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# Knowledge, Awareness and Opinion Related to Sickle Cell Disease Among the Professional College Students of Amravati, Maharashtra

**A. U. Deore**

Professor, Jawaharlal Nehru College, Nagpur, Maharashtra, India

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## ABSTRACT

The aim of this study is to investigate the awareness, clinical manifestations, treatment and populations at risk of Sickle Cell Disease (SCD) amongst the professional college students of Amravati district. This study was also focus on knowledge about carriers (HbAA) and sufferers (HbSS). The total 842 students from technical streams such as engineering, pharmacy and biotech were enrolled. All participants were assessed on their general knowledge of the disease. The structured questionnaire containing the questions on origin, prevalence, incidences, life expectancy, painful crisis, counseling methods, treatments, management, attitude and behavior towards SCD were provided to all participants. The results had shown that, only 144(17.1%) subjects were found to be known about SCD. Out of them, 56(38.8%) individuals had appreciable knowledge, 80(55.5%) had limited knowledge and 8(5.5%) had marginal knowledge of SCD. The 30.5%(n=44) respondents were known about need of blood transfusion and 18.75%(n=27) participants had knowledge of interrelation between sickle cell anemia and the disease jaundice be an important clinical complaint in SCD. 25.69% (n=37) respondents known to have about intimate relationship between sickle cell disease and pain crisis. Majority of respondents (512/842) was believed that, people should have knowledge and awareness about the genetic diseases that helps to restrict its further spread.

***Key words:*** Sickle cell disease, Professional college, Amravati, Maharashtra

## INTRODUCTION

Sickle cell disease is the most common of the hereditary blood disorders and affecting millions of persons. Sickle disorders are seen commonly in sub- Saharan Africa [1] but also occur in the Mediterranean, India, and the Arabian Peninsula. Due to a variety of reasons, sickle cell anemia (SCA) became one of the most studied genetic alterations affecting mankind. The condition could either lead to natural resistance to major infectious diseases such as malaria among heterozygous individuals or to a debilitating disease that could leads to early death of the homozygous carriers of the gene. The sickle cell trait is known to be confined or occurs in higher frequencies in particular affected populations in the tropics and therefore it recognizes as one of the most classical population specific markers [2-4].

The African continent is considered as epicenter with an annual estimated number of 200,000 new born affected by sickle [5, 6]. This constitutes 66.6 % of the children born with the hemoglobin disorders in the whole world. It is estimated that, every year 15,000 children are born with sickle cell disease in Ghana [7] and over 80% of these children die before they celebrate their fifth birth day. In India, the extensive surveys performed by the Anthropological Survey of India estimate an average sickle cell trait frequency of 15% across the states of Orissa, Madhya Pradesh and Maharashtra which, with the estimated population of 300

million people, implies that, there may be more cases of sickle cell disease born in India than in Africa. In Maharashtra especially in Vidarbha region, [8] noticed alarming and consistent frequency of this disease.

In recent years, newborn screening [9], better medical care, parent education, immunization and penicillin prophylaxis have successfully reduced morbidity and mortality and have tremendously increased life expectancy [10].

## MATERIALS AND METHODS

The students had participated to this study were selected from the Amravati city of Maharashtra, India. A total of 842 subjects from technical streams such as engineering, pharmacy and biotech were enrolled. The sickle cell disease questionnaire was distributed to all participants along with consent form. The consent clearly informed that this investigation is voluntary and they can leave the study anytime. The name will not be disclosed and participants would not be placed at any risk following the completion of the research work. The filling of questionnaire was completed under the supervision of college professors. The questionnaire was containing the questions on origin, prevalence, incidences, life expectancy, painful crisis, counseling methods, treatments and management attitude and behavior towards SCD in present circumstances in India. The opinion of respondents on the prospects of married individuals with sickle cell traits having children with sickle cell disease was also sought. To avoid confusion, terminologies were explained to respondents during the data collection processes. The data retrieved from the questionnaire was analyzed by using software SPSS 19.0.

## RESULTS

A total of 842 subjects were enrolled, of them 717(85.15%) subjects were associated to engineering, 88(10.45%) with pharmacy and 42(4.98%) were biotech students. The results of this study demonstrated that, 144 (17.1 %) subjects were found to be known about this disorder. Out of them 56(38.88%) individuals had appreciable knowledge, 80(55.55%) had limited knowledge and remaining 8(5.55%) students as marginal knowledge. A total of 367 students only know that sickle cell anemia is a disease. However, 512 believed that people should have detail information about genetic diseases.

**Table 1: Knowledge about sickle cell disease**

| Group | Participants | Percentile |
|---|---|---|
| Are you aware of SCD | | |
| Yes | 144 | 17.1 |
| No | 698 | 82.8 |
| Sources of information (multiple responses) | | |
| Health professionals | 38 | 26.38 |
| friends | 18 | 12.5 |
| Books | 59 | 40.97 |
| Family | 25 | 17.36 |
| Causes of SCD | | |
| Acquired | 47 | 32.63 |
| Inherited | 74 | 51.38 |
| Don’t know | 23 | 15.97 |
| Know someone with SCD | | |
| Yes | 12 | 8.33 |
| No | 132 | 91.66 |
| How is SCD diagnosed | | |
| Blood test | 118 | 81.94 |
| Urine test | 09 | 6.25 |
| Don’t know | 17 | 11.80 |
| Measures of preventive measures on SCD | | |
| Genetic counseling | 59 | 40.97 |
| Penicillin prophylaxis | 16 | 11.11 |
| Genetic counseling and Penicillin prophylaxis | 48 | 33.33 |
| Don’t know | 69 | 47.91 |
| What should be done by couple when they discover that their genotype predispose them to having children with SCD | | |

| | | |
|---|---|---|
| Discontinue their relationship | 03 | 2.0 |
| Continue with their relationship | 134 | 93.05 |
| Don't know | 07 | 4.86 |

The clinical symptoms are concerned, 29 (20.13%) students observed to known about few important symptoms such as body pain, chest pain and joint pain. 15 (10.41%) participants found to known about joint pain and anemia The 44 (30.55%) participants were aware about a need of blood transfusion and 27 (18.75%) participants had knowledge of jaundice to be one of the important signs of SCD.

The treatments and management point of view, 12.5% (n=18) respondents had found to have limited knowledge, 2.77% (n= 4). They rarely knew about bone marrow transplant and gene therapy. Majority of the participants unknown about inherited nature of SCD Some of them found to have misconception about SCD transmission and they believed that due to eating of flesh of dead animals may cause the sickle cell anemia. Major source of information includes text books, friends, family members, health professionals and internet.

Related to behavior towards SCD, few respondents (17/144) believed that sickle cell carrier and disease individual should know their status. According to 29.16% (n=42) of total respondents, SCD genotype should be considered as an important factor for getting married; the patients should either become unmarried or get married with normal partner. When they asked for their opinion in case of couples both partners having sickle cell disease,2.0 %(n=3) were in favor to be discontinued their relationship. Majority of respondents (n=134) wanted to be carried on their relationship by taking special care of them, 4.86% (n=7) students could unable to take any firm decision.

## DISCUSSION

The students participated in this study were belonged to engineering, pharmacy and biotech, thus educational level has been thought to influence awareness and attitudes regarding genetic testing, although better-educated groups appear to be more knowledgeable [11,12]. However, this investigation had very limited participants found to be known about the sickle cell disease. These findings were exactly opposite to the findings by different authors especially studies from other countries where they obtained majority to be known about SCD [13]. For instance, the studies of school and undergraduate students in Nigeria revealed that more than 80% of respondents claimed to be heard about this disease. The differences may be attributed because Nigeria is highly affected by SCD therefore they are familiar with, contrast to that in Maharashtra its frequency is very low and therefore it is ignored. The lower level of awareness of the current study may also affected by certain factors such as, they either did not expose to opportunities such as mass media which could widen their knowledge base about genetic diseases especially sickle cell anemia.

The results clearly reveal that majority of Indian population is still unaware about the sickle cell disease. However, many studies have been observed alarming frequency of this disease in Maharashtra [8, 14]. Limited knowledge of genetic disorders may lead to the implications of genetic risks among people. Moreover, in terms of inheritance patterns majority of students did not know about. However, students of biotech and pharmacy were found to have knowledge about SCD. Interestingly this disease included in the syllabus of life science at UG level, thus that could be the reason behind the good response by pharmacy students. Many students had misconception that the SCD is transmitted through the eating habits. The reason could be attributed to their beliefs and lack of knowledge about genetic diseases. But there is no association between eating habits and genetic diseases [15]. As far as the knowledge of inheritance pattern the results of this study are in confirmation with study conducted by Boyd

et al [16], although the investigation by Dyson [17] demonstrates that ¼th subjects were answered the question related genetic inheritance of sickle cell anemia.

## CONCLUSION

Number of factors such as cultural beliefs, behaviors and attitudes including spiritual faith and religious practices are associated with openness and response to testing for genetic disease [18-20] in India. Literacy and poverty are thought to be the prime hazards for limited knowledge and awareness especially about genetic diseases. Thus, the Indian government and non-governmental organizations should focus on raising knowledge and awareness of sickle cell disease by using television, mobile apps, and news papers. Employees of health department are required to work in association with educational institutions [21]. Special projects should be started and should increase the participation of local people.

### *Declaration by Authors*

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