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Assessment of informational needs in Behcet's patients

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***Abstract*---**Behçet's disease (BD) is one of the rare rheumatologic diseases which affects most commonly young adults in the third or fourth decade of life. Inspite of the multi system nature of the disease can lead to temporary or permanent functional disability, informational needs of BD patients is still unknown as no studies has investigated such issue, hence the aim is to assess the informational needs among patients with Behçet's disease. A cross-sectional descriptive design on a convenient sample of 68 adult BD patients was utilized. Data was collected using the following tools: (a) structured interview questionnaire and (b) the Arabic version of Toronto Informational Needs Questionnaire (TINQ) adapted for BD. The highest percentage of the study sample was male (82.40%) came from rural area (61.80%) and aged 31-42 (58.00%) with a mean age of (38±7.01 years). The study results showed the information related to treatment, disease characteristics, investigative tests and psychosocial items are highly important needs among BD patients. Age, gender and education are influencing factors for informational needs in the sample of the study. Further replication of the study is recommended from different geographical areas.

***Keywords*---**information needs, Behcet's disease, Behcet's patients' assessment.

Introduction

Behcet's Disease (BD) is a relatively uncommon systemic vasculitis, affecting vessels of different types, sizes and locations and characterized by recurrent episodes of acute inflammation, including mucocutaneous manifestations (oral aphthous ulcers, genital ulcers and skin lesions) and pulmonary, gastrointestinal, musculoskeletal, neurological, ophthalmic and vascular involvement which lead to a significant morbidity and mortality (Gheita et al., 2019; Gorial, & Jabbar, 2020; Beça& Espinosa, 2021). While the cause remains unknown, it may be an autoimmune disorder, involving both genetic predisposition and environmental factors(De Chambrun, Wechsler, Geri,Cacoub&Saadoun, 2012).

The systemic manifestations can be variable. The incidence of oral ulceration in BD is thought to be 97 % to 100%. The presence of mouth ulcers can cause difficulty in eating, drinking, and speaking leading to a reduction in quality of life. Ocular disease has the greatest morbidity, followed by vascular disease generally from active vasculitis. Cutaneous manifestations can occur in up 75% of patients and can range from acneiform lesions, to nodules and erythema nodosum.Gastrointestinal manifestations can be severe and usually start 5–10 years after the onset oforal ulceration (Davatchi, Assaad Khalil, Calamia, Crook, Sadeghi Abdollahi, et al., 2014; Hatemi, Hatemi&Çelik, 2018). Additionally, it was determined that patients with Behcet's disease experienced fear, sadness, anxiety, hopelessness and ambiguity.Health challenges may arise due to insufficient support and information for such rare illness(Tai, Lindsay, Sims, & McQueen, 2017).

Patients with chronic disease such as BD are in need for information to enable them to achieve, maintain and restore an acceptable level of social independence and reach optimal level of health. The required needs include a direct and comprehensive evaluation of the multidimensional impact of the disease on the patient's lives and address the important areas of disease characteristics, physical, psychosocial, laboratory investigations and treatment modalities (Lei, Har & Abdullah, 2011). Information on BD allows patients to understand their disease, to develop a positive attitude towards the life amidst the threatening implications of the disease, and to cope well with the condition. Provision of relevant and accurate information in a social-culturally appropriate manner will lead to proper understanding of the treatment options and outlook that the patient needs to adopt towards a healthy future (Christalle et al., 2019).

Measurement of informational needs require a tool which should be culturally appropriate. A famous tool is named as Toronto Informational Needs Questionnaire (TINQ), has been developed in the European region to assess the need of information related to diagnosis, treatment modalities and follow up careofpatients with metastatic breast cancer(Galloway et al., 1997). The informational needs in BD as a serious potentially organ and life-threatening disease and one of the most frequently encountered vasculitis disorders in Egypt was not previously investigated, despite the similarities between cancer and vasculitis disorders including the complexity, potential seriousness of both diseases and the use of immunosuppressive encouraged researchers to adapt and validate the questionnaire (Mooney et al., 2014; Greco et al., 2018; Attia, 2021).

Study Conceptual Framework

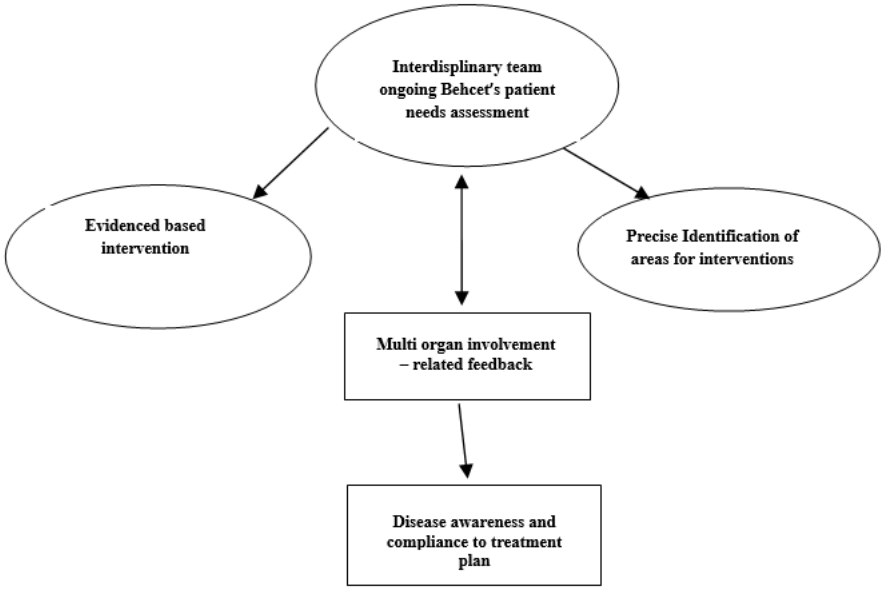

Figure 1. Proposed Scheme for Behcet's patient assessment. ©Elmetwaly O., Abdelaziz S., and Maged L.

Material and Methods

The present study was conducted with the aim of assessing the informational needs in BD patients.

Design

This study is a cross-sectional descriptive study was conducted to provide a snapshot of the informational needs of patients with BD. The benefit of a cross-sectional design is allowing the researchers to look at numerous things at once. However the design may not provide definite information about the cause and effect relationship (Gerrish & Lacey, 2010).

Setting

The study was conducted at Rheumatology and Rehabilitation Department affiliated to University Teaching Hospital.

Sample

A convenient sample of 168 adult male and female BD patients were initially selected for the study. Of these,85 did not give consent for participation because they did not attend to the unit because of COVID-19 and 15 were unable to

complete the study for the same reason. Finally, 68 patients were recruited for the study. The Rheumatology and Rehabilitation department served 290 patients with Behcet›s Disease. The sample size calculated using Solvin Formula n=N/ (1+ Ne^2) in which (n) is the sample size, (N) is total population and (e) is a margin of error. Confidence interval was considered at 95% and margin Error of 0.05 were utilized (TAHERDOOST,2016).

The following selection criteria were adhered to: (a) adult, literate male and female BD patients having the interest to participate in the study,(b) age ranging from 18 to 60 years, (c)diagnosed with BD at least 3 months before the initiation of the study. The following exclusion criteria were established:(a) Patients suffering from central nervous system (CNS) manifestations that prohibit expressing self clearly including disturbed conscious level, (b)Patients suffering from psychiatric illnesses.

Tools

To collect the data pertinent to the study; the following tools were utilized.

a) Structured Interview Questionnaire: Developed by the researcher and consisted of two parts: First part: included Socio-demographic data related to age, gender, level of education, occupation and marital status. The Second part: included data related to life styles, reported symptoms of exacerbation, general health since diagnosis and health history such as duration of illness and history of co morbid diseases.
b) Behcet's disease informational needs questionnaire. Adopted and modified from the Toronto Information Needs Questionnaire-Breast Cancer(TINQ-BC) which consists of 51 items measuring five subscales: disease characteristics subscale (9 items), treatment subscale (16 items), investigative tests subscale (7 items), physical subscale (11 items) and psychosocial subscale(8 items). TINQ-BC had good internal consistency reliability with Cronbach's alphas of 0.94 for the total questionnaires and alphas ranging from 0.85 to0.90 for the subscales (Galloway et al., 1997). After removal of questions solely related to breast cancer, The researchers did the necessary modifications all over the 5 subscales, hence the resultant 49 items are matched with the aim of the study as follows; one item which is (How to know if serious complications are approaching) was modified for the disease characteristics subscale, the overall items included (9 items). Two items for the treatment subscale were added, which are; (the different ways to help me adhere to my treatment and not forget it) and (If I have other side effects, how to deal with them?), the overall items included (15 items). Five items were deleted from investigative tests subscale which is not related to BD, the overall items included (2 items). Three items were added to the physical subscale which are; (How to care for my body pain), (How do I deal with my inability to move my hand joint) and (How do I deal with my inability to move my knee joint), the overall items included (14 items). Two items were adapted to the psychosocial, subscale which are; (What to do if I become concerned about sadness/fear) and (What to do for being concerned with the fear from death) the overall items included (9 items).The patient

informational needs questionnaire (patients' version) was translated into Arabic language and reviewed by panel of expertise.

Scoring system

The tool used the five Likert scale system, whereby responses range from 'not important' to 'extremely important'. Each of the responses is graded from 1 to 5. The total scale score ranges from 1 to 245. Putting into consideration that the higher the score the higher the informational needs.

Validity, reliability and internal consistency of the tools

Content validity of the designed tool was reviewed by a panel of experts in the field of medical surgical nursing and rheumatology and rehabilitation on 2nd of February 2021.The internal consistency and reliability of the adapted informational need questionnaire was statistically examined with Cronbach's alpha test(table 2) and it was excellent for the whole questionnaire (49 items; r=0.97) , r = 0.94 for disease characteristics subscale, r = 0.96 for treatment subscale,r = 0.92 for investigative tests subscale, r = 0.88 for physical items subscale and r = 0.90 for psychosocial items subscale.

Procedure

An official permission was granted from the concerned authoritative departments to conduct the proposed study. The researchers then individually interviewed BD patients who met the inclusion criteria to explain the nature and purpose of the study. After that, the investigators obtained verbal and written consent from the patients who agreed to participate in the study. During the individualized interviews, each patient was given the two data collection tools and they were asked to respond to the designed question items. The average time spent for filling the two tools is ranged from 45to 1 hour. Finally, every patient was thanked by the investigators.

Data Analysis

Collected data were tabulated, computed and analysed with the use of statistical package for the social sceince(SPSS)program,version 22. Descriptive statistics such as frequency ,percentage ,mean and standard deviation were utilized .In-addition inferntial statistics including One Way ANOVA test, independent t- test and Pearson correlation were used to analyze data pertinent to the study variables.Level of significant was adopted at $P \leq 0.05$.

Pilot Study

Was conducted on 10% of the sample; to ensure objectivity, clarity, feasibility, and reliability of the study tool and to determine the time required to fill the different data collection tools. So that, necessary modifications were done. Pilot study results are included in the final study findings.

Results

Table 1
Frequency and percentage distribution of demographic characteristics among the study sample (No=68)

Sociodemographic characteristics	No	%
Age		
- 19 -30	12	18
- 31-42	40	58
- ≥ 43	16	24
	Mean age	38±7.01
Gender		
Male	56	82.40
Female	12	17.60
Residence		
Urban	26	38.20
Rural	42	61.80
Education		
Do not read & do not write	8	11.80
Read & write	22	32.40
Primary	4	5.90
Prep	6	8.80
Secondary	20	29.40
University	8	11.80
Occupation		
Employed	28	41.20
Unemployed	40	58.80
Marital status		
Single	24	35.30
Married	44	64.70
Duration of disease (Years)		
3- 6	20	20.50
7- 10	22	32.40
11- 13	12	26.50
14- 18	2	5.90
18 and more	12	14.70
	Mean±SD= 10 ± 5.65	

As shown in Table 1. The mean age of the studied population was 38±7.01. More than half (58.00%) of patients' age ranged between 31-42. The majority (82.40%) of patients were males and were from rural areas (61.80%). The highest percentage (32.40%)has a disease duration of 7-10 years.

Table2
Rank andMean scores of Informational needs subscales items among Behcet patients (No=68)

Rank	Subscales of Toronto informational needs	Mean ± SD	Range	Cronbach's alpha
1	Treatment (15 items)	4.48±0.78	(2.06-5.63)	.960
2	Disease characteristics (9 items)	4.10±0.78	(2.4-5.4)	.949
3	Investigative tests (2 items)	3.79±1.04	(1-5)	.925
4	Physical (14 items)	3.44±0.72	(2.14-5)	.884
5	Psychosocial (9 items)	2.90±0.83	(1.44-5)	.909
	Total (49 items)	3.75±0.83	(2.19-5.21)	.973

Table 2. Illustrated the five subscales of BD Informational needs questionnaire. Owing to unequal number of items on each subscale, the mean score was used to identify the areas of highest informational needs. The highest mean of informational needs among Behcet patients was related to treatment (4.48±0.78) followed by disease characteristics (4.10±0.78),followed by investigative tests (3.79±1.04), followed by physical (3.44±0.72). The lowest mean scores were related to psychosocial needs (2.90±0.83).

Table 3
Correlation between total mean scores of informational needs and disease characteristics, treatment, investigation, physical and psychosocial needs

		Total mean of information needs	Disease	Treatment	Investigation	Physical	Psychosocial
Total mean of information needs	R	1	.896**	.932**	.842**	.843**	.750**
	P		.000	.000	.000	.000	.000
Disease	R	.896**	1	.858**	.750**	.713**	.507**
	P	.000		.000	.000	.000	.000
Treatment	R	.932**	.858**	1	.735**	.748**	.648**
	P	.000	.000		.000	.000	.000
Investigation	R	.842**	.750**	.735**	1	.566**	.444**
	P	.000	.000	.000		.000	.000
Physical	R	.843**	.713**	.748**	.566**	1	.636**
	P	.000	.000	.000	.000		.000
Psychosocial	R	.750**	.507**	.648**	.444**	.636**	1

P	.000	.000	.000	.000	.000

** Correlation is significant at the 0.01 level (2-tailed).

Table 3. demonstrated a strong positive relationship between total mean scores of informational needs and all the related subcategories (P=.000). Also, all subcategories of informational needs correlated with each other (P=.000).

Table 4
Relation between characteristics of patients (No=68) and mean of informational needs scores

Variables	Categories	Mean	SD	One-way AONVA	
				F	*P value*
Age	19- 30	3.30	0.64	4.195	0.019*
	31- 42	3.92	0.69		
	≥ 43	3.62	0.64		
Gender	Male	3.64	0.67	7.385*	0.008**
	Female	4.22	0.69		
Residence	Rural	3.70	0.77	0.450	0.504
	Urban	3.82	0.59		
Marital status	Single	3.63	0.78	0.992	0.323
	Married	3.80	0.66		
Education	cannot read & write	3.02	.86	3.484*	0.008*
	read and write	3.92	.77		
	Primary	3.70	0.11		
	Prep	3.86	0.26		
	Secondary	3.98	0.63		
	University	3.33	0.24		
Occupation	Employed	3.67	0.65	0.500	0.482
	Unemployed	3.79	0.75		
Duration of disease(years)	3- 6	3.84	0.50	3.84	0.175
	7- 10	3.69	0.96		
	11- 13	4.04	0.39		
	14- 17	2.98	0.00		
	18 and more	3.50	0.65		

Significant at *$P \leq 0.05$; *Means independent t test; **means one way ANOVA test
As seen in table 4,age, gender and level of education were identified as factors that can affect informational needs. Information needs were higher in females in comparison to males, were the highest in the age category 31-42 years and were the least in patients who could not read and write in comparison to other educational levels.

Discussion

Health related informational needs always represent a knowledge deficit that could be corrected by information and/or education (Timmins, 2006). Chronic illnesses have always been coupled with high need of information (Gille,Griese, & Schaeffer, 2021) and the rarity of such illnesses further contributes to lack of information (Schieppati, Henter, Daina, &Aperia, 2008).To highlight, this is the first study to examine informational needs for Bechet's population. It was clear from the findings of the study that, the highest percentage was male with an age group ranged between 31-42yrs.This finding showed similar patients' profile with El-Najjar et al., (2015) studied sample of male predominance with mean age of 31.5±7.1 years (20–44 years). The findings could be interpreted in the light of Oguz, Hizli, &Gonul, (2017), description ofthe disease as most appearing between the second and fourth decades of the life. Furthermore Ucar-Comlekoglu, & Sen, (2014) pointed out that; the disease to be more prevalent in males from certain geographic regions and particular ethnic groups; however, recent reports indicated more even gender distribution across the world. Davatchi, Shahram,Chams-DavatchiShams, Nadji, Akhlaghiet al., (2010) had previously explained that with the only exception being Arab countries where higher male prevalence persists.

Using TINQ that is designed initially for patients with breast cancer is supporting the reliability of the tool and the safe use in BD. (O'Connor, Coates, & O'Neill, 2010;Hsieh, Chou, & Guo, 2018). The questionnaire showed excellent reliability for the whole questionnaire as well as all its subscales with Cronbach's alpha score above 0.8 (table 2); the level Nunnally (1978) suggested being necessary for instruments used in research. The correlation between the total score and all the individual subscales (r=0.75-0.93) was high as well as in between the individual subscales (r=0.44-0.93). The total information needs scores were high and were high all over the individual subscales. Informational needs were highest for treatment followed by disease characteristics subscales whereas psychosocial subscale scored the least.These findings came generally consistent with literature; treatment was amongst the most common informational needs in patients attending primary care clinics (Clarke et al, 2016), in patients with other vasculitis disorders (Mooney et al, 2014) and in patients with breast cancer and lung cancer (Galloway et al., 1997; Graydon et al., 1997; Hseieh, Chou & Guo, 2018). All the individual questions in this subscale generally scored high and costs of medications and ways to prevent side effects had particular importance (table 6). Taheri, Torabizadeh, Aflaki, Mohammadi, &Khademian (2021), identified the financial burden as well as the side effects of medications as barriers to adherence with treatment in patients with BD.Financial constraints and scanty social insurance coverage represent challenges to health care in Egypt(Gerike, 2006) and explain the patients, concerns. Improving patients' knowledge about medications and their side effects were associated with improved quality of life in patients with chronic diseases(Carpenter, Thorpe, Lewis, Devellis, & Hogan, 2009).

In the disease characteristics domain, needs where highest in the effect of disease on body systems and the chronicity of the disease (table 5). The question 'Is my disease chronic' is one of the 1st questions a patient with a newly diagnosed

medical condition asks his attending physician. Apart from being life-threatening, chronic illnesses including BD tend to persist and may result in disabilities particularly in patients with ocular and neurological affection explaining the patients' need. The importance of informational needs regarding the effects on different body systems is explained by the multisystem nature of the disease (Greco, et al., 2018).Fatigue was identified as a major concern and a determinant of worse quality of life in a study by (Robson et al.,2018), a finding compatible with the current findings as the question about care of fatigue scored highest in the physical domain (table 8). In spite of the association of BD with depression, anxiety questions covering psychosocial needs scored lower than other domains a finding that paralled studies in rheumatic diseases and breast cancer (Mooney et al, 2014; Galloway et al, 1997).

A considerable number of studies highlighted the impact of age, gender and education on patients' information needs. A study conducted by Oskay-Ozcelik et al., (2007) reported that young women have more often unsatisfied needs than men and older patients. Abi Nader, Kourie, Ghosn, El Karak, Kattan, Chahine& Nasr (2016), explained that women aged less than 45 years were less satisfied about the quality and quantity of information that they received. Connelly et al. (2019) found the younger women patients reported more needs. These findings are in line with the current study results where women had higher informational needs.Patients aged 31-42 years had the highest informational needs (table 4). Speaking in the same line with Erci&Karabulut (2007) who illustratedthat women who had certified from high school had more informational needs than women who were not graduated, in this study the patients who cannot read or write showed the least informational needs in comparison to patients with higher educational levels.Zirkzee, Ndosi, Vliet Vlieland&Meesters (2014), reported an association between educational needs and female gender. The present results revealed differences regarding the education and the information needs among Behçet patients.

Conclusions and Recommendations

Behcet›s disease patients showed high information needs in the following domains; treatment, disease characteristics, investigative tests, physical and psychosocial. Ongoing longitudinal assessment of BD needs all over the course of the disease journey and future studies are recommended for implementing health education programs and evaluating the impact of meeting informational needs among BD patients. Further replication for large different sample sizes from different geographical areas is recommended for future researches.

Limitations of the Study

This study contains limitations in that because of the discrepancy between the numbers of available Bechet patients in reality and the graphic statistics in the place, the available sample size was less than the number calculated statistically.It was also a single-institution study and may, therefore, not represent the reality of patients of other institutions. So, generalization is difficult.

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Supplementary Tables

Table 1
Rank &Mean±SD of the study sample (No = 68) on Likert scale regarding scores of disease characteristics items

Rank	Disease characteristics (9 items)	Mean±SD
1	How Behcet's disease affects my body systems?	3.85±0.95
2	Is Behcet's disease a chronic disease?	3.79±0.91
3	How the illness may affect my physical ability in the future?	3.74±1.07
4	How to know if serious complications are approaching?	3.74±0.96
5	What is the expected prognosis of Behcet's disease?	3.61±1.09
6	Causes of increased disease activity & symptoms.	3.59±0.95
7	If it is known what causes Behcet's disease.	3.38±1.09
8	If Behcet's disease is infectious disease.	3.21±1.09
9	If my illness is hereditary.	3.17±1.16

Table1. illustrates the highest three top averages among the studied sample regarding disease characteristics awarded to item (How Behcet's disease affects

my body systems) with mean ±SD (3.85±0.95), followed by item (Is Behcet's disease a chronic disease) with mean ±SD (3.79±0.91), followed by item (How the illness may affect my physical ability in the future) with mean ±SD (3.74±1.07).

Table 2
Rank and Means±SD of the study sample (No = 68) on Likert scale regarding scores of treatment items

Rank	Treatment (15 items)	Mean±SD
1	Cost of medications.	4.00±1.09
2	If there are ways to prevent side effects.	4.02±0.89
3	What do I do, if I take an overdose?	3.88±1.08
4	What to do if a dose is missed?	3.85±1.14
4	Action and possible side effects of medications.	3.85±1.14
5	Frequency and duration of treatment.	3.82±1.13
6	Names, doses and administration of prescribed medications	3.79±1.21
7	Food interfering with drug actions.	3.79±1.08
8	If I have other side effects, how to deal with them.	3.73±1.01
9	What side effects I should report to the doctor/nurse?	3.70±0.99
9	The different ways to help to adhere to treatment and not to forget.	3.70±0.99
10	If I am prone to infection because of my treatment.	3.67±0.90
11	What to do if allergic symptoms to medications occur?	3.64±1.03
12	Indicators of medication effectiveness.	3.64±0.84
13	Indicators for the need for the medication to be changed.	3.61±0.97

Table 2. Reveals the highest three top averages among the studied sample regarding treatment awarded to items (Cost of medications) with mean &SD (4.00±1.09), followed by item (If there are ways to prevent side effects) with mean ±SD (4.02±0.89), followed by item (What do I do, if I take an overdose?) with mean±SD(3.88±1.08).

Table 3
Rank and Means±SD of the study sample (No = 68) on Likert scale regarding scores of investigative tests items

Rank	Investigative tests (2 items)	Mean±SD
1	The importance of conducting certain laboratory or radiological examination.	3.9±1.1
2	The meaning of the results of laboratory tests/x rays.	3.7±1.1

Table3. Illustrates the highest average among the studied sample regarding investigative tests awarded to item (The importance of conducting certain laboratory or radiological examination) followed by item (The meaning of the results of laboratory tests/X- rays), with mean ±SD (3.9±1.1and3.7±1.1 respectively).

Table 4
Rank and Means±SD of the study sample (No = 68) on Likert scale regarding scores of physical items

Rank	Physical (14 items)	Mean±SD
1	How to care for my fatigue and tiredness?	3.82±0.89
2	How to care for the recurrent allergy and inflammation in my skin?	3.73±1.12
3	How to care for my oral ulcers?	3.61±1.12
4	How long my ulcers will take to heal?	3.61±0.94
5	How to care for my constant headache?	3.55±0.88
6	How to dealwith sleep disorders?	3.44±1.27
7	How to care for my decreased vision?	3.41±1.46
8	How to care for my genital ulcers?	3.41±1.22
9	How to care for the recurrent inflammation in my eyes?	3.38±1.33
10	How do I deal with my inability to move my knee joint?	3.26±1.17
10	I need help taking care of myself.	3.26±1.17
11	If I can continue my usual hobbies and sports.	3.23±1.14
12	How do I deal with my inability to move my hand joint?	3.23±1.12
13	How do I deal with feeling unsteady while walking?	3.02±1.23

Table 4. illustrates the highest three top averages among the studied sample regarding physical items awarded to item (How to care for my fatigue and tiredness) with mean ±SD (3.82±0.89), followed by item (How to care for the recurrent allergy and inflammation in my skin) with mean ±SD (3.73±1.12), followed by item (How to care for my oral ulcers) with mean ±SD (3.61±1.12).

Table 5
Rank and Means±SD of the study sample (No = 68) on Likert scale regarding scores of psychosocial items

Rank	Psychosocial items (9 items)	Mean±SD
1	If there is a certain way to talk with my family or friends for my illness.	3.97±0.99
2	What to do for a continuous feeling of anxiety from the disease and its treatment?	3.14±1.12
3	Where my family can go if they need help dealing with my illness?	3.11±0.90
4	What to do if I feel uncomfortable in social situations?	3.02±0.92
5	If there will be changes in the usual things I can do with and for my family.	3.00±0.91
6	What to do for the feeling that I cannot control what happens to me?	2.85±1.31
7	Where I can get help to deal with my feelings toward my illness?	2.82±1.28
8	What to do for the feelings of upset and depression?	2.76±1.19
9	What to do for being concerned with the fear from death?	2.41±1.09

Table 5. illustrates the highest three top averages among the studied sample regarding psychosocial items awarded to items (If there is a certain way to talk with my family or friends for my illness) with mean ±SD (3.97±0.99), followed by item (What to do for a continuous feeling of anxiety from the disease and its treatment?) with mean± SD (3.14±1.12), followed by item (Where my family can go if they need help dealing with my illness?) with mean ±SD (3.11±0.90).