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A study of Knowledge, Attitude, Practice and Hospital Facilities Provided to Individuals with Positive Sickle Cell status in South Gujarat: A Cross-Sectional Study

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ABSTRACT

Background: Sickle cell disease (SCD) is a group of inherited red blood cell disorders and is a genetically transmitted autosomal recessive hemoglobinopathy that causes significant morbidity and mortality. Sickle cell anemia patients experience blood-related problems, which can be identified through clinical examination or family history. It is connected to episodes of severe illness and the development of organ damage. This causes illnesses that affect not only the organs but also the tissues, increasing the risk of infection and causing painful events such as anemia and tissue damage. Therefore, in order to combat this sickness, we must concentrate on this tribal community. So the aim of our study was to assess the Attitude, Knowledge, Practice and hospital facilities provided to patients with positive Sickle cell anemia status.

Methodology: Total 226 Individuals with Positive sickle cell status who met inclusion and exclusion criteria were recruited in our study. After getting informed consent from participants, a Self structured questionnaire was filled by participants.

Results: Descriptive statistics and frequency analysis was used to analyze the data. Majority of them 212 (93.8) had ever heard about sickle cell anaemia with the highest source of information was from Education (40.7%) followed by health care professionals (34.1%). More than half of the participants (85.4%) knew about signs and symptoms with fatigue (31.8%) and joint pain (20.8%) were the most common one. Majority of the respondents knew how SCD is diagnosed. 154 (68.1%) and 101 (44.7%) participants responded positively to their sickling status and premarital counseling respectively. Near half of the applicable respondent (34.1%) knew about sickling status of their partners before marriage or first child and (32.7%) knew about their children's sickle cell status. 157 individuals were aware of government services in which Anemia Mukt Bharat (87.9%) was most commonly used by them. More than half of the individuals (74.8%) agreed that they are getting high quality care from the hospitals.

Conclusion: Participants had showed moderate knowledge, attitude and practice on Sickle cell disease. Hospitals were delivering high quality care by providing different services and medical facilities among tribal population.

Keywords: Sickle cell disease, knowledge, practice, attitude, hospital, questionnaire

INTRODUCTION

Sickle cell disease (SCD) is a genetically transmitted autosomal recessive hemoglobinopathy that causes significant morbidity and mortality [(1).] The most widespread monogenic blood illness globally is sickle cell disease [(2)]. SCD is a hereditary disorder that comes in a variety of forms, the most prevalent of which is Hemoglobin S (Hb S), which differs from Hemoglobin A (Hb A), the normal hemoglobin. Sickle Cell Anemia is a chronic blood condition that Sickle Cell Anemia sufferers experience when they have two Hb S genes [(3)].The word "sickling" was coined by James B. Herrick, the first doctor to identify the sickle-shaped red blood cells in a Grenadan medical student that could be fatal in 1910[(4).] In the tribal groups of South Gujarat, sickle cell anemia is very common [(1)]. An estimated 312,000 children are born each year with SCD, according to calculations [(2)]. India boasts the world's highest concentration of tribal people, who are thought to have been among the first people to settle in our country [(5)]. The tribal population of Gujarat is dispersed throughout the state in places like Sabarkantha, Banaskantha, Panchmahal, Vadodara, Rajpipla, Bharuch, Surat, Valsad, Dang, and Diu-Daman[(1)]. Numerous tribal groups in South Gujarat, including the Bhils and Dhodias of Panchmahal, the Dublas, Naikas, Koli, Dhanka, Gamit, Vasava, Bariya, Varli, Vaghari, Kukna, Halpati, and Chaudhari, have been found to have a high prevalence of the sickle cell gene[(1)].

This is a hereditary condition with a global distribution that was initially identified in American Blacks. Later, it was found in the Arabian Peninsula, the Indian Subcontinent, and areas of Europe, particularly Greece and Sicily [(1)]. People who have the Sickle cell trait (SCT) who are typically asymptomatic carry one normal gene and one Hb S gene. Sickle cell disease carriers are healthy and typical people who are unaware that they carry the Hb S electrophoresis gene [(3)]. In the tribal communities of the Nilgiri Hills in South India, Lehman and Cutbush provided the first description of sickle hemoglobin in 1952[(4)]. One of the most prevalent inherited conditions in the world; it can affect every organ or system in the human body. Sickle cell anemia patients experience blood-related problems, which can be identified through clinical examination or family history. A chronic hemolytic anemia caused by defective hemoglobin is known as sickle cell anemia, an autosomal recessive condition [(1)]. Sickle cell illness has a significant socioeconomic impact on those who are affected, their families, friends, and communities. This influence extends to the patient's life in terms of their access to education, employment, and psychosocial development [(3)].

SCD cannot be cured, thus specialists have proposed controlling it by premarital and preconception genetic testing, counseling, and education for those with the sickle cell trait [(3)]. Even yet, there have been studies carried out in a number of nations that have assessed the population's awareness, knowledge, and prevalence of SCD [(3)]. It is

connected to episodes of severe illness and the development of organ damage. This causes illnesses that affect not only the organs but also the tissues, increasing the risk of infection and causing painful events such as anemia and tissue damage [(2)]. Fatigue, fever, yellow eyes, recurrent illness, arthralgia, anorexia, potentially harmful and painful bone and joint issues, and pallor are only a few of the clinical signs of sickle cell disease [(3)]. Therefore, in order to combat this sickness, we must concentrate on this tribal community [(1)].

In India, a program to control sickle cell disease was initially put into place in the state of Gujarat in 2006. Here, we provide the preliminary findings of a tribal group in South Gujarat that was subjected to a sickle cell program with few resources [(6)]. This information is essential for highlighting potential areas for development and intervention in order to achieve better results in the prevention, awareness, and knowledge of sickle cell disease [(2)]. Among SCD patients, infection, acute splenic sequestration, hemolytic crisis, and severe anemia are the leading causes of death [(7)]. The variations of hemoglobin are diverse genetically, racially, and geographically [(8)]. In order to attain the greatest level of active engagement from the population, it is important to conduct numerous programs, surveys, educate, and raise awareness among the public. Without active involvement and a commitment to restrict the sickness, success cannot be attained [(1)].

Patients with sickle cell disease frequently have unanticipated, acute disease-related consequences, necessitating several trips to the emergency room and inpatient hospitalization [(9)]. Direct hospital admissions for patients diagnosed with sickle cell trait who are younger than 18 years old have increased statistically significantly between 2006 and 2015[(10)]. The delivery of healthcare has three main challenges: enhancing quality, expanding access, and cutting costs. Because of the poor quality of services provided by the public sector, there has been a continued underutilization of facilities. This has resulted in increased use of private providers [(11)]. Therefore, it has been ruled out of scope for this survey to ascertain the prevalence, attitude, perception, and knowledge of SCD among South Gujarat residents [(1)].

Wide knowledge about Sickle Cell Disease is considered an important strategy in its prevention, as this can provide an opportunity for people to take informed decisions concerning marriage and procreation. Consequently, assessing the knowledge about sickle cell disease can help to develop appropriate public health programs to increase awareness and knowledge about this condition. Hospital Facilities is essential to delivering high quality services and providing an environment of care that aids in treatment outcome as well as patient satisfaction. Our study is focused on the patients' needs and health of individuals and facilities like free health services, free medication, healthy diet and disease prevention awareness. So the aim of our study is to assess the Attitude, Knowledge, Practice and hospital facilities provided to patients with positive Sickle cell anemia status.

MATERIALS & METHODOLOGY

- **Study Design:** A Cross-Sectional study
- **Study Population:** Individuals with Positive Sickle Cell status
- **Sampling Technique:** Convenient sampling
- **Study Duration:** 6 months

- **Study Setting:** PHC's Centre and Hospitals of South Gujarat
- **Sample Size:** 226
- **Outcome measure:** Self-structured Questionnaire consist of Demographic data, 10 questions of Knowledge, 9 questions of Attitude, 6 questions of Practice and 11 questions of Hospital facilities.
- **Inclusion Criteria:**
  - Age Above 18 years
  - Only individual with positive sickle cell status
  - All gender are involved
  - Both married and unmarried participants are taken.
  - All occupations are involved.
- **Exclusion Criteria:**
  - Participants who had not given their consent
  - Excluded other forms of Sickle cell disease
  - Other blood related disorders

PROCEDURE

After getting approval from PHC's Centres and Hospitals in South Gujarat, the background and purpose of the study was explained before administration of Questionnaire. All the participants signed a written informed consent form as a prerequisite to participate in this study. Questionnaire was filled in the known language of participants (English/Gujarati).

STATISTICAL ANALYSIS

The demographic data - Age, height and weight were given as means and standard deviations. Other baseline characteristics and outcome variables were analysed by Frequency analysis. IBM SPSS Statistics for window was used for the analysis. The level of significance was kept "$p<0.05$".

RESULT

The present study included 226 participants with positive sickle cell status with the mean age of 33.07±14.32. Table 1 showed subject characteristics of samples in which there were 89 (39.4%) male and 137 (60.6%) female participants. It showed education level in which majority 89 (39.4%) were graduated and 63 (27.9%) completed their secondary education. 133 (58.8%) participants were married.

Knowledge of participants on Sickle cell disease

From Table 2, majority of them 212 (93.8) had ever heard about sickle cell anaemia with the highest source of information was from Education (40.7%) followed by health care professionals (34.1%). More than half of the participants (85.4%) knew about signs and symptoms with fatigue (31.8%) and joint pain (20.8%) were the most common one. Majority of the respondents knew how SCD is diagnosed. 188 (83.2%) Participants said that SCD is diagnosed by blood test. The highest proportion 111 (49.1%) of the respondents agreed that the chance of having a preterm or low birth weight babies when all the parents have SCD.

Attitude of participants towards Sickle cell disease

Table 3 showed that 154 (68.1%) and 101 (44.7%) participants responded positively to their sickling status and premarital counseling respectively. Near half of the applicable respondent (34.1%) knew about sickling status of their partners before marriage or first child and (32.7%) knew about their children's sickle cell status.

Respondent's practice on Sickle cell disease

From Table 4 below, the majority (63.7%) had tested for SCD, most of the respondents (91.7%) reported that they wanted to know their SCD status as their reason to test and the highest proportion (64.9%) noted that knowing their SCD status influenced or can influence their decision to marry.

Hospital facilities provided to SCD individuals

More than half of the participants (65.9%) preferred to go PHC Centre for the treatment of SCD and majority centres are available near their residential areas shown in Table 5. 157 individuals were aware of government services in which Anemia Mukt Bharat (87.9%) was most commonly used by them. Majority of the participants (72.6%) were getting benefits from Ayushman Bharat Pradan Mantri Jan Arogya Yojana Digital cards where free iron tablets and free hospital services are provided. More than half of the individuals (74.8%) agreed that they are getting high quality care from the hospitals.

Table 1: Baseline characteristics of the Participants (n=226)

Subject Characteristics	Frequency (percentage)
Gender	
Male	89 (39.4)
Female	137 (60.6)
Education Level	
Primary	9 (4.0)
Secondary	63 (27.9)
Higher secondary	57 (25.2)
Graduation	89 (39.4)
Post-graduation	7 (3.1)
Uneducated	1 (0.4)
Marital Status	
Married	133 (58.8)
Unmarried	93 (41.2)

Table 2: Knowledge scores of respondents about Sickle Cell disease

KNOWLEDGE	
Variables	**Frequency (percentage)**
Ever Heard of Sickle cell anemia?	
Yes	212 (93.8)
No	14 (6.2)
Source of information	
Education	92 (40.7)
Family, Friends	57 (25.2)
Health professionals	77 (34.1)
Do you know about signs and symptoms of Sickle cell anemia?	
Yes	193 (85.4)
No	33 (14.6)
Do you have any of these symptoms?	
Fatigue	72 (31.8)
Fatigue, Joint pain	42 (18.6)
Fever	16 (7.1)
Fever, Fatigue, Joint pain	13 (5.8)
Fever, Joint pain	8 (3.5)
Joint pain	47 (20.8)
Others	28 (12.4)

Do you know your current Hemoglobin status?	
Yes	42 (18.6)
No	159 (17.3)
Don't know	25 (11.1)
Does your family/relative have Sickle Cell Disease?	
Yes	92 (40.7)
No	109 (48.2)
Don't know	25 (11.1)
How Sickle cell is diagnosed?	
Blood test	188 (83.2)
Urine test	11 (4.9)
Don't know	27 (11.9)
How Sickle cell prevented?	
Genetic Counseling	128 (56.6)
Testing before marriage	42 (18.6)
Don't know	56 (24.8)
Can Sickle Cell be cured?	
Yes	123 (54.4)
No	72 (31.9)
Don't know	30 (13.3)
Disagree	1 (0.4)
Are Pregnant SCD sufferers prone to preterm or low birth weight babies?	
Yes	3 (1.3)
Don't know	56 (24.8)
Agree	111 (49.1)
Disagree	56 (24.8)

Table 3: Attitude score of respondents towards Sickle Cell Disease

ATTITUDE	
Variables	**Frequency (percentage)**
Do you currently know your sickling status?	
Yes	154 (68.1)
No	71 (31.4)
Not Applicable	1 (0.4)
Do you feel that there is a need to inquire about Sickle Cell status of your spouse?	
Yes	95 (42)
No	80 (35.4)
Not Applicable	51 (22.6)
Do you ever involved in premarital counseling on sickle cell?	
Yes	101 (44.7)
No	74 (32.7)
Not Applicable	51 (22.6)
Did you or your partner know your sickling status before marriage or first child?	
Yes	77 (34.1)
No	73 (32.3)
Not Applicable	76 (33.6)
When did you get to know your spouse sickling status?	
After marriage	57 (25.2)
Before marriage	57 (25.2)
Not applicable	91 (40.3)
Not yet known	21 (9.3)
Will you marry your spouse if both of you have Sickle Cell?	
Yes	85 (37.6)
No	57 (25.2)
Not Applicable	85 (37.6)
Do you know your children's Sickle Cell Status?	
Yes	74 (32.7)

No	56 (24.8)
Not Applicable	96 (42.5)
Do you have chance of getting a healthy baby when the parents have Sickle Cell?	
Yes	74 (32.7)
No	56 (24.8)
Not Applicable	96 (42.5)
If Spouse not undergoing screening (after knowing your status) then why?	
Afraid of testing	19 (8.4)
Don't know	21 (9.3)
Expired	12 (5.3)
Not applicable	172 (76.1)
Separated	2 (0.9)

Table 4: Practice score of respondents on Sickle Cell Disease

PRACTICE	
Variables	**Frequency (percentage)**
Are you taking any treatment of Sickle Cell?	
Yes	173 (76.5)
No	53 (23.5)
Have you ever tested for sickle cell?	
Yes	144 (63.7)
No	82 (36.3)
Reason to test?	
Curiosity	12 (8.3)
To know sickle cell status	132 (91.7)
Did/Would knowing your sickle cell status influence your decision to marry?	
Yes	124 (54.9)
No	102 (45.1)
Comparatively Sickle cell sufferers do not cope up well in life?	
Yes	132 (58.4)
No	94 (41.6)
Medication for people with sickle cell?	
Conventional medicine	101 (44.7)
Don't know	42 (18.6)
Herbal medicine	69 (30.5)
Prayers	14 (6.2)

Table 4: Hospital Facilities scores provided to SCD Participants

HOSPITAL FACILITIES	
Variables	**Frequency (percentage)**
Where do you go for the treatment of sickle cell?	
Hospital	74 (32.7)
PHC Centre	149 (65.9)
Other	3 (1.3)
How far do you have to go for treatment of sickle cell?	
Available at your residential area	158 (69.9)
Far from residential area	68 (30.1)
Are you aware of government services?	
Yes	157 (69.5)
No	69 (30.5)
If yes, which services (yojana) you are getting?	
Anemia Mukt Bharat	138 (87.9)
Poshan Abhiyan-2018	10 (6.3)
Others	9 (5.8)
Do you know about Ayushman Bharat Pradan Mantri Jan Arogya Yojana Digital Card?	
Yes	164 (72.6)
No	62 (27.4)

If yes, what services are you getting?	
Free hospital services	107 (65.2)
Healthy	5 (3.1)
Medicines	35 (21.3)
Others	17 (10.4)
Do the Hospitals / Health centers provide free iron tablets?	
Yes	208 (92)
No	18 (8)
Does your emergency department have protocol for the treating Sickle Cell Disorder?	
Yes	86 (38.1)
No	60 (26.5)
Don't know	80 (35.4)
Do you feel that the treatment you are getting is effective or not?	
Yes	186 (82.3)
No	40 (17.7)
Does hospital staff provide you safe and high quality care?	
Yes	169 (74.8)
No	57 (25.2)
Do you feel that your financial status affect your good health care services?	
Yes	135 (59.7)
No	91 (4.03)

DISCUSSION

The present study aimed to assess the Attitude, Knowledge, Practice and hospital facilities provided to patients with positive Sickle cell anemia status. Total 226 participants were there in our study in which female participants were more compared to male. Maximum participants were educated and graduated.

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 [(4)]. This study is an effort to reach people in the community mostly in tribal areas, consisting of people in the age group of above 18 years, who carry abnormal sickle cell gene, and are either suffering from Sickle Cell Trait or from Sickle Cell disease and it is a hereditary disorder which is most likely to transmit the same gene to their future generation when they get married [(1)].

Most of the participants have heard of SCD which may imply that they know of its existence and large proportion obtained such information from education and health professional or community meeting suggested that there is an increased effort in health care settings/system to inform the public of SCD [(2)]. On inquiry about symptoms of Sickle Cell Anaemia, only 85.4% of the study participants knew correct symptoms of SCA. In our study, fatigue and musculoskeletal pain in the form of joint pain and body pain was observed in 31.8% and 20.8% respectively. Similar findings of common clinical presentation as fever and pain were also observed by Patel Archana et al and in a study by Ibidapo in Nigeria (12, 13). Ideally a person diagnosed as having Sickle Cell Anaemia should get their haemoglobin level examined every three months. So inquiry was made regarding same in the present study. It was discouraging to find that only about 18.6% of the participants got their haemoglobin level examined on regular basis [(1)].

Participants were asked if they would like to know the Sickle Cell Status of their future spouse. Almost half of them replied positively [(1)]. This study recorded 44.7% of respondents undergoing premarital screening and counselling on SCD and also

just about a third of respondents knew their own sickling status or that of their spouses before marriage or first child. Again less than half of respondents knew their children at the time of the study. The overall attitude of respondents towards SCD of 41.7% is rather poor. Similar poor attitudes towards SCD were reported in Oman. (14).

Families have sometimes been identified as precipitators of stigma and discrimination. The results indicate a maximum percentage of people who consider conventional medicine as a form of therapy for sickle cell disease. This is in contrast to another study where rural Ugandans considered prayer as a form of treatment for chronic diseases. This strengthens the need to promote more health education of sickle cell disease and other chronic illness [(2)].

The concentration of hospital care is inherently important in our current healthcare system since patients and their medical health providers are unique to each system or hospital [(9)]. Our findings showed that adults with sickle cell disease are more likely to go to PHC Centre 149 (65.9%) and they are available at their residential area. After collecting the survey samples, our study participants showed that highest services used from Anemia Mukt Bharat about (87.9%). In addition, the hospital health care facilities provide free iron tablets to our study participant as their treatment for acute care. In addition, there is further fragmentation of care at the physician level for individuals who require inpatient hospitalizations given the more recent use of a hospitalists' system of care. Our findings showed that emergency department have better protocol for the treating sickle cell disorder and the treatment that they are getting is effective as well. Study also showed that the hospital staff provides them safe and high quality care, about 74.8% participants have given positive responses. Previously many studies have found that utilization of modern healthcare facilities was very poor among tribal population.

This study had some limitations.

1) The use of closed questions requiring respondents to choose among the options did not permit them to explain their answers hence the introduction of some bias.
2) There was the small sample size from a single area interviewed over a limited period of time. The small sample size affects our ability to generalize the findings.
3) There were least male participants in the study in comparison to female participants.

CONCLUSION

We concluded from our study that Individuals with positive sickle cell status had moderate knowledge about SCD by responding positively to source of information by education, signs and symptoms of SCD, Diagnosis, prevention and complications of SCD. Majority of them knew their sickling status and getting benefited by various services and the emergency department has a better protocol for treating sickle cell disorder delivering high quality care to the survivors.

Declaration by Authors

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REFERENCES

1. Gamit CL, Kanthariya SL, Gamit S, Patni M, Parmar GB, Kaptan KR. A study of knowledge, attitude and practice about

sickle cell anaemia in patients with positive sickle cell status in Bardoli Taluka. Int J Med Sci Public Health. 2014 Mar 1;3(3):365-8.
2. Tusuubira SK, Nakayinga R, Mwambi B, Odda J, Kiconco S, Komuhangi A. Knowledge, perception and practices towards sickle cell disease: a community survey among adults in Lubaga division, Kampala Uganda. BMC Public Health. 2018 Dec;18(1):1-5.
3. Ameade EP, Mohammed BS, Helegbe GK, Yakubu S. Sickle cell gene transmission: Do public servants in Tamale, Ghana have the right knowledge and attitude to curb it?
4. Colah RB, Mukherjee MB, Martin S, Ghosh K. Sickle cell disease in tribal populations in India. The Indian journal of medical research. 2015 May;141(5):509.
5. Gamit C, Patni MM, Gamit S. A cross sectional study to understand socio demographic profile of patients of sickle cell anemia in a Taluka of South Gujarat. International Journal of Community Medicine and Public Health. 2017 Jun;4(6):2167.
6. Desai G, Dave KK, Banerjee S, Babaria P, Gupta R. Initial outcomes of a comprehensive care model for sickle cell disease among a tribal population in rural western India. Int J Community Med Public Health. 2016 May;3(5):1282-7.
7. Nagar S, Patel H. Clinico-Epidemiological Study of Patients Suffering from Sickle Cell Anaemia In a District Level Private Hospital of a Tribal District in South Gujarat.
8. Brahme K, Mehta K, Shringarpure K, Parmar M. Clinical profile of Sickle Cell Disease patients coming to a tertiary care hospital from central Gujarat. Int J Res Med. 2016;5(2):161-4.
9. Panepinto JA, Owens PL, Mosso AL, Steiner CA, Brousseau DC. Concentration of hospital care for acute sickle cell disease-related visits. Pediatric blood & cancer. 2012 Oct;59(4):685-9.
10. Peterson EE, Salemi JL, Dongarwar D, Salihu HM. Acute care utilization in pediatric sickle cell disease and sickle cell trait in the USA: prevalence, temporal trends, and cost. European Journal of Pediatrics. 2020 Nov; 179:1701-10.
11. Andaleeb SS. Service quality perceptions and patient satisfaction: a study of hospitals in a developing country. Social science & medicine. 2001 May 1;52(9):1359-70.
12. Patel Archna et al. Clinical profile of children of sickle cell anemia with reference to oral penicillin prophylaxis. Indian Pediatr 2003; 12(11):1017-21.
13. Ibidapo MO, Akinyanju OO. Acute sickle cell syndromes in Nigerian adults. Clinical & Laboratory Haematology. 2000 Jun;22(3):151–5.
14. Al-Farsi OA, Al-Farsi YM, Gupta I, Ouhtit A, Al-Farsi KS, Al-Adawi S. A study on knowledge, attitude, and practice towards premarital carrier screening among adults attending primary healthcare centers in a region in Oman. BMC Public Health. 2014 Apr 17;14(1).

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