

A STUDY OF KNOWLEDGE, ATTITUDE AND PRACTICE ABOUT SICKLE CELL ANAEMIA IN PATIENTS WITH POSITIVE SICKLE CELL STATUS IN BARDOLI TALUKA

Chintan Gamit, SL Kantharia, Sukesha Gamit, Mohamedanas Patni, Gaurang Parmar, Kumarbhargav Kaptan

Department of Community Medicine, Government Medical College, Surat, Gujarat, India

Correspondence to: Chintan Gamit (chintangamit@ymail.com)

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ABSTRACT

Background: Sickle cell anaemia is widely distributed in African and American negroes. It also seen in Arabian peninsula, Indian Subcontinent and parts of Europe. A high prevalence has been demonstrated in various tribal communities of Gujarat.

Aims & Objective: To assess Knowledge, Attitude and Practice about sickle cell anaemia in patients with positive Sickle Cell Status.

Materials and Methods: Cross Sectional Observational Study from June 2010 to May 2011. 276 patients with purposive sampling in Bardoli Taluka having sickle cell positivity in age group of 18 to 30 years were taken.

Results: Only 16% of the study participants knew correct symptoms of Sickle cell anaemia. 30 % patients were availing the treatment of some kind. It was observed that females were more active as compared to males in taking medication for Sickle Cell Anaemia and the difference between them was found to be significant. It was found that 96 % of the study participants had received Color coded cards after testing showing the high accomplishment of mass screening programs in identifying Sickle Cell Status by simple means. But approximately 90% didn't know the cause of disease and only 52 (18 %) were counselled about this disease. More than 95% of the participants were unaware regarding their haemoglobin status.

Conclusion: All the strategies for the prevention of this outrageous disease will be effective only if they are utilized to its maximal extent by creating more awareness to the affected and also the other population.

Key Words: Sickle Cell Anaemia; Knowledge; Attitude; Practice; Awareness; KAP Study

Introduction

Sickle cell disease is an autosomal recessive genetically transmitted haemoglobinopathies responsible for considerable morbidity and mortality.^[1] It is one of the most common hereditary diseases worldwide, which may affect any organ or system of the human body. James B Herrick reported peculiar elongated sickle shaped red blood cells in a case of severe anaemia at Detroit, which may lead to death and termed it as sickling. This genetically determined disorder however, first noted in American Negroes, and has a worldwide distribution. For long haemoglobin S was believed to be restricted to African and American Negroes. It was later discovered in other parts of world viz. Arabian Peninsula, Indian Subcontinent and parts of Europe mainly Greece and Sicily.^[2] With Itano, a physical chemist Linus Pauling demonstrated electrophoretically abnormal haemoglobin, HbS as abnormal variant of HbA in 1949.^[3] In India the HbS was first detected in Veddoid tribe in Nilgiri hills of Tamilnadu, in 1952 by Lehman and Cutbush. It was later discovered in other states.^[4] However, the incidence varies from 5% to 34% and it is mainly restricted to the tribal population.^[5] A high prevalence of the 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.^[6] The tribal population contributes 15 % of the total population of Gujarat and distributed in various parts of the state such as Sabarkantha, Banaskantha, Panchmahal, Vadodara, Rajpipla, Bharuch, Surat, Valsad, Dang and Div-Daman.^[7] Sickle cell anaemia 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 HbS electrophoresis. The patient suffering from sickle cell anaemia develops blood related complication and can be suspected due to a family history or by conducting clinical examination. But confirmation of case can only be carried out by laboratory investigation. For this blood examination of community at large is needed to estimate the load of cases and carriers of sickle cell anaemia. Conduction of blood investigation of community at large is an exertive and laborious exercise. Many NGOs who are involved with sickle cell anaemia and identification work are doing camps, where large number of people gathers, and their blood samples are collected to carry out laboratory investigation. Sickle cell anaemia is an autosomal recessive disorder in which abnormal haemoglobin leads to chronic haemolytic anaemia with a variety of severe clinical consequences.^[8] On reviewing the international data in various standard textbook publications and various

population based surveys, it is found that sickling positive rate among various tribal populations is somewhere between 20 % to 30 % out of which 1 % to 2.25 % are estimated to be suffering from the sickle cell anaemia.^[9] So to combat against this disease we need to focus on this tribal population. Major steps for prevention is to carry out various programs, surveys, educating and increasing awareness among the people so that maximum active participation is from population can be achieved which is very vital. Success cannot be achieved without people being actively involved and show willingness towards limiting the disease and its consequences including morbidity and mortality which can improve quality of life among this people.

Materials and Methods

It was a Cross Sectional Observational Study with purposive sampling was carried out in all Sickle Cell Anaemia patients in the age group of 18 to 30 years of Bardoli Taluka of Surat District, Which were registered at PHCs of Bardoli region during the period of June 2010 to May 2011. The study included 276 cases of sickle cell including both sickle disease and sickle trait which were registered at PHCs of Bardoli region, in the age group of 18-30 years of age. Sickle cell disease affected patients not in the age group of 18 to 30 years were excluded from the study. Those not willing to participate were also excluded from the study. A pre-tested semi structured questionnaire was used to take interview of the participants. A pilot study to validate the tool was also carried out by interviewing 25 participants. This tool was endorsed with the help of deliberations by faculties of Department of Community Medicine, Government Medical College, Surat. All these individuals with sickle cell trait or disease were contacted at their residence while some of them were interviewed at PHC. All those who were approached gave verbal consent to be part of study. During interview, information was gathered about their knowledge, awareness and practices regarding Sickle Cell Anaemia. Analysis was done with help of Epi Info 7, MS excel.

Results

This study included total 276 cases of which 264 (96%) had Sickle Cell Trait, while 12 (4%) had Sickle Cell Disease. Only 9 % of participants knew that Sickle Cell Anaemia is a hereditary disease. This is the first weak link in knowledge of the high risk population which will need correction rapidly (Table 1). Out of 174 females, only 11 of them knew that SCA is a hereditary disease. While, out of 102 male participants 14 knew about hereditary nature of SCA.

Table-1: Distribution of study participants according to their knowledge of reason for Sickle Cell Anaemia

Cause	Frequency	Percentage
Hereditary	24	8.7
Mosquito Bite	2	0.7
Don't Know	250	90.6

Table-2: Gender wise distribution of study participants according to correct knowledge of hereditary nature of Sickle Cell Anaemia

How sickle cell anaemia occurs?	Sex		Total
	F	M	
Hereditary	11	13	24
Lack of knowledge of reason of occurrence of SCA	163	89	250
Total	174	102	276

Table-3: Distribution of study participants regarding their knowledge and attitude of various aspects of Sickle Cell Anaemia

Questions	Yes	No
Do they know about symptoms of Sickle cell anaemia?	44 (16%)	232 (84%)
Do they know that SCA is more prevalent in tribal communities?	22 (8%)	254 (92%)
Do they know their current Haemoglobin status?	7 (2.50%)	269 (97.50%)
Are they taking any treatment?	89 (32.20%)	187 (67.80%)
Do they feel that, there is a need to inquire about Sickle Cell status of their spouse?	29 (49.15%)	30 (50.75%)

Table-4: Distribution of study participants (who came to know their Sickle Cell Status after marriage) according to time (in relation to important landmarks of reproductive life)

When did you come to know about your status?	Frequency	Percentage
Before 1st Pregnancy	1	0.53
During 1st pregnancy	5	2.67
During 2nd pregnancy	1	0.53
After 1 child	23	12.29
After 2 children	146	78.07
After 3 children	10	5.34
After 4 children	1	0.53
Total	187	100

Table-5: Distribution of Study Participants (whose spouse didn't undergo Screening even after knowing Positive Sickle Cell Status) according to Reason why their respective spouses didn't undergo for screening (N=129)

If spouse not undergone screening (after knowing your status) then, why?	Frequency	Percentages
No response	88	68.1
Afraid of testing	21	16.3
Not available at home	17	13.2
Don't know about this	1	0.8
Expired	1	0.8
Separated	1	0.8
Total	129	100.0

Table-6: Distribution of Study Participants by Regarding Planning for Next Pregnancies (N=217-married)

How did it affect your planning for next / subsequent pregnancies?	Frequency	Percentage
Nothing	65	29.95
No Response	140	64.52
Operated for TL	11	5.07
To keep gap of 2 to 3 years between two pregnancies	1	0.46
Total	217	100

But, the difference in knowledge of the same between two sexes was insignificant (Table 3). The overall percentage of knowledge the correct cause of Sickle Cell Anaemia was low (only 9%). This lack of correct knowledge of cause of

Sickle Cell Anaemia will prevent this tribal high risk population to come to health care facility even if they know about the availability of services of testing for Sickle Cell Anaemia and thus this can affect to a great extent the prevalence of Sickle Cell Anaemia in this community. Lack of significant difference between Male and Female indicated that we will have to increase the knowledge of both sex side by side to change their understanding, attitude and behaviour with regard to this disease.

Only 16 % of the participants knew about the symptoms of Sickle Cell Anaemia. Only 8 % of the participants knew that regarding Sickle Cell Anaemia is more common in Tribal communities. Only 2.50% of study participants knew about their haemoglobin level so majority of participants (about 97.5%) did not know their current haemoglobin level. 30% of participants reported taking some medications for SCA which comprised mainly of Iron and Folic acid (Table 3). Majority (78%) of the participants as per table 4 came to know their Sickle Cell Status after having 2 children. Only one participant who was married, came to know about his/her sickle cell status before 1st pregnancy.

Around 68% did not respond to the question of 'why did not undergo screening after positive Sickle Cell Status?' 16% of the study participants responded that their spouse was afraid of blood testing and 13% were not available at home at the time of mass screening campaign (Table 5). 64% of participants did not respond and 30% of the study participants had changed nothing in their planning for subsequent pregnancies. Only 5% had undergone for permanent sterilization (Tubal Ligation) (Table 6).

Discussion

As per 2011 census, the population of Gujarat has crossed 6 crores.^[10] Gujarat ranks 10th amongst the most populated states of India and is the 7th largest state, area-wise. 14.79% of the population in Gujarat is tribal.^[11] Out of total 26 districts of Gujarat; more than half are tribal districts. Gujarat is the 4th most schedule tribe populated state of India after Madhya Pradesh, Maharashtra and Orissa.

Southern Gujarat includes districts of Dangs, Valsad, Navsari, Surat and Bharuch. The population of Bardoli taluka was 210789 according to census 2001.^[12] Out of which, 99213(47%) of the population belonged to Scheduled Tribe.^[13] The incidence of genetic disorders that cause severe anaemia, including thalassemia and sickle cell disease, is the highest in Gujarat. This is the finding of a

recent study conducted on samples taken from different states by the sickle cell anaemia control programme supported by the Gujarat government. Of the samples from Gujarat examined for the study, 34% were found to have sickle cell anaemia.^[14] In the year 2005-2006, Department of Health & Family Welfare of Government of Gujarat passed a resolution No. S.C.K.-102005, New Matter-10-G dated 30th January 2006, to initiate Sickle Cell Anaemia Control Program in the 4 districts of south Gujarat.^[15] As a part of strategy of Sickle Cell Anaemia Control Programme, mass Sickle Cell Screening was taken up by Government of Gujarat. This study is an effort to reach people in the community mostly in tribal areas, consisting of people in the age group of 18-30 years, who carry abnormal sickle cell gene, and are either suffering from Sickle Cell Trait or from Sickle Cell disease. With this frame in mind, Bardoli taluka of Surat district was selected purposively. Age group of 18 to 30 years was selected for study because Sickle Cell Anaemia is a hereditary disorder, people in the age group of 18-30 years, who carry abnormal gene, are most likely to transmit the same gene to their future generation when they get married. Out of 276 participants, 264 of them had Sickle Cell Trait, while 12 had Sickle Cell Disease. So, 4% of study population had Sickle Cell Disease. On inquiry about symptoms of Sickle Cell Anaemia, only 16% of the study participants knew correct symptoms of SCA. In contrast to this, in a study conducted in Lomé city of Togo (the country located in West Africa), it was found that 78.6% of the participants had a fairly good knowledge of its symptoms.^[16] Regarding their status of availing any treatment for Sickle Cell Anaemia, about 30% of them reported of availing treatment of any form for the same. Ideally a person diagnosed as having Sickle Cell Anaemia should get their haemoglobin level examined every three months.^[17] So inquiry was made regarding same in the present study. It was discouraging to find that only about 10% of the participants got their haemoglobin level examined on regular basis. Out of 276 study participants, 59 were unmarried. These 59 participants were asked if they would like to know the Sickle Cell Status of their future spouse. Almost half of them replied positively. While it is expected that all of the study participants should be curious to know about the Sickle Cell Status of their future spouse, it was not so, which is disheartening.

Conclusion

Overall Knowledge, attitude and practice about sickle cell anaemia is poor because of which we find it difficult to combat against the outrageous disease. So study recommends: (1) Increasing the Awareness about importance of inquiring Sickle cell status of future spouse

is necessity of the time once an unmarried person is tested positive. (2) Health education programme can be started from Schools, as the results have suggested that the school enrolment has improved in this high risk tribal population. We can improve the knowledge about this disease in present students. As they are the future parents, this knowledge will alter their attitude and behaviour regarding this disease and this will help in reducing child births with Sickle Cell Disease. (3) Sickle Cell Anaemia control programme needs to be strengthened by improving in manpower resources especially true in relation to counsellors. There are very less number of counsellors and by increasing the number of counsellors, we can improve the knowledge of Sickle Cell Status positive persons. (4) Prevention entails setting up sickle cell screening and genetic counselling programmes in high prevalence region. Mass screening programme provides an ideal opportunity to make people aware.

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