



## Prevalence and Determinants of Depression Among the Patients with Sickle Cell Disease: Pilot Study

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### ABSTRACT

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**Background:** Depression and its determinants among the patients with sickle cell disease (SCD) is a complicated issue in low resource setting like Nepal. The objective of this study is to determine the prevalence of depression and its determinants among the patients with SCD in community.

**Methods:** A cross sectional study based on community setting was conducted among randomly selected 40 patients. Bio-psycho-social model was taken to understand the phenomena of depression and its determinants. Validated nepali version Beck Depression Inventory (BDI) was used to determine prevalence of depression among patients with SCD. Standard questionnaires, Rosenberg self-esteem scale and Multidimensional scale of Perceived Social support (MSPSS) were used to identify determinants of depression.

**Results:** Prevalence of depression among patients with SCD was found 32.5%, in which 5% had severe depression using BDI scale. Depression was found associated with average family income, blood transfusion, self-esteem, difficulties for access to specialized doctor, and means of transportation among the patients.

**Conclusion:** One out of three patients with SCD are suffering from depression. Biological, psychological and social factors were the contributing factors for developing depression among people with SCD. Hence, it is therefore important to assess and treat depression among all patients with sickle cell disease to improve their mental and overall health. The validated tools were used for further study also.

### KEYWORDS:

depression, sickle cell disease, Tharu, Nepal

### INTRODUCTION

Depression is common mental disorder leading cause of disability worldwide and one of major contributor to overall global burden of disease that occurred from complex interactions between biological, psychological and social factors(1,2). The total number of people living with depression is 322 million around the world where nearly half of these people belongs to south east Asia region(3). Sickle cell disease (SCD) is common genetic blood disorder due to hemoglobin polymerization affecting the erythrocytes rigidity resulting vasculopathy and complications(4). SCD is

major public health concerns due to its acute and chronic medical complications which persists lifelong(5). Psychiatric issues in SCD have not received sufficient attention in clinical and research where these issues are further complicated by the social, economic and healthcare disparities(6). Association of psychiatric disorder among patients with SCD is not well defined and recognized(6,7).

The worldwide prevalence of depression among patient with SCD has been found 21.6% to 44% (8). Study done in USA reported 22% prevalence of major depression in SCD patients using Beck Depression Inventory (BDI) scale and significantly associated with social support, frequent vaso-occlusive pain crisis and hospitalizations in adults(5). In Nigeria 49.8% prevalence of depression in SCD using BDI scale and significant with age, marital status, educational level and chronic medical complications(9).

A study from Jamaica showed significant association between

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## Bhuwan D. et al, Prevalence and Determinants of Depression Among the Patients with Sickle Cell Disease: Pilot Study

the leg ulceration in people with SCD and psychological disorder. Up to 11% of affected persons suffer due to stroke and 20% have suffered from ischemic brain damage on MRI by the age 20 years(10). In eastern province of Saudi Arabia 48.2% prevalence of depression using BDI and significant association with lower educational qualification, high frequency of vaso-occlusive crisis and frequent visit to hematology clinic(8). The majority of the accessible studies have shown that higher level of social support were remarkably related with declined depressive symptoms(11). Study done by Nepal Health Research Council in 2015 reported that 18% of the Tharu population were affected from sickle cell disease(12). Tharu ethnicity was the most affected community with SCD and traits especially in Western Terai of Nepal where as Bardiya, Dang and Kailali district has 41.4%, 28.5% and 15.3% of SCD patients respectively(13). Due to the chronic conditions and continuous adherence to treatment regimen in SCD, it diminishes the productive livelihood and provokes the poor mental status(14). There was no any study available in Nepal which sheds light on the prevalence and determining factors for depression among the patients with SCD. Thus, the pilot study was aimed to determine the prevalence of depression among patients with SCD, to identify its determinants associated and to validate locally of selected tools used in pilot study.

### METHODS

The study was community based cross sectional study. The prevalence of SCD and traits in Kailali district, Sudurpaschim province of Nepal was found 15.3% in Tharu ethnicity(13). The study was conducted at local level of Kailali district (Tikapur and Janaki rural municipalities) where most of patients with SCD were belonged to Tharu community. The study population was taken those patients who were diagnosis with SCD and confirmed through hemoglobin electrophoresis test. These patients were registered for subsidies in health section of municipalities for their medical treatment.

Bio-psychosocial model was applied to describe the phenomena of depression and its determinants among patients with SCD by using structured questionnaires. Validated nepali version Beck Depression Inventory (BDI) tool was used to determine the prevalence of depression(15).

**Table 1. Prevalence of depression among SCD patients**

Depression	Frequency	Percent (%)
No	27	67.5
Yes Total	13	32.5
	40	100
Category	Frequency	Percent (%)
No Depression	27	67.5
Mild Depression	8	20
Moderate Depression	3	7.5
Severe Depression	2	5

Similarly, standard questionnaires, Rosenberg Self-esteem (RSE)(16), Multidimensional Scale of Perceived Social Support (MSPSS)(17), Pain Assessment Quadruple Visual Analogue Scale (PAQVAS)(18) and Kuppuswamy's socioeconomic scale(19) were used to identify the associations between depression and its determinants factors such as demographic, biological, psychological and social factors. Content and face validity was maintained through extensive review of literatures, incorporated expert's opinions and peer discussion. Most of questionnaires had been used which were already validated in Nepalese context.

Since, there is no any study conducted for prevalence of depression among patients with SCD in context of Nepal. Total 384 sample size number was calculated assuming 50% prevalence. After that 10% of the total sample size 38.4(~40) respondents was taken for the pilot study(20). Simple random sampling technique was employed for this piloting study. Data was collected in 40 individual patients. Face to face interview was done with age above 13 years who were present during data collection. Written informed consent was taken from eligible participants and assent was taken who were under 18 years prior to interview. Patients of SCD age below 13 years were excluded. The ethical approval was taken from IRC-PAHS (Ref: PHP2008251436) of Patan Academy of Health Sciences to conduct its final study. During data analysis, the collected data were coded, entered and analyzed in Epi-info version 7, STATA MP Version 13 software. Descriptive analysis was done and then inferential analysis was done by using Pearson's chi-square and Fisher exact test.

### RESULTS

The computed alpha reliability of the Nepali version scales Beck Depression Inventory(BDI), Rosenberg self-esteem (RSE), and Multidimensional scale of Perceived Social support (MSPSS) was calculated as 0.7945, 0.7249 and 0.9693 respectively. One out of three patients had experienced depressive mood disorder nearly every day for more than two weeks. The median age of respondents was 26 years.

#### Prevalence of depression among SCD patients

Table no.1 represents prevalence of depression among the patient with SCD was found 32.5%. The category of depression shows that 5% severe depression.

**Demographic determinants of Depression among patients with SCD**

Table 2 represents the demographic determinants of respondents. Of the respondents, 33.3% females had depression and 31.8% male had depression. Depression was found among married couple i.e. 29.2 % followed by the

never married group. The highest level of prevalence of depression was found in lower secondary group. Depression was found around 61.5 % who belongs to average family income Rs (24351-36550). Among the demographic determinants, Average family income was found to be associated with depression.

**Table 2. Demographic determinants of Depression among patients with SCD (n=40)**

Variables	No Depression(%)	Depression(%)	P value
<b>Gender</b>			
Male	15(68.2)	7(31.8)	0.091
Female	12(66.7)	6(33.3)	
<b>Marital status</b>			
Never married	9(60)	6(40)	0.485
Married Separated	17(70.8)	7(29.2)	
	1(100)	0(0)	
<b>Educational Status</b>			
Illiterate	3(100)	0 (0)	
Read & Write (Literate) Primary	3(75)	1(25)	
Lower secondary Secondary	2(50)	2(50)	0.505
Higher and above Total	7(53.8)	6(46.2)	
	7(87.5)	1(12.5)	
	5(62.5)	3(37.5)	
	27(67.5)	13(32.5)	
<b>Average family Income</b>			
Rs (36551-48750)	1(100)	0(0)	
Rs (24351-36550)	3(75)	1(25)	
Rs (4851-14550) Rs ≤4850	5(38.46)	8(61.54)	0.0363*
Total	18(81.82)	4(18.18)	
	27(67.50)	13(32.50)	

\*= p-value<0.05

**Bio-Psycho-Social determinants of Depression among patients with SCD**

Table 3 represents the Bio-Psycho-Social determinants of Depression among patients with SCD. Out of total patients, 64.3 % depression was due to blood transfusion and was found to be associated with Depression among biological determinants. The Rosenberg self-esteem scale was applied among patients and depression was found by 66.7% with low

self-esteem which was associated with self-esteem as a psychological determinant. Similarly, as a social determinants Depression was found by 70% with difficulties for access to Specialized Doctor and found to be associated with Depression. Moreover, Depression was found by 75% with means of transportation to go hospital for their treatment i.e. walking and found to be associated with Depression.

**Table 3. Bio-Psycho-Social determinants of Depression among patients with SCD(n=40)**

<b>A. Biological determinants</b>			
Variables	No Depression(%)	Depression(%)	P value
<b>Hemoglobin genotype</b>			
SS	25(65.8)	13(34.2)	
SC	2(100)	0(0)	1
<b>Emergency visit or Hospital admission</b>			
No	7(58.3)	5(41.7)	
Yes	20(71.4)	8(28.6)	0.092

<b>Blood transfusion</b>			
No	22(84.6)	4(15.4)	
Yes	5(35.7)	9(64.3)	0.003*
<b>Experience complication due to SCD</b>			
No	10(66.7)	5(33.3)	
Yes	17(68)	8(32)	0.931
<b>Pain crises</b>			
No	0(0)	0(0)	
Yes	27(67.5)	13(32.5)	1
<b>Pain intensity(PAQVAS)</b>			
Low Intensity	13(81.3)	3(18.7)	
High intensity	14(58.3)	10(41.7)	0.103
<b>B. Psychological determinants</b>			
<b>Self-esteem (RSE)</b>			
Low self –esteem	2(33.3)	4(66.7)	
Moderate self –esteem	22(81.8)	5(18.2)	0.020*
High self esteem	3(42.9)	4(52.1)	
<b>Genetic counselling</b>			
Received No	12(85.7)	2(14.3)	
Received Yes	15(57.7)	11(42.3)	0.089
<b>Discrimination</b>			
No	8(53.3)	7(46.7)	
Yes	19(76)	6(24)	1
<b>C. Social determinants</b>			
<b>Type of Social support (MPSSS)</b>			
Low social support	3(50)	3(50)	
Mild social support	6(54.5)	5(45.5)	0.0935
Higher social support	18(78.26)	5(21.74)	
<b>Visited HFs in 12 months</b>			
No	7(58.3)	5(41.7)	
Yes	20(71.3)	8(28.7)	1
<b>Difficulties for access to specialized doctor</b>			
No	24(80)	6(20)	
Yes	3(30)	7(70)	0.0064*
<b>Free Medicine</b>			
Yes	6(66.7)	3(33.3)	
Partially Yes	15(65.2)	8(34.8)	
No	6(75)	2(25)	1
<b>Means of Transportation</b>			
Walking(Foot)	1(25)	3(75)	
Local bus	22(78.6)	6(21.4)	
Ambulance	2(100)	0(0)	0.0133*
Others	2(33.3)	4(66.7)	
<b>Satisfied with medical care provider</b>			
Satisfied	3(50)	3(50)	
Partially satisfied	15(65.22)	8(34.78)	0.357
Not satisfied	9(81.82)	2(18.18)	

\*= p-value<0.05

## DISCUSSION

The pilot study shows that the prevalence of depression among the patients with sickle cell disease is 32.5%.

Meanwhile, 5% was found with severe depression during study period. This prevalence is very high when compared with the general Nepalese population in which the prevalence

## Bhuwan D. et al, Prevalence and Determinants of Depression Among the Patients with Sickle Cell Disease: Pilot Study

of mental disorder is 13.2% (21). There was no study conducted before to find out the depression among patients with sickle cell disease in the context of Nepal. There were a few studies done in Nepal which looked at the relationship between chronic diseases and depression. Those studies, all of that used BDI scale showed that prevalence of depression was found as 35.6% among the patients with diabetes mellitus(22), 28% in cancer(23), 51.8% in those undergoing maintenance hemodialysis in chronic kidney disease(24) and 15% in hypertension(25). The prevalence of depression in this study was par to the prevalence of depression in other chronic disease.

In Middle East countries, the prevalence of depression from cross-sectional studies among the patients with sickle cell disease had been identified high as 58.5% in Bahrain(26), 85.9% in Saudi Arabia(27). These results show uniquely high proportion rather than present studies. A study from the Nigeria that conducted in 2016 showed that 16.6% which is lower to higher than current study(28). Likewise, prevalence of depression in sickle cell disease in Uganda had shown 68.2%(29). Depression had been identified by different universities from USA shown similar to this current study which was 35.2%(30). The worldwide prevalence of depression among patients with sickle cell disease had shown similar to this finding.

The study was limited to small local level area with sample size. There was high chance of recall bias leading to differences in accuracy or completeness by the study participants regarding events or experiences from the past. During the analysis, association of the level of depression with the various factors was not analyzed. Children under 13 years were also excluded. Similarly, not all of Bio-Psychosocial factors for depression were taken as its determinants in this.

## CONCLUSION

From this pilot study, the reliability has been assessed of different scale and it was satisfactory to use for further research. The prevalence of Depression among the patients with sickle cell disease was determined which was found in one out of three (32.5 %) patients. Hence, bio-psychosocial model of depression could be applied to fulfill the research objectives.

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**Bhuwan D. et al, Prevalence and Determinants of Depression Among the Patients with Sickle Cell Disease: Pilot Study**

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