

Percentage and Features of Anxiety, Depression and Stress in Adolescents and Adults with Sickle Cell Disease in Bahrain

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ABSTRACT

Objectives: To estimate the percentage of depression, anxiety, and stress among patients with Sickle Cell Disease (SCD); and to study the demographic variables of patients with high depression, anxiety, and stress scores.

Study Design: This study is a cross-sectional study

Setting: The Study took place at Salmaniya Medical Center (SMC) and Hereditary Blood Disorders Center (HBDC) for a period of 2 months from June to August 2019

Method: Data from 52 adolescents and 166 adults was obtained by questionnaires through convenient sampling from patients who were admitted to SMC and HBDC and were interpreted using the DASS-21 scoring system.

Results: The prevalence of anxiety was 74.9%, depression 60.7%, and stress 54.6% in the study sample. In the study population, female patients showed extreme-severe anxiety, whereas males showed moderate anxiety. Severe-extreme grades of depression were also more prevalent among the female patients. The stress-gender association was found to have no significance (P-value 0.475). The study also showed no statistical association between anxiety and age (P-value 0.095). Most of the extreme depression grades were seen among patients in the elder age group, and the majority of normal grades were within the age group of 20-35 years. The results also showed that stress levels increased with age.

Conclusion: Given the high prevalence of depression, anxiety, and stress found among the study population; screening sickle cell disease patients for depression and anxiety is recommended for all age groups, especially for high-risk patients. Furthermore, we advocate for incorporating appropriate care and support for patients who are affected with mental disturbances as part of their treatment plan.

INTRODUCTION

Sickle cell disease (SCD) is an autosomal recessive inherited hematologic disorder that occurs due to a defect in the β -globin chains of the hemoglobin molecules. Due to this, red blood cells appear mutated, stiff and elongated, which is commonly known as sickled cells. Affected cells are unable to flow smoothly through small blood vessels, resulting in obstruction and eventual ischemia (Powars, 2017). Patients exhibiting SCD present with severe anemia, acute bursts of pain, fatigue, and are more prone to further complications. The combination of pain crises, fatigue, and frequent hospitalizations may cause SCD patients to exhibit signs of despondency and dejection, commonly known as depression (Hajeri, 2017).

Clinical depression, a psychiatric disorder that falls into the more severe form of depression, presents as a feeling of constant sadness, emptiness, loss of interest, and energy (Parekh, 2017). According to "Davidson's Principles and Practice of Medicine", major depressive disorder has a prevalence of 5% in the general population and approximately 10-20% in chronically ill medical outpatients. Studies have also shown that if a major depressive disorder arises due a medical condition, it could magnify the disability, reduce the patient's adherence to treatment and rehabilitation, as well as noticeably shorten life expectancy (Shapre &

Lawrie, 2014). Depressive symptoms may also present more among adolescents in comparison to children and adults, suggesting that among the general population, adolescents are at the highest risk for depression (Wight, SepÚlveda, & Aneshensel, 2004)^{1,2}.

Often closely associated with depression is anxiety disorder, and in many cases, the two disorders may be comorbid together. Anxiety is defined as a subjective state of fear, apprehension, or tension. Adverse life events such as unemployment, trauma, grief, or in the case of SCD, illness and sometimes disability play a role in being susceptible to having anxiety³.

By estimating the percentage of depression, anxiety, and stress among patients with SCD; and studying the demographic variables of patients with high depression, anxiety, and stress scores, this research will aim to improve the quality of life in sickle cell disease patients^{4,5}.

LITERATURE REVIEW

Sickle cell disease is an inherited hematological disorder due to a mutation of the beta-globin gene of hemoglobin, causing a substitution of the glutamic amino acid for valine in the beta chain. This results in the formation of an abnormal hemoglobin, called hemoglobin S (Hb S),

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instead of normal hemoglobin, hemoglobin A (Hb A)⁶. The pattern of inheritance was discovered to be autosomal recessive in an experiment done by J. V. Neel; Neel discovered that heterozygous individuals expressed a sickle cell trait, whereas individuals with the homozygous gene expressed SCD⁷.

SCD is a health burden in the Kingdom of Bahrain with a high prevalence rate. This group of inherited red blood cell disorders lead to chronic hemolytic anemia, and complex chronic diseases manifested by sudden, severe, and life-threatening complications. Acute complications may occur in any organ system and may present from early childhood to even last throughout the course of the patients life⁸. Vaso-occlusive crisis is one of the most common and painful manifestations of SCD. Within the blood vessels the hemoglobin structure changes resulting in the emergence of helical bundles, these bundles disrupt the membrane function resulting in defective permeability to ions, alteration to the shape of the red blood cells and its movement within the vessel. The resulting effect of the phenomena of vaso-occlusion causes many complications and these range from tissue ischemia to painful crises and osteo-articular crises as well. Chronic end organ damage effects the kidneys, heart, lungs and can also result in functional asplenia; such patients get frequently hospitalized⁶.

Previous studies have shown a link between the incidence of depression and anxiety in patients suffering from chronic diseases, as their quality of life depreciates. Depression is a common and major medical disease that adversely affects a person's feelings, thoughts and behavior. Depression causes a feeling of despair and loss of interest in activities that an individual used to enjoy before⁹. Depression and catastrophizing are associated with the severity of pain, physical disability, and poor treatment outcomes in diseases that are characterized by chronic pain or episodic pain¹⁰. In addition, during a study conducted at Howard university hospital female patients with SCD that had poor pain control were mostly depressed¹¹⁻¹⁴.

Anxiety is one's body natural response to an external stress. It is an emotion that's characterized by feeling of tension, worried thoughts, and physical changes like increased blood pressure. Recurrence in intrusive thoughts or concerns are some signs that patients with anxiety disorder experience. The cognitive behavioral model of anxiety suggests that anxiety is not caused by stressors and is rather by the individual's perception to that stressor¹². A study supports the fact that negative thinking and depression is a precipitative factor in increasing pain in SCD patients as well as the interference of such attacks of pain with daily activity as they are generally associated with anxiety¹³.

According to the World Health Organization (WHO), an adolescent is any person in the age group of 10–19 years¹⁵⁻¹⁷. Adolescence is typically a period of rapid physical, cognitive and psychosocial change that takes place in the context of shifting relationships and roles within the family¹⁸⁻²⁰. This has an important significance especially on the SCD patients since male and female adolescents reported lower scores in emotional wellbeing and social functioning domains compared to controls from the same age group according to a study conducted in Saudi Arabia²¹.

In a study conducted in Central Middlesex Hospital NHS Trust, children with SCD reported 240 days with a pain event out of 700 in comparison to 182 days out of 700 in the control. The longer episodes of pain combined with its high intensity makes SCD patients report severe attacks of pain in comparison to the controls. This leads to high rates of disruption with some not able to take part in their favorite activities, doing sport, or socializing. In terms of coping with pain in adolescence from both groups, the most common response to coping

with pain was talking to a parent, and there was no difference in the frequency of discussing pain events with either siblings, friends, or teachers¹⁹.

In a study conducted in Salmaniya Medical Complex and Hereditary Blood Disease Center in Bahrain about 192 patients with SCD (149 males and 47 females) were questioned and it showed that about 58.5% had mild to severe depression, whereas 39% were normal with no signs of depression but 2.5% were extremely depressed. However, it showed that the prevalence of mild to extreme depression is higher amongst women, about 74%, while in males it was 57%. However, extreme depression was noted among 3% of the males but not in the female patients. Males also had strong suicidal thoughts, and some admitted that if they had the chance, they would end their own lives. The study also suggested that age, marital status, occupation, and education level had no significant effect on depression levels¹⁶.

While in Bahrain, the ministry of health has incorporated a new program in the primary health care setting aimed at improving mental health in the Bahraini population. Currently, seven clinics are available for referral by physicians and are only for individuals aged 18 and older. Children and adolescents are referred to child, adolescent and Al-Moayed care units in the psychiatric hospital¹⁸.

Pharmacological treatment of depression secondary to SCD is nearly neglected. As well as depression among SCD patients is usually undiagnosed or they are misdiagnosed. This highlights the need for and importance of diagnosing depression by primary healthcare or by psychiatric referral in order to reduce the possibility of chronic and severe depression among the patients¹⁵.

MATERIALS AND METHODS

Type of Study: The Cross-sectional study was conducted in SMC by Arabian Gulf University students by collecting data and interpreting it, over the time-period of June to August 2019.

Sampling Technique: After contacting the Genetics Department at SMC, who are concerned with studies conducted on SCD patients, we were able to conclude that SMC, as well as Hereditary Blood Disorder Center (HBDC) are the suitable locations for conducting the research. To maintain the privacy of the patients, we decided to include patients with SCD that are admitted in adult and pediatric wards. Convenient Sampling Technique was used to collect the data.

Study Population: Individuals with SCD aged 12 and above attending SMC during the research period (June-August 2019). Patients aged 12-19 are considered as adolescents and those aged 20 and above as adults.

Inclusion Criteria: Bahraini SCD patients of both genders at the age of 12 and above attending SMC during the research period of June till August 2019.

Exclusion Criteria: Bahraini SCD patients of both genders at the age of 12 and above attending SMC during the research period of June till August 2019, who are sedated and not aware of their surroundings, and patients who are in severe attacks of pain.

Sample Size: Information on attendees to SCD clinics in SMC was obtained from SMC information center and thus sample size was estimated. Adolescent sample size was 52 patients, it was estimated as 20% of a population of 260 patients per year and adults sample size was 166 patients, which was estimated as 15% from a population of 1107 patients per year. A total of 218 patients of both genders attending

SMC during the research period from June to August 2019 should be obtained.

Setting:

1. Salmaniya Medical Complex (SMC)
2. Hereditary Blood Disorder Center (HBDC)

Statistical Analysis: The data was analyzed using the SPSS statistics version 23. The scores from the questionnaire were added up according to the DASS-21 scoring system, which categorized the severity of the disease from mild to extremely severe. The data was interpreted in the form of tables. To analyze the data, frequencies and percentages were deduced for both quantitative and qualitative demographical information as well as the scores of the parameters measured. Chi-square test was performed and a P-value less than 0.05 was considered significant.

Ethical Consideration: The research proposal was approval to the Arabian Gulf University College of Medicine and Medical Sciences Research and Ethical Committee and the Ministry of Health in Bahrain.

RESULTS

A total of 227 patients answered the questionnaire of which 52 patients were adolescents and 175 were adults. All of the patients were included in the study. It is important to mention that male patients aged 18 and above were obtained from the Hereditary Blood Disorder Centre while all female patients and adolescents were obtained from inpatient wards in SMC.

From the data collected, there was a wide distribution in the age as well as the gender of the patients that took part in the study. The majority of the patients included in the study were males with a minority being females. Based on the different age groups, most of the patients fell under the age group of 20 to 35. The least number of patients were aged 51 and above. (Table 1).

Table 1: Demographic Data of patients in study population

		No.	%	Total
Gender	Male	159	70.0	227
	Female	68	30.0	
Age/years	12 to 19	52	22.9	227
	20 to 35	115	50.7	
	36 to 50	49	21.6	
	51 and above	11	4.8	

Furthermore, when comparing anxiety percentages within both genders, it is noted that a small proportion of male and female patients are normal. However, the greatest proportion of males fell under the category of ‘moderate anxiety’ while the greatest proportion of females fell under the category of ‘extremely severe anxiety’. A significant Chi-square test (P-value = 0.006) was obtained indicating that there is an association between gender and anxiety. Moreover, when comparing the values amongst different age groups, it is strongly noted that a larger percentage of patients between the ages of ‘51 and above’ complain of ‘extremely severe anxiety’ while the younger age groups fell under milder levels of anxiety. However, the results of the Chi-square test (P-value= 0.095) showed that there isn’t a significant association between the level of anxiety with the different age groups. (Table 2).

When interpreting the depression scores majority of males and females did not experience depression. However, the remainder did experience varying levels of depression with females mostly falling under severe

and extremely severe categories of depression. When compared with the males within the study population, low percentages of males were in the severe and extremely severe categories. A significant Chi-square test (P-value= 0.036) indicates the presence of a relation between gender and level of depression. In addition, when comparing the depression scores with different age groups, a larger percentage of those in the ‘51 and above’ experienced extreme depression. On the other hand, most of the younger age groups were normal. This shows a difference between the age groups with the oldest group exhibiting high depression levels in comparison to younger age groups that mostly didn’t experience depression. A significant Chi-square test (P-value =0.022) was obtained indicating an association between age and level of depression. (Table 3).

Comparing stress levels amongst males and females in the research sample, almost half of the male and female patients did not experience stress. A Chi-square test (P-value= 0.475) showed no association between stress and gender. In addition, when comparing the stress scores with different age groups, within patients aged ‘51 and above’ they mostly fell under severe and extremely severe categories of stress. On the other hand, most of the younger age groups were normal. Therefore, a significant Chi-square test (P-value= 0.006) was obtained which indicated that there is an association between stress and age. (Table 3).

DISCUSSION

Based on the outcomes of this study, the prevalence of anxiety, depression, and stress varied amongst the sample of SCD patients.

The prevalence of anxiety amongst the sample is 170 (74.9%). As seen in the tables above, more females fell under the category of extreme-severe anxiety, while the average male population in the sample fell under moderate anxiety. There was no general association between anxiety and age (p-value = 0.095); however, it is noteworthy to mention that the majority of the elderly population in this study fell under the severe-extreme anxiety category.

The prevalence of depression amongst the sample was 115 (50.7%). Depression was more common in the mild-moderate grades. It was seen that depression was more prevalent among the female population, especially in the severe-extreme grades. The majority of the patients who did not suffer from depression were in the working age group (20-35); whereas 5 patients (45.5%) of those in the ‘51 and above’ experienced extreme depression. Thus, a significant association between age and gender with the level of depression was made.

The prevalence of stress in the study was 124 (54.6%). Stress levels among the population studied proved almost equal between males and females, with no association (p-value = 0.475). According to the results, the prevalence of stress appears to increase with age, with the younger range having the least prevalence and the older range of the sample having the highest prevalence of severe-extreme stress.

When comparing this study to a previous one done in 2017¹⁶ regarding the prevalence of depression amongst SCD patients in Bahrain, it appears that depression was less prevalent within this current sample. In the previous study, the prevalence of depression among the SCD sample was 117 (61%) whereas in this study it was 115 (50.7%). Depression was more prevalent among the female patients in comparison to male patients in this study; despite the small population of female patients in this sample. Similar to the previous study, the higher grades of depression (severe-extreme) were more common in females compared to males, who were mostly in the mild-moderate depression grade. Also, extreme depression was found to be higher amongst the older population (51 and above).

Table 2: Categories and Scores of Anxiety among patients in study population

		Anxiety										Chi-Square Test	
		Normal		Mild		Moderate		Severe		Extremely severe			Total
		No.	%	No.	%	No.	%	No.	%	No.	%		
Gender	male	44	27.7	16	10.1	51	32.1	17	10.7	31	19.5	159	0.006
	female	13	19.1	2	2.9	15	22.1	12	17.6	26	38.2	68	
Age/ years	12 to 19	17	32.7	7	13.5	16	30.8	6	11.5	6	11.5	52	0.095
	20 to 35	29	25.2	9	7.8	30	26.1	15	13.0	32	27.8	115	
	36 to 50	10	20.4	1	2.0	19	38.8	6	12.2	13	26.5	49	
	51 and above	1	9.1	1	9.1	1	9.1	2	18.2	6	54.5	11	
Total		57	25.1	18	7.9	66	29.1	29	12.8	57	25.1	227	

Table 3: Categories and Scores of Depression among patients in study population

		Depression										Chi-Square Test	
		Normal		Mild		Moderate		Severe		Extremely severe			Total
		No.	%	No.	%	No.	%	No.	%	No.	%		
Gender	male	81	50.9	25	15.7	34	21.4	6	3.8	13	8.2	159	0.036
	female	31	45.6	6	8.8	14	20.6	10	14.7	7	10.3	68	
Age/ years	12 to 19	26	50.0	8	15.4	12	23.1	4	7.7	2	3.8	52	0.022
	20 to 35	60	52.2	16	13.9	22	19.1	7	6.1	10	8.7	115	
	36 to 50	24	49.0	5	10.2	13	26.5	4	8.2	3	6.1	49	
	51 and above	2	18.2	2	18.2	1	9.1	1	9.1	5	45.5	11	
Total		112	49.3	31	13.7	48	21.1	16	7.0	20	8.8	227	

Table 4: Categories and Scores of Stress among patients in study population

		Stress										Chi-Square Test	
		Normal		Mild		Moderate		Severe		Extremely severe			Total
		No.	%	No.	%	No.	%	No.	%	No.	%		
Gender	male	72	45.3	26	16.4	29	18.2	20	12.6	12	7.5	159	0.475
	female	31	45.6	8	11.8	9	13.2	14	20.6	6	8.8	68	
Age/ years	12 to 19	26	50.0	12	23.1	8	15.4	4	7.7	2	3.8	52	0.006
	20 to 35	54	47.0	14	12.2	18	15.7	19	16.5	10	8.7	115	
	36 to 50	21	42.9	7	14.3	12	24.5	7	14.3	2	4.1	49	
	51 and above	2	18.2	1	9.1	0	0.0	4	36.4	4	36.4	11	
Total		103	45.4	34	15.0	38	16.7	34	15.0	18	7.9	227	

Furthermore, another study that was conducted in Saudi Arabia in 2011²¹ concerning the health-related quality of life of adolescents with sickle cell disease it appears that female adolescents had a significant deterioration in emotional wellbeing which correlated with our findings showing that females showed more extreme degrees of anxiety and depression. On the other hand, in the 2011 study male adolescents with SCD showed a decrease in the domains of social functioning, emotion and vitality while in our study male patients had milder scores in anxiety and depression.

A study in Ghana in 2017²² dedicated to anxiety, depression and quality of life showed that anxiety and depression was significantly higher in the 40-49 years old age group. However, in our study the 36-50 years old age group had mostly normal or milder depression and anxiety scores.

The main strength of this study was that it addressed the prevalence of depression amongst both SCD adults and adolescents in Bahrain, whereas previous studies only addressed adults²³. The data was not limited to only depression, but also included stress and anxiety, which is another first.

Access to the hereditary blood disease center situated in SMC provided a large sample size. The simplicity of the depression, anxiety, and stress (DASS) scale made it possible for participants of differing educational levels to answer with clarity and ease^{24,25}.

The contributions of this study must be considered with certain limitations. It is important to note that the study was not representative of the general population of SCD patients in Bahrain; rather, it was limited to those who were admitted to SMC during the specific period in which the data was collected. Low representation of individuals between the ages of 12-19 and 51 years and above in the sample size was due to their lack of admittance in the hospital at the period of data collection. In addition, observations were made that the adolescent participants particularly may not have answered the questionnaire with sincerity due to fear and nervousness caused by the consistent presence of their legal guardian. Lastly, due to the extended hospitalization of patients prior to the data collection, sample results of anxiety, depression, and stress may have been affected due to the hospital environment and not purely due to the effect of the chronic disease on the patient.

CONCLUSION

Among our study population many patients experienced varying degrees of Anxiety, Depression and Stress. We were thus able to demonstrate that a high percentage of patients are affected by psychological disturbances. Ideally, psychological care should be provided to all patients, however special care is recommended to be directed towards the older patients (51 and above) and females, as they are at high risk to develop depression, anxiety and stress. Therefore, this illustrates the major mental burden and stigma the disease upholds on women and elderly.

RECOMMENDATIONS

It is highly recommended that all SCD patients, whether outpatient or inpatient, be screened for psychological disturbances. The integration of mental health professionals in primary care settings would ideally ensure that high risk patients are being followed up. All adolescent and adult patients should be educated and informed about their health situation and treatment plan and should understand the importance of staying up to date. Furthermore, establishing support systems such as 'support groups' where patients share their experiences and coping mechanisms might provide emotional support, and improve the quality of life of such patients. Further studies should be conducted to determine the association of different parameters such as educational level, economic status, occupation, and familial circumstances on the quality of life of SCD patients.

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