

Educating patients: Self-Management approaches

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Abstract

Purpose. To review and evaluate approaches to educating patients with fibromyalgia syndrome (FMS).

Methods. A narrative literature review was undertaken to summarize the published literature on patient education for FMS patients.

Results. A number of studies contain specific education strategies while others are combined with exercise or movement therapies or cognitive-behavioural therapy.

Conclusions. Self-efficacy provides an effective theoretical model from which to understand how patients change as a result of education strategies that focus on self-management. Programmes that combine education with cognitive-behavioural techniques and exercise are most effective in enhancing self-efficacy and decreasing symptoms of FMS.

Keywords: *Fibromyalgia syndrome, patient education*

Introduction

Patient education has an historic and valued place in health care. A recent meta-analysis found that patient education was an integral part of most chronic disease management programmes [1]. In fibromyalgia syndrome (FMS) treatment, a well-educated patient who is able to self-manage and make modifications based on symptom fluctuation is the most important member of a successful management team.

The Arthritis Foundation defines patient education as ‘planned, organized learning experiences designed to facilitate voluntary adoption of behaviours or beliefs conducive to health’ [2]. Goals of FMS education include shifting patients’ perceptions from helplessness, frustration, and hopelessness to a positive sense of ability to cope with and manage symptoms in a way that enhances functioning and quality of life. The ability to maintain desired work and social roles, experience satisfying interpersonal relationships, and engage in leisure activities are among the goals most often cited by patients with FMS [3,4].

Because uncertainty, negativity, and misinformation are too often a part of FMS patients’ experience, educating them on what FMS is, treatment options,

and positive expectations for outcomes is a crucial step that clinicians can take when first meeting an individual patient. Many patients are relieved when their symptoms are validated with a name and become willing to educate themselves and work with clinicians in managing the symptoms and getting on with their lives.

Although much education takes place informally within one-to-one, provider–patient or patient–patient interactions, education may be delivered by multiple media, including face-to-face contact with individual patients or groups of patients, written materials, audio and videotapes, and websites.

This paper will describe a theoretical model for framing FM patient education, summarize the evidence base for patient education with FM patients, suggest content that is essential, review some recent work on tailoring education to patient subgroups and, finally, examine an emerging strategy for enhancing patient potential for behaviour change.

Self-management

The most successful education programmes in FMS treatment are those that rest on a theoretical

basis of self-management, emphasize self-efficacy change in relation to healthful behaviours, and are multidisciplinary and multicomponent in content. The theoretical basis for treating fibromyalgia in outpatient or community settings is guided by three general assumptions – that patients need skills for managing their symptoms on a day-to-day basis, that they can learn how to manage their fibromyalgia symptoms, and that effective practice of healthy behaviours will lead to positive changes in symptoms and health status. Bodenheimer and colleagues [5] suggest that self-management education is different from traditional patient education in that traditional education offers information, technical skills and tends to be disease specific while self-management teaches generalisable problem-solving skills. Self-management means that the patient assumes the major responsibility for activities that lead to positive change in symptoms. The relationship between patient and health care provider is a collaborative one with the health care provider available to share expert knowledge, teach necessary skills, and deliver specialized treatments.

Self-efficacy

Effectiveness in the self-management process depends on many factors. However, the sense of control that comes from patients' own beliefs in their ability to perform specific behaviours or change specific thinking patterns and thus, manage and minimize their symptoms is of primary importance. The term most commonly used for this sense of control is self-efficacy. First described by Bandura in relation to phobia treatment, self-efficacy is defined as the confidence one has in one's ability to perform a specific behaviour or to change a specific cognition [6]. In other words, it is the perception or belief and not 'true' capability that determines behaviour. Self-efficacy expectations strongly influence a patient's choices, decisions, behaviours, and persistence [7]. Changes in self-efficacy significantly predict changes in pain, depression, and health status, independent of changes in medical regimens or adherence to specific behaviours in people with arthritis [8].

The initial goal of patient education should be to help FMS patients gain a sense of self-efficacy. Buckelew and colleagues found that higher pretreatment self-efficacy significantly predicted better physical activity outcomes as well as lower tender point and pain scores in a group of FMS patients participating in a 6-week intervention [9,10]. Thus, patient education, specifically focused on improving self-efficacy, may lead to better treatment outcomes than those that focus on adherence to specific new behaviours or regimens.

Teaching self-efficacy

Self-efficacy is enhanced through four techniques. The first is mastery of experiences – being able to actually perform a desired behaviour or engage in a specific cognition. For example, patients can be assisted to form a realistic goal for increasing physical activity, perhaps to start walking for 10 minutes three times a week. If the patient is able to meet that goal, a sense of mastery will begin to develop that will lead the patient to set higher goals. The key is that the activity must be reasonable in the patient's own estimation. Failure to succeed can be avoided if patients set their own reasonable goals. The clinician can use the strategy of asking patients how confident they are that they can meet the weekly goal using a scale from 0–100%. A rule of thumb that seems to work well in clinical experience is that the patient should be 80% sure. A series of successes is necessary for the development of a sense of mastery. Patients must have the opportunity to practise techniques until they master them, using incremental successes as feedback for continued effort. Developing weekly contracts with written goals is often useful.

The second technique is modeling – watching someone else who is similar succeed in performing a valued activity. Here it is essential that the clinician assists patients to identify people like themselves. Sometimes introducing a patient to another patient who is the same gender, age and doing well can be beneficial. If a positive support group or patient education group exists, there may be places where a patient can find a good role model. These groups enable patients to rely more on each other and to share their own expert knowledge. Sometimes the clinician may need to construct a hypothetical patient from those who have been treated in order to help the patient form an appropriate role model. For example, telling patients that in our experience many patients are able to identify and change negative thinking about themselves. A key factor is that patients learn to compare themselves with appropriate models and not with themselves before they became symptomatic or with family or friends who do not have FMS or other health problems.

The third technique is social persuasion – talking patients into believing that they have the capability to achieve their goals. Although clinicians often use this method, its effectiveness is limited if the clinician and patient do not have a solid, trusting relationship. Even then, the clinician usually does not have the frequent contact necessary to provide ongoing support or feedback; nor is it desirable to create what could become a dependent relationship. Additionally, patients soon come to realize that just

thinking positively does not change negative thinking or motivate behaviour change. If persuasive tactics are beneficial at all, those that come from fellow patients tend to be much better accepted than those that come from health care professionals who do not have FMS.

The fourth technique is physiological feedback – judging capabilities by monitoring anxiety, pain, fatigue, and other bodily states. Patients with fibromyalgia typically interpret these signals as signs of vulnerability or worsening of their condition. This interpretation commonly leads to a loss of self-efficacy for managing symptoms and fear-avoidance behaviour in which the patient limits any activity that might lead to unpleasant bodily sensations [11]. Patients should be taught to monitor these body states from a perspective of positive outcomes of behaviour change. The use of numerical rating scales that anchor with 0, having no problems, to 10, having extreme problems, can be helpful. Patients must keep their own records if they are to reflect accurately their progress over time. Clinicians who use numerical rating scales often find that patients rate a score of 4 or lower on a 0 to 10-point scale as indicating good control of a symptom.

Other factors also affect the management process. Patients whose providers believe that FMS is a legitimate diagnosis are more likely to engage in the therapeutic process and be willing to try new strategies. Support from family and friends as well as support to the whole family enables patients to alter their roles when necessary and find the time to try out new behaviours.

Evidence for the effectiveness of patient education in FMS

The effectiveness of organized education programmes in providing information, facilitating behaviour change and improving symptoms is well documented. A large number of randomized, controlled trials (RCTs) and programme evaluations have been completed over the past 10–15 years. In the summary that follows, patient education alone, cognitive-behavioural strategies which are educational in nature, and multicomponent approaches that include an educational element will be described and evaluated.

Patient education

Four RCTs with FMS patients have focused specifically on patient education as the experimental treatment and compared the experimental group to a wait-list control group [12–15]. The treatments were described as information-focused education given in group format using lectures, written

materials, group discussions, and demonstrations. All experimental groups received content on basic understanding of what FMS is, the role of stress in maintaining and aggravating symptoms, pain coping strategies, basics of ergonomics, pacing, self-care, and setting goals or contracts for behaviour change. Length of the education treatment ranged from 6–12 weeks with one study having follow-up monthly sessions for 10 months [14]. Only two [12,14] found significant changes on any outcome at the end of the study. The education groups were significantly better than the control groups on self-efficacy and quality of life in the first study and had less helplessness in the latter. These results suggest that group education alone is not sufficient to change symptoms.

Cognitive-behavioural therapy

Cognitive-behavioural therapy (CBT) is a generic term that incorporates a wide range of treatment modalities (e.g., stress management, distraction, relaxation, problem-solving, cognitive restructuring) all of which are designed to educate the patient and enhance coping, facilitate self-management and improve function. CBT as a stand-alone treatment has produced significant short-term effects on pain severity, pain coping, self-efficacy, and functional status in five controlled trials of CBT when compared to treatment as usual or no treatment control groups [15–19]. The number of sessions ranged from 6 to 20. Content of all CBT experimental treatments emphasized teaching the patient to use cognitive techniques to recognize and change negative cognitions, muscle relaxation techniques, behavioural goal-setting and homework to practise skills.

Two studies that used cognitive-behavioural intervention as the experimental treatment and patient education as the attention control found that subjects in the patient education group changed as much on the outcome variables as the CBT experimental group subjects [18, 20]. Whether these findings represent weakness in CBT or the active nature of the attention control cannot be determined with certainty. However, the descriptions of the education control lead one to deduct that the attention control was not a sham or placebo treatment but rather that active learning took place in the control group.

Multicomponent strategies

A number of studies provide evidence for the efficacy of treatment by multidisciplinary teams using multicomponent strategies for people with FMS. Of seven RCTs that combined patient education and/or CBT with exercise, six resulted in significant improve-

ments for the experimental treatment group on one or more outcomes at the end of treatment [12, 13, 21–29]. One found significant improvement only at follow-up [24].

Treatment length ranged from six to 24 weeks. Self-efficacy was significantly enhanced in the treated groups in three of the five studies in which it was measured. The Fibromyalgia Impact Questionnaire (FIQ) total score [26], a measure of overall fibromyalgia impact, was significantly decreased in only one study at the end of the experimental programme but showed significant decrease in three of the seven studies at 3–6 month follow-up. Pain was significantly decreased in four of seven trials. Four of five RCTs that used a no treatment or wait-list control group offered consistent evidence of the superiority of a multicomponent approach. One study that used a relaxation attention control did not show differences at end of treatment [25] while the other [22], supported the multicomponent approach when compared to an attention control education programme.

Unlike the single strategy approaches, a number of uncontrolled multicomponent studies have been completed over the past 10 years. Although the weaknesses of single group trials are well known, five published studies with follow-up data [27–35] provide consistent evidence of positive changes in pain and fibromyalgia impact at the end of patient education treatment that were maintained 1–6 months post-treatment. Thus, the research-based

evidence for patient education especially when combined with exercise is strong because of the consistent evidence from multiple RCTs.

Critical elements of successful patient education programmes are shown in Table I. While there is no evidence that programmes must be of a certain length, follow-up studies of all the above treatments have pointed to the need to do some type of ‘booster’ education to assist patients to continue using the skills they have learned.

Tailoring education to subgroups

A number of RCTs noted characteristics of subjects who adhered to and completed the experimental treatment, responded to the experimental treatment or maintained treatment gains at follow-up. Although adherence was measured in various ways, subjects who failed to complete the experimental treatments were more likely to have had a traumatic onset of FMS, missed work because of FMS symptoms and scored lower at pretest on measures of perceived control over pain. Experimental treatment responders were more likely to be less depressed at pretest, have had pain for a shorter period of time, been physically active before entering the clinical trial, have had a high sense of control over symptoms, an idiopathic onset of FMS symptoms and social support from significant others. Maintenance of treatment gains was most clearly linked to continued performance of the skill

Table I. Elements of a self-management programme for people with FMS.

Develop the programme using the Self-Efficacy Model so that participants will have opportunities to experience the following:

- Mastery (perform desired new behaviours).
- Modelling (watch another person like themselves successfully perform an activity).
- Social persuasion (interact with successful patients or trusted health professionals).
- Physiological feedback (monitor change in symptoms as result of new behaviours).

Information on FMS

- Latest research on the causes (triggering events, central sensitization, changes in hypothalamus-pituitary-adrenal axis).
- Major symptoms (pain, fatigue, sleep disturbances).
- Modulating factors (weather, stress, noise).
- Additional rheumatological problems (bursitis, tendinitis, osteoarthritis).
- Concurrent conditions (headaches, irritable bowel syndrome, depression, anxiety).
- Latest treatment options (education, cognitive-behavioural techniques, physical training, complementary therapies).
- Use of medications for sleep, pain, and depression.

Physical training

- Stretching and body mechanics (posture, flexibility).
- Muscle strengthening (low weight repetitions, use of equipment).
- Aerobic conditioning (walking, swimming, cycling).
- Energy conservation (pacing, time management, priority setting).

Cognitive-behavioural techniques

- Relaxation strategies (deep breathing, meditation, visual imagery).
 - Coping strategies (self-talk, problem-solving, distraction, goal-setting).
 - Cognitive restructuring (reinterpreting sensations, shifting perceptions from negative to positive, decreasing catastrophic thinking).
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learned in the experimental programme. Research that identifies characteristics of patients who make long-term behaviour changes and strategies to increase the likelihood that patients will make permanent changes in behaviours are needed at this point.

New strategies

Recently, attempts have been made to explain differential treatment response by classifying FM patients into subgroups based on behavioural responses to pain characteristics [36]. An interdisciplinary treatment study suggested that patients might respond differently to treatment based on these subgroup profiles [37]. FM patients grouped into a dysfunctional subgroup based on Multidimensional Pain Inventory (MPI) [38] scores were found to respond more positively to the programme than patients who were classified as interpersonally distressed. Patients who were characterized as adaptive copers showed less improvement overall primarily because they already had low pretreatment levels of distress. More recent work has not confirmed this finding [13] and at this point the stability of the patient classifications based on the MPI is being questioned [39]. It may be that FM patients change from one subgroup to another based on fluctuating states, such as stress, anxiety and fatigue. Thus, customizing programmes based on the perceived characteristics of specific subgroups may not lead to better outcomes for some individuals within those subgroups.

The transtheoretical model of change provides an alternative way of grouping patients according to their stage of readiness to learn and adopt new beliefs and behaviours [40]. As several authors have pointed out, only patients ready to consider making changes will benefit from self-management education programmes based on active engagement [5,41]. Thus, FM patients who do not see their symptoms as problems that need management (the precontemplation stage) or are aware that their symptoms are interfering with normal living but believe that others, such as health professionals, should manage the problems (the contemplation stage), are not likely to benefit from self-management education. On the other hand, FM patients who are beginning to seek out information in the media, use alternative or complementary treatments, or see multiple practitioners are likely to be in the preparation stage where access to traditional information focused patient education may be very helpful. Patients who begin to make behavioural changes on their own, express openness to working on problems with providers, and make efforts to develop a comprehensive treatment plan are in the action stage of change

and can benefit most from an active learning self-management style of patient education [42]. More research that identifies characteristics of patients who make long-term behavior changes, cope with relapses, and seek expert advice appropriately (the maintenance stage) is needed along with educational strategies that facilitate change behaviour.

Motivational interviewing

Motivational interviewing (MI) is a novel strategy that has not yet been studied in FM patients. This counseling method employs person-to-person interviews with a directive, client-centered style for eliciting behavior change by helping clients explore and resolve ambivalence [43]. It is congruent with current health promotion practice in that it focuses on a person's sense of self-efficacy for making difficult behavior changes. MI differs from traditional health education as the emphasis is not on providing information or advice but rather to use client-centered counseling skills, along with a concerted effort to elicit and strengthen 'change talk' from the person, followed by the facilitation of a concrete action plan [44]. In the only comparison of motivational interviewing to standard education for chronic pain management, Habib and colleagues [45] conducted a randomized controlled clinical trial with 78 participants with chronic pain, 25% of whom had a rheumatic disease. A one-hour face-to-face MI session was offered prior to a 6-week standardized pain clinic self-management program. The control group received an education-based intervention about the importance of self-management for chronic pain before attending the same pain management workshop. Those who completed the MI intervention prior to the pain management course had statistically significant improvements compared to the control group in attendance and completion of the pain management workshops, social and health impact measures, and self-efficacy.

Summary and recommendations

Clinicians using the results of the extant research base can take an optimistic view of the role of patient education for FM. There were no negative outcomes in any of the reviewed studies, although in a few studies the experimental treatment did not prove to be more effective than the education attention control. Rather than viewing this negatively, one could look more closely at the attention control groups and attempt to better understand what they contained that worked as an active treatment. A number of trials included a follow-up component and most found that at least one positive outcome had been maintained. Maintenance of changes is

more likely to occur when patients regularly use the skills that they have learned. The goals of increased self-efficacy, symptom reduction, increased functional status and quality of life along with decreased inappropriate use of health care resources are realistic when FM patients persevere in their use of self-management strategies and receive individualized support from their health care providers.

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