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## The New Perceptions on Life of Iranian Patients with Ankylosing Spondylitis: A Qualitative Study

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### Abstract

Various studies suggest that ankylosing spondylitis (AS) as a chronic inflammatory disease with many disabilities can have impacts on different aspects of patients' life. Despite many quantitative studies, only few qualitative studies have thus far been published on this subject. For the first time, the present study aims at gaining insight into the life experience of Iranian AS patients. We performed a content analysis through semi-structured interviews with twenty-eight patients diagnosed with AS, including three females and twenty-five males with an average age of 38.5 years, to gain insight into their experiences. Whatever the patients expressed was written and transcribed verbatim. Then, we did analysis of the results after each interview. The detailed information completely extracted from the interviews was classified as sub-themes and main themes. Three main themes were identified by the analysis: (i) "Always with pain" describing the effects were found in regard to pain on patients' life, (ii) "The perceived limitation" describing many difficulties that people may face in the society as a result of their disease, and (iii) "Fearing the unknown future" which implies to both patients and their families have concerns about the future and what will happen. Our research findings in line with other qualitative studies showed that AS disease puts a heavy and intolerable burden on patients and their family. It seems that the experiences of people living with AS can be useful to meet challenges caused by the disease and it can enhance their coping with the disease.

### Keywords

patient perspective, qualitative research, content analysis, rheumatic disease, ankylosing spondylitis

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# The New Perceptions on Life of Iranian Patients with Ankylosing Spondylitis: A Qualitative Study

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Various studies suggest that ankylosing spondylitis (AS) as a chronic inflammatory disease with many disabilities can have impacts on different aspects of patients' life. Despite many quantitative studies, only few qualitative studies have thus far been published on this subject. For the first time, the present study aims at gaining insight into the life experience of Iranian AS patients. We performed a content analysis through semi-structured interviews with twenty-eight patients diagnosed with AS, including three females and twenty-five males with an average age of 38.5 years, to gain insight into their experiences. Whatever the patients expressed was written and transcribed verbatim. Then, we did analysis of the results after each interview. The detailed information completely extracted from the interviews was classified as sub-themes and main themes. Three main themes were identified by the analysis: (i) "Always with pain" describing the effects were found in regard to pain on patients' life, (ii) "The perceived limitation" describing many difficulties that people may face in the society as a result of their disease, and (iii) "Fearing the unknown future" which implies to both patients and their families have concerns about the future and what will happen. Our research findings in line with other qualitative studies showed that AS disease puts a heavy and intolerable burden on patients and their family. It seems that the experiences of people living with AS can be useful to meet challenges caused by the disease and it can enhance their coping with the disease.

*Keywords:* patient perspective, qualitative research, content analysis, rheumatic disease, ankylosing spondylitis

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## Introduction

Ankylosing spondylitis (AS) is known as a chronic and progressive inflammatory rheumatic disease that can be attributed to genetic and environmental factors. It tends to appear in young men more often than in young women (Braun & Sieper, 2007). Clinically, two main processes of inflammation and bone fusion are involved in AS (Lories & Schett, 2012). In advanced stages of AS, the radiographic results show bone erosion as well as bone overgrowth (Tam et al., 2010). Inflammatory back pain is the main important clinical characteristic of this disease. Other important symptoms are shortness of breath, restriction in chest expansion, and reduction in lumbar spine flexion. Patients usually complain about back pain, fatigue, and stiffness during the day that may last for some minutes or hours. Therefore, patients face many problems, and their vulnerability increases in AS. It means that resting alone is not helpful to improve such a condition and there is only a very small chance of feeling better with physical therapy and exercise, relieving the symptoms (Ghasemi-rad et al., 2015; Schett & Rudwaleit, 2010). Because AS symptoms are similar to those people who

suffer from mechanical low back pain, there is often a delay in the diagnosis of AS patients with the structural damages, which in turn it leads to the disease progression. The delay in diagnosis and a lack of effective treatment both cause researchers to pay more attention to the factors involved in pathogenesis of AS and to suggest new treatment (Khan, 2002; Seif & Elliott, 2012). Indeed, there are many studies considering different aspects of the pathogenesis of AS, for example genetic and immunological factors contributing to this disease (Aghaei et al., 2020; Shahba et al., 2019). However, a full description of health is attributed to the evaluation of physical (clinical and pathogenesis), social function, and mental health of individuals. AS disease makes seriously impacts upon all mentioned aspects of health leading to reductions in quality of life (Dagfinrud et al., 2004). It could be clearly shown in patients' emotions, due to the low ability to do social activities in their family and community (Boonen, 2006). For a patient, there are only a few options to improve the condition. So, there is a need to determine the burden of AS disease with a focus on the different aspects of health (Mengshoel, 2008). The qualitative studies, developing the new and key concepts of patients' everyday life resulted from the complications of chronic diseases (Bagcivan et al., 2015) seem very important and helpful for clinical research, like the clinical trials (Feudtner, 2013; Hamilton-West & Quine, 2009). In this regard, some studies have been conducted on chronic rheumatic diseases, such as rheumatoid arthritis (RA), systemic lupus erythematosus (SLE), psoriatic arthritic (PsA), and spondyloarthritis. Therefore, the qualitative studies with rheumatology key messages were synthesized on the perspectives of people living with these conditions, concerning that the symptoms are not only a swollen joint and/or stiffness measured in the clinical examination (Moverley et al., 2015; Orbai et al., 2014; Stebbings et al., 2014; Sutanto et al., 2013). The experience of people with AS living in Iran, as well as their information and supportive needs which have not been already described, hence, can add more to such concept. In this study, we aimed to (i) explore the perspectives of what these patients might face in everyday life because of AS and (ii) more importantly, to give researchers an overview in order to understand how to deal effectively with this chronic condition.

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## Methods

### Study Design

A qualitative interview study and content analysis (Tong et al., 2007) were conducted through the interview of 28 patients with AS. Qualitative content analysis is a good approach and commonly used for analyzing the content of narrative data to recognize eminent themes and patterns among the themes (Polit & Beck, 2008).

### Participants

Patients who were clinically diagnosed with AS based on some clinical criteria known as “modified New York criteria” for AS and approved by a rheumatologist in Rheumatology Research Center, Shariati hospital, Tehran took part in face-to-face interviews.

The study population was selected through purposive sampling which means that the patients who had experienced severe AS with high disease activity were considered. In this regard, Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) and Bath Ankylosing Spondylitis Functional Index (BASFI) (Zochling, 2011) were measured. The patients with BASDAI  $\geq 4$  (range of 0-10) were considered as having active and severe AS. To get access to the effects of the disease on everyday living and general well-being, the Ankylosing Spondylitis Quality of Life (ASQoL) and the Bath Ankylosing Spondylitis Patient Global Score (BAS-G) (Zochling, 2011) were used, respectively. Also, the patients were selected with a wide range of the demographic data, such as age, gender, educational level, employment and marital status. Data were collected using semi-structured interviews including some general and specific questions to help us to gain AS patients’ experience, thoughts and concerns. The questions in the semi-structure interviews are shown in Table 1. It should be mentioned that the patients who were willing and able to have interviews were also our priority in this study. All patients’ written consent was obtained before interviews and the Ethics Committee of Tehran University of Medical Sciences approved the study. It was also announced to the participants that they could withdraw from the research anytime they liked, and their information would remain confidential during and after the research.

**Table 1**

#### *Interview Guide*

Questions
<ul style="list-style-type: none"> <li>● Could you explain your living experience with AS?</li> <li>● How did the condition affect your life?</li> <li>● What kind of difficulties have you experienced due to your disease?</li> <li>● Could you please explain more about it?</li> <li>● What is your outlook on the future?</li> </ul>

### Data Collection

To select the participants, the researchers went to Rheumatology Research Center in Shariati hospital, Tehran, Iran and patients who met the inclusion criteria were selected. After explaining the research objective to them and obtaining written informed consent, an interview was conducted. An interview was primarily performed to identify the most appropriate questions for achieving complete concept, to get more information during the interview, and finally for a better analysis. The interviews started with some open-ended questions, such as “if possible, please talk about your disease” or “please talk about your own experience of the disease effects on your life.” The next questions followed as per the

provided answers to these questions with a greater focus and for a better understanding of the issue. All patients' answers were completely written down by the researchers. The next interview was planned based on the results of the previous interview, the questions were asked to fill in the categories, and findings that were not obtained in previous interviews. However, some parts of responses were also recorded to help us for further examination and clarification if needed.

S. Shahba, R. Jafari-Shakib and P. Pourghane were responsible for the drafting of the manuscript, study conception and design. S. Shahba, M. Mahmoudi, A. Jamshidi, and M. Vojdani performed the data collection. S. Shahba, R. Jafari-Shakib and P. Pourghane performed the data analysis and made critical revisions to the paper for important intellectual content.

### **Data Interpretation Procedure**

The data were evaluated using the Colaizzi's phenomenological method (Edward & Welch, 2011). Step 1: After repeated listening, record data were transcribed verbatim. Step 2: Among the statement, related phenomenon of the study spelled out and identified 246 significant statements. Step 3: Significant statements were summarized as restatements by participants. Step 4: From the 246 restatements, 47 meanings were extracted. These extracted meanings were compared to the original statement by identifying the participants' experience for validity. This process was progressed by a professor for objective validity. Step 5: Thirty-one themes were identified from the previous extracted meanings. Then, eight theme clusters and four categories were organized. Step 6: Tried to write an exhaustive description by relating themes to interested phenomenon. Step 7: For constructing essential structure, there was a return to participants for validation of the description. Nine participants identified their description and agreed extracted themes.

The research involved verbatim transcription of the collected notes. The method of the present study is qualitative, and the analysis of results is done after each interview. Therefore, the interviews were read and analyzed separately several times to identify the similarities in terms of content. All phrases were coded and *organized* carefully regarding the themes that were related to the aim. This process was repeated with each transcript so that similar themes were summarized to concepts. After a complete review, the last outcomes were classified as the main categories that represent a complete interpretation of life experience of AS patients with the chronic condition.

To increase the trustworthiness of the data, some factors were taken into account. The patients were first told; the reason for recording the interviews, the confidentiality of their data, the deletion of their data after the results were extracted, their voluntary participation in the research, the possibility of withdrawing from the research to participate in the study, and the possibility of obtaining the research results. They were explained and then, their written consent was obtained. First, regarding the credibility, getting feedback from participants (member checking) and increasing the number of interviews with some participants were conducted. Second, participants who have had long experience in the intended area and with maximal variation were selected to enhance the transferability. Maximum variation sampling is one of the most widely employed purposive sampling methods. In this method, individuals or settings are selected purposefully and with a wide range of variations with regard to the under-study subject. Researchers can attain richer data and a better understanding by selecting participants with various viewpoints and perceptions (Polit & Beck, 2008). Third, in regard to the dependability and confirmability, peer checking, peer debriefing, member checking, and prolonged engagement of all researchers in the phenomenon under-study were performed. For this purpose, the interview texts were given to several experienced

colleagues, along with the emerged codes and classes, to review the data analysis process and comment on their accuracy. Prolonged engagement and ongoing involvement with the subjects and research data were done in order to get in-depth and rich data. Also, peer debriefing for codes matching, ensuring codes, subcategories, and categories match with participants' statements was done.

## Results

In general, 28 patients with AS were interviewed in the study and each interview took time between about 30 and 45 minutes. Table 2 shows the demographic and clinical characteristics of patients.

**Table 2**

*Demographic and Disease Characteristics of the 28 Patients With AS*

<b>Variables</b>	<b>AS patients (N=28)</b>
<b>Number of patients</b>	28
<b>Age (years), Mean ± SD</b>	38.5±10.3
<b>Gender</b>	
Male	25 (89.2%)
Female	3 (10.8%)
<b>Level of Education</b>	
Minimal	2 (7.14%)
High school	8 (28.57%)
University	18 (64.29%)
<b>Employment</b>	
Unemployed	7 (25%)
Employed	16 (57.14%)
Retired	5 (17.86%)
<b>Marital status</b>	
Married	19 (67.86%)
Single	9 (32.14%)
<b>Children</b>	
Yes	13 (46.42%)
No	15 (53.58%)
<b>Age of onset (years), Mean ± SD</b>	24.73 ± 6.79
<b>Age of diagnosis (years), Mean ± SD</b>	32.61 ± 9.30
<b>Disease duration (years), Mean ± SD</b>	12.57 ± 11.86
<b>Disease score, Mean ± SD</b>	
BASDAI	5.36 ± 2.14
BASFI	4.10 ± 2.58
BAS-G	6 ± 2.8
ASQol	9.56 ± 5.51
<b>Currently receiving biological medicines</b>	
Yes	7 (25%)
No	21 (75%)

AS, ankylosing spondylitis; BASDAI, Bath Ankylosing Spondylitis Disease Activity Index (the high scores more than 4 indicating severe disease, range from 0 to 10); BASFI, Bath Ankylosing Spondylitis Functional Index; BAS-G, Bath Ankylosing Spondylitis Patient Global Score; ASQol, Ankylosing Spondylitis Quality of life.

The sentences that the patients explained were analyzed so that the following three main categories were considered: always with pain, the perceived limitations, and fearing the unknown future. As shown in Table 3, so we found three categories, each of them includes three subcategories that will be defined in more details.

**Table 3**

*Three Main Categories Were Identified Through the Analyses of Interviews*

Category	Subcategory	Example
Always with pain	The perpetual tension and pain	<ul style="list-style-type: none"> <li>● Daily pain and stress.</li> <li>● In spite of constant pain, the tolerance threshold is decreased.</li> </ul>
	The ups and downs of pain	<ul style="list-style-type: none"> <li>● High and low pain round-the-clock.</li> <li>● Pain is increased even after sleeping.</li> </ul>
	A small hope for pain relief	<ul style="list-style-type: none"> <li>● To do many activities by taking analgesics.</li> <li>● Briefly, stiffness is improved by taking analgesics.</li> </ul>
Perceived limitations	The tight circle of movement	<ul style="list-style-type: none"> <li>● Movement disability is caused by severe pains.</li> <li>● Being unable to do difficult physical activities.</li> </ul>
	The social phobia	<ul style="list-style-type: none"> <li>● There are limitations to being with friends.</li> <li>● There are worries of vulnerability in crowded surroundings.</li> </ul>
	The unstable job	<ul style="list-style-type: none"> <li>● The chronic pain is a barrier to keeping a job.</li> <li>● A job with the least mobility is desired.</li> </ul>
Fearing the unknown future	The ambiguous vision of the disease	<ul style="list-style-type: none"> <li>● How does the disease progress?</li> <li>● Unknown future.</li> </ul>
	The concerned ring of relatives	<ul style="list-style-type: none"> <li>● There are worries about family.</li> <li>● Disappointing family.</li> </ul>
	The vague role of parenthood	<ul style="list-style-type: none"> <li>● The ability or disability to perform the role of father.</li> <li>● There is a concern for implementing the effective role of being a mother.</li> </ul>

### Category 1: Always with pain

The findings emphasize the importance of pain as the main problem that makes life difficult for the patients. The experience of pain can be mentioned in three principal patterns.

**The perpetual tension and pain:** The patients were describing pain as tension. One patient expressed that “I think that pain, in some parts of my body, is associated with stress. I feel the effects of severe pain on my hip when I am stressed” (male, 31Y). Another patient stated that “I always feel pain during the day and even the night; pain gets on my nerves more

with negative emotions” (male, 40Y). One patient said: “for this disease, my nerves are on edge and with a chronic pain in my life, my tolerance is less than I used to be and sometimes, I feel like crying” (male, 39Y). In fact, some patients' statements indicate the physical pain for most of the hours.

**The ups and downs of pain:** The increasing and decreasing pain at various times was another experience of AS patients. The findings conclude that the level of pain during the day and night was different among patients and the expectation makes an unsuccessful attempt to relieve the pain with sleeping and relaxation. Another participant described the pain like “Sometimes, I feel chronic and severe back pain even after sleeping and sometimes, it goes away. I cannot move a muscle and I become dry, like a bone” (female, 32Y). The patient said: “I cannot sleep comfortably at night because pain becomes far worse than before.” (male, 27Y). In other words, in some other patients, the pain fluctuated.

**A small hope for the relief of pain:** With regard to such situation, some patients hoped that pain would be relieved by suitable therapy procedures. Some patients reported that: “The highest level of pain is often in the mornings. I am not able to do my own responsibilities if I do not take my drugs as if living a normal life depends on *medicines*” (male, 29Y). Other patient said: “For me, the way forward is taking my pills, otherwise I cannot carry out simple tasks” (male, 42Y).

At the beginning stages of my illness, I used to have too much morning stiffness as far as I had to sleep in a sitting position with a lot of pain and suffering; but luckily, it has been lessened by drugs injection that I do once a month (male, 31Y).

These findings showed that patients found taking medication a way to reduce their pain.

## Category 2: The perceived limitation

According to patients' Disease Activity Index and Functional Index, they have usually physical, social and job limitations which prevent them from their goals. Their statements showed three overall subjects.

**The tight circle of movement:** Most patients have implied on disability that makes it difficult for them to deal effectively with their problems and activities needing more power. One patient expressed that: “I suffer from a chronic pain in my neck, shoulder and back. It becomes impossible to move my neck, and therefore there is a serious problem to do simple activities” (male, 41Y). “I often try to do tasks myself but some of them are annoying, for example the easiest things, like bending, sitting on the floor, and wearing shoes, are the hardest for me; I prefer never doing them” (female, 34Y). “I can almost handle walking or getting in and out of my car, but there is nothing worse than running, doing a strenuous exercise and washing my car” (male, 36Y). The results showed high movement limitation and subsequent difficulties in patients.

**The social phobia:** The patients' experience shows that disability in social activities causes them to be offended by others. Accordingly, an unusual fear and anxiety is created contrary to their age and position. “I am worried about taking part in sports with friends. I used to go to the gym, and I used to play volleyball, but I cannot now” (male, 27Y). Indeed, they were worried about presenting in the community. One patient said: “I feel much

disappointed when I cannot use public transportation systems, like the subway. I am afraid of physical contact with people, and I get worried about everything that might happen to my back” (male, 32Y). “I do not want to go out with my friends. I become more sensitive when they put their hand on my joints and bones” said another patient (male, 32Y). When something like anxiety makes them feel like they are in danger, they usually prefer to be isolated.

**The unstable job:** Most of the patients in our study, especially men patients, expressed dissatisfaction with their job position, the possible limitations and changes in their economic conditions, as the biggest challenge of their working conditions. One described: “I used to have two jobs and I had to quit working in the second job. All I can say is that the illness has affected my personal and job conditions” (male, 45Y).

I had decided to do a job based on my situation because this disease makes me feel weak and so exhausted. I sit on a chair more and I have no serious problem now. Sometimes, I have to ignore my responsibilities where I work to have a rest (male, 35Y).

“Unfortunately, I am unemployed. I had never imagined that it could happen to me. Such situation is out of my control, and I do not know what I can do when costs of living are rising” (male, 39Y). In fact, the disease caused movement problems for many patients and due to the impact on their jobs and the occurrence of economic problems, it created considerable psychological stress for them.

### **Category 3: Fearing the unknown future**

It is worth mentioning that to keep thinking about things that they are unable to change in the future, relatives’ attitude towards them and thinking about the future of their family had become a serious concern for patients. By and large, the relevant concern expressed by the patients was an ambiguous vision of the disease, the concerned ring of relatives, and the vague role of parenthood.

**The ambiguous vision of the disease:** The experience of some patients included an opinion that: “I am not well-informed about the disease. I wonder whether it can be curable!? I think that everything would go well if it remained unchanged” (male, 32Y) and “I have felt blue since long time ago and I felt anxious to think about the way forward” (male, 33Y). “Indeed, awful pain really annoys me from when I had the last intravenous injection. Could you please tell me if there is an effective treatment?” (male, 35Y). The unknown condition of the disease, fear and hesitation in recovery were unpleasant experience of the patients.

**The concerned ring of relatives:** “I look nervous when they ask me how I could help them. I am not able to deal with the situation and it disappoints my family’s expectations” (male, 41Y). “I guess that my disease has got worse. I just go out with my family and friends for a few hours, and I cannot spend more time with them” (male, 37Y). “I avoid family entertainments because I feel obliged to do heavy duties. They get fed up with this issue” (male, 41Y). Hence, another increasing concern expressed is about the barriers to effective communication with their relatives which discourages the patients.

**The vague role of parenthood:** The patients reported that the most important issue to consider with their occupation and social situation is how it affects the important

responsibilities of family. One patient said: “I used to help my wife to do housework. While many are difficult to do, I try to do at least the easiest things, for example washing the dishes” (male, 53Y). “I fear I wouldn’t be able to deal with taking care of *household* and family without my spouse, by any means” (female, 59Y). As these findings show some patients were concerned about supporting their spouse and living with their family.

## Discussion

Our findings were central to the pain as a major and continuous condition of AS, the limitations predictably caused by unpleasant situation and a lot of concerns coming to patients and others’ mind.

The living experience of our patients were similar to other findings on individuals with AS and chronic inflammatory diseases. We found that pain is referred as tension which follows stress. Similarly, an association between stressful emotion and the repeated pain were observed in other AS patients. There was the constant lower back pain increasing by stress during the day (Primholdt et al., 2016). This relation between pain and stress, however, has been shown different by some studies. The misconception about the chronic pain was stated as an effective factor by patients with chronic pain causing stress and negative impacts on their quality of life (Lamé et al., 2005). Surprisingly, apart from pain, stress caused by disability was considered as a main problem as long as the disease was becoming worse (Bagcivan et al., 2015; Berenbaum et al., 2014). In our study, the patients were struggling with negative emotions resulted from pain, such as fear and not being able to look after themselves. In general, life is influenced by pain and in addition to all effects on emotions, it is considered to be important for individual needs, such as sleeping (Bagcivan et al., 2015; Madsen et al., 2015).

Pain, as a crucial factor, not only would not be relieved by sleep and relaxation but would also cause sleep disorders (Batmaz et al., 2013; Leverment et al., 2017). There is a little hope to deal with pain through taking medication. As mentioned, it refers to a light at the end of the tunnel or a chance in life. In the present study, drug was considered as the only way forward for dealing effectively with daily activities. In line with previous studies, for some patients, taking biological drugs which temporarily relieve the symptoms should be to live a normal life because the chronic inflammatory diseases, like AS show a dependence on medical remedies and biological drugs (Madsen et al., 2015).

Physical limitations make some activities difficult to do, especially when they need great strength and the control of disease progression is necessary to improve the physical performance of patients (Song et al., 2017). We reported that for the patients based on amount of their movement abilities, some activities seem to be easy, like walking, or hard to do, like running. As expected, AS patients have mostly chosen some activities to help them keep their physical state due to loss of joint flexibility. For instance, fewer patients with high disease activity are able to go cycling and many patients with low disease activity prefer to go walking as the simplest way to be active (Fongen et al., 2013). Hence, this adaptation becomes an important part of their daily routine by avoiding many activities needing a lot of energy (Mengshoel, 2008).

In this study, contrary to the age and social position, the patients often experienced unusual fear and anxiety which negatively affected their personal and social life. Getting away from old friends or stopping exercise due to the fear of being hurt could not be beneficial to them. There was also a very negative attitude towards the exercise because of the fear among other patients similar to our study. However, these patients also implied on the positive effects of activity, in addition to the negative ones. Being physically active is expressed as a successful strategy for improving their symptoms, such as pain, morning

stiffness, stress, and sleep (Martindale et al., 2015; Mengshoel, 2008; O'Dwyer et al., 2016). Unlike these studies that have highlighted both, our findings did not show the positive aspects of living experience with AS and participants have not suggested strategies and solutions to overcome the disease. In *spite* of the fact that AS disease can have negative impacts, for the most part, the awareness of the importance of being active can be the most affirmative action to keep healthy (Hamilton et al., 2009; Madsen et al., 2015).

In the present study, the patients were attempting to create a better work environment. The findings confirmed that workplace increases all challenges, especially for men patients because the ability and physical strength may be needed to hold the conditions of employment open and not being faced with socioeconomic issues. Sometimes, they have to change their *responsibilities* in the workplace compared to healthy individuals who may not care about this issue (Connolly et al., 2015; Farren et al., 2013; Kohler, 2013; Lacaille et al., 2007; Mengshoel, 2008; Primholdt et al., 2016; Ramonda et al., 2016; Thomsen et al., 2015).

Therefore, the evidence shows a common concern about the future among all patients with AS disease (Madsen et al., 2015). It is not surprising that negative thinking about the future would be temporarily stopped during treatment, while would be also started when the symptoms appear (Berenbaum et al., 2014).

Furthermore, public opinion about patients is always a controversial subject. In their view, nothing is according to normal situations. It may lead to losing one's friends, and even worse, losing one's partner. However, some patients are completely supported by their family with positive attitude while there will always be reasons for annoying nonsense thoughts in a society (Stamm et al., 2014). Trying to control over the situations, for example by adaptation could seem an appropriate solution for patients to be a normal partner, parent and/or friend (Grønning et al., 2011; Madsen et al., 2015). The effects of disability are also shown in the patient's role in family, as a father, mother, and partner. Our study similar to other studies showed that the patients' partner had to shoulder a burden of family responsibility alone, like looking after children (Bagcivan et al., 2015; Farren et al., 2013; Kohler, 2013).

This paper goes along with other qualitative studies drawing the first picture of the living experience of Iranian AS patients. Considering the fact that most scientific research mainly concentrate on the pathogenesis of AS, the evaluation of life experience of patients is also deemed essential for better health outcomes. The present study explored some information on the patients and their main difficulties, which in turn would keep the more attentions of the clinical research to the various aspects of the disease, the positive and negative ones. Especially when the patients in this study did not experience any positive aspects or strategies to deal with the situation. Hence, the precise analyses of AS disease will provide great opportunities in order to reach the most effective multidimensional treatment and support, for example medical interventions and positive coping strategies are needed. However, the higher number of AS patients can be suggested to obtain the more details. A large-scale research can cover many subjects, which might not be included by our patients. This study, indeed, can be a good guide to start new studies to better understand the experience of these patients in different aspects of the disease and in different cultures, which should involve asking more questions, spending more time for each interview, and frequently visiting each patient during the years. Also, the mental nature of data collection limited the generalizability of the study results. However, the selection of samples with different experience, reduced the limitations and the results of the study in similar units will largely applicable. The study was conducted in the capital of Iran, Tehran, with the participation of 28 patients. Thus, similar studies in other regions and cultures will help for better generalizability of the data. To ensure data saturation, the use of theoretical sampling as well as efforts to fully saturate the data, helped us to reduce the limitations.

## Abbreviations

AS, ankylosing spondylitis  
 RA, rheumatoid arthritis  
 SLE, systemic lupus erythematosus  
 PsA, psoriatic arthritis  
 BASDAI, Bath Ankylosing Spondylitis Disease Activity Index  
 BASFI, Bath Ankylosing Spondylitis Functional Index  
 ASQoL, Ankylosing Spondylitis Quality of Life  
 BAS-G, Bath Ankylosing Spondylitis Patient Global Score  
 Y, years old

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**Ethics approval and consent to participate:** The Ethics Committee of Tehran University of Medical Sciences has approved this study and the written consent was obtained from all patients in the study.

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