied considerably. Exact costs for the different

Table I. Presentation of 4 programmes. Extension in time, number and length of each session, number of contact hours (number of hours each participant met with therapist), total hours (all hours that personnel were engaged), group size and main interventions

Programme	Extension	Sessions n (length in hours)	Personnel Contact hours (hours/group)*	Group size (n of patients/group)	Intervention Main content
1	6 months	20 (1.5)	30 (110)	10	Information, discussion and practical activity sessions
2	3 months	5 (3.5)	17 (30)	6–7	Information, discussion
3	10 weeks	20 (3)	60 (140)	10	Comprehensive rehabilitation
4	6 weeks	12 (4)	70 (400)	9	Comprehensive team rehabilitation

* Based on estimation from each hospital.

programmes have not been calculated, but an estimation of total costs showed that the most comprehensive programme was 10 times more expensive than the least costly programme.

Programme 1 had 20 1½-hour sessions over a 6-month period. A break of 6–8 weeks was scheduled in the middle of the period. The programme offered information (20%), discussions focused on problems initiated by the participants (60%) and practical activity sessions (20%). One physician and 2 occupational therapists were involved in the programme.

Programme 2 stretched over 3 months but with only 5 days intervention. It was a short information and discussion programme with opportunities to try warm water exercises, relaxation and practical exercises. The participants attended 4 days and came back for an additional day after approximately 3 months. A nurse, occupational therapist, physical therapist and social worker took part in the programme.

Programme 3 was a more comprehensive rehabilitation programme held 2 afternoons per week over a period of 10 weeks. Lectures were given in pain physiology, balanced diet, coping strategies and cognitive/motivational exercises, body awareness training, stabilizing and co-ordination exercises and light massage. A physician, physical therapists, behavioural therapist, social worker and massage therapist were involved. Additional individual treatments were offered.

Programme 4 was a rehabilitation programme based on a team with a physician, occupational therapist, physical therapist and a social worker. The participants attended 2 days per week over 6 weeks. The programme included information, discussion groups, physical therapy with exercises in warm water, relaxation and body awareness exercises, occupational therapy with practical daily activities focusing on ergonomic and energy-saving principles as well as adaptations in the work place. Occasional individual treatments were offered.

All programmes relied mainly on group sessions, though some of the programmes also had lectures and individual treatments. The programmes were client-centred, i.e. the information and exercises were based on the questions, problems, or interests brought up by the participants, and the content of the programme was adjusted to the needs of each group. Information about basic pain mechanisms, the fibromyalgia syndrome, additional symptoms, the practical consequences of a pain condition and various strategies that can be used to manage everyday life were given in all the programmes. The pain reported by the participant was acknowledged, but the consequences of the pain was discussed and challenged. Information and practical exercises were included, but the most important part was to allow time for discussions in the group and for integrating the new knowledge with the participants' own experiences and problems.

Subjects

All the participants had been diagnosed according to the criteria proposed by American College of Rheumatology (ACR; 22) before being offered to take part in the programme. In all, 212 patients joined the programmes during 1997–98, 191 of whom agreed to take part in the study and to answer the questionnaires. The 4 programmes included 57, 53, 40 and 41 participants, respectively. When starting the programme, 5 participants in Programme 1 had fewer than 11 tender points and thus did not strictly fulfil the ACR criteria at that date. These participants had widespread pain and had fulfilled the ACR criteria at an earlier date. As it is known that the number of tender points may change over time, the participants were not excluded from the study. This was not a randomized study, and the size of the groups depended on the

number of patients participating in treatment at the different units during the study periods. Eleven participants did not finish the programmes. The 180 who completed a programme were asked to fill in the questionnaires, which were fully answered by 156 participants (94%). At the 1-year follow-up, 133 of the original 191 participants who had started the programmes replied (70%). There were no significant demographic differences (age, marital status, education, children at home, and work) between the group that replied and the group that did not reply.

Sixty-four percent of the participants were referred from primary care, 21% from occupational health or specialists at secondary healthcare level, and 15% by private doctors, insurance agencies, or had applied directly to the pain or rheumatology units. The information concerning referral was divided into 2 categories: primary care (including occupational health and private clinics) and secondary care (general hospitals, insurance office). These 2 groups were compared using the χ^2 test and were found to differ, $\chi^2 = 24.4$ (df 3); $p < 0.001$. Group 1 had 52% from primary care, group 2 87%, group 3 87%, group 4 79%.

The participants in Programmes 1 and 2 were somewhat older than those in Programmes 3 and 4 ($p < 0.05$). There were no significant differences between the 4 programmes with respect to education, marital status and children at home. Significantly fewer participants in Programme 4 than in the other 3 programmes were working ($p < 0.01$) (Table II).

Methods

Clinical investigation. Rheumatology or pain specialists confirmed the diagnosis and documented the number and location of tender points before and at the end of the programme. The physician followed a protocol and asked questions about heredity, muscle function, infection during the previous 6 months, other ongoing therapy, stressful events earlier in life, and circumstances in connection with the start of the fibromyalgia symptoms.

Before and directly after the programme the participants answered specially designed questionnaires: **Background data:** socioeconomic and general data (work, sickness benefits, duration of pain symptoms, pain characteristics, other symptoms, satisfaction with work situation, and global life situation); the **8-day diary**, which was designed to collect data on pain intensity, stiffness, tiredness, quality of sleep, and global health in the morning and evening over an 8-day period. The participants marked their answers on visual analogue scales anchored with "no" to "worst imaginable" pain/stiffness/tiredness, "very good" to "extremely bad" quality of sleep, and "excellent" to "extremely bad" global health. On the first and the eighth day, the participants also recorded the location of pain on a pain mannequin.

The following instruments were used:

Before the start of the programme the **Beck Depression Inventory** (BDI; 23) was used to compare whether the level of depression differentiated the participants taking part in the different programmes. The Beck Depression Inventory is a well-established measure of depression, where a higher score indicates more severe depression. Recommended guidelines were followed, with 10–18 indicating mild to moderate depression, 19–29 moderate to severe depression, and ≥ 30 indicating severe depression (24).

The **Fibromyalgia Impact Questionnaire** (FIQ; 25), translated into Swedish (26), consists of 10 items rated on visual analogue scales: physical disability; overall well-being during the previous 7 days; sick-leave; impact of fibromyalgia on work; pain; fatigue, morning tiredness;

Table II. Background data before each programme and for the total studied population

	Programme 1 25 weeks (n = 57)	Programme 2 4+1 days (n = 53)	Programme 3 10 weeks (n = 40)	Programme 4 6 weeks (n = 41)	Total group (n = 191)
<i>Age (years)</i>					
Mean (SD)	45.6 (10.6)	45.0 (10.0)	40.0 (9.3)	39.8 (8.9)	42.7 (10.0)
Range	23–68	23–74	23–57	22–57	22–74
<i>Duration (years (SD))</i>					
Pain symptoms	10.3 (7.8)	9.4 (9.2)	6.2 (4.8)	8.0 (7.2)	8.7 (7.7)
Since diagnosis	3.3 (4.0)	1.4 (1.2)	1.2 (2.0)	1.0 (2.0)	1.8 (2.7)
<i>Family situation (n (%))</i>					
Living alone	15 (27)	9 (17)	13 (33)	7 (18)	44 (23)
Married/cohabiting	41 (73)	44 (83)	27 (68)	33 (83)	145 (77)
Children at home	30 (55)	30 (59)	29 (76)	27 (69)	116 (63)
<i>Education (n (%))</i>					
9 years	17 (30)	15 (28)	11 (28)	15 (37)	58 (31)
12 years	30 (54)	27 (51)	23 (58)	19 (46)	99 (52)
University	9 (16)	11 (21)	6 (15)	7 (17)	33 (17)
<i>Employment* (n (%))</i>					
Not working	32 (56)	27 (51)#	30 (75)#	36 (90)	125 (65)
Working full-time	4 (7)	11 (21)	3 (8)	0 (0)	18 (9)
Working part-time	21 (37)	15 (28)	7 (17)	4 (10)	47 (25)

* Refers to the employment situation the month prior to the start of the programme.

Including 1 old-age pensioner.

stiffness; anxiety; and depression during the previous week. A higher score indicates more impact on daily life.

The Swedish version of the *SF-36 Health Survey* (SF-36; 27, 28), is a well-tested instrument that measures global health on 8 scales: physical functioning, role-physical, body pain, general health, vitality, social functioning, role-emotional, and mental health. In a global question the respondents are asked to rate on a 5-point scale their general health compared with 1 year previously. A higher score on the SF-36 indicates a better state of health.

The *Rheumatology Attitudes Index* (RAI; 29, 30) has 15 items, with a higher score indicating a more positive attitude and more control. The instrument has previously been translated and revised by substituting the concept "rheumatic pain" with "fibromyalgia" (31).

A Swedish version of the *Coping Strategy Questionnaire* (CSQ; 32, 33). The instrument has 48 items divided in 8 sub-scales, each consisting of 6 items: reinterpreting pain sensations, coping self-statements, ignoring pain sensations, catastrophizing, increased behavioural activity, diverting attention, pain reducing behaviours, and praying/hoping. Two single-item questions deal with control over pain and the ability to reduce pain. A higher score indicates that the strategy is more frequently used.

The *Arthritis Self-Efficacy Scale* (ASES; 34), translated into Swedish and tested by Lomi (35, 36) has 20 items divided into 3 scales: controlling pain (5 items), performing functions in daily living (9 items), and controlling other symptoms (6 items). A higher score indicates a higher level of self-efficacy.

The Swedish version of the *Quality of Life Scale* (QOLS; 37, 38), is an instrument designed to measure global quality of life in patients with chronic pain. Respondents rate their satisfaction with 16 single items. A higher number indicates a better quality of life.

The participants were reassessed at the end of the programme and answered a short general questionnaire, the 8-day diary, and the above instruments, except the BDI. In an additional questionnaire the participants were asked to give their subjective evaluation of the content, the format (length of sessions and programme), and the implementation of the programme, and an indication of the most and the least valuable intervention.

One year after the participants had finished their programme they were again asked to fill out the instruments and an abbreviated questionnaire with questions about their work situation, sickness benefits, symptoms, and global satisfaction with health and life situation. They were also asked to give their opinion of the benefit of the programme, whether they had had any treatment or support during the previous year, physical

training habits, and health compared with 1 year earlier. Twelve strategies discussed during the programme were listed, and the participants were asked whether they had made any behavioural changes in their life situation. Answers were marked on 10 cm VAS scales anchored with "not changed at all" and "changed totally".

Statistical methods

As all the instruments have ordinal scales, non-parametric analyses were used. The 4 groups served as their own controls, and the Wilcoxon signed ranks sum test was used to compare differences between observations before and after, and before and at the 1-year follow-up. The differences between "start the programme" and "end of programme" and between "start of programme" and "1-year follow-up" were computed for each programme. These within differences were compared between the programmes by using the Kruskal-Wallis test. When differences were significant, the Mann-Whitney test was used to find the groups that differ. One-way ANOVA with Bonferroni correction was used for comparing age, duration of pain, and time since diagnosis. χ^2 was used for comparing frequencies such as education and family situation. The cut-off level for statistical significance was set at $p < 0.05$, two-tailed tests. In the tables, mean and 1 standard deviation are given instead of Md and quartiles. The SPSS 11.5 computer program for Windows was used.

RESULTS

The demographic characteristics of the participants are shown in Table II. The pain was reported to have started as a local pain, gradually spreading to become generalized for 77% of the participants. A physical trauma was reported by 6% in connection with the onset; a psychological trauma by 3%. Four percent reported an infection, 5% quoted more than 1 factor in connection with the start of the pain condition and 5% offered no information.

The mean duration of pain symptoms was 9 years for the population studied, with a range from less than 1 year to 50 years. Significant differences ($p < 0.05$) were found only between Programmes 1 and 4. Time since diagnosis varied, and the

participants in Programme 1 had significantly longer time since diagnosis than participants in the other 3 programmes.

About 25% of the participants had experienced a sore throat, swollen lymph nodes or sub-febrility during the previous 6 months.

The majority of the participants were sick-listed or on disability pension; 65 (34%) were working full-time or part-time before the programmes (Table II). Thirty-nine percent of the people who had previously been working reported that they had left work because of fibromyalgia-related problems.

The 8-day diaries showed great individual variations in symptoms over the 8 days but very little change in mean values over time. Detailed results will be presented elsewhere. No significant differences were found between the programmes.

According to the results of Beck's Depression Inventory, about one-third (36%) had mild to moderate depression and one-third (35%) moderate to severe depression. No significant difference was found between the programmes.

Comparisons between results before and immediately after the programme

Before the programme the average number of tender points was 17 (mean = 16.5, SD 2.2); 5 had fewer than 11 tender points, whereas 56% of the participants had 18 (the maximum number of tender points). At the end of the programmes 12 participants had fewer than 11 tender points, whereas 43% had 18 tender points at the 18 locations tested. The mean number of tender points in the total group was significantly decreased (Table III).

Ongoing pharmacological therapy before the programme was reported by 82%; 37% of the participants used non-narcotic analgesics, and 33% used weak opioids for pain. Antidepressive medication was used by 32%, including low doses for sleep. After the programme the proportion of participants using different types of drugs was essentially unchanged, but fewer used NSAID drugs.

For the total number of participants a few variables or dimensions showed statistically significant improvements between "before" the programme and directly "after" the programme (Table III). In the FIQ, only 1 item, "How many days did you feel well during the last 7 days?" showed improvement, with the impact figure decreasing from 85.7 to 79.5 ($p < 0.01$). In the SF-36 only the Vitality scale was somewhat improved from a mean of 24.4 to 26.9 ($p < 0.05$). The Rheumatology Attitude Index showed improvements in the attitude to the illness situation, mean 46.4 to 47.6 ($p < 0.01$). On the CSQ, the "catastrophizing" strategy was significantly less frequently used, mean 13.5 to 12.1 ($p < 0.01$), whereas "pain reducing behaviour" was used more often. Only the item "controlling other symptoms" of the Arthritis Self-Efficacy scale improved, with the mean of 28.4 increasing to 31.1 ($p < 0.001$). No improvements were observed on the QOLS.

When divided into the different programmes, the improvements were usually not significant (Table III). The differences in improvements between the 4 programmes were tested with the

Kruskal-Wallis test, but no significant differences were found in results between the programmes.

Comparisons of results before the programme and 1 year after the programme

Of the 133 persons who were followed up after 1 year, 52 persons (39%) were working. Many changes in work status had been made. Seven persons were no longer working – 1 previously working full-time and 6 part-time – 1 person was on maternity leave, 1 was in further education and 5 were sick-listed. On the other hand, 16 persons who were not working at the start of the programme were working at follow-up. Three were in full-time work, 12 in part-time work, and 1 was in work training. Changes were also found in the number of work hours: 5 workers had decreased and 7 workers had increased their work hours.

Most results from directly after the programmes were unchanged. A few significant changes were found at the 1-year follow-up (Table IV). The FIQ total score showed small improvements for all programmes, but only the item "How many days did you feel well during the last 7 days?" was still significantly improved from a mean impact of 84.7 to 74.6 ($p < 0.001$). Further analysis showed that 37% of the group reported an increase in the number of days they felt well of an average of 2.7 days; 42% reported no change. The majority of these participants had noted no days feeling well both before the programme and at the 1-year follow-up, 14% reported a decrease of 1.8 days and 9 answers were missing. In the SF-36 question, where the participants rate their general health compared with 1 year earlier, the results had also improved between the "before" ratings and the 1-year follow-up ratings ($p < 0.001$). The SF-36 showed slight increases on all scales, but statistically significant results on only 3 of the subscales: vitality, mean 23.1 increased to 27.9 ($p < 0.01$); body pain from 25.5 to 30.0 ($p < 0.001$); and role-physical from 11.7 to 19.3 ($p < 0.05$) (see Table V). Furthermore, the Rheumatology Attitude Index score showed an increase in positive attitude from 46.9 to 48.5 ($p < 0.001$). In the subscales of the Coping Strategy Questionnaire no significant changes could be detected, but on the additional question, "How much control do you feel that you have over your pain?", a significant improvement was found compared with the results before the programme ($p < 0.01$). The "controlling other symptoms" item on the Arthritis Self-Efficacy Scale still showed improvement, with an increase from 28.4 to 30.7. The results on the QOLS did not indicate change.

When the results before and after 1 year were analysed separately for the 4 programmes, some differences could be found within each programme. Programme 1 showed improvements on all scales but had significant improvements only on SF-36, role-physical, and on the ASES, the "controlling other symptoms" scale. Programme 2 had improvements on most scales, but was significant only on the RAI. Programme 3 displayed improvements on many scales, and was significant on SF-36 body pain and vitality, and on the ASES, "controlling other symptoms". Programme 4 resulted in few improvements,

Table III. Instruments, dimensions, or items where statistically significant improvements were found at the end of programme in the total group of participants (n = 156). Means and p-values are given for each programme and for the total material. Wilcoxon signed ranks test was used

Instrument	Programme 1 (n = 43)			Programme 2 (n = 40)			Programme 3 (n = 37)			Programme 4 (n = 36)			Total material (n = 156)		
	Before	After	p	Before	After	p									
FIQ: felt good last 7 days mean (SD)	90.6 (17.0)	76.3 (32.3)	2.61 **	77.3 (23.4)	71.5 (29.5)	1.31 n.s.	87.3 (16.2)	82.5 (19.4)	1.42 n.s.	88.0 (18.5)	89.7 (15.1)	0.27 n.s.	85.7 (19.6)	79.5 (26.2)	2.74 **
SF36: vitality, mean (SD)	23.9 (17.2)	26.5 (19.2)	1.32 n.s.	26.1 (17.2)	32.0 (20.4)	1.39 n.s.	19.4 (13.8)	25.1 (14.9)	2.64 **	23.2 (15.1)	23.5 (15.8)	0.31 n.s.	23.4 (16.0)	26.9 (18.0)	2.60 **
RAI mean (SD)	46.0 (4.9)	47.7 (5.4)	1.70 n.s.	47.5 (5.3)	48.4 (7.9)	1.46 n.s.	46.4 (5.1)	48.4 (5.1)	2.32 *	45.5 (7.7)	45.8 (7.1)	0.45 n.s.	46.4 (5.8)	47.6 (6.5)	3.07 **
CSQ	13.5 (7.9)	12.5 (7.4)	0.53 n.s.	12.2 (7.1)	9.8 (7.0)	1.52 n.s.	14.9 (6.0)	12.9 (6.8)	2.72 **	13.6 (7.5)	13.4 (6.6)	0.77 n.s.	13.5 (7.2)	12.1 (7.1)	2.59 **
Catastrophizing mean (SD)	20.65 (4.54)	20.10 (4.59)	0.78 n.s.	18.69 (4.76)	19.67 (4.20)	1.98 *	19.88 (4.60)	19.08 (3.86)	0.53 n.s.	21.36 (4.20)	22.06 (4.32)	1.95 n.s.	20.1 (4.62)	20.2 (4.36)	2.04 *
ASES: controlling other symptoms mean (SD)	27.8 (9.6)	31.4 (11.2)	2.79 **	32.5 (11.3)	34.1 (11.6)	1.09 n.s.	26.0 (10.4)	30.8 (11.3)	3.05 **	27.1 (10.1)	27.6 (9.2)	0.03 n.s.	28.4 (10.6)	31.1 (11.0)	3.61 ***
Tender points: mean (SD)	15.0 (2.9)	13.1 (3.2)	3.08 **	17.9 (0.3)	17.6 (1.2)	1.47 n.s.	16.6 (1.7)	15.6 (2.9)	2.05 *	16.9 (1.6)	16.1 (2.0)	2.14 *	16.5 (2.2)	15.5 (3.0)	4.40 ***

* p < 0.05, ** p < 0.01, *** p < 0.001. FIQ: Fibromyalgia Impact Questionnaire; RAI: Rheumatology Attitudes Index; CSQ: Coping Strategy Questionnaire; ASES: Arthritis Self-Efficacy Scale.

Table IV. Instruments, subscales, or items where significant improvements were found between the results from the 133 participants answering the follow-up questionnaire at the start of the programme and at the 1-year follow-up. Means and p values are given for each programme and the total group of participants at the start of the programme and at the 1-year follow-up. Wilcoxon signed ranks test has been used

Instrument	Programme 1 (n = 38)			Programme 2 (n = 35)			Programme 3 (n = 37)			Programme 4 (n = 23)			Total material (n = 133)		
	At start	1-year	p	At start	1-year	p									
FIQ: felt good last 7 days mean (SD)	92.5 (15.0)	75.2 (30.7)	2.31 *	74.0 (30.4)	64.8 (36.1)	1.42 n.s.	83.9 (22.8)	75.5 (30.3)	2.28 *	88.8 (17.9)	85.7 (18.9)	1.04 n.s.	84.7 (23.4)	74.6 (30.8)	3.51 ***
SF36: vitality, mean (SD)	24.0 (17.2)	25.7 (17.9)	1.19 n.s.	26.1 (17.2)	33.2 (24.5)	1.86 n.s.	19.5 (13.6)	26.6 (22.0)	2.11 *	25.4 (14.5)	26.7 (16.1)	0.07 n.s.	23.1 (17.2)	27.9 (20.5)	2.69 **
bodily pain, mean (SD)	27.3 (10.9)	29.8 (13.1)	1.34 n.s.	30.8 (14.0)	33.2 (16.3)	1.48 n.s.	22.1 (12.1)	30.6 (18.2)	3.32 **	23.2 (11.2)	25.7 (11.7)	0.57 n.s.	25.5 (10.9)	30.0 (15.3)	3.62 ***
role physical, mean (SD)	10.4 (18.5)	25.0 (35.4)	2.45 *	20.6 (28.2)	24.1 (35.0)	0.66 n.s.	11.5 (24.0)	14.9 (30.9)	0.63 n.s.	5.4 (16.8)	4.3 (16.3)	0.28 n.s.	11.6 (18.5)	17.8 (31.7)	2.08 *
RAI mean (SD)	46.2 (5.4)	48.1 (6.0)	1.60 n.s.	47.8 (4.1)	50.8 (5.6)	3.07 **	46.4 (5.0)	47.7 (6.7)	1.49 n.s.	47.4 (6.7)	48.2 (7.7)	0.67 n.s.	46.9 (5.2)	48.5 (6.6)	3.51 ***
ASES: controlling other symptoms mean (SD)	27.4 (10.3)	31.9 (12.5)	2.67 **	31.0 (11.5)	30.9 (15.7)	0.08 n.s.	26.1 (10.2)	29.7 (11.5)	2.75 **	30.3 (9.4)	30.3 (9.3)	0.33 n.s.	28.4 (10.6)	30.7 (12.6)	3.04 **

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.
 FIQ = Fibromyalgia Impact Questionnaire; RAI = Rheumatology Attitudes Index; ASES = Arthritis Self-Efficacy Scale.

Table V. SF-36 scales showing results before programme and the 1-year follow-up. Differences are calculated with Wilcoxon signed ranks test

	Before (n = 131)	1 year after (n = 131)	z	p
	Mean (SD)	Mean (SD)		
Bodily pain	25.5 (11.9)	30.0 (15.3)	3.62	0.000
Physical function	46.1 (18.2)	47.9 (20.4)	1.05	0.292
Role-physical	11.6 (22.1)	17.8 (31.7)	2.08	0.038
General health	38.9 (19.5)	40.3 (20.5)	0.47	0.636
Vitality	23.1 (15.9)	27.9 (20.5)	2.69	0.007
Social functioning	54.1 (24.0)	57.3 (25.0)	1.45	0.146
Role-emotional	41.4 (43.6)	47.6 (43.9)	1.00	0.316
Mental health	61.0 (20.8)	62.6 (22.1)	1.27	0.204

but none was significantly improved, and a number of scales or dimensions displayed results that indicated diminished ability (deterioration).

When the improvements between the start of the programme and the 1-year follow-up were compared between the programmes, considering the values at baseline, very few significant differences could be found: SF-36, social function $\chi^2(3) = ; p < 0.05$; only Programmes 1 and 3 were significantly better, and CSQ, Divert attention $\chi^2(3) = 14.4; p < 0.002$. Programme 4 used this strategy less often than the other 3 programmes.

Participant evaluations

After the programme. After the programme participants' subjective evaluations indicated great satisfaction with all the programmes. The group format was the most appreciated and useful aspect. To meet and be able to discuss one's own situation with other people with the same pain diagnosis and similar disabilities and experiences was expressed as the most helpful part of the programmes. Even though the question asked was open with no given answer alternatives, the participants communicated in their own words how important this had been to them. Seventy-five percent in the 6-month programme (Programme 1) mentioned the group discussions as the most valuable. In the other 3 programmes, 32–50% gave the same

answers. Next on the list as the most valuable were information and knowledge concerning fibromyalgia and its treatment. There were few differences between the programmes with respect to satisfaction with the content of the programme, even though the modalities had varied.

One year after the programme. One year after the programme, when the participants were asked to rate their behavioural changes, the mean values of the ratings were 4.0–6.5. This indicates that the participants' own impression was that they had changed their behaviour. When the scale was divided into 3 sections, rating <3 as "no change", 3–7 as "some change" and >7 as "clear change", 30–50% of the participants reported a clear change in the majority of the statements. However, about 20–30% reported only small or no changes [Table VI]. In additional comments the participants also reported that they had changed their way of thinking, felt that they could cope better with the pain, used stress-reducing strategies with pacing and relaxation in activity to relieve pain, made priorities and were more aware of what they could manage. They claimed better insight into their situation and were able to handle relations with peers at work, and family. One year after the programme, more than half of the participants still mentioned the importance of the group format and about 30% reported the increased knowledge of fibromyalgia as the most valuable part. Forty-five percent had had no therapy since the programme, about 25% listed warm water exercises and 25% reported physical therapy, TENS, acupuncture or relaxation techniques.

Half of the group were also involved in ongoing regular physical exercise, usually walking or water exercises. Fifty percent of the participants reported that they still needed help with household routines such as cleaning, shopping, carrying and lifting heavy burdens and hanging laundry. However, they also commented that their need of help varied depending on whether they had a "good day" or a "bad day".

DISCUSSION

The participants in this study were representative of a population of persons with fibromyalgia referred to specialist level. Data

Table VI. Percentages of the participants (n = 133) who experienced a change in use of different strategies 1 year after the programme. The respondents rated experienced degree of change from 0 = "no change at all" to 10 = "totally changed"

Strategy	No change Score <3	Some change Score 3–7	Clear change Score >7	Missing data n
	%	%	%	
Pause more frequently	21	47	31	2
Work in a more relaxed manner	18	50	32	2
Perform activities in a more careful way	19	41	40	2
Adjust working pace in daily routines	16	47	36	4
Make other priorities	19	39	42	3
Think differently in problem-solving	33	43	24	4
React differently to stress	36	42	22	5
Say no to things I do not want to do	16	47	37	2
Say no to things I have no energy to do	13	36	51	1
Say yes to what I wish to do	20	47	33	6
Ask for help to manage certain work tasks	30	46	24	3
Accept help to manage certain work tasks	24	48	28	5

were obtained from over 80% of the participants at the end of programme and from 70% at the 1-year follow-up.

The main aim of this study was to compare 4 programmes with differences in length and staff/patient contact hours to determine whether a longer and more costly programme gave better results than shorter and inexpensive programmes. To our knowledge this type of study has not previously been published.

The participants served as their own controls with comparisons before, after and at the 1-year follow-up. A limitation of the study was that there was no untreated group to control for the natural course over a year. Another limitation was that there were few participants in each programme and large differences between the programmes, especially at the follow-up. The response rate differed between the programmes and was 66%, 66%, 93% and 56%, respectively, in the 4 programmes. This difference in response rate might affect the results.

In the majority of the instruments there were few statistically significant results at group level, measured in symptom relief and disability, though significant and clinically meaningful improvements could be found in individual participants.

The participants had had symptoms for an average of almost 9 years. More than 70% had depressive symptoms (mild to severe), and the results from the SF-36 were low compared with the Swedish population (39). This indicates that the sample represents patients who have permanent pain and allodynia/hyperalgesia with a pronounced impact on their ability to perform daily activities.

There is strong support in the literature for the notion that there is a biological disturbance in fibromyalgia in the function of the nociceptive system, especially in the central nervous system (for references see 40). Therefore, an educational treatment programme may not influence this disturbance to a greater extent. However, it was surprising that very few statistically significant improvements in the ability to manage functional activities were reported in the FIQ and the ASES.

In contrast to the limited results in the instruments, the participants' reports were very positive both directly after the programme and at the 1-year follow-up. The decreased number of tender points seen in some persons may be an indication of less anxiety and of feeling more in control, indicated also in other variables such as a more positive attitudes, increased self-efficacy, and ability to influence pain. This would agree with the findings in a study by Wolfe et al. (41), where the number of tender points was found to correlate with the degree of psychological distress.

Improvements directly after a programme aiming at lifestyle changes could not really be expected. Enough time must be allowed for the participants to apply new strategies and use their knowledge to increase self-efficacy, to gradually change lifestyle and develop coping skills. Results directly after may also be due to the extra attention received during the programme.

The real value of the programmes are the positive changes in the participants' attitudes toward their present life situation, and their belief in their own ability to control daily life and to deal with their limitations. In this study, such improvements were

reported 1 year after the programme, which is an indication that change had taken place. The participants reported considerable changes in their coping strategies. Even with a conservative interpretation, where only results >7 on a 10-point scale were considered as "clear change", the results imply that 1 year after the programme a substantial proportion of the participants had adapted and changed many habits. The responses to the question "How many days did you feel well during the last 7 days?" also showed that somewhat more than one-third of the participants 1 year after the programme had more days when they felt well. This is a clinically meaningful improvement. Another clinically meaningful result is that the number of persons working 1 year after the programme had increased.

An interesting finding was that even though the different programmes were of different lengths and formats and offered different treatment modalities provided by therapists from different professions, the participants were generally satisfied with their own programme. The reason for this could be that all the programmes were client-centred, the diagnosis was confirmed, symptoms were explained and the participants had an opportunity to discuss their problems with peers and professionals. Thus, the focus of the programmes was rather similar, and the extra treatments given at some of the centres did not result in more improvement or more satisfaction. That a short educational intervention can give lasting results has recently been shown in a study from the Mayo clinic (42). In the present study, the 2 more comprehensive and expensive programmes did not lead to further improvements for the majority of the patients. When comparing the programmes, no clear differences could be found. To improve physical function, it is likely that more intensive physical training is necessary.

The instruments used in this study have been used in other studies for estimating quality of life, level of functioning, and severity of symptoms in patients with chronic pain. However, the instruments did not capture the changes in attitudes, daily habits, or the reported feeling of control and ability to handle everyday life.

Continuous pain in many parts of the body and being diagnosed with a chronic disease is a threatening experience for most people. Information about the pain, the consequences of the pain and what can be done to lessen the pain and manage everyday activities is imperative to eliminate unnecessary anxiety and inactivity, and to give patients the support and ability to handle their situation and reach an optimal quality of life.

This study concludes that although interventions for patients with fibromyalgia do not give striking outcomes measured in lower pain intensity or increased function, other important gains had been achieved. Client satisfaction and adaptive changes made in everyday life are valuable results in patients with life-long chronic conditions. All patients with fibromyalgia need information and opportunities to discuss their situation, preferably in a group programme (9, 15, 16). This study shows that also shorter and inexpensive interventions are beneficial, and repeated interventions and group support during a longer period can help participants adjust their habits and routines. Some

patients may need individual interventions focused, for example, on physical reconditioning (11), treatment of depression, and psychological treatment. Thus, more comprehensive and costly programmes should be offered only on special indications. Further comparative and cost-benefit research is needed and suitable instruments for selecting patients with consideration to needs and prognostic factors should be developed. Moreover, instruments for evaluating change in ability to function in everyday life and in quality of life need to be further developed and tested in populations of patients with fibromyalgia or other conditions where pain and tiredness are major symptoms.

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