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Chapter

Self-Management in Patients with Rheumatoid Arthritis

Wen Luo, Xiuli Zhang and Kaijing Ren

Abstract

Despite the effective pharmacological management of the disease over the last two decades, many individuals with RA continue to have psychological distress, and this is associated with poor outcomes. Addressing psychological issues hand in hand with pharmacological treatment will help to maximize outcomes for people with RA. Self-management (SM) is of utmost importance for people with rheumatoid arthritis to minimize their complaints, reduce clinic visits, and reduce disability. Considering the continuous update on the guidelines for disease management, non-pharmacological management remains a poorly addressed need of importance. In this chapter, we will introduce the current and progress of self-management in patients with rheumatoid arthritis.

Keywords: rheumatoid arthritis, self-management, self-efficacy, patient education

1. Introduction

Rheumatoid arthritis (RA) is a severe chronic disabling disease, characterized by joint pain and inflammation as the physical symptoms [1]. Disease-related functional damage with limited mobility of the affected joints, significantly decline patients' quality of life [2]. Although medical treatment is an integral part in rheumatoid arthritis, this disease has a major impact on patients' life. Patients with rheumatoid arthritis are classically influenced by five factors according to the International Classification of Functioning (ICF): physical function, body activities, participation, individual factors, and environmental factors [3]. During the past two decades, self-management (SM) strategies have been emphasized to help patients with rheumatoid arthritis cope with the incapacitating symptoms of the disease [4].

There are many different definitions of self-management worldwide. Now most researchers in various fields accept Lorig's definition, that is, self-management refers to a kind of healthy behavior that maintains and improves one's own health through the behavior of patients; heals and manages the symptoms and symptoms of one's own diseases; reduces the influence of diseases on one's own social functions, emotions, and interpersonal relationships; and persistently treats one's own diseases. The latest theoretical study is the individual family self-management theory proposed by Polly Ryan of the University of Wisconsin. The theory defines self-management behavior as a complex phenomenon with internal motivation, including context, process, and outcome. The situational part includes special situational factors, environmental factors, and personal family factors. The special situational factors consist of treatment, stability, and recovery of the disease.

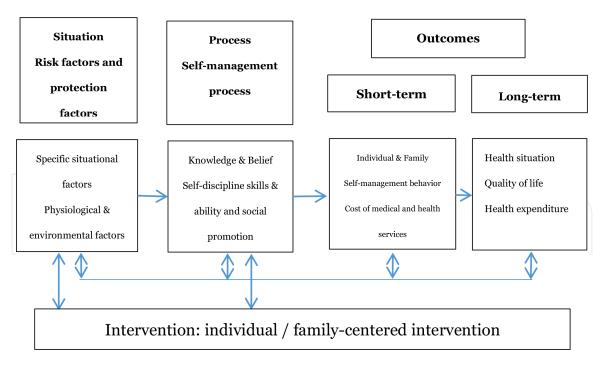


Figure 1.Theoretical framework of individual and family self-management.

The environmental factors include the access and transfer channels of medical resources, transportation, surrounding environment, work, and culture. The individual/family factors include individual development stage, language level, information processing mode, and ability. The process gets into knowledge and belief, for example, self-efficacy. The outcomes include the behavior change, symptom management, and drug treatment. The short-term outcomes consist of treatment and healthcare costs. The long-term outcomes include health status, quality of life, and medical costs (as shown in **Figure 1**). According to the theory, if the patients have enough knowledge, healthy beliefs, skills, and support, they would try beneficial healthy behaviors. At the same time, the researchers could think from different angles the intervention based on self-management, such as reducing the situation. The risk factors or specific situational factors in environmental factors can strengthen knowledge and belief (such as self-efficacy), enhance individual self-restraint behavior, and increase social support. Therefore, the theory has a profound guiding significance for practice. Now it has been widely used in research design, intervention, and development of measurement tools in self-management behavior research and has been verified in a variety of situations and groups of people [5].

Self-efficacy is the core concept in social cognitive theory, which is usually used to assess the efficiency of self-management in chronic disease such as arthritis, diabetes, heart disease, and so on [6]. Improving the level of self-efficacy, which includes developing related knowledge and skills, as well as confidence in individual's ability to accomplish the task/aim in a specific environment, changes behaviors in pain management. Through personal experiences or from the experiences of others, self-efficacy would be improved [7].

2. Self-efficacy for rheumatoid arthritis

Self-efficacy is an index to assess persons' confidence to perform an appointed task or behavior, which is one of the most important factors in terms of personal

behavior. Self-efficacy is the core concept of Bandura's social learning theory that attempted to predict the human behavior by referring to the assessment of an individual's competence towards a specific behavior successfully [8]. The self-efficacy theory suggests that the most influential elements for changing health behaviors are perceived threat (influenced by perceived severity and susceptibility to the disease and cues to action, such as increased disease symptoms and advice from others), perceived barriers to using health behaviors, and self-efficacy which would bring the benefits on health behaviors (outcome expectancy) and person's ability (efficacy expectancy).

Thus, self-efficacy of health behavior confirmed the persons' needs to take appropriate and meaningful action. It is nowadays the important theory in predicting and guiding health behavior. Meanwhile, some studies confirmed that the perceived ability to perform a given behavior is strongly related to one's actual performance of the behavior.

3. Review of self-management interventions in rheumatoid arthritis

A recent meta-analysis revealed that such interventions provide additional benefits for pain relief 20–30% as great as the effects of nonsteroidal anti-inflammatory drug treatments [9].

The researchers suggest that the influence of self-management programs on pain and disability is small yet significant. The researches on self-management program for patients with rheumatoid arthritis have focused primarily on patient education, self-expression, pain management, stress management, and depression management. The arthritis self-management program (ASMP) has been confirmed effective [10]. In general, self-management programs bring many benefits and decrease the medical costs in the long term. Now self-management programs have been recommended by the US National Arthritis Action Plan as an important component of rheumatic care.

4. Traditional patient education

Traditional patient education programs are typically designed to encourage behavioral change and to promote healthy living by lectures or videos. The general intent of patient education programs is to provide information to patients with rheumatoid arthritis regarding ways to modify or adjust essential daily activities to circumvent limitations associated with the disease process [11]. Several studies confirm that support the benefits of educational programs as evidenced by improvements in pain and functional and psychological status; those programs that also incorporated behavioral interventions revealed many good benefits [12].

Traditional patient education is the important part in treatment and nursing. Hence, it would be helpful to enlist advantages and disadvantages for educational relevance. Now the researchers look for better methods on patient education.

5. Mail-delivered, tailored self-management intervention

Mail-delivered, tailored self-management intervention (SMART) is a "tailored print intervention" in which the intervention is tailored specifically to the diagnosis information, medical and nursing problems, physical symptoms,

Number	Content
1	"Self-test" to help people determine how arthritis affects their lives and how to use with the tool kit. The items include pain, fatigue, physical limitations, and health worries
2	Information sheets: working with your doctor and nurse, exercise, medications, healthy eating, fatigue and pain management, finding community resources, and dealing with your emotions
3	Information sheets on key process components of the ASMP: action planning, problem solving, deciding what to try, and individualizing an exercise program
4	The Arthritis Helpbook
5	Audio relaxation and exercise compact discs (CDs)
6	Audio CD of all material printed on the information sheets

Table 1. *Mail-delivered, tailored self-management intervention kit.*

characteristic of demographics, health status, medications, self-efficacy, and other personal features of the patients with osteoarthritis or rheumatoid arthritis [13]. SMART based on a one-page arthritis questionnaire can construct literally billions of patient-specific responses. The elements include a questionnaire asking questions about pain disability, exercise levels, and other arthritis-related behaviors (**Table 1**) [14]. They are mailed to a central processing center. Each successive letter builds on patient's information from before and rewards positive changes and gives expanded recommendations when appropriate. Each intervention in mailing kits was done 4 months after the results from the previous assessment in patients with rheumatoid arthritis. Hence, the actual length of the intervention ranged from 12 to 18 months. Self-management kits by mail-delivered could be a good alternative for patients who cannot participate in classroom sessions or community lectures, as well as for those in locations and times where there are not enough potential patients to offer classes or lectures. A mailed arthritis self-management tool kit proved effective in improving health status, health behavior, and self-efficacy variables than traditional patient education such as subject talks [15].

Last but not the least, the intervention by mail is a good method of self-management in patients with rheumatoid arthritis. It is more convenient than traditional patient education. But the effect of intervention has been easily influenced by patients' education, age, and other factors. Moreover, it is limited by public services, for example, postal service [16].

6. Internet-based education

Internet-based education provides consistent program delivery, because both the content and process are programmed [17]. The Internet arthritis self-management program consists of password protected, interactive, web-based instruction (The Learning Center); web-based bulletin board discussion (the discussion center); tools that the participants can use individually, such as exercise limbs, medication diaries, and tailored exercise programs (Tools); and *The Arthritis Helpbook*, which contains all of the program content. Meanwhile, it contains discussions of the major types of arthritis and medications and has drawings of suggested exercises [18]. The Internet-based arthritis self-management program (ASMP) proved effective in improving health status in 1 year and is better than the small-group ASMP. In addition, some researches confirm the emerging literature

supporting acceptance and utility of Internet-based programming as a venue for self-management education and social support system among individuals with chronic diseases [19].

The results of many researches show that the Internet-based education in arthritis self-management is better than group education or traditional self-management. However, the researchers found that the limitations of Internet-based education are that (1) the effects of intervention have been influenced by educational level of patients, (2) the researches cannot supervise the behaviors of patients, and (3) the patients' learning ability affects the results of treatment and nursing [20].

7. Pain management program

Pain has long been considered a significant source of disability and emotional distress for persons with rheumatoid arthritis. Hence, there is an important index or standard in pharmacological and non-pharmacological interventions to manage the consequences of chronic diseases. In addition, some patients with rheumatoid arthritis pain experience only a minimal response to medical intervention, which may lead to pain inadequately managed [21].

Pain management interventions are focused on minimizing the negative emotional memory of chronic pain through the establishment of effective coping strategies [22]. Coping pain skills are used to increasing the available personal resources for managing pain and improving control ability. Emotional disclosure paradigms is a method by encouraging emotional expression of stressful life events; this method is thought to result in decreased pain [23].

There are some empirically based arthritis-specific online sites focused on arthritis self-management. In randomized controlled trial of adults [24], researchers found improvement in health distress, activity limitation, global health, and self-efficacy. A study of an Internet-based self-management program for patients with arthritis found that people in the experimental condition reported lower pain intensity at posttreatment follow-up compared to people in the attention control condition [25].

The painACTION.com is the Internet web of pain management, which includes many informational lectures designed to enhance both knowledge and patient-provider communication; self-assessments that give chronic pain patients the ability to help determine confidence and awareness about self-efficacy; lessons that deal with specific issues that face chronic pain patients and how to better navigate those hurdles; personal stories that allow for sharing of thoughts, feelings, and solutions from other patients suffering with similar conditions; and tools that can help provide chronic pain persons with skill sets to help navigate their chronic pain experiences and interactions with healthcare providers [26].

Prior to developing the arthritis module for painACTION, the researchers conducted an assessment of the needs in 32 people with arthritis and 12 practitioners to learn what was important to include in an online self-management program. Concept mapping of qualitative data revealed that the information about self-management and chronic pain in the literature and in the other modules on painACTION was desired [27]. When the arthritis module was completed, researchers conducted a randomized controlled trial to assess the efficacy of the program for people with arthritis pain. It was hypothesized that patients randomized to the painACTION intervention would report increased positive cognition, reduced negative cognition, increased frequency of self-management behaviors [28], reduced pain, and improved functioning compared to those in the control condition [29].

Perhaps those with arthritis pain who receive an independent online self-management intervention require more than 6-month period for cognitive changes in self-efficacy and decrease pain level in arthritis. In addition, future researches of online interventions with patients with arthritis could emphasize setting-specific personal health behavior goals that are tracked and monitored over time to help maximize the potential impact on pain [30].

8. Stress management programs

Stress defined as a demand upon an organism to respond to environmental changes may have important implications on the course of rheumatoid arthritis [31]. Psychological responses to stress that might lead to physical function dysregulation can be decreased by interventions aimed at reducing psychological stress. In the research, stress management program usually consisted of four individual 1-hour sessions of stress management with a trained therapist over 2 consecutive weeks and included applied, progressive, cue-controlled, and differential relaxed techniques, such as psychological education, breathing, visualization exercises, and so on [32].

Cognitive-behavioral treatments usually include stress management training, which has been used in several researches with persons with rheumatoid arthritis, and results indicate improvements in psychological variables; moreover, the joint tenderness in patients with arthritis has been decreased in some cases [33]. Some researches studied the long-term effects of stress management training on pain behavior exhibited by people with rheumatoid arthritis [34]. However, the results show that stress management based on cognitive-behavioral principles does not have a significant impact on reducing pain behaviors in persons with RA [35].

9. Joint protection education program (JPEP)

Joint protection (JP) is a self-management method which aims to solve physical symptoms of arthritis by reducing pain, inflammation, joint swelling, and preserving joint integrity. Some researches [36] confirm that the use of an educational-behavioral JP program can increase coping ability among people with rheumatoid arthritis and that it is maintained at 6-month period after education. Much of JP education focuses on teaching the use of different movement patterns to perform activities in daily life. Researches of JP education programs have identified that knowledge of JP methods can be improved, as can ability to show JP skills after education [37].

Barry [38] recommended that a number of criteria are followed when developing joint protection programs: conduct a problem analysis at the beginning of the development; use a correct theoretical model; aim to improve knowledge, behavior, and health status; teach effective self-management skills through strengthening self-efficacy and learning knowledge; and involve significant others and accurately evaluate the program. The education program aimed to enhance the self-management strategy. Joint protection skills would be used to assess the effects of them. Joint protection might bring many benefits in self-management and routine care.

10. Exercise program

Although people with arthritis tend to be less fit than their peers without this condition, studies have demonstrated that persons with arthritis can safely

participate in appropriate exercise programs to improve their physical fitness, muscular strength, psychosocial status, and functional status [39]. On the basis of these reports and other research findings, healthcare providers have been advising participation in exercise programs for persons with arthritis [40].

The People with Arthritis Can Exercise (PACE) program is a community-based program developed by the Arthritis Foundation in 1987 (revised in 1999) to improve the self-management of arthritis through exercise [41]. This is an 8-week program, administered twice weekly for 1 hour, is offered at disease-management levels, and is available for widespread use in community-based settings [42]. In summary, the study demonstrated that PACE improve symptoms and strength, exercise endurance, and physical activity by offer two times per week. The program was well received by the people with arthritis and instructors in a variety of communities [43].

11. Fatigue management program

Many studies show that fatigue is a major issue, as important as pain, overwhelming, unmanageable, and ignored by clinicians and healthcare providers. The study team developed the cognitive behavior theory (CBT) intervention from chronic pain and fatigue syndrome in arthritis self-management programs, incorporating experiences of rheumatoid arthritis fatigue from clinics, patients, and healthcare providers. The program was piloted, refined, and then co-delivered by clinical psychologist, doctors, nurses, and specialist occupational therapist, with 6×2 hour sessions (weeks 1–6), with a 1-hour consolidation session (weeks 7–14) [44]. Thoughts, feelings, and behaviors related to fatigue were addressed using reflective questioning and guided discovery to enable people to work out links by themselves. Problem solving, goal-setting, self-monitoring in activity/rest, and energy management aimed to help people turn cognitive and behavioral changes into improved well-being. CBT for fatigue self-management in rheumatoid arthritis improves fatigue impact, coping and perceived severity, and well-being [45].

12. Self-management program

Self-management is increasingly being accepted as an important part in the management of chronic disease such as hypertension, diabetes, and so on. Self-management interventions (SMI) are patient-centered, problem-focused, and action-oriented, addressing physical and psychosocial issues [46]. It makes use of educational, behavioral, and cognitive strategies to enhance patients' abilities on self-management [47].

Social and economic benefits research on rheumatoid arthritis has related the financial burdens associated with prolonged disability. In response to the need for inexpensive and effective treatments, the utility of the ASMP was confirmed in a number of studies [48]. The arthritis self-management program (ASMP) was designed by the Stanford Arthritis Center and is a community-based patient education program. This program was developed as a result of a measurement of the needs of people with rheumatoid arthritis; the ASMP covers the characteristic of arthritis, conventional uses of medication, exercise, relaxation techniques, joint protection, nutrition, communication with physicians, and evaluation of nontraditional treatments [49]. The ASMP was found to lead to an increase in rheumatoid arthritis knowledge and the adoption of taught behaviors. Participants in the program also decreased pain; the beneficial effects remained at a 20-month follow-up [50].

The ASMP is one of the leading arthritis patient education programs in the world serving thousands of persons with rheumatoid arthritis each year. The program has been modified in recent years. This modification has resulted in improvement use in assessment of arthritis knowledge and has encouraged people with rheumatoid arthritis to seek other Arthritis Foundation services. Meanwhile, the community-based self-management education interventions and the disease-specific Arthritis Self-Help Course (ASHC) have been found to be effective in improving quality of daily life and reducing healthcare costs [51].

RA-SMI has been demonstrated to have many significant benefits. Any contact with healthcare providers with a specific disease focus appears to be beneficial for patients with rheumatoid arthritis. There appear to be additional benefits of adding health professional intervention and SMI. Improvements on depression and mental health were observed in response to the SMI. Moreover, the results were maintained more than 12 months. The study reported that increasing in prescription of DMARDS by patients' medical practitioner should be viewed as a positive and essential strategy for disease modification and reducing impairment and disability. Empowering patients through education may allow them to be more proactive in seeking better evidence-based medical treatments earlier. As it is one of the important studies on RA-SMI future development which is necessary to continue to optimist the positive outcomes of the program. In particular refinement of the program focusing on the SE and pain outcomes needs to be planned, implemented, and evaluated [52].

13. Nurse-led program on RA

Nurses use a booklet of the systematic identification and assess the comorbidities associated with rheumatoid arthritis. In case of a detected risk factor such as hypertension and/or a nonoptimally managed comorbidity such as the lack of vaccination against pneumococcus, the nurse reminds the patient to pay attention to the management of such comorbidity and advises the patient to visit general practitioner or rheumatologist to deal with it. Meanwhile, a report of this visit was sent to the general practitioner and the rheumatologist of each evaluated patient [53].

Palmer et al. demonstrate [54] the short-term benefit of a nurse-led program on RA comorbidity management and the impact of patient self-assessment of disease activity on rheumatoid arthritis treatment intensification. Nurse-led programs have demonstrated their benefit in the cost-effective management of disease risk factors and improved pneumococcal vaccination coverage in at-risk patients and the management of osteoporosis with fracture risk in older women. Such evidence is not yet achieved in the field of rheumatoid arthritis [55, 56].

14. Critical assessment of self-management approaches

Outcome research on the effectiveness of self-management programs for people with rheumatoid arthritis is encouraging. However, support systems for the efficacy of some interventions have been confounded by methodological limitations. For example, the small sample sizes found in many researches have limited the conclusiveness of the results. Additional missing rates are a major obstacle when studying chronic disease and are especially problematic in the context of rheumatoid arthritis due to the associated physical discomfort and disability. Such factors, in addition to the diagnostic ambiguity of early-stage rheumatoid arthritis, pose methodological challenges. In summary, randomized trials and longitudinal

designs have produced the most definitive results regarding the utility of self-management in rheumatoid arthritis [57].

Self-management programs that focus on active coping, such as cognitive restructuring and relaxation training, appear to be more helpful than passive approaches that do not encourage the application of learned skills. Overall, the preponderance of evidence suggests that self-management programs for rheumatoid arthritis are generally helpful for reducing the emotional responses commonly associated with the disease. Clearly, reductions in pain and disability can lead to improved quality of daily life; self-management programs also appear to help offset the cumulative direct and indirect costs associated with rheumatoid arthritis [58].

15. Practical implications for self-management methods

The success of self-management programs for rheumatoid arthritis is based on several factors. First of all, specific skills set for the facilitator and participant are required for different programs. For instance, programs focused on stress and depression management frequently involve strategies which require facilitators to have adequate training in cognitive-behavioral interventions [59]. Additionally success is contingent upon participants motivation and ability to implement learned strategies in their daily life [60].

Secondly, adequate financial resources are often required for many programs; self-management programs typically require nominal yet potentially significant, fees for materials such as workbooks and instructor costs. Given that rheumatoid arthritis can lead to sizeable economic demands as a result of direct and indirect medical costs, additional treatment fees may not be feasible for some persons. Therefore, cost-effectiveness is an important consideration for program development [61].

Last but not the least, physical limitations have been found to impact participant performance and program adherence in programs that employ measures requiring sustained effort or a high degree of geographic mobility [62].

16. Future directions for research and practice

Physical disability and mobility limitations can reduce the ability of persons with RA to participate in treatment outcome studies, so future research might examine the development of self-management programs for persons with RA who have severe physical limitations [63]. Specifically, Internet-based delivery systems may help to overcome the major accessibility challenges. From a methodological standpoint, randomized controlled trials have much to offer to the study of self-management interventions. Without randomization, comparison groups can differ on many potentially confounding variables. Similarly, sample sizes must be adequate in order for the literature to evolve in a definitive manner. Non-randomized designs may be useful in some contexts, but randomized trials with a sufficient number of participants will be critically important for future research on the effectiveness of self-management interventions [64].

Studies of self-management programs that include examination of medical cost offset will be highly advantageous. Evaluation of the cost-effectiveness of self-management programs will be particularly crucial for improving access and third-party reimbursement for psychosocial interventions. Longer-term follow-up of these patients will be of interest to evaluate the sustainability of the observed results, in

particular with regard to the management of comorbidities but also in checking the potential impact of the disease activity self-assessment program on other outcomes such as disease activity and/or functional impairment [65].

Meanwhile, the study found that brain biomarkers of how people deal with health information may be one of the important characteristics on which to individualize health education to optimize self-management in disease [66]. The use of brain biomarkers will facilitate the generalizability and reproducibility of research findings and benefit self-management [67]. It is an important research direction in the future.



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