Original Article

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Nursing Section

Forgotten Needs of Patients with Systemic Lupus Erythematosus: A Qualitative Study in Iran

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ABSTRACT

Introduction: Systemic Lupus Erythematosus (SLE) is a chronic autoimmune disease which affects different body systems and different aspects of health. It has an irreversible course. Identifying the needs of SLE afflicted patients is the first step to help them manage and cope with their illness. Qualitative research among patients with SLE can identify aspects of the disease relevant to clinical research and practice.

Aim: To explore the forgotten needs of patients with SLE.

Materials and Methods: This qualitative study was conducted in Iran from April 2020 to March 2021 using conventional content analysis. All participants were patients with definite diagnosis of SLE purposefully selected from Iranian Lupus Association and Rheumatology Clinics in Kashan, Kerman and Bandarabbas, Iran. Data were collected with deep, semi-structured, and face-to-face interviews, which are focused on patients' experiences of needs. Data collection continued until saturation was reached. Finally, 17 patients with SLE participated in this study. Data collection and data analysis were conducted concurrently. Data were analysed with conventional content analysis, and managed with the MAXQDA software 2020.

Results: The forgotten needs of patients with SLE came into three main categories, namely social needs (with three subcategories), economic needs (with two subcategories), and need for self-control (with two subcategories). The seven subcategories of these three categories were the need for family support, the need for professional support by healthcare providers, the need for social support, the need for financial support by family members, the need for financial support by the government, the need for gaining autonomy, and the need for effective role performance.

Conclusion: Patients with SLE have many forgotten psychological and socio-economic needs. Patient education, referrals to mental health professionals, and support organisations are important supplements to medical treatment. The findings can be used to develop strategies for providing quality care to patients with SLE and other chronic disabling conditions.

Keywords: Autoimmune, Autonomy, Disease burdens, Healthcare, Qualitative research, Socio-economic status, Support

INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a complex chronic disease which affects multiple body systems in several months to several years [1]. The SLE causes damages to body tissues and has courses of relapse and remission [2]. The prevalence of SLE widely varies in different countries and is 30-50 cases per 1,00,000 people in Asian countries [3, 4] and 20-150 cases per 1,00,000 people in the United States [5, 6]. According to a report by the Rheumatology Research Center of Tehran University of Medical Sciences, Tehran, Iran, the prevalence of SLE in Iran is forty cases per 1,00,000 people. In other words, one out of each 2500 Iranians suffers from SLE [7]. SLE affects different racial and ethnic groups though its prevalence in some groups is greater. For instance, SLE affects the black race 2-5 times more than the white race [8, 9]. Similarly, SLE differently affects different age and gender groups. For instance, a study in Iran showed that the ratio of women with SLE to afflicted men was 8.8:1 and the age of SLE onset was 24.2 years [1]. A study in the United Kingdom also showed that the ratio of SLE-afflicted women and men was 15:1 in adults and 5:1 in children [10]. The SLE symptoms and manifestations are usually unpredictable [11]. The clinical manifestations of SLE appear in most body systems, including musculoskeletal (prevalence: 85.2%), integumentary (prevalence: 83.1%), circulatory (prevalence: 67.1%), renal (prevalence: 66.6%), nervous (prevalence: 24%), respiratory (prevalence: 22.3%), and cardiac (17.5%) [7]. Fatigue is one of the most common symptoms of SLE which negatively affects the ability to perform daily activities [8] and the ability to perform personal roles as mother, spouse, friend, and colleague and thereby, leads to marital and familial problems [12].

Long-term affliction by SLE, particularly its dermatologic manifestations, can cause a wide range of mental problems. For instance, it threatens identity, changes roles, responsibilities, and lifestyle [13,14], alters body image [13,15], reduces self-confidence, and causes ineffective role performance, despair, and frustration [15]. The SLE in women also causes fears and concerns over getting pregnant, medication side effects for the neonate, and affliction of the neonate by the disease, and thereby results in depression and social isolation [16]. In younger women, SLE-associated skin rashes and lesions, hair loss, weight gain, hormonal disturbances, pain, fatigue, depression, anxiety, altered body image, low self-confidence, and emotional problems can cause sexual dysfunction [17]. Studies reported that SLE may cause employment loss in young ages [15,18] and thereby can impose heavy financial burden on patients and their families [19,20].

Because of the different physical, mental, and socio-economic problems of SLE, afflicted patients have a wide range of needs [21]. Although studies on unmet needs of patients with SLE have been conducted in different countries [22,23], studies conducted in Iran on this issue are limited. However, there are limited in-depth data about their needs. Therefore, the present study was conducted to narrow this gap. The aim of the study was to explore the forgotten needs of patients with SLE.

MATERIALS AND METHODS

This qualitative study was conducted in Iran from April 2020 to March 2021 using conventional content analysis approach.

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 aim and their freedom to voluntarily participate in and unilaterally withdraw from the study. All participants provided written informed consent for participation.

Study Procedure

Study participants were patients with definite diagnosis of SLE purposefully selected from the Iranian Lupus Association (ILA) in Tehran, and rheumatology clinics in Kashan, Kerman and Bandarabbas, and the medical records of patients referred to ILA and Rheumatology Clinics were scanned. Eligibility criteria were definite ability to share experiences, and willingness to participate in the study. Then, they were contacted on telephone, the aim of the study was explained to them, and they were invited to the study. An appointment for data collection was made with each eligible patient. A total of 17 patients with SLE took part in this study.

Face-to-face semi-structured interviews were held for data collection. The corresponding author of the study conducted all interviews at participants in Persian, preferred place and time and using an interview guide. Examples of the main interview questions were:

- "Can you explain your experiences of SLE?"
- "What new needs have been created for you since affliction by SLE and what measures have you taken in response to your new SLE-related needs and problems?"

Based on participants' responses to these questions, clarifying questions were used. Examples of these questions were

- "What does this mean and can you explain more?"

The phone numbers of participants were taken for any possible follow-up interview, though only one participant was interviewed twice. The length of the interviews was 45-60 minutes. All interviews were held in a private room and were audio-recorded with participants' permission. Study data were saturated with 18 interviews with 17 participants. when no new conceptual codes were acquired from the interviews and all of the categories extracted from the data were adequately developed [24].

Accordingly, each interview was immediately transcribed word by word in the Microsoft Office word and its transcript was frequently read for immersion in the data. Then, words and sentences related to the study aim were determined and coded. The generated codes were grouped into subcategories according to their similarities.

Then, the transcript was read and reviewed for several times and meaning units were identified and coded based on the study aim. The codes were categorised into subcategories according to their conceptual similarities. Subcategories were also compared and categorised into main categories and main themes.The MAXQDA software 2020 was used for the data management.

Credibility was ensured through sampling with maximum variation from four cities of Iran (Tehran, Kashan, Kerman and Bandarabbas), respecting participants' experiences, data collection through in-depth semi-structured interviews, providing clear descriptions about data analysis, providing quotations from participants' experiences, exclusion of irrelevant data, close relationship with participants, prolonged engagement with the study, immersion in the data, member checking, and peer checking [25].

For member checking, 10 interviews together with their corresponding codes were provided to participants through the WhatsApp Messenger to check the congruence between our findings and their own experiences. For peer checking, two qualitative researchers external to the study assessed and approved the accuracy of the data analysis.

To ensure dependability, identical questions were used in all interviews, all interviews were recorded and transcribed word by word, the steps of the study were documented with details, and participant's experiences were cited in the final report of the study One strategy to ensure confirmability was to document all research-related activities over time so that outsiders can track the activities through the documentations [25]. Therefore, authors attempted to carefully document all steps of the study and all research-related decisions in order to provide others with the opportunity of tracking our activities during the study. Transferability of the findings was also ensured through providing detailed descriptions about the study context, participants, sampling method, and data collection method.

STATISTICAL ANALYSIS

The conventional content analysis was used for the data analysis and the data was managed using MAQDA software 2020.

RESULTS

Total 17 patients with SLE participated in the present study. Their age was in the range of 18-59 years and the mean of their SLE duration was 6.83 years. [Table/Fig-1] shows participan's characteristics.

Patient	Age (years)	Gender	Marital status	Educational level	Occupation	SLE duration (years)
1	39	Female	Single	Bachelor	Nurse	12
2	19	Female	Married	Diploma	Housewife	1
3	28	Female	Married	Diploma	Housewife	0.5
4	37	Female	Married	Diploma	Housewife	8
5	40	Female	Married	Primary	Housewife	11
6	36	Female	Married	Bachelor	Housewife	4
7	43	Male	Married	Diploma	Car mechanic	6
8	34	Female	Married	Bachelor	Accountants	10
9	48	Female	Married	Diploma	Housewife	18
10	36	Female	Married	Bachelor	Housewife	4
11	16	Female	Single	High school	Student	1
12	45	Female	Married	Diploma	Hairdresser	5
13	59	Female	Married	Illiterate	Housewife	20
14	22	Female	Single	Student	Student	2
15	59	Male	Married	Diploma	Clothing retailer	5
16	30	Female	Married	Bachelor	Nurse	4
17	24	Female	Married	Bachelor	Employee	6

[Table/Fig-1]: Participants' characteristics.

Data analysis revealed three main categories and seven subcategories for the forgotten socio-economic needs of patients with SLE. These three categories were social needs, economic needs, and need for self-control [Table/Fig-2].

Categories	Subcategories
Social needs	The need for family support
	The need for professional support by healthcare providers
	The need for social support
Economic needs	The need for financial support by family members
	The need for financial support by the government
The need for self-control	The need for gaining autonomy
	The need for effective role performance

[Table/Fig-2]: The forgotten needs of patients with systemic lupus erythematosus.

Social Needs

The participants felt that the necessity to spend a large amount of time on SLE treatment and care reduces their time to engage in social activities, changes their social relationships, causes them employment-related problems, and reduces their ability to afford household expenses. These problems create the need for support. The subcategories of this main category were the need for family support, the need for professional support by healthcare providers, and the need for social support.

1.1. The need for family support: Participants' experiences showed their need for family support. Most participants highlighted the key role of their families in providing them with physical, emotional, and informational support throughout the course of SLE. Most of them reported that they needed unconditional kindness and support and believed that receiving kindness from family members gave them sense of well-being, helped them better cope with their suffering and disabilities, and thereby, reduced the risk of depression.

"I thank my husband very much because if he hadn't supported me, I might not have been able to cope with my illness. He has always been with me during difficulties, problems, and hospital stay" (P. 9).

Participants highly valued family members' understanding of their conditions and noted that such understanding gave them hope for the future, enhanced their motivation for life, and promoted their self-confidence for self-care.

"My husband has always been with me and has made me happy and helped me keep my family happy and make more attempt to rear my children" (P. 10).

Participants with a nurse in their families had higher level of satisfaction and noted that family members' greater knowledge about SLE helped them feel assured and peace of mind because with the help of knowledgeable family members, they could instantly find answer to their questions and thereby, manage their concerns and less frequently experience fear and anxiety.

"As my sister is a nurse, she knows the normal ranges of laboratory tests and told me that the results of my tests were in the normal range and my disease was under control" (P. 14).

As SLE has debilitating symptoms and manifestations during its relapses, afflicted patients cannot have an independent life and cannot independently fulfill their self-care needs. Therefore, family members have key roles in caregiving to them. All participants highlighted the importance of receiving care from their families and considered their spouses' and mothers' support very helpful.

"I can't do anything at home and my mother and sister do all my tasks. Sometimes, I even can't do my self-care activities such as bathing. My sister helps me in these occasions" (P. 2).

1.2. The need for professional support by healthcare providers: The SLE is a chronic illness and hence, afflicted patients frequently visit healthcare providers, particularly physicians and nurses. Therefore, healthcare providers' professional support helps them ful fill their needs and more effectively cope with their conditions. The different types of professional support by healthcare providers include emotional support, informational support, and establishment of accurate diagnosis. Participants considered healthcare providers' empathy and emotional support as significant factors contributing to their senses of satisfaction and well-being and believed that healthcare providers' good relationships with them helped them better accept and cope with their conditions, reduced their stress, and boosted their morale and hope.

"During a medical visit, I told the doctor that I had many problems and asked him just to listen to my words and not prescribe anything. He sat and listened to me when I told him about my back pain and all of my problems" (P. 10).

As SLE is a chronic illness with a wide range of problems and complications, afflicted patients need information about their conditions and self-care. Therefore, participants reported the need for informational support by healthcare providers and highlighted that healthcare providers' educations and informational support were crucial for promoting their coping with their illness, reducing their uncertainties, and enhancing their adherence to their treatments and self-care activities.

"A good doctor and his/her ability to establish accurate diagnosis have many positive effects. My doctor is very good and compassionate. He spends time for me and provides me with explanations about my medications" (P. 4).

1.3. The need for social support: Like all human beings, patients with SLE have the need for establishing social relationships and interactions. Social interactions helped participants verbalise their concerns and others' empathy with them reduced their sense of isolation and gave them good feelings.

"At my workplace, I attempted to tell my colleagues about my disease. Now they know my disease and help me. I also attempt not to burden them with my own responsibilities" (P. 8).

Economic Needs

Participants reported that they had great economic needs, suffered great financial strain, and carried heavy financial burden. This main category had two subcategories which are explained in what follows.

2.1. The need for financial support by family members: Financial strains considerably affect patients with SLE and their ability to receive treatment and care. Those participants who could not afford the costs of treatment and care reported problems in receiving treatments and performing self-care activities.

"I should go to doctor and undergo laboratory tests every two months. Each medical visit costs me 5,00,000 Rials and the costs of laboratory tests are considerable. My husband is a worker with low income. A charity has so far paid the costs of my medications" (P. 4).

In this study, most patients with SLE were females and housewives and usually had neither income nor insurance, they had problems in meeting the costs of treatments, medications, and medical visits. Therefore, they might experience mental problems in addition to their physical problems if their husbands or families could not provide them with adequate financial support.

"It is for 2.5 years that I haven't referred to my doctor because the costs of medical visits are very high. I go to the pharmacy and buy my medications without medical prescription. My financial status is not very good and I have no insurance" (P. 5).

As SLE is a debilitating condition with early disability, it causes financial problems for afflicted patients through affecting their employment, ability to work, and income.

"I'm a hairdresser. But I can't work anymore due to joint pain. I get tired very easily and have no energy for work. Therefore, I closed my beauty salon and all my expenses are with my husband" (P. 12).

2.2. The need for financial support by the government: Participants reported that healthcare costs were very high and the government did not adequately provide them with financial support and insurance.

"I've been hospitalised three times so far. The costs of hospitalisation are very high. My father is an employee in the Department of Education and suffers from multiple sclerosis which costs him a lot" (P. 11).

The Need for Self-control

Participants reported the need for effective self-control in order to effectively cope with their conditions. The two subcategories of this category were the need for gaining autonomy and the need for effective role performance.

3.1. The need for gaining autonomy: Participants reported that they needed to regain their autonomy. Therefore, they attempted to independently perform their activities and less frequently ask help from their family members because self-confidence and self-reliance gave them a sense of well-being. Moreover, autonomy in performing activities improved their self-confidence and boosted their morale for self-care.

"[When I could independently perform my activities,] I felt highly satisfied with life. I did not have such feeling before. I really could manage at least my own life" (P. 10).

3.2. The need for effective role performance: Along with attempting to gain autonomy, our participants reported that they attempted to effectively perform their familial and social roles. They noted that effective role performance gave them senses of pleasure and satisfaction and helped them manage their SLE related tensions.

"As I'm an energetic person, I never allow this disease to easily affect my life. For example, if I feel I can't walk, I attempt to stand up and cook food and clean the house. I perform all my tasks under any condition" (P.13).

DISCUSSION

This study revealed that patients with SLE have different forgotten needs which were categorised into three main categories, namely social needs, economic needs, and need for self-control. One of the most important forgotten needs of these patients was social needs which included the need for family support, the need for professional support by healthcare providers, and the need for social support.

Social support is considered as a factor with significant effects on disease course, disease-associated complications, and role performance. It enables patients and their families to effectively select and use social and healthcare resources [26]. Patients with SLE may have low income and hence, may be greatly dependent on their family members [27]. Their inability to actively participate in social activities also negatively affects their social relationships with friends and relatives and may even cause other people misconceptions about SLE [28]. A study reported that other's poor understanding of SLE, particularly family members, together with the unpredictable course of the disease were associated with frustration and social isolation for afflicted patients [27]. Another study reported the unkind behaviours of family members and other people towards patients with SLE [29]. Similarly, a study found that patients with SLE considered themselves as heavy burden to their families and friends and reported that they needed their familie's and friend's physical help and emotional support [11]. Patients with SLE also need strong professional support from healthcare providers. Such support fulfils their needs, provides them with respect and sense of confidence, enhances their engagement in clinical decision making, and improves their capacity for effective coping with SLE [11,30]. Nonetheless, a study showed that healthcare providers mainly focus on the management of SLE-related symptoms and mostly neglect the psychosocial effects of the disease on patients [31].

The participants of this study, also reported that they had some forgotten economic needs. Financial strains associated with SLE and its treatments as well as disability and loss of employment make afflicted patients dependent on others and reduce their ability to fulfill their own healthcare needs. Some studies reported Economic burden was greater for patients with moderate to severe SLE. Patients with SLE had greater health care resource and costs [19,32] The indirect costs of SLE which are related to the loss of employment and income are usually greater than its direct costs. Loss of employment and its associated costs reduce patient's self-confidence, restrict their interpersonal relationships, reduce their ability to receive support from friends, limit their access to insurance services, and result in disability [26,33].

It was also found that participants had a forgotten need for financial support by the government. A study reported that compared with other patients with chronic conditions, patients with SLE usually receive less benefit for disability because their medical records do not accurately reflect their functional limitations [34]. Therefore, healthcare managers need to develop strategies to provide strong financial support to patients with SLE, particularly those who have low income and inadequate support.

It was also found that patients with SLE had the need for self-control and autonomy. SLE severely affects self-esteem and autonomy, limits physical and social functioning, and causes anxiety over their future [11]. Therefore, psychoeducational interventions are needed to promote patient's self-confidence and self-efficacy for stress management [35]. The current study finding also showed the great need of patients with SLE for effective role performance in family and society. The SLE is associated with physical disability due to neurological and musculoskeletal disorders [11]. The severity of physical disability has significant direct relationship with the severity of SLE and its complications. In other words, patients with severer SLE suffer from severer physical disability [36]. Fatigue also is a common manifestation of SLE which can result in physical disability. Therefore, these patients need quality educations about effective time and energy management in order to more effectively use their energy, particularly for their occupational activities [8].

Limitation(s)

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

CONCLUSION(S)

This study concluded that patients with SLE have many forgotten psychological and socio-economic needs including the needs for family, professional, and social support, the need for financial support, and the need for self-control, autonomy, and effective role performance. These findings can be used to develop strategies for providing quality care to patients with SLE and other debilitating chronic conditions. Each patient with SLE should be considered as a unique patient with unique needs. As most patients with SLE are young women, interventions are needed to effectively fulfill their socio-economic needs.

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Author contributions: MD and MT supervised all of the stages of the data collection and data analysis, and provided critical points during the manuscript preparation. BZ validation and Supervision. FM performed the study conception, data collection and analysis, and wrote the first draft of the manuscript.

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