



# Swinging Between Hope and Despair: Experiences of Patients with Behçet's Disease: A Phenomenological Research Study

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## Abstract

**Background:** Behçet's disease (BD) can severely impact the psychosocial and emotional aspects of patients, significantly disrupting their quality of life.

**Objectives:** The purpose of this study was to describe the psychosocial and emotional experiences of patients with BD and their coping strategies.

**Methods:** This study was conducted using a qualitative method with a hermeneutic phenomenological approach. Data were collected through unstructured and in-depth interviews (9 conducted face-to-face and 6 via WhatsApp video calls) until data saturation was reached. Face-to-face interviews took place at the rheumatology clinic and the rheumatologist's office from April to July 2023. Data analysis was performed using Diekelmann's seven-step method. The trustworthiness of the study was ensured based on the criteria of Lincoln and Guba, as well as Sim and Sharp.

**Results:** By analyzing the data, 580 codes were extracted, leading to the identification of 12 sub-themes and 2 main themes. The first theme, "emotional, mental, and communicative instability," included the sub-themes of indecisiveness and uncertainty, moving away from desires and wishes, feelings of despair and demise, fears caused by the disease outcomes, sadness and mental anguish, isolationism, and reluctance to seek support. The second theme, "psychological and communicative strengthening strategies," comprised the sub-themes of having an occupation, seeking support, hoping for miracles and healing, doing mental exercises, and engaging in hobbies.

**Conclusions:** This study revealed numerous emotional, psychological, and communicative challenges faced by patients with BD, as well as the strategies they use to cope with these problems. It is recommended that the findings of this study be used to enhance the care team's understanding of the mental and communicative issues experienced by these patients and to improve their skills in teaching psychological strengthening strategies.

**Keywords:** Behçet's Disease, Psychosocial Functioning, Emotional Depression, Coping Strategies, Qualitative Research

## 1. Background

Behçet's disease (BD) is a chronic multisystem vasculitis and autoimmune disease of unknown etiology, characterized by a wide range of clinical manifestations, distinct geographic distribution, and a significant genetic background in the occurrence of the disease (1). This disease was first described in 1937 by a Turkish dermatologist named Hulusi Behçet as a triple symptom complex: Aphthous stomatitis, genital ulcers,

and recurrent uveitis (2). The most widely used classification criteria were proposed by the International Study Group (ISG) for BD in 1990. According to the ISG, the main criterion required for an exact diagnosis is recurrent oral ulcers occurring at least three times per year. Additionally, at least two of the partial criteria—such as genital ulcers, skin lesions (erythema nodosum, folliculitis necrotica, papulopustular lesions), eye lesions (posterior uveitis,

total uveitis, and retinal vasculitis), and a positive pathergy test—are required for diagnosis (3). Furthermore, BD may involve multiple systems, including the pulmonary, musculoskeletal, gastrointestinal, and nervous systems (1).

Behçet's disease has a global distribution but is usually seen in countries along the Silk Road and around the Mediterranean Sea, such as Spain, Portugal, Turkey, Iran, and Far Eastern countries like China and Japan (4, 5). The prevalence of the disease along the Silk Road is 14 - 20/100,000 (6). Behçet's disease is most prevalent in Turkey, with a prevalence of 20 - 602/100,000 (7, 8). After Turkey, the countries most affected by the disease are Iran, China, Tunisia, Korea, Israel, and Japan (7, 9, 10). Behçet's disease is less prevalent in Northern Europe, America, and African countries (11, 12).

Behçet's disease can involve almost all organs. Whether the brain is involved or not, psychiatric clinical manifestations may occur. The most common psychiatric symptoms are psychosomatic symptoms, anxiety, and depression. It has been suggested that the probability of psychiatric manifestations in these patients is about 86%. Although it seems that the occurrence of psychiatric manifestations can be related to disease progression, the presence of functional disorders, and the steroids used, the etiopathogenesis of the psychiatric symptoms observed in BD is not completely clear yet. Additionally, the existence of highly stressful life events, anxiety, and depressive manifestations in diagnosed patients, before the onset and exacerbation of BD, suggests that the disease also has psychosomatic aspects. Therefore, one of the challenging issues is whether psychological problems in BD are the cause or the result (13, 14).

Furthermore, psychiatric disorders associated with chronic diseases can be linked to high morbidity and mortality rates, as seen in diseases such as BD (15). Although the mental aspects of BD have been discussed in many case studies and reports, there is a limited number of original research articles that exclusively address this aspect (16). Most of these studies have been conducted using a quantitative approach. For instance, Koca et al. found that the level of depression in patients with BD is higher compared to a control group (17). Similarly, Fawzy et al.'s findings indicated that depression is a significant comorbidity in patients with BD, showing a direct relationship with fatigue, the number of major organ involvements, and overall

disease activity. This adversely affects the patients' quality of life, underscoring the importance of early intervention and depression management to reduce symptoms and improve quality of life (18). A study by Bagheri et al. on the prevalence of psychiatric symptoms in patients with BD in Shiraz, Iran, revealed a significant prevalence of mental symptoms. Therefore, physicians should carefully monitor their patients for early detection of psychiatric disorders that may develop due to the disease (19).

Based on the results of these studies, it is essential to use comprehensive approaches to understand the problems of patients with chronic diseases such as BD from their perspective. While quantitative research can easily collect more objective information about the desired phenomena, it does not provide comprehensive insights into emerging and unknown phenomena. To deeply investigate and obtain comprehensive information about these types of phenomena, qualitative research is necessary (20). Qualitative research explores individuals' mental dimensions and emphasizes the dynamic, comprehensive aspects as well as the individual's experiences. It aims to consider all dimensions in the context and from the perspective of the individuals who have experienced them, thus providing deep and profound information on which to base planning (21).

Therefore, conducting phenomenological research on the psychosocial problems and coping mechanisms in BD patients is crucial. It will provide a deeper understanding of their lived experiences, inform clinical practices, and guide the development of comprehensive support systems tailored to their unique needs. This research is imperative to enhance the quality of life for Behçet's patients and foster a more empathetic and effective healthcare environment.

## 2. Objectives

The purpose of this study was to describe the psychosocial and emotional experiences of patients with BD and their coping strategies.

## 3. Methods

### 3.1. Design

The current research is a qualitative study using an interpretive phenomenological approach, aimed at deeply understanding the experiences of patients with

BD, particularly focusing on their psychosocial and emotional health status and coping strategies. The research was conducted at the Rheumatology Clinic of Golestan Hospital, affiliated with Jundishapur University of Medical Sciences, Ahvaz, as well as at the rheumatologist's office, where patients with BD were referred. Sampling took place from April to July 2023.

### 3.2. Participants and Setting

Inclusion criteria for participants included having BD based on the diagnosis of a rheumatologist and experiencing the disease for at least one year. The samples were selected through purposeful sampling. Sampling continued until data saturation was reached, such that the semantic units extracted from the 12th interview onwards repeated previous findings, and the data from the last three interviews supported the previous findings without introducing new data. Therefore, sampling was terminated with a final sample size of 15 participants.

Data collection was conducted through unstructured and in-depth interviews, both face-to-face (9 participants) and via WhatsApp video calls (6 participants). Before the interview, a phone call was made to each participant to agree on the purpose, place, and duration of the interview. Face-to-face interviews were conducted in a private room provided at a rheumatologist's office or a rheumatology clinic. The WhatsApp interviews were conducted via video call with prior coordination. After the interview, if the researcher had further questions or if the participant wanted to elaborate on some topics, additional communication was conducted via WhatsApp chat.

During the interviews, the recommendations made by Ryan et al. regarding the nature of questions, questioning techniques, listening and interaction, ethical considerations, and patient protection were followed (22). Interviews began with general questions such as "How do you feel about your illness?" and "Describe your experience of psychological problems and the communicative limitations associated with the disease." The researcher minimized interference in the interview process and used probing questions such as "Explain more," "Give an example," and "What do you mean by ...?" Since writing down all points mentioned during the interview would interrupt the process, participants were reminded that their voices would be recorded. Each interview lasted one to two sessions, depending on the participant's tolerance and

willingness, with a mean duration of 40 minutes. All interviews were conducted by one researcher.

To ensure the confidentiality of participants, direct identifiers were removed from the data (e.g., name, address, phone number), and unique codes were assigned to participants instead of using real names. A separate, secure document linking the codes to identities was maintained. Additionally, interviews were conducted in a private and safe place, and secure and encrypted communication platforms were used for remote interviews.

### 3.3. Data Analysis

Data analysis began simultaneously with data collection. In other words, as soon as the first interview was completed, data analysis commenced. The analysis was based on hermeneutic phenomenology, which includes describing and interpreting the meaning of lived experiences. Diekmann, Allen, and Tanner's seven-step method, which is team-based and rooted in this type of phenomenology, was employed (23). The steps are as follows: (1) after completing each interview, the recorded text was transcribed into a Word document and reviewed several times to gain a general understanding, (2) an explanatory summary was written for each interview text, aiming to understand and extract the hidden meanings within the interviews, (3) the researcher discussed the extracted meaning units and their contents with the research team members, (4) to clarify and eliminate any disagreements and contradictions in the interpretations, the process involved repeatedly going back to the texts and sometimes referring to the participants (hermeneutic round or cycle), (5) by combining interpretive summaries and similar semantic units, a more general and combined analysis was formed. Similar semantic units were grouped, forming sub-themes and main themes, (6) a final commentary or structural statement expressing the connection between the extracted sub-themes and themes was written (the highest level of hermeneutic analysis) (Table 1).

### 3.4. Rigor

The trustworthiness of the study was based on the criteria of Lincoln and Guba and Sim and Sharp (24), including credibility (prolonged engagement, persistent observation, triangulation, member check), transferability (thick description), dependability and

**Table 1.** An Example of the Formation Process of One of the Main Themes

Main Theme	Sub-theme	Primary Codes	Quotation
Emotional, mental, and communicative instability	Reluctance to seek support	Failure to accept the disease on the part of the spouse	Since the ophthalmologist told my husband that there was nothing wrong with me, my husband has become sensitive and says that I should stop taking my medicine without informing the doctor. He insisted on not taking the medicine so much that I told him I would take a quarter of a pill from now on, and that 7 months later, I would go to the doctor so that he would stop my medication completely, and then if we decide to have a child, we can take action. My husband thinks I have migraine headaches. Even though the doctor has explained this to him about this problem, he believes that I have migraine headaches and that I have no special problems, and says that I should stop taking my medicine without informing the doctor. Considering my husband's way of treating this issue, I prefer not to let him know anything, and not to ask him for help.
		Trying to convince the wife to stop	
		The desire to hide problems from the spouse taking her medicine	
		Reluctance to ask for help from the spouse	

confirmability (audit trail), and reflexivity (diary). During member checking, the codes and categories obtained from the data analysis were provided to the participants, and their feedback was taken into account to ensure that the findings accurately reflected their experiences and perspectives. Additionally, the obtained codes and categories were reviewed by all three researchers, and a final agreement was reached on the primary codes, sub-themes, and themes.

**4. Results**

The number of participants in this study was 15, including 11 females and 4 males. Eight participants had secondary education or high school diplomas, and seven had university education. Six participants were single, and the rest were married. The age range of the participants was 25 - 53 years, and the duration of diagnosis ranged from 2 to 22 years. Seven participants were employed, while the rest were housewives. All participants were in the controlled stage of the disease.

By analyzing the data, 580 codes were extracted, resulting in 12 sub-themes and 2 main themes. The first theme, emotional, mental, and communicative instability, included the sub-themes of indecisiveness and uncertainty, giving up on desires and wishes, feelings of despair and demise, fears caused by the disease outcomes, sadness and mental anguish, isolation, and reluctance to seek support. The second theme, psychological and communicative strengthening strategies, included the sub-themes of having an occupation, seeking support, hoping for miracles and healing, doing mental exercises, and engaging in hobbies. Table 2 shows the main themes and the sub-themes.

*4.1. The First Theme: Emotional, Mental, and Communicative Instability*

*4.1.1. The Feeling of Indecisiveness and Uncertainty*

The feeling of uncertainty, despair, and the unpredictability of life can lead to mental problems and decreased motivation in patients with BD. In this regard, one patient states: "In the past seven or eight years, my life has been completely shut down. I mean, I have not lived like my peers, and I have never been as happy as I should have been. All I think about is what is going to happen in the next stage of the disease. On one hand, anxiety and depression, and on the other hand, the lack of motivation is knocking me out." (28 years old, female)

*4.1.2. Giving up on Desires and Wishes*

The physical, mental, and psychological problems caused by the disease make patients with BD give up on their dreams and aspirations. In this regard, the participants state: "I like to continue my studies, but the thought of illness does not allow me to study. I want to study so that I can become an official employee, but the thought of this illness has taken over my whole soul and mind. I do nothing. I just think about when it will all come to an end." (35 years old, male)

"Since I was affected by this disease, I completely stopped thinking about getting married. I am 32 years old now, but I reject my suitors. I don't want others to find out about my disease after getting married." (28 years old, female)

*4.1.3. The Feeling of Despair and Demise*

**Table 2.** Main Themes and Sub-themes

Main Themes	Sub-themes
Emotional, mental, and communicational instability	Indecisiveness and uncertainty
	Giving up on desires and wishes
	The feeling of despair and demise
	The fears caused by the disease outcomes
	Sadness and mental anguish
	Isolation
	The reluctance to seek support
Psychological and communicative strengthening strategies	Having an occupation
	Seeking support
	Hoping for miracles and healing
	Doing mental exercises
	Engaging in hobbies

The recurrence of symptoms, the occurrence of pain, discomfort, and loss of hope in treatment lead patients with BD to despair, giving them a feeling of demise and even leading some towards suicidal thoughts. The participants comment on this regard: "At night, when I sleep, I always wonder if I will wake up the next day. It may seem funny, but 80% of the time, when I go out, I suggest that my sister and her children buy the things that I like. I look at them and tell myself I should buy them; suddenly, it strikes me that I may not be able to use the stuff." (25 years old, female)

"Oh, what kind of life I have! Why should this disaster happen to me in my youth? Sometimes, I think about suicide because of the pain and discomfort as well as the fear that I might lose my sight." (28 years old, female)

*4.1.4. The Fears Caused by the Disease Outcomes*

Patients with BD experience various fears and worries: Fear of disease complications, drug side effects, blindness, and the possibility of their children inheriting the disease. The participants state:

"My OCD is that I might develop an eye disease. My beauty is very important to me. I am very sensitive about my beauty. What if this disease affects my beauty and I have to continue taking these drugs or increase the dose of my drugs? These thoughts bother me and trigger my OCD." (41 years old, female)

"The unpredictable nature of this disease causes fear and anxiety. I never know when it might flare up. When it flares up, pain, fatigue, and difficulty in doing my daily activities increase. Besides, I'm also worried about

my children. What if they get affected, too?" (35 years old, female)

*4.1.5. Sadness and Mental Anguish*

Many of these patients suffer from severe emotional distress. They often come to tears while talking about the disease, and their distress increases in situations such as being at the doctor's office. The participants state: "When someone talks about incurable or autoimmune diseases, I can't help crying. Even being at the doctor's office multiplies my sadness and grief." (28 years old, female)

"Actually, as a patient with Behçet's syndrome, my life is all sadness and crying. Every night, when I want to sleep, I try not to cry anymore. But I can't. I fall asleep with a lump in my throat and tears in my eyes." (47 years old, male)

*4.1.6. Isolation*

In these patients, isolation occurs due to the fear of being stigmatized as well as the need for rest due to pain and lower energy levels. One participant states, "I'd rather no one finds out what's wrong with me. I'm a single girl. What will people think if they find out that I have genital ulcers? I think the only thing they can think of will be that I have genital warts. That's why, apart from going to work, I don't hang out with any friends or acquaintances." (46 years old, female)

Another participant states, "Because of my job, I spend a lot of time at work. I also participate in household activities such as shopping. But when the symptoms recur and I feel pain and fatigue, I need to

rest and stay home. I take leave, and thank God, my boss cooperates with me." (31 years old, male)

#### 4.1.7. *The Reluctance to Seek Support*

Some of the patients with BD were not willing to receive support from others, even from their families. This reluctance has various reasons, such as avoiding upsetting and bothering the family, as well as preventing inappropriate reactions from family members due to their not accepting the disease.

In this regard, one of the participants stated, "When my mom accompanies me to the doctor's office, I try not to ask the doctor any questions because I don't want my mom to get upset by hearing our words. I try to hide my pain and problems from my family. I don't want my problems to be a burden on their shoulders." (37 years old, female)

Another participant stated, "Since the ophthalmologist told my husband that there is nothing wrong with me, my husband has become sensitive and says that I should stop taking my medicine without informing the doctor. He insisted on not taking the medicine so much that I told him I would take a quarter of a pill from now on, and that 7 months later, I would go to the doctor so that he would stop my medication completely, and then if we decide to have a child, we can take action. My husband thinks I have migraine headaches. Even though the doctor has explained this to him, he believes that I have migraine headaches and that I have no special problems and says that I should stop taking my medicine without informing the doctor. Considering my husband's way of treating this issue, I prefer not to let him know anything, and not to ask him for help." (50 years old, female)

### 4.2. *The Second Theme: Psychological and Communicative Strengthening Strategies*

#### 4.2.1. *Having an Occupation*

Having a job that suits the patient's physical and mental conditions can create hope and motivation in patients with BD by providing a sense of meaning and setting goals in life, as well as strengthening social relationships.

One participant stated, "I'm a teacher, and I catch many colds because of taking corticosteroids. However, I like to be at my workplace, except when my genital ulcers recur. Communicating with my colleagues and

students helps me put aside all the negative thoughts and feel that I am useful. This way, I feel that my life is not useless and meaningless." (31 years old, female)

#### 4.2.2. *Seeking Support*

Seeking support from family members is crucial for patients with BD. It means that those affected should ask their family members for support and attention to their needs.

One participant stated, "Since I developed this illness, my husband takes care of me much more than before. He tries to be by my side more often. He takes me with him almost everywhere he goes so that I won't feel lonely. Besides, my children pay more attention to me and help me with the house chores." (31 years old, female)

Another participant stated, "My husband understands me very well. He sympathizes with me in every possible way. When genital ulcers recur, he takes care of me. He accompanies me when I go to the doctor. He also has my prescriptions filled." (39 years old, female)

#### 4.2.3. *Hoping for Miracles and Healing*

Believing in miracles and healing can give hope to patients with BD and motivate them. This hope can provide them with more energy and endurance to fight the problems and pain associated with the disease.

One of the participants stated, "I spend the night hoping for miracles. I always think something may happen before morning, maybe a miracle, and I may be healed. I may get rid of this disease for the rest of my life." (37 years old, male)

Another participant stated, "When the disease flares up, I lose hope. But when the symptoms disappear and I lower the dose of the medicine, I feel hopeful and happy again. I wonder if the disease will never occur again. I gain a great deal of hope and motivation, and continue to live with strength." (31 years old, female)

#### 4.2.4. *Doing Mental Exercises*

It seems that mental exercises can help patients with BD manage stress and anxiety and improve their overall mental and psychological performance.

One of the participants stated, "The conditions caused by the disease can lead to losing hope, but I try my best to manage the problems and think positively.

I've been doing yoga for a while, which helps reduce my level of stress and prevent negative thoughts." (53 years old, female)

Another participant stated, "My friends introduced a community to me, and I participate in their online courses. In these courses, they teach us things like prayer therapy, positive therapy, strengthening positive thoughts, and developing creativity. Since I joined this community, I have been coping with my illness much more easily, and I have gained some mental peace." (41 years old, female)

#### 4.2.5. Engaging in Hobbies

Engaging in hobbies can increase the quality of life for patients with BD and improve their mental health. These hobbies can serve as sources of motivation in disease management. Some participants state: "I am very interested in searching for information and studying on the Internet. Especially, when symptoms recur and I rest at home most of the time, I use the Internet more frequently to occupy my mind and try to control my emotions." (35 years old, male)

"We have a garden in the suburbs. I try to go to the garden with my family on weekends. Being in nature, especially with my family, really makes me feel better. This is the best way I can avoid thinking about my problems for a few hours." (31 years old, female)

## 5. Discussion

This qualitative study focused on the experiences of patients with BD, considering their mental health, and revealed many challenges of living with this chronic, rare, and multi-system disease. The results indicated that the challenges experienced by these patients are both physical and mental.

Patients with BD deal with problems such as pervasive pain, fatigue, blindness, and organ failure daily, leading to physical and social limitations. They live with considerable anxiety due to the unpredictable nature of the disease. Additionally, they experience loneliness because many of the symptoms are invisible, causing others to trivialize them. These experiences are common in other chronic rheumatologic conditions such as systemic lupus erythematosus as well (25).

The results of the present study showed that these patients experience isolation due to the fear of being stigmatized as well as feeling the need for rest due to

their pain and lower levels of energy. In line with the results of this research, the study by Tai et al. (26) in New Zealand also showed that these patients experience isolation more deeply due to the rarity of this disease. Additionally, these patients face fear caused by disease outcomes, which are often due to factors such as complications of the disease, drug side effects, blindness, and concerns about their children inheriting the disease in the future. The feeling of uncertainty or despair due to the unpredictability of life, another common experience among these patients, can lead to mental problems and decreased motivation. Consistent with the present study, Tai et al. found that patients experience fear and uncertainty due to the unpredictable and recurring nature of the disease. Furthermore, neurological complications and uveitis, threatening visual acuity, significantly frighten them (26). Emotional, mental, and communicative instability was one of the main themes extracted from the experiences of these patients in the present study. In this regard, Poh et al.'s study on the life experiences of patients with rheumatoid arthritis showed that these patients experience many emotional and mental challenges, manifested through symptoms such as anger, despair, discomfort, helplessness, shame, and reduced self-confidence (27). Similarly, Sutanto et al.'s study on the experiences of patients with lupus found that these patients have many emotional and mental problems, including feelings of being a burden, helplessness, fear of rejection, guilt and punishment, social stigma and indifference, and societal rejection (25).

The results of the present study showed that although the emotional and mental challenges faced by patients with BD are very distressing, many patients try to gain control over their illness using psychological and communicative strengthening strategies. These strategies include having an occupation, seeking support, hoping for miracles and healing, doing mental exercises, and engaging in hobbies, which help them cope with the limitations caused by the disease. Similarly, a qualitative study by Mattsson et al. on uncertainty and opportunities in patients with systemic lupus erythematosus showed that patients can learn to live with the disease using strategies such as appreciation, humility, and higher perception, making them emotionally stronger (28). Additionally, the study by Sutanto et al. found that patients with lupus try to cope with the fears and worries caused by the disease by

maintaining a positive outlook and making practical changes in their lifestyle (25).

The mental adaptation of patients with BD is negatively affected by problems such as difficulties in diagnosing the disease, the lack of definitive treatment, the progressive and recurrent nature of the disease, the unpredictable illness attacks, and the potential of the disease to affect all organs (29-31). The results of a qualitative study by Ozguler et al. showed that the mental effects of BD include experiencing emotions such as anxiety, stress, depression, and anger. It also indicated that patients expressed a need for more mental support from the treatment team (32). Teaching adaptation strategies is of great importance in the process of mental adaptation in chronic diseases, especially to prevent disorders such as depression. Adaptation is defined as the process of making behavioral and cognitive efforts to manage mental stress (33).

There are two types of coping strategies: Problem-oriented and emotion-oriented. In problem-oriented coping, efforts are focused on changing environmental aspects and interpersonal relationships. Individuals using this strategy try to fix the cause of the problem or eliminate or change the source of stress. In contrast, the emotion-oriented strategy focuses on changing the way one responds to the stressor, with the goal of relieving stress by reducing the impact of stressful factors. This strategy may involve changing the meaning of the stressor or redirecting attention away from it (34). Each of these strategies includes active and passive coping mechanisms (33, 35). Choosing active or passive mechanisms is crucial in the patient's adaptation process. Studies have shown that relying more on inactive mechanisms is associated with a higher risk of mental disorders such as anxiety and depression in patients with chronic diseases (36). Patients with chronic diseases typically use different types of coping strategies during their illness. Teaching active coping strategies, such as planned problem-solving methods, seeking social support, and positive reassessment, is associated with an increase in quality of life and a reduction in depressive symptoms (35-38).

Furthermore, the results of the studies have shown that interventions such as counseling, stress management programs, and cognitive behavioral therapy can reduce anxiety, depression, and stress, and improve activity in patients with lupus. These interventions may have similar benefits for patients

with BD as well (39). In addition, support groups have also been found to improve the perceived quality of life in other chronic rheumatologic conditions such as rheumatoid arthritis (40). Due to the rarity of BD and the difficulty of accessing a sufficient sample size, research on these patients is limited. Based on the searches conducted by the researchers, there are few qualitative studies on patients with BD. In Iran, not only were qualitative studies not found, but quantitative studies are also limited. Therefore, the present study is the first qualitative study on BD patients in Iran, which explains their psychological and social problems.

### 5.1. Conclusions

The findings of the present study reveal the psychosocial problems experienced by Behçet's patients and the strategies they use to cope with these challenges. These insights can enhance the knowledge of the care team, enabling them to develop comprehensive care plans that address the psychosocial issues of these patients. Additionally, it is recommended that policymakers, recognizing the unique problems associated with rare diseases such as BD, prioritize the needs of this patient group in health planning and policy development. Furthermore, conducting additional qualitative studies using other methodologies, such as grounded theory, is advised to develop suitable models for addressing and adapting to the psychological and communicative problems of patients with BD.

### 5.2. Limitations

Nevertheless, the present study has some limitations. The first limitation was the small number of male participants compared to female ones. In Iranian culture, men often neglect health problems, making them less willing to cooperate with the researcher and share their issues. Additionally, since some interviews were conducted over WhatsApp, it was not possible to observe the patients' non-verbal reactions.

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## Footnotes

**Authors' Contribution:** N. S.: conceived and supervised the study. S. J. developed the research protocol. S. J. collected the data. N. S., S. J., and E. R.: wrote the manuscript. All the authors critically revised the manuscript. All the authors read and approved the final manuscript.

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