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Why sickle cell disease elimination in tribal India is a necessity

India has the second-highest global prevalence of Sickle Cell Disease, wherein 1 in 86 births have Sickle Cell Disease (SCD). According to estimates, the tribal population living in India's southern, central, and western states are particularly susceptible to it. Considering 10 percent of our country's population lives in tribal areas, it is important to focus on Sickle Cell Anaemia (SCA) detection in this community.

Tribal people often lack access to essential public health services and have lower levels of awareness, leading to delayed or missed detection of sickle-cell traits. Addressing information gaps requires more engagement from frontline workers (FLWs) like ASHA and ANM to generate and increase community-level awareness about SCD and SCA.

Frontline worker Theresa Naik is an Auxiliary Nurse and Midwife (ANM), associated with Unmukt at Khunti, Jharkhand. She has been diagnosed with SCD. She works closely with communities to address this issue. She supports the screening of people and is committed to building knowledge and awareness amongst the communities about sickle cell anaemia, and how to cope with it and manage it well. When she shares with the community that she also has sickle cell anaemia, people are more open with her in sharing their issues and symptoms. Theresa has started counselling people diagnosed with SCD and advising them on a proper diet to manage the condition.

Unmukt Program in Kanker district, Chhattisgarh and Khunti district, Jharkhand, has adopted a Mobile Medical Unit (MMU)-based approach to screen communities. The beneficiaries under this program include adolescents aged 15 to 19 years, pregnant women and their spouses and immediate blood relatives of those who tested positive for SCA. Those identified as positive on the solubility test are referred to the district hospital for treatment and follow-ups. Community mobilisation at schools and community-based sessions are carried out along with periodic awareness sessions with frontline workers to increase awareness about SCA.

OCCURRENCE OF SCD IN TRIBAL COMMUNITIES

Sickle cell disease (SCD) is an inherited blood disorder, caused by a mutation in the gene that affects the shape of red blood cells. In people with sickle cell disease, their red blood cells are shaped like a crescent instead of the normal round shape. The disease causes a constant shortage of red blood cells leading to serious health issues such as infection, acute chest syndrome, and even stroke. A recent study estimated the life expectancy of adults with SCD to be 54 years, approximately 20 years shorter than that of adults without SCD.

Tribal populations are most susceptible to SCD. There is a high prevalence of malaria in these geographies. The tribal areas were endemic to malaria for many years leading to many deaths, thus, as an evolutionary

trait, their red blood cells were becoming sickle-shaped. This led to their high susceptibility to SCD, including alpha-thalassemia. The protective mechanism to prevent malaria led to the incidence of SCD and it passed through generations, becoming a hereditary disease.

BATTLING SICKLE CELL ANAEMIA

It is crucial to bridge the knowledge and resource gaps in community screening and provide adequate and suitable quality facilities for confirmatory testing at district-level hospitals. The central government has taken several steps to address SCD. During the Union budget 2023, Finance Minister announced a mission to eliminate sickle-cell anaemia by 2047. The project would focus on raising awareness, universal screening of about seven crore individuals—aged 0-40—in afflicted tribal areas, and counselling through combined efforts of central ministries and state governments.

In 2016, the Ministry of Health and Family Welfare released national guidelines on the prevention and control of Haemoglobinopathies in India. In addition, the Ministry of Tribal Affairs established the National Council for SCD. It launched the SCD Support Corner to bridge the gap between patients and health facilities in tribal areas.

Under the budget allotment, in the next three years, Rs15,000 crore will be provided under the PM PVTG (Particularly Vulnerable Tribal Groups) Development Mission as part of the development action plan for scheduled tribes.

These efforts by the government and private organisations have borne fruit as the timely diagnosis has increased along with awareness of SCA, including the marginalised communities. We need to further augment these efforts through collaboration and technology for faster elimination of the disease.

MORE NEEDS TO BE DONE

A collaborative effort between the government, corporates, and NGOs is crucial to eradicate sickle cell disease. Lessons from past interventions should be implemented and on-ground efforts should be increased. According to the Assisted Reproductive Technology (Regulation) Act, 2021, early detection and treatment of SCD can be achieved through preimplantation genetic testing (PGT), which can identify the disease at a pre-natal stage to avoid future complications. Additionally, advances in genetic testing have made it possible for carriers of the illness to avoid passing it on to their offspring. In some cases, a saviour sibling can be born and become a bone marrow donor for the elder child. Awareness and rigorous training of all public healthcare workers will aid timely and sensitive SCA care and management, especially in the tribal belt of India.

Therefore, all stakeholders need to come together, implement these methods, and work towards the eradication of SCD. This will go a long way in transforming our nation, the health and well-being of our people living in tribal areas, and ensuring no one is left behind.