

Identification of the Health Educator's Role in the Management of Fibromyalgia Syndrome Through an Examination of Patients' Needs

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Abstract

The role of the health educator in the management of Fibromyalgia (FMS) was explored by examining patient symptoms, quality of life, coping strategies, and needs. An 85-item questionnaire administered to 600 FMS support group participants (response rate – 46.5%) indicated that pain is the worst symptom, FMS has a negative impact on quality of life and stress levels, and many are using alternative treatments. Health educators can help by promoting exercise, teaching stress management techniques, teaching consumerism issues, assisting with alcohol and drug abuse treatment when necessary, and educating the public about this disease.

Introduction

Fibromyalgia Syndrome (FMS), a disorder characterized by widespread pain and fatigue, has been in existence since the 17th century and has been referred to by a variety of different names throughout its history: fibrositis, fibromyositis, myofibrositis, tension myalgia, tension rheumatism, and myofascitis (Backstrom & Rubin, 1992; Clauw, 1995; and Fibromyalgia Network, 1999). Although people have been suffering from the symptoms of this disorder for centuries, FMS was not recognized as a true illness and as a major cause of disability by the American Medical Association until 1987 (Starlanyl, 1996). In 1993 the World Health Organization adopted the diagnostic criterion for FMS developed by the American College of Rheumatology and recognized FMS as a true syndrome (Gremillion, 1998). Despite the fact that this syndrome is now officially recognized as a true physical disorder, many FMS sufferers are still not receiving an initial diagnosis or the treatment they need, because many physicians are either still skeptical and consider the disease a psychological problem or they are uneducated about FMS (Bennett, 1993; Bennett & McCain, 1995; Dunkin, 1997; Russell, 1995; Silverman, 1994; Starlanyl, 1996; and Wolfe, 1994).

The symptoms of FMS are numerous, hence the reason it is referred to as a syndrome. These symptoms include pain in tender point areas, fatigue, sleep disorders, irritable bowel syndrome, chronic headaches, temporomandibular joint dysfunction syndrome, multiple chemical sensitivity syndrome, PMS, anxiety and

depression, stiffness, cognitive or memory impairment, and restless leg syndrome (Aaron, Bradley, Alarcon, Triana-Alexander, Alexander, Martin, & Alberts, 1997; Bennett, 1998; Clauw, 1995; Fibromyalgia Network, 1999; Gustafsson & Gaston-Johansson, 1996; Littlejohn, 1995; Millott & Berlin, 1997; Reiffenberger & Amundson, 1996; Russell, 1995; Schaefer, 1995; Soderberg and Norberg, 1995; Verstappen, von Sonten-Hoeufft, van Sloren, Bolwijn, & van der Linden, 1995; Waylonis & Heck, 1992; and Yunus, 1994). Because there is no known cure for FMS, treatment is limited to symptom management (Bennett et al., 1995; Buckelew, 1994; and Waylonis & Perkins, 1994). Treatment options include drugs to relieve pain, fatigue, sleep problems, and/or depression; exercise; dietary modification, stress reduction; and alternative medicine (Aaron et al., 1997; Backstrom & Rubin, 1992; Bennett et al., 1995; Buckelew, 1994; Burckhardt, 1994; Burckhardt, O'Reilly, Wiens, Clark, Campbell, & Bennett, 1994; Clauw, 1995; Goldenburg, Kaplan, Nadeau, Brodeur, Smith, & Schmid, 1994; McCain, 1994; Pioro-Boisset, Esdaile & Fitzcharles, 1996; Reiffenberger et al., 1996; Schaefer, 1997; Waylonis et al., 1994; Wilke, 1995; and Wolfe, Ross, Anderson, Russell & Hebert, 1995). Because the management of symptoms of FMS usually involves more than one of these techniques, disease management often requires a "team approach" including a variety of health professionals, each who specializes in a different type of treatment (Gremillion, 1998). Health educators are uniquely qualified to be a part of FMS management teams because of their expertise in the areas of exercise, stress management, and dietary modification. Because

patients must often make lifestyle changes in order to successfully manage their symptoms, health educators are essential to providing the education, support and motivation needed to help patients achieve and maintain these lifestyle modifications. The purpose of this article is to explore the role of the health educator in the management of FMS by examining: 1) what FMS patients consider to be their worst symptoms and how they cope with those symptoms, 2) FMS patients' perceived quality of life and level of support, 3) what FMS patients say they need from health care providers.

Procedures

A questionnaire, developed by the researchers, was administered to FMS support group members in three states: Washington, Illinois, and Pennsylvania. The questionnaire was pilot tested with members of a local FMS support group and includes 85 questions which address a variety of issues regarding FMS: demographics; progression of the disease; symptoms; management; quality of life; social support; exposures to factors theorized to be linked to FMS; and coping strategies. Approximately half of the questions were open-ended and the remaining half were yes/no or check all that apply format.

The participants were recruited through their FMS support group leaders. Support group leaders from each state were randomly selected from a list of FMS support groups broken down by state (the list was provided by the Fibromyalgia Network). The support group leaders were contacted via telephone and asked if they would be willing to administer the questionnaire at a support group meeting. If they agreed, they were asked how many members were in their support group. The researchers continued randomly selecting support groups from within each state until the number of questionnaires to be distributed in each state reached at least 200 (for a total of 600 in the target population). The questionnaires were mailed to support group leaders and were distributed at the next support group meeting. Support group members took the questionnaires home with them to complete and mailed them directly back to the researchers. A total of 270 useable surveys were returned (response rate = 46.5%).

Results

Demographics

The respondents were primarily female (93.6%), which is consistent with demographic characteristics of FMS patients reported in other studies (Wolfe et al., 1995; Clauw, 1995; and Reiffenberger et al., 1996). The average age of the respondents was 50 (sd=10.66), which is also consistent with findings from previous studies (Richman, 1996). Almost 90% of the sample

was Caucasian (89.2%), 6.9% were Hispanic, 1.5% were Native American, 0.8% were African American, 0% were Asian, and 1.5% indicated "other". The majority of the sample consisted of married persons (69.2%), 12% were single, and the remaining respondents were either separated, divorced, or widowed.

Symptoms

Although FMS is a disease which causes many symptoms, the respondents were asked to indicate what they consider their worst symptom of FMS to be. Most indicated that pain is their worst symptom (52.8%). Less than half that number indicated that fatigue is their worst symptom (21.5%). Sleep disturbance was the third most common response, although only 6.4% indicated this as their worst symptom. Memory/concentration loss, muscle spasms, and muscle weakness were all indicated as the worst symptom by 2.4% of the sample. Approximately 2.0% reported that headaches/migraines were the worst symptom. The remaining symptoms were reported by less than 2% of the respondents: disability, stiffness, irritable bowel syndrome, depression, anxiety, arthritis-like symptoms, being wired, bursitis, flu-like symptoms, helplessness, immune system problems, itching, lightheadedness, and tendomandibular joint disorder.

Symptom Relief

Most (81.5%) of the respondents reported using prescription drugs to relieve their symptoms (Table 1). However, 52% of those using prescription drugs report that these drugs are not effective in relieving symptoms. Most respondents indicated using additional techniques to manage their symptoms. Over half indicate using vitamin or mineral supplements (55.7%), 44.6% report using various other types of nontraditional remedies (massage therapy, biofeedback, etc.), and 44.6% indicate using exercise to help.

Quality of Life

Many respondents reported making major alterations in their lifestyles including quitting their jobs or cutting back their hours, giving up hobbies they love, and not being able to spend as much time with friends and loved ones. As can be seen in Table 2, the majority of respondents indicated that FMS has brought about a decrease in their quality of life. The mean ranking on a 10-point quality of life scale (10 being the highest) was 8.4 for life prior to the onset of FMS. Quality of life since the onset of FMS went down approximately 4 points to 4.76. When asked to speculate what their quality of life would be if their FMS were to disappear, the mean score went up to 9.12.

Table 1. Methods Used to Relieve Fibromyalgia Symptoms

METHOD USED	RESPONSE INFORMATION Percent (No.)
Prescription Drugs ^a	
Yes	81.5 (212)
Are these drugs effective? ^b	
No	51.9 (110)
Yes	25.5 (54)
To A Degree	6.1 (13)
Don't Know	1.9 (4)
Varies	0.9 (2)
Not Applicable	1.4 (3)
No	18.5 (48)
Vitamin or Mineral Supplements ^c	
Yes	55.7 (141)
No	44.3 (112)
Nontraditional Remedies ^d	
Yes	44.6 (107)
No	55.4 (133)
^a n = 260 ^b n = 212 ^c n = 253 ^d n = 240	

Coping Strategies

Respondents were asked about techniques they use to cope with their FMS symptoms. These techniques are divided into positive and negative coping strategies in Table 3. Coping strategies that did not have the potential to be detrimental to health were considered positive and those with that potential were considered negative. In regard to negative coping strategies, approximately 12% indicated using alcohol to escape from FMS. Of those, 40.6% indicated having a history of alcohol abuse. One-third of the sample indicated using nonprescription drugs to escape from FMS. Of these, only 12.5% had any history of drug abuse. Most respondents reported using positive strategies to cope with their disease. The positive coping strategy reported most frequently by the respondents was talking to a friend or family member (62.4%). Praying ranked

second with 60.2% of respondents using this technique. Exercise was reported by 59.4%, which makes it the third most popular strategy. Various other techniques were reported by a number of the respondents: getting involved in hobbies (45.9%), practicing relaxation techniques (42.5%), talking to a professional (41.0%), meditation (33.1%), and reading about FMS (28.2%).

Social Support

Respondents were asked to rank the social support received from various family members. The mean ranking of social support (on a scale from 1 to 10) was highest for the patient’s significant other and children and was higher in female relative than in male relatives (Table 4).

What FMS Patients Want from Health Care Providers

Table 5 represents the “wish list” of the FMS patient respondents. Most FMS patients simply want

the support of their health care providers (51.1%) for people to become better educated about the disease to increase the understanding of health care professionals and the public (50.4%), and for people to believe that

this disease actually exists (30.1%). These wants took precedence over issues such as the development of better medications (15.0%), conducting more research on FMS (13.5%), and the development of better diagnostic tools (7.5%).

Table 2. Quality of Life Measurement

RANKING (ON 1-10 SCALE)	QUALITY OF LIFE PRIOR TO ONSET OF FMS ^a Percent (No.)	QUALITY OF LIFE SINCE ONSET OF FMS ^b Percent (No.)	QUALITY OF LIFE IF FMS WENT AWAY ^c Percent (No.)
1	0.77 (2)	7.60 (20)	0.00 (0)
2	0.77 (2)	9.51 (25)	0.40 (1)
3	1.15 (3)	11.03 (29)	0.40 (1)
4	1.54 (4)	14.45 (38)	0.00 (0)
5	5.00 (13)	23.19 (61)	1.20 (3)
6	2.69 (7)	15.21 (40)	2.01 (5)
7	6.92 (18)	6.08 (16)	6.43 (16)
8	24.52 (64)	7.60 (20)	15.66 (39)
9	23.85 (62)	2.66 (7)	18.07 (45)
Highest 10	32.69 (85)	2.66 (7)	55.82 (139)
Mean Score (sd)	8.40 (1.79)	4.76 (2.18)	9.12 (1.30)

^a n = 260
^b n = 263
^c n = 249

Discussion

Implications

Because there is no known cause of FMS and thus no cure, health care professionals are limited to secondary and tertiary prevention efforts. Detecting this disease at its earliest possible stages enables the patient to initiate a symptom management regimen as soon as possible, which can greatly impact quality of life. Public health education is essential to secondary prevention of this disorder. Education about the wide array of symptoms of FMS can enable those suffering from these symptoms to identify the need to seek specialized care as soon as possible.

Tertiary prevention, the management of FMS, is complex and often requires a team approach due to the myriad symptoms and their associated treatments. Health educators can assist in this team approach in two ways. Symptom management and the control of problems associated with unsuccessful symptom management are the most important issues health educators can assist FMS patients with. Because of the

lack of success with prescription medications, many respondents in this study, as well as those from previous research studies, are turning to alternative treatments to relieve their symptoms (Aaron et al., 1997; Backstrom et al., 1992; Bennett et al., 1995; Burckhardt, 1994; Clauw, 1995; McCain, 1994; Millott et al., 1997; Pioro-Boisset et al., 1996; Reiffenberger et al., 1996; Schaefer, 1997; and Wilke, 1995). Failure to manage symptoms of FMS successfully has a tremendous impact on quality of life as evidenced by the results of this study and others (Burckhardt et al., 1993; Burckhardt, Clark, O'Reilly, & Bennett, 1997; Gaston-Johansson, Gustafsson, Felldin, & Sanne, 1990; Henriksson, 1994; Neumann & Buskila, 1997; Schaefer, 1997; Uveges, Parker, Smarr, McGowan, Lyon, Irvin, Meyer, Buckelew, Morgon, Delmonico, Hewett, & Kay, 1990; Wilke, 1995; and Wolfe & Hawley, 1997). And occasionally unsuccessful management of FMS symptoms leads to negative coping strategies like alcohol and drug misuse as reported by respondents in this study. Health educators

can assist FMS patients with symptom management and control of problems centering around symptoms in several ways:

Promoting Exercise. Exercise often helps alleviate the pain and fatigue associated with this disease, can improve sleeping patterns of FMS patients, and can have a positive impact on depression in FMS patients. Many experts in the area of FMS highly recommend exercise as a strategy to relieve FMS symptoms

(Backstrom et al., 1992; Bennett et al., 1995; Burckhardt, 1994; Clauw, 1995; McCain, 1994; Reiffenberger et al., 1996; and Wilke, 1995). Although some respondents in this study reported using exercise, many others did not. It is a very difficult behavior to maintain when one is having a great deal of pain and fatigue. Health educators are uniquely qualified to help FMS patients initiate and maintain an exercise program due to their expertise in behavior modification and exercise knowledge.

Table 3. Positive and Negative Coping Strategies of Fibromyalgia Patients

COPING STRATEGIES	RESPONSE INFORMATION Percent (No.)
<i>Negative Coping Strategies</i>	
Using Alcohol to Escape from FMS ^a	12.1 (32)
History of Abusing Alcohol Prior to Onset of FMS? ^b	
Yes	40.6 (13)
No	59.4 (19)
Using Nonprescription Drugs to Escape from FMS ^c	33.5 (89)
History of Abusing Nonprescription Drugs Prior to Onset of FMS? ^d	
Yes	12.5 (11)
No	87.5 (77)
<i>Positive Coping Strategies^e</i>	
Meditation	33.1 (88)
Relaxation Techniques	42.5 (113)
Talking to a Professional	41.0 (109)
Joining a Support Group	75.2 (200)
Praying	60.2 (160)
Exercise	59.4 (158)
Talking to a Friend or Family Member	62.4 (166)
Getting Involved in Hobbies	45.9 (122)
Reading About Fibromyalgia	28.2 (75)
Other ^f	4.9 (13)

^a n = 265

^b n = 32

^c n = 266

^d n = 88

^e n = 266

^f "Other" responses included: rest, volunteer work, massage and/or physical

Therapy, reading, working, having/walking dogs, water aerobics, positive thinking

Stress Management. Meditation, positive imagery, and various other stress management techniques have been shown to alleviate pain and improve sleeping patterns in FMS patients (Aaron et al., 1997; Clauw, 1995; Goldenburg et al., 1994; Henriksson, 1994; McCain, 1994; and Wilke, 1995). More and more FMS patients are recognizing the benefits of stress management, as evidenced by the number of respondents in this study using stress management techniques as positive coping strategies. These patients need health professionals trained in a variety of stress management techniques to help them to make these techniques a part of their FMS treatment regimen.

Self-Efficacy. Studies have demonstrated that patients with a higher degree of confidence in their ability to manage their symptoms report less pain and fatigue than those who have lower self-efficacy levels, have a higher perceived quality of life, and respond more positively to treatment (Buckelew, Huyser, Hewett, Parker, Johnson, Conway & Kay, 1996 and Buckelew, Murray, Hewett, Johnson, & Huyser, 1995). Health educators can develop programs which specifically aim to raise self-efficacy levels in FMS patients.

Consumerism. Because many FMS patients are turning to alternative therapies for symptom management, the potential exists for FMS patients to be taken advantage

of by clever marketers. Health educators can provide FMS patients with information regarding alternative products and services and how to determine which claims are real.

Alcohol and Drug Abuse Treatment. Although alcohol and drug abuse was not common among the respondents in this study, it is a very real problem for a minority of patients. Prevention of alcohol and drug abuse and treatment for those who are already abusing is critical.

Impacting social support is the second way health educators can assist FMS patients. Social support is extremely important in the management of FMS. In this study it was reported as the number one desire of the respondents. Public health education would not only educate people with the symptoms of this disease and encourage them to get treatment, but would also educate the family, friends, and various health care providers that the FMS patient may come into contact with. This education may enable these people to provide the FMS patient with the support he or she needs emotionally to cope with this disease. Additionally, public health education can help to ensure that this disease has a voice in regard to advocacy efforts, which may help channel research and programming funding toward FMS.

Table 4. Level of Support Received from Family

RANKING	SIGNIFICANT					
	OTHER ^a Percent (No.)	MOTHER ^b Percent (No.)	FATHER ^c Percent (No.)	SISTER ^d Percent (No.)	BROTHER ^e Percent (No.)	CHILDREN ^f Percent (No.)
0 (least supportive)	4.17 (9)	20.25 (33)	32.45 (49)	22.03 (39)	25.66 (39)	9.41 (19)
1	4.17 (9)	6.13 (10)	9.27 (14)	7.91 (14)	15.79 (24)	6.44 (13)
2	1.85 (4)	6.75 (11)	5.96 (9)	3.95 (7)	10.53 (16)	4.95 (10)
3	2.78 (6)	2.45 (4)	3.31 (5)	7.91 (14)	4.61 (7)	9.41 (19)
4	2.78 (6)	4.29 (7)	7.95 (12)	3.39 (6)	3.29 (5)	3.96 (8)
5	11.57 (25)	10.43 (17)	6.62 (10)	8.47 (15)	15.13 (23)	11.39 (23)
6	4.63 (10)	5.52 (9)	7.95 (12)	5.08 (9)	3.95 (6)	6.44 (13)
7	11.57 (25)	4.91 (8)	4.54 (7)	8.47 (15)	2.63 (4)	7.43 (15)
8	16.20 (35)	12.88 (21)	8.61 (13)	12.4 (22)	8.55 (13)	15.35 (31)
9	11.11 (24)	6.13 (10)	4.54 (7)	5.65 (10)	3.29 (5)	6.44 (13)
10 (most supportive)	29.17 (62)	20.25 (33)	8.61 (13)	14.69 (26)	6.58 (10)	18.81 (38)
Mean (SD)	7.14 (2.90)	5.25 (3.78)	3.73 (3.56)	4.81 (3.68)	3.45 (3.30)	5.75 (3.33)

^a n = 216
^b n = 163
^c n = 151
^d n = 177
^e n = 152
^f n = 202

Future Research

Health educators need to become a part of future research efforts targeting FMS. Much of the research to date has been clinical in nature and the results of this study and others show that clinical management of this disease is only a part of the disease management process (Aaron et al., 1997; Backstrom et al., 1992; Bennett et al., 1995; Burckhardt, 1994; Clauw, 1995; McCain, 1994; Millott et al., 1997; Piro-Boisset et al., 1996; Reiffenberger et al., 1996; Schaefer, 1997; and Wilke, 1995). Education and treatment programs for

FMS patients need to be designed, implemented, and evaluated for effectiveness. Specific program topics should include exercise, stress management and self-efficacy.

Additionally, longitudinal studies assessing the effectiveness of various treatments should be undertaken. Because symptoms change over time and fluctuate for most patients on a frequent basis, subjects should be followed over time to see how programs and/or treatments work during the course of this disease.

Table 5. What FMS Patients Want

What FMS Patients Want	Percent (No.)
Support	51.1 (70)
Better Educated Health Professionals	50.4 (67)
Belief that the Disease Exists	30.1 (40)
Better Medications	15.0 (20)
More Research Funding	13.5 (18)
Better Diagnostic Tools	7.5 (10)
Other	21.1 (28)

n = 133

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