7. Summary and Conclusion

A comprehensive and multidimensional approach is presented in the present research work to study and explore the Sickle Cell Disease situation among the Tribal population of the Nilgiris. Sickle cell disease is an inherited genetic condition that involves defects in the shape and function of haemoglobin in the blood. This increases the likelihood of blockages in the blood vessels and disrupted blood flow, which can result in serious complications. The public health implications of sickle-cell anaemia are significant. Its impact on human health may be assessed against the yardsticks of infant and under-five mortality. As not all deaths occur in the first year of life, the most valid measure is under-five deaths. An increasing proportion of affected children now survive past five years of age but remains at risk of premature death or due to medical aid, suffer from prolonged illness.

The study concentrates on the hilly district of the Nilgiris in Tamil Nadu which is an abode of the most primitive and abundant tribal communities of India accounting to a total of 5 to 10% of the total mass of population of the state. Sickle Cell Anemia is the most prevalent disease among the tribes of this district though the disease is also seen in other parts of India. A total 2867 tribes were identified with either the disease (HbSS) or carrier (HbAS), ranging from all age groups. Though six tribes existed in the study region, except the Todas and the Kotas, the rest of them (Irulas, Paniyans, Kurumbas and Kattunayakans) displayed disease characteristics.

Sickle-cell anaemia covers a wide spectrum of illness. Most affected people have chronic anaemia with a haemoglobin concentration of around 8 g/dl. The main problems arise from the tendency of the red blood cells to become sickle-shaped and block capillaries at low oxygen tension. In children, sickle-shaped red blood cells often become trapped in the spleen, leading to a serious risk of death before the age of seven years from a sudden profound anaemia associated with rapid splenic enlargement or because lack of splenic function permits an overwhelming infection. Between 6 and 18 months of age affected children most often present with painful swelling of the hands and/or feet (hand-foot syndrome). Survivors may also suffer recurrent and unpredictable severe painful crises, as well as “acute chest syndrome” (pneumonia or pulmonary
infractions), bone or joint necrosis, priapism or renal failure. For most patients the incidence of complications can be reduced by simple protective measures such as prophylactic administration of penicillin in childhood, avoiding excessive heat or cold and dehydration, and contact as early as possible with a specialist centre. These precautions are most effective if susceptible infants are identified at birth. Some patients have such severe problems that they need regular blood transfusion and iron-chelation therapy. This situation, together with the changing manifestations of sickle-cell anaemia, creates an urgent need to develop models of care appropriate to the management of the disease in the Nilgiris. But before exploring the precautions and the managements of disease, it was urged to explore the causative factors and influences of various parameters that cause the disease burden among these select populations. The present study was therefore aimed to explore the status of the SCD among the primitive tribal groups in terms of their demography, health and environment through GIS, Remote Sensing and Spatial Statistics.

The data for the study consisted of 2867 cases of SCD cases and Carriers or Traits during the period 1997-2012 obtained from various NGOs and Tribal research centers in the Nilgiris. The data were additionally supported by satellite images, base maps for the study area and study period and climatic parameters such as Rainfall, temperature, humidity; geographical and physical factors such as Altitude, vegetation, land use land cover, Barometric pressure, Partial pressure of Oxygen and Oxygen saturation level. To explore in a more social manner, Socio economic and demographic data pertaining to the community was also collected. These data were subjected to various spatial analytical and statistical methods according to the specific objective of each section.

The study is presented in a more explorative manner displaying various parameters that have been unexplored so far in the case of Sickle Cell Disease among the tribes of the Nilgiris. An individual and community level approach describing the geographical and physical accessibility barriers focusing on the environmental and climatic influence that also burden the socio economic status which directly or indirectly affects the tribes have been put forth in a more elaborate manner.
The first section deals with the status and distribution of the tribes in general and the SC diseased and carrier cases in particular through spatial approaches. The highest number of cases was observed in location such as Jakkanarai and Cherankode among the Irulas and Kurumbas. The Paniyans and Kattunayakkans displayed moderated disease characteristics. The approach then focused on determining the Age and Gender based impact on the diseased tribal population and age standardization methods were adopted to determine the age at which high risk is observed and the gender that is mostly affected by the disease. The most vulnerable age groups are 0-14 and 25-49 and the most number of cases were observed in males. The next section deals with assessing the physical and geographical barriers that determine the health seeking behavior among the tribes. Euclidean distance and Cost distance analysis in GIS was identified to determine the terrain instability that is a major problem for distant tribes to approach the health care centers. A total of 185 tribal hamlets were within the closest proximity (5 kms) of the respective health centers. An average of 40 minutes was needed to approach the health centers for those tribal hamlets at reasonable distances. However during the wet season, 7-8 hours were required for the farthest tribe to reach these health care centers. This only worsened the pain crisis experienced by the tribes seeking emergency care. Based on Network analysis for shortest path to reach health care facility, alternative suggestive routes have been mapped for the farthest hamlets (Erumad and Kadanad).

The third part of the results explore the influence of severe climatic stress on the disease in combination with vegetation and altitude. Poisson regression models was proposed for physical parameters such as Barometric pressure (kPa), partial pressure of Oxygen (PaO₂kPa) and Oxygen saturation (SaO₂) for significance on altitudinal impact of the diseased tribes. This was proposed based on the assumption that severe oxidative stress or Hypoxia caused sickling of RBCs which remain the same on failure of the cells to oxygenate or rejuvenate. Later a time lag model was put forth to associate past rainfall (heavy) and temperature (cold) on the diseases outcomes to identify the lag time between the climatic stress and the highest cases. A 9 month lag period was identified for rainfall- disease onset assuming that severe rainfall triggers mutation on the foetus carried by the exposed mother. Similarly, a 5 month lag period was identified for temperature- disease exposure by the mother. Furthermore, a Poisson
Autoregressive Distributed Lag Model was performed to forecast previous months rainfall i.e., 9 month earlier, and temperature of previous 5 months to identify the influence of past climate on the present disease situation. This is used as a forecast model to prepare the pregnant women for severe climatic exposures so as to avoid SCD occurrences. Rainfall was taken as a parameter based on the capacity of freely available Oxygen to bind or dissolve with the precipitation leading to hypoxic stress during severe rainy seasons. Further assumption have proposed the possible occurrence of the disease as a genetic mutation during the past years in the region.

The next section deals with the relationship between the socio economic variables such as income, education, occupation, marital status and environmental variables like vegetation, land use cover, temperature and rainfall on the disease burden among the tribes. A GIS based GRID mapping method in combination with GLM was used to determine the influence of these variables on the population. Social factors such as Age, Income, Primary and Secondary Educational level and Occupation and environmental variables such as temperature, rainfall and very sparse vegetation were significant in influencing the disease burden among these tribes. Out of total 2734 grid cells, 3 grids cell fall in very high cases, 14 grid cells in high cases, 23 grids in moderate and 59 in low cases.

In most countries where sickle-cell anaemia is a major public health concern, its management has remained inadequate, national control programmes do not exist, the basic facilities to manage the patients are usually absent, systematic screening is not a common practice and the diagnosis is usually made when a patient presents with a severe complication. Simple, cheap and very cost-effective procedures such as the use of penicillin to prevent infections are not widely available in many regions or not immediately available to the tribes situated farther away. Activities for management of patients with sickle-cell anaemia should be based at the primary health-care level, with emphasis on programmes that use simple, affordable technology and should reach a large proportion of the community. Research and surveillance are important for planning and evaluating appropriate interventions. A stepwise approach to surveillance and monitoring of sickle-cell anaemia and its risk factors is required in order to
collect data for better decision-making and to allow technical collaboration with countries having similar conditions, especially those with limited resources.

The most important challenge is, thus, to improve the prospects for the patients with Sickle-Cell Anaemia in the study region and hence the last section of the results provides measures and suggestion to improve the condition of the tribes for better treatment and care. The main aspect of comprehensive care for patients is early intervention for preventable problems with pain medication, antibiotics, nutrition, folic acid supplementation and high fluid intake. Treatment with hydroxyurea has reduced many of the major complications. There is evidence that the neonatal screening for sickle-cell anaemia, when linked to timely diagnostic testing, parental education and comprehensive care, markedly reduces morbidity and mortality from the disease in infancy and early childhood. Even well-organized holistic care including expert genetic and pre marital counseling using Punnet Square and GATHER approach and to improve access to needed care, irrespective of patients’ ability to pay, can significantly reduce illness and deaths. Modifying existing governance and making changes in the health care policy so as to accommodate the tribal illness or diseases in a more effective manner can improve the quality of lives of people living with sickle-cell anaemia in the Nilgiris District.

7.1 Conclusion

The presented study explores all resources in terms of data, technology and methods to put forward a complete and dynamic picture of the Sickle Cell disease condition among the Tribes of the Nilgiris. Various facets of the influences of the disease was explored without limiting to the status and distribution alone but also to extended explore the increased burden of the disease among the population and to assessed the complications arising due to various factors that directly and indirectly impose the population to be exposed to the triggering factors. The study can be used as model for assessing tribal disease condition elsewhere and also has put forth various research assumptions that could be explored for future research.