

## Distribution of Sickle Cell Disease Among Tribal Population of Nilgiri District of Tamil Nadu



### Environment

**KEYWORDS :** Tribe; consanguinity marriage; ethno medicine; Sickle cell disease; GIS

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### ABSTRACT

*Tribes are the integral part of our civilization. The scheduled tribal population of Tamilnadu was found to be 6.51 lakhs constituting 36 tribes which include six primitive tribal communities in Nilgiri district. Sickle cell anemia is one among and is a major health concern for the tribes in Nilgiri district whose control and cure are still under medical research. GIS is commonly used to combine spatial data from different sources, for mapping disease and for performing spatial analyses to identify the high risk areas. Hence, there is a need to map the prevalence of this gene (i.e.) its variation in different tribal groups and within tribal group that spread over a large area. This paper focuses to study the ethnic population in Nilgiris and the prevalence of SCD with relation to gender, age, disease pattern and community. The spatial variation of SCD based on taluk and village level are analysed using Geographical Information System (GIS). Out of 55 village panchayats 33 villages are identified as infected with SCD in which female incidence was observed high when compared to male with carrier state. GIS mapping would help us to update information and to identify the trouble spots at the village level within the district and the policy makers to formulate the control strategy indentifying areas where greatest efforts should be focused. However, the disease impact in terms of speed of spread varies with demographic profile helps in also identifying the most exposed or effected tribe in the study area.*

### 1. Introduction

Tribes are an integral part of our civilization but they mark distinct difference from the ordinary population in terms of defying change. According to anthropologist T.B.Nayak 1988 "A Tribe is a social group with territorial affiliations, endogamous, with no specialization of function, ruled by tribal officers, hereditary or otherwise, united in language or dialect, recognizing social distance with tribes or castes without any as it does in caste structure, following tribal traditions, beliefs and customs illiberal of naturalization of ideas from alien sources, above all conscious of a homogeneity of ethnic and territorial integration". India possesses a total of 635 tribal groups and subgroups including 75 primitive communities (Balgir 2006). The scheduled tribal population of Tamilnadu was found to be 6.51 lakhs widely distributed in 30 districts constituting 36 tribes. The Nilgiri district includes six primitive tribal communities viz., Todas, Kothas, Kurumbas, Irulas, Paniyas and Kattunaikkans unevenly distributed in forest and hilly areas of six taluks of this district. Though they live in constant and close contact with each other, they possess distinct culture, linguistic religion, moral values, tradition, folklore styles and food habits.

These tribal groups who are exposed to various environmental stresses are mainly characterised by their individual socio-economic, socio-cultural and socio-biological set up. Hence, the health of these tribal groups is as such a function of the interaction between socio-cultural practices, genetic characteristics and the environment conditions. The widely varying prevalent health practices, use of indigenous herbal drugs, taboos and superstitions are also responsible for determining the health behaviour and health status of the tribal groups. (Basu 1994).

#### 1.1 Nilgiri Tribal Culture

"A culture that complex whole which includes knowledge, belief, art, moral, law, customs and any other capabilities and habits acquired by man as a member of society" (Tylor 1874). Culture also includes all the elements in man's old endowment that he has acquired from his group by conscious learning or by a conditioning process - techniques of various kinds, social and other institutions, beliefs and patterned modes of conduct (Herskovits 1955). Marriage is universal form that has been accepted by all. It varies from culture to culture and people to people. The commonly known forms of marriage are monogamy, polygamy and polyandry.

#### 1.1.1 Thodas

The Thoda are the original inhabitants of The Nilgiris Hills and they are one of the most picturesque tribes in India. Classically described as patriarchal, the Thodas actually possess some patrilinear and matrilinear divisions they were undoubtedly polyandrous (Emeneau 1984).

#### 1.1.2 Kothas

The Kothas inhabiting Nilgiri district within a cultural framework and they are strict followers of their culture. Both monogamy and polygamy form of marriage is practised among them but most of kotas prefer monogamy. Polyandry is not prevalent among the Kota people.

#### 1.1.3 Kurumbas

Kurumbas are the least civilized group in the district and they mostly live in the hill slopes and feverish places. There are five divisions of Kurumba viz., Allu kurumba, Jenu Kurumba, Betta kurumba, Urali kurumba and Mullu Kurumba, each group maintain different ethnic social organisations and social design based on their living habitats. All these five groups follow endogamy to regulate their marriage systems and cross-cousin marriage is practiced except for Mullu kurumba. They follow monogamy form of marriage. Polyandry is forbidden, but polygyny is a status symbol.

#### 1.1.4 Irulas

Irulas the second largest scheduled tribe in Tamilnadu. In Nilgiri district, Irula are found in the lower regions of the hills. Irulas strictly follows community level endogamy i.e., marrying within their own community. They also prefer cross-cousin consanguinity. Monogamy is the common form of marriage. Polygyny is sanctioned but polyandry is strictly forbidden.

#### 1.1.5 Paniyas

The word 'Paniyan' means 'servant' in both Malayalam and Tamil. They are the traditional farm laborers for Chetty landlords. They do not easily mingle with other tribal communities of these areas. The paniyas usually avoid marrying their cross-cousins. Monogamy is the most common form of marriage among Paniyas whereas, polygyny form of marriage is also found in few settlements in the district. However, polyandry form of marriage is completely absent in Paniyan society. Levirate form of marriage is prevalent in both male and female.

### 1.1.6 Kattunaikans

This tribal community is also found only in Pandalur and Gudalur Taluk. They are also known as kadu or shoal nayakans. The Kattunayakans are unique endogamous tribe. In order to regulate their endogamy marriage system they have clan wise exogamy pattern and avoid marrying within clan. Cross-cousin consanguinity marriage is practiced and also they prefer consanguinity of marrying maternal uncle niece. Sasikumar 1999 reported that there is no ban on the marriage between the members of the same settlement in recent times. Senior sororate system is absent but in few cases they practice junior sororate.

The detrimental health effects highly associated with consanguinity marriages are caused by the expression of rare, recessive genes inherited from a common ancestor(s). According to Bittles 2001 the less common a disorder the greater the influence of consanguinity on its prevalence a generalisation that applies to recessive multigene disorders as well as to single gene conditions. For this reason, many previously unrecognised genetic diseases have first been diagnosed in highly endogamous communities. This has made the epidemiology of genetic disorders complicated as many families and ethnic groups who are descended from a limited number of ancestors and some conditions are confined to specific villages, families and tribal groups leading to an unusual burden of genetic disease. Hence, most of them have been practicing endogamy for a long period of time, for which tribal communities are highly vulnerable to various hereditary diseases, especially for sickle cell diseases.

### 1.2 Ethnic health and Ethno medicine

Ethnic communities in Nilgiri district are mostly forest dwellers. These tribal groups living in diversity rich area possess a wealth of knowledge and skills on the utilization of medicinal plants. The use of medicinal plants in the treatment of disease was conceived by these people thousands of years ago. Many tribal groups have been using several plants or animals products for medicinal preparation and these medicines are known as ethno medicine. Ethno-medicine is also refers to the study of traditional medical practice which is concerned with the cultural interpretation of health, diseases, illness and healing practices of people.

Tribes in Nilgiris have their own system of treatment or cure of any ailments in the village. About 37 plant species were identified which are being used by these community to treat a number of ailments and diseases. Thodas possess good knowledge of medicinal herbs and flowers. Around 32 plant species were used by these people for curing ailments (Rajan 2005). A description of 19 flowering plants with 18 medicinal applications by the Kattunayakans tribe living in and around Gudalur taluk of the Nilgiri district has been recorded (Rajan 2003). Paniyas dwell in the border of the forest and most of drugs they prepared are from the wild plants. However, in the recent days these tribes are facing threats of high degree towards modern medicine opting out from traditional healing to modern treatment. Their misery is compounded by poverty, illiteracy, ignorance of cause of disease, holistic environment; poor sanitation. This leads to intervention of many diseases such as tuberculosis, malaria, gastroenteritis, nutritional deficiency diseases.

Similarly, consanguinity and endogamous marriage practice among the tribes the high incidence of hereditary disease was also prevalent and it is one of the major health problems in these people. Hereditary genetic disease includes sickle cell anemia, alpha-and-alpha thalassemia, G6PD deficiency etc. Hence, the present study focuses on sickle cell disease in Nilgiri district of Tamilnadu which is one of the major health problems among the tribes.

### 1.3 The Incidence of sickle cell disease

Sickle cell disease (SCD) is an inherited disorder of haemoglobin synthesis. About 5% of the world's population carries gene responsible for haemoglobinopathies and sickle cell disorders account for about 70% of the worldwide haemoglobin disorders (Angastiniotis et al 1995). It is the second most common hae-

moglobinopathy in the world. Sickle cell disease is commonly found among people of tropical countries and transmitted as autosomal recessive character (Gupta 1991). The incidence of this condition is most common in people of Africa, Sub-Saharan, Mediterranean and Indian origin. SCD is widespread among the ethnic groups or tribal raises of India. It has been reported that nearly 20 million people suffer from this disease in India (Ghai OP 2000). It is well documented that the gene for Sickle cell haemoglobin is located on the short arm of chromosome 11 and has an autosomal inheritance. Hence, it can manifest in two forms viz. Heterozygous (HBAS) a carrier and homozygous (HBSS) a sufferer.

As per WHO report of 1983, 60 million carriers of sickle cell and 1,20,000 sickle cell homozygotes are added every year in the world. With a population of 1000 million at the new millennium (2000) year and a birth rate of 25 per 1000 liveborns, there would be about 45 million carriers and about 15,000 infants born each year with hemoglobinopathies in India (Balgir 2000). There were 1,86,096 sickle cell anemia cases present in the Indian subcontinent according to Bhasin 1994. Based on 1981 census figures of population in India, it was estimated that there were 24,34,170 carriers and 1,21,375 sickle cell homozygotes among the tribes of India (Rao 1988). This was estimated that based on the prevalence rates of sickle cell haemoglobin, there were over 50,00,000 persons carriers and 2,00,000 homozygous sickle cell disease cases among tribals alone in India (Malhotra 1993).

In India this gene was first described among tribal group of Nilgiri hills (Lehman 1952), the incidence varies from 5% to 34% and it is mainly restricted to the tribal population. In 1953 Buchi in his study confirmed the presence of the disease in Veddois of South India followed by Sukumaran 1955 in Western India. Later spread in central India where the prevalence rate ranged between 9.4 to 22.2% (Shukla 1985). Gorakshakar reported that during the last fifty years several groups of investigators conducted hospital based of epidemiological surveys in various ethnic groups. According to this survey it was noted that the prevalence of SCD was found to be 0 to 18% in North-eastern India, 0 to 33.5% in western India, 22.2 to 44.4% in central India and 1 to 40% in southern India. However, the first review on sickle cell hemoglobin in India was done by Balgir and Sharma 1988 and followed by Balgir (2001, 1996a, 1996b, 2004) which highlighted the wide spread distribution of the sickle cell disorders in India. The following table 1.1 depicts the prevalence of sickling in states of India (Rao 1991).

**Table 1. Prevalence of SCD in some states of India.**

State	Prevalence of Sickling (%)
Andhra Pradesh	0-34.6
Bihar	0-0.6
Gujarat	0-30
Karnataka	0-25
Kerala	0-29.7
Maharashtra	0-45.4
Orrisa	0-12.4
Tamil Nadu	0-35.3
Utter Pradesh	0-32.6
West Bengal	0-1.1
Madhya Pradesh	0-48.5

**Source: Rao VR. (1991) New Delhi, Department of Science and Technology**

In Tamil Nadu, Nilgiri district records the highest tribal population accounting to 5 to 10% of the total mass. Many of these studies have reported high incidence of SCD (30%) among tribal living in hill areas of (Bhatia 1987). According to the studies by All India Institutes of Medical Sciences (AIIMS) reported that prevalence of SCD in three tribes. It is observed that kurumba reported 5.1% (HbSS) and 20.4% (HbAS), Panniya 1.5% (HbSS), 13.7% (HbAS) and kattunaikan 0.6% (HbSS) and 11.6% (HbAS).

The increasing cases among tribal groups have been observed

due to the invasion of modern medicine, Consanguinity practice of marriage, urbanization, climate change, degradation of the status of the environment, change in food habits. In yester years tribal pockets were totally secluded from the outside world having culture and tradition of their own. This was not disturbed by the other population or moving population. But in the recent years these tribal groups have moved outside their pockets or groups in search of education employment and technology. Therefore, the disease which was persistent among an individual tribal population has started to spread to other tribal regions.

The generation of data on prevalence and distribution of sickle cell disorder is essential for the effective study and management among the tribes. Disease maps (spatial distribution of disease) provides researchers with visual display than suggest through pattern of physical facilities and the human environment ,useful avenues of research into casual process (Langford et al 1999). Spatial epidemiology is defined as variation in disease risk or incidences geographical mapping would help to update information instantly and identify the vulnerable zones at village level within the district. Therefore, a wider range of studies examine different determinants of health and clustering of health outcomes ,either within demographic and socio-economic classification or spatial location (Wenberg 1999;Bond 2001 and Rickets et al 2001).

GIS is commonly used to combine spatial data from different sources, for mapping disease and for performing spatial analyses to identify the causal factors of observed spatial pattern cluster detection or landscape fragmentation analyses (Graham et al 2004 and Robinson 2000).The risk and spread of diseases are heterogeneous in space, population distributions and counts should be resolved to higher levels rather than regional estimates. Accurate and detailed information on population size and distribution are therefore of significant importance for deriving population at risk and infection movement estimates in spatial epidemiological studies (Tatem et al 2011).

To monitor and programme an effective control strategy a regress assessment of the geographical distribution of the disease is needed (Neeru 2009), through this the case and spread of the disease can be mapped for better management. Hence, there is an urge to map the prevalence and also within a tribal groups with respect to sex, age, SCD pattern using GIS.

This paper focuses to study the ethnic population in Nilgiris and the prevalence of SCD with relation to gender, age, disease pattern and community.And also focus on the distribution of SCD incidence was in order to determine when and where unusually high concentration cases occurred among the tribes in the Nilgiri district of Tamil Nadu.

**2. Methodology**

**2.1 Study location and data preparation**

Nilgiri 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. Its latitudinal and longitudinal dimension being 11°30'00" and 19° 30 ' 00" N and 76°29'52" & 76°36' 00" E covering total geographical area of 2549 sq.km. The district is divided into six taluks viz., Udthagamandalam, Gudalur, Pandalur ,Coonoor, Kotagiri and Kundah consisting of six primitive tribal communities namely Iruulas, Kurumbas, Kattunaikans, Panniyas, Kothas and Thodas were the spatial distribution of all communities is uneven. The hills and forests have been home to these tribes of this area for centuries.

The secondary datasets specific to Sickle cell disease was obtained from NGO's ASHWINI (Association for health welfare in the Nilgiris) in Gudalur taluk, NAWA (Nilgiris adivasi welfare association) in Kotagiri taluk and CTRD (Centre for tribal and rural development trust) located in pandalur for 15 years between 1997 to 2012.

A total of 1748 tribals were identified for sickling. The basic

characteristics including patients Id, age, sex, community and SCD pattern were recorded for each person along with clinical history of illness. A database was created from the obtained data based on above mentioned characteristics. Spatial variation of SCD risk areas were visualized using choropleth map. A choropleth map consists of coloured or patterned areas which represent different values or categories of a quantitative attributes. The base map for taluk and village of Nilgiri district were prepared using 58 A series toposheet of 1:50,000 scale and digitized using ArcGIS 9.3 software. Thematic map was prepared for indentifying the gender, age, community and SCD pattern incidences. The risk categories were classified into four equal intervals such as high, moderate, low and no incidences.

**3. Results and discussion**

The distribution of SCD in various tribal populations in Nilgiri district of Tamilnadu has been studied to identify the high risk areas. A total of 1748 tribal population with SCD was recorded in the study area. Among these population 205 were found to be sickling homozygous (HbSS), whereas 1543 population examined heterozygous state (HbAS). The results of the distribution of SCD and trait, sex, age and community distribution of the study area were identified and presented as thematic maps. Figure 1 depicts the spatial distribution of total incidences of SCD in Nilgiri district. The incidence categories were very high, high, moderate, low and no incidence. The resultant map shows scattered distribution of the disease in which the highest incidence of SCD cases were reported in six village panchayat namely Cherangode ,Nellakota, Jakkannarai, Konakkarai, Kengarai and Arakkode. A maximum of 313 cases were recorded in Jakkannarai of Kotagiri taluk. Moderate incidence were in three village panchayat where as the lowest incidence were observed in nineteen village panchayats. No incidence was found in twenty villages in the study area. There were wide variations in the distribution of SCD incidence between the villages.

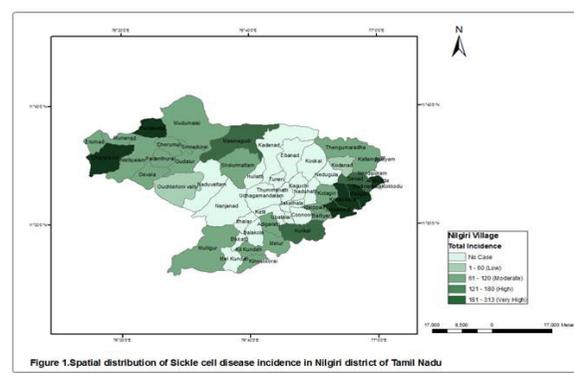


Figure 1.Spatial distribution of Sickle cell disease incidence in Nilgiri district of Tamil Nadu

**3.1 The distribution of SCD incidence by sex and age**

Age and sex wise distribution of SCD was studied and mapped. Out of total 1748 SCD cases, about 48% of SCD was prevalent in male and 52 % were females. Figure 2 shows the incidence of SCD based on gender. The highest female incidence of SCD was observed in Jakkannarai, Cherankode, Nellakota, Kengarai, Konakkarai and Arakkode, whereas in male cases it is observed only in Jakkannarai. The moderate cases of female were observed in six village panchayaths and the male incidences were observed in four village panchayaths. As regards to sex distribution of the disorder, Wintrobe 1993 in his study states that sickle cell trait is more common in females than males and similar results were also observed in the present study.

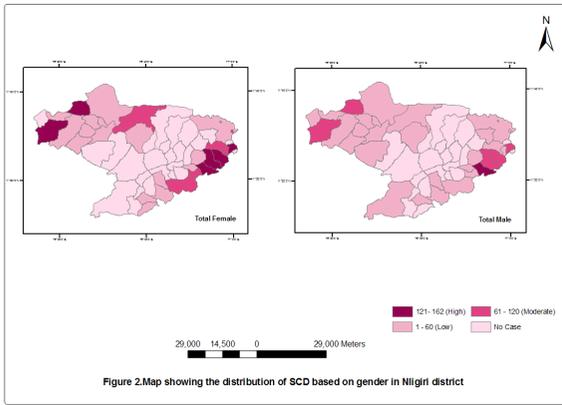


Figure 2. Map showing the distribution of SCD based on gender in Nilgiri district

The study shows that a gender related research is needed to analyze the spatial influence. Out of total SCD incidence 502 cases were from pediatric age group (< 15 years) and 1246 cases from the adult age group (> 15 years) were identified and mapped. From the figure 3 it is inferred that highest incidence was observed in Cherankode and Jakkannarai of the age group above 25 years, whereas the moderate and low incidence was recorded in the age group of 0-4, 5-9, 10-14, 15-19 and 20-24.

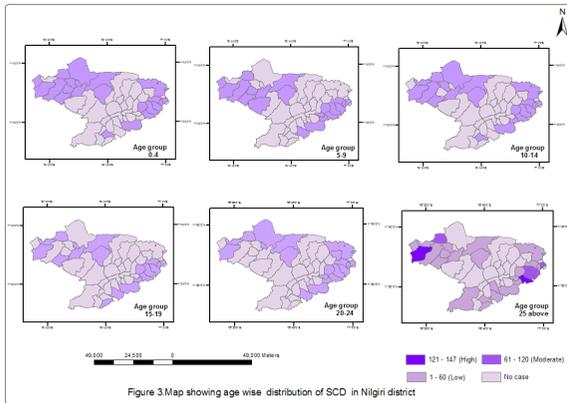


Figure 3. Map showing age wise distribution of SCD in Nilgiri district

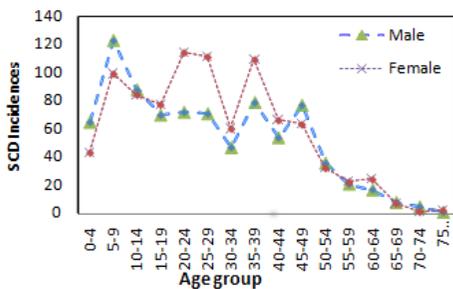


Figure 4. Graph showing the distribution of Sickle cell disease incidence by age and gender

A line graph was prepared to the incidence of SCD in males and females by age (Figure 4). The graph shows that the SCD incidence are higher in females than males in all age groups (except around 15-19 years) indicating that females are at high risk than male. The maximum incidence of SCD was peak between 5 to 9 years in male whereas in females it was observed between the age group 20 to 24. It is observed that similar results were seen in Western Orissa where the investigators found that 52 % of the SCD patients were within 15 years of age (Kar 1997). The maximum frequency of cases was found in 5 to 9 years of age group (Kar et al 1986).

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**3.2 Distribution of SCD incidence by disease pattern**

The frequency of sickle cell trait (HbAS) and sickle cell disease (HbSS) among male and female was prepared and presented in figure 5. The frequency of carrier was higher (1543) than the disease (205) cases. The highest incidence of HbAS was recorded in Cherankode, Jakkannarai, Konakkarai, Kengarai, Arakkode in female and Jakkannarai in male HbAS. The moderate incidence of HbAS in male and female was observed in four villages and six villages respectively. However, it exhibits that many villages in the district showed low or no incidence both in male and female HbAS and HbSS disease pattern.

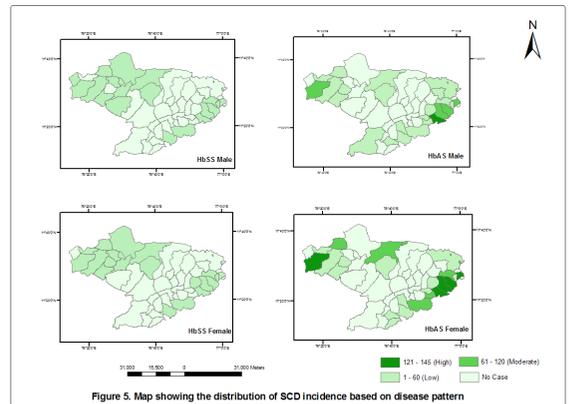


Figure 5. Map showing the distribution of SCD incidence based on disease pattern

**3.3 Distribution of SCD incidence based on Tribal community**

The distribution of SCD varies among and within the tribal communities scattered over a geographical area in Nilgiri district. Thematic map was prepared for each tribal community and presented as maps. Figure 6 shows the notified incidence for different tribal community and observed from the result that of all the six tribes, the highest incidence of SCD was recorded in Irulas and Panniyas includes area like Jakkannarai, Konakkarai, Kengarai, Arakkode, Cherankode and Nellakota. Moderate incidence includes Masinagudi, Kadinamala and Denand for Irula and Gudalur for Panniya community. The remaining villages showed low or no incidence.

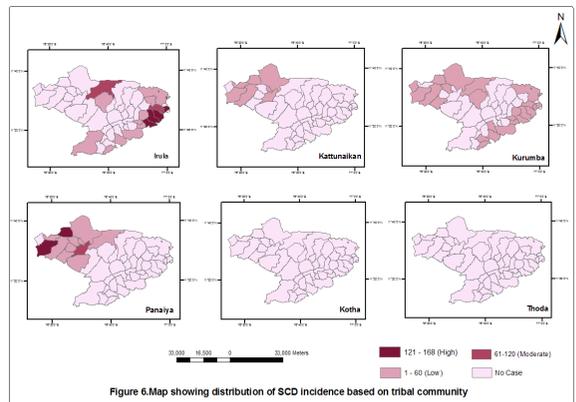


Figure 6. Map showing distribution of SCD incidence based on tribal community

However, it was observed that Kattunaikans and Kurumbas showed only low or no incidence and in case of Kothas and Thodas it was found that no incidence for SCD was observed. The results showed a non-uniform pattern of distribution of the disease. According to Ramasamy (1994) in his study revealed

that the higher frequency of SCD in Irula community might have been due to epidemic occurred during 1950's in the eastern parts of the Nilgiris. The variation of distribution in villages might be due to the scattered population settlement in the study area. The tribal community Irulas and Kurumbas lives largely on the eastern parts of the Nilgiris. Hence cultural, environmental, original settlements of each tribe must be studied to determine the disease pattern.

#### 4. Conclusion

The study has shown the visual evidence of spatial distribution of SCD incidence in Nilgiri district. From the observations, it is clear that the highest incidence of SCD was found to be in western and eastern regions of Nilgiri district which includes Cherankode, Nellakotta, Jakkannarai, Konakkarai, Kengarai, and Arakode respectively. The most serious problem is the sickle cell trait which acts as carrier for propagation of anaemia among the society through consanguineous marriage. The reason for the higher incidence in these villages may be attributed to more number of Irulas, Kurumbas and Paniyas population in the villages. Negi 1975 in his study also observed high frequency of Sickle-cell trait among Kurumba and Irula tribal groups excepting that of Thodas and Kothas. Similarly G - 6 -PD deficiency was detected more Kurumba and Irula of the Nilgiris but was absent in the Thodas and Kothas (Saha, 1976). The protein and calorie content of the diets of Thodas indicate that they are well fed and their protein intake is high (Sen Gupta, 1960; Reddy, K. N, 1988).

The high risk areas were found to be in Jakkannarai among Irulas population, where the intensity of disease is very high among

this tribe. This is due to early epidemic of the disease among Irulas community. The study has also brought difference in distribution in gender where females are more prone to be exposed than males. There is also a gender bias among the males and females and might be males are given better care and females are neglected. The highest prevalence of sickle cell trait may be a result of a higher frequency of consanguineous marriage within the relatively small community. The presence of interaction between sex and age further highlights the difference in exposure to the risk of disease. However, the movement of population becomes diverse, and altering social and ethnic demographics can change the disease pattern (Harper et al 2008). Hence, medicinal plants may not strictly act as curative agent for a specific disease in the case of Sickle cell disease which is genetically modified.

Hence, the knowledge of the spatial distribution and structure of health status helps us to understand a community's social framework related to health determining factors can help in efficient and effective spatial allocation of the resources and better management of living standards. Irrespective of prevailing legislation, a future decline in the prevalence of consanguineous unions can be predicted, accompanying the expected reduction in family sizes.

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