Prevalence of sickle cell disease in tribal adolescents of the South Gujarat region, India

B Vasava, R Chudasama, N Godara, R Srivastava

Citation

B Vasava, R Chudasama, N Godara, R Srivastava. *Prevalence of sickle cell disease in tribal adolescents of the South Gujarat region, India*. The Internet Journal of Tropical Medicine. 2008 Volume 6 Number 1.

Abstract

Objectives: to create awareness, to screen samples of school adolescents and then to reach their community through them by doing surveillance for sickle cell diseaseSettings & Design: School adolescents studying in St Xavier`s high school and Vanraj high school of Umarpada taluka of Surat district were included in the field based cross-sectional studyMethod: After taking permission from school authority, pre-test (n=881) and post-test (n=743) evaluation was done to asses their knowledge regarding SCD. Blood samples of 948 school adolescents were taken for DTT test and then for electrophoresis. Blood samples of motivated parents and friends of those adolescents found positive for DTT was taken in subsequent visit and results were communicated to them.Results: Out of 1081 adolescents, various aspects of sickle cell disease were assessed among 881 during pre-test and among 743 during post-test evaluation. Blood samples of 948 school adolescents were tested for DTT test. Prevalence of sickle cell disease was found 25.5%. Electrophoresis was done in 242 adolescents who found positive for DTT test, of which 92% found having sickle cell trait and 8% having sickle cell disease. Then electrophoresis done among 64 parents and friends and 24 (37.5%) found positive of which 14 (58%) having sickle cell trait and 10 (42%) having sickle cell disease.

SOURCE OF SUPPORT

Laboratory investigations were done as part of sickle cell disease control programme in the south Gujarat region

ACKNOWLEDGEMENT

Authors are thankful to pathology department, Government Medical College, Surat and principles of Vanraj high school and St Xavier`s high school for giving permission to conduct this study and school adolescents and their parents and friends who participated in this study for their valuable support.

INTRODUCTION

Sickle cell disease is an autosomal recessive genetically transmitted hemoglobinopathy responsible for considerable morbidity and mortality (1). It is one of the most common hereditary diseases occurring worldwide, which may affect any organ or system of human body. It is irreversible, untreatable health problem predominately seen amongst various tribes. With its present rate of spread, in another 25-40 years, over 150 lakh children will suffer and die of sickle cell disease, and over 300 lakh person will inherit the abnormal hemoglobin trait (2). In India the Hemoglobin S (Hb S) was first detected in Veddoid tribe in Nilgiri hills of Tamilnadu and later discovered in other states (3). The incidence varies from 5 % to 34 % and it is mainly restricted to the tribal population (4). High prevalence of sickle gene has been demonstrated in various tribal communities of Gujarat including Bhils and Dhodias of Panchmahal, Dublas, Naikas, Koli, Dhanka, Gamit, Vasava, Bariya, Varli, Vaghari, Kukna, Halpati, Chaudhari etc (5). Tribal accounts 15 % of the total population of Gujarat and distributed in various districts of the state such as Sabarkantha, Banaskantha, Panchmahal, Vadodara, Narmada, Bharuch, Surat, Valsad, Dang and Div-Daman (2).

Sickle cell disease carriers are absolutely normal and healthy, unless they have a special blood test investigation for Hb S electrophoresis. Confirmation of patient suffering from sickle cell disease is carried out only by laboratory investigation. Therefore blood examination of community at large is needed to estimate the load of cases and carriers of sickle cell disease. In present study an effort has been made to assess the current knowledge and to create awareness by education of secondary and higher secondary school adolescents, the prevalence of sickle cell disease by using Dithionate Tube Turbidity (DTT) test in school adolescents and then subsequently electrophoresis test among those

found positive for DTT test to confirm their status as Sickle Cell Trait or Sickle Cell Disease and then reaching to community through them for identification of people suffering from sickle cell disease or the carriers of sickle cell disease.

MATERIAL & METHOD

This study was done with objective to create awareness, to screen samples of school adolescents and then to reach their community through them by doing surveillance for sickle cell disease. Present study was done in Umarpada taluka of Surat district in South Gujarat region, which has a predominant tribal population (85-95%). Sickle cell disease (SCD) is a most common genetic disease and major health problem found in tribal population of South Gujarat region. Approval was taken from ethical committee of Government Medical College, Surat before conducting study on school adolescents.

Study was conducted with purposive sampling selecting two main schools of this taluka namely St. Xavier`s High School and Vanraj High School having more than 90% students from tribal community. Permission was taken from school authorities to do conduct the study. Schools were selected in such a manner that they represent adolescents of tribal population in their area. Data was collected during September & October 2006. Study subjects were school adolescents of 8 th to 12 th standard as they can understand and disseminate the information about sickle cell disease to their community at large after getting tested for sickle cell disease and getting adequate education about same. School authorities were informed prior and date was fixed for both the schools to collect the data and blood samples.

Total 1081adolescents studying in 8 th to 12 th standard in two schools, St Xavier`s high school and Vanraj high school. During first visit, pre-test evaluation was done to asses their knowledge regarding SCD and 881 school adolescents have participated. Followed by this, a lecture was delivered on various aspects of sickle cell disease and a printed booklet in local language (Gujarati) was given to these school adolescents. Post-test evaluation was done after 7 days of pre-test evaluation and 743 adolescents out of 881 were present.

During second visit of schools after 3 days, total 948 students were present out of 1081 students. They were motivated to come forward for giving their blood samples. The blood samples were collected by trained personnel after taking their informed consent. All students present on day of visits to each school have participated in the study. Total 948 samples collected and then sent to Department of Pathology, Government Medical College, Surat for Dithionate Tube Turbidity (DTT) test. Those found positive for DTT test, were further analyzed by electrophoresis to confirm their status as either sickle cell trait or sickle cell disease.

Though present study was cross sectional, consequent visits were made in same schools later on after getting results of DTT test and electrophoresis test. In subsequent visits, all those adolescents who found positive (242) were contacted in school. Their status on sickle cell disease was communicated to them and also motivated to come with their parents and friends in next visit. The date for next visit was decided and communicated to these school adolescents. In subsequent visit, blood sample of motivated parents and friends of those found positive came to school was collected. They were also tested for their status and informed in next visit. Health education regarding symptomatology, clinical management and treatment, laboratory investigation, care of patient and carrier, and marriage counseling was also given to them. After data collection, data was entered and analyzed by using Epi Info software version 6.04.

RESULTS

Various aspects of sickle cell disease were explored in school adolescents by pre-test and post-test evaluation (table 1).

Figure 1

Table 1 Assessment of awareness about various aspects of sickle cell disease (SCD) among school adolescents

Awareness about	Pre-test evaluation (n=407)		Post-test evaluation (n=743)		Change in knowledge	Z test
	No.	%	No.	%	%	
Heard about SCD	407 / 881	46.2	743	100	53.7	9.5 (P<0.05)
Mode of transmission of SCD	150	36.8	723	97.3	60.5	12.1 (P<0.05)
ShaPe of Red Blood Cells in SCD	148	36.4	715	96.2	59.8	14.2 (P<0.05)
Hemoglobin level in SCD	123	30.2	554	74.6	44.3	7.9 (P<0.05)
TyPe of care required for SCD carrier	4	0.9	305	41.0	40.0	11.1 (P<0.01)
TyPe of care required for SCD Patient	9	2.2	291	39.2	37.0	10.2 (P<0.01)
Method of diagnosis for SCD	275	67.6	727	97.8	30.2	6.3 (P<0.01)
TyPe of Hemoglobin found in SCD	100	24.6	590	79.4	54.8	10 (P<0.01)
Laboratory investigation needed to identify SCD	76	18.7	523	70.4	51.7	10.3 (P<0.01)
Precautions taken during marriage of Carrier or trait	313	76.9	703	94.6	17.7	4.2 (P<0.01)
Reason for increasing trend of SCD	118	29.0	465	62.6	33.6	6 (P<0.01)
Control of transmission of SCD	7	1.7	266	35.8	34.0	9.4 (P<0.01)
Who can marry among carrier, case and health individual	3	0.7	258	34.7	34.0	10 (P<0.01)
Who can't marry among carrier, case and healthy individual	4	0.9	225	30.3	29.4	8.7 (P<0.01)

Out of 1081 adolescents, 881 were present during pre-test evaluation. Post-test evaluation was done in 743 out of these 881 adolescents who were present during pre-test evaluation. Remaining students were absent during post-test evaluation. Only 407 students (46.2) have heard about sickle cell disease out of 881 during pre-test evaluation, while it was increased to 743 during post-test evaluation. Awareness was further checked about various aspects of SCD among those who have heard about SCD during pre-test evaluation(n=407) and post-test evaluation (n=743). The overall mean age was 14.94 ± 1.68.

Figure 2

Table 2 Tribal caste wise distribution of school adolescents participated for Dithionate Tube Turbidity (DTT) test

Caste	Boys		Girls		Total	
	No.	%	No.	%	No.	%
Vasava	400	86.8	359	85.5	759	86.2
Chaudhari	17	3.7	32	7.6	49	5.5
Gamit	5	1.0	7	1.7	12	1.4
Dhodias	2	0.4	1	0.2	3	0.3
Others	37	8.0	21	5.0	58	6.6
Total	461	52.3	420	47.7	948	100

Out of 1081 total adolescents studying in two schools, in St Xavier`s high school, there were 254 students studying in 8 th to 12 th standard and out of this 239 (94%) students were tribal, while in Vanraj high school 827 students studying in 8 th to 12 th standard of which 764 (92.4%) students belonged to tribal community. During first visit of schools, total 948 students were present out of 1081 students. So study was conducted in these 948 school adolescents. The overall mean age was 14.94 ± 1.68 for these school adolescents. As shown in table 2, majority of school adolescents (86.2%) belongs to Vasava caste and 5.5% belongs to Chaudhary caste. Only 6.6% adolescents belong to non tribal community, while remaining 93.4% study adolescents belongs to tribal community.

Figure 3

Table 3 Result of Dithionate Tube Turbidity (DTT) Test for sickle cell status among school adolescents

Standard	No. of students registered	No. of students whose blood sample was tested	Coverage %	Point Prevalence of sickle cell carrier	
				No.	%
8	341	310	90.9	69	22.2
9	212	184	86.8	52	28.2
10	137	119	86.7	30	25.2
11	238	212	89.0	54	25.5
12	153	123	80.3	37	30.0

Blood samples of 948 (87.7%) school adolescents were collected out of 1081 registered students. These adolescents were tested for sickle cell disease by using Dithionate Tube

Turbidity (DTT) test. Table 3 shows that 948 adolescents were tested and among them 25.5% (n=242) adolescents found positive for sickle cell disease. Those found positive for DTT test were further tested for their sickle cell status whether trait or disease by using electrophoresis technique.

Figure 4

Table 4 Caste wise distribution of school adolescents showing their status of sickle cell trait or disease as per electrophoresis result

Caste	DTT Positive	Sickle Cell Trait		Sickle Cell Disease		Total Positive	
		No.	%	No.	%	No.	%
Vasava	218	201	83.1	17	7.0	218	90.1
Chaudhari	17	15	6.2	2	0.8	17	7.0
Gamit	5	5	2.1	0	0	5	2.1
Dhodias	2	2	0.8	0	0	2	0.8
Others	0	0	0.0	0	0	0	0
Total	242	223	92.2	19	7.8	242	100

As shown in table 4, 92% adolescents having sickle cell trait and 8% have sickle cell disease. Among all the tribal castes, majority (90%) adolescents belong to Vasava community, followed by Chaudhary (7%), Gamit (2.1%) and Dhodias (0.8%). Out of 64 motivated parents and friends, 47 parents and 17 friends were tested further for electrophoresis. Among these, majority (95%) belongs to Vasava community (table 5). All positive results for either sickle cell trait (58.3%) or disease (41.7%) were found in Vasava community.

Table 5 Caste wise distribution of Parents and friends of Positive school adolescents showing their status of sickle cell trait or disease as per electrophoresis result

DISCUSSION

If any person has sickle cell disease, he/she should learn as much about the disease as possible. This will help them to recognize early signs of problems, such as fever or chest pain, and seek early treatment. Centers and clinics for sickle cell disease diagnosis can provide information and counseling to help the parents to handle the stresses of coping with this serious chronic disease. School-aged children and adolescents should participate in physical education. School teachers can support such children with sickle cell disease to rest if they are tired and to drink fluids after exercise. Many non-governmental and voluntary organizations working for sickle cell anemia and identification work are doing camps, where large number of people gathers, and their blood samples are collected to carry out laboratory investigation but that`s all on temporary basis. Unfortunately neither the diagnostic nor the treatment facilities are available in tribal area and all this are beyond their reach. Without diagnosis and comprehensive care, children suffer crippling medical problem leading to lack of education, employment opportunities and integration into the society.

The coverage in the current study was above 77.2% in Vanraj high school and 95.2% in St Xavier's high school during pre-test. The over all mean age for the school children was 14.94 ± 1.68 in this study. Mukherjee K (6) reported mean age of school children as 15 years in his study. During pre-test evaluation, 46% adolescents have heard about the sickle cell disease and during post-test evaluation, it was 100% among those who were present during pre-test evaluation and also statistically significant. Awareness regarding sickle cell disease in these adolescents during pre-test evaluation might be because of various educational activities conducted by voluntary and non governmental organizations working in same areas. Sahu T et al (7) reported 16.55% prevalence of sickle cell disorder in below fifteen years children in tribal areas of Gajapati district of Orissa. So, high awareness about sickle cell disease ultimately benefits the community in way of early detection and management. Awareness regarding mode of transmission, shape of red cells, and level of hemoglobin in sickle cell disease was assessed and found statistically significant.

When awareness assessed regarding type of care required for SCD carrier like, they must take folic acid tablet daily and drink plenty of water, the difference found significant. Similarly, when questions asked about type of care required for SCD patient, the difference observed was also significant. When awareness was assessed about method of diagnosis, type of hemoglobin found in SCD, type of laboratory investigation (electrophoresis) required to diagnose SCD, during pre-test and post-test evaluation, the difference observed was significant, indicating significant change in knowledge of adolescents regarding SCD. Ambekar S S et al (8) have used electrophoresis for diagnosis of SCD in their study at Western Maharashtra. When questions asked regarding precautions to be taken during and reason for increasing trend of SCD, it was found statistically significant. Similarly, when knowledge

regarding control of transmission of SCD, who can marry and who can`t marry among carriers, cases and healthy individual, the difference observed in pre-test and post-test evaluation was found significant.

In present study, majority (86.2%) of adolescents belongs to Vasava community, followed by Chaudhary, Gamit and Dhodias. These are the main tribal communities of south Gujarat region. Sahu T et al (7) has reported Raita, Sabar, Beera, Mandal, etc tribal community in their study in south Orissa. Balgir R S et al (9) has reported sickle cell disease in Bhuyan and Kharia tribes of north-western Orissa. This study has reported 25.5% prevalence of sickle cell disease in school adolescents. These adolescents were DTT test positive. Patel J (10) in his study reported similar prevalence of sickle cell disease among tribal community in another part of Gujarat. Saxena D (11) has reported 1.8% prevalence of sickle cell disease among school children in same study area. Kamble M et al (12) has reported 5.7% prevalence of sickle cell disease in their study of central India. The difference could be explained by statement made by Italia Y (4), who has reported prevalence of sickle cell anemia varying from 5% to 34% from different parts of Gujarat.

Majority (90%) adolescents found positive for sickle cell trait (83%) or disease (7%) belongs to Vasava community, while Dalal M (12) has reported 18.4% prevalence of sickle cell trait in Dhodias in South Gujarat region. The variation in proportion of people with different communities depends on their distribution. Meta-analysis may be done to detect overall frequency and distribution of sickle cell disease in different tribal population of Gujarat. When 242 adolescents positive for DTT test were motivated, 47 parents and 17 friends were come forward for their blood investigation. Out of 64, sickle cell trait was found positive in 14 (58.3%) and sickle cell disease in 10 (41.7%). Ambekar S S et al (8) have used electrophoresis for diagnosis of SCD in their study at Western Maharashtra. The highest frequency of sickle cell gene in India is reported in Orissa followed by Assam, Madhya Pradesh, Utter Pradesh, Tamilnadu and Gujarat (13). Patel A B et al (14) reported older age of presentation, absence of sever anemia, male preponderance in their study. It indicates limited availability of health services, education and counseling available to susceptible populations (15), which was also observed in present study. When information received in form of lectures, booklets, pamphlets, from teachers, friends, people more likely shows their interest to know their sickle cell status then those who do not receive information (16). So, efforts to reach community through school adolescents by giving information and education to them, more population can be covered.

CONCLUSION

It can be concluded that effective improvement in knowledge of adolescents regarding the sickle cell disease after education and approaching community can be possible through school adolescents for conduction of surveillance of sickle cell anemia. As it was small study, similar study of large size can be repeated by regular and planned visit to school adolescents. A new method may be developed for approaching community through school adolescents.

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Author Information

Bipin Vasava, M.D. – Community Medicine
Tutor, Community Medicine Department, Government Medical College, Surat, Gujarat.

Rajesh K Chudasama, M.D. – Community Medicine
Assistant Professor, Community Medicine Department, Government Medical College, Surat, Gujarat.

Naresh R Godara, M.D. – Community Medicine
Assistant Professor, Community Medicine Department, Government Medical College, Surat, Gujarat.

Ratan K Srivastava, M.D. – Community Medicine
Associate Professor & Head, Community Medicine Department, Government Medical College, Surat, Gujarat.