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PREVALENCE AND ASSOCIATED RISK FACTORS OF DEPRESSION AND GENERALIZED ANXIETY DISORDER IN CAREGIVERS OF CHILDREN AFFECTED WITH SICKLE CELL DISEASE IN DAMMAM, SAUDI ARABIA, 2017

Medicine

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ABSTRACT

Background: Sickle Cell Disease is one of the most common hereditary blood disorders in Eastern Province of Saudi Arabia. The caregiver of the affected child may face psychological maladjustment because of the practical or emotional coping with this disease.

Method: A cross-sectional study was performed with complete coverage of all caregivers of children affected with Sickle Cell Disease who presented to the Pediatric Hematology Outpatient Clinics in Maternity and Children Hospital in Dammam, Saudi Arabia.

Results: The prevalence of depression among caregivers of children affected with Sickle Cell Disease comprises 46.5% (29.9% mild, 8.9% moderate, 4.5% moderately severe and 3.2% severe). Generalized Anxiety Disorder comprises 31.8% (19.1% mild, 7% moderate and 5.7% severe). Co-existence of both disorders was 29.5%.

Depression is observed to be higher in non-married individuals and among caregivers who have more than one child affected with Sickle Cell Disease.

Generalized Anxiety Disorder is noted to be increased in caregivers who have Sickle Cell Disease. Also, there is a significant association between Generalized Anxiety Disorder and the number of ICU admissions due to a cerebrovascular event or acute chest syndrome for children affected with Sickle Cell Disease.

Conclusion: The prevalence of depression and Generalized Anxiety Disorder in caregivers of children affected with Sickle Cell Disease is higher than the prevalence of depression and GAD in general population and similar to rates found in chronically ill patients.

Recommendation: Physician and healthcare workers should be more aware of the psychological distress in caregivers of children affected with Sickle Cell Disease to provide the needed screening and follow up.

KEYWORDS

Sickle Cell Disease (scd), Depression, Generalized Anxiety Disorder (gad).

Background

Sickle Cell Disease is a monogenic disease in millions of people worldwide. It is an autosomal recessive disorder that affects the hemoglobin molecule by a substitution of the glutamic acid residue at position β6 with a valine residue. SCD complications can be acute painful episodes if the red blood cells obstruct blood flow through limbs or organs. Chronic complications result from repeated vaso-occlusive crisis causing tissue ischemia and organ damage. The severity of symptoms varies from the recurrent painful crisis and ER visits to severe complications that require ICU admission [1].

SCD is common among people whose ancestors come from sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries. SCD is an increasing global health problem. Estimates suggest that every year approximately 300,000 infants are born with SCD and this number could rise to 400,000 by 2050. In Saudi Arabia, the reported prevalence of cases affected with SCD is 2.6%, and between 2% to 27% for sickle-cell trait. The prevalence of SCD in Saudi Arabia varies in different parts of the country, with the highest prevalence is in the Eastern Province [2].

Caregivers of children affected with Sickle Cell Disease have high rates of psychosocial maladjustment similar to the rates found in individuals diagnosed with a medical condition [3].

Mental disorder is a syndrome characterized by a clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning [4].

The most prevalent mental disorders in Saudi Arabia were anxiety in its various forms and depression. With regards to the sub-classifications of anxiety, the most common variety was the Generalized Anxiety Disorder. In the Eastern Province of Saudi Arabia, the prevalence of depression is 23.3% and the prevalence of GAD is 19.5% [5].

According to DSM V, Major Depressive Disorder is characterized by depressed mood or a loss of interest or pleasure in daily activities for more than two weeks. Generalized Anxiety Disorder is a condition marked by excessive worry and feelings of fear, dread, and uneasiness for at least six months.

Patients who meet the criteria for both a depressive episode and an anxiety disorder should be diagnosed with Major Depressive Disorder (MDD) with comorbid anxiety disorder. Of the patients with MDD and comorbid disorders, GAD was the most prevalent associated disorder. They are more disabling, more resistant to treatment, have a higher risk of suicide than either condition alone. Early recognition of depression and anxiety will lead to decrease disease burden, disability, and reduce treatment cost [6].

The psychological burden of SCD on families has been investigated in few studies. In the Southeastern United States, a study was conducted in Georgia. This article studied the physiological adjustment in parents of children with SCD. It suggested that the frequency of VOC's is an integral factor in both the well-being of children with SCD and their parents [7].

In Amsterdam, a case-control study compared 54 caregivers of children with SCD and 28 caregivers of a control group which shares the same socio-economic status. This study reported that the quality of life of caregivers of children affected with SCD has a reduced quality of life compared to the caregivers of healthy children with the same socio-economic status. This study recommends that doctors and other healthcare workers should be aware of the emotional and functional needs of these caregivers [8].

In Nigeria, a recent study has shown that the caregivers and families of children with SCD go through a significant psychosocial burden. Hence, clinicians and policymakers should provide the necessary psychological care and support to these individuals [9].

A study conducted in Brazzaville, Africa, shows an association between depression and number of VOC, number of blood transfusions and number of hospital admissions. Moreover, this study found that GAD was influenced by the number of VOC and number of blood transfusions [10].

While in Basra, southern Iraq, a study was published in 2015 to measure the impact of SCD on caregivers. This study concluded that SCD might be a source of psychosocial distress to the child's caregivers [11].

In Jeddah, Saudi Arabia, the psychological impact of caregivers whose children have SCD was studied using adult quality of life questionnaire. This study concluded that psychotherapist advice is needed for caregivers [12].

Method

This study included all caregivers of children affected with SCD who are treated at the Pediatric Hematology Outpatient Clinic of Maternity and Children Hospital in Dammam, Saudi Arabia, from October 1st, 2016 to September 20th, 2017. A total of 206 caregivers were approached. One hundred fifty-seven participants (76.2%) agreed to be enrolled in the study. The data was collected by using a telephone interview to fill out the questionnaire which contains three parts. The first part is composed of caregiver's background information. While the second and third parts are composed of validated questionnaires to determine the prevalence of depression and GAD among caregivers of children affected with SCD.

1) Background information was divided into the following subgroups:

- Socio-demographic characteristics of the studied population which are: age, gender, level of education, occupation, marital status, family support and family income.
- Participants health status which consists of questions about whether the caregiver is affected with SCD, mental illness or chronic diseases.
- Clinical severity of children affected with SCD which include: number of sick children that the caregiver is taking care of, number of ER visits due to VOC crisis per month, number of blood transfusion in the past year, number of hospital admission in the past year, number of ICU admission due to cerebrovascular event or acute chest syndrome in the past year and death of a child due to SCD.

2) Depression screening tool

The PHQ-2 and PHQ-9 are components of the longer Patient Health Questionnaire for assessing depression. PHQ-2 is composed of two questions to quickly screen depression. If this test is positive, then PHQ- 9 is used.

PHQ-9 has nine-items to assess the patient's health status during the last two weeks. It is a reliable and valid measure of depression severity. PHQ-9 scores of 5, 10, 15, and 20 represented mild, moderate, moderately severe, and severe depression, respectively. Sensitivity and specificity of the PHQ-2 were 86% and 78%, respectively, with a score of 2 or higher and 61% and 92% with a score of 3 or higher. For the PHQ-9, sensitivity and specificity were 74% and 91%, respectively, with a score of 10 or higher.

3) Generalized Anxiety Disorder screening tool

GAD-7 has seven-items to assess the patient's health status during the last two weeks. It is reliable and valid in general population. The sensitivity of GAD -7 was 89% and the specificity was 82%.

The maximum score of GAD-7 is 21. Scores of 5, 10 and 15 represent cut-off points for mild, moderate and severe anxiety, respectively. When screening for GAD, a recommended cut-off point for referral for further evaluation is 10 or greater.

Arabic translation was adapted from the English version of PHQ-2, PHQ-9, and GAD-7.

Result

Socio-demographic characteristics of the studied population

Age groups of the participants vary with the majority clustered between 30 to 49 years representing 75.8% of the study sample. Most caregivers are females (79%). The highest proportion of caregivers were married (93.6%). In term of education, 57.4% of the caregivers have a secondary school degree or a bachelor degree. Fifty-seven caregivers (36.3%) are employed, and approximately two-thirds of caregivers did not have support from other family members or domestic help. Family income is more than 5000 SR in 72.6%.

Table 1. Socio-demographic characteristics of the studied population (n= 157)

Characteristics	n	%
Caregiver gender	124	79%
Female	33	21%
Male		
Caregiver age	27	17.2%
From 18 to 29 Years	119	75.8%
From 30 to 49 Years	11	7%
50 Years and older		
Caregiver marital status	147	93.6%
Married	4	2.5%
Widow	4	2.5%
Divorced	2	1.3%
Single		
Caregiver education	8	5.1%
Illiterate	3	1.9%
Can read and write	12	7.6%
Elementary	23	14.6%
Intermediate	48	30.6%
Secondary	17	10.8%
Diploma	42	26.8%
Bachelor	4	2.5%
Higher education		
Family income	43	27.4%
Less than 5000 SR	114	72.6%
More than 5000 SR		
Family support	54	34.4%
Yes	103	65.6%
No		

Participant's health status

Around 18% of Caregivers are affected with SCD. Mental illness such as Obsessive Compulsive Disorder is seen in 1.3% of caregivers. Finally, caregivers suffering from chronic diseases are 9.6% distributed among diabetes, chronic pain, hypothyroidism, and stroke accounting for 4.5%, 1.9%, 1.3%, and 0.6 %, respectively.

Clinical severity of children affected with Sickle Cell Disease

As shown in table 2, nearly half of the caregivers (47.7%) have more than one child affected with SCD. Furthermore, sixty-five percent of caregivers visited ER due to VOC of their children in the past month. In the past year, caregivers who reported the need for blood transfusion, hospital admission, and ICU admission for their affected children count for 54.8%, 80.9%, and 18.5% respectively. Caregivers also reported that up to 3.8% of the affected children have passed away as a result of SCD complications.

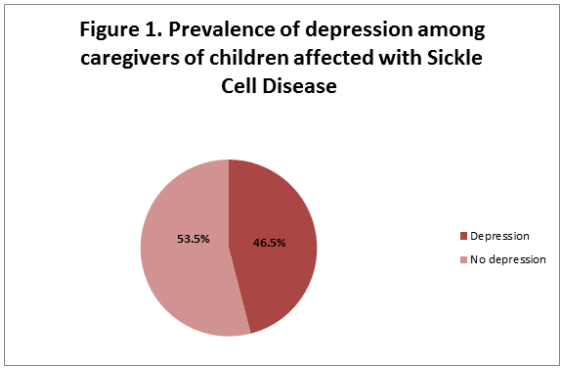
Table 2. Clinical severity of children affected with Sickle Cell Disease (n=157)

Characteristics	n	%
Number of SCD affected children in the family	83	52.9%
One	74	47.1%
More than one		
Number of ER visits due to VOC per month	55	35%
None	66	42%
Once	14	9%
Twice	22	14%
More than twice		
Number of blood transfusion in the last year	71	45.2%
None	36	22.9%
Once	20	12.7%
Twice	30	19.1%
More than twice		
Number of hospital admission in the last year	30	19.1%
None	32	20.4%
Once	25	15.9%
Twice	70	44.6%
More than twice		

Number of ICU admission due to a cerebrovascular event or acute chest syndrome in the last year	128	81.5%
None	20	12.7%
Once	4	2.5%
Twice	5	3.2%
More than twice		
Death of a child	6	3.8%
Yes	151	96.2%
No		

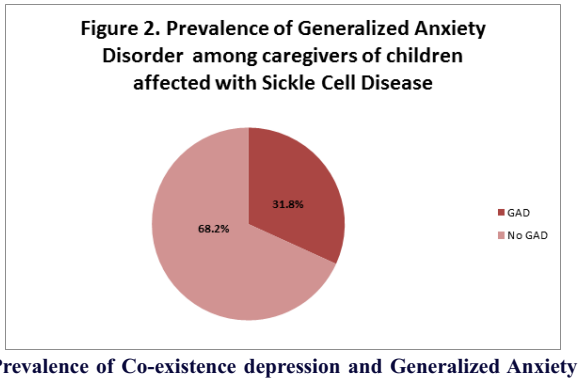
Prevalence of depression among caregivers of children affected with Sickle Cell Disease

The Prevalence is estimated to be 46.5% as shown in figure 1. Mild depression represents 29.9% of the studied population, moderate depression is 8.9%, moderately severe is 4.5%, and severe depression is 3.2%.



Prevalence of Generalized Anxiety Disorder among caregivers of children affected with Sickle Cell Disease

Figure 2 shows the prevalence of GAD among caregivers of children affected with SCD which scores of 31.8%. Mild GAD represents (19.1%) while moderate GAD is (7%) and severe GAD is (5.7%).



Prevalence of Co-existence depression and Generalized Anxiety Disorder

It is found to be 27.38%.

Depression correlation with the associated risk factors

There is a significant association between depression and marital status (P-value 0.046), where depression is observed to be higher in non-married individuals. There is no significant association between depression and caregivers who have SCD, chronic disease or mental illness. Depression is noted to be more prevalent among caregivers who have more than one child affected with SCD (P-value 0.038). Besides, there is a statically significant inverse relationship between the number of ICU admission per year and depression (P-value 0.02).

Generalized Anxiety Disorder correlation with the associated risk factors

There is no significant association between GAD and socio-demographic characteristics of the studied population with P-value more than 0.05 in all parameters. Regarding the relationship between GAD and caregivers who have SCD, there is a significant association with P-value 0.012. There is no significant relationship found between GAD and clinical severity of children affected with SCD.

Discussion

Prevalence of depression and Generalized Anxiety Disorder among caregivers of children affected with Sickle Cell Disease

Up to our knowledge, there is no sufficient evidence of the prevalence of depression and GAD in caregivers of children affected with SCD in Saudi Arabia.

In the present study, the prevalence of depression and GAD in caregivers of children affected with SCD was found to be 46.5%, and 31.8% respectively. Co-morbid depression and GAD in caregivers of children affected with SCD is found to be 27.38%. When comparing this result to recent studies conducted in the Eastern Province of Saudi Arabia, the prevalence of depression and GAD among caregivers of children affected with SCD appears to be higher than the prevalence in general population and similar to the prevalence in chronically ill patients [5,13].

Depression/ Generalized Anxiety Disorder and socio-demographic characteristics of the studied population

As discussed in the literature review, depression has multiple underlying risk factors which include female gender, younger age, low income, and lack of social support. Moreover, lower levels of education and employment have been shown to contribute to depression [14,15,16]. In this study, these demographic variables have been investigated for correlation with depression. There is no significant association between depression and the above-mentioned risk factors.

Marital status as being single, divorced or widow plays a role in the risk of depression [14]. In the present study, the highest rates of depression were found among non-married individuals (80%).

Data in the literature reported that GAD is likely to be associated with female gender, non-married individuals, unemployment, low education, and low socioeconomic status [17]. In this study, there was no significant association between GAD and those expected risk factors.

Depression/ Generalized Anxiety Disorder and participant's health status

Several studies have shown that adults who have chronic diseases are at risk of depression and/or GAD [13]. Nevertheless, in this study, there was no established association between chronic diseases and depression/GAD.

In literary analysis, the prevalence of depression and GAD in SCD patients is higher than healthy peers [5,18].In the present study, the prevalence of GAD among SCD patients is statically significant where it represents 53.6% of the studied sample. On the other hand, P- value was insignificant when studying the correlation between depression and the presence of SCD in the affected caregivers.

Depression/ Generalized Anxiety Disorder and clinical severity of children affected with Sickle Cell Disease

Although there was an established association in some studies between depression and number of VOC, the number of blood transfusions and the number of hospital admissions [7,10], this study revealed no significant association between depression and the frequency of VOC crisis, blood transfusion, hospital admission.

The present study also shows no association between GAD and clinical severity of children affected with SCD. On the contrary, GAD was influenced by the number of VOC and number of blood transfusions in the literary [10].

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