

Do Support Groups Help People with Chronic Fatigue Syndrome and Fibromyalgia? A Comparison of Active and Inactive Members

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ABSTRACT. *Objective.* To examine the benefits and problems of a chronic fatigue syndrome (CFS) and fibromyalgia (FM) support organization as reported by its participants.

Methods. Active members ($n = 32$) and inactive members or dropouts ($n = 135$) of a regional support organization for people with CFS and FM completed a 26 item questionnaire by telephone interview or by self-completion and postal return.

Results. The most frequently endorsed benefits of membership were illness legitimization (67.8%), finding out helpful new information (66.4%), and feeling understood by others (62.2%). Lower frequency endorsements were given to: helped to find (35.0%) or deal with (38.5%) doctors, and helped to improve my illness (36.4%). The most frequently reported reasons for dropping out were inconvenient location (37.8%) or time (37.0%), too much negative talk or complaining (33.3%), too sick to attend (28.8%), and illness or coping improvement (29.6% each). The active-member group showed significantly higher ($p < 0.04$) symptom severity scores and less illness improvement ($p < 0.01$) in comparison to the inactive/dropout group.

Conclusion. This cross-sectional study suggests that support groups for CFS are viewed as helpful by participants on a number of illness related issues. On the other hand, active members reported greater symptom severity and less illness improvement than inactive members or dropouts. (J Rheumatol 2005;32:2416–20)

Key Indexing Terms:
FIBROMYALGIA
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CHRONIC FATIGUE SYNDROME
STIGMATIZATION

Support groups can provide an opportunity for people with a common problem to come together, share their experiences and concerns, and learn in a context that is controlled by the participants and requires little or no professional input^{1,2}. Support groups for people with chronic fatigue syndrome (CFS) and fibromyalgia (FM), both poorly understood and often stigmatized illnesses^{3,4}, have not been studied until recently. In a comparative study⁵ of social support outcomes in patients with CFS, other fatigued and nonfatigued patients, and healthy controls, it was found that CFS and other fatigued patients reported significantly more negative interactions and lower levels of supportive interactions than nonfatigued patients and healthy controls. For the CFS patients, negative social interactions significantly decreased after cognitive-behavioral treatment, but did not change in support groups or a natural course condition over the same period.

In a study of support group participation for 20 disease categories in 4 metropolitan areas and 2 online forums⁶, the authors argued that the embarrassment and stigma of medically unexplained conditions, such as CFS and FM, were important factors in generating group support. The experience of embarrassment carries with it the ongoing burden of chronic emotional arousal accompanied by the suppressed desire to talk to others. Such social barriers represent a significant health risk^{7,8}.

Based on the first author's personal observations of a number of state and local CFS and FM support organizations, a typical agenda consists of regular monthly meetings involving a featured professional or patient speaker. Alternatively, a support group facilitator may present new illness information and encourage questions and interactions among participants. Many of these support organizations also publish periodic newsletters and sponsor special events, such as fundraisers or annual conferences for patients and professionals.

One concern regarding these support group meetings is the possible negative influence they may have on participants. A behavioral perspective cautions that these groups may reinforce the assumption or maintenance of a sick role⁹. In addition, fatigue and pain and its associated disability, if expressed in a group situation, may reinforce illness related

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cognitive distortions such as exaggerated catastrophic beliefs, self-deprecation, and intolerance of symptoms¹⁰. In a cognitive-behavioral treatment trial¹¹ for CFS that used a CFS support group and a natural course condition as control groups, the support group outcomes were comparable to the natural course condition, and significantly less effective than the cognitive-behavioral treatment condition.

This cross-sectional study examined the benefits and problems of a CFS and FM support organization as reported by its members. A comparison between active and inactive members in the support organization provided additional information about perceptions of the group experience. Given the well documented difficulties patients with CFS and FM have with their healthcare providers and social networks¹², an effective support organization assumes an especially important role for these medically underserved and stigmatized patients.

MATERIALS AND METHODS

Subjects and assessment. Using the membership list of the Long Island CFIDS Alliance, a regional support organization for people with CFS and FM, 341 individuals were contacted to request completion of a 26 item questionnaire (Table 1) developed in consultation with support group leaders. The questionnaire obtained data on demographics, patient diagnoses, symptom severity ratings, a global rating of illness change¹³, illness attribution¹⁴, a self-efficacy rating (based on Vercoulen, *et al*¹⁵), support group membership status, benefits and problems of the support network, and reasons for dropping out of the network. A consent script approved by the Stony Brook Institutional Review Board was either read to the subject over the telephone or sent with the questionnaire.

One hundred sixty-seven participants completed the questionnaire, yielding a response rate of 49.0%. Thirty-two active members (i.e., individuals who at least occasionally attended monthly support group meetings), 114 inactive members (i.e., individuals who received mailings, but had no other involvement or participation), and 21 dropouts (i.e., individuals who neither received mailings nor participated in any way) completed the questionnaire by telephone interview (n = 84) or by self-completion and postal return (n = 83). No significant differences of demographic or illness

variables were found between the 2 modes of data collection.

Active members reported attending 3.25 support group meetings, on average, in the past year. The data for the inactive and dropout groups were combined (n = 135) for all analyses because (1) the delineation of these 2 groups — based on receiving or not receiving a quarterly newsletter — relied on self-report for information that may have been difficult to remember and could not be independently confirmed; and (2) no significant differences on demographic or illness severity variables were found between the 2 groups. The active-member group compared to the inactive/dropout group showed no significant differences on the variables of age, employment status, illness duration, length of membership, physical illness attribution, or self-efficacy ratings.

Statistical analysis. Descriptive statistics, frequency analyses, and inferential statistics (chi-square tests and t tests for independent samples) were performed using SPSS. Alpha was set at 0.05.

RESULTS

Sociodemographic data for the full sample (N = 167) are presented in Table 2. From the full sample, 80.4% considered the support organization to be generally helpful (Table 3). The most frequently endorsed benefits of membership were illness legitimization (67.8%), finding out helpful new information (66.4%), feeling understood by others (62.2 %), and increased political awareness of illness issues (48.0%). Lower frequency endorsements were given to: helped to find (35.0%) or deal with (38.5%) doctors, and helped to improve my illness (36.4%).

In comparison to the combined inactive-member and dropout group, the active-member group was significantly more likely to endorse the following benefits (Table 3): the overall helpfulness of the group, finding out helpful new information, feeling understood by others, increased political awareness of illness issues, dealing with doctors better, and illness improvement. Of the 135 inactive members or dropouts, the most frequently reported reasons for dropping out were inconvenient location (37.8%) or time (37.0%), too much negative talk or complaining (33.3%), illness or cop-

Table 1. Key items and [concepts] from the study questionnaire.

| | |
|---|---|
| 11. [CFS/FM Symptoms: Frequency and Severity] | |
| Significant fatigue | Muscle weakness |
| Muscle pain | Nausea |
| Joint pain | Fevers and chills |
| Headaches | Memory/concentration difficulties |
| Wake up feeling tired | Depressed mood |
| Sore throats (apart from colds and flu) | Anxiety or tension |
| Tender/sore lymph glands (apart from cold and flu) | General loss of desire (not motivated) to do things |
| Post-exertional malaise (feeling worse after doing physical or mental activities) | Loss of enjoyment |
| 13. Compared to when you first joined the Long Island CFS/FM support network, your illness now is: [global impression of change]. | |
| 14. Do you think that the cause of your illness is: [physical/psychological attribution]. | |
| 15. My personal attitude helps me cope with my fatigue [self-efficacy]. | |
| 21. How has the CFS/FM support network helped you? [benefits of membership]. | |
| 22. If you are an inactive member or dropout, which of these reasons best describes why you have become inactive? [past problems with the support network]. | |
| 23. If you are still active in the support network, what do you not like about it? [current problems with the support network]. | |

Table 2. Characteristics of the sample.

| Variable | n | % | Mean | SD |
|-------------------------------------|-----|------|------|------|
| Age, mean yrs | 167 | | 52.5 | 10.9 |
| Education, mean yrs | 167 | | 14.8 | 2.6 |
| Sex | | | | |
| Male | 29 | 21 | | |
| Female | 132 | 79 | | |
| Ethnicity | | | | |
| Caucasian | 159 | 95.1 | | |
| Hispanic | 2 | 1.4 | | |
| Asian | 1 | 0.7 | | |
| Other | 5 | 2.2 | | |
| Employment status | | | | |
| Disability | 54 | 33.5 | | |
| Unemployed/retired | 53 | 33.3 | | |
| Part-time | 19 | 11.8 | | |
| Full-time | 38 | 22.4 | | |
| Marital status | | | | |
| Married | 91 | 54.5 | | |
| Divorced | 35 | 12.0 | | |
| Never married | 39 | 23.4 | | |
| Illness duration (CFS/FM; mean yrs) | 167 | | 12.7 | 6.4 |
| Length of membership, yrs | | | | |
| ≥ 5 | 78 | 47.0 | | |
| < 1 | 21 | 12.7 | | |
| 1–5 | 67 | 40.3 | | |
| Member status | | | | |
| Active | 32 | 19.2 | | |
| Inactive/dropout | 135 | 80.8 | | |
| Diagnoses | | | | |
| Chronic fatigue syndrome | 126 | 75.5 | | |
| Fibromyalgia | 99 | 62.2 | | |
| Multiple chemical sensitivity | 46 | 28.0 | | |

ing improvement (29.6% each), and too sick to attend (28.8%). For active members, the most frequently cited problems were inconvenient time or location (31.1% each) and too much negative talk or complaining (25.0%).

The active-member group showed significantly higher symptom severity scores in comparison to the inactive/dropout group ($t = 2.14$; $df = 145$; $p < 0.04$). In addition, the active-member group was significantly less likely, since joining the support group, to report illness

improvement on a 7 point global impression of change rating (chi-square = 6.65; $df = 1$; $p < 0.01$; Figure 1). Specifically, since joining the support group, illness change was rated as “improved” or better by 35.7% of the active-member group as compared to 55.4% of the inactive/dropout group; “worse,” “much worse,” or “very much worse” by 46.4% of the active-member group as compared to 25.4% of the inactive/dropout group; and “unchanged” by 17.9% of the active-member group compared to 19.2% of the inactive/dropout group. In the full sample, the self-efficacy rating was significantly correlated with global rating of change ($r = 0.23$; $p < 0.01$), but illness attribution was not.

DISCUSSION

This cross-sectional study of the Long Island regional support organization for people with CFS and FM found that a majority of both active members and inactive members or dropouts reported a number of benefits of membership. The most frequently endorsed benefits included illness legitimization, finding out helpful new information, and feeling understood by others. The most often-cited problems included inconvenient time or location and too much negative talk or complaining. Although 49.1% of the full sample reported some level of illness improvement, the majority of participants were unemployed.

Active members reported significantly greater symptom severity and less illness improvement in comparison to the inactive members and dropouts. Yet other study variables that have been shown to predict both naturalistic and clinical outcomes in CFS and FM including self-efficacy^{16,17}, illness attribution¹⁸, illness duration^{19,20}, and age^{21,22} were not significantly different between the active and inactive/dropout groups in this study. Although self-report avoidance behavior, another predictor of outcome²³ in CFS, was not measured in this study, employment rates, an important indicator of overall functioning, were not significantly different between the active and inactive groups.

The greater symptom severity and lower level of illness improvement in the active-member group also raises important questions about causal ordering that cannot be resolved

Table 3. Participant-rated benefits of support group membership.

| Benefit of Support Group Membership | Active Members, % | Inactive Members/ Dropouts, % | Total Sample, % |
|-------------------------------------|-------------------|----------------------------------|-----------------|
| Generally helpful | 96.6* | 76.7 | 80.4 |
| Illness legitimization | 71.9 | 66.7 | 67.8 |
| Helpful new information | 81.3* | 62.2 | 66.4 |
| Feeling understood by others | 81.3** | 56.3 | 62.2 |
| Increased political awareness | 65.6* | 43.0 | 48.0 |
| Helped to find new doctors | 50.0 | 31.1 | 35.0 |
| Helped to deal with doctors | 59.4* | 34.1 | 38.5 |
| Helped to improve illness | 53.1* | 31.9 | 36.4 |

* $p < 0.05$, ** $p < 0.01$.

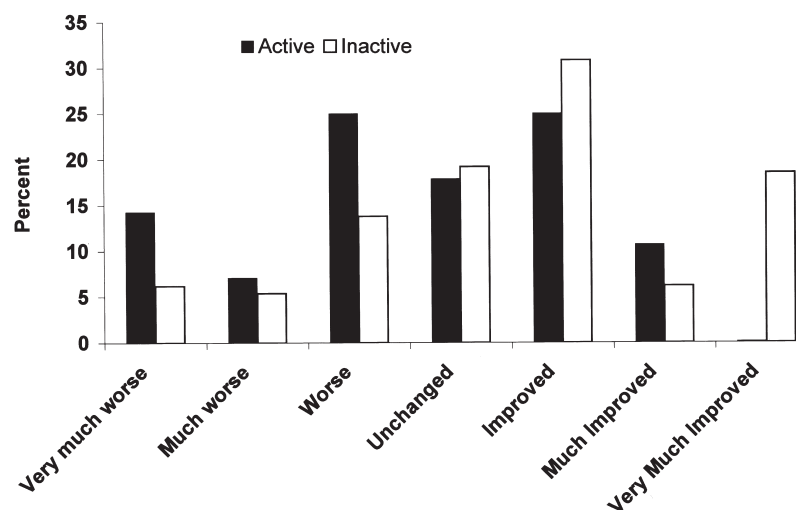


Figure 1. Global impression of change ratings.

in a cross-sectional study. For instance, it could be argued that sicker individuals would be more likely to join the support group because they could not find help from skeptical healthcare providers who often view CFS and FM as non-illnesses²⁴. Yet the improved social support associated with CFS and FM support group membership may not adequately satisfy the need for companionship and empathy⁵ that may be important to illness improvement²⁵. Further, support group membership may be associated with increased illness severity if participants are exposed to illness-magnifying social interactions, such as dwelling on symptom complaints¹³ or catastrophizing^{26,27}. Indeed, negative talk and complaining were cited as a problem by one in 3 participants in the inactive/dropout group. On the other hand, nearly 60% cited illness or coping improvements as reasons for becoming inactive in the support group. To study the possible reasons for illness severity differences between the active and inactive groups further, in-depth interviews with selected participants could provide important insights into the illness experience and the lifestyle factors that may influence it²⁸.

An apparent paradox in the findings is that a slight majority (53.1%) of the active-member group reported illness improvement as a benefit of the support group, yet only 35.7% of the active group reported improving illness on the global rating. Because active group participants attended less than 4 monthly meetings on average in the year prior to completing the study, it seems unlikely that such minimal involvement could result in substantial improvements in illness severity or coping. In comparison to the typically unstructured monthly support meetings of CFS and FM groups, successful cognitive-behavioral treatment studies in CFS²⁹ and FM³⁰ have employed 6–16 session clinical protocols over 3–6 months, while professionally led structured groups for arthritis and FM³¹ have used 6 weekly sessions.

Yet it is understandable that support group participants, even without professional guidance, want to feel hopeful that meetings will provide useful information about illness control strategies that may yield improvements⁶.

The group members in this study cannot be considered representative of the CFS and FM populations as a whole, but rather are a motivated self-selected group seeking illness information and support. The group participants included those who could conveniently attend meetings and those who were not too disabled to do so. In addition, the self-report assessments in this study for important issues such as diagnosis and work status were not independently verified.

The largely favorable perceptions of this support organization by its members may be viewed as a tribute to the dedicated volunteers who ran the group despite their ongoing personal struggles with chronic illness. What makes a support group for people with CFS and FM optimally beneficial to participants? A prospective controlled study would be required to definitively answer this question. A comparative longitudinal study of different support groups could examine the effects of important organizational characteristics including meeting content and process, and leadership quality.

Alternatively, the success of professionally developed time-limited protocols in structured support groups, such as those used in arthritis³¹, could be modified to fit the monthly meeting format typical of CFS and FM support groups. These structured groups typically present specific topics at each session such as illness education, living with unpredictability, identification of negative feelings, and illness coping skills^{32,33}. Developing a well defined program would require ongoing funding and support from interested agencies as well as input from behavioral health professionals who understand the mind-body issues in these enigmatic illnesses.

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