

Symptom management in Behcet's disease

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Abstract

Objective: To determine the symptoms experienced by patients diagnosed with Behcet's Disease and how they cope with them.

Methods: The qualitative study was conducted from September 2013 to March 2014 at Ege University Medical Faculty Hospital, Turkey, comprising patients having all symptoms of Behcet's Disease. Data was collected through semi-structured focus-group interview form. The findings were assessed using Theory of Unpleasant Symptoms and Symptom Management Theory. SPSS 20 and Nvivo 10 were used for data analysis.

Results: Of the 35 patients, 16(45.8%) were female and 19(54.2%) were male. The symptoms affected patients' lives, and the patients used either positive or negative symptom management strategies, leading to either positive or negative results during symptom management.

Conclusion: Behcet's Disease patients needed effective symptom management.

Keywords: Behcet's Disease, Theory of Unpleasant Symptoms (TOUS), Symptom management theory. (JPMA 68: 46; 2018)

Introduction

Behcet's Disease (BD) is a chronic multi-systemic disease observed in young adults and characterised by artery and vein nerve vasculitis.^{1,2} The symptoms occurring in BD may negatively affect the patient in terms of physical, psychological and social aspects, and patients use a variety of methods to cope with this disease.³⁻⁶ BD may negatively affect individuals' appearance, psychosocial status, personal relationships and daily activities. It also affects quality of life by restricting individuals' daily activities and lifestyle, and causing distortions in their mental health.^{7,8} So, this study used the Theory of Unpleasant Symptoms (TOUS) and Symptom Management Theory to understand patients' symptoms and coping methods. TOUS has three main components: symptom(s), affecting factors and performance results.^{6,9,10} It is observed that three factor categories (physiological, psychological and situational) connect with each other and affect the type of symptom experience. Additionally, this theory accepts that the symptom experience affects the individual's performance (including cognitive, physical and social functions).^{3,6} Symptom Management Theory was established in order to eliminate the symptom or minimise the distress caused by the symptom experience.¹¹⁻¹³ The three main concepts of Symptom Management Theory are symptom experience, symptom management strategies and symptom status results.¹² The current study was planned

to determine the symptoms experienced by patients diagnosed with BD, the factors that affect the symptoms, the effects of symptoms on patients, and the methods and resources patients use to cope with these effects.

Patients and Methods

The qualitative study was conducted from September 2013 to March 2014 at Ege University Medical Faculty Hospital Rheumatology Polyclinic, Turkey, and comprised patients having all the symptoms. However, patients expressed their complaints that they experienced most frequently. The study collected data after conducting focus-group interviews through a semi-structured focus-group interview form. Each patient was given 10-15 minutes to talk during the focus-group interview and the data was noted. An appropriate physical environment was created prior to the focus-group interviews to make the exercise comfortable and efficient. The executive and the observer were also introduced prior to initiating the interviews.

The concepts, cases, and processes that emerged were included in the subsequent data-collection stages. The interviews were transcribed from tape recordings. Permission was obtained from the institutional ethics review committee. Participating patients gave verbal and written consent after necessary explanations were given regarding the purpose and methodology of the study and the results expected to be obtained. SPSS 20 and Nvivo 10 were used for data analysis.

Results

Of the 35 patients, 16(45.8%) were female and 19(54.2%) were male. The mean age of the patients was

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Table: Themes Concerning Symptoms of Patients with Behcet's Disease and Their Symptom Managements.**Main Theme****Symptoms****Sub-Theme 1:**

Mouth Sores - "My mouth sores were bad for me."

Genital Sores - "Initially, there were two major injuries in the genital region in one year."

Blurred Vision - "I do not see with the left eye at the moment because of Behcet Disease."

Joint Involvement - "My left arm was never used because of my rheumatism."

Neurological Involvement - "I've experienced a nervous breakdown. I do not remember what I have done for a week."

Sub-Theme 2:

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Main Theme**Symptom Perceptions****Sub-Theme 1:**

Serious Disease - "Everyone needs to say that they have Behcet's disease. Very serious disease"

Fate - "We're fatalist on some issues. I must learn to live with that if it's given to me. And if I should live with this, why would I get depressed? Then, what will I do? There's nothing else but using my medicines and doing my controls."

Bad Luck - "That's just bad luck, so there's nothing else to do I guess."

Annoyance "My mouth injuries make me sick."

Contagious - "I started to reserve and use my fork and spoon because I have been suffering from wounds since I was diagnosed with Behcet's disease. This disease is contagious."

Genetic - "Look, I experienced these kinds of things. I wonder, will they pass to my children?"

Sub-Theme 2:

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Main Theme**The Effects of the Symptoms on Individual's Life****Sub-Theme 1:**

Effect on Family - "I couldn't take care of my child. I couldn't caress him, take him out for walks."

Effect on Work - "I've lived a lot of negativity about work. I've changed 10 or 15 jobs since I got Behcet's disease."

Economic Effect - "It was financially very difficult."

Effect on Social Life - "I cannot go to a place because of eye problem."

Psychological Effect - "We've got a little depression, of course. It was unavoidable. Sometimes I argued with my husband. Look, everyone has their own opportunities."

Effect on Physical Movements - "I cannot cook and chores."

Effect on Eating - "I suffered when I ate. I had stress when I went to the cafeteria. It was so difficult thinking how I was going to finish a meal."

Effect on Speaking - "You do not understand if I talk."

Sub-Theme 2:

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Main Theme**Symptom Management: The Results of Effective Symptom Management****Sub-Theme 1:**

Well-Being - "I overcome this disease better. I am on medication. I take painkiller.

Thank God! I'm great."

Self-Confidence - "Luckily, my blood test results are good because my morale is high."

Sub-Theme 2:

Increase in Knowledge

Increase in Experience

Main Theme**The Results of Ineffective Symptom Management****Sub-Theme 1:**

Suicidal Ideation - "I had periods that I even thought about suicide because of intolerable pains."

Introversion - "I withdrew into myself. I didn't want to see anyone, I didn't want to talk."

Depression - "I don't know, I guess I can overcome BD by myself. I mean, I don't have so many problems."

Need for Attention - "We are outpatients but people regard us as normal. I want to be cared about as if I am a patient. I was extremely angry. I wanted people to ask me "You are ill, how are you?" that they care about me."

Applying Ineffective Complementary and Alternative Medicine Methods - "Nothing is useful."

Occurrence of Attacks - "Attacks have begun."

Sub-Theme 2:

Fear of Attacks

Fear of Death

Main Theme**Symptom Management Strategies****Sub-Theme 1:**

Being/Not Being Able to Do One's Best - "I can perform my routines whenever I can."

Having An Optimistic/Pessimistic Perspective - "But after all, whenever I come here and see those who are worse than me, I thank God again."

Accepting/Not Accepting BD - "I accept that in two months."

Getting/Not Getting Used To Having BD - "We just got used to it and lived, and I didn't have so many difficult times. I mean, I had difficulties sometimes. I got used to it. I just live like that."

Thinking Positively/Negatively about BD - "Oh! If you think badly about something, it will be bad."

Bothering/Not Bothering BD - "I've forgotten everything."

Receiving Psychological Support - "I got psychological support."

Distraction/No Distraction Not to Think about BD - "I do not care."

Stressful/Stress-Free Life - "A stress-free life. Being away from the crowd and tiredness made me feel good."

Paying/Not Paying Attention to BD - "I try very hard to consume liquid."

Forgetting/Not Forgetting - "I forgot my sickness now."

Positive/Negative Future Expectation - "It could have been worse. People suffer from cancer and desperation, so I am thankful for the way I live."

Sub-Theme 2:

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BD= Behcet's Disease

44.8±10.8 years (range: 19-62 years) and their mean duration of disease/week was 565.4±506.8 (range: 3.0-2160.0). All the themes generated through the interviews were noted (Table).

Discussion

This study discussed three sub-themes, titled Symptoms, Symptom Perception, Symptoms' Effects on Individuals' Lives and Symptom Management. Symptoms are based on the perceptions of individuals.¹⁴ The symptom experience involves personal symptom perception,

symptom evaluation, and symptom response. Symptom perception defines people's feelings or behaviours regarding the symptom.¹ In this study, the patients expressed that they have so much trouble because their disease is seen as contagious by themselves and the people around them. The patients also believed that the disease is completely contagious and feared that their children will be exposed to the same difficulties.

The symptoms of BD have negative effects on people's lives; therefore, patients need individual symptom management.¹⁵ Literature shows that patients have some stress about not being able to perform their familial roles. Eren et al. evaluated the quality of life of BD patients having or not having symptoms with Short Form-36 (SF-36) questionnaire and observed a similar increase in role difficulties due to physical health and mental problems in patients with symptoms.¹⁶ Joint involvement prevents the BD patients from performing their activities of daily living and restricts their social relationships by causing pain and limiting range of motion.⁷ Kilinc et al. reported that the patients' relationships with other people are destroyed, they distance themselves from the people around them, had negative thoughts, had difficulties in performing daily activities, and became more anxious about future.¹ The recurrent and painful oral ulcers in BD patients also cause nutrition problems.¹⁶ Gilworth et al. stated that BD limits patients' activities of daily living and negatively affects their self-confidence and their relationships with other people, and the painful oral ulcers hinder patients' ability to speak and eat; they also have a negative effect on body image.⁸ BD symptoms negatively affect individuals' lives and require symptom management. Due to the relationship between symptoms and quality of life, effective symptom management is important in terms of improving patients' quality of lives.¹⁷ For these reasons, effective symptom management should be determined and supported by evidence-based studies.¹⁴ Patients cope with these negativities as they gain information and experience over time. The more logically the informed patients interpret the effects emerging after treatment, the more easily they accept them.⁷ Health professionals have a major task at this point.¹⁸ BD means uncertainty for patients' lives and therefore prevents the development of effective coping methods. It is critical for all medical staff to recognise the concept of uncertainty, which may be experienced in all periods of life but gains more importance in case of a disease, and to take it into consideration in understanding and helping the patient during the recovery period. People begin to seek knowledge in order to interpret the situation objectively and develop effective coping behaviours.¹⁹

This study showed that patients used a variety of positive and negative symptom management strategies (Table). Some people cope with BD better than others. The characteristics of self-effectiveness are tolerance, hope, personal skills, optimism and consistency.²⁰ The optimistic patients use problem-oriented coping strategies because they show a positive change.¹⁵ Researchers generally regard non-problem-oriented coping methods as variations of emotion-oriented coping (focussing on and expressing emotions, interrupting behavioural attention, and interrupting mental attention).²¹ Acceptance should not be seen as hopelessness; it is an understanding of the seriousness of both the disease and the situation.^{21,22} Hopelessness, despair, different expectations, ignorance and social pressures on the family are among the most important factors that push patients and families to seek methods other than traditional treatment methods.²³ As seen in this study, patients receive supportive treatments due to depression. Cognitive-behavioural or self-treatments improved pain and depression symptoms in rheumatic diseases. The fact most emphasised by patients in symptom management was the importance of stress-free life. Stress is a common problem occurring in most arthritis patients.¹⁵ The patients in this study again emphasised the importance of avoiding distress which is in line with literature.²⁰ When interviewed, patients also stated that they pay attention to treatment plans and disease symptoms and stressed self-efficacy. There was only one previous study regarding the coping methods used by BD patients. Karlidag et al. reported that patients' first feelings about BD were fear, sadness, anxiety, despair and curiosity (74.9%), and they mostly used active relaxation strategy (36.1%), distraction strategy (25%) and avoidance strategy (25%) to cope with the disease. They emphasised that psychiatric symptoms occurred more frequently in those having difficulty in coping with their problems.²⁴

Conclusion

This study found that the symptoms affected the way patients live and thus need symptom management. The patients performed effective or ineffective symptom management using positive or negative symptom management strategies. Those performing effective symptom management had fewer symptoms than those who performed ineffective symptom management. It is therefore recommended that healthcare providers should give patients detailed information about the symptoms and symptom management strategy. Healthcare providers should also emphasise the importance of adjusting to medical treatment, diet and regular exercise, and teach how to cope with their disease.

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