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Community Awareness on Sickle cell anemia in Tribal area: An Initiative

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ABSTRACT:

Objective: A survey was conducted to know and spread awareness in people on various aspects of sickle cell anemia, like do they know, what it is and how it is occurs, basic treatments, and contingency and to know if they have sickle cell or not will help in estimation of disease in tribal area of Valsad District, Gujarat.

Methodology: A well designed questionnaire and leaflet about disease was prepared with the help of clinical pharmacist and physician. With an initiative to spread awareness and estimating cases of sickle cell anemia we received fully filled 100 forms and dispatch leaflets on the disease spreading community awareness. A percentage analysis for each question was carried out.

Result: 26% people were aware about the Sickle cell anemia and know it is autosomal disease. 25% people know how it is occurs and aware about its contingency and basic treatment.3% were the sufferer of sickle cell anemia and only 1% know the government facility for them. In this study 46% were male and 54% were female, 60% were interested to know about the disease but only 2% were ready to spread awareness on the disease in others as only 10% were graduates so it might be the cause of less involvement.

Conclusion: As sickle cell anemia is a disease affects in tribal area, there is a much need to spread awareness in tribal areas to improve healthcare sector of the country. For the improvement of healthcare of tribal's through community awareness is an initiative to lifting up the community healthcare.

Keywords: Sickle cell anemia, Awareness, Valsad

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INTRODUCTION:

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.[1, 2] 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.[3]

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.

Etiology: I) The amount of Sickle hemoglobin in cells: - In heterozygote: - 40% Sickle hemoglobin, 60% Adult hemoglobin, weakly aggregation with each other so have little tendency to sickle this is Sickle cell trait. In homozygote: - Almost 80% - 90% Sickle hemoglobin, so have a full blown sickle cell anemia. [4]

The amount of hemoglobin F:- Fetal hemoglobin interact poorly with Sickle hemoglobin hence new born child with sickle cell anemia do not manifest the disease until they are 5-6 month old, when Fetal hemoglobin falls to adult levels.[4]

Presence of other Hemoglobinopathies: - 'Cooley's' hemoglobin is characterized by substitution of glutamate by lysine at sixth position of β-chains have greater tendency to aggregate with Sickle hemoglobin then Adult hemoglobin and hence a Cooley's hemoglobin have more severe disease then do a sickle cell trait.[4] Coexistence of α-Thalassemias characterized by reduced synthesis of globin chains reduces mean cell hemoglobin concentration, therefore the severity of sickling. [4]

The amount of Adult hemoglobin in red blood cell: - The higher the Adult hemoglobin concentrations within the cell greater are the chances of contact and interaction between Sickle hemoglobin molecules. Thus, dehydration by increase mean cell hemoglobin concentration facilitates sickling and may trigger occlusion of small blood vessels. [4]

Symptoms: The sickle cell anemia may present with some clinical features like pallor, palpitation, giddiness, dizziness, weakness, fatigue, headache, painful episodes, anemia, epistaxis, spleenomegaly, jaundice, etc. acute illness characterized by relatively common sign and symptoms like fever, cough, abdominal pain, pallor and can rapidly become life threatening. Even delayed or inadequate evaluation or lacks of proper treatment in patients lead to develop sever sickle complications.

Complications: Complications due to the sickling of the red blood cells therefore continue to be a significant issue to patients and physicians in today's medical world. Physicians remain confused by the biological and clinical ins and outs of Sickle cell anemia, and Sickle cell anemia researchers are trying to find a cure to reverse the "sickling effect" in the human body.

Prevention: Even World Health Organization has mentioned that Surveillance and education must be delivered at the community level through the primary healthcare system so as to increase public awareness of the problem and lengthen the survival of affected individuals.

•Premarital screening

•Pre-school screening.

Diagnosis: Blood count and film examination. Cellulose agar or acid Agarose gel electrophoresis, pH 6.0, Automated High Performance Liquid Chromatography, Iso-Electric Focusing, Globin chain electrophoresis, test for Sickle hemoglobin like Emmel's test.

Management:

Management of sickle cell anemia includes supportive, symptomatic and preventative approaches to treatment. Patient counseling and education are the major aspects of supportive care. Symptomatic management includes the main problem that is pain management with pain killers, blood transfusion and treatment of organ failure. Symptomatic management for Pain should follow certain principles that include assessment, individualization of therapy and proper utilization of drugs. Preventative therapy includes prophylactic penicillin in infants and children, blood transfusion in patients with stroke, and anticancer agent Hydroxyurea in patients with frequent acute painful episodes. Cord blood and bone marrow transplantation have been successful operative procedure of curative therapy in selected children with sickle cell anemia. Newer approaches to preventative therapy include cellular rehydration with agents that inhibit the Gardos channel or the KCl co-transport channel.5-8 Curative gene therapy continues to be investigational at the level of the test tube and transgenic mouse models.

Methodology: A well designed questionnaire and leaflet was prepared with the help of clinical pharmacist and standard WHO questionnaire format and received fully filled 100 forms and dispatch leaflets by door to door spreading community awareness with an initiative to person to person communication. A survey was carried out in Pathri village of Valsad district. A percentage analysis for each question was carried out.

Result: 26% people were aware about the Sickle cell anemia and know it is Autosomal and 25% know how it is occurs and aware about its contingency and basic treatment.3% were the sufferer of sickle cell anemia and only 1% know the government facility for them. In this study 46% were male and 54% were female, 80% were interested to know about the disease but only 2% were ready to spread awareness on the disease in others as only 10% were graduates so it might the cause of less involvement.

Discussion: More research on the public's general knowledge about this disease will help determine the areas where more education is needed on Sickle cell anemia. There is not much

research has specifically focusing the awareness of this disease in all populations. It is important to emphasize on awareness via media like Twitter, Facebook, television, WhatsApp, celebrity involvement which will help the public's awareness on this disease. If this same approach was used to increase Public awareness, more people would be informed about Sickle cell anemia, as well as their status as a carrier. Another factor that can help address this issue is placing a public figure in the forefront for sickle cell Anemia. With more education and training, patients will be able to receive optimum care, and more centers can be built to specifically treat this disease in high-risk communities and areas.

Conclusion: There is a much need to spread awareness in tribal areas to improve healthcare sector of the country. As sickle cell anemia is a disease affects in tribal area, there is a much need to spread awareness in tribal areas to improve healthcare sector of the country. For the improvement of healthcare of tribal's through community awareness is an initiative to lifting up the community healthcare.

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