



## SELF-MANAGEMENT, THE MAIN EXPERIENCE OF RHEUMATOID ARTHRITIS PATIENTS: A QUALITATIVE STUDY

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### ABSTRACT

**Aim:** Rheumatoid arthritis is debilitating as a result of their progressive nature. Indeed, it affects different aspects of individuals' lives.

**Aim:** This study aimed at description and interpretation of self-management experiences in patients with rheumatoid arthritis.

**Methods:** In this qualitative study, Van Mannen's methodological approach was used. This study was performed on 11 patients with rheumatoid arthritis who had been referred to clinic of rheumatology in Hafez hospital and Shahid Motahari polyclinic affiliated to Shiraz University of Medical Sciences, Shiraz, Iran, from November 2015 to October 2016. These patients were selected based on purposive sampling. The data were collected by semi-structured interviews and field notes. Then, Van Mannen's six-step approach and thematic analysis were used to describe and interpret the experiences of self-management in rheumatoid arthritis patients.

**Results:** In this study, four main themes, including "self-care", "overcoming the illness", "social support", and "empowerment of relationship with God" and thirteen subthemes, namely "changing their dietary patterns", "turning to complementary medicine", "performing appropriate physical activities", "maintaining independency", "obtaining knowledge", "adapting with the illness", "struggle with the disease", "optimism", "moral improvement", "family support", "peers support", "tendency to pray" and "being thankful" were emerged.

**Conclusion:** This study highlighted self-management experiences of rheumatoid arthritis patients. Therefore, healthcare providers and family members are suggested to be aware of these experiences. By improving these experiences, patients will be able to deal with the illness and improve their quality of life and achieve a normal life. Moreover, they can prevent disease' complication by using self-management strategies.

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### Introduction

Rheumatoid arthritis patients deal with many challenges in life.[1-3] Despite these problems, they gradually learn to manage the negative consequences of the disease.[4,5] Self-management plays an important role in dealing with stressful situations.

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[6,1] Patients used different methods, such as accept their conditions, positive thinking, information seeking, spirituality and religion, and receive social support and to fight the disease. [7-11]

Up to now, few quantitative studies have been done on self- management experiences of rheumatoid arthritis patients. [12,13] However, no qualitative studies have done regarding self-management experiences among Iranian rheumatoid arthritis patients. Since, every human being has unique experiences and self management experiences cannot be summarized in form of quantitative researches, Therefore, the present study aimed to determine the essence of self-management experiences in rheumatoid arthritis patients.

### Material And Methods

This was a qualitative study with hermeneutic phenomenological approach that was applied from November 2015 to October 2016 in Shiraz, Iran. This study was conducted in clinics of rheumatology in Hafez hospital and Shahid Motahari polyclinic affiliated to Shiraz University of Medical Sciences, Shiraz, Iran. The study participants included eleven patients with rheumatoid arthritis. The inclusion criteria of the study were suffering from rheumatoid arthritis for at least 6 months, speaking Persian, having no other diseases except for rheumatoid arthritis, and being alert and oriented. The participants were chosen through purposeful sampling.

Van Mannen's six-step methodological framework was used in this study. [14] In the first-step, turning to a phenomenon, the phenomenon of interest that was self- management experience in rheumatoid arthritis patients was chosen. The second step was investigating the patients' self-management experience. In order to achieve deep experiences, semi-structured interviews and field notes were used.

The interview started with general questions, such as "What are your lived experiences with rheumatoid arthritis" and "What is the meaning of living with rheumatoid arthritis". Then, emphasis was put on their self-management experience. Each interview lasted for 50-90 minutes. The participants referred to the nature of self-management from their personal experiences. The process of data collection was continued to access rich and deep information. Then, the interviews were recorded for later transcription.

The third step was reflection on the essential themes that characterized the self-management. In this step, emphasis was put on analysis of the data by reflecting on the themes identified from the interviews. Thematic analysis was used to explore the meaning of self-management experiences in rheumatoid arthritis patients. The analysis process was done using holistic, selective, and line-by-line readings of the transcripts.

In the fourth step, the phenomenon; i.e., self-management experiences, was described using the art of writing and rewriting as well as intuition to the participants' feelings, thoughts, and attitudes. In the fifth step, a strong and orientated relationship was maintained with the self-management and the research question was taken into account.

In the sixth step, balancing the research context was done by considering the parts and the whole. In doing so, reading the interview transcripts, considering one's understanding of the whole, writing about the phenomenon, and scrutinizing the parts were repeatedly performed in order to achieve the meaning of self-management experiences in rheumatoid arthritis patients. It should be noted that the researchers tried to keep the research questions in mind at all stages of the research. Although these 6 steps seem sequential, there is a back and forth movement among the steps and there is no beginning or end, no top or bottom in this process.

Four criteria including creditability, dependability, confirmability, and transferability were used to increase the trustworthiness. [15] To enhance the credibility of the data, purposeful sampling, prolonged engagement (9 months), and peer debriefing were applied. To ensure dependability, an audit trail was used. In this part, all field notes, audio recordings, products of data analysis, and interview guides were approved by three phenomenologists. To guarantee confirmability, the interview transcripts were investigated and revised by one external and two internal supervisors and professors who were familiar with qualitative researches. Transformability of the study should be evaluated by readers. Ultimately, the researchers were responsible for providing thick descriptions. [16] Almost all of the researchers' team was active in this study.

This study was approved by the Ethics Committee of Shiraz University of Medical Sciences (94-7609, date: November 30, 2015). Verbal and written informed consents were obtained for recording the interviews. Additionally, the participants were reassured regarding the confidentiality of their information and were given the right to withdraw from participation at any stage of the research.

### Results

Eleven rheumatoid arthritis patients participated in this study. All participants were married, two were male, and the rest were female. Their age ranged from 31 to 75 years and their disease experience varied from 13 to 25 years. Besides, their education levels ranged from high school to master's degrees.

In this hermeneutic phenomenological study, four major themes and 13 sub-themes were emerged. The main themes included "self-care", "overcoming the illness", "social support", and "empowerment of relationship with God".

"Self-care" included six subthemes; i.e., "Changing their dietary patterns" , "Turning to complementary medicine", "Performing appropriate physical activities", Maintaining independency", "Obtaining knowledge" and "Adapting with the

illness". "Overcoming the illness" also included the following subthemes: "struggle with the disease", "optimism" and "moral improvement". In addition, "social support" included "family support" and "peers support". Finally, "empowerment of relationship with God" included "tendency to pray", and "being thankful" [Table 1].

**Table 1:** Themes and sub-themes of the patients' self-management experiences with rheumatoid arthritis

Themes	Sub-themes
Self-care	Changing their dietary patterns Turning to complementary medicine Performing Appropriate physical activities Maintaining independency Obtaining knowledge Adapting with the illness
Overcoming the illness	Struggle with the disease Optimism Moral improvement
Social support	Family support Peers support
Empowerment of relationship with God	Tendency to pray Being thankful

### 1. Self-care

Self-care was one of the patients' experiences of self-management with the disease. Self-care involved, changing their dietary patterns, turning to complementary medicine performing appropriate physical activities following up the disease, Maintaining independency, information seeking and adaptation with the illness in the lived experiences of the patients with rheumatoid arthritis.

**1.1. Changing dietary patterns:** The patients tried to take care of themselves by consuming proper diets and avoiding some foods. According to their interviews, most of them controlled their disease by refraining from eating foods with cold nature. In this regard, a participant stated "I tried not to eat things with cold nature like cabbage, lettuce, tomato, cucumber, and especially dairy products. I removed them from my life and then I felt better" (P1). Another participant explained: "I always eat foods with warm nature and I eat date and sesame with whatever I eat. For example, in the mornings that I don't feel well, I eat a little honey with ginger and cinnamon" (P3).

**1.2. Turning to complementary medicine:** The patients used different pharmacological and non-pharmacological methods for their pain relief. Some participants referred to complementary medicine to manage their disease. In this regard, one of the participants stated: "I did homeopathy for about a year and a half. I felt my pain and the morning stiffness got better". Another participant mentioned: "Because we are immobile from night till morning, it stays as it is. At nights, I fasten my knee strap to prevent my legs from tilting. I fasten my wrist strap to prevent my hands from tilting" (P1). Another participant also maintained: "I massage my hands with warm water in the morning" (P2). Another patient mentioned: "I attended traditional medicine classes. At nights, I pour a spoon of harmel (Peganum harmala) at the end of my throat and I drink quince and lemon herbal tea and green tea. When I drink these, I feel much better (P5)".

**1.3. Appropriate physical activities:** Most participants dealt with their disease by listening to the sound of their bodies, paying attention to their body conditions, and doing appropriate physical activities. In this context, one of the participants said: "I wear plimsolls, I exercise, and go walking in the morning not to get deformed" (P7). Another participant stated: "Whenever I feel better, I do my tasks, I go out; but when I feel bad, I prefer to rest and do not exhaust my joints (P6)". One other participant also said: "I try to do my tasks with gloves and I try not to sink my hands in water" (P11).

**1.4. Maintenance of independency:** Most patients reported that despite their pain, they tried to do their daily activities as they did in the past. In this regard, a participant mentioned: "I do my tasks as I do everyday although I'm in pain" (P9).

**1.5. Obtaining knowledge:** Obtaining information about the disease and its management involves seeking for information from various sources and sharing experiences with others. In the current study, the patients tried to get adequate information and knowledge from different sources, such as doctors, family members, friends, other patients, and the media to deal with the disease and control its complications. In this respect, a participant explained: "... I didn't know what ESR was! ... Well then I asked others". Another participant also said: "In the clinic, nobody told me what I had to eat, what exercises I had to do. I myself searched the Internet, books..." (P4).

**1.6. Adaptation with the illness:** The study patients tried to deal with the disease to reduce its negative effects. They were compatible with the inevitable deformity of their joints, took their medications, and coped with their pain. Most of them had adapted with the disease with patience and tolerance and believed that rheumatic disease was their partner. In this regard, one of the participants said: "Rheumatic disease is your life partner. You have to languish with it, it's my life partner" (P3).

One other participant also talked: "First, I was upset that my hands were deformed... I hated when I saw people looking at me. But, now I don't hate when they look at me" (P2).

## 2. Overcoming the illness

Overcoming the illness in life with rheumatoid arthritis meant struggle with the disease, optimism and moral improvement

**2.1. Struggle with the disease:** The participants struggled with rheumatoid arthritis as a progressive disease with unpredictable nature. In fact, they tried to compromise with the concerns caused by the disease. In this respect, a participant said: "Totally, when rheumatism comes, you have to fight with it" (P6). Besides, another participant stated: "I stand firmly against it... I always try to do something that would make me feel better when I deal with rheumatism" (P8). Another one also mentioned: "I always tell the illness: You cannot overcome me. It's me who is victorious over you" (P2).

**2.2. Optimism:** The participants pointed to the impact of having a positive attitude towards drugs as medicines for healing and pain relief. A participant maintained: "I don't look at negative things about drugs ... I see only one edge of the sword that is eliminating rheumatism" (P7).

**2.3. Moral improvement:** The participants pointed to their moral promotion to overcome the illness. For instance, a participant maintained: "I improve my moral. When I have a good morale, I feel I can struggle with my disease more efficiently" (P10).

## 3. Social support

social support in dealing with rheumatic disease consisted of family and peers supports.

**3.1. Family support:** Most patients used family and others support as one of the most important available resources to deal with their disease. Family support was effective in creating a safe and calm environment and helping the patients perform their responsibilities as they did before affliction with the disease and develop more compatibility with the new conditions. In all patients' conversations, presence of family members was raised at different stages of disease and treatment, and this support was principally from their partners followed by other family members including children and parents. Of course, types and methods of support were different in different conditions. For instance, most female patients expressed satisfaction with their husbands' cooperation and support in terms of creating hope, encouragement, and feelings of not being alone. In this regard, a participant said: "My husband is very helpful; he supports me a lot and provides me with consolation. He always says that I will get better" (P6). Another one indicated: "My children give me money and help me. They take me to doctor's office. So I can deal with the illness" (P11).

**3.2. Peers support:** The patients noted that their peers' attention and support created a feeling of confidence and peace in them. In this context, a participant stated: "I had pain, but I didn't take medicine. There was a patient who was afflicted with this disease for many years, he encouraged me. He helped me a lot. When I saw he had taken medications for forty years and is still alive, I learned it and got better. In fact, I learned a lesson from him" (P1).

## 4. Empowerment of relationship with God

In the experience of the patients with rheumatoid arthritis, empowerment of relationship with God was most evident. The patients had tendency to pray and being thankful. Most participants did not forget God. Despite specific conditions of the disease, they stated that God would always be with them. Indeed, they considered trust in God as a mentally reinforcing agent. They increased their ability to adapt with the disease through the support of God. Pain tolerance and coping with the illness were also easier for them through relationship with God and getting spiritual relaxation. In this regard, one participant stated: "When I have severe pain, I constantly ask God for help and by referring to and remembering God, I forget my pain" (P4).

**4.1. Tendency to pray:** Some of the participants asked God to heal them and other patients by praying. For example, a participant mentioned: "When I'm in pain, I bid the beads, say Salutations (Salavat), and ask God to heal all patients as well as me" (P7).

**4.2. Being thankful:** The patients regularly thanked God. One of the participants said: "In the mornings, when I get up and feel less pain and see that I can go out, I thank God" (P6). One of the participants also mentioned: "I always say thank God. Even this disease was God's mercy. It makes me rely on God more" (P4). Another participant explained: "I say thank you God; if you gave me the disease, you also gave me the medication" (P9).

## Discussion

The study showed that the participants managed their disease through self-care, overcoming the disease, receiving social support, and empowerment of relationship with God. They managed their disease by using different strategies, such as, changing their dietary patterns, turning to complementary medicine performing appropriate physical activities, maintaining independency adapting with disease, and obtaining knowledge. They also attempted to take care of themselves and decrease their dependence on others. Maintaining independency and reducing reliance on others are important factors in improving health and quality of life of patients with rheumatoid arthritis. Generally, one of the goals of controlling chronic diseases is empowering patients in self-care, which improves strategies of disease management. [17], [18]the current study patients also did their best to return to a normal life. Previous studies also indicated that patients with rheumatoid arthritis could effectively be prepared to deal with the disease through self-care education. [19], [20]

Our patients had accepted and tolerated their illness. The need for patience and tolerance against the disease was one of the issues that the patients used for adapting with their disease. The patients tolerated and were satisfied with their present situation. These results are consistent with those of other studies indicating that the majority of patients with rheumatoid arthritis managed their disease through accepting the limitations, gaining new skills, adapting with changes in life, restoring the lost abilities, listening to their body signals, and doing appropriate activities. [21-23]

Obtaining knowledge was another experience of the present study participants. They managed their disease by acquisition of knowledge about their disease, which is in agreement with the findings of other studies. On the other hand, other studies revealed lack of information about diseases as an obstacle against self-care. [18, 20, 21, 22, 24] In a study, the patients tolerated their disease by obtaining information about self-management strategies of their disease. [25] Therefore, increasing patients' knowledge enhances managing their illness, helps their care taking, and improves their quality of life.

Overcoming the illness was one of the self-management experiences of rheumatoid arthritis patients in the present study. They tried to overcome the disease by struggle with the disease, optimism and moral improvement. Although our study participants suffered from rheumatoid arthritis, they had not lost their hope and they continued their efforts to deal with the disease with a positive attitude towards treatment. Hope is a prerequisite to adapt with duration of the disease. Individuals with high levels of hope believed that they would experience physical and emotional recovery. These results were consistent with other studies. [5] Additionally, in other study, demonstrated the effect of positive thinking training on spiritual health of patients with coronary artery disease. It also revealed a strong relationship between positive thinking training and hopefulness. [26] Therefore, by focusing on these issues in interventions, nurses can help patients deal with the disease and promote their health.

One of the themes emerged in this study was family and peers supports. This point has been raised in several studies. The patients stated that receiving support from one's family, especially the partner, was one of the important factors in managing and coping with the disease. It also relationship between family and others' supports and quality of life of patients with rheumatoid arthritis revealed in other study. [27] Thus, it is necessary to put more emphasis on the role of patients' families and partners.

Empowerment of relationship with God was another theme emerged in this study. The participants tried to deal with rheumatoid arthritis by tendency to pray and being thankful. Spirituality had an important role in managing and compatibility with disabilities in rheumatoid arthritis patients in New Zealand. [28] Additionally, in other study, demonstrated that daily religious/spiritual experiences had a key role in managing of disease by rheumatoid arthritis patients. [29] Since the majority of Iranian people are Muslim and have strong religious beliefs, paying attention to this aspect of life in patients with rheumatoid arthritis is of particular importance in dealing with the disease. Therefore, healthcare providers should consider prayer and spirituality as an important factor in helping patients with chronic diseases.

The present study was conducted on experiences of self-management in rheumatoid arthritis patients. Future researches are recommended to explore the experiences of patients and their families about disease management, coping with the disease, and overcoming the disabilities and restrictions as well as spiritual experiences of patients with rheumatoid arthritis.

## Conclusion

Rheumatoid arthritis can have negative impacts on different dimensions of patients' lives. This study explored the self-management experiences of rheumatoid arthritis patients. The following themes were emerged: self-care, overcoming the disease, social support, and empowerment of relationship with God. The study findings may increase the knowledge of nurses and healthcare team about self-management styles of patients with rheumatoid arthritis and help them provide patients with useful educational programs about managing the disease. Thus, it prevents disease' complications and might improve patients' health.

Empowerment of relationship with God, support from family and peers, optimism and moral improvement were the patients' self-management strategies in rheumatoid arthritis. On the other hand, lack of spiritual and religious counselors in patients' care was an important problem. Thus, in addition to the physical dimension, spiritual and social dimensions should be taken into account to adjust with the illness. Overall, managers and policymakers must provide holistic care to patients, provide the ground for patients to meet their peers, and attract the attention of patients' families towards their effective supportive role in patients' self-management. Furthermore, understanding the meaning of patients' lived experiences provides valuable information for development of nursing programs. The results of this study also recommended official administrators of the health system to strengthen these dimensions in order to improve the lives of patients with rheumatoid arthritis.

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