

# Assessment of Knowledge and Premarital Screening Regarding Sickle Cell Disease among Adults

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## ABSTRACT

**Introduction:** Sickle Cell Disease (SCD) is the disorder of the blood having tendency to get transferred from one generation to the next generation. Sickle cell disorder may be avoided if people become conscious of their carrier status and can do so by enhancing awareness and undertaking premarital screening. Understanding that even the Government of India promotes premarital screening of SCD before marriage.

**Aim:** To assess the knowledge and screening regarding SCD among unmarried adult.

**Materials and Methods:** An analytical research study with a cross-sectional research design was used. A total of 40 unmarried adults including male and female were participated in the study from November 2019 to December 2019. The

samples were selected using purposive sampling technique and structured questionnaire was used for data collection and sickling test was used for premarital screening.

**Results:** Most of the unmarried adults had average (40% subject) and good (42.5% subject) level of knowledge (Mean score  $9.10 \pm 3.07$ ) for SCD, 17.5% of adults had positive premarital screening results. There was significant association of knowledge score in relation to education ( $p$ -value=0.02) and caste ( $p$ -value=0.047) of the adults.

**Conclusion:** The study concluded that considering seriousness of SCD it is needed to get control over SCD and prevent transfer of it from one generation to next generation through public education, screening of SCD and other preventive measures.

**Keywords:** Genetic disorder, Grown-ups, Pre-wedding screening, Sickling test, Structured questionnaire

## INTRODUCTION

Sickle Cell Disease is the serious inherited disorder of the blood which causes several health problems and ultimately affects overall quality of life and shortens life expectancy of the person affected by it. In order to improve overall prognosis of SCD and to reduce the morbidity and mortality rates associated with it, several technological and scientific advances are made in the past some decades but still its effective management is something that professional health care providers find challenging. The community to be knowledgeable and aware of SCD by health education and undergoing SCD screening is very essential to get control over it and prevent its transfer from one generation to the next generation. Moreover, sickle cell carriers are free of clinical manifestations and remain unaware of their carrier state and hence they are the major contributors for transferring SCD from one generation to the next generation unknowingly. Both cases and carriers of SCD can be easily identified by blood examination of community at large [1].

SCD is a genetic condition with an estimated 5200 live births per year pointing towards a significant public health problem in India. While in many ethnic groups, SCD has been identified in India, it is most prevalent in the tribal population. In tribal populations, which have a high prevalence of socio-economic deprivation and are therefore medically underserved, sickle cell gene prevalence is 5 to 34 percent. A cross-sectional sample design was used by Bindhani BK et al., and a total of 152 individuals were recruited using a multi-stage sampling method, including 43 individuals with sickle cell haemoglobinopathy. While people are aware of SCD and Sickle cell trait (SCT), most accept that the disease is spread by sickle cell carriers and they do not realise that marriage between sickle cell carriers must be prevented [2].

Abioye-Kuteyi EA et al., done a cross-sectional descriptive study of the knowledge about SCD, attitude towards premarital sickle cell screening and marital decisions among local government workers. The findings revealed that 69 percent of the study subjects had poor knowledge of SCD, while 95 percent of the study subjects had a positive outlook

towards premarital screening. Among subjects with tertiary education, information and attitude were considerably better. Most (86.7%) of the respondents and 74.0% of their partners have had sickle cell screening. When one or both of them have haemoglobinopathy, one-third to two-thirds of research participants will maintain their relationship with their partner [3]. In present study, little attempt has been made to assess the knowledge and premarital screening of SCD among adults.

## MATERIALS AND METHODS

In this study, an analytical research approach with a cross-sectional research design was used. The study was conducted during November 2019 to December 2019 and the setting was selected in Acharya Vinoba Bhave Rural Hospital, Sawangi (Meghe), Wardha after getting Institutional Ethical Permission (Ref. no: SRMMCON 2019/8026). The population of the study was unmarried adults aged between 18 to 26 years of the age.

**Sample size calculation:** Purposive sampling technique was used. The sample size was 40 adults selected based on the calculation. The sample size is calculated using Daniel formula:

$$n = \frac{Z^2 pq}{d^2}$$

Where, 'n'=sample size

'z'=z statistics for a level of confidence of 95%, which is conventional, 'z' value is 1.96

p=proportion of people with good knowledge of SCD.

q=1-p

d=absolute error. On the basis of a previous study [2], After giving detailed explanation of the study and explaining cooperation expected from them written consent was obtained prior to the study.

**Inclusion criteria:** Adults who are willing to participate in the study, adults who were available during the period of data collection, who were in the age group of 18 to 26 years and both unmarried male and female adults.

**Exclusion criteria:** Adults who have already attended the class on SCD, adults diagnosed with systemic diseases, adults diagnosed with SCD and carrier trait and those who were married.

Demographic variables were collected in terms of age, gender, residence, education, father and mother status and structured questionnaire was used for data collection. A structured questionnaire, has 20 multiple choice questions and these were classified in different areas, such as: (i) meaning, causes, signs and symptoms of SCD; (ii) Medical management, lifestyle management, Complications and prevention of SCD and with the help of experts, the structured questionnaire was prepared which was discussed in previous sections, and clinical experiences of handling of sickle cell patients. Each correct answer carries one mark and the total score was 20 (Annexure 1). Prepared tool was validated by expert from the Nursing Department. Reliability analysis was done by the Guttman split-half coefficient and was 0.90, hence the tool found to be reliable, valid, and feasible. The interview technique was processed for 40 samples was planned to gather demographic information and the knowledge on SCD. The questionnaire was given to every study participant; each one requires approximately 30 minutes filling the standardised questionnaire. Sickling test was done for premarital screening of SCD.

## STATISTICAL ANALYSIS

The collected data were coded, tabulated, and analysed by using descriptive statistics (mean percentage, standard deviation) and inferential statistics. Significance of difference between pre and post-test readings was tested by using a t-test, association of knowledge with demographic variables was done by one-way ANOVA test and independent t-test. For statistical analysis Statistical Package for the Social Science (SPSS) version 16.0 was used.

## RESULTS

The above [Table/Fig-1] depicts frequency and percentage wise distribution of adult according to their age, gender, education, residence, caste and religion etc. Distribution of their age reveals that 17 (42.5%) were of 18-20 years, 15 (37.5%) were of 21-23 years, 8 (20%) were of 24-26 years. Distribution of adults according to their gender reveals that 20 (50%) were males and 20 (50%) were females. Distribution of adults according to their education reveals that 2 (5%) completed primary education, 3 (7.5%) completed secondary education, 9 (22.5%) completed higher secondary education and 26 (65%) completed degree and above education. Distribution of adults according to their residence reveals that 15 (37.5%) lives in an urban area and 25 (62.5%) lives in a rural area. Distribution of adults according to their caste reveals that 12 (30%) belongs to SC caste, 5 (12.5%) belongs to ST caste, 15 (37.5%) belongs to OBC caste and 8 (20%) belongs to open caste. Distribution of adults according to their religion reveals that 23 (57.5%) belongs to Hindu religion, 4 (10%) belongs to Muslim religion, 12 (30%) belongs to Buddha religion and 1 (2.5%) belongs to Christian religion. Distribution of adults according to their occupation reveals that 10 (25%) are employed, 5 (12.5%) are unemployed and 25 (62.5%) are student.

[Table/Fig-2] showed 2 (5%) of adult were having poor level of knowledge score, 16 (40%) of them had average and 17 (42.5%) of them had good level of knowledge score, and 4 (10%) of them had very good level of knowledge score 01 (2.5%) of them had excellent level of knowledge score. The minimum score was 2 and the maximum score was 17, the mean score was  $9.10 \pm 3.07$  with a mean percentage score of  $45.5 \pm 15.35$ .

[Table/Fig-3] reveals that 17.5% adult had positive report of sickle cell test. [Table/Fig-4] shows the significant association of knowledge scores with the education ( $p$ -value=0.02) and caste ( $p$ -value=0.047). There was no significant association of knowledge score relation to age, gender, area of residence, religion and occupation.

Sr. No.	Variable	Categories of the variable	Frequency	Percentage
1.	Age (years)	18-20	17	42.5
		21-23	15	37.5
		24-26	08	20
2.	Gender	Male	20	50
		Female	20	50
3.	Education of adult	Primary	02	05
		Secondary	03	7.5
		Higher secondary	09	22.5
		Degree and above	26	65.0
4.	Residence	Urban	15	37.5
		Rural	25	62.5
5.	Caste	Scheduled Castes (SC)	12	30
		Scheduled Tribes (SC)	05	12.5
		Other Backward Class (OBC)	15	37.5
		Open	08	20
6.	Religion	Hindu	23	57.5
		Muslim	04	10
		Buddha	12	30
		Christian	01	2.5
7.	Occupation	Employed	10	25
		Unemployed	05	12.5
		Student	25	62.5

**[Table/Fig-1]:** Distribution of the demographic characteristics of the study subject. n=40; Open denotes general caste

Level of knowledge score	Score range	Percentage score	Knowledge score	
			Frequency (n)	Percentage (%)
Poor	0-4	0-20%	2	5
Average	5-8	21-40%	16	40
Good	9-12	41-60%	17	42.5
Very Good	13-16	61-80%	4	10
Excellent	17-20	81-100%	1	2.5
Minimum score	2			
Maximum score	17			
Mean score	$9.10 \pm 3.07$			
Mean %	$45.5 \pm 15.35$			

**[Table/Fig-2]:** Assessment of knowledge regarding Sickle Cell Disease (SCD) among adult. (n=40).

Premarital screening test report	Screening report frequency	Screening report percentage
Positive	07	17.5
Negative	33	81.5

**[Table/Fig-3]:** Premarital screening about Sickle Cell Disease (SCD). (n=40)

## DISCUSSION

The study was conducted for assessment of knowledge and premarital SCD screening among adults. Most of the adults had average and good level of knowledge, the mean score was  $9.10 \pm 3.07$  with a mean percentage score of  $45.5$  ( $SD \pm 15.35$ ) and 17.5% adults have positive report of premarital SCD screening. There was significant association of knowledge score in relation to education ( $p$ -value=0.02) and caste ( $p$ -value=0.047) of the adults.

The similar study by Jahan F et al, cross-sectional study was conducted on 400 adults aged 20-35 who attended primary healthcare institutions. To assess the level of awareness, knowledge and attitude about SCD, statistical analysis was performed on  $n=279$ , of which 27 (9.7%) were males and 252 (90.3%) were females. Majority of study participants (81.4%) 20-25-year-old and single (92.1%) adults have adequate knowledge

Demographic variables	Frequency	Knowledge score	F-value/t-value	p-value
<b>Age in years</b>				
18-20 year	17	9.27±2.93	0.66	0.51
21-23 year	15	8.87±3.04		
24-26 year	08	8.25±3.53		
<b>Gender</b>				
Male	20	8.45±3.20	1.83	0.46
Female	20	9.75±2.86		
<b>Education</b>				
Primary	02	7.50±0.70	0.35	<b>0.02</b>
Secondary	03	8.53±5.13		
Higher secondary	09	8.78±1.71		
Graduate and above	26	9.42±3.34		
<b>Resident</b>				
Urban	15	8.67±3.84	0.47	0.12
Rural	25	9.36±2.54		
<b>Caste</b>				
SC	12	9.25±3.38	2.74	<b>0.047</b>
ST	05	8.00±2.34		
OBC	15	9.33±2.58		
Open	08	9.12±4.12		
<b>Religion</b>				
Hindu	23	9.00±3.69	0.44	0.83
Muslim	04	9.60±3.16		
Buddha	12	9.25±3.38		
Christian	01	10.00±3.07		
<b>Occupation</b>				
Employed	10	8.60±3.95	1.30	0.28
Unemployed	05	7.40±1.67		

**[Table/Fig-4]:** Association of knowledge score regarding Sickle Cell Disease (SCD) against demographic variables: n=40.

The statistical ANOVA test and independent t-test was used

regarding SCD and in present study, adults had average and good level of knowledge [4].

Supporting study by Tusuubira SK et al., cross-sectional study was conducted where knowledge, perception and practices of adults towards SCD. Total 110 adults were study participants and structured questionnaire was used. The study findings revealed that 91.2% of the participants were aware of existence of SCD and for most of the participants, 38.7% family and friends were main source of being known about SCD. Only 48% participants were aware that SCD is the inherited and 44.2% participants were not aware about the cause of it and 68.7% participants shown strong denial towards getting married with the person suffering from SCD. More efforts are needed to create awareness amongst the people about SCD to obtain the required results. [5].

Supporting study by Adewoyin AS et al., an analytical cross-sectional study was conducted where knowledge, attitude and control practices of SCD of 370 participants, most aged between 22-29 years and large proportion being the females (63.5%) were studied using a structured questionnaire. The findings of the study revealed that the good knowledge of SCD was only in 17.8% participants and 80.8% denied for carrier marriages. Very less participants 38.1% shows their willingness to undergo prenatal diagnosis and selective abortions if services are easily available and accessible in their region. From this, it was concluded that more focus need to be given in making the premarital diagnosis of SCD and selective abortion facilities easily available and accessible and there is a need to emphasise on control and prevention of SCD through health education and screening of the same [6].

A related research by Uche E et al., a cross-sectional comprehensive study was conducted on 200 undergraduates. Despite high levels of understanding, 37.5 percent had strong SCD expertise. A mean score of 12.05±3.14 demonstrating equal general knowledge of the respondents was exposed by the knowledge level of the respondents based on the score. A 67.5 percent of respondents were aware of the phenotypes of their haemoglobin. More than half (59%) of respondents knew someone with SCD and 154 (77%) accepted that the phenotype of haemoglobin would play a major role in choosing a life partner. The student's understanding of SCD is high, but this awareness did not translate into strong general knowledge of the disease. In order to improve awareness on SCD, this underlines the value of growing public health education on SCD [7].

Supporting study by Memish ZA and Saeedi MY, high prevalence of hereditary haemoglobin disorder. Data was collected by the various premarital screening and genetic counseling programs. Hence, to estimate the actual number of cases of SCD and  $\beta$ -thalassemia the premarital screening data was collected over a period of six years. Result of the blood analysis was disclosed to all participants and counseling done for those couples who were at high risk. Carriers or cases of SCD and  $\beta$ -thalassemia were 70,962 (4.5%) and 29,006 (1.8%), respectively. There was constant prevalence of SCD while prevalence of  $\beta$ -thalassemia showed decreasing trend from 32.9 to 9.0 per 1000 person undergone screening [8].

Supporting study by Al-Qattan HM et al., knowledge, attitude and practices of SCD and premarital genetic counselling of 351 participants who attended primary care clinic was studied using a self-administered questionnaire. The results of the study revealed that best attitude was of 41% participants, 28.8% knowledge and 19.1% practice. Among various socio-demographic variables (age, gender, marital status and educational level), knowledge, attitude and practice score in relation to age of the participants was having significant association. Many initiatives have been taken to create awareness regarding SCD and premarital genetic counseling but still there needs more efforts [9]; a self-administered questionnaire. The results of the study revealed that best attitude was of 41% participants, 28.8% knowledge and 19.1% practice. Among various socio-demographic variables (age, gender, marital status and educational level), knowledge, attitude and practice score in relation to age of the participants was having significant association. Many initiatives have been taken in Saudi Arabia to create awareness regarding SCD and premarital genetic counseling but still there needs a more efforts.

From present study, the authors revealed that 17.5% adults had positive report of premarital SCD screening. Further studies and screening to be done before getting married is the need of the time to prevent transfer of sickle cell gene from one generation to the next. Moreover, research also supports that SCD can be prevented if people are known about their carrier (sickle cell trait) state and go through genetic counselling and make wise reproductive decisions. Considering seriousness of SCD, it is needed to get control over SCD and prevent transfer of it from one generation to next generation through public education, screening of SCD, formulation of better health policies and other preventive measures.

### Limitation(s)

The study was limited to small sample size i.e., 40, which might be inadequate to generalise the study findings. More time duration would give more relevant results with variations of any research, but the investigator planned to complete the research work within one month to get more feasibility of getting sample. Therefore, sufficient number of sample and time duration was required for screening of sickle disease, in general.

### CONCLUSION(S)

Based on the above results, it was concluded that premarital sickle cell screening is necessary to diagnosed before marriage and can reduce

the incidence of SCDs. Considering seriousness of SCD, it is needed to get control over SCD and prevent its transfer from one generation to next generation through public education, screening of SCD, formulation of better health policies and other preventive measures.

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## ANNEXURE-1

Tools for assessment of knowledge and premarital screening regarding sickle cell disease among adults.

### Section-1

#### Demographic variables

Instruction: kindly fill appropriate information in the space provided. Tick the appropriate answer where ever applicable

Demographic Variables	Tick the appropriate answer where ever applicable
<b>1. Age in years</b>	
a) 18-20 year	
b) 21-23 year	
c) 24-26 year	
<b>2. Gender</b>	
a) Male	
b) Female	
<b>3. Education</b>	
a) Primary	
b) Secondary	
c) Higher secondary	
d) Graduate and above	
<b>4. Resident</b>	
a) Urban	
b) Rural	
<b>5. Caste</b>	
a) SC	
b) ST	
c) OBC	
d) Open	
<b>6. Religion</b>	
a) Hindu	

b) Muslim	
c) Buddhism	
d) Christian	
<b>7. Occupation</b>	
a) Employed	
b) Unemployed	
c) Student	

### Section-2 Knowledge Regarding Sickle cell disease

Knowledge regarding sickle cell disease	Tick the appropriate answer where ever applicable	Correct answer
<b>1. Sickle cell disease is....</b>		
a) Auto-immune reaction		
b) Inherited disease		√
c) Acquired disease		
d) Infectious disease		
<b>2) Cause of sickle cell disease is....</b>		
a) Decreased haemoglobin level		
b) Sickle shaped red blood cells		√
c) Sickle shaped white blood cells		
d) Increased haemoglobin level		
<b>3) Shape of following blood component is changed in the sickle cell disease....</b>		
a) Haemoglobin		
b) Red blood cells		√
c) White blood cells		
d) Platelets		
<b>4) Client with sickle cell disease often feels tired due to reduced supply of following to tissue...</b>		
a) Carbon dioxide		
b) Oxygen		√

c) Blood		
d) Platelets		
<b>5) Types of sickle cell disease are...</b>		
a) One		
b) Two		√
c) Three		
d) Four		
<b>6) More severe form of sickle cell disease is...</b>		
a) Haemoglobin SS disease		√
b) Haemoglobin SC disease		
c) Haemoglobin AA disease		
d) Haemoglobin SSS disease		
<b>7) Carrier state in sickle cell disease refers to....</b>		
a) Person having sickle cell disease		
b) Person who carry a sickle cell gene for whole of their life		
c) Person who pass sickle cell genes to next generation		√
d) None of the above		
<b>8) Sign and symptoms of sickle cell disease...</b>		
a) Anemia		
b) Episodes of pain		
c) Painful swelling of hands and feet		
d) All of the above mentioned		√
<b>9) Sign and symptoms develop in sickle cell disease because of...</b>		
a) Sickle shaped red blood cells block the blood flow		√
b) Sickle shaped red blood cells increase the blood flow		
c) Sickle shaped red blood cells flow with speed through the blood vessel		
d) Sickle shaped red blood cells form harmful substances in the blood		
<b>10) Diagnosis of sickle cell disease is established on the basis of...</b>		
a) Urine examination and urine culture		
b) Blood culture and sensitivity		
c) Complete blood count and peripheral smear		
d) Peripheral smear and haemoglobin electrophoresis		√
<b>11) Early diagnosis of sickle cell disease is important because.....</b>		
a) It is hard to identify disease in the late stage		
b) Diagnosis of sickle cell disease can only be made in the early stage		
c) To treat appropriately and prevent the complications		√
d) Without early diagnosis treatment cannot be initiated		
<b>12) Treatment of sickle cell disease includes....</b>		
a) Medications to reduce pain and prevent complications		
b) Repeated blood transfusions		
c) Bone marrow transplant		
d) all the above mentioned		√

<b>13) Genetic counseling is important in the couple having sickle cell disease</b>		
a) To cure the sickle cell disease		
b) To control the sickle cell disease		
c) To prevent the complications of sickle cell disease		
d) To prevent the sickle cell gene transfer to next generation		√
<b>14) Main purpose of genetic counseling in sickle cell disease is....</b>		
a) To advice couple to not to conceive		
b) To plan for better pregnancy and healthy child		
c) To explain the possible effect of sickle cell disease on lifestyle		
d) To explain possible outcome of the pregnancy, to conceive or not to is their choice		√
<b>15) Organ damage occurs in sickle cell disease because of...</b>		
a) Sickle shaped red blood cells block the blood flow		√
b) Sickle shaped red blood cells contain organ damaging factors		
c) Sickle shaped red blood cells reduces growth factor.		
d) Sickle shaped red blood cells widens the blood flow		
<b>16) Most serious complication of sickle cell disease which needs immediate treatment is...</b>		
a) Stroke		√
b) Blindness		
c) Infection		
d) Leg ulcer		
<b>17) Serious complications arise in sickle cell disease because of....</b>		
a) Autoimmune reaction		
b) Lack of oxygen in red blood cells		
c) Obstruction to circulation		√
d) Increased blood bilirubin level		
<b>18) For a baby to born with sickle cell disease</b>		
a) Both mother and father carry and pass sickle cell gene to the child		√
b) Only mother pass sickle cell gene to the child		
c) Only father pass sickle cell gene to the child		
d) Neither mother nor father pass sickle cell gene to the child		
<b>19) When both parents have sickle cell disease risk for child to have sickle cell disease is...</b>		
a) 100%		√
b) 80%		
c) 99.9%		
d) 98%		
<b>20) It is advised to people going to get married to undergo sickling test</b>		
a) To cure the disease		
b) To control the disease		
c) To prevent the disease transfer to next generation		√
d) To identify the disease in the early stage and start the treatment		