Living With Systemic Lupus Erythematosus: A Qualitative Study Exploring The Experiences of Women

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ABSTRACT

Purpose: The aim of this study was to examine the life experiences of women with systemic lupus erythematosus.
Materials and Methods: This study design was qualitative design-phenomenological. Individual in-depth, semi-structured interviews were conducted with 18 women with systemic lupus erythematosus at the rheumatology outpatients' department of a university hospital between January and April 2018. The patients were chosen with purposive sampling. Interviews were semi-structured, using a descriptive questionnaire and a semi- interview form. The interviews conducted with face-to-face in-depth interview method, were audio-taped and fully transcribed. Thematic analysis of data from semi-structured interviews were analysed using the steps of Colaizzi.
Results: Five categories and 11 themes were identified by phenomenological data analysis. The categories were disease perception, self-perception, role-relationship, coping-stress tolerance, financial impact.
Conclusions: In the treatment and care process of women with SLE, the effects of the disease and treatment on an individual's life should be determined, taking into account individual characteristics and conditions, and the necessary improvement and support should be provided.
Keywords: Systemic lupus erythematosus, life experience, qualitative, women, phenomenological

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INTRODUCTION

Systemic lupus erythematosus (SLE) is a multifactorial, chronic, autoimmune, inflammatory connective tissue disease [1,2]. Females are nine times more likely to be affected compared to males [3,4].

SLE is a chronic disease with high morbidity with physical, psychological and social effects in the daily life of patients [5]. In the study by Morgan et al. (2018), 91% of patients expressed fatigue/weakness, 77.4% of them expressed joint pain/swelling and 73% noted having some problems to carry out their usual daily activities [4]. However, the psychosocial experiences of patients with SLE still not well understood [6].

It has been determined in the majority of qualitative studies examining the experiences of lupus patients that patient experiences are various and negative [7,8]. In the results of these qualitative studies, themes were identified such as body image, aching, physical and emotional fatigue, emotional changes (anxiety, depression, impaired concentration and memory loss), managing treatment and care, financial difficulties caused by the illness, pregnancy, adaptation to a new life, social support and skin problems, and these hindered everyday life [9,10]. In a systematic review by Sutanto et al. (2013), patients explained that their fear about the uncertainty and complications of SLE [10]. Anxiety, sleep disturbance and depression concerned patients with SLE in a study by Ogunsanya et al (2018) [11].

Improving nurses understanding of the experience of women who live with SLE may be important to improve physically and psychologically patient-centered care. The aim of this study was to examine the life experiences of women with systemic lupus erythematosus using qualitative methodology.

MATERIALS AND METHODS

Design

The study used a phenomenological design (qualitative study). Individual in-depth, semi-structured interviews with 18 women with SLE who met the inclusion criteria of the study, and were voluntary to participate in the study, were conducted between January and April 2018 at the rheumatology outpatients' department of a university hospital in Türkiye. Patients registered in this rheumatology outpatients' department are followed, patients with SLE are admitted (approximately 7-8 patients) one day a week. There is no specific sample size in qualitative studies [12]. The sample was determined using homogeneous and purposive (criterion) sampling method. The purpose of this method is to work with a sample group that meets a set of predetermined criteria. The criteria were created by the researchers. The data saturation concept considered guiding the principle for determining the sample size [13].

The inclusion criteria were as follows: (1) participating voluntarily in this study (2) being a patient with SLE (diagnosed at least 6 months ago), (3) being female, (4) being over 18 years of age, (5) having no communication problem and (6) having no psychiatric problem. Patients were excluded from the study if they who did not meet these criteria and had not attended regular checks within the last 12 months.

Data collection

Interviews were semi-structured, using a descriptive questionnaire and a semi- interview form. The semi-structured question form was prepared upon the literature review on experiences of the patients with SLE and the form was evaluated by the relevant experts [5,7-10]. Three patients were interviewed for the validity and reliability of the semi-structured question form and revisions (revisions about sentence to increase the clarity of the questions) were made to the form after the pilot study. Two of the researchers carried out the interviews in an empty room after the required arrangements were made for the interviews. Interviews conducted with face-to-depth interview method at the rheumatology outpatients' department of a university hospital and lasted for about 40 to 60 minutes, were audio-taped and fully transcribed. Saturation is a core guiding principle to determine sample sizes in qualitative research. Therefore, our interviews continued until no further pertinent information was forthcoming (18 interviews) [14,15].

The semi-structured questions were as follows: What does it mean to you to be a patient with SLE? How does the disease feel to you? What does it affect the most in your life?

Data Analysis

Descriptive statistics were calculated for socio-demographics and information about SLE variables by means of the software SPSS 22.0. After semi-structured interviews, the data obtained from the interviews were written down by two researchers within 24 hours. Thematic analysis of data from semi-structured interviews were analysed using the steps of Colaizzi (Table 1) [16].

Ethical considerations

The ethical institutional permission was obtained from Ege University Health Sciences Scientific Research and Publication Ethics Committee (285-2017) for this study. Informed consent was obtained from all individual participants included in the study.

Table 1. The Phases in Colaizzi's Phenomenological Data Analysis

1	To read all the description of the phenomenon by explained the participants
2	To extract significant expressions that relate directly to the phenomena
3	To formulate the meaning of these significant expressions
4	To categorize the prepared meaning into clusters of themes
5	To integrate the results into an exhaustive explanation of the phenomenon studied
6	To validate the exhaustive explanation by returning to some of the participants for the suitability of their experiences
7	To incorporate any changes stated by the participants into the final description of the essence of the phenomenon

RESULTS

As shown in Table 2, all of the respondents were female, their mean age was 40.50±13.14 years and their mean duration of disease was 10.22±7.26 years (Table 2).

Five categories and 11 themes were determined by the phenomenological data analysis. The categories were (1) disease perception, (2) self perception (3) role-relationship, (4) coping-stress tolerance, and (5) financial impact. The themes defined under the categories were acceptance, fear, anger**,** change in self perception, social support, social isolation, loss of role, comparison, fatalism, participation in social activities and financial difficulties (Table 3).

Table 2. Demographic Characteristics of the Patients

Patient	Age	Duration of disease (year)	Education	Marital status	Children	Employment	Living situation
P1	55	15	College degree	Married	Yes	No	With spouse
P2	54	4	Less than high school	Married	Yes	No	With spouse
P3	20	3	Postgraduate	Single	No	No	Alone
P4	58	14	College degree	Single	No	No	Alone
P5	49	7	Less than high school	Married	Yes	No	With children
P6	21	1	College degree	Single	No	No	With others
P7	54	9	Less than high school	Married	Yes	No	With spouse
P8	53	20	College degree	Single	Yes	No	With children
P9	46	21	Less than high school	Married	Yes	No	With spouse
P10	42	22	College degree	Single	No	No	With others
P11	34	10	Less than high school	Married	Yes	No	With spouse
P12	23	3	College degree	Married	No	Yes	With others
P13	25	3	College degree	Married	Yes	No	With spouse
P14	26	3	College degree	Married	Yes	No	With spouse
P15	36	11	College degree	Single	No	Yes	With spouse
P16	45	21	Less than high school	Married	Yes	No	With spouse
P17	52	4	Less than high school	Married	Yes	No	With spouse
P18	36	13	College degree	Married	Yes	No	With spouse

Table 3. Categories and Themes in the Interviews

	Category	Theme
1	**Disease Perception**	Fear (fear of disease, fear of treatment) Acceptance Anger
2	**Self Perception**	Change in self perception
3	**Role-Relationship**	Social support Loss of role Social isolation

4	**Coping-Stress Tolerance**	Comparison Fatalism Participation in social activities
5	**Financial Impact**	Financial difficulties

Category 1: Disease Perception

The “disease perception” category included ***three themes*** (fear, acceptance, anger). Most of the patients stated that they experienced fear, and that the reason for this fear was the disease or effects relating to the treatment. Some of the statements relating disease perception were:

P 1: “I read the prospectus of the medication the doctor gave. When I saw the side effects, I held off taking it for a month. But I couldn’t keep it up.” ***(fear of the treatment)***

P 15: “I’m taking a lot of medicines, and I sometimes miss a dose. I know I’m wrong.” ***(fear of the treatment)***

P 5: “The internal organs hold it. There’s always a fear. I feel apprehension about what’s going to happen.” ***(fear of the disease)***

P 12: “When I first heard, I was upset, but now, my life won’t be the same as before… I’ve stopped worrying about it..” ***(Acceptance)***

P 8: “Thank God, I don't want to go back to the old days... I'm fine now... I wouldn't say I was at all ill... I don't see myself as ill.” ***(Acceptance)***

*P 10: “I can’t stand people. I can’t be breezy. Because I’m ill, the happy way they talk upsets me..”****(Anger)***

Category 2: Self Perception

One theme (changes in self perception) formed this category:

P 9: “I used cortisone. My face swelled up, and my hair fell out. When I look in the mirror, I see myself as different. Nobody recognizes me, not even my grandfather..” ***(Change in self-perception)***

Category 3: Rol-Relationship

In this category, ***three themes*** (social support, loss of role, social isolation) were determined with these statements:

P 3: “My friends are very supportive. If I couldn’t walk they’d carry me on their backs if necessary. They always ask about me. My family the same.” ***(Social support)***

P 11: “My daughter wants a brother. I’m sorry for her. When I had flare-ups, I couldn’t take care of my child. I always want to look after my child myself..” ***(Loss of role)***

*P 6: “There's a big lack of will, a breakdown of morale... I don't want to go out and see people in those circumstances... so I don't see my friends much..”****(Social isolation)***

Category 4: Coping-Stress Tolerance

Three themes were identified in this category: comparison, fatalism and participation in social activities.

P 4: “I couldn’t let myself go just because I’m ill. I take my grandson to the theater. I visit my daughter. I can’t sit at home..” (***Participation in social activities)***

P 13: “This illness neither kills nor makes you laugh. I’ve learned to live with it..” ***(Fatalism)***

“Hope in God is never lost. Thank God, I’m better..” ***(Fatalism)***

P 2: “Friends who I’ve met have genital sores. I haven’t had any. There are those who are worse off than me. In that way, I count myself lucky...” ***(Comparison)***

Category 5: Financial Impact

Financial difficulties were recorded from an economic aspect with the following statements:

P 7: “I use sunscreen. Sometimes I have to change it. It’s very expensive. I come to the hospital and it’s deducted from my pay. I have debts, and so I’m under a lot of stress.” ***(Financial difficulties)***

DISCUSSION

The discussion section will consider five themes: disease perception, self-perception, role-relationship, coping-stress tolerance and financial impact.

Disease Perception

Fear

We can explain the fear as the feeling of being afraid. In SLE, the prognosis of the disease, the side effects of the drugs used in treatment, and the symptoms caused thereby can have the effect of causing fear in patients. They may fear the disease worsening or fear that other organs may be affected, that they may suffer again, or lose control and autonomy. Also, they fear becoming dependent, becoming a burden on their relatives and not being able to provide for their families’ care [17,18].

The participants stated in our study that they feared the progression of the disease and the effects of the treatment. In another study, patients with lupus feared that their diseases would worsen and that they would not be able to take care their children. They worried about becoming dependent [19]. In addition, Mazzoni et al. (2018) found that patients with SLE often live in a state of suspension. The beginning of the disease makes patients feel an unexpected state consisting of emotional, behavioural and cognitive blackout. They had to face new situations, and they stated that they were worried about the disease and its prognosis. However, at the beginning (the acceptance process), they said that they tried to deny the disease and not allow fear and depression [20]. In a systematic review by Sutanto et al. (2013), patients expressed their fear about the uncertainty and complications of the disease [10].

Anger

This is a reaction to disappointment, perceived threats and social provocation. Anger is accepted as the reaction of all living things in order to stay alive [21,22]. Psychological distress as depression, anxiety, anger/aggressive impulses is relevant in SLE. Anger is a psychopathological experience that has been associated with depression and anxiety and SLE patients have higher levels than healthy population [23].

Coping with a chronic disease and its implications is difficult. In a study by Farinha et al. (2017), patients with lupus stated that they felt very angry and needed help from a specialist [19]. Anxiety, sleep disturbance and depression concerned patients with SLE [11]. The results are in accord with this study, in which anger was a category in disease perception by patients.

Acceptance

Chronic diseases are open-ended and continue in previously unimagined waves. In the study by Mazzoni et al. (2018), patients stated that they started searching for more information about the diagnosis, and they sometimes had unrealistic hopes. They thought that their diagnosis might be wrong. The denial which they expressed at the beginning of the illness later gave way to acceptance [20]. After receiving the diagnosis, they stated that they accepted the disease and did not think about the end of it. In our study, one patient stated *"when I first heard I was upset… my life won't be the same as before… I've stopped thinking about it."*

Self Perception

Change in self perception

Self-concept means how we think that others view us. It is closely linked to body image and involves concepts such as femininity, physical prowess, endurance and capabilities. Most of the patients were worried about their physical appearance due to changes caused by the disease and its treatment. These changes affected the patients' lives and caused negative views about body image. It could cause some worries about their attractiveness [24]. Other studies have shown similar results regarding the effect of changes in physical appearance [11,19,25]. The participants worried about their physical appearance relating to the treatment and symptoms of the disease [19,25].

Role-Relationship

Social support

Patients may feel the need for various kinds of physical, social and emotional support at different stages of their illness [24]. Social support is the interaction between people who contribute to the wellbeing of an individual. In general, its positive effects are social relationships, support and understanding, and as negative effects, it can create criticism and blame. Difficulties arising from accommodation to living with SLE also increase patients' need for social support. In Turkey, people live in both nuclear and extended families and family bonds are strong, and this increases social support within the family. According to the results of our research, it was seen that patients obtained most of their social support from their families.

Loss of role

Functional inadequacy and changes in fulfilling social roles with SLE will be more difficult for family members, and therefore they will recognize alterations in habits and mood. If the family has not received information from a nurse about the effects of the disease, this can worsen relationships [24]. Symptoms such as pain and fatigue reported by patients affect physical, social and sexual lives and cause losses in their fulfillment of their roles in their daily and working lives. In the present study, another statement by many of the patients concerned loss of role. The patients especially stated that fatigue affected their lives and roles. In previous studies, patients reported effects and difficulties caused by symptoms on their emotional, domestic, social, sexual and working lives [19,26,27]. Another area in which role loss is experienced is in parenthood. Before becoming parents, patients with SLE have to take into account their physical capacities and abilities to care for a child. The mother may not be able to keep up the caregiver role and this may lead to a great deal of emotional distress for both of them. As a result, the family dynamics may be changed. As a result, some members of the family will have to take on additional responsibilities [24].

Social isolation

The physical effects of chronic rheumatological diseases, which restrict patients' social activities and affect their body image and self-esteem and the emotional changes experienced in the course of the illness can cause social isolation. This makes it difficult for the patient to create new contacts [19,24,27]. Recent studies have shown that patients feel frustrated about the impact of fatigue and other symptoms of disease such as changes in physical appearance on their roles and social activities [19,20,26]. In this study, the participants stated that their skin changes, alopecia and the swelling on their faces caused limitation in social activities, and they did not want to go out. It was seen that a reduction in self-esteem caused social isolation when others did not recognize them.

Coping; Stress Tolerance

Fatalism

Fatalism is the tendency to believe that a person's fate is governed by some outside force. It is a belief that health and illness are determined by fate and that they are outside a person's control, and is a concept which can affect self-efficacy with regard to healthy behaviors [28].

Long-term stress in chronic illnesses requires long-term coping skills. In some cultures and religions, fatalism and trust in God in people under stress can help to develop their coping skills [29]. In a qualitative study by Ogunsanya et al. (2018), most participants with SLE stated that religious faith helped them to cope. In this study, many of the patients stated that fatalism was a coping method [11].

Participation in social activities

Being social and active makes patients joyful and happy. In this way, they can forget the disease and have a sense of wellbeing. Larsen et al. (2018) and Mazzoni et al. (2018) note that joyful activities and social connections have a positive impact of life and behavior [20,30]. In a systematic review by Sutanto et al. (2013), patients with SLE adopted a healthy lifestyle with regular exercise and avoided stress [10].

Financial Impact

Financial difficulties

In the following of chronic diseases, important regular checks, treatment, and other health expenses can constitute a heavy financial burden on patients. At the same time, transportation difficulties caused by loss of the ability to work as a result of the illness, accessing the health system and physical inadequacies affect patients financially. Our study includes statements concerning patients' financial difficulties. Many previous studies have described that missing work, the difficulties of working, and paying for appointments and transportation costs caused financial diffulties [2,26,27]. These barriers to maintaining employment with SLE were mentioned particularly in a study by Booth et al. (2018) and Williams et al. (2015) also mentioned the burden of travel for SLE patients [26,27].

Limitations of this study include one hospital and limited sample size. This limits the generalizability of the research findings to only similar groups.

CONCLUSIONS

In conclusion, our research data underlined that Turkish women with SLE have many complex, and challenging life experiences. At the same time, it was seen that they used participation in social activities as a coping method. According to these results, women with SLE should adopt a multi-directional approach to the process of treatment, psychological support and care. In this process, the physiological and psychological effects of the disease and treatment on an individual's life should be determined. Our results suggest that revealing the experiences of patients determines the content of the education and counseling to be provided during the treatment and care process.

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Conflicts of Interest

There is no conflict of interest.

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