



Behavioral Determinants of Self-Management Behaviors in Rheumatoid Arthritis Patients: A Qualitative Study

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Abstract

Background: Self-management behaviors (SMB) play a significant role in controlling the adverse effects of rheumatoid arthritis (RA) as a chronic disease.

Objectives: The main purpose of this study was to explore the behavioral determinants of SMB who suffer from RA.

Methods: This is a qualitative study with directed approach to content analysis of in-depth semi-structured interviews. A total of 30 RA patients (15 in good and 15 in worst SMB) were recruited in this study based on the PRECEDE model (predisposing factor). The participants were recruited using a purposeful sampling to reach the maximum variation sampling. This sampling took over 6 months in 2015 at the Rheumatology Clinic in the Shariati Hospital, Tehran University of Medical Sciences.

Results: Five main theme and 14 sub-categories came out from the interviews. The main themes include: perceived benefit, perceived severity, perceived barrier, attitude, and self-efficacy. Most of the participants considered self-efficacy and perceived barrier as the most significant determinants of SMB in RA patients.

Conclusions: The study provided better understanding of behavioral determinants of SMB in RA patients, the finding suggested that improving self-efficacy and eliminating barriers in RA patients can help researcher, physician, health worker, and planner design proper program and strategy in order to improve SMB and their health.

Keywords: Rheumatoid Arthritis, Self-Management Behavior, PRECEDE Model

1. Background

Rheumatoid arthritis (RA) is a systemic, chronic inflammatory, autoimmune, and debilitating disorder that influences almost 0.018% to 10.7% of the adult population worldwide (1). It is more common in 40 to 60-year-old adults. RA is a two times as seen in women as in men (2). In 2008, the prevalence of RA in Iran was 0.33% (3). The prevalence of RA was 0.98% in Zahedan (2008 - 2009) and 0.51% in Sanandaj in 2012 (4, 5). People with RA encounter different problems such as pain, tiredness, stiffness, and reduced muscle strength, which make their daily activities difficult. One of the important symptoms of RA is progressive joint destruction, which districts the patient's physical activity and affects his/her quality of life. RA may also have destructive impacts on patient's mental health and social roles. These complications impose costs like medical costs, absence from work, etc. (6).

Self-management is part of daily routines that an individual conducts to control the symptoms of the disease (7). According to Barlow et al., self-management is an individual's capacity to manage the disease and change ones lifestyle in order to deal with his/her chronic condition (8).

Self-management in RA patients involves taking medicine, complementary therapies (e.g. thermotherapy, massages therapy, etc.), hydrotherapy, relaxing, and social support from family and others (9-12). Self-management behavior boosts the positive effects of medical treatment. Nevertheless, taking a crucial role in several self-management activities can be a complicated task for these patients (13).

To make effective intervention, it is necessary to contemplate the behaviors of the target group. Qualitative methods are useful for collecting in-depth information for better perception of the health problems and related be-

havioral and environmental determinants from different perspective (14). The PRECEDE model has worked well for health education and promotion topic. This model is a logical model that explains the causes of health problems. Based on the study by Green, the determine factors are generally categorized into three factors as predisposing, enabling, and reinforcing. These factors work as determinants for desired behavior (15).

Previous studies have found that patients' beliefs influence their self-management behaviors (SMB) (10, 16, 17). For example, for people with RA perceived benefit and self-efficacy were important determinants of joint protection (18).

Multiple studies have examined self-management by focusing on evaluating and comparing educational interventions, coping strategies, and specific factors such as stress and physical activity in RA patients (19-21). It should be noted that quantitative designs cannot completely describe the factors that influence SMB. Furthermore, challenges with SMB have not been qualitatively studied for RA patients living in Iran. Qualitative studies help us better understand the socioeconomic, cultural, political, and environmental factors influencing SMB. In addition, the outcomes of qualitative studies help us design proper intervention programs for empowering RA patients and improve the effectiveness of such programs.

2. Objectives

The main purpose of this study was to explore the behavioral determinants of SMB who suffer from RA.

3. Methods

This study is a qualitative study that describes self-management behavior determinant in RA patients following the quantitative study (this study is a part of explanatory mixed method). In this step, we carried out content analysis (directed) based on the PRECEDE model. The goal of this approach is to conceptually validate or expand a framework or theory. This approach was utilized by Hsieh and Shannon (22).

3.1. Data Collection

Data were gathered through semi-structured in-depth interviews. A total of 30 interviews (15 best and 15 worst SMB score) were carried out with RA patients in a private room at the Rheumatology Clinic at the Tehran University of Medical Sciences in 2015.

The interview consists of open-ended questions based on the PRECEDE model (predisposing, enabling and reinforcing factors) that RA patients express their experience

and perception of SMB. The interview guide is shown in Table 1.

Table 1. Semi-Structured Interview Guide

No.	The Interview Guide
1	What are you doing to take care of RA?
2	Do you feel that SMB are dealing with RA?
3	What are the benefits in SMB with regards to RA?
4	How worried are you about RA?
5	Which aspect of RA interferes with person life?
6	Do you feel that you have an active role in using of SMB? Why or why not?
7	Do you have any information about SMB?

3.2. Setting and Participation

The mean age of patients was 50 ± 11.7 years. Inclusion criteria included individuals over the age of 17 years, diagnosed with RA over one year ago by a rheumatologist and American College of Rheumatology (ACR), and no history of chronic diseases and mental disorder. Participants were chosen based on the SMB scores (the extreme SMB score in an earlier study to 185 RA patients) (23). In an earlier study, the SMB questionnaire consisted of 17 SMB activities in RA patients. According to the extreme case sampling, 10% of patients who had the best scores and 10% who had the worst SMB scores were entered into the study.

The ethical approval was taken by the Human Research Ethics Committee of Shahid Sadoughi University of Medical Sciences (No. P/17/1/57794). Participating in the study was voluntarily and they all had to give written consent. Moreover the patients were reassured about confidentiality and anonymity.

We carried out interviews at the extreme SMB score to achieve maximum variation sampling (purposive sampling). Sampling was done until data saturation was attained.

3.3. Data Analysis

Content analysis approach (directed) was used to analyze the interview. Interviews were recorded and immediately transferred to Microsoft Word. At the end, MAXQDA10 software was used to analyze the qualitative data. Based on directed content analysis, interviews were carefully read three or four times to fully realize the data and then, the highlighted sentences were underlined to recognize the premier codes that are seen in the interview. Next, similar codes were put in barriers and reinforcing subcategories.

3.4. Consideration of Rigor

Involvement in data collection from October 2014 to February 2015 helped us give trust and rapport with participants. To validate dependability and conformability of the data, initial codes and subcategory of the PRECEDE model were checked by authors who are all experts in health education and promotion, qualitative research, and rheumatology. Purposeful sampling and depth interview with extreme case from patients (good and worst scores of SMB in premier phase) confirmed conformability and credibility of the data.

4. Results

In total, 30 RA patients (24 females and 6 males) with the 15 best and 15 worst SMB scores entered this study. Table 2 shows characteristics of the participants. In this study, based on the PRECEDE model, five main categories and 14 sub-categories of predisposing factors (behavioral determinant) were drawn out. The main categories included attitude, self-efficacy, barriers, perceived benefits, and severity.

4.1. First Theme: Perceived Benefit

4.1.1. Physical Health

Most patients believed that SMB such as anger management, joint protection, keeping the joints warm, light exercise, and exercising in water reduced their pain, improved their functionality, and enhanced their efficiency in activities of daily living.

Walking has reduced my pain; therefore, I keep doing it (participant 17).

4.1.2. Long Term Benefit

Patients believed that SMB protect their joints and have long-term benefits such as reduced medical costs. These beliefs were considered as the main motives for behaviors such as losing weight.

If I don't pay attention to my diet, I gain weight quickly and my knees and ankles become painful (participant 5).

4.1.3. Mental Well-Being

Another benefit of SMB is psychological well-being, which leads to feeling better and comfort. Stress management, medications, diet, social interactions, spending time with friends, and exercises such as swimming and walking give a positive feeling and self-image. The followings are some of the comments given by the participants in this regard:

Swimming relaxes my body, makes me happy, and changes my mood (participant 8).

I feel embarrassed about my crooked fingers. I don't want them to be seen by others, therefore, I always take my medication on time (participant 1).

4.2. Second Theme: Perceived Barriers

4.2.1. Lack of Knowledge

Lack of knowledge about RA, the proper methods of treatment, and control are among other barriers to SMB that were mentioned frequently by the participants. Patients thought the most important way to manage their illness was to take their medications. Furthermore, they did not know the side effects of their medications and how to control them. Participants generally complained about the lack of proper communication between patients and physicians and inaccessibility of educational materials such as pamphlets, booklets etc. They also complained that since the clinics are usually crowded, physicians do not have enough time to explain the disease, treatments, side effects, and other information.

Somebody should tell me what I should do to feel better. I only take my tablets (participant 4).

4.2.2. Reluctance and Negative Attitude

Reluctance (lack of motivation, laziness, forgetfulness, and boredom) and negative attitude towards SMB prevented the patients from taking their medication, following a proper diet, exercising, socializing, and protecting their joints (for example by using proper bathroom facilities, and protective equipment). Furthermore, some patients were reluctant to take their medications due to the fact that they were tired of taking too many medications on a daily basis, or could not tolerate the negative side effects of medications.

Ever since the illness became worse, I missed motivation for exercising. I feel tired (participant 21).

It was a fact that my medications control my pain, but they will destroy my joints (participant 29).

4.2.3. Joint Pain, Cost

Joint pain and lack of time due to household chores and parental duties were among other barriers to physical and social activities mentioned by the participants.

I try to go for regular walks, but when I do, my knees hurt (participant 29).

I have to take care of my kids, and therefore, I can't spend two hours per week exercising (Participant 27).

4.3. Third Theme: Self-Efficacy

4.3.1. Having a Sense of Empowerment

Some participants were aware of their own ability to control their condition by regulating SMB such as stress

Table 2. RA Patient's Characteristics

Number	Sex	Age	Duration	Occupation	Education Level	SMB Score
1	Female	30	5	Housekeeper	Diploma	Best
2	Female	54	5	Housekeeper	Elementary	Worst
3	Female	51	7	Housekeeper	Diploma	Worst
4	Male	55	7	Staff	Intermediate	Worst
5	Female	47	10	Housekeeper	Elementary	Worst
6	Female	51	12	Housekeeper	Elementary	Worst
7	Female	45	2	Housekeeper	Intermediate	Worst
8	Female	65	5	pensionary	Academic	Best
9	Female	51	12	pensionary	Intermediate	Best
10	Female	49	33	Housekeeper	Elementary	Best
11	Female	43	7	Housekeeper	Intermediate	Worst
12	Female	42	15	Housekeeper	Intermediate	Best
13	Female	41	6	Housekeeper	Elementary	Best
14	Female	61	8	Taylor	Diploma	Best
15	Male	58	30	Staff	Diploma	Best
16	Male	47	13	Taylor	Elementary	Worst
17	Female	64	11	Retired	Diploma	Best
18	Female	62	9	Housekeeper	Diploma	Worst
19	Male	63	4	Staff	Elementary	Worst
20	Male	59	14	Retired	Academic	Best
21	Male	19	11	Student	Diploma	Worst
22	Female	47	10	Housekeeper	Elementary	Best
23	Male	63	18	Retired	Diploma	Best
24	Female	51	10	Housekeeper	Diploma	Best
25	Female	56	28	Teacher	Diploma	Best
26	Female	55	6	Housekeeper	Diploma	Worst
27	Female	31	2	Housekeeper	Academic	Worst
28	Female	54	24	Housekeeper	Diploma	Best
29	Female	37	10	Housekeeper	Intermediate	Best
30	Female	63	33	Housekeeper	Elementary	Worst

management, tracking their medication consumption, exercising, and diet.

I make sure to get some exercise. Even when I travel, or walking down the street (participant 25).

4.3.2. Personal Role in Self-Care

An individual's self-concept and how much he considers himself responsible for his SMB affects the way he controls his illness.

My recovery depends on my attitude towards the disease than on my doctor's expertise in treating it (participant 15).

4.3.3. Having Proper Information About SMB

The majority of participants believed that having enough information plays a significant role in adopting proper SMB. Knowledge about proper diet, the effect of different factors such as stress, medication, and use of protective equipment were among the codes pointed out by the participants.

I make sure to include calcium-rich foods, such as broccoli, vegetables, and milk in my diet (participant 20).

4.4. Fourth Theme: Perceived Severity

4.4.1. Physical Problems

Some participants pointed to the physical consequences of the disease, such as the side effects of RA medications and damage to the joints. Vision problems such as cataract, joint deformity, kidney diseases, iron deficiency anemia, and digestive problems were among the codes most frequently pointed out by the participants.

These medications are not good for me. They are destroying my bones, osteoporosis (participant 20).

4.4.2. Being Worried About the Future

Some participants believed that potential problems will reduce their functional capacities and interfere with their social life.

I'm worried about my future. I'm afraid I end up crippled and in need of someone to take care (participant 6).

One of the consequences of RA is decreasing the ability to perform their daily activities, which leads to frustration and stress.

When I'm driving I use this foot to lower the clutch. This hurts my ankle, then driving difficult and painful for me (participant 4).

4.5. Fifth Theme: Patient's Attitude

4.5.1. Beliefs About the Cause of the Disease

The participants believed that a wide range of factors might have contributed to their illness such as stress, water, humidity, infectious disease during childhood, ageing, and heavy workload.

They say water causes this disease; cold water (participant 4).

4.5.2. Their Attitude Towards SMB

There were both positive and negative attitudes regarding some SMB such as medication, joint protection, exercise, and diet. Most patients had negative views towards medications side-effects. On the other hand, most patients found foods such as honey, dates, lamb meat, etc., which are traditionally believed to have a warm nature and are beneficial. Instead, cold nature foods were considered harmful.

I eat warm nature foods more often. For example, I eat honey frequently; but I do not eat condiments since they are believed to be cold nature foods (participant 10).

5. Discussion

Results of the present study showed that behavioral predisposing factors such as knowledge, attitude, perceived benefits, perceived barriers, perceived self-efficacy,

etc. play an important role in self-management behavior. Based on the findings of this study, the benefits of SMB, including reduced pain, enhanced functionality and efficacy in performing the activities of daily living, reduced health costs, prevention from joint damage, and well-being, encourage patients with RA to practice SMB. These findings are in line with the findings of the study by Niedermann et al. (18), who found physical and mental health as subcategories of perceived benefits of joint protection in patients with RA. Patients acknowledged that controlling stress, regular physical activity, swimming, and social interactions lead to mental health, which in turn affects their level of success in controlling the disease. These studies have shown the role of physical activity on enhancing the quality of life of RA patients (24, 25).

All participants agreed that perceived barriers had a significant effect on their SMB. In our study, inadequate knowledge of the nature of the disease and its treatment, reluctance and negative attitude towards SMB, joint pain, financial cost, and time limitations were the main barriers against SMB. These findings are similar to what was reported by Meyfroidt who studied patients with limited knowledge about their disease (26). In the present study, some participants considered reluctance and/or negative attitude towards use of medications, diet, exercise, and social interactions as predisposing factors for failing to adopt SMB. In studies by Dixon and Bansback (27), Lempp et al. (28), patients had negative attitudes towards medications and their side-effects. Furthermore, in this study, some of the female participants expressed negative attitudes towards using canes or neck orthotics and supports due to the fact that their devices were not accepted by their partner and perceived as a sign of disability.

In the present study, participants pointed out that financial problem affects SMB. Three participants complained about the high cost of medications (biologic) and hip joint surgeries, which are generally not covered by group or community. Preparing proper health insurance and/or offering free medical examinations and treatments can solve such problems to some extent (29-31). Lack of time was another barrier that most of our female participants complained about.

Based on the results of the present study, most participants had low self-efficacy in stress control, and did not use a specific method for controlling their stress level. In our study, patients who had been living with RA for 15 years or more showed a high level of self-efficacy in performing SMB. This might be due to the fact that patients gradually learned how to cope with their illness and made necessary changes to their living conditions to accommodate their current circumstances, and this in turn affected their level of compliance with SMB.

Nadrian et al. (10), and Primdahl et al. (32), showed that in patients with RA, self-efficacy is the strongest predictor of SMB. Benka et al. also found that self-efficacy has a positive effect in dealing with their functional and psychological problems in RA patients (33). Exchanging experiences with others has a significant effect on a person's self-efficacy. By participating in peer education and social networking, patients can educate themselves about their disease and reach a common understanding of the problems they face.

Our participants attributed RA to water, humidity, stress, infectious disease in childhood, ageing, and heavy workload. They also believed that living in cold and humid environments, high level of stress, and poor diet cause a sudden flare of RA symptoms. Which is consistent with Niederman et al. who reported on the patients view about the disease (18). Our participants emphasized on the effect of diet on severity of the disease. They observed that a diet of warm nature foods alleviated joint pain while eating cold nature foods and condiments exacerbated the symptoms and increased their pain. Our participants also pointed out that using ginger reduced their pain and decreased RA disease activity score.

The physical problems reported by our participants include the side-effects of medications and damage to joints. These physical problems have been reported by RA patients in a previous study (34). In studies by Meyfroidt et al. (26), Dixon and Bansback (27), long term side-effects of glucocorticoids have been reported among RA patients. Meeting with other patients increase the perceived severity of the disease and improve SMB. In our study, participants complained about the inability to perform their activities of daily living and their work places. Detrimental effects of RA on patients' activities of daily living and functionality have also been shown in these studies (35, 36).

Disability and functional limitations due to RA reduce patients' participation in the society and his/her level of interactions with others. The aforementioned trigger feelings of lack of understanding and sympathy from others, social stigma and rejection, loneliness, and disappointment. Kristiansen et al. (35), showed that the social stigma imposed on a patient by his friends and relative's due to his inability to perform his social duties has psychological consequences and detrimental effects on patient's quality of life and his self-efficacy. Social support from family and friends plays a significant role in eliminating such negative feelings and hence their detrimental effects. Feldthusen et al. (37), noted the effects of RA on patients' roles in the society and suggested that patient-centered care can bring back balance to patients' everyday life.

Fear about the future was another motive for SMB. Many patients performed SMB to live independently and

to prevent from disability and other side-effects of the disease. Dadoniene et al. (38), also found functional disability as the most important cause of dependency in RA patients. In a review article by Zuidema et al. (39), informational, emotional needs, and social support have been considered as RA patients' needs.

The findings of this study are applicable only to the communities that have been studied and cannot be generalized to other populations. Nevertheless, purposefulness and sample diversity were the advantages of this study. Both males and females participated in this study. Furthermore, participants were selected from a wide age range and had diverse socioeconomic statuses. The aforementioned allows transferability and generalizability of the findings to some extent. There are a few limitations on this study, which must be determined. Firstly, the low cooperation of men in the interview also led to a smaller number of them entering the study. Secondly, inability of some participants due to visual problems and inflammation of the joints made it difficult to answer the questionnaire.

5.1. Conclusions

Results of the present study show that many factors influence SMB. Self-efficacy and perceived barriers are the most important determinants of SMB. Identifying these determinants helps policy makers choose the best strategies and interventions for changing these factors in order to facilitate patients' adherence to SMB. Based on this result, it is recommended that in the future research, interventional research is done considering behavioral determinant of SMB.

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