

## Experiences of Iranian Female Patients With Systemic Lupus Erythematosus: A Qualitative Study

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### ABSTRACT

**Objectives:** This study aims to explore the perceptions, concerns, expectations, and viewpoints of female patients with systemic lupus erythematosus (SLE) regarding reproductive health in Iran.

**Patients and methods:** This qualitative research was conducted using 27 semi-structured deep interviews with 19 married female patients (mean age 37.4±7.0 years; range, 15 to 49 years) suffering from SLE selected through purposive sampling in the Rheumatology Center of Shariati Hospital, Tehran, Iran between August 2017 and March 2018.

**Results:** Patients' perceptions were classified into six categories and 14 subcategories: physical suffering (debilitating pain, gradual disability, and apparent transformation), psychological stress (family disturbance and sexual dissatisfaction), challenging fertility (bothersome pregnancy and impaired parenting), adaptation to the disease (self-care and lifestyle modification), need for a supporter (support from the spouse, support from the family and acquaintances, and lack of occupational and social support), and spirituality (forgiveness of sins and resorting to God).

**Conclusion:** The findings clearly suggested the negative effects of SLE on the reproductive health of these patients. This study emphasized the importance of care and support for female patients with SLE. We hope that this research enhances the awareness of care providers about physical, sexual, psychological, social, and spiritual factors, since taking care of these patients requires strategic and multidisciplinary management.

**Keywords:** Females, qualitative study, systemic lupus erythematosus.

Systemic lupus erythematosus (SLE) is a chronic, complex, and autoimmune disease. Females of childbearing age are affected about nine times more often than males (90%).<sup>1-3</sup> Rate of SLE varies between countries from 20 to 150 per 100,000 in the United States (US), from 72.8 to 97 per 100,000 in England, and 40 per 100,000 in Iran. Furthermore, its prevalence in females varies from 164 (white females) to 406 (African-American) per 100,000.<sup>4-6</sup> SLE most commonly

begins between the ages of 15 and 45, and the mean age of SLE in Iran is 24 years. Research indicates that factors such as ethnic mixing, tobacco use in industrial countries, and different types of infections among people in different regions may contribute to these differences.<sup>4</sup>

Knight et al.<sup>9</sup> in England and Makel Hen et al.<sup>8</sup> in the US reported that fatigue was the most common sign of SLE worldwide. SLE

**Received:** December 28, 2019 **Accepted:** May 31, 2020 **Published online:** December 10, 2020

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### Citation:

Moghadam ZB, Faezi ST, Zareian A, Rezaei E. Experiences of Iranian Female Patients With Systemic Lupus Erythematosus: A Qualitative Study. Arch Rheumatol 2021;36(x):i-ix.

limits socioeconomic roles and daily activities by developing physical, sexual, and psychological disability. It also impairs the general understanding of the person about health and adversely affects the patients' capabilities causing marital and familial problems. SLE lowers the quality of life of the patients, particularly females (psychological, sexual, physical, and social).<sup>7-9</sup> Menstruation at young ages, irregular menstruation cycles, and use of oral contraceptives<sup>8-10</sup> affect the health of females with lupus. These patients may have different problems including infertility,<sup>9-11</sup> spontaneous abortion, and a lower rate of planned childbearing.<sup>12,13</sup> Itziar et al.<sup>14</sup> mentioned a huge gap in reproductive health in the care of young females with SLE. Furthermore, physicians, healthcare providers, and interviewers overlook sexual and reproductive functions when measuring the quality of life of females with SLE.<sup>15</sup> Carp et al.<sup>16</sup> reported that the effect of SLE on reproductive health was largely neglected in clinical practice and research. Most females with SLE believed that physicians just treated their SLE and did not pay attention to issues such as their childbearing, sexual relationship, contraceptives etc. that were really essential for their lives. Reproductive health has physical, psychological, and social wellbeing dimensions,<sup>17</sup> which allow people to have a safe and satisfactory sexual life and freely make decisions about the time and method of desired fertility.<sup>18</sup> Females with SLE also have the right to decide freely about their reproductive health like other females. One of the goals of the United Nations Population Fund is global access to health, sexual rights, and fertility<sup>17</sup> and the commitment of all countries to promotion of females' health (according to the objectives of the United Nations Sustainable Development Goals by 2030 as well as the World Health Organization Health and Wellbeing Strategy by 2021).<sup>19,20</sup> Therefore, by encouraging, assessing, and improving the quality of females' healthcare, particularly those with chronic diseases such as SLE,<sup>12</sup> attempts should be made to achieve sustainable development objectives. Furthermore, few studies have investigated the viewpoints of female patients with SLE on reproductive health worldwide. Therefore, in this study, we aimed to explore the perceptions, concerns, expectations, and viewpoints of female patients with SLE regarding reproductive health in Iran.

## PATIENTS AND METHODS

Experience is the source of our beliefs, which does not need justification and reasoning. Empiricists believe that the entire cognition is achieved through experience. Since experiences and beliefs are related to the context (in which they are acquired in order to enable them to deeply understand the experiences of participants through free expression of perception, behaviors, and experiences), this qualitative study was conducted using the content analysis approach. Content analysis is one of the most important research techniques in social sciences that seeks to understand phenomena through analyzing them. This method has also been used in nursing research and education in a wide range of data to obtain a rich interpretation.<sup>21</sup>

The study was conducted between August 2017 and March 2018. Participants were selected from Iranian Lupus Association and the Lupus Unit of the Rheumatology Research Center of Shariati Hospital affiliated with Tehran University of Medical Sciences. The center is considered the largest information bank of lupus in Asia and Oceania.<sup>4</sup> The participants were 19 married female patients (mean age  $37.4 \pm 7.0$  years; range, 15 to 49 years) diagnosed with SLE by the Rheumatology Center for at least 12 months. Due to religious conditions of Iran regarding sexual issues, married female patients were used in this study. The status of SLE was diagnosed according to Systemic Lupus Erythematosus Disease Activity Index (SLEDAI), the American College of Rheumatology (ACR) criteria for SLE ( $\geq 4$ ) as well as ACR Guideline of Reproductive Health in Rheumatic Diseases,<sup>22,23</sup> while disease damage was assessed using the Brief Index of Lupus Damage (BILD), a validated, self-reported measure of damage (score range 0-26).<sup>24</sup> Patients had no history of participation in qualitative interviews about reproductive health. They had reading and writing skills and could speak Farsi, and were chosen through purposive sampling with maximum diversity. Furthermore, eight participants were interviewed twice to obtain a complete and rich content; therefore, 27 qualitative interviews were performed. The study protocol was approved by the Tehran University of Medical Sciences Ethics Committee (9513151002;

2017/August/13). A written informed consent was obtained from each patient. The study was conducted in accordance with the principles of the Declaration of Helsinki. The principles of research ethics including data confidentiality and anonymity, the right to withdraw the research at any time, and the right to receive the audio file and transcript were considered in this study. Furthermore, the research team provided small gifts for the participants at the end of the interviews. The research was part of the PhD thesis of the first author.

A rheumatologist evaluated SLE based on SLEDAI. In-depth, open, and semi-structured interviews were used to extract thorough data using the interview guide. Furthermore, a review of the literature and available references were also investigated. The participants were informed about the approximate length of interview. In the beginning of the study and after giving a general description about the research objectives, oral consent was obtained from all participants to record their voice. The participants were also assured that they could stop the interviews at any time and the data would be anonymous and confidential. The researcher recorded and wrote down the interviews with the permission of the participants. The interviews were transcribed verbatim and analyzed as the main data within the first 24 hours. Each interview lasted between 40 and 110 minutes. The interviews continued until no new data were extracted and data saturation was achieved.

Table 1 shows the personal characteristics, administered drugs, and SLE characteristics. The questions used as the interview guide were as follows: what do you think about and what is your experience of pregnancy and childbearing with SLE? What changes do you think SLE has caused in your relationship with your spouse and parents? What do you think about and what is your experience of sexual relationship after having SLE? What is your experience of using contraceptive methods with SLE?

### Statistical analysis

Conventional content analysis approach was used for data analysis based on the method proposed by Zhang and Wildemuth<sup>26</sup> and applied in eight stages as follows:

1. Preparing data for qualitative content analysis
2. Making decisions about the unit of analysis
3. Classifying
4. Testing the coding in a sample text
5. Generalizing the coding testing process to the entire text
6. Obtaining coding stability
7. Concluding the classified or coded data
8. Reporting<sup>[25,26]</sup>

It was previously decided that both implicit and explicit contents should be taken into account. Twenty-seven interviews were included in the analysis. Data analysis was performed with a content analysis approach using the MaxQDA 10 software (VERBI Software GmbH Berlin, Germany). For this purpose, the text of each interview was considered as a whole, and the fundamental meaning or general concept of the text was described as a whole in one or several paragraphs. For enriching their interview researchers used field note and memo, when they were talking. Then, each sentence or paragraph was given one code and taken as unit of analysis, respectively. Primary codes were grouped into subcategories according to similarities and differences. Subcategories formed categories based on their relationship with one another. Finally, main categories were organized to have internal consistency and external incompatibility. In addition, repeated categories and codes were merged after frequent analyses.

Datasets were restudied separately to ensure the validity of the extracted themes and extract the source of supportive evidence. For this purpose, the transcripts were read and coded again a couple of days after primary coding. Then, the results were compared with the results of primary coding. If similar results were achieved, the stability and consistency of the data and thus their reliability were confirmed. Constant investigation and observation, allocation of adequate time to data collection, good communication with participants, discussion and examination of the research team about contradictory findings and final consensus<sup>[27,28]</sup> were the other methods applied to ensure acceptability. Furthermore, after complete coding of each interview, key

**Table 1.** Characteristics of participants (n=9)

	n	%	Mean±SD
Age (year)			37.4±7.0
Age at diagnosis (year)			26.7±7.8
Duration of marriage (year)			14.2±10.1
Length of interview (min)			45.5±14.4
SLE characteristics			
Disease duration (year)			10.7±7.10
Disease activity, SLEDAI score			10.2±6.7
Disease damage, BILD score			1.9±2.0
ACR criteria, numbers			6.5±1.5
Positive anti-nuclear antibodies	17	89.4	
Positive anti-dsDNA, Sm or phospholipid antibodies	15	78.9	
Ethnicity			
Persian	9	47.5	
Turk	5	26.3	
Lore	3	15.7	
Baluch	2	10.5	
Education (year)			
≤6	5	26.3	
7-12	9	47.4	
Higher	5	26.3	
Employment status			
Full-time employment	4	21.5	
Part-time employment	2	10.5	
Not employed	3	15.5	
Not working, on disability	1	5.2	
Retired	1	5.2	
Housewife	8	42.1	
Life status			
With her husband or children	17	89.5	
With parents	2	10.5	
Economic status			
Good	5	26.3	
Moderate	9	47.4	
Bad	5	26.3	
Menstrual status			
Normal	10	52.6	
Abnormal	5	26.3	
Amenorrhoea	4	21.1	

**Table 1.** Continued

	n	%	Mean±SD
Immunosuppressants			
Hydroxychloroquine	13	-	
Corticosteroids	17	-	
Azathioprine	5	-	
Methotrexate	1	-	
Mycophenolate mofetil	1	-	
Cyclosporine	1	-	
History of endoxone use	8	-	
Other medications			
ACEI or ARB	8	-	
Bisphosphonates	2	-	
Calcium	11	-	
Warfarin	2	-	
Low-dose aspirin	7	-	
NSAIDs	10	-	
Clinical features			
Immunological	19	100	
Mucocutaneous	11	57.8	
Musculoskeletal	17	89.4	
Hematological disease	10	52.6	
Neurological disease	5	26.2	
Articular	13	68.4	
Renal disease	4	20.3	
Serositis	4	20.3	
Number of children before diagnosis			
None	10	52.6	
One	4	21.1	
Two or more	5	26.3	
Number of children after diagnosis			
None	9	47.5	
One	7	36.8	
Two or more	3	15.7	

SD: Standard deviation; SLE: Systemic lupus erythematosus; SLEDAI: Systemic Lupus Erythematosus Disease Activity Index; BILD: Brief Index of Lupus Damage; Sm: Smith; dsDNA: Double stranded deoxyribonucleic acid; ACEI: Angiotensin-converting enzyme inhibitor; ARB: Angiotensin II receptor blocker; NSAIDs: Nonsteroidal anti-inflammatory drugs.

codes and statements were provided to a number of participants to evaluate the consistency of the codes with the experiences of the participants. Two observers (university professors) who were familiar with qualitative research methods and data analysis reviewed, confirmed and corrected codes, categories, and themes extracted from each interview. They also confirmed the accuracy of the coding process.

## RESULTS

Among the female patients selected for the interview and according to the rheumatologist assessment based on the SLEDAI, 15 were in the active stage of the disease (11 mild or moderate

and four severe) and the rest (n=4) were not in the active stage. Also, based on BILD and ACR criteria, the mean ± standard deviation scores of patients were 1.9±2.0 and 6.5±1.5, respectively. Of the patients, 89.4% had positive anti-nuclear antibodies and 78.9% had positive anti-double stranded deoxyribonucleic acid, Smith or phospholipid antibodies. Most patients were Persian (47.5%), 47.4% had education between seven to 12 years, 42.1% were housewives, 89.5% were living with their husbands or children (one widow, two divorced, and the rest were living with their families), 47.4% were from the middle class, and most patients had immunological (100%) and musculoskeletal (89.4%) features. Other demographic characteristics are provided in Table 1.

**Table 2.** Analysis grid (MaxQDA codebook)

Category	Subcategory
Physical suffering	Debilitating pain
	Gradual disability
	Apparent transformation
Psychological stresses	Family disturbance
	Sexual dissatisfaction
Challenging fertility	Bothersome pregnancy
	Impaired parenting
Adaptation to the disease	Self-care
	Lifestyle modification
	Support from the spouse
Need for support	Support from the family and acquaintances
	Lack of occupational and social support
Spirituality	Forgiveness of sins
	Resorting to god

During the analysis of the interviews, 1050 primary codes were obtained from semantic units, which formed 14 subcategories and six categories through analyzing, removing, and merging primary codes and subcategories. The information of the categories is presented in Table 2.

The physical suffering category had three subcategories: debilitating pain, gradual disability, and apparent transformation. SLE can involve all body organs in a multisystem way. Debilitating pain, the most common experience of the disease, results from bone and joint pain, severe and persistent back pain, and oral ulcers. A participant living with the disease for 13 years (participant no. 17) said that the disease involved the joints. She knew the disease by joint pain and her knees swelled very much. The majority of the patients had an orthopedist's visit rather than a rheumatologist's visit.

Gradual disability is experienced with a range of feelings including fatigue, physical disability, motor disability, and a sense of paralysis in the limbs. Participant no. 16 stated that her body became very weak in six years. The disease was like a wolf, which attacked from the head to toes. She used to go walking and play volleyball but then she did not have such abilities at all.

The appearance of a patient with SLE may be affected by the disease or the drugs' side effects. Apparent changes are experienced as facial skin melasmas (ranging from sparse melasma to butterfly rash and inflammation), skin lumps, skin hyperpigmentation, and fingers inflexibility. Participant no. 15 who had been living with the disease for nine years indicated that the main thing that annoyed her more than anything else was skin melasma because they were on her face. She tried not to be frustrated, but when she saw their effects on her body, the disease really tortured her. Very severe and large stretch marks had developed on her body like the effect of a knife so that she felt embarrassed. Those changes had occurred because of corticosteroid consumption. In her opinion, those changes would occur in the appearance of a person gradually dying and were annoying more than the disease itself.

The psychological stress category had two subcategories: family disturbance and sexual dissatisfaction. Family disturbance can have an intensifying role in the adverse experiences of SLE given the status of the disease. According to the participants, these disturbances can be experienced in response to the spouse's apathy, behavior change of the spouse due to the disease, no support from the spouse related to the disease, and humiliation and insult by the spouse and others. Participant no. 6 reported that her husband did not follow the course of her disease. He avoided and did not pay attention to her. He changed his behavior after her diagnosis. Her husband and she were barely tolerating each other in their marital life, and they had no feelings to each other.

Sexual dissatisfaction can be the source of many family disturbances and psychological stresses, either alone or following SLE and its complications. According to the participants, sexual dissatisfaction is experienced following poor sexual desire and dissatisfaction. Participant no. 19 who had been married for 29 years and had lived with the disease for six years stated that her sexual desire diminished by lupus. When she heard the name of the disease for the first time, she was shocked. Over time, the sexual relationship weakened significantly. She felt that she was doing something compulsory and forcefully. Following the disease, she had become very weak sexually.

The challenging fertility category had two subcategories: bothersome pregnancy and impaired parenting. Childbearing age is a stressful period and one of the major concerns of women. If the disease impairs its physiological course, it can have an intensifying role in fertility challenges. According to the participants, patients with SLE experienced pregnancy problems such as frequent abortions, increased fetal disorders, seizure during pregnancy, lack of authority for making decisions about pregnancy, psychological problems, activation of the disease after delivery, and inability to use preventive methods. Participant no. 9 indicated that she had been pregnant with lupus and both eyes of her son had congenital cataract. One of his eyes was operated, but the other was waiting for its time to come. She felt that she was the cause of his condition, which bothered her a lot.

According to the female patients with SLE, disturbed parenting occurs because of loss of a sense of motherhood, impatience in taking care of the child, fear from death with the child being left alone, and concerns about the child's future. Participant no. 2 reported that she herself took care of her child but she did not feel like it at all. Another participant (no. 4) who was very sad, who had the disease for three years, and had a 15-year-old daughter said that she was afraid of something happening to her daughter in her absence. She was worried about her daughter's future. She did not know what would happen to her daughter in her absence.

Adaptation to the disease category has two subcategories: self-care and lifestyle modification. Patients with SLE are those who can help themselves. They should adapt to the disease through accepting the disease, talking with it as a friend, taking part in self-analysis courses, and managing their stress. Participant no. 15 stated that she was taking part in self-analysis courses. This course helped her manage the stress by knowing herself and her disease.

According to the female patients suffering from SLE, lifestyle modification can result in adaptation to the disease by quitting bad habits and getting along with the disease, being visited by the physician, changing diet, doing exercises and recreational activities, and travelling. Participant no. 12 indicated that she realized that only she

could help herself, but she had to manage her stress. She had to cope with her disease and quit bad habits.

The fifth category of need for support included three subcategories: spouse's support, support from the family and others, and lack of occupational and social support. Support from the spouse is the most important factor in dealing with life crises, and most participants believe that female patients with lupus could cope with the disease challenges better if they had a sympathetic spouse and received their spouses' emotional support. Participant no. 18 reported that her husband talked to her a lot. He tried to encourage her and wanted her not to worry about her disease or even her child. She was not under pressure at all.

If we analogize the spouse's support to success steps, family support acts as the stairs guard, which supports these patients to pass through the crises of this disease. Female patients with SLE can cope with the disease challenges more easily if they have the necessary support of their family, their husband's family, and positive influence of friends and others. Participant no. 11 stated that she participated in classes and saw patients like herself. Although the disease bothered her, she found some friends with the same conditions. She felt that she was far better than the others.

According to these patients, they can tolerate their disease in case of occupational and social support. Therefore, they want to block out the thoughts of the disease by working and undertaking different activities, and they want to afford the costs of the disease. Participant no. 14 said that in her opinion, apart from the physician's constant and compulsory visits and the expensive tests she had to undergo, she did not have any bad experience due to the disease. She complained about the government for not supporting patients of such a disease financially. Her family was under financial pressure to pay for treatment costs.

The sixth category of spirituality had two subcategories: forgiveness of sins and resorting to God. According to the participants, repenting for sins is a way of mitigating sins and approaching God. Participant no. 13 reported that when she realized about her heart problem, she had complained to God about why he had taken her



spouse at a young age and given her that disease. In the early phases, her situation was so terrible that her husband carried her on his back. Over time, she gradually improved and then she was walking and taking care of herself. She thanked God. Although he had taken her husband, he improved her condition to the extent that she was able to do her tasks.

Resorting to God is the key to locked doors and a facilitator for the hopeless when they are deep in crises. They can prevent sins through thanksgiving and with the help of God. Many participants considered the disease as a way to approach God, and spiritual beliefs were a mediator to this end. Participant no. 17 indicated that she could tolerate the disease by resorting to God, participating in Quran classes, and *nazr* (in Islam, *nazr* is a vow or commitment to carry out an act). Her disease was controlled and she tried to manage the housework and took care of her children even with pain.

## DISCUSSION

The findings clearly suggest the negative effects of SLE on the affected female patients' perceptions and experiences of the reproductive health. According to them, reproductive health is achieved in spite of physical suffering, psychological stress, and fertility challenges through spirituality, and they adapt to the disease by the help of others. These patients go through the process of accepting and adapting to the disease. Their major concern is fear of disease aggravation, complete dependence on others, and fear of not being able to care for the family and children, and transferring lupus to their children. According to different studies, lupus patients are concerned about their appearance, weight gain, and even ignorance of the healthcare providers. The reason for treatment and rheumatologist visits is to avoid lupus manifestations and their trust on rheumatologists.<sup>29</sup> Sutanto et al.<sup>30</sup> studied patients with lupus and emphasized the healthcare providers' attention to the effect of lupus on reproductive health of the patients. In this research, most female patients with lupus reported diminished motivation and desire for sexual relationship following the disease. In line with the present research, García Morales et al.<sup>31</sup>

in Spain and Akbarian et al.<sup>4</sup> in Iran showed that persistent pain and fatigue associated with lupus could complicate dealing with the emotional and physical aspects of the sexual relationship. The rate of sexual avoidance in these females is higher (50%) while the rate of sexual desire, provocation, vaginal lubrication, and orgasm is lower.<sup>4,31,32</sup> Some other studies have reported similar results about the effect of lupus on the life of the patients. In one study, 8% of the patients reported the negative effect of lupus on their lives, while 60% of them had to accept the responsibilities of the household to maintain the balance in their life. As household responsibilities, parental roles, recreational activities, working performance, and academic achievements are affected by lupus signs and symptoms, the patients need the help of their families to reach financial and social independence.<sup>33,34</sup> Moreover, some studies have pointed to the role of involving SLE patients in treatment decisions and improving their knowledge of the treatment and its complications, and emphasized that these measures would decrease their concerns and worries.<sup>35</sup> As more than 60% of these patients are concerned about reproductive health, which is not usually addressed during medical visits or healthcare,<sup>12</sup> perinatal multidisciplinary counseling and care showed an 85-point increase in the successful rates of pregnancy in patients with lupus.<sup>10</sup> Knight et al.<sup>9</sup> found a negative relationship between lupus, old age, and weak physical and psychological outcomes. They also indicated that high anxiety and lack of social support were associated with lower physical and psychological health in patients with lupus. High anxiety in response to lack of knowledge and awareness results in greater dependence on healthcare providers and reduction of ability, adaptation, and self-management skills of lupus patients.<sup>10</sup> Furthermore, patients with lupus need psychological support to adapt to lupus challenges and improve clinical and psychosocial aspects.<sup>9</sup>

One of the limitations of the present study was due to cultural considerations of Iran about sexual relationships. Since studies have shown that lupus affects females 9-10 times more often than males, only female patients were included in the study. Since there was only a single research center, it may compromise the

generalizability of the results. However, since the aim of qualitative studies is to achieve theoretical data saturation, it may not create any problems, because attempts were made to use maximum variety in terms of disease severity, disease duration, severity of symptoms, and socioeconomic status. The interviews continued until data saturation was achieved. In addition, only one referral center was used in Iran. Since corticosteroid therapy in patients with lupus might have a minor effect on sexual and psychological disorders, we included females who received minimum doses of corticosteroid and toxic drugs in the past month. Since SLE patients commonly believe that physicians only see lupus and their body and do not care about their mind and how they feel, this study can develop new care horizons in treating these patients.<sup>36</sup>

In conclusion, this study explored the perceptions, experiences, and viewpoints of female patients with SLE on reproductive health. The results can be used to design a reproductive health instrument for females with lupus and enhance the awareness of healthcare providers about physical, sexual, psychological, social, and spiritual factors. According to female patients with SLE,<sup>15,16</sup> physicians only saw and cured their SLE but did not pay attention to their issues such as childbearing, sexual relationship, and contraceptives etc. that were really essential for their lives. More importantly, taking care of these patients requires strategic and multidisciplinary interventions, particularly in cooperation with reproductive health and psychology consultants.

### Acknowledgements

The authors would like to thank the participants, healthcare personnel of rheumatology centers, and authorities of Tehran University of Medical Sciences for their kind cooperation.

### Declaration of conflicting interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

### Funding

This research was supported by the Ethics Committee of Tehran University of Medical Science, Iran.

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