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Quick Response Code:

Website: www.jehp.net
DOI: 10.4103/jehp.jehp_1080_22

Uncertainty and its related coping strategies in systemic lupus erythematosus. Life in the fog

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Abstract:

BACKGROUND: One of the most prevalent problems of patients with systemic lupus erythematosus (SLE) is the uncertainty over an indefinite future. Uncertainty has significant effects on quality of life. The aim of this study was to explore uncertainty and personal strategies to cope with it among patients with SLE.

MATERIALS AND METHODS: This qualitative study was conducted in 2020–2021 using conventional content analysis. Participants were 21 patients with SLE who were purposefully selected from rheumatology clinics in Kashan, Kerman, and Bandar Abbass in Iran. Data collection was performed using face-to-face, in-depth, semi-structured interviews and was continued up to data saturation. Data were analyzed concurrently with data collection through conventional content analysis approach proposed by Graneheim and Lundman.

RESULTS: Two main themes, namely, “life in the fog” and “attempt to find peace” emerged from patients’ experiences of illness uncertainty of SLE. Life in the fog included three main categories of “perception of threat to health”, “challenge of doubt and certainty,” and “indefinite future.” Attempt to find peace included three main categories of “spirituality,” “reflection,” and “attempt to acquire SLE-related knowledge.

CONCLUSIONS: Uncertainty is a major psychological stress for patients with SLE. Healthcare providers should therefore consider the challenges and concerns faced by patients and, through utilizing appropriate training and communicational practices, plan interventions and strategies to empower patients for coping with uncertainty.

Keywords:

Content analysis, strategies coping, systemic lupus erythematosus, uncertainty

Introduction

Systemic lupus erythematosus (SLE) is a complex chronic disease which affects multiple systems of the body, causes extensive injuries to different organs and tissues, and has periods of remission and exacerbation.^[1] SLE prevalence in different areas of the world varies from 4 to 45 cases per 100,000 people in Asian countries to 20–150 cases per 100,000 people in the United States.^[2] SLE prevalence in Iran is 40 cases per 100,000 people with a male-to-female ratio of 1:8.8.^[3]

The clinical manifestations of SLE appear in most systems of the body including the musculoskeletal, integumentary, hematopoietic, renal, nervous, respiratory, and cardiovascular systems.^[1,4] Patients with SLE and their families experience serious challenges in different aspects of life such as general health, mental health, and quality of life.^[5,6] Functional limitations and limited financial, familial, and social support also affect patients’ physical and mental health and the stress associated with these problems causes them uncertainty about the future.^[7]

Uncertainty is a cognitive state due to an inability to predict disease-related

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How to cite this article: Mazhariadzad F, Dianati M, Taghadosi M, Zamani B. Uncertainty and its related coping strategies in systemic lupus erythematosus. Life in the fog. J Edu Health Promot 2023;12:233.

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Received: 27-07-2022

Accepted: 09-09-2022

Published: 29-07-2023

events.^[8] The concept of uncertainty was first introduced by Mishel in a nursing theory and has so far been used for patients with different acute and chronic diseases.^[9] The Uncertainty in Illness Theory (UIT) by Mishel states that uncertainty is a combination of doubt, indecision, ambiguity, and perplexity and appears when individuals are in critical, unexpected, and life-threatening conditions and cannot predict future events.^[8,9] Studies into uncertainty among patients with cancer and thalassemia in Iran reported uncertainty as a psychological stress which necessitates strategies for patient empowerment and coping.^[10,11]

Every country has its own cultural characteristics, ideas, customs, and social behaviors, both nationally and within particular groups or communities.^[12] Uncertainty is a multidimensional concept which is markedly influenced by the immediate sociocultural context and the characteristics of the underlying disease.^[9] When self-management is the main focus of behavior, a person experiences continuous uncertainty that affects other parts of a person's life and disrupts their life patterns. Acceptance of uncertainty is a growth process, which happens gradually over time and by rebuilding a new perspective on life. However, Brown *et al.*^[13] argued that acceptance over time is not always evident for chronic conditions, with some patients remaining with high levels of uncertainty, especially if one perceives uncertainty as a risk.

The main question of the study is this: how do patients with SLE describe uncertainty and its related coping strategies?

Given the various meanings of uncertainty in different diseases, the significance of this concept in SLE patients and the important effects it has on the quality of life of these patients, and the need to identify different dimensions of uncertainty in the cultural context of Iran and its coping strategies, this study was conducted to investigate uncertainty and personal strategies to deal with it in patients with SLE.

Materials and Methods

Study design and setting

This qualitative study was conducted in 2020–2021 using conventional content analysis.

Study participants and sampling

Participants were patients with definite diagnosis of SLE purposefully selected from rheumatology clinics in Kashan, Kerman, and Bandar Abbass, Iran. Eligible patients were identified using the patients' medical records in the study setting and were invited to the study through telephone contact.

Data collection tool and technique

Data were collected from May 2020 to September 2021 through in-depth and semi-structured interviews. The corresponding author of the study conducted all interviews at the participant's preferred place and time and by using an interview guide [Table 1]. Examples of the main interview questions were "Can you explain how SLE has affected your life?" Probing questions such as "Can you explain more about this?", "What concerns did you have about this?", and "What did you do in the face of these concerns?" were also used to further explore participants' experiences. In total, 25 interviews were conducted with 21 patients. The length of the interviews was 45–60 minutes. All interviews were held in a private room and were audio-recorded with the participant's permission.

Inductive qualitative content analysis as described by Graneheim and Lundman.^[14] was used for data analysis: Recorded interviews were transcribed verbatim, then were read through several times to obtain a sense of the whole. At first, researchers independently extracted all meaning units. Then they were discussed, and after resolving the discrepancies, they assigned codes to the condensed meaning units, reflecting the words of the participants in a more abstract way. Finally, basic codes were created and compared based on differences and similarities and were sorted into six main categories, and two main themes.

The rigor of this study is based on Lincoln and Guba.^[15] Confirmability was established by registering and reporting various steps of the study. Credibility was enhanced by using the prolonged involvement with the data (15 months). To ensure dependability and to avoid bias during data analysis, a limited literature review was conducted at the beginning of the study. To facilitate transferability, researchers tried to explain the characteristic of the research setting and the samples.

Ethical consideration

This study was approved by the Ethics Committee of Kashan University of Medical Sciences, Kashan, Iran (code: IR.KAUMS.REC.1399.006). Participants were informed about the study's aim and their freedom to voluntarily participate in and unilaterally withdraw from the study. All participants provided written and informed consent for participation.

Results

Participants were five male and sixteen female patients with SLE with an age range of 19–59 years and a mean SLE duration of 7.76 years [Table 2]. Six main categories, and two main themes were extracted [Table 3].

Life in the fog

Participants' experiences showed that they had senses of ambiguity, unknown fate, bafflement, and fear and concern over their future.

Perception of threat to health

Participants reported perception of threat to their health due to latent fear in daily life, unwanted turn into a burden, and perceived risk of the complications of SLE and its treatment.

Latent fear in daily life

Participants reported fear and concern due to physician visits, interactions with peers, limited confidence in the effectiveness of treatment, progression of SLE, and periodical disease remission and exacerbation.

My condition progressively worsened day by day. I felt that my knees were swelling and hence, I couldn't bend anymore. After a month, I was completely unable to sit. I had great fear (P. 12).

Unawareness of the time of the occurrence of further symptoms or witnessing peers with specific problems also aggravated their fear.

Table 1: Interview guide

Interview guide

- Can you explain how SLE has affected your life?
- How do you feel about living with SLE?
- Can you explain more about this?
- What concerns did you have about this?
- What did you do in the face of these concerns?

Table 2: Participants' characteristics

Age (Years)	Gender	Marital Status	SLE Duration (Years)	Educational Level	Occupation	City
48	Female	Married	18	Diploma	Housewife	Bandar Abbas
36	Female	Married	4	Bachelor's	Housewife	Kashan
40	Female	Married	11	Elementary	Housewife	Kashan
19	Female	Married	1	Diploma	Housewife	Bandar Abbas
36	Female	Married	4	Bachelor's	Housewife	Kashan
45	Female	Married	13	Bachelor's	Beautician	Kerman
30	Female	Married	7	Diploma	Shopkeeper	Kashan
30	Female	Married	4	Bachelor's	Nurse	Kashan
39	Female	Married	6	Diploma	Housewife	Kashan
50	Female	Married	3	Diploma	Housewife	Kerman
49	Female	Married	18	Diploma	Housewife	Kashan
24	Female	Single	6	Bachelor's	Employee	Kashan
39	Female	Single	12	Bachelor's	Nurse	Bandar Abbas
40	Male	Married	2	Diploma	Self-employed	Kerman
59	Male	Married	9	Associate diploma	Retired employee	Bandar Abbas
24	Female	Single	2	Bachelor's	Student	Kashan
48	Male	Married	4	Diploma	Repairman	Kerman
38	Female	Single	22	Bachelor's	Employee	Kerman
52	Female	Single	5	Bachelor's	Employee	Bandar Abbas
34	Male	Married	10	Bachelor's	Shopkeeper	Kashan
32	Male	Single	2	Bachelor's	Shopkeeper	Bandar Abbas

In the physician's office, I would wait several hours till my turn comes. There, I see patients with SLE who are critically ill. I experience great fear due to the possibility of experiencing their conditions (P. 8).

Unwanted turn into a burden

Participants had concerns over progressive disability and did not know whether their disability and problems were temporary or permanent. They experienced significant changes in life and serious despair and frustration. Accordingly, they needed the help of their families and felt that they were a burden to their families and friends.

When my disease recurs, I can't do anything like sweeping, washing clothes, combing my hairs, and bathing. My mother does all these for me. Therefore, I have cleared my mind of the thought of marriage because I don't want to be a burden to another one (P. 19).

Perceived risk of the complications of SLE and its treatment

Awareness of the potential or actual risk of multiple complications of SLE aggravated the participants' sense of threat. Complications associated with SLE treatments such as skin lesions, weight gain, hair loss, potential negative effects of treatments on pregnancy, and the risk of SLE among children were also unpleasant experiences which made the future indefinite and unsafe.

Because of my renal SLE, the doctor had said that pregnancy would be dangerous for me and said that I had to avoid pregnancy; however, I got pregnant because I couldn't take contraceptive pills. Then, the doctor ordered

Table 3: Subcategories, main categories, and main themes of SLE-afflicted patients' experiences of uncertainty and their strategies to cope with it

Subcategories	Main Categories	Themes
Perception of threat to health	Perception of threat to health	Life in the fog
Latent fear in daily life		
Unwanted turn into a burden		
Delayed diagnosis	Challenge of doubt and certainty	
Doubt over disclosing SLE		
Wandering in unawareness	Indefinite future	
Annoying preoccupations		
Acceptance of God's will	Spirituality	Attempt to find peace
Performance of religious practices		
Intentional forgetfulness	Reflection	
Self-control and self-reliance		
Seeking information from the treating physician	Attempt to acquire SLE-related knowledge	
Seeking information in cyberspace		
Using the useful experiences of peers		

Themes	Main categories	Subcategories
Life in the fog	Perception of threat to health	Perception of threat to health
		Latent fear in daily life
		Unwanted turn into a burden
Attempt to find peace	Challenge of doubt and certainty	Delayed diagnosis
		Doubt over disclosing SLE
		Wandering in unawareness
Attempt to find peace	Indefinite future	Annoying preoccupations
		Acceptance of God's will
		Performance of religious practices
Attempt to find peace	Reflection	Intentional forgetfulness
		Self-control and self-reliance
		Seeking information from the treating physician
Attempt to find peace	Attempt to acquire SLE-related knowledge	Seeking information in cyberspace
		Using the useful experiences of peers

eight days after discharge from hospital, my kidneys were gradually affected and I was hospitalized again (P. 6).

Doubt over disclosing SLE

Some participants were doubtful and uncertain over disclosing their disease. Fear over SLE disclosure and fear over others' pity had caused social isolation for some participants.

All people thought that my disease was contagious and hence, I ended my relationships with most of my friends so they do not get aware of my disease (P. 14).

Consideration of an indefinite future

Participants were preoccupied with fear and concern over the consequences of SLE in their future and described their life as indefinite.

Wandering in unawareness

Participants had limited knowledge about SLE and its management. Unawareness, delays in treatments, and disease progression gradually caused most participants critical conditions and severe symptoms such that they felt they had become paralyzed and had reached the end of their lives.

I referred to different physicians. I didn't know whether this is a bad illness or an acute problem until my symptoms exacerbated and I couldn't walk anymore. Then, I became extremely concerned over becoming paralyzed (P. 12).

Annoying preoccupations

Affliction by SLE caused participants disturbances in life and inability to focus on activities and hence, they were deeply preoccupied with their disease and their indefinite future. Moreover, affliction by an incurable disease in young ages, concern over the effects of SLE on the integrity of life, and hearing the disappointing words of others caused participants unpleasant thoughts.

abortion at a gestational age of two months. I curettage and my baby was aborted (P. 8).

Challenge of doubt and certainty

SLE progression and delayed and inaccurate diagnosis made multiple medical visits inevitable for participants so that most of them frequently referred to physicians to receive the most effective treatment and controlled their SLE.

Delayed diagnosis

SLE diagnosis is the most critical stage of SLE management and is associated with many different challenges for patients. They usually receive different diagnoses from physicians and hence, experience doubt and bafflement, lose their mental stability, and refer to different physicians instead of focusing on treatment.

I referred to hospital with hives on my face and chest pain, where they performed a series of laboratory tests and ultrasound assessment which showed no problem. Seven to

My irritation is due to my thoughts about my disease. I'm concerned that how much pain I should experience, how much medications I should take. It is unknown what will be the end, how much I will live, and whether I can have a baby or not (P. 15).

Attempt to find peace

Attempt to find peace was the second main theme of the study which was developed based on participants' experiences of coping with uncertainty. Participants used different strategies to cope with uncertainty and find peace.

Spirituality

Spirituality is the metaphysical aspect of human life and is experienced through one's relationship with God, self, others, and nature. Religious beliefs have relationships with all aspects of health and illness, guide daily habits, and are a source of power and recovery. Almost all participants described spiritual values as one of the most effective strategies for coping with uncertainty.

Acceptance of God's will

Participants attempted to cope with SLE-associated problems by resorting to spirituality, relying on God, and accepting SLE as God's will. Based on their firm beliefs in God and His compassion, some participants not only were not dissatisfied with their conditions, but also were thankful to God for their life events.

When I think about my disease, I tell myself that this is God's will and I tell myself how I can tolerate the punishment of my sins in the afterlife if they are not washed away in this world. I believe that this pain reduces my sins (P. 18).

Performance of religious practices

Participants also attempted to cope with their fears and concerns by performing religious practices such as praying. Although disease progression reduced some participants' ability to perform some mandatory religious practices such as praying, they attempted to perform such practices due to their firm religious beliefs and the peace they found in them.

I have never ignored praying despite all my pains and discomfort. I pray to God for myself and for all patients and ask God to heal them all (P. 12).

Psychological coping

The use of psychosocial coping strategies were other techniques used by the patients to cope with uncertainty caused by the illness.

Intentional forgetfulness

Participants intentionally attempted to forget and ignore their SLE and its associated problems through distraction, avoidance from negative thoughts, avoidance

from thinking about SLE and its relevant memories, engagement in physical exercise and recreational activities, listening to music, and comparing themselves with patients who had severer problems. These strategies helped them forget SLE-related discomfort even for a short period of time.

I do artworks and handcrafts such as knitting to spend my time and avoid thinking about my disease (P. 19).

Self-reliance and self-control

Participants had acquired some levels of self-reliance and self-control and attempted to improve their strengths. Self-control and self-reliance improved their self-confidence and helped them less frequently focus on their problems and understand that they still had many capabilities despite being afflicted by SLE.

I really value my health. Every patient knows which activities worsen his/her symptoms and which activities reduce them. Control over self, activities, and life can help you control and cope with your disease (P. 6).

Attempt to acquire SLE-related knowledge

Attempt to acquire information and knowledge about SLE, its complications, and its treatments from different sources was another strategy of participants for reducing their uncertainty.

Seeking information from the treating physician

Seeking information from the treating physician was one of the most important strategies of participants for reducing their uncertainty and bafflement. Information acquired from physicians about dietary regimen, physical activity, and disease control reduced their SLE-related tensions.

I expect my physician to explain about my disease and tell me during laboratory test assessment about abnormal test results and what I should do. I feel comfortable when my physician provides information to me (P. 18).

Seeking information on the internet

Patients with SLE need information to manage their problems and concerns and perform self-care activities. Some participants noted that they acquired some information about their disease and self-care from the internet.

Sometimes, I search internet about my disease, my medications, and self-care (P. 5).

Using the useful experiences of peers

Peers were another source of information for participants. They noted that they spent time on communicating with patients who had similar experiences and perceptions to know more about their experiences and highlighted that

this reduced their problems and improved their resilience. Sometimes, they attempted to find their own symptoms in their peers and understand how to manage them.

In physician's office, I saw several other women with lupus. One of them said that she had undergone cupping and felt better after it. I also went and underwent cupping. I didn't have itching that year at all (P. 7).

Discussion

This study explored the experiences of uncertainty in SLE-afflicted patients and their strategies for coping with it. The two main themes of the study were life in the fog and attempt to find peace. Concerns over SLE incurability, symptom exacerbation, changes in lifestyle, disturbances in the management of daily activities, and disability in the future cause SLE-afflicted patients great stress, shatter their peace, and give them feelings of threat, fear, and anxiety. In line with our findings, a study on the experience of uncertainty among patients with SLE in Sweden found the two main themes of multifaceted uncertainty and focus on health and opportunities.^[16] Two other studies also reported concern and despair over the future in patients with SLE.^[17,18]

Concern over becoming disable and a burden was one of the most important uncertainty-related concerns of patients with SLE in the present study. They reported that they were heavy burden to their families and friends. SLE has serious effects on patients' self-esteem and autonomy, restricts their physical and social functioning, and causes them anxiety over the future.^[17-19] Concern over SLE complications and its treatment side effects were among the most important aspects of uncertainty among patients with SLE in the present study. Previous studies also reported that progression of SLE, its complications, and treatments cause afflicted patients great fear and multiple concerns.^[20,21] Moreover, our participants had uncertainty over future due to their concerns over infertility and childbearing. In agreement with this finding, previous studies reported that fear over pregnancy, fear over the negative effects of treatment on pregnancy, fear over the possibility of SLE in the child, and the unpredictability of SLE were associated with social isolation for SLE-afflicted women.^[22,23] Fear over complications can result in negative or positive consequences. For example, fear over the aggravation of SLE or the occurrence of its complications was a facilitator to SLE acceptance, treatment adherence, and self-care in the present study. On the other hand, fear can lead to anxiety and endanger mental health. Therefore, it is necessary to control this feeling of fear in patients and to teach them how to overcome their fear and live without fear of illness. Our findings also showed that delayed diagnosis endangered patients'

physical and mental health, life, and future, led to doubt and uncertainty for them, made them refer to different physicians for a definite diagnosis, and hence, delayed treatment onset. SLE affects most systems of the body and hence, patients usually go through a lengthy and difficult diagnosis process in which their symptoms may be attributed to medically unexplainable or stress-induced problems.^[24,25]

Consideration of an indefinite future was one of the main categories of the present study that implied participants' concern over their future. A thematic synthesis of qualitative studies into the experiences and perspectives of adults with SLE also showed that after affliction by SLE, patients lose control over their life and cannot further focus on their activities.^[26] The major causes of SLE-afflicted patients' concern are chronic and progressive attributes of SLE, poor prognosis, and SLE complications. Consequently, care plans for these patients should include psychological support, opportunities to express their concerns, and strategies to help them overcome their fear.

The second main theme of the study was attempt to find peace which referred to the participants' strategies to cope with their uncertainty and find peace in life. Based on Mishel's UIT, if these coping strategies are effective, adaptation will occur.^[8] The use of coping strategies not only leads to the management of fear and anxiety^[27] and overcoming uncertainty but also influences patients' adherence to treatment.^[28] As the results of the present study showed, spirituality, psychosocial coping, and attempt to acquire SLE-related knowledge were three strategies used by thalassemia patients to cope with uncertainty. The spiritual support of patients in addressing the concerns that arose from lifestyle changes, including financial problems and home care, could help to cope with disability and increase the level of tolerance.^[29]

In adaptation to uncertainty and to reduce its negative effects on their lives, the patients seek spirituality. Belief in God as the Supreme Being, confidence in God's will, and performance of religious practices were spiritual strategies of participants for coping with uncertainty. Previous studies also showed that SLE-afflicted patients who used spiritual strategies coped better with SLE-associated complications and stress. Moreover, some studies reported the positive effects of spirituality on hope, coping with disease, and management of anxiety and concerns.^[30-32]

It seems that the attitude of patients toward this category is very important. A study showed that some patients considered the disease as a gift from God due to their positive attitude.^[33] While Roman reported different

results, a group of patients did not receive a response to prayer and worship when they were diagnosed with a debilitating and chronic disease. They doubted God or they considered the disease to be a punishment for their sins and thought that God intended to punish them. Therefore, they were disappointed and could not rely on their spiritual beliefs which might have had a negative impact on health outcomes.^[34] Therefore, it is recommended that in such situations, when patients experience spiritual conflict, they should receive spiritual counseling from competent people. Some studies reported that patients who had more religious activities experienced significantly less depressive symptoms and felt better.^[35,36]

Mental support and providing an opportunity to express their concerns and helping them to overcome their fears should be considered in supportive care of these patients.

Study findings revealed psychological coping as another strategy of participants for coping with uncertainty. Similarly, a former study reported that patients with chronic conditions used psychological interventions such as mindfulness, cognitive behavioral therapy, tai chi exercise, and yoga for coping with uncertainty.^[37] Patients relied on their abilities and values by positive thinking and focusing on their possessions; the use of this technique increased self-confidence and controlled the tension created to a great extent.^[38]

Our participants used techniques such as positive thinking and distraction in order to intentionally forget their problems. In agreement with our findings, a study reported distraction as a useful and effective strategy for coping with breast cancer among Iranian women.^[31] Similarly, another study reported strategies such as gardening, watching television, and walking as effective in reducing tensions and improving coping with uncertainty among patients with burn injuries.^[39] Cognitive and behavioral stress management techniques are effective in improving physical and mental functioning among patients.^[37] Mindfulness-based metacognitive skills may improve depression, anxiety, stress, and sense of well-being in patients with SLE.^[40] Therefore, healthcare providers need to educate their patients about these techniques in order to enable them to better cope with uncertainty.

Study participants also attempted to cope with their uncertainty through acquiring SLE-related knowledge. In agreement with this finding, two former studies showed that patients sought information from their treating physicians, peers, or internet in order to cope with their uncertainty and control their conditions.^[41-43] Inadequate information and poor readiness to manage the illness and its complications can prevent the patient from predicting changes and lead to uncertainty of the

patient about the occurrence of mental and physical problems in the future; Therefore, access to information as an effective factor is important in coping with uncertainty.^[44,45] A previous study reported that peers with positive experiences of effective SLE management can share their knowledge and experiences with other patients and thereby improve their well-being and reduce their anxiety.^[21] One important aspect of UIT is the need for information. According to this theory, nurses play an important role in providing information to patients for confrontation with and management of uncertainty.^[8] The findings showed that the virtual network and websites play an important role in increasing disease knowledge in patients.^[12,46] Therefore, nurses need to assess patients' educational needs and provide them with quality need-based information in order to reduce their anxiety and improve their ability to cope with their uncertainty.

Limitation and recommendation

Qualitative research is influenced by the researcher's thoughts, ideas and mentality due to its nature. The researcher tried to control this by bracketing.

Conclusions

This study suggests that uncertainty is a major mental stressor for patients with SLE. Uncertainty about the future of the disease and the treatment and complications, on one hand, and the concern about inadequate information and poor readiness to manage the illness, on the other, presented these patients with uncertainty and many challenges. Therefore, it is recommended that future researchers conduct studies to investigate how information provision and teaching coping strategies can reduce uncertainty. Finally, studies are suggested to develop appropriate tools for measuring this concept in these patients.

Acknowledgements

This study is a part of a PhD thesis and approved by Kashan University of Medical Sciences.

The authors appreciate all of the authorities in Kashan University of Medical Sciences who supported this research. The authors also thank all of the participants in this study.

Author Contributions: M.D. and M.T. supervised all of the stages of the data collection and data analysis and provided critical points during the manuscript preparation. B.Z. validation and Supervision. F.M.A. performed the study conception, data collection and analysis, and wrote the first draft of the manuscript. All authors have read and agreed to the published version of the manuscript.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Financial support and sponsorship

The funding was provided by the Kashan Medical Science University under grant number 9907.

Conflicts of interest

There are no conflicts of interest.

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