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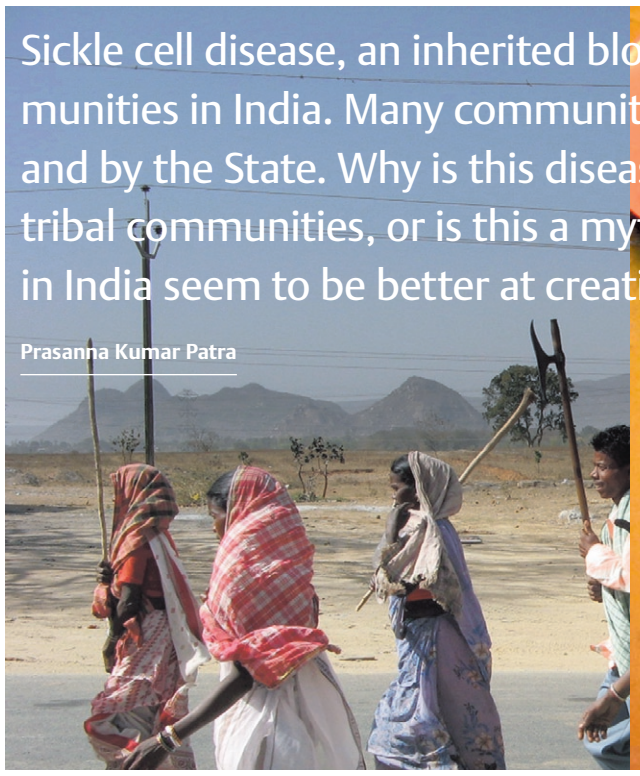
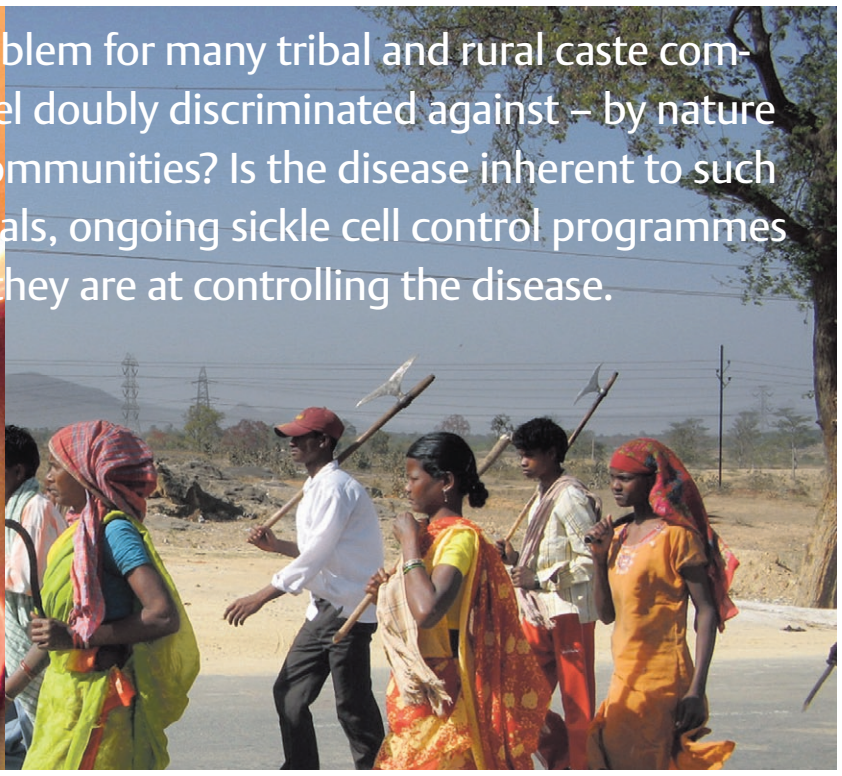
Double discrimination Sickle cell anaemia prevention programmes in India





Sickle cell disease, an inherited blood disorder, is a public health problem for many tribal and rural caste communities in India. Many community members with the condition feel doubly discriminated against – by nature and by the State. Why is this disease more prevalent among such communities? Is the disease inherent to such tribal communities, or is this a myth? As Prasanna Kumar Patra reveals, ongoing sickle cell control programmes in India seem to be better at creating social and ethical issues than they are at controlling the disease.

Prasanna Kumar Patra

SICKLE CELL DISEASE is a blood condition resulting from the inheritance of abnormal genes from both parents. Since the sickle cell gene in North and South America, the Caribbean, and Europe is usually seen among peoples of African origin, it is commonly believed to be associated with African ancestry. Similarly, wide reporting of a high incidence of the sickle cell gene among marginalised groups, such as the tribal communities and 'lower-caste' people in India, causes many to believe that it is an ethnicity specific disease. There have been many genetic health management programmes in India that are initiated by individuals, non-governmental organisations, and public and private healthcare institutions to manage the perpetuation of this disease and its carrier status. These programmes include population genetic screening, premarital genetic counselling, and medical treatments.

Those at greater risk for the sickle cell disease gene among tribal and rural caste communities in India believe themselves to be unfortunate on two accounts: first, because there is a 'faulty' gene in their population as a consequence of 'natural selection', and second, because they are not provided with proper healthcare services by the state to prevent these faulty genes from increasing. Some blame it on God, some on the government, and others on both. One wonders why it is that this disease is more prevalent among people of African ancestry or the tribal communities in India. Is it just a coincidence or a myth based on incorrect facts? Why are population-based genetic disease management programmes in India unsatisfactory, and why do they create more problems than they solve?

'It's not everybody's illness. It's only *adivasis* who get it.'

Sickle cell anemia affects an estimated 60 to 70 million people worldwide and nearly 20 million in India. Of India's 437 scheduled tribe communities, the sickle cell trait rate (carrier for the disease) ranging from 15% to 20% is found among 20 communities and it is even higher in certain communities.[1] One question that many tribal people ask is why is it mainly tribal people who suffer from this disease? The answer is a geographical and historical one. The distribution of the sickle gene coincides with areas of the world where a particularly deadly form of malaria was prevalent. The sickle cell trait has been found to be a protection against this malaria parasite. Thus, tribal people in India, and people of African origin in many parts of the world, have a higher prevalence of the disease than that of the mainstream population. Although current studies show an equally high prevalence of the sickle cell gene among several caste communities, the relatively higher frequency and wide reporting of the disease among the tribals crystallises the impression that it is a 'tribal disease', or ethnic-specific. Healthcare provisions at a local level often fail to cater adequately to the needs of the community; tribal peoples feel that the reason for such poor provision of services lies in the fact that the upper caste or mainstream population do not normally suffer from sickle cell disease, and that they are being discriminated against on a local and national level. Complaints such as the following are common across affected tribal and 'low-caste' regions:

"You know, as you see it here, it is not a rich or high-caste people's illness. It is not everybody's illness. It is only adivasis who get it".
(Bhil tribal man, 34, Dhadgaon tahsil, Maharashtra)

"We hear that there is not enough money, healthcare and research on sickle cell. It is not a disease of the people who matter. It's a poor man's disease".
(Village leader, Sahu-Teli caste community, Raipur district, Chhattisgarh)

'Our blood is pure and strong'

In medical science, sickle cell disease is defined as a genetic blood disorder, a disease inherited from both parents. But for many tribal and caste communities in India the aetiology of sickle cell disease and illness behaviour are primarily defined in terms of culture, black magic, and superstition. When the genetic nature of the disease is explained to such people as part of a genetic disease awareness campaign or a genetic counselling programme, some people find it hard to accept. Rather, they believe the disease to be a malicious attempt by programme officials and jealous neighbouring communities to give a bad name to their community. As a community member of the Bhil tribe in Dhadgaon district of Maharashtra said:

"We Bhils are the descendants of Rajput (a princely clan/ caste), our blood is pure and strong; how can we have any deficiency in our blood? I do not believe in what these people (the medical team) say. They just talk rubbish; they have some ulterior motive, and they want to pollute our community".

This illustrates the gap between lay people and experts regarding this problem.

Colouring the gene

Many sickle cell control programmes distribute colour cards in rural and tribal villages that pictographically show the inheritance pattern of the sickle cell disease gene. Programme managers believe these colour cards are a useful tool to educate genetically illiterate rural and tribal people. There are two types of colour cards. The 'full yellow' colour card signifies a person as someone affected by the sickle cell disease, whereas 'a half-yellow-half-white' card indicates that the person is a carrier for the disease. The purpose of such cards is to easily identify an individual, helping doctors treating an emergency to easily know the person's sickle cell disease status. But the card is also used to regulate marriage; it's a way of avoiding marriage between two carriers through premarital counselling. This is believed to decrease the risk of spreading the disease within the population. While from a public health policy-making perspective, the distribution of colour cards make sense, in a small and closely-knit village where tribal and caste people are bounded by marital or affiliatory relations, these colour cards become a source of identification with a disease or a 'deficiency', adding stigma and discrimination to the disease burden.

Genetic horoscopes

Genetic counsellors use the colour cards to explain the inheritance pattern of the disease to people, as a way of avoiding the same genetic combination in their future offspring. Much of the genetic counselling is directive in nature. The health officials and programme managers consider premarital counselling as a key preventive strategy. For this reason, unmarried youths and their parents remain the main target groups for counselling. Prospective couples are advised to match their genetic status during marriage negotiations, based on their genetic screening results. Since the vast majority of people in tribal and rural areas still follow the tradition of 'arranged marriage', genetic matching based on colour cards play a significant role. As one genetic counsellor working with the Sickle Project at Raipur in Chhattisgarh said:

"Now we advise people to replace their age-old janam-kundalis [astrological horoscopes] with that of gene-kundalis [genetic horoscopes]. We believe that this will help reduce the chance of marriage between two carriers and eventually lessen the disease burden on a community. This has been our slogan in rural and urban areas as this is a cultural practice with which people can easily associate".

In this exercise, carrier unmarried girls are especially subject to discrimination, as the genetic status shown on the colour cards clouds their marriage prospects. Prospective grooms avoid initiating marriage negotiations with a girl with a carrier gene. Though in the absence of adequate medical testing facilities for prenatal testing at local levels such counselling seems acceptable, in many localities this has created a sense of risk among all community members irrespective of their sickle cell disease status or related symptoms. This 'manufactured risk'[2] has brought the people in these close-knit societies into the ambit of a genetic screening culture.

'She will ruin my *vansh* (family line)'

The impact of colour cards on the marriage prospects of unmarried girls is not the only issue of stigma and discrimination based on gender. Married women who are carriers are made a scapegoat for having given birth to a diseased or carrier child. Even though their husbands are equally responsible for children with such a genetic make-up, most of the blame goes to women. Sickle cell sufferers have recurrent crises with severe joint pain that makes them sick and unable to do physical labour for certain periods of time. In rural areas where daily labour or physical work is the only source of income, women that became sick become economically dependent on their family. In such cases, they receive little sympathy from their in-laws and family members. Many mothers-in-law complain and view this as a curse on their family. As one Kondh tribal woman of Phulbani in Orissa said of her sickle cell diseased daughter-in-law:

"She is an abhisap (curse) on my family. She has brought this problem, you know, from her family. She always remains sick. She has not been a healthy wife for my son. She ruined his life. She has given birth to two children who are also sick like her. She has ruined my vansh (family line)".

Such statements are commonly encountered in tribal and rural areas where people have a low literacy rate, a low level of awareness about genetic diseases, have minimal access to basic healthcare, and the society is patriarchal in structure.

Some blame it on God, some on the government, and others on both.

The disease burden is huge and it not only impacts the social and physical well-being of the affected people or community but also has a debilitating effect on the economy of the nation itself. The measures taken by the state are sporadic and ad hoc in nature. The genetic literacy gap between lay people and experts needs to be minimised with comprehensive policy programmes. The programmes should be based on an understanding of cultural sensitivities, focus on unmet healthcare needs, and provide regular follow-up treatment. The double disadvantage experienced by sickle cell patients among certain tribes and caste communities requires double effort and the state has to decide if it is ready to make that effort or not.

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