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The Sickle Cell Anemia health problems
Traditional and Modern treatment practices among the Soliga tribes at B.R.Hills, South India

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Abstract
The Sickle Cell Disease or the Sickle cell anemia common genetic disease affects millions of people worldwide. Many Soliga tribals suffer from the genetic disorder of the Sickle Cell Disease, 4.2% of the Soligas have AS type of Sickle cell trait (heterozygous), 0.2% of the Soligas have the Sickle cell anemia (homozygous), and the remaining 95.6% of the Soligas have normal haemoglobin, Traditionally, they include different types of folic acid related green leaves, fruits, and tubers in their daily diet which helps in the natural control of the disease since there is a lack of Sickle cell anemia treatment facilities in the tribal areas. This paper will focus on the spread of the Sickle Cell Disease among the Soligas, including their food habits, traditional treatments, and the different types of pains which the patients are facing, as well as their awareness and expected Sickle cell anemia steps to help in curbing it.

Key words: Sickle cell anemia, Soligas, VGKK, Medicinal plants,

Introduction

The Sickle Cell Disease also known as Sickle cell anemia is very common among the tribals in India and other parts of the world. Sickle Cell Anaemia is hereditary and occurs due to an inherited abnormal haemoglobin (Hb) gene passed through their ancestors from Africa, Saudi Arabia, and India. The Soliga tribe also has the Sickle cell anaemia disease which was first revealed by Dr. H. Sudarshan in B.R. Hills whereby treatment was started in the tribal hospital and the Sickle cell test was conducted to identify the number of individuals so as to enable a regular follow up of such affected patients (Veena et al., 2006). Sickle-cell anaemia (also known as Sickle-cell disorder or Sickle-cell disease) is a common genetic condition due to a haemoglobin disorder – inheritance of mutant haemoglobin genes from both parents. Such haemoglobinopathies, mainly thalassaemias and Sickle-cell anaemia, are globally widespread. About 5% of the world's population carries genes responsible for haemoglobinopathies. Each year about 300,000 infants are born with major haemoglobin disorders – including

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more than 200,000 cases of Sickle-cell anaemia in Africa. Sickle-cell anaemia is particularly common among people whose ancestors come from sub-Saharan Africa, India, Saudi Arabia, and Mediterranean countries (World Health Organisation, 2006). In their research study it was found that usually the Mean Cell Volume (MCV) is high in Sickle Cell Disease (SCD) patients because of the increasing need of erythropoiesis due to chronic hemolysis leading to macrocytosis. It would also be related to a folic acid deficiency. The low MCV in the study as compared to other studies may be due to co-existing iron deficiency anaemia and other unknown factors such as a- thalassemia which is frequent and often associated to SCD. Mean HbF level was high and no sex related difference in HbF values was observed in the present study [9(P>0.05)]. Although the HBF value (12.3%) was higher in the Africa study it was low as compared to India studies (Sanjeev Shyam Rao et al., 2012). In the present study, iron deficiency anaemia was found to be more common in Sickle cell anaemia patients as compared to Sickle cell trait and normal controls and this could be due to low dietary intake during vasoocclusive crisis, infections, and malabsorption. It is suggested that iron deficiency anaemia is a potential problem in Sickle cell patients and iron supplementation should be given only in proven cases of iron deficiency anaemia to improve their general condition and work efficiency (Mohanty et al., 2008).

However, people with Sickle Cell Disease (SCD) seem to have more problems than the general population, and in severe cases, this is likely to deteriorate with the approach of adulthood. As the quality of life is dependent on the symptoms and the impact that an illness or condition has on an individual, early intervention is very crucial for people with SCD. Medical treatment, as well as adequate psychological support, could help to improve an individual's quality of life; however, psychological interventions should be directed at the specific aspects of their lives that are deemed important at the time (Kofi A. Anie, 2005). Antiphosholipid antibodies are detected in relatively high frequency in patients with SCD. In addition, levels of certain sub- types of antiphospholipid autoantibodies, particularly those directed against phosphatidylserine (PS), are markedly elevated in patients with homozygous SCD (HbSS), whereas they are normal in patients with HbSC disease. In patients with HbSS, a strong correlation exists between antibodies against PD and plasma D- dimmers, suggesting a significant role for anti-Pd antibodies in coagulation activation in SCD (Ataga and Key, 2007). Sickle Cell Disorder was present in 6.28% of the study subjects (7.995 in boys and 2.2% in girls). The prevalence of anaemia was 89.75% (28.315% - mild, 29.40% - moderate, and 32.04% - severe anaemia). The results showed that 87.69% boys and 91.91% girls were anaemic suggesting that all subjects with Sickle cell disorder were anaemic (Sandeep et al., 2012). The study reports a very high incidence of significant clinical events with 30% patients having severe disease (Jain et al., 2012).Sickle cell anaemia is a single point mutation red cell hereditary disorder. It is an autosomal recessive disorder and hence occurs in two forms, i.e., Carriers (AS type) and Sufferers (SS type). Haploype studies suggest that it is Arab- Indian haplotype in majority of the cases. This disorder is mostly confined to economically and socially backward communities known as Scheduled Caste (SC), Scheduled Tribe (ST), and Other Backward Communities (OBC) groups. It is rare in other communities (Kate and Jwar, 2002). One of the first observations made by Dr. Sudarshan was that the Soligas suffered from a genetic disorder called Sickle cell anaemia. This disorder was first observed among African tribes with significantly low susceptibility to malaria caused by

plasmodium falciparum. It probably evolved as an adaption against the high mortality caused by falciparum malaria. It occurs in a mild (heterozygous) and severe (homozygous) form. In the severe form (homozygous), the individual may die very young due to a Sickle cell crisis (Veena et al., 2006). Tribals suffer from diseases which are genetic as well as ecological. Some people suffer from Sickle cell which is genetic (Panda, 2012). Sickle cell gene is widely prevalent among the tribal population in India. These have been investigated in over 100 tribal population spread over different parts of the country. The prevalence rate varies widely (0.5 to 45%) among different tribes. Interestingly, this gene is restricted amongst the tribes of central, western, southern, and eastern India and is conspicuously absent in north–east India. With G6PD deficiency and thalassaemia, the incidence of Sickle cell haemoglobin was found to be 22.3% in Baiga and 14% in Bharias of Madhya Pradesh; 3% in Kondha, 7.4% in Kharia, 3% in Munda, 14.2% in Gonda, and1% each in Santal, Bhatudi, Bhuyan, and Kolha tribes of Orissa. Contrary to expectations the frequency of Sickle cell gene was observed to be low (0.6% in Bondo, 3.2% in Didayi, 1.3% in Juanga, and 1.5% in Kondha) among the primitive tribes of Orissa similar to that of the Hill Korwas of Madhya Pradesh (28%).The intriguing feature of the Sickle Cell Disease in Orissa is the presence of high foetal Hb, and less sequestrational crisis (Chhotray, 2003).

The alternative healthcare systems prevalent at BRT are allopathy at the Vivekananda Girijna Kalyan Kendra (VGKK) and Ayurveda at the Government Ayurvedic Health Unit. A discussion with the practitioners of alternative medicines and traditional Soliga healers revealed that MM has been greatly effective in treating and lowering the incidence of general diseases, infant mortality, and Sickle-cell anaemia. The contribution of allopathy was 100% in the treatment of Sickle-cell anaemia, inherent in the ethnic Soliga tribe. Ayurvedic medicines played a greater role in the treatment of some chronic diseases like jaundice and tuberculosis (Ghoshi et al., 2007). According to an ICMR survey the Sickle cell gene is found amongst different tribal groups of India, which varies from 5 to 34 %. According to WHO, 10 % of the Sickle Disease patients die by the age of 1 year and in many sub-Saharan countries the mortality rate is much higher than that. India also has a very huge population of about 18 crores tribal community, of which 1.80 crores may be expected to carry the Sickle cell trait and 14 lakhs the Sickle Cell Disease. This shows a big burden on the public health of India. Other states like Maharashtra, Chhattisgadh, Madhya Pradesh, Orissa, Andhra Pradesh, and Tamil Nadu also have a problem of Sickle cell anaemia in the tribal areas in variable quantum (Dept. of Health & Family Welfare, Gujarat Report).

Methods

The present study was conducted in B. R. Hills of Chamarajanagar district, Karnataka, India. For centuries 12,500 Soliga tribals have been living in and around the B. R. Hills. The Vivekananda Girijana Kalyana Kendra (VGKK) hospital conducted the Sickle cell anemia test on 5250 individuals and the patients who tested positive were provided treatment for it. Of the 5250 patients, 14 have the SS and 219 have the AS Sickle cell anemia. Of the 14 selected, 10 (71.4%) homozygous (SS) Sickle cell disorder patients were selected for the study. The study conducted in 2013 and the researchers used the structured interview schedule and six group discussions were also conducted with the Soliga healers on medicinal plants treatment use on Sickle Cell Anemia.

Result and Discussion

The Soligas suffer from the genetic disease of Sickle cell anemia as identified by Dr. H. Sudarshan in B. R. Hills. The VGKK hospital did the Sickle cell anemia screening test for 5250 Soligas. The Soligas could not name the disease, but were experiencing joint pains, swelling problems, etc. The following table lists the number of individuals with the Sickle cell disorders.

The status of Sickle cell disease among Soligas

Types (Geno)	No. of individuals screened (%)
AA	5017 (95.6)
AS	219 (04.2)
SS	14 (00.2)
Total	**5250 (100)**

The data sources from VGKK hospital

The table indicates that of the 5250 Soligas screened for Sickle cell anemia, 4.2% of them have the AS type of Sickle cell trait (heterozygous), 0.2% have the Sickle cell anemia (homozygous), while 95.6% have normal haemoglobin. It proved that 0.2% individual Soligas have the Sickle Cell Disease and 4.2% individuals have the Sickle cell trait. The VGKK hospital provides the treatment along with and Sickle cell test, but the other Primary Health Centers in the tribal areas do not offer any treatments as mentioned by the Soligas. The Primary Health Centre doctors are not aware of the Sickle Cell Disease among the tribals and hence are treating the condition on common lines, so there is a need for the government to conduct a mass scale Sickle cell screening programme and supply the appropriate medicine to all the tribal areas through the Primary Health Centers.

Types of pains faced by the Sickle cell anemia patients

The types of pains and health problems faced by Sickle cell anemia patients are joint pains in leg, hand, body and all the joints, while some of them had body ache, abdominal pain, and swelling in legs. Based on age, 10 Sickle cell patients mentioned that they were suffering from Sickle cell anemia health problems from 3 - 15 years. The interview was conducted in the age group of 25 - 63 year patients. The younger Sickle cell anemia patients had become afflicted 3 - 5 years previously and those who were above 40 years mentioned that they had been experiencing it for the past 15 years and these health problems still continued.

One common factor mentioned by all the respondents was that among their entire families one or more persons showed the Sickle cell anemia genetic symptoms of joint pains, etc. This shows that the Sickle Cell Disease gets transferred from parents to their children. All of them mentioned that they did not know the name of disease, but they had been suffering from different types of pains and swelling on their legs. The Sickle cell pains are mostly experienced during the cold season and very few mentioned the rainy season of every year.

Food habit

The staple food of the Soligas is Ragi (finger millet) as also rice and different types of grains. They collect 35

types of green leaves, 40 types of fruits, tubers, honey, mushrooms, seeds, bamboo shoots, etc. from the forest, and it provides good sources of nutrition. These products are available in the forest in different seasons and the Soligas also cultivate crops for consumption.

The types of food used during the time of the Sickle cell anaemia illness are as mentioned by 10 respondents. 70% (seven) respondents mentioned using all types of foods and 10% (one) of respondent mentioned Ragi ball (finger millet ball) and green leaves. 20% (two) of the respondents mentioned that they were using Ragi ball, (finger millet ball), Pigeon pee, horse gram, green leaf of Honnegane soppu (Ahernanthera trindra), Nela nelli (Phylanthus amarns), Ganake soppu (Solanum nigrum), Tanunigana kudi (Ampelocissus tomentosa), Mande sige soppu (Acacia canescons),etc. The Soligas are also consuming folic acid related green leaves, fruits, and foods items naturally control the Sickle cell anemia to some extent.

When the patients get Sickle cell illness their family members take care by providing food and medicine from time to time and even the community people visit the patient and offer their own suggestions on Sickle Cell Anaemia treatments, in this ways supported by the family and community.

Types of medicinal plants and other traditional methods used for treatment

The Soligas use different types of medicinal plants for the Sickle Cell Disease. A majority, i.e., 100% of the Sickle cell anaemia patients are using castor oil massage. Whenever the patients experience pain they apply castor oil on the afflicted parts in the morning and wash it off with boiling water in the evening, and the process can also be reversed by applying castor oil in the evening and washing it off with boiling water in the morning. All the respondents mentioned in their interview that this method is strictly adhered to till the pain subsides as this is their traditional method practiced using castor oil whenever any of them experiences pains of any kind.

Sira honne (Bridelia retusha): The Sira honne bark is crushed on the stone and the juice thus extracted is mixed with Ragi flour (Finger millet flour) and made into a paste and applied on the painful joints and swollen parts. The mixed Sira honne paste is applied in the morning and washed off in the evening by taking a hot water bath. Similarly, if the paste is applied in the evening it is washed off with a hot water bath in the morning. This process is practiced regularly for five days. Before the application of the Sira honne, prayers are offered to the gods and the goddesses as told by the respondents and healers.

Elisinge beru (Scutia indica): Elisinge beru means the root of the Elisinge is crushed on the stone and made in to a paste. The gods and goddesses are then offered prayers after which the paste is applied on the affected parts of the body. If the paste is applied in the morning it is washed off with hot water in the evening, and if the paste is applied in the evening it is washed off with a hot water bath in the morning. This application is strictly followed for three days continuously.

Manasige habbu (Todalia asetiea): The leaves of the Manasige are boiled in a pot covered with a cloth and the smoke emanating from the pot is inhaled for five days continuously. Also the bark and root of the Manasige are crushed on the stone and made in to a paste and applied on the affected joints in the morning and washed off in the evening by taking a hot water bath. This method is continued till the pain abates.

Kakke (Casia fustal): The Kakke bark or root is crushed on the stone and made in to a paste and applied on the affected joint parts in the morning and washed off in the evening by taking a hot water bath. This practice is followed for five days continuously.

Huli soppu (Exiles corinulata): The boiled Huli leaves are put on a cloth and placed on the affected joints. This is called Sudu Koduvudu which means giving heat of the boiled leaves on the affected joint parts for five days continuously in which the Sudu (heat) is given in the morning and evening.

Hurigilu beru (Chloroxylon swetneides): The root of the Hurugilu aridu achuvudu means the root is crushed on the stone and made in to a paste and applied on the affected parts of the body. If the paste is applied in the morning it is washed off with hot water in the evening, and if the paste is applied in the evening it is washed off with a hot water bath in the morning. This application is strictly followed for five days continuously till the pain eases.

Pudumavu or Ku mavu (Chinnmamum malabaricum): The Pudumavu sekke aredu achuvudu means the bark of Pudumavu is crushed on the stone and made in to a paste and applied on the affected parts of the body. If the paste is applied in the morning it is washed off with hot water in the evening, and if the paste is applied in the evening it is washed off with a hot water bath in the morning. This application is strictly followed for five days continuously till the pain eases.

Tannunigana Kudi (Ampelocissus tomentosa): The Tannunigana Kudi or climber tender leaves is crushed on the stone and mixed with lemon juice to make a paste and applied on the affected parts of the body. If the paste is applied in the morning it is washed off with hot water in the evening, and if the paste is applied in the evening it is washed off with a hot water bath in the morning. This process continues till the pain abates.

Ekka (Calotrophis giziniedes): The leaves of the Ekka Kayici Kavu koduvudu are heated in the little fire and then placed on the affected joints or parts one hour in the morning and evening till the pain decreases. The root of the Ekka plant is crushed on the stone and made in to a paste and applied on the affected parts of the body. If the paste is applied in the morning it is washed off with hot water in the evening, and if the paste is applied in the evening it is washed off with a hot water bath in the morning. The application continues till the pain subsides.

Sanna Malige (Jasuminum malabaricum / Serreta): The Sanna malige leaves is boiled in water and the boiled leaves are crushed on the stone and made in to a paste and applied to whole body in the morning and washed off with a hot water bath in the evening. This process continues for five days.

The Soligas also go to their traditional temple and worship the god, goddess, and the God's possession on the priest (Tammadi) or priest who give the assurances that he would solve their health problems and gives ash to the patients to be ingested for three days and in some cases five days, morning and evening. The Soligas still use different types of medicinal plants to control the Sickle Cell Disease along with religious treatments.

Hospital treatment for Sickle cell anemia

All the Sickle cell anaemia patients mentioned that whenever they are affected by severe pains, they go to the

VGKK hospital for treatments. The VGKK hospital provides folic acid tablets. 30% (three) of the respondents had been made aware of the Sickle cell anaemia awareness from VGKK and 70% (seven) of respondents mentioned that they did not receive the knowledge from anybody. It shows lack of awareness about the Sickle Cell Disease, towards which the Government and NGOs should shed light on its causes and prevention. The studies mentioned that the main aspects 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 neonatal screening for Sickle –cell anaemia, when linked to timely diagnostic testing, parental education, and comprehensive care, markedly reduces morbidity and mortality from diseases in infancy and early childhood. As also well-organized holistic care including expert counseling and access to needed care (World Health Organization, 2006). This study suggests that iron deficiency anaemia is an important problem in India (Mohanty,.et al., 2008). Early intervention is very crucial for people with Sickle Cell Disease. Medical treatment, as well as adequate psychological support, could help to improve the individual quality of life (Anie, 2005). Stem cell transplantation will bring a hope of survival for all Sickle Cell Disease patients in Gujarat (Department of Health & Family Welfare, Gujarat Report). People with homozygous Sickle cell anaemia are advised against prolonged physical stress or exertion such as long treks or walks, to maintain good hydration, and treat any infections promptly. Along with this, food rich in folic acid like Jamun (syzium species) and green leafy vegetables are recommended. In addition, folic acid tablets have now become a routine supplement for many of the Soligas afflicted with this disorder (Veena et al., 2006). It shows that Soliga Sickle cell anemic patients used three types of treatments, namely, hospital treatments, medicinal plants, and soul or religious treatment to control Sickle cell anemia. Majority, i.e., 100% of the patients used the VGKK hospital for treatment. The government needs to provide Sickle cell anemia treatment to the Soligas in Primary Health Centers.

Social Work Intervention

Sickle Cell Anemia is found to be common among Soliga tribe and the patients suffering from it, face stress and crisis. Social Worker along with other medical staff can work as a team, in early identification of the diseases prevention and treatment. Social Workers can be involved in creating awareness education and providing counseling to the affected persons. During the counseling sessions the Social Worker can educate the patient and other family members to eat folic acid related green leaves, fruits and vegetables and other food items rich in iron contents. The Social Workers can play major role with Government to conduct mass Sickle cell Anemia screening, awareness and counseling activities.

Expected steps for control of Sickle Cell Disease

The respondents mentioned the following steps expected in the future as:

1. Free medical treatment and medicines
2. Awareness on Sickle Cell Disease

3. Identify the Sickle Cell Anemia patients for medical treatment
4. Need for medicinal plants treatment

Conclusion

Sickle cell anemia is found among the Soligas. 4.2% of the Soligas have the AS type of Sickle cell trait (heterozygous), 0.2% of the Soligas have the Sickle cell anemia (homozygous), while 95.6% of the Soligas have the normal haemoglobin. Soligas eat different types of folic acid or iron related green leaves and fruits from the forest which helps to a certain extent in controlling the Sickle cell anemia. During times of illness they eat foods like finger millet, legumes, and green leaves, and use different types of medicinal plants for physical application on the joint pains and swollen parts while some of the medicinal plants are taken orally. They also accept the VGKK hospital treatments. A lack of awareness on the Sickle Cell Disease was found in the course of the present study. The Government needs to provide mass awareness and mass screening of Sickle cell anemia, medical treatments, and counseling for Sickle Cell Anemia patients.

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