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Original Article

Reaching Community Through School Going Children for Sickle Cell Disease in Zankhvav Village of Surat District, Western India

Authors
Mihir Prafulbhai Rupani, Resident,
Bipin Chandubhai Vasava, Assistant Professor,
Kallol Harichand Mallick, Assistant Professor,
Vaibhav Vasant Gharat, Resident,
Rajkumar Bansal, Professor & Head,
Department of Community Medicine, Surat Municipal Institute of Medical Education & Research (SMIMER), Surat.

Address for Correspondence
Dr. Mihir Rupani,
B-23, Meghna Society, Opp. Maninagar Society,
Manjalpur, Vadodara – 390011,
Gujarat, INDIA.
E-mail: mihirrupani@yahoo.com

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Abstract: Objectives: The objective of the study was to explore a method to reach the community via school going adolescents for screening tribal people for Sickle Cell disease. **Methodology:** A cross-sectional study was conducted in a total of 1023 school going adolescents for Sickle Cell Disease screening by Dithionite Tube Turbidity (DTT) test with subsequent Hemoglobin Electrophoresis for confirmation among those testing positive for DTT. They were then advised to get their family members tested for the same. **Results:** 24.41% of school going adolescents tested positive by DTT test. 152 family members of those positive school children came forward for testing. On performing the DTT test on the family members, 53.94% tested positive. Out of those who tested positive, 61% belonged to Vasava caste; 36.6% belonged to Chaudhari caste followed by Gamit and Dhodhia Patel. On the subsequent Hemoglobin electrophoresis, 52.63% of the family members were found to be positive for Sickle Cell Trait and 1.97% tested positive for Sickle Cell Disease. **Conclusions:** School going children can be an effective medium to approach the community for the screening of Sickle Cell Disease.

Key Words: Sickle cell disease; Screening; Tribal; School going children

Introduction:
Sickle Cell Anemia (SCA) is a hereditary anemia, predominantly seen amongst various tribal population of India. People affected by SCA are frequently misdiagnosed and mistreated. According to ICMR survey, Sickle Cell gene is found amongst different tribal groups of India, which varies from 5 to 34 %. Gujarat has 64.70 lakh tribal population and is expected to have 6,47,025 Sickle trait and 48,257 Sickle disease patients.(1) The Dhodia, Dubla, Kukna, Gamit, Chaudhary, Halpati, Varli, Kokni, Kathodi, Kolcha, Kotwadia, etc. are among the major tribes having Sickle Cell problem in Gujarat.(2) The Sickle disease patients suffer a lot of pain throughout their life, right from their birth. 20% of the Sickle Disease children die by the age of two. According to one survey by ICMR amongst the primitive tribes of south of Gujarat, viz; Kolcha, Kotwadia & Kathodi 30 % of Sickle diseased children die before they reach adulthood (14 years) and the remaining 70 % die by the age of 50. Thus, mortality in sickle cell disease is high at young age group.(1)
Tribal areas are hard to reach and thereby are most often neglected by health care professionals. Tribal community is ignorant that they are suffering from such a disorder and what precautions they need to take. They are unaware of the dangers of having Sickle cell disorder, even in its milder form. This ignorance often leads to marriage of sickle cell disordered people with people with the same disorder which lead their offspring prone to getting the severe forms of the disease. Several studies carried out in tribal areas of India have shown higher frequency of sickle cell trait as well as disease in tribal communities than in general communities.(2-6)
Sickle cell traits are normal healthy individuals, who can only know about the condition after hemoglobin electrophoresis for HbS. This study screened the family members of school going adolescents and imparted information regarding Sickle cell disorders to them to spread awareness among tribal population regarding this disease.

Materials and Methods:
Study design, period and setting: Zankhvav village is situated 85 km to the east from Surat city (Gujarat). It is a business hub for the surrounding 40-50 villages of Mangrol Taluka. It has the biggest residential-cum-boarding school of Mangrol Taluka named Shantiniketan High School. This cross-sectional study was conducted for a period of 3 months from June to August 2010 in this school. We decided to select this school for our study as more than 90% children from tribal areas of South Gujarat were studying in this school.
Sample size and data collection: Written permission was taken from school authorities for conducting this study. We sensitized the students by taking a lecture on sickle cell disease and also circulated a booklet (in Gujarati) among them. They were encouraged to come forward to give their blood samples. Verbal consent was taken from them before collecting blood samples by

trained personnel. We screened all the students of 8th standard to 12th standard (1023 students) attending this school for Dithionite Tube Turbidity test (DTT test). Those students testing positive for DTT test (247 students) were instructed and counselled to call upon their family members for screening them too for this test in the subsequent visit to the school. But, family members of only 71 students came to us for testing. So, a total of 152 family members were subsequently tested for DTT. Both, the students and their family members testing positive for DTT were then subjected to Hemoglobin electrophoresis test for diagnosing whether they were heterozygous Sickle cell trait (SCT) or homozygous Sickle cell disease (SCD). All the subjects were given complete information regarding Sickle cell disease including clinical features, screening methods, precautions like avoidance of exposure to extreme temperatures, importance of vaccination of children, prenatal diagnosis and marriage counselling to help reduce births of homozygous children.

Materials: The Primary test used in field was DTT test developed by Huntsman also known as Solubility test.(7) The principle of DTT test is that when RBCs are lysed, HbS is reduced to dithionate and the reduced HbS is insoluble in concentrated inorganic buffer.(7) The polymers of deoxy HbS obstruct light rays and produce opacity. About 2-3 drops of blood from a finger prick was taken in a 75 x 12 mm glass tube containing buffer and a pinch of sodium di thionate was added and mixed. After keeping it for 5 minutes the test tube was seen against black lines at a distance of 1 inch and results were interpreted in terms of opacity i.e. inability to see black lines. Those samples, which had given opacity in DTT testing, were assumed to have either sickle cell disease or sickle cell trait. To differentiate between these two variants of sickle cell anemia, 2 ml venous blood was drawn from these students and stored between 4 to 8 degrees in a vaccine carrier and sent to the laboratory within 24 hours. Later electrophoresis test was done to know the exact sickle status. Electrophoretic test was done by Hemoglobin Electrophoresis on Cellulose Acetate Membrane.(8)

Statistical analysis: Data was computerized and analyzed by Epi Info version 3.5.1.

Results:

A total of 1023 school going adolescents were tested for DTT and 247 (24.14%) of them tested positive. The caste and gender distribution of these 247 adolescents is shown in Table 1.

Table 1: Hemoglobin electrophoresis results of school going children with their caste and gender distribution (n=247)

Caste	Boys		Girls		Total (%)
	Sickle Cell Trait %	Sickle Cell Disease%	Sickle Cell Trait %	Sickle Cell Disease%	
Vasava	86 (34.81)	1 (0.004)	59 (23.88)	2 (0.008)	148 (59.91)
Chaudhary	42 (17)	1 (0.004)	40 (16.19)	1 (0.004)	84 (34)
Gamit	5 (2.02)	0	2 (0.8)	0	7 (2.83)
Dhodhia Patel	5 (2.02)	0	3 (1.21)	0	8 (3.23)
Total	138 (55.87)	2 (0.8)	104 (42.1)	3(1.21)	247 (100%)

As evidenced from table 1, majority of those adolescents testing positive for DTT belonged to Vasava caste (59.91%) followed by 34% belonging to Chaudhary caste; 2.83% belonging to Gamit caste and 3.23% belonging to Dhodhia Patel. On the subsequent Hemoglobin electrophoresis test, 242 (97.97%) of the adolescents tested positive for Sickle cell trait (SCT) and 5 (2.02%) of them tested positive for Sickle Cell Disease (SCD).

Table 2: Age and gender distribution of the family members of the students (n=152)

Age group	Male (%)	Female (%)	Total (%)
<20 yr	21 (13.81)	18 (11.84)	39 (25.65)
20-40yr	42 (27.63)	59 (38.81)	101 (66.44)
>40yr	9 (5.92)	3 (1.97)	12 (7.89)
Total	72 (47.36)	80 (52.63)	152 (100)

Out of the 152 family members who came forward for getting tested for DTT, 72 (47.36%) were males and 80 (52.63%) were females. Among these family members, 25.65% were below 20 years of age; 66.44% of them were between 20-40 years and 7.89% were above 40 years of age.

Table 3: Relation of family members as per caste (n=152)

Caste	Father (%)	Mother (%)	Sibling (%)	Total (%)
Vasava	31 (20.39)	36 (23.68)	21 (13.81)	88 (57.89)
Chaudhary	18 (11.84)	24 (15.78)	18 (11.84)	60 (39.47)
Gamit	1 (0.65)	2 (1.31)	0	3 (1.97)
Dhodhia Patel	1 (0.65)	0	0	1 (0.65)
TOTAL	51 (33.55)	62 (40.78)	39 (25.65)	152 (100)

Among the family members who turned up for testing, 33.55% were fathers; 40.78% were mothers and 25.65% were siblings of the school going adolescents.

Table 4: DTT result as per caste (n=152)

	DTT results		
Caste	**Negative (%)**	**Positive (%)**	**Total (%)**
Vasava	38 (25)	50 (32.89)	88 (57.89)
Chaudhari	30 (19.73)	30 (19.73)	60 (39.47)
Gamit	2 (1.31)	1 (0.65)	3 (1.97)
Dhodhia Patel	0	1 (0.65)	1 (0.65)
TOTAL	70 (46.05)	82 (53.94)	152 (100)

On performing the DTT test on the family members, 82 (53.94%) tested positive. Out of these 82 members who tested positive, 50 (61%) belonged to Vasava caste; 30 (36.6%) belonged to Chaudhari caste and 1 (1.2%) each belonged to Gamit and Dhodhia Patel.

Table 5: Hemoglobin electrophoresis as per caste (n=152)

Caste	Normal (%)	Sickle cell trait (%)	Sickle cell disease (%)	TOTAL (%)
Vasava	37 (24.34)	50 (32.89)	1 (0.65)	88 (57.89)
Chaudhari	30 (19.73)	28 (18.42)	2 (1.31)	60 (39.47)
Gamit	2 (1.31)	1 (0.65)	0	3 (1.97)
Dhodhia Patel	0	1 (0.65)	0	1 (0.65)
TOTAL	69 (45.39)	80 (52.63)	3 (1.97)	152 (100)

On the subsequent Hemoglobin electrophoresis, 80 (52.63%) of the family members were found to be positive for Sickle Cell Trait and 3 (1.97%) tested positive for Sickle Cell Disease. Out of those with Sickle Cell Trait, 50 (62.5%) belonged to Vasava caste; 28 (35%) belonged to Chaudhari caste and 1 (1.3%) each belonged to Gamit and Dhodhia Patel. Among those with Sickle Cell Disease, 2 (66.7%) belonged to Chaudhari caste and 1 (33.3%) belonged to Vasava caste.

Table 6: Caste-wise distribution of anemia (n=152)			
Caste	**Anemia (%)**	**No anemia (%)**	**Total (%)**
Vasava	26 (17.1)	62 (40.78)	88 (57.89)
Chaudhari	31 (20.39)	29 (19.07)	60 (39.47)
Gamit	0	3 (1.97)	3 (1.97)
Dhodhia Patel	0	1 (0.65)	1 (0.65)
TOTAL	57 (37.5)	95 (62.5)	152 (100)

We assessed anemic status of the family members based on the cut-off points proposed by the WHO Expert Group.(9) Based on this classification, we found that 57 (37.5%) of the family members were anemic. Out of those who were anemic, 26 (45.6%) belonged to Vasava caste and 31 (54.4%) belonged to Chaudhari caste, while members of Gamit caste and Dhodhia Patel were found non-anemic.

Discussion:

It is generally agreed that SCA is more common among the tribal community. In the present study, majority of the school going adolescents belonged to the Vasava community, followed by Chaudhari and Gamit community. Sharma RS, et al. also found high prevalence of Sickle Cell Anemia (SCA) among these communities.(2) The tribal predominance of this disease was also highlighted in studies carried out in Orissa and Southern India. (5,6,9,10) However, Kar BC claimed that the sickle cell gene is not confined to tribal people, but is prevalent throughout the society. His research showed 11.1% prevalence in a hospital survey and 15.1% prevalence in a population survey.(4) In the present study, the prevalence of sickle cell disease among the school going adolescents was found to be 24.14%. Samal GC, et al. claimed a prevalence of 29% in their study on school going children in Orissa.(6) Patra PK, et al. reported a prevalence of SCA of 9.51% in Chattisgarh state.(3) Kamble M., et al. stated a prevalence of 5.7% of SCD and 38.4% of SCT among the hospitalized patients in Wardha.(12) This variation in prevalence of SCA might be due to the fact that we conducted this study in a tribal area of Gujarat, where the prevalence is expected to be high.

Conclusion:

It can be concluded that school going adolescents can be an effective medium to reach the community for the screening of the tribal people for SCA. Also, it is desirable to screen adolescents initially as they would be sensitized at a tender age to the most common disease of tribal. School children can in turn spread the awareness about this disease effectively by educating their school mates.

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