

Anxiety and Coping Strategies of Students with Sick Cell Disease: Three-Year Cross-Sectional Study

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Abstract

Introduction: Sick cell disease (SCD) is the most prevalent inherited blood disorder worldwide and estimated 18 million Indians have sickle cell trait¹ and 4 million have sickle cell disease². The study aims to find out the prevalence of sickle cell disease among university students and to identify coping strategies, they have adopted by them to deal with anxiety.

Methods: A retrospective cross-sectional survey was done among 2126 students over duration of three years to identify with simple random sampling technique followed by purposive sampling technique. Diagnosis confirmed by DTT and haemoglobin Electrophoresis before assessing the anxiety level and coping strategies using Hamilton-Anxiety Scale and Brief COPE scale through interview technique.

Result: Total 143(6.73%) students was found sickling positive while 63(44%) was suffering with mild to moderate level of anxiety and 52(36%) was in the range of moderate to severe. Among them 53(46.09%) has used approach coping strategies whereas 62(53.91%) preferred avoidant coping strategies.

Conclusion: Study finding suggest that students with SCD experience anxiety and they developed coping strategies to deal with anxiety. Proper guidance will be helpful for developing effective coping strategies to reduce level of anxiety.

Keywords: Anxiety, Coping Strategies, Sick cell disease, Students.

Introduction

Sickle cell disease is an autosomal the multi system blood disorder and characterized by red blood cells, that assume an abnormal, rigid, sickle shape, which aggregate and disrupt blood flow in small vessels^{1,2}. Sickle gene is mainly found in people originated/migrated from Malaria endemic areas of Africa and Asia³. As per

ICMR survey the estimated prevalence of sickle cell disease varied from 5 to 34% among different states of India, where WHO stated that mortality is much higher in many sub-Saharan countries⁴. Gujarat is reported to have at least 9,00,0000 sickle cell positive people in population survey 2011⁵.

The common suffering of a student with sickle cell disease vary from painful episodes because of blocking small blood vessels, frequent jaundice, bone ache and body ache, fever, enlarged spleen, retarded growth, frequent infections, dactylitis (hand-foot syndrome)⁷. Teenage years may make this even more difficult as they begin to understand the gravity of the problem and may find this a bit daunting or even frightening, as they start to think about choosing a career, building intimate relationship & future employment scope⁶.

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In addition to medical complications, students with sickle cell disease go through with different emotional phases such as feeling of confusion, anxiety, fear, depression, delayed puberty, which may lead to college absenteeism, short stature and limitation on social and academic activities⁸⁻¹⁰. They become more emotionally mature and the frequency of painful crises may increase because of hormonal changes. They find it hard to keep focused in their studies and university work¹¹.

Frequent painful sickle cell crisis necessitates repeated hospitalization, leading to limitations in activities, socialization and emotional disturbances. This period can be distressing and requires lots of encouragement and support from family and friends, so that correct coping mechanisms can be developed. Having a chronic condition like sickle cell disease often creates extra demands and challenges the student's capacity to cope. A condition like sickle cell disease always needs time, energy, and financial resources to handle an unpredicted and stressful situation. Although medical system has advanced and created a great significant improvement in the survival and quality of life¹². In this study the researchers are trying to find answers to the following questions: what is the prevalence of sickle cell disease among university students in the institution? 2. Do the students living with SCD experience anxiety? 3. What are the coping strategies adopted by them? This study aims to identify anxiety and coping strategies among students diagnosed with SCD.

Material and Method

Setting and participants

This study was done in Uka Tarsadia University, Bardoli, Surat. Which is situated in a tribal belt and caters to a large number of students from the surrounding tribal population. University admits around 3000 students per year to 18 different courses conducted by it. Among them 2126 students participated voluntarily in SCD screening process. Prevalence of SCD was identified by checking the reports of 2126 students who have undergone SCD testing from 2018 to 2020. Using a retrospective cross-sectional survey design, the prevalence of sickle cell disease was identified and purposive sampling technique was used to identify anxiety and coping strategies.

Instrument & Procedure

Retrospective data of three years durations was analysed to identify prevalence of SCD. New students who volunteered for screening was tested for SCD, using bio physiological blood sample testing named dithionate tube turbidity test (DTT) in collaboration with pathology laboratory of Indian red cross society of Ahmadabad. Positive DTT samples of blood were further analysed by haemoglobin electrophoresis for confirmation of SCD. The subjects with positive SCD test was identified from the register and their contact number and email ID was collected. Each student was contacted by telephone and purpose of study was explained and verbal consent was obtained. Anxiety was assessed using Hamilton anxiety scale and coping strategies was studied using brief COPE tool. Soft copy of consent form, socio demographic data, Hamilton anxiety scale and brief COPE was sent to the subjects by mail. The subjects completed the tool and returned them in 10 days. Coping strategies has been assessed for those students, having mild to moderate and moderate to severe anxiety level and students with mild anxiety level has been excluded.

In socio-demographic tool includes age, gender, family income, year of diagnosis done and family type was included. The anxiety level measured by Hamilton-Anxiety Scale had 14 items rated on a five-point scale, which included Anxious mood, Tension, Fears, Insomnia, Intellectual, Depressed mood, Somatic(muscular), Somatic(sensory), Cardiovascular symptoms, Respiratory symptoms, Gastrointestinal systems, Genitourinary symptoms, Autonomic symptoms, Behaviour at interview. Each item rated with a score of 0 (not present) to 4 (severe) on the scale. Total range of score is 0–56, and less than 17 indicates mild severity, score between 18–24 is considered as mild to moderate severity and 25–30 moderate to severe anxiety.

The coping strategies was assessed by Brief COPE-28 scale, developed by Professor Charles S. Carver from the University of Miami has developed the Brief COPE scale and has been cited by more than 900 articles. Brief COPE scale-28 is the version of the original scale of COPE Inventory and measures 14 coping types through 28 questions. Sample opinion can be measured with two major approach, named as Avoidant and Approach Coping. Scores of the scale has been divided following

subscales. – There are total 12 items fall under Avoidant coping which are mentioned as, Self-distraction (1 and 19), Denial (3 and 8), Substance use (4 and 11), Behavioural disengagement (6 and 16), Venting (9 and 21), Self-blame, (13 and 26). The other 12 items fall under Approach coping and mention as, Active coping (2 and 7), Emotional support (5 and 15), Use of informational support, (10 and 23), Positive reframing, (12 and 17), Planning (14 and 25), Acceptance (20 and 24). There are four more items which falls under Humour (18 and 28) and Religion (22 and 27) and are neither consider as Approach or Avoidance coping. All the study instrument has been validated. Reliability of the brief COPE scale was tested by calculating the Cronbach's alpha coefficient and test-retest method with interclass correlation coefficient, where ranges are one to zero shows perfectly reliable.

Inclusion: Study included all male and female students those were diagnosed as Sick cell disease with HbSS, HbSC, HbSBO Thal, HbSB+ Thal genotypes.

Statistics

The collected data was analysed using descriptive statistics like mean, Standard deviation and frequency. Association has been measured with inferential statistic chi square and Pearson coefficient of correlation used to assess the existing correlation.

Ethical Consideration

Permission was obtained from the university ethical committee of Uka Tarsadiya University before conducting study. Written consent was taken from students after assuring the confidentiality of the data collected.

Results

Findings of the study revealed that the prevalence of SCD was 6.24% as shown in table 1.

Table-1: Shows the prevalence of sickle cell disease among university students

Year	No of students tested	SCD positive	percentage
2018	700	72	10.29
2019	670	34	5.07
2020	756	37	4.89
Total	2126	143	6.73

Sample characteristics:

Age of the subjects varied from 18 to 25 years with a mean of 21.06 .Majority (45.45%) belonged to the age group of 22-23 years, seventy eight percent of them were males, and 35.66% of them belongs from low income group of less than Rs.10,000/month, 61.54 percent lived with their family and rest of them were staying in hostel or paying guest.

Anxiety levels: As shows in the figure-1: Majority of students 63(44%) were having mild to moderate level of anxiety, whereas 52(36%) samples were having moderate to severe level of anxiety and only 28(20%) students were identified with mild level of anxiety with a mean score 23.06 and SD 4.43.

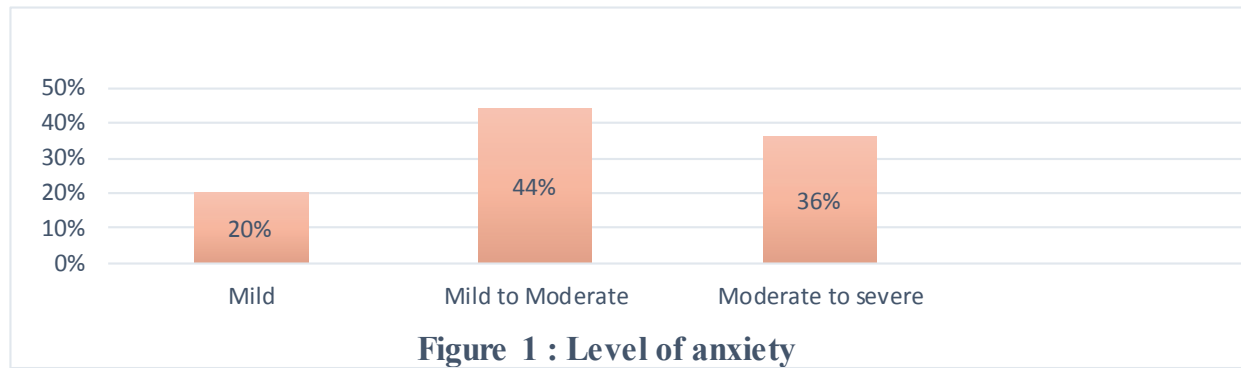


Figure-1 : Bar diagram representing the percentage distribution of the anxiety level of diagnosed students.

Coping Strategies : As shown in table 2 acceptance coping was the highest and humour was the lowest acceptance coping strategies.

Table 2: Brief Coping scale consist of 28 items with subdivision of 14 parts style score (Brief COPE-28) in samples screening positive for anxiety.

Brief COPE coping style	Mean	SD	Range
Acceptance	5.75	1.41	2-8
Self-blame	5.7	1.56	2-8
Use of Informational support	5.68	1.56	2-8
Venting	5.68	1.56	2-8
Positive reframing	5.6	1.33	2-8
Planning	5.6	1.61	2-8
Substance use	5.55	1.48	2-8
Active coping	5.48	1.35	2-8
Emotional Support	5.39	1.3	2-8
Religion	5.11	1.24	2-8
Self-destruction	5.49	1.44	2-8
Behavioural	5.45	1.51	2-8
Denial	5.38	1.55	2-8
Humor	4.79	1.37	2-7

As shown in **figure-2** Avoident coping was adopted by 53.91% of students and approach coping by 46.09% as frequently used coping strategies. In avoident coping, self blame was the highest (mean 5.7 and SD-1.56 on Range 2-8) and Denial the lowest (mean 5.38 and SD 1.55 on Range 2-8). In Approach coping Acceptance was highest (maen-5.8 and SD-1.41 on Range 2-8) and emotional support was lowest (mean 5.39 and SD-1.3 on Range 2-8).

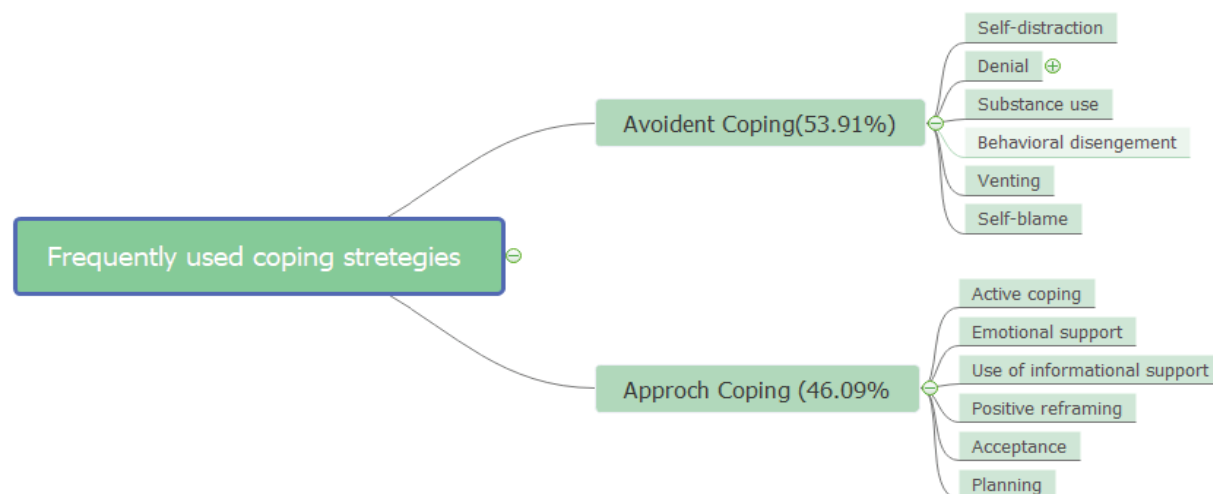


Figure 2: Categorization of the frequently used coping strategies by students to deal with anxiety.

Study reveals that there was a significant association between the anxiety level with their monthly income.

Discussions

The study finding shows the prevalence rate of sickle cell disease is 143(6.7.3%) after screening of 2126 university students. with the evidence of previous research, the prevalence rate varies from 5 % to 34 % among the population of western India ⁽¹²⁾. It was estimated that the sickle cell disease is phenotype and are mild in India than the other country like African phenotype¹³. However, study identified anxiety as a common psychological issue that the students are experiencing with the disease condition. Most of them were adjusting with anxious mood, restlessness, fear, insomnia and poor concentration related to uncertain disease process and treatment regimen.

Study shows the students were having anxiety due to pains and aches, twitching, stiffness of note, and worries related disease prognosis. The results found 53.91% students were using avoidant coping like self-distraction, denial, substance use, Behavioural disengagement, venting, self-blaming and 46.09% students were using approach coping with active coping, emotional support, use of informational support, positive reframing, acceptance and planning. Study revealed that the longer period students has been diagnosed with sickle cell disease were experiencing higher level of anxiety than

the students diagnosed recently. Further investigation is needed to understand barriers and facilitators of follow-up and identify strategies to minimize the anxiety disorder.

Limitations: The generalizability of the study results is limited among university students due to small size of sample. Moreover, some outcomes, such as pain crises at home, are self-reported and subject to recall bias.

Conclusion

The conclusion builds on existing evidence, Majority of students were suffering from mild to moderate level of anxiety, due to SCD which is a matter of serious concern. Any form of anxiety can affect the performance of students, which can reflect vigorously in later life. Study result shows the maximum use of avoidant coping approach rather than approach coping to minimize their suffering. Proper guidance & counselling will be helpful for developing effective coping strategies to reduce level of anxiety.

Recommendation:

The study sample was restricted to the university students with lack of comparison group and follow up to determine changes in coping strategies that the students are using to deal with anxiety. Therefore, a follow up study design could have been adopted based on random

sampling with a comparison group.

Ethical Approval: Permission for the project was taken from Ethical research committee, Uka Tarsadia University. Written consent was obtained from the students after motivating for the voluntary and anonymous participation.

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Conflict of Interest: The authors declare that there are no conflict of interests relevant to this work.

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