Awareness about various aspects of sickle cell disease among tribal adolescents

B Vasava, R Srivastava, R Chudasama, N Godara

Citation

B Vasava, R Srivastava, R Chudasama, N Godara. *Awareness about various aspects of sickle cell disease among tribal adolescents*. The Internet Journal of Epidemiology. 2008 Volume 6 Number 2.

Abstract

To assess knowledge before and after giving education regarding sickle cell disease among tribal adolescents in schools, study was conducted in two schools of Umarpada taluka of Surat district having predominant tribal population during September & October, 2006. Out of 1081 adolescents including boys and girls studying from 8th to 12th standard, 881 were present during pre-test evaluation and out of these 881 adolescents 743 were present during post-test evaluation. Various aspects of SCD were assessed and significant differences were observed for pre-test and post-test evaluation.

INTRODUCTION

Sickle cell disease is one of the most common hereditary diseases occurring worldwide, which may affect any organ or system of the human body. Sickle cell disease is irreversible, untreatable health problem predominately seen amongst various tribes. The genetic character of the disease dictates that it will grow in geometric proportions over the years. It is now definitive that at 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 ([1]). In India the Hemoglobin S (Hb S) was first detected in Veddoid tribe in Nilgiri hills of Tamilnadu, in 1952 by Lehman and Cutbush. It was later discovered in other states ([2]). However, the incidence varies from 5 % to 34 % and it is mainly restricted to the tribal population ([3]), a 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 ([4]). The tribal population contributes 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 ([1]).

Sickle cell disease carriers are absolutely normal and healthy like any healthy person and do not know that they are carriers unless they have a special blood test Hb S electrophoresis. The patient suffering from sickle cell disease develops blood related complications and can be suspected according to a family history or by conducting clinical examination. But confirmation of case can only be carried out by laboratory investigation. Therefore blood examination of community at large is needed to estimate the load of cases and carriers of sickle cell disease. Conduction of blood investigation of community at large is an exertive and laborious exercise. 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 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

Sickle cell disease (SCD) is a most common genetic disease in tribal population. It is a major health problem in South Gujarat region. Present study was done in Umarpada taluka of Surat district, which has a predominant tribal population (85-95%). Before conducting study, approval was taken from ethical committee of Government Medical College, Surat. 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. Data was collected during September & October 2006. Study subjects were school adolescents of 8th to 12th standard as they can understand and disseminate the information about sickle cell disease to

the community at large after getting adequate education about same. Total 1081 students were registered in both these schools, of which 881 school adolescents were present during pre-test evaluation. During post-test evaluation, 743 adolescents were present out of 881, who were present during pre-test evaluation.

The study was field based cross sectional using two separate structured proforma to conduct pre-test and post-test evaluation. Interview was conducted after getting an informed consent by using pre-tested proforma with few open ended questions to facilitate collection of information. Questionnaire included regarding epidemiology, symptomatology, clinical management and treatment, laboratory investigation, care of patient, carrier state and marriage counseling. After assessing their awareness and knowledge as pre-test evaluation, health education was given in form of lectures, supported with a booklet on sickle cell disease in local language, explaining about the disease with figures where necessary. The main focus of health education was exploration of facts about sickle cell disease and sickle cell trait. After giving health education, second evaluation was done as post-test evaluation in after 7 days of pre-test activities. After data collection, data was entered and analyzed by using Epi Info software version 6.04.

RESULTS

The current study was carried out among adolescents of two schools, Vanraj and St Xavier`s. As shown in table 1, Vanraj high school has registered 827 students; out of which 639 (77.2 %) students were present during the conduction of pre-test. There were 254 adolescents studying in St Xavier`s school and on the day of pre-test, 242 (95.2 %) students were present. So, out of 1081 students studying, total 881 were interviewed for pre-test evaluation, as remaining students were absent on that day. After 7 days of pre-test, among these 881 students post-test evaluation was done in 743 students, because remaining students were absent on day of post-test evaluation. The overall mean age was 14.94 ± 1.68.

Figure 1

Table 1: School wise attendance of adolescents on day of pre-test & post-test evaluation

Test		Vanraj High School		St Xavier`s High School		Total (n=1081)
		Boys	Girls	Boys	Girls	
Pre-test	Present	325	136	106	314	881
	Absent	132	1	11	56	200
Post-test	Present	227	134	93	289	743
	Absent	230	3	24	81	338

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 2

Table 2: Tribal caste wise distribution of school adolescents participated in the pre-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	881	100

Various aspects of sickle cell disease were explored in school adolescents by pre-test and post-test evaluation (table 3). 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).

Figure 3

Table 3: Assessment of awareness about various aspects of sickle cell disease 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)

DISCUSSION

If any child/adolescent has sickle cell disease, he/she should learn as much about the disease as possible. This will help to recognize early signs of problems, such as fever or chest pain, and seek early treatment. Sickle cell centers and clinics can provide information and counseling to help the parents to handle the stresses of coping with this serious chronic disease. School-aged children should participate in physical education. Teachers in school should allow children with sickle cell disease to rest if they are tired and to drink fluids after exercise. Children and teenagers may also play competitive sports. Coaches should watch for signs of fatigue and allow the athlete to rest. 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 ([5]) reported mean age of school children as 15 years in his study. The highest frequency of sickle cell gene in India is reported in Orissa followed by Assam, Madhya Pradesh, Utter Pradesh, Tamilnadu and Gujarat ([6]).

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. Patel A B et al ([9]) 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 ([10]), which is also present in present study. Treadwell M J et al ([11]) reported that majority of community members have correct knowledge about genetic basis and severity of sickle cell disease, but very few knew their own status.

CONCLUSION

Present study shows that there has been effective improvement in knowledge of adolescents regarding the sickle cell disease after education and this may improve their health seeking behavior for same and ultimately it will be beneficial to their community.

ACKNOWLEDGEMENT

Authors are thankful to principles of Vanraj high school and St Xavier`s high school for giving permission to conduct this study.

CORRESPONDENCE TO

Dr. Rajesh K Chudasama, D-1/1, New Assistant Professor's Quarters, New Civil Hospital Campus, Majura Gate, Surat – 395 001, Gujarat, India. E-mail address: dranakonda@yahoo.com, dranakonda@gmail.com

References

1. Commissionerate of Tribal Development and Commissionerate of Health and Family Welfare, Govt. of. Gujarat, sickle cell disease control and research project Gujarat, December, 2007.
2. Lehmann H, Cutbush M. sickle cell trait in southern India. British Medical journal 1952; 1: 404-405.
3. Italia Y. Sickle cell disease book for health worker, sickle cell disease control program, Commissionerate of Health and Family welfare, Govt. of.Gujarat.2006; 1-3.
4. Sharma RS et al: Hemoglobinopathies in Western India. Journal of Association of Physician India 1973; 2: 969-973.
5. Mukherjee K. Study of gutka consumption and its determinants among secondary school male students in Mumbai. Ind J Comm Med 2006; 31(3): 177.
6. Balgir RS. Genetic epidemiology of the three predominant abnormal hemoglobins in India. JAPI 1996; 44: 25-8.
7. Sahu T, Sahani NC, Das S, Sahu SK. Sickle cell anemia in tribal children of Gajapati district in South Orissa. Ind J Comm Med 2003; 28 (4): 180-183.
8. Ambekar SS, Phadke MA, Mokashi GD, Bankar MP, Khedkar VA, Venkat V et al. Pattern of Hemoglobinopathies in western Maharashtra. Indian Pediatr 2001; 38: 530-534.
9. Patel AB, Athavale AM. Sickle cell disease in central India. Indian J Pediatr 2004; 71 (9): 789-793.
10. Patra PK, Tripathi S, Khodiar P, Dalla AR, Manikpuri PK, Sinha A. A study of carrier status of sickle cell disease among inmates of central jail Raipur (Chhattisgarh). J Comm Med 2008; 4(1): 11-12.
11. Treadwell MJ, McClough L, Vichinsky E. Using qualitative and quantitative strategies to evaluate knowledge and perceptions about sickle cell disease and sickle cell trait. J Natl Med Assoc 2006; 98 (5): 704-710.

Author Information

Bipin Vasava, MD
Assistant Professor, Department of Community Medicine, Surat Municipal Institute of Medical Education & Research

Ratan K. Srivastava, MD
Professor & Head, Department of Community Medicine, Banaras Hindu University & Medical College

Rajesh K. Chudasama, MD
Assistant Professor, Department of Community Medicine, Government Medical College

Naresh R. Godara, MD
Assistant Professor, Department of Community Medicine, Government Medical College