

The Lived Experiences of Iranian Patients with Rheumatoid Arthritis: A Qualitative Research

Abstract

Background: Rheumatoid Arthritis (RA) is a chronic inflammatory disease that affects various systems of the body. The present study was conducted with the aim to explain the lived experiences of Iranian patients with RA. **Materials and Methods:** According to the research question, the phenomenological research approach was used. The participants were selected through purposive sampling, and sampling was continued until data saturation was achieved. The data was collected by conducting unstructured interviews and using an audio recorder. To interpret the data, an interpretive/hermeneutic approach was implemented using Van Manen's method. In addition, Lincoln and Guba's criteria were used to evaluate data robustness. **Results:** A total of 24 participants participated in the study. Overall, 145 basic concept codes were extracted which were classified into the four main themes of self-management with the participation of the family, spiritual resilience in the face of existing problems, the tendency to hide the disease, and the fear of an uncertain future. **Conclusions:** It is recommended that care providers use the findings of this study to develop care plans in the various aspects of the physical, mental, social, and spiritual needs of patients with RA based on their concerns and deep experiences. It is also suggested that other qualitative research approach methodologies such as grounded theory for explaining the process of patient care and providing an appropriate model, or action research for solving the problems of hospitalized patients through suitable care at home be implemented.

Keywords: Arthritis, lifestyle, Qualitative Research, rheumatoid

Introduction

Rheumatoid Arthritis (RA) is a prototypical, chronic, inflammatory rheumatic condition that affects 5–10 adults per 1000 in industrialized countries. Delayed care leads to severe RA, along with physical disability, poor Quality of Life (QOL), and early death.^[1] It should be noted that from 1990 to 2017, RA was responsible for 3.4 million years of disability living worldwide.^[2] In addition, the mortality rate in RA patients is recorded to be 50% more than that in the general population.^[3-5] In Iran, the incidence rate of this disease is reported to be 0.37% of the total population.^[6] RA is a chronic inflammatory disease that causes cartilage and bone damage in multiple joints,^[7] pain, joint stiffness, and functional defects.^[8] RA has periods of improvement and exacerbation that cause a decline in QOL of patients and makes it a severely debilitating disease.^[9-11] The challenging study by Chaleshgar Kordasiabi *et al.*^[12] in Iran showed that the patients with

RA have a poorer physical QOL compared to other aspects. In the study by Bala *et al.*^[13] and Pedraz-Marcos *et al.*, pain intensity and depression were reported that had a great impact on the QOL.^[14]

In a study by Bai *et al.*,^[9] age, gender, pain, income, education level, employment status, social status, and Body Mass Index (BMI) were found to impact the QOL of RA patients. In the study of Poh *et al.*,^[15] the complications affecting the QOL had negative impacts on the physical, mental, and social aspects of health, and patients adapted to these effects through different approaches.

In the study by Edwards *et al.*,^[16] findings showed that patients' experiences during hospitalization played an important role in the promotion of rheumatic care by nurses. In the study conducted by Hwang *et al.*^[17] on the experiences of Korean women with RA, although RA was recognized as a very painful and stressful disease, the real life of patients with the disease was not well

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understood even by their families. Goma *et al.*^[18] found that RA affects patients' sex function and in the majority of patients RA affected their sexual lives. Fatigue is also one of the predominant manifestations in patients with RA,^[19] and up to 75% of patients experience high levels of fatigue.^[20]

The researchers found the use of a quantitative approach in previous studies but found no qualitative studies among Iranian patients with RA. Therefore, it seems necessary to conduct a qualitative study using a phenomenological approach to obtain in-depth knowledge of the experiences of patients with RA with the aim of understanding the nature of the disease in these patients, and taking a step toward providing higher quality nursing care, in addition to increasing nursing knowledge in this field. Thus, this study was performed to evaluate the lived experiences of patients with RA. According to the research question, the most appropriate method to study the experiences of living with RA is the interpretive phenomenological approach (hermeneutics) that can reflect the nature of the experiences of patients with RA. Van Manen believes that what highlights phenomenological research is that it begins with a living world and focuses on the meaning of the human living experience. Phenomenology does not question how a phenomenon occurs but focuses on the nature or essence of this experience.^[21] Bracketing was used to reduce the potentially deleterious effects of preconceptions. The present study was conducted with the aim to explain the lived experiences of Iranian patients with RA.

Materials and Methods

In this study, an interpretive/hermeneutic approach was implemented using Van Manen's method for data analysis. Interpretive phenomenology does not focus solely on descriptions but also takes into consideration the interpretation and perception of human experiences. Therefore, it goes beyond description and seeks to interpret the phenomenon in question. This qualitative study was conducted between 2017 and 2019. The study population included all patients with RA referred to the rheumatology clinic and rheumatology ward of Golestan Hospital affiliated to Ahvaz University of Medical Sciences, Iran. The inclusion criteria included age of over 18 years, at least 1 year of illness experience, and the ability to communicate. Sampling was performed purposefully, and after obtaining informed consent from the participants, interviews were conducted in a private room in the clinic or next to the patient's bed in the ward.

Unstructured interviews and an audio recorder were used to collect data. The participants were asked to talk about their experiences regarding RA through the following questions. Tell us about your experiences with RA and living with it. Tell us about your experiences with RA and how to live with it. What does living with this disease mean to you? How do you feel about this disease? To increase the depth of the interviews, exploratory questions were asked, including "Explain further," "What do you mean?," or

"Give an example." For example, the participant stated: "*The disease has affected me and my life a lot,*" and the researcher asked: "What kind of effects do you mean?"

Each interview lasted between 20 and 65 min. It should be noted that during the interview, the researcher paid attention to non-verbal data such as moods, the tone of voice, field notes, and the incidents related to the phenomenon under study to record data.

In this study, an interpretive/hermeneutic approach was implemented using Van Manen's method for data analysis. Interpretive phenomenology does not focus solely on descriptions but also takes into consideration the interpretation and perception of human experiences. Therefore, it goes beyond description and seeks to interpret the phenomenon in question.^[22] According to Van Manen's method (2011), the stages of interpretation include participant reflection including 1-separating thematic expressions, 2-converting thematic expressions into primary codes, 3-converting primary codes into primary cluster themes and cooperative themes, 4-converting secondary cluster themes into subthemes, 5-converting subthemes into major themes, and 6-the separation of main themes from themes.^[21] Table 1 shows an example of the steps of formation of one of the major themes. To separate thematic sentences and extract themes, the two holistic and selective approaches of Van Manen's thematic analysis process were used. According to this approach, after each interview, the text of the interviews is transcribed, and then, reviewed several times to gain a general understanding of it. Subsequently, the main concept of the text is written as a general understanding in two to three paragraphs, which helps the researcher to immerse himself in the data and, in Van Manen's words, to think more about the phenomenon under study. In fact, this is a holistic approach to thematic analysis. Then, based on the selective approach, the text of each interview was read several times and the sentences or phrases that seemed to be the essence of the life phenomenon of patients with RA were selected and revealed. The members of the research team then exchanged views on extracting topics and themes. This trend continued with other interviews until new findings were found or changes were made to previous findings. To resolve any discrepancies and inconsistencies in the interpretations, the process of returning to the texts continued regularly and frequently until the resulting themes and themes were connected in the best possible way.

Lincoln and Guba's criteria were used to evaluate the robustness of the data.^[23] In the present study, the researcher increased credibility through prolonged engagement with data, integration of data collection sources, and member check. In the participants' review method, the transcript of the interviews and other data were provided to the participants both in their initial form and coded form to obtain their corrective-supplementary opinions. The

Table 1: An example of the steps of the formation of one of the major themes

Major themes	Subthemes	Cluster themes	Primary codes	Thematic expressions
The fear of an uncertain future	Concerns about role functioning in the family and community	1. Concerns about changing maternal and spouse duties	1. Concern about the inability to do things for children	Before I got sick, I did all the housework myself, from shopping to cooking and cleaning. I am also a teacher and I like my job very much. But, since I got sick, I have been very involved in medicine and treatment. I feel like I cannot be a good mother and wife like before. I cannot be a good teacher, and this worries me that my family will get tired of me or that I will lose my job. When the disease becomes active, I stop working and living. I cannot do the usual housework. Everything is the responsibility of my wife. I cannot go to work. Although my employer cooperates with me, with these economic conditions, I am afraid of losing my job and income.
		2. Concerns about changing job duties	2. Concern about the inability to do housework	
			3. Concern about the inability to perform marital affairs	
			4. Concern about losing a job and income	
			5. Concern about the family's fatigue due to the mother's illness	

researcher increased dependability through the original data availability, clarification of coding, evidence-based writing (quotations), and use of an external reviewer. The opinions of friends and colleagues familiar with the qualitative research of the external reviewer title were used. In cases in which there was disagreement, discussions were held until an agreement was reached. For confirmability, to prevent interpretive bias, the researcher observed his presuppositions in bracketing and refused to review the texts until the final stages of data collection and formation. During the data collection and analysis period, the expert panel method and member check were also used to resolve disagreements and confirm the data. Since, in the present study, the participants were varied in terms of age, sex, level of education, and illness severity, the research has the maximum sampling variance.

Ethical considerations

The present study was approved by the Ethics Committee of Ahvaz Jundishapur University of Medical Sciences under the code IR.AJUMS.RES.1396.810. Moreover, the researcher obtained informed consent from the participants, after becoming acquainted with them and explaining the purposes of the study to them.

Results

A total of 24 participants, 16 women and 8 men, participated in the present study. The age of the participants ranged from 21 to 60 years. In addition, seven subjects had a university education, and 10 were employed. Among the participants, five had deformities, and three were in the active stage of the disease. A total of 145 initial conceptual codes were extracted, and finally, the four major themes of self-management with the family's participation, spiritual resilience in the face of existing problems, the tendency to hide the disease, and the fear of an uncertain future emerged [Table 2].

Self-management with the family's participation

This main theme included the subthemes of self-management of physical, psychological, and social problems, self-management of medications, and

Table 2: The major themes and subthemes emerged from initial codes

Major themes	Subthemes
Self-management with the family's participation	Self-management of physical problems
	Self-management of psychological problems
	Self-management of social problems
	Self-management of medications
	Family support for self-care
Spiritual resilience in the face of problems	Tolerating physical and psycho-social disabilities
	Tolerating changes in one's role
	Tolerating others' opinions on the new situation Tolerating the current situation through a spiritual approach
Tendency to hide the disease	Receiving pity from family and friends
	Feeling detached from family and friends
	The feeling of being considered unworthy by family and friends
The fear of an uncertain future	Concerns about the development of physical symptoms and disability
	Concerns about role functioning in the family and community
	Concerns about total dependence on others
	Concerns about being rejected
	Concerns about early death

family support for self-care. One of the most important problems of the participants was the incidence of physical, psychological, and social problems, and the subsequent complications. They realized that managing the disease-related physical, psychological, social, and medication problems by themselves plays an important role in controlling the disease and that their family's participation and support pave the way for them. *"At first, I really suffered from joint pain and stiffness, and fatigue, as well as other symptoms. My sole hope was my physician. As soon as I had the slightest problem, I would visit my physician. I gradually learned that I had to do something for myself. I learned how to take care of myself and how to control my pain"* (Female, married, 34 years old).

Another participant stated: *"In addition to taking my medication regularly, I also implemented the advice of*

nurses and doctors, such as massage therapy, swimming, and hot-water bags. They affected both my fatigue and my joint pain and stiffness. I needed less analgesic” (Male, married, 37 years old).

Regarding the self-management of psychological problems, one of the participants said: “At first, I was very worried about the consequences of my illness. I was very stressed out. I was bored, grumpy, and aggressive. My life was full of problems, but with the advice of a clinical psychologist, I learned how to control these emotional behaviors. I try to calm myself down by reading the Quran, listening to music, watching movies, and using cyberspace like Instagram” (Male, married, 28 years old).

Regarding self-management of social problems, a participant stated: “Both physical problems and disturbing thoughts and fantasies made me reluctant to interact with relatives and friends. The thought of what others would say about me, and that they would see me as a disabled person bothered me a lot, but as time passed and the people around me realized my problem, I realized that I was wrong, and often, talking to them makes me feel better and I use their tips” (Male, single, 25 years old).

Regarding self-management of medications, one of the participants stated: “I did not know anything about drugs at the beginning of the disease. I had problems with heartburn and weight gain. Over time, I learned about the side effects of medications through training I received from physicians and nurses, and through Internet searches. I go to the doctor as soon as a problem occurs and I try to follow the doctor’s recommendations as much as I can” (Male, married, 39 years old).

The participants stated that their family has played an important role in disease management. “If it were up to me, I would have even given up taking medication and visiting doctors. I was very disappointed, but my parents tried very hard to get me out of this state. They booked doctors’ appointments on time, and took care of my medication. They supported me in every way. I really owe my current good mood to my parents” (Female, single, 22 years old).

“Sometimes the pain and fatigue make me so tired that I cannot get up and move, but my husband and son help me get up and walk a little. They talk to me to help me forget some of my pain and discomfort. They make sure I take my medication on time. My mother helps a lot in cooking and cares a lot about my nutrition” (Female, married, 40 years old).

“Fear, anxiety, and despair were ruining me. I avoided everyone. I would not leave the house. I did not want anyone to set foot in our home. My husband talked to me a lot at this stage. When I got better, he persuaded me to go out. He takes me with him almost wherever he goes. My communication with relatives has been improved. I try to think less about my problem. I have found a bit of self-control” (Female, married, 47 years old).

Spiritual resilience in the face of existing problems

Spiritual resilience in the face of existing problems is one of the major themes consisting of the subthemes of tolerating existing physical and psycho-social conditions, tolerating changes in role, tolerating others’ opinions of the new situation, and tolerating the current situation through a spiritual approach.

Regarding tolerating her current physical and psycho-social condition, one of the participants said: “The pain is excruciating. Sometimes, I scream due to the intensity of pain. My body tingles, and sometimes I feel like I am paralyzed. I am always taking painkillers so that I may be able to endure this pain. Sometimes, I feel depressed and frustrated. But I have no choice. I have to make it through for the sake of my life, for the sake of my children” (Female, married, 52 years old).

In addition to the physical and psycho-social conditions, tolerating the problems in role functioning is another example of resilience in these patients. “I live in the countryside. I was used to getting up early in the morning and doing my routine activities. But now, I feel down due to this pain and the intense feeling of fatigue. Sometimes, I cannot bear to get out of bed due to the severity of pain and fatigue. It is very difficult not to be able to do your duties the way you want, and attend to your husband and children the way you want. It is hard to bear. But we are coping with it” (Female, married, 32 years old).

Tolerating others’ views of the new situation was one of the subthemes. “In addition to all the pain and misery, the thing bothering you the most is the changes in the way others think about you and in their behaviors towards you. They treat you as if you have a disability, as if you have an incurable disease. My husband’s family pities their son and think his life has been wasted” (Female, married, 27 years old).

Despite the existing problems, the participants try to tolerate the situation and continue to live through a spiritual approach. “Each day and every moment I am suffering, I rely on God. It is only by remembering Him that I can calm myself and endure this situation. God has said: ‘without doubt in the remembrance of Allah do hearts find satisfaction.’ How can my family rely on me, if I cannot calm myself in this way” (Male, married, 53 years old)?

“Sometimes there are too many problems, arthritis and limited mobility on the one hand, and the financial costs of treatment on the other. Frequent hospitalizations really require patience and endurance. I try to advance this force of tolerance by seeking refuge in God and resorting to prayer and supplication. I did not have strong beliefs before, but now I think I have no greater refuge than God” (Female, married, 42 years old).

Tendency to hide the disease

The major theme of a tendency to hide the disease consists of the subthemes of receiving pity from family and friends,

feeling detached from family and friends, and the feeling of being considered unworthy by family and friends.

Some participants expressed hatred for receiving pity from family and friends. *"I do not want anyone, but my parents and my brother, to be aware of my problem. I do not like to be looked at like a disabled person. I hate pitiful looks. I want to be treated like a normal person"* (Female, single, 22 years old).

Feeling detached from family and friends was among the other concerns of the participants. *"My husband is one of those people who wants all the housework done regularly and on time. Whenever he comes home from work, he expects to see me fresh and energetic. He nags at me a lot whenever he finds me bored and tired. He does not understand my situation at all. I am frightened that he may finally divorce me"* (Female, married, 52 years old).

The feeling of being considered unworthy by family and friends is another subtheme. *"Only my wife and I know about this issue. We did not tell anyone about it, not even my parents. I really do not like it when others think I am disabled and cannot handle my life. I do not want to be humiliated in their eyes"* (Male, married, 53 years old).

Fear of an uncertain future

The fear of an uncertain future is a major theme consisting of the subthemes of concerns about the development of physical symptoms and disability, concerns about role functioning in the family and community, concerns about complete dependence on others, concerns about being rejected, and concerns about early death.

One of the worries of the participants is related to the development of physical symptoms and disability. *"One of my major concerns is about what will happen in the end. How far will this pain and symptoms go? What if I suffer from joint deformities? What if I become disabled? How long can I tolerate physical problems? What if one day I cannot stand it anymore"* (Male, single, 25 years old).

The concern about total dependence on others is another subtheme. *"I am afraid of the day when I can no longer rely on myself. I will be completely dependent on my family. I have always been on my own. I used to give everybody a hand. I used to help them with their celebrations, weddings, and mourning ceremonies. I was my parents' helping hand, but what about now"* (Female, married, 59 years old).

The concern about being rejected is another concern of the participants. Another participant stated: *"I am afraid of the day when I will be completely disabled. Then, no one will want me anymore. I always think what my husband will do with me when that day comes? Will he divorce me? Will my children tolerate me? Will there be anyone to take care of me?"* (Female, married, 34 years old).

Fear of early death is another subtheme. *"They say rheumatoid arthritis also affects the heart and arteries.*

I always fear of dying of a sudden infarction or of pericardial effusion. What will happen to my family if this happens? Who will address my wife and children's financial needs" (Male, married, 47 years old)?

Discussion

Because according to studies conducted by researchers So far, studies have been performed in Iran in patients with rheumatoid arthritis was quantitative, therefore, a qualitative study was necessary to better understand the experiences and problems of these patients.

In the present study, self-management with family participation was one of the main themes. Chronic disease requires someone to follow self-management behaviors to maintain good health and prevent life-threatening complications. Therefore, a patient with multiple disabilities has to follow various complex self-management behaviors prescribed by healthcare providers.^[24]

The study by Hwang *et al.*^[17] emphasized the role of self-reliance on overcoming the disease with regard to the theme of recovery from disease. Self-management in patients with RA includes the management of medications prescribed by the physician and complementary therapies such as heat therapy, exercise, massage, hydrotherapy, rest, and spending time with family and friends to receive support or advice.^[25-35] In the challenging study by Chaleshgar Kordasiabi *et al.*,^[36] some self-management behaviors such as medication management, frequent referrals to physicians, changing medication dosage or medication intervals, and sufficient rest were reported in more than 90% of patients with RA. However, behaviors such as exercise, swimming, massage, heat therapy, stress management, meditation, swimming and hot-water bags usage, and joint protection were reported less frequently.

Lawson *et al.*^[37] argued that in adolescents with chronic rheumatic diseases, the mastery of self-management skills is the vital component of the transition to adult care, and adolescents need more support to achieve self-management independence. In this study, most participants stated that self-management of the disease is difficult without the family's support. Voshaar *et al.*^[38] found that family and friends' involvement in patient care is one of the activities in patient-centered care of RA patients. Hwang *et al.*^[17] also referred to this issue in the theme of support from family and others. Lööf *et al.*^[39] found that people with positive body awareness have experienced life with others in the community and the feeling of being accepted by others, and have spent quality time with their family and friends. Others associated positive body awareness with the feelings of being loved by others.^[39]

Spiritual resilience in the face of existing problems was another major theme of the present study. Studies show that the costs caused by workplace absence and reduced working hours in patients with RA are significant, estimated to be 32% of the total annual costs per patient

of RA in Europe, which is higher than other costs such as medical costs (21%), medication costs (14%), non-medical costs (14%), and informal care costs (19%).^[40,41] The current study shows that despite the high cost of treatment, patients try to cope with the problems caused by physical, mental, and social complications by relying on religious beliefs to achieve resilience. In the study by Hwang *et al.*,^[17] patients tended to continue to play the roles they used to play when they were healthy. The theme of recovery from the disease also points out patients who rely on religion to adapt to the disease.^[17]

The tendency to hide the disease was another main theme in this research. The feelings of being pitied, being detached from, and being considered unworthy by family and friends encourage the patient to hide the disease from others. With regard to the theme of self-esteem, Hwang *et al.*^[17] showed that female patients tried to hide the abnormal changes in their bodies from others, even their husbands, by hiding bodily changes and pretending everything is fine. They were more inclined to share their disease with their parents than with their spouses. Most Korean women do not feel comfortable with their husband's families.^[17] Edwards *et al.*^[16] recommend that nurses reinforce a positive body image in patients and encourage them to share their feelings by responding in a reassuring and non-judgmental way, as nurses' reactions greatly impact how patients will cope with the disease in the future.

The fear of an uncertain future was another major theme in this research. Palominos *et al.*^[42] reported the fear of the consequences of the disease in the future and disability, fears related to pregnancy and parenting role, fear of disturbing other people, and fear of negative evaluation by other people due to their appearance in patients with RA. Lööf *et al.*^[39] found that during the recurrence of the disease, some participants expressed a fear of bodily changes that increased negatively toned body awareness. Some felt sad about the disease process, and others worried about losing their ability due to the disease and body degeneration. They did not want to be a burden to family, friends, and society.^[39] In the study of Pedraz-Marcos *et al.*,^[14] some men reported that relying on others for helping in household chores, like chopping firewood and repairing household items destroyed the feeling of masculinity in them, and mothers were physically and emotionally challenged to maintain their caring roles.

The present study has some limitations that may affect the results of the study. One of the main limitations of this study was that despite trying to gain the participants' trust, some participants, especially men, were reluctant to talk about their problems, pretended that everything was fine, and did not want to continue the interview. In the case of patients who were hospitalized because they were in the active phase of the disease, the patient was usually tired and the researcher had to end the interview.

Conclusion

The findings of the present study show that patients with RA, despite various physical, psychological, medication, and social problems, can strengthen their self-management with family support and try to cope with their fears and worries by resorting to spiritual issues. It is recommended that the findings of this study be used by care providers to develop care plans in the various aspects of the physical, psychological, social, and spiritual needs of patients with RA based on their concerns and deep experiences. Moreover, the use of other qualitative research methodologies such as the grounded theory to explain the process of patient care and provide an appropriate model, or action research to solve the problems of hospitalized patients through appropriate home care is suggested.

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Conflicts of interest

Nothing to declare.

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