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# SICKLE CELL DISEASES IN NILGIRIS DISTRICT TAMIL NADU - A MICRO ANALYSIS

**Article Particulars**

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## Abstract

*Health is a basic fundamental right of all citizens and health promotion forms an intrinsic part of health care. The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well- being and not merely the absence of disease and infirmity." In recent years, this statement has been modified to include the ability to lead a "socially and economically productive life". Preventive healthcare is an important of health since prevention means avoiding or slowing the course of a disease which is essential for a good quality of life. The health problems need special attention in the context of tribal communities of India. Available research studies point out that the tribal population has distinctive health problems which are mainly governed by their habitat, difficult terrains and ecologically variable niches. The health, nutrition and medico-genetic problems of diverse tribal groups have been found to be unique and present a formidable challenge for which appropriate solutions have to be found out by planning and evolving relevant research studies. Sickle cell anemia continues to be a global health problem that presents major challenges to our health care systems. The reviewed Sickle cell anemia literature indicates a much need for more public education and awareness on Sickle cell anemia in the India especially the tribal parts of the country. Sickle cell Anemia (SCA) and its variants are genetic disorders resulting from the presence of a mutated form of hemoglobin, hemoglobin S (HbS). The most common form of SCA is homozygous HbS disease (HbSS), an autosomal recessive disorder first described by Herrick in 1910. In 1952 Lehmann and Cutbush reported Hb-S in tribal population of Nilgiri in south India. Sickle Cell gene is mainly present amongst tribal group, from malaria endemic forest areas. According to one of the hypothesis, HbS is a natural mutation in Hemoglobin molecule to protect RBCs from malarial parasites by making them a little rigid, so that malarial parasites cannot enter into RBCs. Sickle shaped cells often get entangled resulting in blockage of the blood vessels leading to severe health complications. The present study is proposed to know about the prevalence, incidence treatment seeking behavior and economic burden of Sickle Cell Disease Affected Tribal's in Nilgiris district.*

***Keywords:*** *WHO, Sickle cell Anemia, hemoglobin S, HbS disease, RBCs, Tribal's in Nilgiris district*

## Introduction

The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well- being and not merely the absence of disease and infirmity." It is well recognized that health is not the exclusive domain of medical

science because every culture, irrespective of its simplicity and complexity, has its own beliefs and practices concerning diseases. No culture works in a meaningless fashion in its treatment of diseases in its own way. Thus, treatment of disease may vary from group to group. To understand health and health-related problems in a proper perspective, it is very important to consider the social issues and economic dimensions.

Health is a basic fundamental right of all citizens and health promotion forms an intrinsic part of health care. The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well- being and not merely the absence of disease and infirmity." In recent years, this statement has been modified to include the ability to lead a "socially and economically productive life". Preventive healthcare is an important of health since prevention means avoiding or slowing the course of a disease which is essential for a good quality of life. It is well recognized that health is not the exclusive domain of medical science because every culture, irrespective of its simplicity and complexity, has its own beliefs and practices concerning diseases. No culture works in a meaningless fashion in its treatment of diseases in its own way. Thus, treatment of disease may vary from group to group. To understand health and health-related problems in a proper perspective, it is very important to consider the social issues and economic dimensions.

The health problems need special attention in the context of tribal communities of India. Available research studies point out that the tribal population has distinctive health problems which are mainly governed by their habitat, difficult terrains and ecologically variable niches. The health, nutrition and medico-genetic problems of diverse tribal groups have been found to be unique and present a formidable challenge for which appropriate solutions have to be found out by planning and evolving relevant research studies. Primitive tribal groups of India have special health problems and genetic abnormalities like sickle cell anaemia, G-6-PD red cell enzyme deficiency and' sexually transmitted diseases. (Commissioner Report for Scheduled Tribe and Scheduled Caste, 1986-87). The health and nutrition problems of the vast tribal population of India are as varied as the tribal groups themselves who present a bewildering diversity and variety in their socio-economic, socio-cultural and ecological settings. Nutritional anaemia is a major problem for women in India and more so in the rural and tribal belt. This is particularly serious in view of the fact that both rural and tribal women have heavy workload and anaemia has profound effect on psychological and physical health. Anaemia lowers resistance to fatigue, affects working capacity under conditions of stress and increases susceptibility to other diseases. Maternal malnutrition is quite common among the tribal women especially those who have many pregnancies too closely spaced. Tribal diets are generally grossly deficient in calcium, vitamin A, vitamin C, riboflavin and animal protein.

Sickle cell anemia continues to be a global health problem that presents major challenges to our health care systems. The reviewed Sickle cell anemia literature

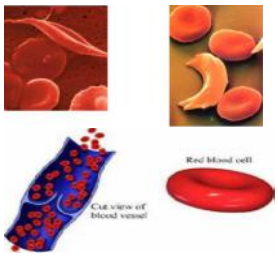
indicates a much need for more public education and awareness on Sickle cell anemia in the India especially the tribal parts of the country. In comparison with other chronic diseases and Hemoglobinopathies, sickle cell disease remains one of the least understood and confusing medical conditions by health care workers and the general public, as well as the least funded blood disorder. In addition, current research on Sickle cell anemia focuses on the awareness of the disease among tribal areas of the Valsad district where majority of the people involved in study are belongs to schedule cast. Socioeconomic condition, lack of education and knowledge are the main issues and therefore, a lack of information exists regarding the awareness among these people. This study hopes to determine whether or not people, who are more likely to be genetically affected by this disease, are more or less aware of their Sickle cell condition or not.

**Economics of Sickle cell**

There is much more that needs to be done to support those who have SCD. Among the most important areas to address is that of economics, for SCD causes tremendous economic hardships for patients and families. Due to its cruel behavioral characteristics including chronic pain, physical debilitation and emotional distress, SCD prevents many otherwise productive citizens from being able to acquire and maintain employment. Many SCD patients live at or below the poverty level. SCD crises, which can last for days or weeks at a time, often require hospitalization and the administration of narcotic pain killers, hydration and blood transfusions. In addition to the suffering caused by the pain and the inconvenience of frequent hospitalizations, SCD families often find themselves overburdened with medical expenses. The economic ramifications of SCD are staggering. It also places an extremely heavy burden on the nation's health care system.

**What is Sickle Cell Disease**

Sickle cell Disease is a genetic disorder related to blood. Where the blood cells contain abnormal hemoglobin (hb) called sickle hemoglobin. As a result red cells which are normally circular in shape, become sickle shaped when exposed to low oxygen levels.



Normal blood cells smoothly pass through blood vessels without any obstruction as given in the following image.

But, blood cells of a Sickle Cell patient assume an abnormal sickle shape and rupture, resulting in blockage of the blood vessels

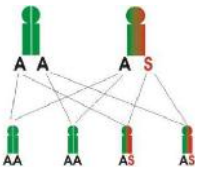
**Transmission**

Sickle Cell Disease is caused only genetically, i.e., always transmitted from parents to their children. It does not get transmitted from one person to the other through any other means. The blood of the parents can be tested in a laboratory (more details of the screening and technical specifications are given in later sections) and we can easily find out if there is a possibility for their children getting the disease.

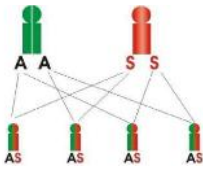
The blood cells of the parents can have one of the three conditions:

1. AA - Blood cells are free of sickle cell trait or disease (ie have normal hemoglobin)
2. AS - Blood cells have sickle cell trait (have per cent normal and per cent sickle Hb)
3. SS - Blood cells have sickle cell disease (have all sickle Hb)

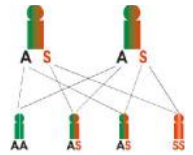
If blood cells of both the father and mother are AA, then there is absolutely no possibility of the child getting the sickle cell disease or sickle cell trait. However, if one or both of them have either the disease or trait, then there is a possibility of their children getting the sickle cell disease or trait.



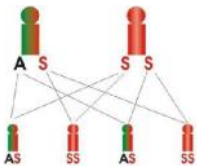

**Scenario 1:** If one of the parents is tested as AA (i.e., free of sickle cell disease and trait) and the other is tested as AS (i.e., with sickle cell trait), then there is no danger that their children will have sickle cell disease. But, there is 50 per cent possibility that their children can have sickle cell trait.



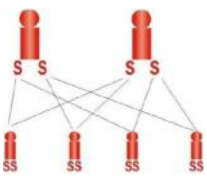

**Scenario 2:** If one of the parents is tested as AA (i.e., free of sickle cell disease and trait) and the other is tested as SS (i.e., with sickle cell disease), then there is no danger that their children will have sickle cell disease. However, all their children will have sickle cell trait. Also if the mother has SS, then there is high risk for her during delivery.




**Scenario 3:** If both the parents are tested as AS (i.e., with sickle cell trait), then there is 25 per cent possibility that their child will have sickle cell disease and there is 50 per cent possibility that their child will have sickle cell trait.




**Scenario 4:** If one of the parents is tested as AS (i.e., with sickle cell trait) and the other is tested as SS (i.e., with sickle cell disease), then there is 50 per cent possibility that their child will have sickle cell disease and there is 50 per cent possibility that it will have sickle cell trait.




**Scenario 5:** If both the parents are tested as SS (i.e., with sickle cell disease), then there is 100 per cent possibility of their child getting sickle cell disease. Besides, the mother will have very high risk during delivery.

Since the disease gets transmitted to the children only from their parents, genetic counseling becomes extremely important in the management of sickle cell disease. (More details about counseling are given in the next section).

**Data Sources and Methodology**

The Nilgiris district is located in the southwest of the Indian Peninsular, bounded on the West by Kerala, on the North by Karnataka on the East and South side by Tamil Nadu. Nilgiris hills are a range of mountains with at least 24 peaks situated at an elevation of 6500 feet above mean sea level in the western most part of Tamilnadu at the junction of Karnataka and Kerala states in Southern India. The Nilgiri hills are vast mountain ranges covering an area of about 2545.40 Sq.km. The district is divided into six taluks viz., Udhagamandalam, Gudalur, Pandalur ,Coonoor, Kotagiri and Kundah consisting of six primitive tribal communities namely Irulas, Kurumbas, Kattunaikans, Panniyas, Kothas and Thodas were the spatial distribution of all communities is uneven. The total population of the district according to latest official figures (2011) is 764,826, of which about one-third is natives or tribal and the rest are migrants. Out of this, the tribal population accounts for 32,048. These tribal communities are not evenly distributed in the four taluks of this district. There is as heavy concentration of about 50 per cent of the tribes in Gudalur and Pandalur Taluk followed by Kotagiri Taluk with 25 per cent of the Tribal population. Udhagamandalam and Coonoor taluks have with 16 per cent and 9 per cent of the tribal population respectively. This geographical distribution has invested the different tribes with district characteristics and mode of living. The hills and forests have been home to these tribes of this area for centuries.

The present study is proposed to know about the prevalence, incidence treatment seeking behavior and economic burden of Sickle Cell Disease Affected Tribal's in Nilgiris district. Among the tribal population of 11,506 in Gudalur Block, 1172 Tribals were affected by sickle cell anemia. In Kothagiri Block , the overall population of 15872 Tribals, it shows a positive sign of 1498 tribals affected by sickle cell anemia. The researcher is planning to collect 50 per cent of the total population of Sickle Cell anemic affected Tribals in Nilgris District. The total sample of the current study will be around 1334 sickle cell affected tribals.

A secondary survey of literature of the sickle cell disease affected tribals will be collected from NGO'S ASHWINI (Association for Health Welfare in the Nilgris) in Gudalur taluk, NAWA (Nilgris Adivasi Welfare Association) in Kotagiri taluk, CTRD (Centre for Tribal and Rural Development Trust) located in Pandalur. After identified the names and address of the sickle cell disease patients in Guddalur, Kotagiri areas of Nilgiri District, interviews will be placed in the hospital/tribal villlages of the sickle cell disease patients. Interview method will be used for collection of data from the patients.

The interview schedule consist of difference section dealing with Demographic, Socio-Economic variables, Health Status, Awareness of sickle cell disease, Screening, Treatment Seeking Behavior, treatment cost incurred on pre-hospitalization, hospitalization and post hospitalization (one month, six months and past one years) for diagnostics, drugs and transportation respectively. In case of multiple illnesses in the

reference period information will be gathered for each separately. To estimate indirect costs, survey also collected information on days of work lost by the respondents and others and value of forgone earnings. Healthy year of life lost of daily, source of finance, Awareness, Counseling and willingness to accept or utilize the Medical services provided by the Government, Non-Governmental Organisations and impact of the sickle cell Anemia intervention.

**Table 1 Health Status, Illness last 30 days, and Illness during Last 365 Days of Sickle Cell Disease Tribals**

| Health Status, Illness last 30 days, Chronic and Hospitalized last 1 Year | | Sickle cell patients |
|---|---|---|
| SCD | Yes | 313 |
| Health Status | Very good | 15 (4.8) |
| | Moderate | 47 (15) |
| | Bad | 181 (57.8) |
| | Very bad | 70 (22.4) |
| Sick On Last 30 Days | Yes | 217 (69.32) |
| | No | 96 (30.68) |
| Illness during Last 365 days | Yes | 313 (100.0) |
| | **Total** | **313 (100.0)** |
| **Source:** Primary Data | | |

Health status of the Sickle cell disease patients and their sickness is given in Table 1.

Among the sickle cell disease affected Tribals (313), the researcher asked the general health status of the diseased tribals. Nearly three-fifths of the Sickle Cell Disease patients expressed their opinion their bad health status and more than one-fifths of the Sickle cell Disease tribals expressed their view on their health status very bad condition due to this disease. The data also reveals that 80 per cent (251 Sickle cell diseased Patients) expressed their opinion on either bad health status or very bad health status. Only less than five percent (15 Sickle cell Patients) of the Sickle cell disease patients view that they have good health status though they have Sickle cell disease and 47 Sickle cell disease. Sickle cell disease affected tribals expressing their opinion that they were moderate health status. The researcher observed that all the Sickle cell disease affected tribals were having very bad health status and they don't understand the nature of the disease.

The researcher the asked the Sickle cell disease affected tribals regarding the illness during the last 365 days, they opined that nearly 70 per cent (217 tribals) were fall under sick during the last 30 days and only 30 per cent of Sickle cell disease affected tribals were not fall sick for the last 30 days. It explains that Sickle cell disease affected patients were fall sick within 30 days at the time of the field survey. The research also asked the Sickle cell disease patients, for the last one year, the Sickle cell disease tribals admitted hospital for taking treatment related to Sickle cell disease. They all expressed their opinion that all the sample Sickle cell disease affected tribals were admitted hospital for taking treatment related to Sickle cell disease. The researcher's observation in the field that, all the Sickle cell disease affected tribals were hospitalized maximum of six times for taking treatment related to Sickle cell disease.

**Table 2 Treatment Seeking Behaviour and Demand for Health care Service by the Sickle Cell Disease affected Tribals in Nilgiri District**

| Treatment Seeking Behaviour at Hospital | | Sickle Cell Patients |
|---|---|---|
| If Sick Are You Going For Hospital | Yes | 279 (89.1) |
| | No | 34 (10.9) |
| | Waiting For Mobile Van | 34 (10.9) |
| | **Total** | **313 (100)** |

**Source:** Primary Data

Regarding the treatment seeking behavior of the Sickle cell disease affected tribals, out of the total Sickle cell disease affected tribals (313 Sickle cell disease) patients, nearly 90 per cent of the Sickle cell disease they opted for treatment at nearby hospitals and 11 per cent of the Sickle cell disease affected expressed their opinion that they were not opted for treatment at hospitals. They opined that they were taking treatment at the time of Mobile van's (Mobile hospital van visiting regularly once in a month) arrived at their respective villages. The researcher also observed that the mobile hospital van visiting tribal villages regular intervals as per the Scheduled given by the NGO hospital. Each village the mobile arrival and the time were known by the respective village tribals.

The Mobile van visiting time, date already given and availability to their respective villages. The tribals also know the visiting day of mobile hospitals van services to the Sickle cell disease affected tribals.

**Age of Screening, Symptoms of Sickle Cell Disease, Disease Status at the Time of Screening Current Status and Reason for Sickle Cell Patients**

The age of identification of Sickle cell disease or Screening of Sickle cell disease, Symptoms and reasons for Sickle cell disease were analysed in the Table 3.

The age identification of Sickle cell disease among the 313 Sickle cell disease patients, two-fifths of the Sickle cell disease patients were identified through screening process of Sickle cell disease fall under the age group category of 16-25 years, one-fourth of the Sickle cell disease identified below the age group of 15 years. Nearly one-fifth of the Sickle cell disease know the Sickle cell disease of his/her system at the age group of 30 to 35 years of age and 51 Sickle cell disease patients (16.24 per cent) know their disease above 35 years of age only. The data shows that Sickle cell disease affects the different age groups, it affects more in the prime age group of 16-25 and below 15 years of age. The data explains that the sickle cell disease may affect all the age group. The symptoms of Sickle cell disease identified and classified into five categories. Out of the total Sickle cell disease patients (313 tribals) more than one-third understands the Sickle cell.

**Table 3 Age They Screen SCD, Symptoms of SCD, At First of Screening Time You Have AS or SS, Now You Have AS or SS and Reason for SCD of Sickle Cell Patients**

Disease through the symptom of low hemoglobin Count (Anemia) and 30 per cent of the Sickle cell disease patients (94 patients) they know Sickle cell disease through the body pain, 48 tribals know Sickle cell disease through some damage of the body organ

and 21 Sickle cell disease patients expressed their opinion that they have bone Abnormalities in their body. After the screening process, they have classified AS (SCD traits), SS (SCD confirmed) ot AA (No Sickle cell disease). Based on this criterion, at the time first screening they know whether they are AA, AS and SS category. Out of 313 Sickle cell disease patients, from screening nearly three-fourth of the Sickle cell disease patients (227 patients) fall under the category SS category the remaining one-fourth of the Sickle cell disease confirmed and were belong to the category of AS (Sickle cell traits).

| **Age They Screen SCD, Symptoms of SCD, At First of Screening Time You Have AS or SS, Now You Have AS or SS And Reason For SCD of Sickle Cell Patients** | | **Sickle Cell Patients** |
|---|---|---|
| Are You A Sickle Cell Patient | Yes | 313 (100.00) |
| Age of Screening | Below 15 Years | 76 (24.30) |
| | 16- 25 | 126 (40.10) |
| | 26- 35 | 60 (19.20) |
| | Above 35 | 51 (6.70) |
| | 49 | 7 (2.20) |
| Symptoms of SCD | Low Hemoglobin Count (Anemia) | 116 (37.10) |
| | Infections | 34 (10.90) |
| | Body Pain | 94 (30.00) |
| | Damage To Various Body Orgns | 48 (15.30) |
| | Bone Abnormalities | 21 (6.70) |
| At the time of screening disease status by SCD | AS | 86 (27.50) |
| | SS | 227 (72.50) |
| Present Status Disease | AS | 86 (27.50) |
| | SS | 227 (72.50) |
| Reason for SCD | Hereditary | 180 (57.50) |
| | Do Not Know | 133 (42.50) |
| | **Total** | **313 (100.00)** |
| **Source:** Primary Data | | |

The researcher also wants to know the present status of the Sickle cell disease, at the time of field survey more than four-fifths of the patients were fall under the category of SS (SS-category Sickle cell disease) and 56 patient were under the category of AS (AS- Sickle cell disease- traits) which shows that nearly 10 per cent of the AS tribals become the SS category. Reasons for Sickle cell disease, expressed by the tribals, out of the total Sickle cell disease patients nearly three-fifth of the patients gave their opinion that the hereditary is the reason for the Sickle cell disease and more than two-fifths expressed their opinion that they don't the exact reasons behind the Sickle cell disease. Without knowing the prevalence of reasons for this diseases the tribals population were suffering lot with their Sickle cell disease.

**Marriage Counseling**

Marriage counseling for the Sickle Cell Patients and its process is given in Table 4.8.

Marriage counseling and its process of Sickle Cell Patients in Nilgiri district, the researcher approached the sickle cell patients, before your marriage you know, you are having Sickle Cell, more than half of the Sickle Cell Patients were know they all having Sickle cell Disease and little less of the Sickle Cell Patients were not know they were having sickle cell disease.

The researcher get opinion from the Sickle Cell Patients, before marriage you can understand that the your life partner has sickle cell or she is suffering of Sickle Cell disease, out of 313 Sickle Cell patients, nearly one- third of the Sickle Cell disease patients has Sickle Cell and more than two-third of the Sickle Cell disease patients were don't know his/her life partner has Sickle Cell disease. The data shows that without

knowing the consequences of the Sickle Cell disease, the tribals getting married with a sickle cell girl or boy, they again Sickle Cell transmitted to his/her son or daughter. This process was continuously going on among the Sickle Cell patients. This was the main reason for not abolishing the Sickle Cell among the tribals in Nilgiris.

Regarding the marriage counseling more than three-fifths of the Sickle Cell disease patients was undergone marriage counselling an two-fifths of the Sickle Cell disease patients were not marriage counseling the researchers get information related to who gave marriage counseling. Among the marriage counseling attended Sickle Cell Patients (192 tribals), nearly 87 per cent ie., 167 tribals were get marriage counseling from the NGO's and rest of the 13 per cent (25 tribals) were get marriage counseling from the friends and family members in the Nilgiri District.

**Table 4 Marriage Counseling and its Process**

| Marriage Counseling and its Process | | Sickle Cell Patients |
|---|---|---|
| Before Marriage You Know You Have SCD | Yes | 166 (53) |
| | No | 147 (47) |
| Before Marriage You Know Your Wife Have SCD | Yes | 93 (29.7) |
| | No | 220 (70.3) |
| Had Marriage Counseling | Yes | 192 (61.3) |
| | No | 121 (38.7) |
| Who Give Marriage Counseling | No Marriage Counseling | 121 (38.7) |
| | Friends | 12 (3.8) |
| | Family | 13 (4.2) |
| | NGO | 167 (53.4) |
| You Know SCD Is Genetical Disease | Yes | 191 (61) |
| | No | 122 (39) |
| Are You Agree The Marriage Counseling | No Marriage Counseling | 121 (38.7) |
| | Yes | 77 (24.6) |
| | No | 115 (36.7) |
| | **Total** | **313 (100)** |

**Source:** Primary Data

The awareness of Sickle Cell Patients the researcher asked the tribals the Sickle Cell Patients is genetically transmitted to their children. Among the 313 Sickle Cell Patients affected tribals, opined that three-fifths of the tribals gave their opinion that they asked yes and two-fifths of the tribals were opined that this disease was genetic disorder. They don't understand how it comes.

Among the tribals they don't know the importance of counseling process. The researcher expressed and after the knowledge about marriage counseling. Among the 313 tribals, only 192 tribals were knowing about the marriage counseling and the reaming tribals don't know about the marriage counseling. Among the marriage counseling attended (tribals 192), two fifth of the tribals were accepted the marriage counseling and remaining three-fifth of the tribals were not interested to get marriage counseling. The data reveals that three-fourth of tribals were not interested to get the marriage counseling in Nilgiri District.

## Choice of Hospital

**Table 5 choice of Hospital**

| Choice of Hospital | Sickle Cell Patients |
|---|---|
| NGO | 186 (59.4) |
| Government | 127 (40.6) |
| Private | - |
| **Total** | **313 (100)** |

**Source:** Primary Data

The choice of hospital by the Sickle Cell disease affected tribals in Nilgiris District is given in table 4.13.

The choice of hospital by the Sickle Cell disease affected patients, nearly three-fifths of the tribals, (186

the Sickle Cell disease tribals), were opted for NGO Hospital, ASWINI in Gudalur, NOVA in Kothagiri, another two-fifth of the tribals were taking treatment in government hospital in guideline and Kothagiri. Among the total tribal, no one opted for private hospital for taking treatment of the Sickle Cell disease. The researcher also find that moderate, bad and very bad health conditions. The reasons for not opted for private hospitals, the Sickle Cell disease tribals expressed two reasons viz., high cost for treatment and there was no special care for Sickle Cell disease treatment. All Sickle Cell disease tribal patients opted for NGO hospital and Government hospital of Nilgiris District.

**Utilisation of Diagnostic Test and its Process**

The opinion of Blood-Test, Sickle cell Disease related health services presented in Table 6

**Table 6 Utilisation of Healthcare Services (Diagnostic Test)**

| **Utility of Blood Test, SCD Service, Mobile Van Service, Bed Grand** | | **Sickle Cell Patients** |
|---|---|---|
| Blood Test | Very Good | 26 (8.3) |
| | Good | 237 (75.7) |
| | Moderate | 50 (16) |
| SCD Service | Good | 222 (70.9) |
| | Moderate | 67 (21.4) |
| | Bad | 24 (7.7) |
| Mobile Van Service | Very good | 6 (1.9) |
| | Good | 232 (74.1) |
| | Moderate | 75 (24) |
| Bed Grand Service | Very good | 10 (3.2) |
| | Good | 224 (71.6) |
| | Moderate | 79 (25.2) |
| | **Total** | **313 (100)** |

**Source:** Primary Data

The health services received by the Sickle cell Disease patients from the mobile van services to the respective villages of tribals. Regarding the blood test, the opinion from the Sickle cell Disease affected tribals taking blood test from the mobile van services provided by the NGO in Gudalur and Kothagiri. Out of 313 Sickle cell Disease affected patients opinion regarding blood test process by the mobile van. Among the total tribals (313) more than three-fourth opined that it was good as 16 per cent expressing that the services by the mobile van regarding the blood test process was moderate and only eight per cent viewed that the blood test process was very good.

Sickle cell Disease related services by the mobile van to the tribal villages, out of 313 tribal Sickle cell Disease affected patient, 70 per cent (222 tribals) were given their opinion of good and one-fifth of the Sickle cell Disease patients expressing their opinion of moderate services. Out of 7.7 per cent (24 tribals) expressing the treatment process related to Sickle cell Disease services was bad. The opinion of regular visit of mobilr van, three-fourth of the Sickle cell Disease patients expressing their opinion of good services by the mobile an, nearly one-fourth of the Sickle cell Disease patient view that the services was moderate and less than two percent (six Sickle cell Disease patient) accepted that services and they worked very good services provided by the mobile van to the tribal villages.

Bed Grant Services: It was received by the Sickle cell Disease patients from the NGO, nearly three-fourth of the Sickle cell Disease patients expressing that it was good and one-fourth if the Sickle cell Disease patients viewed that the bed grand services

provided by the NGO to the Sickle cell Disease was moderate. Only 10m Sickle cell Disease tribals that bed grand services provided by the NGO were very good.

**Satisfaction of the Sickle cell Disease Health Program of the Government**

The Sickle cell Disease program implemented by the NGO hospital to the near by tribal villages of the Nilgiri district. The researcher gets opinion from the services rendered by the NGO in these areas. The level of satisfaction, use of the medical care, improvement of healthcare and other benefits by Sickle cell Disease patients is given in Table 7.

The Sickle cell Disease program implementation by the NGO's hospital in these regions, the opinion received from the Sickle cell Disease patients. Among the 313 Sickle cell Disease affected Sickle cell Disease patients nearly 70 per cent of the Sickle cell Disease patients were accessed that the patients were satisfied the Sickle cell Disease program, willing to take treatment in NGO hospital. This program reduce the practice of reduce the traditional medical intake, benefirs received from the NGO for their services, Awareness of Sickle cell Disease from the NGO's mobile medical care unit or hospitals, this programme reduces the financial shows in the medical care cost and other available services for the Sickle cell Disease patients in the Nilgiri District. The rest of 30 per cent of the Sickle cell Disease affected patients expressed their view on the above facilities , they received less than their expectation level as very few Sickle cell Disease affected patients expressed their opinion of not satisfaction the services from the NGO's mobile van medical care unit or hospital in the Nilgiri District.

**Table 7 Sickle cell Disease Health Program of the Government**

| Sickle cell Disease Health Program of the Government | Obseravtion about the Program | Frequency |
|---|---|---|
| SCD Programme Satisfied | Yes, Definitely | 241 (77) |
| | May Be/Some What | 72 (23) |
| Willing To Take Treatment In NGO | Yes, Definitely | 245 (78.3) |
| | May Be/Some What | 66 (21.1) |
| | Definitely Not | 2 (0.6) |
| NGO Programme Reduce Tradition Medicine | Yes, Definitely | 251 (80.2) |
| | May Be/Some What | 52 (16.6) |
| | Definitely Not | 10 (3.2) |
| Use Fullness Of NGO | Yes, Definitely | 221 (70.6) |
| | May Be/Some What | 83 (26.5) |
| | Definitely Not | 9 (2.9) |
| Is SCD Scheme Improved Health Awareness | Yes, Definitely | 169 (54) |
| | May Be/Some What | 122 (39) |
| | Definitely Not | 22 (7) |
| SCD Programme Reduces Financial Burden | Yes, Definitely | 215 (68.7) |
| | May Be/Some What | 98 (31.3) |
| Avail The Facility Of SCD Programme | Yes, Definiterly | 212 (67.7) |
| | May Be/Some What | 101 (32.3) |
| | **Total** | **313 (100)** |
| **Source:** Primary Data | | |

**Direct Cost Incurred by the Sickle Cell Patients-Hospitalisation**

The direct cost included in taking treatment by the Sickle Cell patients in Nilgiris District has classified into Admission Cost, Doctor's Fees, Screening Test Charges, Blood test Charges Expenses for Iron Tablets, Vitamin Tablets, Vaccines Charges, X-Ray Charges are classified and presented in Table 8

**Table 8 Direct Cost of Admitted Sickle Cell Patients**

| Direct Cost | | Sickle Cell Patients |
|---|---|---|
| Admission Fee | Up to 10 | 257 (82.1) |
| | 11 – 20 | 21 (6.7) |
| | 21 – 30 | 26 (8.3) |
| | 31 – 40 | 9 (2.9) |
| Doctor Fees | Up to 10 | 49 (15.7) |
| | 11 – 20 | 124 (39.6) |
| | 21 – 30 | 102 (32.6) |
| | 31 – 40 | 6 (1.9) |
| | 41 – 50 | 32 (10.2) |
| Screening | Up to 20 | 21 (6.7) |
| | 21 – 40 | 216 (69) |
| | 41 – 60 | 20 (6.4) |
| | 61 -80 | 24 (7.7) |
| | 81 – 100 | 32 (10.2) |
| Blood Test | Up to 20 | 129 (41.2) |
| | 21 – 40 | 120 (38.3) |
| | 41 – 60 | 26 (8.3) |
| | 61 -80 | 6 (1.9) |
| | 81 – 100 | 32 (10.2) |
| Iron Tablets | No Iron Tablets | 174 (55.6) |
| | Up to 20 | 70 (22.4) |
| | 21 – 40 | 20 (6.4) |
| | 41 – 60 | 39 (12.5) |
| | 61 -80 | 10 (3.2) |
| Vitamin Tablets | No Vitamin Tablets | 64 (20.4) |
| | Up to 20 | 103 (32.9) |
| | 21 – 40 | 32 (10.2) |
| | 41 – 60 | 96 (30.7) |
| | 61 -80 | 18 (5.8) |
| vaccines | Up to 10 | 137 (43.8) |
| | 11 – 20 | 118 (37.7) |
| | 21 – 30 | 9 (2.9) |
| | 31 – 40 | 17 (5.4) |
| | 41 – 50 | 22 (7) |
| | Above 50 | 10 (3.2) |
| X-Ray | No X-Ray | 244 (78) |
| | Up to 100 | 11 (3.5) |
| | 101 – 200 | 9 (2.9) |
| | 201 – 300 | 6 (1.9) |
| | 301 – 400 | 15 (4.8) |
| | 401 – 500 | 28 (8.9) |
| Operation | No Operation | 269 (85.9) |
| | Up to 1000 | 10 (3.2) |
| | 1001 – 2000 | 22 (7) |
| | 2001 – 3000 | 6 (1.9) |
| | 3001 – 4000 | 6 (1.9) |
| Others | Up to 20 | 111 (35.5) |
| | 21 – 40 | 169 (54) |
| | 41 – 60 | 11 (3.5) |
| | 61 – 80 | 22 (7) |
| | **Total** | **313 (100)** |

**Source:** Primary Data

**Admission Fees:** Regarding the Admission fees of the Sickle Cell Disease patients pald to the NGO hospital, one of 313 Sickle Cell patients paid Rs. 10 as Admission at the time of their visit to NGO Hospitals and the remaining one-fifths paid Rs. 20, (6.7 per cent) as Rs. 30 (8.3 per cent of the Sickle Cell Disease patients) as Rs. 50 paid by the nine Sickle Cell Disease patients at the time of visit for their treatment respectively. The data reveals that NGO hospital was collecting some of money in the form of Admission fees.

**Doctor's Fees:** The NGO hospitals also collected the fees for the physician from the Sickle Cell Disease patients, out of 313 Sickle Cell Disease patients, two-fifths of the Sickle Cell Disease patients were paid Rs. 20 in doctor's fees and nearly one-third were paid Rs. 30 and rest of the Sickle Cell Disease patients were paid different amount to the hospital as physician fees during their treatment period.

**Vitamin Tablet:** For Sickle Cell Disease patients, there is a regular intake of vitamin Tablets out of 313 Sickle Cell Disease patients nearly one-third were paid Rs. 20 and cost of the tablets are less than one-third of the Sickle Cell Disease patients were paid Rs. 50 as Vitamin Tablets. Nearly one-fifth of the Sickle Cell Disease affected patients were received their vitamin Tablet as free of cost for the remaining Sickle Cell Disease affected patients from the NGO Hospital.

**Vaccines:** Regarding the Vaccines the cost incurred by the Sickle Cell Disease patients, more than two-fifths of the Sickle Cell Disease patients (44 per cent) were paid Rs. 10 as vaccine cost and nearly two-fifths of the Sickle Cell Disease patients were paid Rs. 20 as Vaccines fees to the hospital remaining one-fifths of the Sickle Cell Disease patients were paid between Rs. 30 and Rs. 100 as vaccines fees to the hospitals.

**X-Ray:** Out of th313 Sickle Cell Disease patients, nearly four-fifths of the Sickle Cell Disease patients were not incurred any cost for taking X-Ray as remaining one-fifths of the Sickle Cell Disease patients were paid different cost for X-Rays to NGO hospital between Rs. 70 and Rs. 200.

**Screening:** In the Screening process, the NGO hospital collecting money from the Sickle Cell Disease patients. Among the 313 Sickle Cell Disease nearly seven per cent of them paid Rs. 40 as screening fees and the remaining Sickle Cell Disease patients were paid different amount like Rs. 20, Rs. 70, Rs. 100 and Rs. 300 as screening test fees to the hospital.

**Blood Test:** Out of the 313 Sickle Cell Disease patients, more than two-fifths were paid Rs. 20 as fees for the Blood test towards to Blood Test Charges as the remaining one-fifths paid Rs. 50 and Rs. 100 respectively for the Blood Test Charges.

**Iron Tablet:** Out of the 313 Sickle Cell Disease patients, more than half of the Sickle Cell Disease patients were received Iron Tablet as free cost and the remaining 44 per cent of the Sickle Cell Disease patients 22.4 per cent were paid Rs. 20 as Iron Tablet charges and the remaining 49 Sickle Cell Disease patients were paid Rs. 40 and Rs. 50 respectively for their Iron Tablets from the NGO Hospital.

**Indirect Cost incurred by the Sickle Cell patients-Hospitalisation**

The Indirect cost of Sickle Cell Disease patients during the hospitalization is analysed in Table 9.

**Transport Cost:** The total transport cost incurred by the Sickle Cell Disease patients, out of 313 Sickle Cell Disease patients, nearly half of the Sickle Cell Disease patients incurred a Transport Cost of Rs. 100 for reaching Hospitals from their tribal village and one-third of the Sickle Cell Disease patients were incurred Rs. 200 as transport cost for their risk to hospital for taking treatment. The remaining 34 Sickle Cell Disease patients were incurring of Rs. 300 and Rs. 1000 respectively for their transport cost.

**Wage Loss:** During the hospitalization period, among the Sickle Cell Disease patients (313), the wage loss incurred by the Sickle Cell Disease patients, more than half of the Sickle Cell Disease patients, more than half of the Sickle Cell Disease tribals had a wage loss of Rs. 200 during their treatment process and more than one-fourth were incurred a wage loss of up to Rs. 400 during their hospitalization period. The remaining nearly one-third of the Sickle Cell Disease patients were opined that they incurred a wage loss of Rs. 400 ad above and source of the tribals expressed that they incurred a wage loss of up to Rs. 3000, it is bared on the days of treatment during the hospitalization period.

**Table 9 Indirect Cost incurred by the Sickle Cell Patients- Hospitalisation**

| Indirect Cost | | Sickle Cell Patients |
|---|---|---|
| Transport | Up to 100 | 155 (49.5) |
| | 101 – 200 | 105 (33.5) |
| | 201 – 300 | 12 (3.8) |
| | 301 – 400 | 22 (7) |
| | 401 – 500 | 9 (2.9) |
| | 501 – 600 | 10 (3.2) |
| Wage Loss | Up to 200 | 161 (51.4) |
| | 201 - 400 | 81 (25.9) |
| | Above 400 | 71 (22.7) |
| Care taker Expenses | Up to 100 | 111 (35.5) |
| | 101 - 200 | 80 (25.6) |
| | 201 - 300 | 21 (6.7) |
| | 301 - 400 | 101 (32.3) |
| Care taker Wage Loss | Up to 100 | 50 (16.0) |
| | 101 - 200 | 179 (57.2) |
| | 201 - 300 | 84 (26.8) |
| | **Total** | **313 (100)** |

**Source:** Primary Data

**Caretaker Expenses:** The caretaker expenses incurred by the Sickle Cell Disease patients during the hospitalization period, out of 313 Sickle Cell Disease tribals, more than one-third had a expressed Upto Rs. 100 and one-fourth of the Sickle Cell Disease patients spends between Rs. 10o and Rs. 200. Nearly one-third of the Sickle Cell Disease patients spends between Rs. 301-400 for care taker expenses and only 21 Sickle Cell Disease patients spends Rs. 201-300 for the caretaker during the hospitalization period.

**Caretaker Wage Loss:** Regarding the wage loss of the caretaker of Sickle Cell Disease patients during the hospitalization treatment. Among the care taker of 313 Sickle Cell Disease patients, nearly three-fifths of the care taker had a wage loss of Rs. 101-200 and more than one-fourth of the caretaker had a wage loss of Rs. 201-300 and very few opinion that they had a wage loss Up to Rs. 400 and 16 per cent were gave their opinion of wage loss RS. 100 by the caretaker. Regarding the visitors expenses among the total Sickle Cell Disease patients, nearly 90 per cent spends upto Rs. 50 as visitor's expenses during their hospitalization stay.

**Concluding Observation**

There is a greater worldwide awareness that sickle cell anemia is a chronic disease, which is the consequence of a genetic mutation. Since the observation made by James Herrick in 1910, great strides have been made in our knowledge and understanding of this inherited disease and how to best treat and manage it. Screening programs and early preventive measures have improved health outcomes for most patients. Life expectancy of patients with the disease continues to raise, with better quality of life now a qualified possibility. With BMT, a cure is now possible for some patients when genetically matched donors are available. Hydroxyurea treatment to increase fetal hemoglobin level is effective in ameliorating the disease symptoms, and various anti-sickling agents are under trial. New therapies such as nitric oxide treatment and gene replacement theraphy are on the horizon. Unlike in the recent past when patients with this debilitating chronic disease were condemned to a certainty of early death, early preventive intervention and accessibility to modern medicine and medical technology have now given patients greater hope and a

better lease on life. The future for new therapies looks promising, but the appropriate role for many of these therapeutic interventions remains to be determined.

Most of the tribal populations where sickle cell disease is common rely on the primary healthcare facilities in rural and often remote areas. Thus, the goals of medical genetic services should be to help these people with a genetic disadvantage and their families to have access to quality care as well as social and genetic counseling support to make informed choices for reproduction to have healthy children with the availability prevention programmes when needed. The Indian Council of Medical Research (ICMR) under its tribal Health Research Forum (THRF) activities as well as other programmes under the National Rural Health Mission (NRHM) in different states have initiated programmes to enable advances in genetics to reach these communities.

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