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# KNOWLEDGE, PRACTICE AND BARRIERS TO CONTRACEPTIVE METHODS: A COMPARATIVE STUDY OF TRIBAL AND NON-TRIBAL COMMUNITIES OF THREE DISTRICTS OF JHARKHAND

### Neetu Purohit,\* Sonia Luna,\*\* Lalit Mohan Nayak\*

**Abstract:** Tribal population, constituting 8.3 % of the total population in India, is the most backward section of the community with poor health indicators. The present study focuses on the knowledge, practice and barriers to contraception among the tribal and non-tribal communities of Jharkhand state. The study was conducted in three districts, viz., Simdega, West Singhbhum/Chaibasa and Giridih, where some focused interventions had been conducted by the health department and development agencies for improving the reproductive life. A total of 542 respondents (282 tribal and 260 non-tribal male and female) were included in the study. Using the descriptive statistics and chi square test, gender wise comparison was made between the two groups by controlling literacy and parity. Contrary to earlier studies, present study reveals wide spread knowledge and practice of contraceptives among tribals in comparison to non-tribals. Awareness about spacing methods was observed around 60.3% among tribals and 44.6% among non-tribals (p<.001). Regarding use of contraception, tribals were found to be better (28.4%) than the non-tribals (12.7%). No significant difference was found between the two communities regarding barriers to use of contraceptive methods

### INTRODUCTION

The family planning program was launched in India in 1952 with the objective of population stabilization. During the first decade of its existence, family planning was considered more as a mechanism to improve the health of mothers and children than the method of population control.<sup>1</sup> Research studies have shown that Family Welfare Program has been successful in spreading the message of small families, use of contraceptive methods and reduction of fertility rates; though its overall achievements have been modest.<sup>2-5</sup> Contextual factors like high level of illiteracy, poor access to education, poverty, and gender-based disparities and structural factors like the direction, emphasis and strategies followed in the Family Welfare Program have been identified as largely contributing factors to the limited success of the program.<sup>6</sup> Further, there is lack of uniformity in the success achieved. The socioeconomically marginalized communities have been most disadvantaged as regards obtaining the services.<sup>7,8</sup> Tribal

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populations have been reported as the most backward section of the community wherein majority lie below the poverty line<sup>9</sup> and hence remain marginalized. Studies have also established that poor education and poverty are negatively associated with the knowledge and practice of family planning methods.<sup>10</sup> As per 2001 census, tribal population of the country is 8.43 crores constituting 8.3% of the total population with 91.7% of them living in rural areas and only 8.3% in urban areas. During 1991-2001, growth rate of the tribal population was 24.45%. More than half of the schedule tribe population is concentrated in Madhya Pradesh, Maharashtra, Orissa, Gujarat, Rajasthan and Jharkhand.<sup>11</sup>

Figure 1 and 2 show the contraceptive prevalence among females and males respectively at the national level and in above mentioned states (NFHS-3, 2005-06). As can be observed that at national level contraceptive use was highest among the women of other castes





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(51.4%) and lowest among the schedule tribes (42.7%). Among all the states, Jharkhand had the lowest contraceptive prevalence with about 42% of the general caste women and around 15% of the scheduled caste women using modern contraceptive methods. In comparison, males reported only 25% and 7% contraception use among general caste and scheduled caste respectively.





Present study focuses on Jharkhand that constitutes 8.4 % of the total tribal population of the country. Jharkhand formulated the 'State Population and Reproductive and Child Health Policy' in 2004 with the objectives of achieving a total fertility rate (TFR) of 2.1 children by 2020 and a contraceptive prevalence rate (CPR) of 60 % by 2015.<sup>12</sup> However, the National Family Health Survey III, 2005-06 showed that the Total Fertility Rate (TFR) in Jharkhand was 3.3 and 26.8 was the Crude Birth Rate (CBR).<sup>13</sup> Further, District Level Health Survey (DLHS-III), 2007-08 showed that around 86.5 % of

the tribal and 98.1% of the non-tribal currently married women in the age group of 15-49 years of Jharkhand were aware of any modern contraceptive methods. As far as use of family planning method is concerned, about 21% of the tribal and 52% of the non-tribal women reported to have ever used any contraceptive. Currently, only 17.2% tribal and 50.3% non-tribal women use any form of modern contraceptive methods. The data clearly indicates that non-tribal women are more aware and use modern methods of contraception as compared to the tribal women. These findings indicate that the targets set by the health department are hard to realize unless better efforts are made. Further, the health system has improved its resources by setting up tribal friendly integrated quality health care services and is implementing many innovative Information, Education and Communication/Behavior Change Communication (IEC/BCC) activities i.e., street plays. Special training programs of Tribal Village Health Committees (VHCs), orientation of Sahiyas (ASHAs) etc by BTT (Block Training Team) were conducted in insurgency affected tribal districts to increase the awareness and practice of family planning among the tribal community.<sup>14</sup> The present study includes findings from the 3 districts of Jharkhand. Among them, 2 districts, viz., Simdega and Chaibasa constitute more than 50% of the tribal population (Simdega-72.5%, West Singhbhum/ Chaibasa-66.4%). The third district, namely, Giridih has low tribal population of about 9.9 %.<sup>15</sup> Several factors influence the adoption of contraceptives methods and spacing or limiting child birth. Lack of knowledge about contraception,

disagreement of partner (husbands), fear of side effects or dissatisfaction with the used methods, and poor access to, or a limited range of, contraceptive choices had been identified as primary reasons for low contraceptive prevalence.<sup>16</sup> Access to methods is also a key determinant in the choice of methods.<sup>17</sup> Further, the differences in the culture and beliefs of the community act as barriers to acceptance of family planning methods, particularly with low education levels and poverty.<sup>18</sup> Socio-cultural and socioeconomic factors, the users' knowledge of, and access to, contraceptive methods and the attitude of the service providers towards the beneficiaries have also been some of the identified reasons for the low utilization of family planning methods among the tribal communities.<sup>19</sup>

The present study was carried out with the following objectives:

- To assess the situation in the tribal districts with respect to knowledge and practice regarding contraceptive methods.
- To assess the difference between tribal and non-tribal communities with respect to their knowledge and use of family planning methods.
- To identify the barriers in the use of family planning methods.

### METHODOLOGY

A cross-sectional study was conducted in 3 districts of Jharkhand, namely, Giridih, Simdega and West Singhbhum/Chaibasa to identify the knowledge and practice of family planning methods of the local communities. A total of 11 villages were covered from each district. These villages were selected randomly from the list of villages where or within 10 kms of which some communication intervention had been executed in past two years of the survey with respect to family planning.

In total, 33 villages were covered. A total of 542 (282 tribal and 260 non-tribal) respondents were included. Among them, 274 were males and 268 females.

The list of eligible couples was procured from Anganwadi worker(AWW) and requisite number of respondents were selected from each type (parity). Of every woman or man selected for the study, the spouse's name was included in the list.

## Analysis

The sample was distributed across all tribal and non-tribal respondents and parity. The sample consisted of 100 tribals and 76 non-tribals with no child, 118 tribals and 124 non-tribals with two children and 64 tribals and 60 non-tribals with two or more children. Frequency distribution and chi square were used to analyze the findings.

### **RESULTS AND DISCUSSION**

Jharkhand's performance on reproductive health indicators is low. The tribal ethnicity coupled with low literacy (37 % of women and 69 % of men aged 15-49 years) and low access to modern means of communication (21% having radio, 27.1% possessing TV, 12.4% having mobile phones) (NFHS-3, 2005-06) is often viewed as a reason for poor health indicators.<sup>20-22</sup> Hence, many development agencies have included use of innovative methods to create awareness and educate the population about family planning methods.

### **Background Characteristics**

Table 1 shows the demographic profile of the community. It reveals that the tribal and non-tribal communities were comparable in all respects other than the religion. About 87% of the non-tribals followed Hinduism whereas 49% tribals were Sarnas (the nature worshippers), and around 45% followed Christianity. Interestingly, no non-tribal practiced Christianity. With regards to occupation, the two groups were nearly comparable with majority of males engaged in farming (tribal, 59%; non-tribal, 39%) and females as housewives (tribal, 74%; non-tribal, 92%).

Knowledge of Family Planning: As can be seen from Table 2, tribals were comparatively more aware about family planning methods than the non-tribal population. The noted difference (p<0.001) for the awareness regarding spacing methods (IUD, pills, condoms) was significant as around 60.3% tribal and 44.6% non-tribal population indicated awareness. Similarly, the awareness about limiting methods was higher among tribals (94.7%) as compared to the non-tribals (86.5%).

Table 2 also shows the comparative awareness of tribal and non-tribal males and females about contraceptive methods. About 27% of tribal men had complete knowledge about modern contraceptive methods compared to 25% of non-tribal men. Excluding injectables too, tribal men were more aware (52.1%) than the non-tribal men (40.2%). With

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Percent distribution by	Tribals	Non-tribals			
Ν	282	260			
Age					
Less than 18 yrs	1.4	5.8			
18-25 yrs	38.7	46.2			
26-35 yrs	51.4	35.8			
36-45 yrs	8.5	12.3			
Education					
Illiterate	29.8	26.2			
Literate	70.2	73.8			
Religion					
Hindu	5.67	87.31			
Muslim	0.71	9.62			
Christian	44.68	0.00			
Sarna	48.94	3.08			
Occupation					
Males (N)	142	132			
Unemployed	4.2	3.0			
Not working	0.0	2.3			
Agricultural labourers	3.5	3.0			
Farmers	59.2	38.6			
Self employed	4.9	6.0			
Unskilled workers	14.1	23.5			
Skilled workers	12.7	22.0			
Others	1.4	1.6			
Females (N)	140	128			
Unemployed	0.7	0.8			
House wife	73.6	92.2			
Agricultural labourers	17.9	0.8			
Farmers	4.3	0.0			
Self employed	0.7	1.6			
Unskilled workers	0.7	1.6			
Skilled workers	1.4	2.3			
Others	0.7	0.8			

### Table 1: Background characteristics of the respondents

respect to limiting methods also, tribal men (95.8%) were more aware than the non-tribals (91.7%). Although tribal men surpassed the non-tribals regarding awareness yet the difference between these two groups was insignificant. On

the contrary, significant difference was found among women regarding awareness about modern contraceptive methods (p<0.001) with 45% of tribal and 41.4% of non-tribal females being aware. Excluding injectables, 68.6%

Table 2: Gender-wise and community-wise distribution of the percent<br/>respondents regarding their awareness about limiting and spacing<br/>family planning methods

Attributes	Tribals	Non- tribals	Chi-	P-Value
Total (N)	282	260	Square	
Awareness about spacing methods (Pills, Condoms,IUCD and Inject-able)	35.8	33.1	18.072	0.000***
Awareness about spacing methods (Pills, Condoms and IUCD)	60.3	44.6	13.325	0.000***
Awareness about limiting methods (Vasectomy and Tubectomy)	94.7	86.5	19.284	0.000***
Males (N)	142	132		
Awareness about spacing methods (Pills, Condoms, IUCD and Inject-able)	26.8	25.0	4.074	0.130
Awareness about spacing methods (Pills, Condoms and IUCD)	52.1	40.2	3.936	0.053
Awareness about limiting methods (Vasectomy and Tubectomy)	95.8	91.7	2.625	0.269
Females (N)	140	128		
Awareness about spacing methods (Pills, Condoms, IUCD and Inject-able)	45.0	41.4	14.486	0.001***
Awareness about spacing methods (Pills, Condoms and IUCD)	68.6	49.2	10.378	0.002**
Awareness about limiting methods (Vasectomy and Tubectomy)	93.6	81.2	19.043	0.000***

Level of significance, p<0.001\*\*\*; p< 0.01\*\*

tribal and 49.2 % non-tribal females were found aware about modern contraceptive methods (p<0.002). With respect to limiting methods, more of tribal females (93.6 %) were found aware than the nontribal (81.2%) with significant difference (p<0.000).

To know about the probable role and influence of education and parity on the awareness of the tribal and non-tribal community, tribal and non tribal respondents were compared after controlling parity and education. As the awareness of limiting methods was already high, the comparison was limited to spacing methods. Also, awareness about injectable was not analyzed as these are not available at the public health facilities.<sup>23</sup> Table 3 indicates that awareness of tribals was higher than the

Table 4 shows that alike education and experience, parity too plays a role in increasing the awareness about contraceptives. As can be observed in the table, the awareness about spacing methods among non-tribal with no child (34.2%) was much lower than the tribals (65%); (P<.001). Similarly, the knowledge regarding limiting methods was high among tribals (95%) as compared to the

Attributes	Tribals	Non-tribals	Chi-	P-Value	
N (Illiterate respondents)	84	68	Square		
Awareness about spacing methods (Pills, Condoms and IUCD)	46.4	26.5	6.387	0.012**	
Awareness about limiting methods (Vasectomy and Tubectomy)	88.1	75.0	4.411	0.054*	
N (Literate respondents)	198	192			
Awareness about spacing methods (Pills, Condoms and IUCD)	66.2	51.0	9.193	0.003**	
Awareness about limiting methods (Vasectomy and Tubectomy)	97.5	90.6	8.241	0.005**	

 Table 3:
 Literacy and community based percent distribution of the respondents regarding their awareness about spacing methods

Level of significance, p<0.01\*\*; p< 0.05\*

non-tribals in both illiterate and literate groups. The awareness of literate tribals for spacing and limiting methods was 66.2% and 97.5% respectively as compared to non-tribals with 51% for spacing and 90.6% for limiting methods. Among the illiterate group too, awareness of non-tribals (26.5% spacing and 75% limiting) was lower than the illiterate tribals (46.4% spacing and 88.1% limiting methods).

non-tribals (84 %) (p<.05). However, the difference in the knowledge level of the tribal (53%) and non-tribal (48%) community narrowed in couples with 2 children. This difference was found to be insignificant. Res-pondents having more than 2 children were also not found to be significantly different with respect to knowledge about spacing methods which shows that experience results in increased knowledge.

 Table 4: Percent distribution of the respondents regarding their awareness about spacing and limiting methods of contraception

Attributes	Tribals	Non-tribals	Chi- Square	P-Value	
N (Total respondents)	282	260			
n (Respondents with no child )	100	76			
Awareness about spacing methods (Pills, Condoms and IUCD)	65.0	34.2	16.393	0.000***	
Awareness about limiting methods (Vasectomy and Tubectomy)	95.0	84.2	5.761	0.021*	
n (Respondents with 2 children)	118	124			
Awareness about spacing methods (Pills, Condoms and IUCD)	53.4	48.4	0.605	0.444	
Awareness about limiting methods (Vasectomy and Tubectomy)	92.4	89.5	0.597	0.506	
n (Respondents with more than 2 children)	64	60			
Awareness about spacing methods (Pills, Condoms and IUCD)	65.6	50.0	3.105	0.101	
Awareness about limiting methods (Vasectomy and Tubectomy)	98.4	83.3	8.739	0.003**	

Level of significance, p<0.001\*\*\*; p<0.01\*\*; p<0.05\*

The influence of income on awareness regarding family planning methods was also explored. Since the data on income was not collected, occupation was taken as a proxy indictor to identify the financial status of the respondents. However, the occupational engagement was not found to influence their behaviour towards family planning methods.

**Use of Contraceptives:** As awareness regarding limiting method was found high among both the groups and since spacing methods affect Total Fertility Rate (TFR),

data was analyzed only to see the practice of spacing method. Table 5 shows that the use of contraceptives was low, but proportion of tribals (28.4%) was higher as compared to non-tribals (12.7%) regarding the use of spacing methods. Though the difference between the ever used methods was found insignificant, the difference in the current practice was found significant (p>.001) for both- any family planning method and any modern family planning spacing method. Data was further analyzed gender wise to know the difference in knowledge and practice of family

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planning methods among tribals and nontribals. Comparing all the respondents, tribal men (20.4%) and women (15%) were found to be better users of modern contraceptives in comparison to nontribal men (10.6%) and women (4.7%); and the difference between them was found to be significant (p<.05).

Similar trend was observed with respect to parity as well. However, this

difference was significant only in the case of tribals and non-tribals with 2 children. In addition for women with more than 2 children, the use of any contraceptive was lower among the non-tribal women than the tribal women and the difference was found significant (P<.01). However, earlier studies found non-tribal women better regarding knowledge and use of contraceptives.<sup>24</sup>

Attributes		Any F	P method		Any modern FP method					
	Tribals	Non- tribals	Chi-	P-Value	Tribals	Non- tribals	Chi-	P-Value		
N (Total Respondents)	282	260	Square		282	260	Square			
Ever used any method	36.5	30.8	2.004	0.173	24.1	24.6	0.018	0.920		
Currently using any method	28.4	12.7	20.146	0.000***	17.7	7.7	12.120	0.000***		
N (Total Males)	142	132			142	132				
Currently using FP method	26.1	15.9	4.221	0.054	20.4	10.6	4.982	0.031*		
n ( Males with no child)	52	37			52	37				
Currently using FP method	15.4	13.5	0.061	1.000	13.5	8.1	0.621	0.513		
n (Males with 2 children	60	66			60	66				
Currently using FP method	36.7	18.2	5.450	0.027*	30.0	13.6	4.998	0.031*		
n (Males with more than 2 children)	30	29			30	29				
Currently using FP method	23.3	13.8	0.885	0.506	13.3	6.9	0.669	0.671		
N (Total Females)	140	128		-	140	128				
Currently using FP method	30.7	9.4	18.668	0.000***	15.0	4.7	7.849	0.007**		
n (Women with no child)	48	39			48	39				
Currently using FP method	14.6	7.7	1.004	0.501	8.3	5.1	0.344	0.687		

 Table 5:
 Percent distribution of the respondents with respect to ever used and currently used contraceptive method

Table contd....

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n (Women with 2 children)	58	58			58	58		
Currently using FP method	43.1	8.6	17.984	0.000***	20.7	3.4	8.123	0.008**
n (Women with more than 2 children)	34	31			34	31		
Currently using FP method	32.4	12.9	3.456	0.081	14.7	6.5	1.150	0.430

Level of significance, p<0.001\*\*\*; p<0.01\*\*; p<0.05\*

**Barriers to Use of Contraception:** The respondents who were not using any contraceptive method were inquired for the reasons. Majority of the respondents gave similar reasons. As can be seen from Table 6, except for the reasons like

postpartum/breast feeding (p<.01), inconvenient contraceptive methods, or infrequent sex (p= .05), the difference between other reasons was found to be insignificant.

Table 6:Percent distribution of the respondents on the basis of the reasons for<br/>the non-usage of contraceptives

Attributes	Tribals	Non-tribals	Chi	
N (Respondents not using FP method)	194	194	square	P-value
Reasons for not using FP metho	ds			
Husband lives away/in other town	16.0	17.0	0.075	0.891
Infrequent sex	18.0	19.6	4.483	0.057
Not having sex	2.6	1.5	0.152	0.795
Postpartum period/breastfeeding	6.2	14.9	7.882	0.008**
Wants more children	47.4	38.1	3.411	0.081
Husband opposes	2.6	1.5	0.511	0.724
Other people oppose	0.5	0.5	0.000	1.000
Against religion	0.5	1.5	1.010	0.623
Knows no method	2.6	3.6	0.344	0.771
Knows no source	2.6	1.5	0.511	0.724
Health concerns	1.0	4.1	3.695	0.105
Worries about side effects	12.4	10.3	0.410	0.631
Hard to get FP methods	0.5	1.0	0.336	1.000
Cost too much	1.0	1.0	0.000	1.000
Inconvenience using contraceptive methods	1.0	5.7	6.447	0.020*
Afraid of sterilization	1.0	0	2.010	0.499
Not liking existing methods	3.1	2.6	0.094	1.000

Level of significance, p<0.01\*\*; p<0.05\*

Since majority of the respondents reported the desire for more children (47.4% tribals and 38.1% non-tribals) and having infrequent sex (18% tribals, 19.6% non-tribals) as a reason for not using modern methods of contraception, analysis was carried out to know the existing number of children of such respondents. Table 7 shows that around 10 % of the tribal and 19 % of the nongovernment and other development agencies in these areas. Since the goal is still distant, awareness generation and innovative methods focused on addressing the barriers need to be used to promote the use of contraception.

The improvement in these districts can provide model for the other tribal areas. The health system of Jharkhand has unified its efforts with other

Attributes	Tribals	Non-tribals
N (Respondents want to	92	74
have more children )		
Zero parity	64.1	50.0
One child	26.1	31.1
Two and more children	9.8	19.0
Percent respondents not ha	aving sex by parity	
Ν	35	38
Zero parity	40.0	15.8
One child	14.3	44.7
Two and more children	31.5	39.5

Table 7: Percent distribution of the respondents not using contraceptives

tribal respondents had 2 or more children. Of those reported infrequent sex, 31.5% tribals and about 39.5 % non-tribals had 2 or more children. This indicates that both tribal and non-tribal respondents who have 2 or more children need to be informed about the importance of small family and motivated for the use of contraceptives.

## CONCLUSION

The findings of the study indicate that the tribal communities are better informed than their non-tribal counterparts. The improvement in awareness, knowledge and practice of contraceptives can be attributed to the efforts made by the developmental agencies to implement innovative strategies for widening its scope for the marginalized, isolated and vulnerable tribal population. Future studies could explore the effectiveness of various IEC-BCC interventions employed by the state. Since non-tribals were found less aware as compared to tribals, the health system needs to ensure that the services offered by them do not isolate the non-tribals.

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# TRIBAL HEALTH AND LABORATORY DIAGNOSIS OF RED CELL INHERITED HEMOGLOBIN DISORDERS IN CENTRAL INDIA: A CASE STUDY OF THREE TYPICAL FAMILIES

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Abstract: Red cell inherited hematological anomalies are commonly encountered in the Central region of India. They cause a public health concern due to high degree of morbidity, mortality, and fetal wastage in the vulnerable, backward and underprivileged people. Particular Vulnerable Groups (PVG) of India encounter special hereditary hemolytic health problems such as sickle cell anemia, -thalassemia, glucose-6-phosphate dehydrogenase (G6PD) red cell enzyme deficiency etc. Out of a total of 445 families with 1526 persons (848 males and 678 females) referred from a tertiary hospital in Central India for investigations of anemia/hemoglobinopathies during March 2010 to February 2013, we came across three typical and rare families of hemoglobin disorders worthy of detailed investigations. We detected double heterozygosity in two members each of sickle cell-E-disease and hemoglobin E- -thalassemia disease; three carriers of each hemoglobin E disease and sickle cell disease, two carriers of -thalassemia major, and six normal members in these three families from Madhya Pradesh. This is the first study of its kind from the state. These communities, for convenience, marry within the radius of less than 50 km from their native place which amounts to inbreeding and leads to increased homozygosity of the defective lethal genes resulting in immense morbidity and mortality in the vulnerable communities. Emphasis has been laid on the preventive programs with performing reliable screening tests. Neonatal and prenatal screening should be conducted at tertiary hospital and preliminary screening at peripheral Primary Health Centre (PHC) in all affected tribal populations to expedite the rehabilitation of vulnerable people.

Keywords: Tribal health, Inherited hemoglobin disorders, Compound heterozygosity, Homozygosis, Hemolytic anemia, Preventive genetics, Madhya Pradesh.

### INTRODUCTION

### **Tribal Health Dimensions**

The widespread poverty, illiteracy, absence of safe drinking water and sanitary living conditions, malnutrition, communicable and preventable infections, disabling genetic afflictions, poor maternal and child health care services and ineffective coverage of national health and nutritional services have been reported as the probable contributing factors to the poor health conditions of the tribal population in India.<sup>1,2</sup> The scheduled tribes differ considerably from one-another in terms

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of race, language, culture and beliefs. Notwithstanding so much geo-ecological diversity, there are certain broad similarities between the mutually divergent tribal groups. Striking similarities are noticed in their modes of living. Each tribe has a definite habitat and ecological niche, common dialect, cultural homogeneity and unifying social organization.<sup>2</sup>

Health is a pre-requisite for human growth and development and is essentially concerned with the well being of a common man.<sup>3</sup> The United Nations Development Program has Human Development Index (HDI) comprising of three components i.e. health, education and income generating capacity. Health is a function not only of medical care but also of the overall integrated development of society in cultural, economic, educational, social and political aspects.<sup>3</sup> The health status of a society is closely associated with its value system, philosophy and cultural traditions, and social, economic and political organization.<sup>4</sup> Each of these aspects affects health deeply which in turn influences all other activities. Hence, it is not possible to raise the health status and quality of life of people without making attempts to bring about overall transformation of the society. Health development can be integrated with the larger programs of overall development in such a manner that the two become mutually self-supporting. Good health and good society go hand-in-hand together. This is possible only when supportive services such as nutrition and improvements in the environment and

education reach them in the true sense that has a higher level of acceptability.<sup>2</sup>

Primitive tribal (particular vulnerable) groups (PVG) of India face special health problems as genetic abnormalities like sickle cell anemia, glucose-6-phosphate dehydrogenase (G6PD) red cell enzyme deficiency, diabetes, hypertension, diarrhea and dysentery, scabies, and sexually transmitted diseases.<sup>4</sup> The health and nutrition related challenges of the vast tribal population of India are as varied as the tribal groups themselves who present a bewildering diversity and variety in their socio-economic, sociocultural and ecological settings.

Nutritional anemia is a major challenge for women in India and more for those in the rural and tribal dominated areas.<sup>5</sup> This is serious particularly in view of the fact that both rural and tribal women have heavy workload. The anemia has profound effect on pathophysiology, psychological behavior, physical stress and reproductive health.<sup>6</sup> Anemia lowers resistance to fatigue; affects working capacity under stressful conditions, and increases susceptibility to other infectious diseases.<sup>6</sup> Maternal malnutrition is guite common among the tribal women especially those who have many and closely spaced pregnancies.

# Red Cell Inherited Disorders of Hemoglobin

The inherited disorders of human hemoglobin (Hb) are the commonest monogenic disorders in India. Hemoglobin, the red pigment in blood cells that transfers oxygen to the tissues,

changes structure during human development. In adults, two components exist: a major fraction of adult hemoglobin, Hb A, and a minor fraction of adult hemoglobin, Hb A2. The bulk of the hemoglobin during later fetal life is Hb F. Each of these hemoglobins consists of two pairs of unlike globin chains. The adult hemoglobins and fetal hemoglobin have chains combined with (Hb A,  $_{2}$  <sub>2</sub>), (Hb A<sub>2</sub>, <sub>2</sub>), or chains (Hb F, 2 2). Each of the different globin chains is controlled by distinct genes; two genes exist for and chains and one for each of the other chains. The structure and region of the genes that control the production of different globin chains have been determined. These disorders fall in two main groups:

- a) The structural hemoglobin variants (such as C, D, E, S, Q) and
- b) The thalassemias which are caused by defective globin chain production.

Both these groups follow a recessive form of inheritance. The structural variants generally result from single amino acid substitutions in or chains. Most of the known structural variants are harmless but in some cases they may alter the stability or functional properties of the hemoglobin and lead to clinical manifestation.

The clinical features of sickle cell disorders reflect the red blood cells' propensity to assume a sickle shape in deoxygenated blood, leading to shortened red cell survival and a tendency to block small blood vessels. Even though patients may adapt to their anemia (low level of hemoglobin), their illness is interspersed with acute

episodes including attacks of bone pain; sequestration of blood into the lungs, liver, or spleen; or thrombosis of cerebral vessels, which may cause a stroke. They are highly susceptible to infection (particularly during early childhood) and to a wide range of chronic complications.<sup>7</sup> For unknown reasons, the severity of the disease varies extensively. And, it is true even for the populations in eastern Saudi Arabia and parts of India which have a high frequency of thalassemia and an unusual ability to produce Hb F in adult life, both of which, when inherited with sickle cell disease, result in a milder form of the illness;<sup>7</sup> however, the morbidity is still higher.

Clinical picture of sickle cell disease in India is extremely variable. Earlier it was believed that the course of this disease is benign but several reports from various parts of the country have shown that this conception is not true.8 Anemia, hepato-splenomegaly and vasoocclusive crisis in the form of bone and joint pains and infections are very common. The other symptoms include jaundice, fever, gall stones, epistaxis, priapism and leg ulcers are also observed in India.<sup>8</sup> The causes of mortality are septecemia, acute splenic sequestration, severe anemia and hemolytic crisis.9 Improvement in the life style of the tribals would help to control morbidity and mortality especially among sicklers. Extensive health education programs must be initiated in the tribal dominated areas to create awareness about various symptoms of sickle cell disease (SCD) especially in the pediatric (children) age group. It has been observed that the prevalence of under nutrition and malnutrition and non-compliance to medications increase their susceptibility to infection.<sup>10</sup>

If untreated, many of the inherited hemoglobin disorders may result in death during the first few years of life. Their effect on the burden of disease has only recently been recognized following an epidemiological transition caused by improvements in hygiene, nutrition, and control of infection that has reduced childhood mortality.<sup>11</sup> Babies with severe hemoglobin disorders are now able to survive long enough to present for diagnosis and treatment. The impact of these diseases is being felt throughout the Indian subcontinent and much of Asia. Although the situation will worsen in Sub-Saharan Africa as it undergoes a similar transition, such diseases are in fact responsible for a major health burden. International health agencies and the governments of affected countries need to understand the implications of the problem and should develop programs to control and manage these diseases.

In view of wide spread hemoglobinopathies being in Madhya Pradesh, this study is focused on three rare families encountered during the course of screening and investigation for anemia and hemoglobinopathies referred from a tertiary hospital in Central India.

### MATERIALS AND METHODS

Suspected couples including their offspring with at least one suspected/ confirmed case of anemia/ hemoglobinopathies (homozygous -thalassemia/ HbE/Sickle cell anemia or compound heterozygosity) routinely referred by the experts (in Gynaecology, Pediatrics, and Blood Bank, Netaji Subhash Chandra Bose Medical College & Hospital, Jabalpur,) to RMRCT for the confirmation of diagnosis/investigations were included in the study. A total of 445 couples were referred during March 2010 to February 2013. Out of 445 couples, 200 were found normal and 245 couples had different hemoglobin disorders. A total of 1526 persons (848 males and 678 females) were investigated for hemoglobinopathies.

During the screening of suspected/ referred couples for anemia/ hemoglobinopathies, three families having typical hematological features were encountered with variable electrophoretic pattern and genetic history worthy of further investigations.

Intravenous 2-3ml blood was taken under aseptic conditions from each individual after obtaining informed/written consent for screening of hemoglobinopathies and -thalassemia syndrome. Laboratory investigations were carried out following the standard procedures after the cross checking for the quality control from time to time. Hematological parameters were studied using an automated Blood Cell Counter (Model-MS<sub>5</sub>9, Melet Schloesing Laboratories, Cergy-Pontoise Cedex, France).

The sickling test was performed by using 2% freshly prepared sodium metabisulphite solution as a reducing agent for the presence or absence of sickle cell hemoglobin.<sup>12</sup> The routine hemoglobin lysate electrophoresis was carried out on cellulose acetate membrane (CAM) in Tris-EDTA-Borate buffer at pH 8.9 and quantification of  $A_2$ fraction of adult hemoglobin was done by elution method.<sup>12,13</sup> The value more than 3.5% of  $A_2$  fraction of adult hemoglobin was taken as the cut-off point to determine the -thalassemia trait. Individuals with very high hemoglobin  $A_2$  value, i.e. more than 10%, were suspected to have Hb  $A_2$  plus Hb E; and the test was confirmed by the investigations of other family members. Estimation of the fetal hemoglobin was done following the technique described by Weatherall.<sup>13</sup>

The diagnosis of sickle cell- thalassemia was based on the findings of hemoglobin (Hb) A, F, S and  $A_2$  on electrophoresis under alkaline pH, elevated HbA<sub>2</sub> levels (>3.5%). All the doubtful cases were further subjected to hemoglobin variant analysis for detecting discrepancy, if any (Bio-Rad Diagnostics, Hercules California, USA).

Results were provided to parents and doctors for the treatment and further clinical management. All the carriers/ affected persons were imparted genetic/ marriage counseling.<sup>14</sup>

### RESULTS

A summary of typical hematological and genetic features of 3 families is presented in Table 1. It may be noted that 2 members with sickle cell-E-disease (double heterozygosity), 2 members with hemoglobin E- -thalassemia disease (double heterozygosity), 3 members with hemoglobin E trait (carrier), 3 members with sickle cell trait (carrier), 2 members with -thalassemia trait (carrier) and 6 normal members were observed for the first time in Madhya Pradesh region. Average family size was of 6 members and average children born was four.

It is a matter of serious concern that one of the parents from Singrauli district of Madhya Pradesh was found suffering from sickle cell-E-disease. This scenario reflects ignorance and unawareness about the prevalent hereditary hemolytic disorders in the vulnerable communities of Madhya Pradesh. Another interesting point emerges out from the present study is that these carrier parents have married for convenience within the radius of less than 50 km of their native place (Table 1).

### DISCUSSION

The findings of the present study are the matter of serious concern to the health administrators, women and child development agencies, health planners and policy makers, health care providers and researchers and research organizations. These findings demand immediate and corrective measures to health care needs and services to rural, poor and vulnerable communities as their very survival is at stake.<sup>15,16</sup>

The situation of inherited hemoglobin disorders in general is very grim in India<sup>17, 18</sup> and particularly critical in Madhya Pradesh. There are a large number of families who are genetic victims and have to bear the brunt of clinical manifestations of sickle cell disorders and -thalassemia syndrome. The vulnerable people are not aware of these hereditary health problems, their mode of transmission, testing facilities and the remedies.<sup>19</sup> It is unfortunate that in the regions that fall within the ambit of hemoglobinopathies, the local Medical





Districts		Dindori			Singrauli					Rewa								
Castes		Dhimar				. Te	eli							Kalar				
	(Sc	heduled C	aste)		(Ot	her Bac	kward Ca	aste)		(Other Backward Caste)								
Marital Distance		8 Km			3 Km								30 Km					
Relationship	Father	Mother	Son	Father	Mother	D-1	D-2	D-3	Son-4	Father	Mother	D-1	D-2	Son-3	D-4	D-5	Son-6	D-7
Age in years	31	28	9	45	39	23	20	15	12	45	40	25	23	19	17	15	11	5
Sex (Male/Female)	М	F	М	М	F	F	F	F	М	М	F	F	F	М	F	F	М	F
Hb (g/dl)	13.5	10.4	6.0	9.9	10.0	10.6	2.7	10.2	9.8	12.0	8.8	10.7	11.6	11.5	2.9	10.7	10.2	10.6
RBC(x10 <sup>3</sup> /µl)	6.3	5.7	2.9	3.7	3.1	3.6	0.8	5.5	3.9	4.0	4.9	4.7	4.3	4.8	1.1	5.0	4.3	3.6
MCV (fl)	76.7	63.5	68.8	84.6	102.8	91.7	103.2	62.6	87.2	94.4	59.2	75.6	87.7	79.0	72.6	71.3	77.1	87.0
HCT (%)	48.5	35.5	19.7	31.7	32.0	33.8	8.8	34.3	32.1	38.0	29.5	35.5	36.7	37.7	8.6	35.7	33.2	31.9
MCH (pg)	21.4	18.1	20.8	26.4	32.0	28.7	31.3	19.8	27.2	29.7	17.7	22.7	26.7	24.2	24.6	21.3	23.7	28.9
MCHC (g/dl)	29.9	28.8	30.3	31.2	21.2	31.3	30.6	27.6	30.1	31.5	29.8	30.1	31.6	30.6	33.8	29.9	30.8	33.2
RDW (%)	12.4	14.3	12.0	14.6	14.4	13.8	34.7	13.1	12.6	12.0	14.0	13.9	13.4	13.4	17.5	14.7	12.6	10.3
WBC(x10 <sup>3</sup> /µl)	4.5	8.4	10.2	5.9	6.8	12.7	12.7	7.8	6.8	6.4	7.2	6.7	5.9	10.4	2.8	10.1	8.2	6.9
Sickling	+ve	-ve	+ve	+ve	-ve	+ve	-ve	-ve	+ve	-ve	-ve	-ve	-ve	-ve	-ve	-ve	-ve	-ve
Electrophoresis (pH 8.9)	AS	AE	SE	SE	AA <sub>2</sub>	AS	EF	AE	AS	AE	AA <sub>2</sub>	AA	AA	AA	EF	AA	AA	AA
Hb A <sub>2</sub> /E (%)	2.3	26.7	-	-	5.2	2.6	67.4	27.1	2.3	24.6	4.2	3.0	3.2	2.3	48.4	2.9	2.6	2.7
Hb Fetal (%)	0.3	1.2	2.5	2.6	1.2	1.1	6.5	1.0	0.8	1.6	0.4	0.6	0.8	0.5	13.4	0.7	1.0	1.2

# Table 1: Three typical families with variable hemoglobinopathies and - thalassemia in Central India

D= Daughter, AA= Normal Adult Hemoglobin, AS= Sickle Cell Trait, SE= Sickle Cell- E Disease,  $AA_2 = -$ Thalassemia Trait, AE= Hemoglobin E Trait, EF= E- -Thalassemia Disease

College Hospitals and Primary Health Centres (PHCs) are not adequately equipped with necessary infrastructure and trained staff to tackle the emerging emergencies of blood transfusion and treatment for the affected people. This study shows the practical scenario of hemoglobin disorders in the rural and inaccessible tribal dominated areas of Madhya Pradesh.

It is an important aspect of disabling disorders of sickle cell disease and thalassemia syndrome that the practices of community genetics, endogamy, and consanguineous marriages have an impact on neonatal and infants health. In populations where consanguineous marriage is widely practiced, recessive genetic disorders will continue to gain greater prominence in the overall spectrum of ill health.<sup>20</sup> Following of community endogamy brings less variety in the population because same normal or abnormal genes in combination amplify in the community. In addition, endogamy and consanguineous marriages lead to inbreeding which consequently increases the homozygosity (homozygosis) of recessively inherited deleterious genetic traits such as sickle cell disease or -thalassemia. This lowers the fitness of mating parents or of the population.<sup>21,22</sup> The practice of communities to marry for convenience within the radius of less than 50 km from their native place amounts to inbreeding and increases homozygosity of the defective genes. Thus, the outcome of

carrier parents of these disorders, as revealed by the present study, is disastrous.

Once such cases are identified, the genetic/marriage counselors should explain to the parents about the general supportive measures such as use of oral rehydration solution, drinking lot of liquid, juice or water, avoidance of adverse climatic conditions, complete immunization, prophylactic dose of penicillin and pneumococal vaccine as these may avert repeated infections. Thus, it would be worthwhile to study the natural history of the disease. Prenatal diagnosis is one of the important aspects of preventive program of genetic disorders or birth defects.<sup>23</sup>

Therefore, for a successful prevention program, good peripheral units performing reliable screening tests should be established. Awareness regarding hereditary disorders should be generated. Neonatal and prenatal screening should be conducted at a tertiary hospital and preliminary screening should be done at peripheral Primary Health Centre (PHC) in all tribal population groups living in different geographical areas, which are yet untouched and intervention programs should be initiated in such areas to get detailed clinical picture of the disease and appropriate steps need to be expedited to rehabilitate the vulnerable people.

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# MATERNAL AND CHILD HEALTH CARE PRACTICES AMONG THE VULNERABLE TRIBAL POPULATION 'HILL KHARIA' IN PURULIA DISTRICT, WEST BENGAL, INDIA

### Suvendu Kundu\*, Pinak Tarafdar\*\*

**Abstract :** Present report enumerates the health needs and health care practices of the mother and child among the Particularly Vulnerable Tribal Group (PTG) 'Hill Kharia' of Purulia district of West Bengal. The study was carried out in 2 villages of Purulia district. Maternal and child health care practices indicate the sum total of tribal health. These health care practices differ from one tribe to another due to their socio-cultural and ecological niche. Traditional Birth Attendant (TBA), or Dai, conducts majority of births at home in both the villages. In addition, nutritional deficiencies are most common among the children of 0-6 years age group.

### INTRODUCTION

Child health care services in tribal areas have remained largely neglected.<sup>1</sup> It has been enumerated that there are 635 tribal communities in India. Of these, 75 are listed among 'Primitive Tribes' (Census, 2001).

However, due to recent tribal policy changes indicating sensitivity, the Ministry of Tribal Affairs, Government of India has redesignated them as 'Particularly Vulnerable Tribal Group' (PTG).<sup>2</sup> According to 2001 census, Hill Kharia constitute only 1% of the total scheduled tribe population of West Bengal. This article is an attempt to decipher major issues related to maternal health, child health care practices and other services concerned with the Maternal and Child Health (MCH) among the Hill Kharia population of Purulia district.

Health is a component of three

distinctive interdependent aspects as a person can be stated 'completely healthy' only if he/she is satisfied with all three health related aspects: (a) Body (Physical health-Health), (b) Mind (Mental health-Happiness) and (c) Soul (Social health-'Atma' - an invisible organization that operates body and mind). And; malfunctioning of either of these three adversely affects the other two too.<sup>3,4</sup> However, health may vary on different biological and socio-cultural variables as age, sex, food habit, education and culture.<sup>3</sup> Maternal and child care is an important aspect of health seeking behavior which is largely neglected among this tribal group-'Hill Kharia'.1

### **Study Area and Population**

The study was carried out in two villages of Purulia district of West Bengal, India. The villages were selected on the basis of urban influences in terms of the distance from urban centre, i.e., District Head Quarter (HQ) Purulia and its modern

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SET of Village	Village	Block	Distance from District HQ, Purulia	No. of Households		
SET-I	Rahidi	Hura	30 kms.	22		
SET-II	Damodarpur	Puncha	42 kms.	78		

Table 1: Location of the villages



Figure 1: Geographical location of SET- I (Rahidi) and SET- II (Damodarpur) villages at Purulia, West Bengal

healthcare infrastructure. Locations of the study areas are given in Table 1 and Figure 1.

The Hill Kharias are mostly distributed in Purulia district but some segments of the population are also found in Bankura and Paschim Midnapore districts. Hill Kharias have been named so due to their habit of living in and around the hilly tracts. They are also referred to as '*wild Erenga'* or '*Pahari* Kharia'. The tribe now uses the mythical term '*Sabar'* as their name.<sup>5</sup> The Hill Kharias are thought to be 'criminals', which is not ascertained though, and they are fairly

old. In the beginning of the twentieth century, Coupland (1911) had reported that Hill Kharias were involved in some criminal activities like burglary, stealing etc. As a consequence of this stigma, they came under the purview of "Criminal Tribe Act" of 1924 declared by the British Government; although this Act was replaced in 1952 and the Hill Kharias were redesignated as a "Denotified Tribe". Hill Kharias are an indigenous group of Proto-australoid group. The Hill Kharias prefer to be known as 'Sabar', the mythical hunter of Ramayana.<sup>6</sup> They mainly inhabit the hilly tracts region in the South-

Western part of Bengal, i.e., the border region of the Jharkhand and West Bengal. The total population of Rahidi village (SET-I) is 90 [Male-44(48.89%) and Female-46(51.11%)] and population of Damodarpur village (SET-II) is 390 [Male-181(46.41%) and Female-209(53.59%)]. The family structure is mostly nuclear in both the villages (SET-I-77.27% and SET-II- 55.13%). Their income sources mainly depend on forest products. Due to ecological degradation,

# METHODOLOGY

The primary data for the present study was collected from two different Hill Kharia villages namely Rahidi (SET-I) and Damodarpur (SET-II). The villages were selected on the basis of their accessibility and distance from the urban centre or district head quarter Purulia and its subsequent medical infrastructure. The distance of both SET-I and SET-II villages from the district Head Quarter Purulia is about 30 km and 42 km and they are

Table 2 (A): Monthly income and expenditure in SET-I village

Total No.	Cat	egories	of Month	ly income	Categories of Monthly Expenditure (in Rupees)							
Families	Up to 1000	1500	2000	2500	3000	3500 and above	Up to 1000	1500	2000	2500	3000	3500 and above
22	2	7	8	3	2	0	2	7	11	2	0	0
	(9.09)	(31.82)	(36.36)	(13.64)	(9.09)	0	(9.09)	(31.82)	(50)	(9.09)		

#Source: Field work; 2010-2012

Table 2 (B): Monthly in	ncome and expenditure in S	ET-II village
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Total	Categ	ories of	Monthly	income	(in Ru	Categories of Monthly Expenditure (in Rupees)						
Families	Up to 1000	1500	2000	2500	3000	3500 and above	Up to 1000	1500	2000	2500	3000	3500 and above
78	38 (48.71)	28 (35.89)	10 (12.82)	2 (2.56)	0	0	46 (58.97)	29 (37.18)	4 (5.13)	0	0	0

#Source: Field work; 2010-2012

it has become very difficult for them to pursue their traditional occupation. The primary economy is also different in two SET of villages: in SET-I, 70.59% people are stone crushers whereas in SET-II, they pursue their traditional practices of making bamboo handicraft products (50.38%). In average, monthly income of these two communities is between Rs 1000 to Rs 1800 [Table 2 (A) and (B)].

under Hura block and Puncha block respectively (Table 1). The location of the SET-II village is near periphery unlike the SET-I which is interior. The Set-I village is not well connected to the urban center. The study included 100 families (Table 1).

The study involved both qualitative and quantitative data and other techniques as census schedule, interview, key informant interview and case studies. Traditional healers and traditional and modern health care providers were the respondents in this study. The following indicators were used for the analysis of the maternal and child health care practices: A) Socio-economic condition, B) Major health problems, C) Physical proximity of the villages and surrounding modern healthcare infrastructure, D) Pattern of treatment, E) Preferences for treatment, F) Perception about the causes of sickness, G) Perception of the traditional healers and H) Role of the health workers.

### RESULTS

Health is concerned with the well-being of a common man and it is a pre-requisite for human development.<sup>1</sup> Mother and child health is an important dimension of community health aspects. The main aim of the maternal and child health care is to improve the availability and accessibility of the high quality services and primary health care for all the women of the reproductive age group, i.e., 15-45 years, and the children born by them. The concerned tribal population dwells in inaccessible areas and belongs to lower/ poor economic class. Their perceptions and cultural practices concerned with maternal and child health care also vary among them.

### Ante-Natal, Natal and Post-Natal Care

Antenatal care refers to pregnancy related care provided by a health worker or family members with some local medical knowledge either in medical institution or at home.<sup>7</sup> In general, some of the ailments reported by Hill Kharia pregnant women are indigestion, vomiting, weakness and body ache. Some home remedies are practised among them including usage of medicinal plants against vomiting and general weakness. On persistence of these symptoms, they consult the Traditional Birth Attendant (TBA) or Dai. In addition, homemade tablets are used to reduce the pain. These tablets are generally made from local plants Chetcheti with liquor tea (laal cha) to reduce the labour pain. The habit of taking alcohol during pregnancy has been reported to be usual among the Hill Kharia women and majority of them continue their regular activities including hard labour even during the advanced stage of pregnancy.

The significant problem during the childbirth was excessive bleeding and weakness following the delivery. The home remedy for these included a glass of sugar water. Post delivery, the mother was also given a preparation of local Gub plants leaf and cow dung (Gobar) as they believe that this practice helps in relieving the post pregnancy pain of the mother. Locally available 'Arum' (ool) is used as pain killer. After the third day of the childbirth, women are allowed to consume food items like rice and boiled vegetables. They believe that consumption of food and water immediately after the delivery is harmful for the mother.

The child is also given a massage with locally available mustered oil. Most of the children are put on breastfeeding after 2-3 days of delivery, but colostrum is usually not discarded. Pre lacteal, child is fed with things like goat milk and sugar solution with warm water, which is a common practice among them. Apart from their indigenous health care practices, the status of ante-natal health care provided to pregnant women in that area is very poor in both the villages. Most of the Hill Kharia women do not utilize the maternal and child health (MCH) services provided through Government health services. Lack of communication to sub-urban centre, absence of private doctor, poor economic condition and poor awareness about modern health services are the main causes of the under-utilization of Government health services including pre-natal, natal and post natal services.

## Immunization (Pregnant Mother)

Majority of the pregnant women do not undergo required immunization. The consumption of iron, calcium and vitamin by women during pregnancy was very poor in SET-I village in comparison to SET-II village due to lack of communication with the urban centre. Mothers received Tetanus Tonus injection and Iron Folic Acid tablets. Local health workers indicated continuous visits to villages and counselling to Hill Kharias in both the villages for better health care.

## Nutritional Status (Pregnant Mother)

The nutritional deficiency of women directly affects their reproductive life and new born babies. A nutritional deficiency was quite common among the women of this community. Malnutrition in women can result in reduced productivity, slow recovery from infection and increased susceptibility to infection, baby with low birth weight (LBW), production of low quality of breast milk and other complications. Nutritional feeding programme also covers the pregnant woman up to 6 months after delivery. However, no pregnant woman utilized these facilities. Due to lack of awareness, pregnant women failed to get vaccination or utilize the nutritional feeding programme sponsored by Integrated Child Development Services (ICDS). Their diets are generally grossly deficient in protein and other nutritional elements. Their daily basic diet usually depends upon the forest produces gathered by the male members of the family. The malnourishment among the new born babies was found highly prevalent in both SET of villages of this region.

## **Delivery System**

Pregnancy is considered as a normal phenomenon among the Hill Kharias and no special care is observed by the pregnant women. Place of delivery is one of the most important factors affecting the maternal and child health. According to Kharias, if married women miss their menstrual cycle, they are pregnant. Most of the deliveries are supervised by the Traditional Birth Attendant (TBA) or Dai and assisted by mother-in-law, sister-inlaw and other elder women of their community. Before delivery process begins, the root of 'apang' [Achyranthus asperal is placed on the pregnant woman's head. From their cognitive point of view, it is helpful to relieve from the labour pain. Deliveries are usually conducted in lying condition on bed. The umbilical cord is tied with a white thread before severing. After the delivery, the umbilical cord is cut with a Snail (Jhinuk). TBA or Dai assists the pregnant women for safe delivery. Five or six hours after the delivery, the baby is given bath with warm water by the TBA. Mustered oil is applied



on baby's entire body and it is followed by hot fomentation to protect the baby from infection and to keep it healthy. But no specific precaution was reported during the deliveries, which results in increased infection rates.

In these two villages (SET-I and SET-II), most delivery cases occur at home (92.22% in SET-I and 87.69% in SET-II) and very few cases of institutional delivery were reported (7.78% from SET-I village and 12.31% from SET-II village). Choices are clearly made on the basis of perceptions regarding care as well as cultural comfort. According to them, women prefer deliveries at home for the reason of familiarity with the local tradition and supportive environment. The locals are dependent on local "Dai", who generally lives close to villages. Moreover, no modern health institutions are available near SET-I village and poor connectivity to the nearest health centre forces them to rely on home delivery (92.22%).

### **Food Habit and Nutrition**

Hill Kharias generally take two major meals in a day. One meal is taken around 10 am and another in the evening around 6.30 to 7 pm. They take a cup of red tea with salt or sugar. According to them, salt tea gives them extra energy and it is available in every household. If enough rice is available then they keep some boiled rice soaked in water overnight, locally called 'Chalseja', and it is a daily breakfast for both women and children. They believe that Chalseja keeps their body cool and provides energy for work. During pregnancy and post pregnancy, women do not consume any special nutritious food. Post delivery, the mother's

milk with colostrums is the first nutritious drink for every Hill Kharia child.

The alcoholic beverage of rice- beer and *mahua* liquor is very popular among them as drinks. It is consumed by members of both the sexes daily afternoon. Mahua liquor is prepared with *Bassia latifolia* fruits through the process of distillation. The Hill Kharia population believes that it helps them in getting energy and keeping good health. At times, pregnant women consume it prior to delivery.

### Pattern of Diseases

The disease pattern can be divided as High Frequent Diseases (HFD) and Low Frequent Diseases (LFD) among the mother and child. In the present study, we have selected the point of scale for LFD as <1%-20% population whereas >20% in case of HFD, according to the distribution of diseases.



In SET–I village, children of 0-5 years age group were found affected by skin disease (32%) and worms (28%) [Table-3] and women suffered from white discharge (20.83%) and anaemic problems (20.83%). As the percent population exceeds 20%, it was designated as HFD. In SET-II village, children were more vulnerable to skin diseases (34.88%) [Table-4] and others diseases were categorised under LFD. HFD among women in SET-II village was white discharge (23.08%) [Table 5(A) & (B) and 6(B)]. According to the PHC health workers, the tuberculosis (TB) was

								Disea	ises								
Age Groups	Skin Disease			I	Dysentery			Cough & cold			Fever			Worms			NAF <sup>#</sup>
	м	F	т	м	F	т	м	F	т	м	F	т	м	F	т		
0 to 2	3 60	2 40	5 45.45	1 50	1 50	2 18.18	2 100	0	2 18.18	0	0	0	1 50	1 50	2 18.18	11 91.67	1 8.33
3 to 4	1 100	0	1 14.28	0	3 100	3 42.86	0	0	0	0	0	0	2 66.67	1 33.33	3 42.86	7 87.5	1 12.5
5	1 50	1 50	2 28.57	0	0	0	1 50	1 50	2 28.57	0	1 100	1 14.29	0	2 100	2 28.57	7 100	0
Total-	5 62.5	3 37.5	8 32	1 20	4 80	5 20	3 75	1 25	4 16	0	1 100	1 4	3 42.86	4 57.14	7 28	25 92.59	2 7.41

# Table 3: Different types of diseases among 0-5 years old children in SET-I village

Source: Field work; 2010-2012

# AF- Affected, NAF- Not Affected

# Table 4: Different types of diseases among 0-5 years old children in SET-II village

	Diseases																
Age Groups	Sk	Skin Disease			Dysentery			Cough & cold			Fever			Worms			NAF <sup>#</sup>
	М	F	Т	М	F	Т	М	F	Т	М	F	Т	М	F	Т		
0 to 2	4 44.44	5 55.56	9 37.5	2 100	0	2 100	3 50	3 50	6 25	0	4 100	4 16.67	2 66.67	1 33.33	3 12.5	24 68.57	11 31.43
3 to 4	3 60	2 40	5 45.45	3 75	1 25	4 36.36	1 100	0	1 9.09	1 100	0	1 9.09	0	0	0	11 78.57	3 27.27
5	0	1 100	1 12.5	0	1 100	1 12.5	0	0	0	1 33.33	2 66.67	3 37.5	0	3 100	3 37.5	8 61.54	5 38.46
Total	7 46.67	8 53.33	15 34.88	5 71.43	2 28.57	7 16.28	4 57.14	3 42.86	7 16.28	2 25	6 75	8 18.60	2 33.33	4 66.67	6 13.95	43 69.35	19 30.64

Source: Field work; 2010-2012

# AF- Affected, NAF- Not Affected

# Table 5(A):Different types of diseases among the reproductive women (15- 45 years age group) in SET-I village

Age Groups	White discharge	Anaemia	Dysentery	Skin disease	Cough & cold	Chest Pain	Pregnancy Problem	Arthritis	Piles	Pox	Abdominal Problem	<u>AF</u> #	<u>NAF</u> #
	2					1	1			1		5	0
15-24	40					20	20			20		100	0
	3	2	2	1			2	1			2	13	1
25-34	23.08	15.38	15.38	7.69			15.38	7.69			15.38	92.86	7.14
		3			1	1					1	6	0
35-45		50			16.67	16.67					16.67	100	0
	5	5	2	1	1	2	3	1		1	3	24	1
Total	20.83	20.83	8.33	4.17	4.17	8.33	12.5	4.17		4.17	12.5	96	4

Source: Field work; 2010-2012

# AF- Affected, NAF- Not Affected

highly prevalent among women of both SET of villages. The health workers also indicated that smoking was high among women. However, there is a marginal decrease in smoking due to awareness and cultural contact with other communities.

### **Health Care Practices**

### **Traditional Health Care Practices**

Hill Kharia people in these two villages continue practising traditional medicine. All Kharias believe that traditional healers have supernatural power that is required to get rid of any ailment specifically those

Age Groups	White dis- charge	Anemia	Dy- sentery	Skin disease	Cough & cold	Chest Pain	Pregnacy Problem	Arth- ritis	Piles	Pox	Abdo- minal Problem	тв	Eye Problem	AF <sup>#</sup>	NAF <sup>#</sup>
15- 24	2 18.18	2 18.18	2 18.18	2 18.18	2 18.18	1 9.09	0	0	0	0	0	0	0	11 30.56	25 69.44
25-34	5 21.74	2 8.69	2 8.69	0	5 21.74	2 8.69	1 4.35	1 4.35	0	1 4.35	2 8.69	1 4.35	1 4.35	23 63.89	13 36.11
35-45	5 27.78	1 5.56	1 5.56	1 5.56	1 5.56	0	1 5.56	1 5.56	1 5.56	1 5.56	4 22.22	0	1 5.56	18 85.71	3 14.28
Total	12 23.08	5 9.61	5 9.61	3 5.77	8 15.38	3 9.61	2 3.85	2 3.85	1 1.92	2 3.85	6 11.54	1 1.92	2 3.85	52 55.91	41 44.09

Table 5 (B) : Different types of diseases among the reproductive women (15-45years age group) in SET-II village

Source: Field work; 2010-2012

related with maternal and child health. They believe that the traditional healers can appease the deities and their ancestors who have direct bearing on their health and well-being of the children. It is also believed that the traditional healers can control and protect the children from the evil spirit. As an indigenous method of treatment, the locally available Geru (Local name) stone was applied to relieve chest or abdominal pain for both children and women. This stone is heated through fire and applied on the aching portion of the body. Another indigenous method practised by Hill Kharias for the treatment of constipation, or Harsha, is that they consume rat meat.

Hill Kharias believe that the breast milk is useful for the treatment of conjunctivitis of children and has additional medicinal value. They also believe that a portion of the umbilical cord should be kept underneath the soil of the house where the child is born and rain water should pass through the roof of that house as it ensures healthy child. Table-6 (A) shows the traditional treatments used by these tribes.

#AF-Affected. NAF-NotAffected

**Modern Medical Practices** 

It was found that for different type of diseases, different type of service providers were consulted by the Hill Kharias. Both the villages have been introduced to modern health care system through Government PHC. However, there is government hospital only in Manbazar and Puncha. It was observed that new generation of Hill Kharia did not practise traditional health care system. A comparison of respondents on the basis of treatment pattern used by them is shown in Graph 2.

It was also observed that there is only one PHC near SET-II village and no PHC was found in the close vicinity of SET-I village. Therefore, people were totally dependent on the PHC which is situated near Damodarpur (SET-II) village. Hence, people of SET-I are forced to seek treatment from traditional healers and when their treatment fails they consult modern health care providers. Primary Health Centre (PHC) is usually approached as the last option.

Integrated Child Development Services (ICDS) is one of the most

Plant's Name (SN)	Local Name	Parts used	Usage				
Justicia adhatoda	Basak	Leaf	Basak leaf juice mixed with ocimum sanctum (Tulsi) leaf juice and taken twice a day. It helps to get relief from cough and cold				
Centella asiatica	Thankuni	Leaf	Leaf juice taken thrice a day and helps to get relief from Abdominal pain and dysentery problem				
Terminali arjuna	Arjun	Bark	Tree Bark (Boiled juice) taken to relive stomach and chest pain.				
Holarrhena pubescens	Indajab	Bark	Bark paste is used to cure loose motions.				
Ambroma auguta.L	Olotokambal	Root and Bark	Paste of bark & root taken to reduce white discharge by women				
Bombax malabaricum	Shet simul	Flower	Flower juice is used to cure white discharge of women.				
Datura metel	Dhutura	Leaf	Pasted leaf is applied on the throat for pain and for ear pain applied twice daily				
Azadirachta indica Neem		Leaf	Leaf juice is administered to relieve body poisoning and skin disease.				
Mangifera indica	Aam	Bark	Bark paste juice is taken to relieve fever and clean stomach. Works as germicide				

# Table 6A: Different medicinal plants used in different diseases for women and children.

important programmes of the central government. The schemes aim to improve the nutritional and health status of pre-school children (0-5 years age group) and nursing mothers through providing them nutritional supplement, immunization and education. The nearest *Anganwadi* centre was approximately 2 km away from SET-I village and situated in Maguria village. Consequently, parents in SET-I were reluctant to visit Maguria village and only 55.56% used ICDS in comparison to 64.52% of SET-II village (Graph 3). In SET-II village, primary school was used as an *Anganwadi* centre as parents were interested in sending their children to *Anganwadi* centre for some cooked food like rice, *dal* and boiled eggs. However, food supply was very irregular and uncertain.

Nutritional feeding programme also covered the pregnant women up to 6

30



Table-6 (B): HFD and LFD in both SET of villages among children and women

Source: Field work; 2010-2012

to 7 months even after their delivery. But among the studied villages, no such instance of any woman availing the said facilities was found.

### **Sanitation and Drinking Water**

Tube-wells provide safe drinking water in these two villages. There were two tubewells, one in Rahidi village (SET-I) and another in Damodarpur village (SET-II). Traditionally, the Hill Kharias collect water for bathing, washing clothes and other domestic purposes from well and ponds. However; during summer, they totally rely on those small numbers of tube-wells (Graph 4). Sanitation system was also poor in these areas and forced the people defecate in open ground which leads to worms infestation, dysentery and skin diseases. This was a common practice for both women and children of both the villages.

### Immunization

Vaccination and immunization of infants

# AF- Affected, NAF- Not Affected

and children have been inadequate among the Hill Kharias. Awareness regarding health care was lacking among them. Immunization coverage was low in both villages (SET-I and SET-II) among children. Children in the age group of 0-5 years of both the villages were found to take DPT, pulse-polio, tetanus and measles vaccination from nearest PHC.

Quantitative data showed that there was low need immunization in both villages (72% in SET-I and 86% in SET-II village). According to the health workers, as this community was isolated, the immunization might be harmful for the children as well as mother. This perception is changing now.

### DISCUSSION

Present study reveals that the distance from the urban centre and remoteness of the villages have affected the health status of both mothers and new born babies among the Hill Kharias. The maternal and child health care practices among them in both SET of villages revealed that utilization of antenatal and post-natal health care services were dependent only on the traditional belief in the initial stages of diseases. The study points out that the traditional health care system still finds its meaning of survival among Hill Kharia population. The traditional healer acts as the medium between man, nature and supernatural entity. It was also observed that Hill-Kharias did not pay any attention to the problems during pregnancy and often neglected the hygienic practices during the child birth.

Poverty, illiteracy, ignorance, unawareness resulting in malnutrition, lack of government hospitals, poor sanitary conditions and scarcity of safe drinking water are the identified factors for the poor health status of both mother and new born babies among the Hill Kharia population of both the villages. Food habit without any major nutritional supplements has directly affected the children as well as pregnant women. Low income, ignorance and geographical isolation were found to be common variables that directly affected the child as well as maternal health in both SET of villages. There was a noticeable impact of traditional healers on SET-I villagers due to their distance from the health facilities. In SET-II village, the parents were more interested in sending their children to nearest ICDS center situated within the village. In contrast, people of the SET-I village were reluctant to avail the said services due to the distance from the concerned center (Graph 3). The ICDS centres have not been able to supply proper cooked food everyday in Maguria village. Thus, there is a need to strengthen the ICDS and to extend the nutritional supplementation for all the children and pregnant as well as lactating women in these villages.

Low coverage of modern health services indicates a need for improving their health care during pregnancy. As shown in Graph 1, most of the deliveries were conducted at home by the 'Dai' (TBA). It was also found that in both the villages people were less aware about the significance of breast feeding. Hence, feeding breast milk and colostrums to the new born for the first few days was avoided by them. They also observed harmful practices like cutting the umbilical cord with a snail (Jhinuk) or application of unhygienic items to cut the cord. All of these practices might be unsafe for the mother as well as newborn babies. Presently, the Hill Kharias of this region are dependent upon medicinal plants for the treatment of pregnant women and children. But, due to deforestation, it is difficult for them to continue practising traditional healing. The availability and appropriate utilization of medicinal plants for the proper treatment of diseases were lacking in the new generation of the said communities in both the villages. They were also aware about the government programmes like RCH (Reproductive and Child Health Programme), NACP (National AIDS Control Programme), CSSM (Child Survival and Safe Motherhood Programme), UIP (Universal Immunization Programme), and JSY ('Janani Suraksha Youjna') that mainly focus on the mother and child population.


Graph 1: Comparison based on places of delivery

Source: Field work; 2010-2012





Source: Field work; 2010-2012

Graph 3: Gender wise comparison of respondents on the basis of their visits to ICDS centre



Source: Field work; 2010-2012



#### Graph 4: Sources of drinking water in both SET of villages.

Source: Field work; 2010-2012

#### SOME PHOTOGRAPHS OF THE STUDIED VILLAGES



A. Preparation of Mahua (country liquor)



B. Hill Kharia children taking lunch



C. Nutritional Feeding Programme

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## BLOOD DONORS, HEMOGLOBIN DISORDERS AND PUBLIC HEALTH: AN URGENCY OF SCREENING FOR HEMOGLOBINOPATHIES IN INDIA

#### R S Balgir \*\*, Jayant Mahapatra \*1

Abstract: Blood is a highly essential life saving and valuable human tissue. It plays a major role in the transport of oxygen and nutrients to various parts of the body. A blood donor is a person who donates blood to a patient either as a non-remunerated donor or as a remunerated donor, or as a voluntary donor, and renders an important service to the society. The blood of donors is rigorously screened for infection or contamination such as hepatitis, malaria, HIV, and ABO or Rhesus blood groups compatibility, etc. prior to transfusion, but no test is performed for the detection of hemoglobinopathies including -thalassemia or glucose-6-phosphate dehydrogenase (G6PD) enzyme deficiency in India. This study was designed to find the magnitude of hemoglobin disorders, -thalassemia and G6PD deficiency among 52 randomly selected blood donors aged 18 to 50 years in a Blood Bank at a tertiary hospital in the eastern coast of southern Odisha. The prevalence of hereditary hemolytic disorders such as -thalassemia trait and G6PD deficiency was observed to be about 3.9% in both cases among the blood donors of coastal Odisha. These findings are consistent with similar studies conducted elsewhere. Both these genetic disorders cause hemolytic anemia in malaria endemic region of Odisha. Screening of blood donors for hemoglobinopathies including -thalassemia, sickle cell disease and G6PD deficiency should be introduced along with other screening criteria in Blood Banks and should be made mandatory prior to blood transfusion in India. This will reduce the risk and complications among recipients or mitigate the sufferings of the needy individuals.

**Key words:** Blood donors screening, Hemoglobinopathies, Hemolytic anemia, Public health, Coastal Odisha, India.

#### INTRODUCTION

Blood is an essential component of human body. It is a connective tissue fluid that plays a major role in the transportation of oxygen and nutrients to various parts of the body such as tissues, organs and systems. A blood donor is the person who donates blood to Blood Bank as a relative of the patient or friend as a non-remunerated donor or as remunerated donor, or as a voluntary donor, and renders an important service to the needy society as blood is a highly essential, life saving and valuable human tissue. According to WHO report,<sup>1</sup> blood donors are classified in three groups: A) Family or family replacement low risk donors are those who supply the blood to

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a patient from within the family or community. They are not paid donors but may be compensated in some other form by the patient or its relatives. This form of donation is advantageous as it meets the need of blood in emergency. Such donors may become voluntary donors after realizing the importance of blood donation. B) Paid commercial or professional donors who receive money or other rewards in exchange. C) Voluntary or non-remunerated donors who donate blood, plasma or other blood components at their own free will and receives no payment for it.

Donors are rigorously screened for any type of infection or contamination such as hepatitis, malaria, HIV and ABO or Rhesus compatibility, etc. but no test is performed for the detection of hemoglobinopathies (including thalassemias) in India. This unscreened (for hemoglobinopathies) blood may belong to -thalassemia or sickle cell disease or trait patients and when transfused would provide no relief as nearly half of the donated blood of such subjects contains the abnormal hemoglobin, -thalassemia, or glucose-6-phosphate dehydrogenase (G6PD) enzyme deficiency.

Hemoglobinopathies are the most commonly encountered monogenic disorders of blood posing a major genetic and public health problem in Southeast Asia and in the Indian subcontinent.<sup>2</sup> Of the several abnormal hemoglobins so far identified,<sup>3</sup> there are 3 abnormal variants – sickle cell (Hb S), hemoglobin E (Hb E) and hemoglobin D (Hb D), which are predominantly prevalent in India. There

are regional variations for these structurally variants of hemoglobin; the cumulative allele frequency for these variants in different parts of India has been found to be 5.35%.<sup>4</sup> The average allele frequency of sickle cell and hemoglobin D observed was about 4.3% and 0.86%, respectively with hemoglobin E constituting 10.9% in North Eastern region of India.<sup>4</sup> The sickle cell disease is wide spread in tribal as well as nontribal communities especially in Central-Eastern part of India. With the prevalence range of 3-17%, -thalassemia is prevalent throughout India.<sup>3</sup> Therefore, hemoglobinopathies are a huge genetic burden and pose a major public health care challenge in India.

In view of the above scenario of blood donations and high prevalence of hemoglobinopathies including thalassemia<sup>5,6</sup> and G6PD deficiency<sup>7,8</sup> in India, this study was designed with an objective to find the magnitude of prevalence of hemoglobinopathies and G6PD enzyme deficiency among the blood donors at a Blood Bank in a tertiary hospital in Eastern coast of Odisha, India.

#### MATERIALS AND METHODS

For the present study, blood samples were collected from blood donors attending the Red Cross Blood Bank of MKCG Medical College and Hospital, Berhampur, Odisha and were analysed for hemoglobinopathies and glucose-6phosphate dehydrogenase (G6PD) enzyme deficiency at the Department of Human Genetics, Regional Medical Research Centre, Bhubaneswar (Odisha) during May to October 2004. A total of 52 randomly selected blood donors aged between 18-50 years were included in the study. They were both replacement and voluntary healthy blood donors. Blood Donor Selection criteria were used as prescribed in WHO guidelines<sup>1</sup> and physical examinations were done by a medical doctor.

A portion (2-3ml) of donated blood was collected in EDTA containing vials and transported under wet ice cold conditions to Human Genetics Laboratory at Bhubaneswar for the screening of hemoglobinopathies and -thalassemia. Laboratory investigations were carried out following the standard procedures after cross checking for the quality control from time to time. Hematological parameters were studied by using an automated Blood Cell Counter (Model-MS4, Melet Schloesing Laboratories, Cergy-Pontoise Cedex, France).

Sickling test was performed using 2% freshly prepared sodium metabisulphite solution as a reducing agent for the presence or absence of sickle cell hemoglobin.9 The routine hemoglobin lysate electrophoresis was carried out on cellulose acetate membrane (CAM) in Tris-EDTA-Borate buffer at pH 8.9 and quantification of A<sub>2</sub> fraction of adult hemoglobin was done by elution method.<sup>9, 10</sup> The value more than 3.5% of A<sub>2</sub> fraction of adult hemoglobin was taken as the cut-off point for determining the -thalassemia trait. Individuals with very high hemoglobin A<sub>2</sub> value, i.e. more than 10%, were suspected to have Hb A<sub>2</sub> plus Hb E; and the test was confirmed by investigating other family members. Estimation of fetal hemoglobin was done according to

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technique described by Weatherall.<sup>10</sup>

The diagnosis of sickle cell-thalassemia was based on the findings of hemoglobin (Hb) A, F, S and  $A_2$  on electrophoresis under alkaline pH, elevated HbA<sub>2</sub> levels (>3.5%). All the doubtful cases were further subjected to hemoglobin variant analysis for detecting discrepancy, if any (made for Bio-Rad Diagnostics, Hercules California, USA).

The G6PD enzyme deficiency was detected using dichlorophenol indophenol dye (DCIP) as described by Bernstein,<sup>11</sup> and subsequently confirmed by those of Beutler and coworkers.<sup>12</sup>

#### RESULTS

As shown in Table 1, out of 52 blood donors screened for hemoglobinopathies and -thalassemias in the coastal belt of Odisha state, the majority (28.8%) was young people (21-25 years age group), followed by 26-30 years age group (23.1%) and 36-40 years (19.2%).

# Table 1: Distribution of blood donorsin different age groups.

Age in years	No.	Percentage
18-20	4	7.7
21-25	15	28.8
26-30	12	23.1
31-35	7	13.5
36-40	10	19.2
41-50	4	7.7
Total	52	100.0

The caste-wise distribution of these blood donors showed that the majority belonged to general castes (42.3%) followed by the other backward castes (36.5%) and scheduled castes (13.5%). The frequency of blood donors in scheduled tribes was very low (7.7%) [Table 2]. This indicates that the tribals are reluctant to donate blood probably due to fear of weakness or evil spirit which may adversely affect their health.

Caste Groups	No.	Percentage
General castes	22	42.3
Scheduled Castes	7	13.5
Scheduled Tribes	4	7.7
Other Backward	19	36.5
Castes		
Total	52	100.0

Table 2: Distribution of blood donors indifferent caste groups.

Regarding prevalence of hereditary hemolytic disorders among the blood donors of coastal Odisha, thalassemia trait and G6PD deficiency was observed to be about 3.9% in each category (Table 3). More than 90% of the total blood donors were normal/healthy persons. Both these genetic disorders cause hemolytic anemia in malaria endemic region of Odisha. Table 3: Distribution of blood donors inrelation to hemoglobinopathies and G6PDdeficiency

Hemoglobin- opathies/Diagnosis	No.	Percentage
Normal	48	92.2
ß-thalassemia trait	2	3.9
G6PD deficiency	2	3.9

The hematological picture of the blood donors including the carriers of thalassemia major and G6PD deficiency in coastal Odisha is presented in Table 4. The red cell indices also showed the normal status of the blood donors in Odisha.

#### DISCUSSION

It is surprising to know that out of 52 blood donors screened for hemoglobinopathies including -thalassemia and G6PD deficiency at Red Cross Blood Bank of MKCG Medical College and Hospital, Berhampur during May to October 2004, the prevalence of both -thalassemia trait and G6PD deficiency each was

Hematological Indices	Nor (N=	mal :48)	ß-Thalas (	semia Trait N=2)	G6PD Deficiency (N=2)		
	Mean	SD	Mean SD		Mean	SD	
Hb (g/dl)	13.28	1.90	12.45	2.05	13.05	4.03	
RBC (x10 <sup>3</sup> /µl)	5.25	1.11	6.10	0.42	5.26	1.36	
MCV (fl)	85.36	5.27	67.45	6.43	87.95	3.32	
MCH (pg)	27.24	3.75	20.20	2.12	27.30	4.38	
MCHC (g/dl)	32.81	2.25	30.00	0.28	32.30	0.00	
Hb A <sub>2</sub> (%)	1.90	0.47	5.10	0.56	1.60	0.42	
Hb F (%)	0.50	0.22	0.50	0.14	0.60	0.14	

 Table 4:
 Comparison of hematological indices between normal and diseased blood donors

SD= Standard Deviation

recorded to be around 3.9% which was moderately high and may cause clinical complications among blood recipients. None of the cases was found to have either sickle cell anemia or sickle cell- thalassemia although these disorders are commonly encountered in coastal Odisha.<sup>5,6,8</sup> Before taking the blood, blood donors are screened neither for hemoglobinopathies nor for G6PD deficiency which may lead to exaggerations and complications to the recipient. If the blood of a person with abnormal hemoglobin, thalassemia trait or G6PD deficiency is transfused to a normal person, the life span of the red blood corpuscles (RBC), being short (less than 120 days), is expected to cause anemia again and the very purpose of the blood transfusion is defeated.

The blood, as per WHO guidelines<sup>1</sup>, is screened for HIV, hepatitis, malaria, ABO and Rhesus blood group compatibility, etc. However, it is not screened for hemoglobinopathies or G6PD deficiency neither in the state of Odisha nor elsewhere in India. Several studies have shown the blood donors suffering from various genetic disorders as carrier or trait form.<sup>13,14,</sup> These abnormalities may be sickle cell trait <sup>15</sup> or -thalassemia minor<sup>16,17</sup> or G6PD deficiency<sup>18</sup> among the blood donors. Fabritius and coworkers<sup>14</sup> showed sickle cell trait (7.75%), Madan and coworkers<sup>18</sup> recorded G6PD deficiency (1.3%), Jain<sup>16</sup>

presented -thalassemia trait (2.35%) and Meena and coworkers<sup>17</sup> reported 1.58% among the blood donors. The findings of the present study (Table 3) are consistent with the above mentioned studies. Thus, it is concluded that prior to blood transfusion donors' blood should be screened at least for the above mentioned hemolytic disorders as these are highly prevalent in India.

It is a matter of concern that in some cases relatives of the patients who are asked to donate blood for transfusion may be suffering from these disorders and may share defective genes. This should be discouraged as -thalassemia major or homozygous sickle cell disease have the defective blood with shorter or limited span of RBCs life. Therefore, it is not advisable to insist the carrier parents/siblings to donate the blood for replacement unless there is an acute shortage of blood or emergency. However, they may be requested to bring any normal or healthy person, i.e., friends or other relatives, for donating blood for the replacement. This will serve the purpose of the blood bank as well as fulfil the requirement of the needy patients.

It should be borne in mind that the hemoglobinopathies including thalassemia and G6PD deficiency have probably evolved in the world to counter the menace of Plasmodium falciparum malaria in highly endemic geo-ecological regions of the world including India.<sup>19</sup> The indiscriminate use of anti-malarial drugs against malaria can cause acute hemolytic anemia and can also be fatal for the patients suffering from G6PD deficiency.<sup>19,20</sup> Thus, a caution regarding use of antimalarial drugs for the patients suffering from hemoglobinopathies -thalassemia and G6PD including deficiency is advisable.



It is suggested that screening of blood donors for hemoglobinopathies including -thalassemia, sickle cell disease and G6PD deficiency should be introduced along with other screening criteria of the Blood Bank and should be made mandatory prior to blood transfusion especially among the thalassemia major or homozygous sickle cell disease patients in India. This will also reduce or mitigate the suffering of affected and needy patients in the vulnerable communities in India.

#### CONCLUSIONS

Screening for hemoglobinopathies including -thalassemia, sickle cell disease and G6PD deficiency of blood donors should be introduced in the screening protocol of Blood Banks and should be made mandatory prior to blood transfusion in India. This will reduce the complications risk among the recipient patients and help mitigate the sufferings of the needy persons in India.

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# EMPOWERMENT OF TRIBAL WOMEN FOR HEALTH DEVELOPMENT: AN INDIAN PERSPECTIVE

#### M Muniyandi\*, Neeru Singh<sup>\*\*</sup>

**Abstract:** The empowerment of the tribal population has been a major concern. Past three decades have witnessed a steady increase in the awareness regarding need to empower women through increasing the social, economic and political equity, and broader accessibility to fundamental human rights along with improvements in nutrition, basic health and education. In the current article, an attempt has been made to evaluate the roles of educational attainment, economic participation, social capital, knowledge and wealth in women empowerment, and their links to health outcomes with special reference to tribal population in India. Present study is based on published articles and reports on women empowerment. It was found that the health status was poor among the primitive tribal women due to their low proxy empowerment indices, i.e., illiteracy, low exposure to media and impoverished living. Consequently, female empowerment bears a positive influence on the health outcomes. This information is vital for the researchers, government and voluntary agencies, NGOs, social reformers and social activists to take appropriate measures to improve the health outcomes of the tribal population.

**Key words:** Economic growth, socio-economic development, women empowerment, health outcomes

#### INTRODUCTION

To achieve the national demographic goals committed by national population policy and Millennium Development Goals by United Nations Development Programme (UNDPs) and National Health Policy, women need to have access to comprehensive, affordable and quality health care as they play a very critical role in family health. Women need to be empowered as their sexual and reproductive health encompasses their abilities to exercise their rights regarding their body requirements; making choices about intimate relationships, bearing children; protection from diseases associated with reproduction and access to health services. As a prerequisite for the sexual and reproductive health, quality health services must exist, and women and girls must live in environments that enable them to seek services and practice healthy behaviours. Their empowerment, autonomy and improvements in their health status were recognized by the International Conference on Population and Development (1994).

Tribals in India are widely different from each-other geographically, culturally and in terms of their levels of social as well as economic development, and their

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problems vary from area to area within their own groups. Several commissions and committees in recent past have recommended a variety of measures to remove the socio-economic imbalances among them and also to break down their age old psychological barriers confined to the tribal areas. For the tribals' development and their benefits under backward classes in India, special programmes have been in effect since First Five Year Plan (1951-56). Yet; tribes exhibit a great variation in the economic, social, political, educational and health status.

Scheduled tribes (STs) constitute the weakest section of Indian population from the ecological, economic and educational perspectives. They compose the matrix of poverty and represent one of the most marginalized and economically impoverished groups in the nation. As per the Census of India 2001, STs constitute about 8.2% of the total population in India (Graph-1). Majority of the tribals live in rural areas and are engaged in agricultural pursuits. The development of the tribal population has been a major concern for the government, voluntary agencies, NGOs, social reformers, social scientists etc. An integrated multidisciplinary approach has been adopted by different researchers to study the tribal health problems in the country which indicates that the primitive tribes bear distinct health problems, mainly governed by factors like their habitat, difficult terrain, ecologically variable niches, illiteracy, poverty, isolation, superstition and deforestation.<sup>1,2,3</sup>

This article explores the

nature/role of women empowerment in health generation particularly in the tribal areas. It discusses how women empowerment can contribute to improve health status. Further, some examples associated with the links between women empowerment proxy indices (education, economy, social capital), political support and health outcomes have been analysed.

#### Empowerment

The word 'empowerment' is used in different contexts by different people (Box-1). There is a variety of meaning of the term due to its widespread usage. Although the term is used frequently for the development related work, yet it is yet to be defined. However, broadly it refers to the expansion of freedom of choice and action. For the poor people, this freedom is severely curtailed by their poor contribution to representation particularly in the state and markets. Thus, empowerment is the expansion of assets and capabilities of poor people to negotiate influence and control the accountable institutions that affect their lives.4

In 1978, the World Health Organization's Alma Ata Declaration first articulated the goals of community participation and equity with subsequent extension to empowerment.<sup>5</sup> In 2000, United Nations Millennium Development Goals included women empowerment and health interventions.<sup>6</sup> The World Bank's Strategic Framework and poverty reduction strategy identified empowerment of poor people as one of the two prior strategies to improve development effectiveness.<sup>7</sup> Empowerment is a core concept of WHO's vision of health promotion. One of the six key messages to guide action within the European Strategy for the prevention and control of non-communicable diseases is that, "people should be empowered to promote their own health, interact effectively with health services and be active partners in managing the diseases".<sup>8</sup>

#### **Tools for Measuring Empowerment**

Empowerment cannot be seen as a stand-alone strategy as it is a part of a comprehensive approach to promote structural or legal changes to support women community. Ultimately, empowerment is a dynamic interplay between gaining internal skills and overcoming external structural barriers to access resources. It is not easily measurable and most often it refers to women's ability to arrive at a decision that affects themselves, their family, community, society, markets etc.9 Earlier studies on women often covered the aspects of empowerment without explicitly labeling it.<sup>10,11</sup> It was measured by most available indicators in terms of options, choice, control and power such as 'gender equality'12 and 'gender equity'13 (Box-2). Hypothetically, there could be an improvement in the indicators of gender equality had the intervening processes involved women as agents of those changes rather than keeping them merely as recipients. This can happen in different dimensions, viz., economic, sociocultural, familial/interpersonal, legal, political and psychological. However; these dimensions are broad in scope and within each dimension; there exists a

range of sub-domains where women can be empowered. The 'socio-cultural' dimension covers a range of empowerment sub-domains from marriage systems to norms regarding women's physical mobility, to non-familial social support systems and networks available to women. Moreover, in order to operationalize these dimensions, one needs to consider indicators at various levels of social aggregation as education, employment, health care access etc. These will indicate the process of taking control and responsibility for actions that contribute to women empowerment.

There is scant of comparative literature and empowerment projects, and those exist are too complex and infeasible. Employment opportunities are often seen as resources for women empowerment. An access to micro credit, or a job, by women can be best characterized as the manifestation of women's agency and the benefits they get as their achievements i.e., income, discretionary spending, healthcare etc. Similarly, women's economic contribution is an important factor and can be used to predict other outcomes such as their control over important decisions and those related to their family size, or contraceptive use.<sup>14</sup> Similarly, assets owned by them function as sources of their empowerment.<sup>15</sup> The potential influence of any empowerment indicator always depends upon its interrelationships with other variables.

#### Health Profile of Tribal Women

In the present study, the health from the perspectives of mortality patterns and selected infectious and non-infectious



illnesses were reviewed (Box-3). The prevalence of sexual transmitted disease (STD) syndromes in adults tribal population of central India reported that of 2568 individuals interviewed. 326 (12.7%) carried at least one STD syndrome. The prevalence was nearly twice among women in comparison to men. The highest prevalence was observed in the age group of 30-34 years followed by 35-39 years group. The commonest syndrome in women was vaginal discharge while in men it was dysuria.<sup>16</sup> The prevalence of hypertension among males and females was 31.8% and 42.2% respectively.<sup>17</sup> Gastrointestinal problems like acid peptic disease were found in 2.6% to 20% of cases. Nonspecific fever was marked in 10.2% to 24.2% of individuals. The iodine deficiency disorder, namely goiter, was found among 4.2% to 6.0% of individuals. The morbidities in children were acute respiratory infections followed by acute diarrheal diseases, conjunctivitis and skin infections.<sup>18</sup> The various measures of infant and child mortality among tribal population were high as compared to any other segment of the population. The average number of illnesses per elderly person was 3.0. Common disabilities like vision and hearing impairment and mobility-related problems were found in considerable numbers.

Tuberculosis (TB) is an infectious disease that poses a major threat to women's health security and its burden is enormous. Women are at increased risk of progression to TB during their reproductive years. Prevalence of TB infection was estimated from tuberculin survey and the computed Annual Risk of

Tuberculosis Infection (ARTI) is an indicator to assess the extent of transmission of infection with Mycobacterium tuberculosis. In India, the ARTI rates ranged between 1.0% and 1.9% in different zones of the country according to in a nationwide survey conducted during 2000–2003.<sup>19</sup> Very little information is available on the ARTI among tribal populations of India. A survey<sup>20</sup> carried out in a tribal population of North Arcot district in south India showed an infection prevalence of 5% with computed ARTI of 1.1%. In a survey<sup>21</sup> conducted among Saharia, a tribal community of Madhya Pradesh, the prevalence of infection and ARTI were very high being 16.9% and 3.6% respectively. Another survey<sup>22</sup> carried out in tribal community of Car Nicobar island showed that the prevalence of infection and ARTI were 16.4% and 2.4% respectively (Table-1).

National Family Health Survey (NFHS-3) is the first national survey in India to include HIV testing. It was designed to provide a national estimate of HIV in the household population of women aged 15-49 years and men aged 15-54 years. The prevalence of HIV among tribal population is very low- 0.25 (female 0.12 and male 0.39). There is lack of access to services and opportunities for women to protect themselves and negotiate for the safe sex, which endangers them to a greater risk of HIV infection.

#### Empowerment Indices of Tribal Women

Past three decades have witnessed an increasing awareness regarding the need

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to empower women through increasing the social, economic and political equity, and broadening the access to fundamental human rights, improvements in nutrition, basic health and education. These proxy indices among tribal women have been described in the paper.

#### **Economic Participation**

Tribal women in India contribute positively to the local economy and participate with men in subsistence activities. In reality, women perform more work than men as they participate in all agricultural activities (except ploughing) as well as other indigenous cottage industries. In addition, they manage household chores. Child rearing is also their responsibility. In India, over 80% of the tribals work in the primary sector against 53% of the general population. About 45% tribals are cultivators against 32.5% of the general population.<sup>23</sup> Tribal women work hard for the livelihood of their family but maintain a poor life in spite of their contributions. Their whole income spent over their basic requirements i.e., food and other needs. The status of women usually depends on the economic roles they play. Due to lack of skills and regular income generating

activities, they are below the poverty line. Economic environment of women affects the social development. Thus, there is a need to undertake income generating activities among the poor women for their economic empowerment.

#### **Educational Attainment**

Education is a universally recognised powerful instrument of social, cultural and health development. It is crucial to women empowerment. Hence, primary education has been a goal in many developing countries for several years. With the articulation of the Millennium Development Goals (MDGs), there has been an increased focus on meeting this challenge. The proportion of tribal women who have never attended school was highest (Graph-2), and there is a gender difference at different levels of education (Table-2). The reasons associated with not imparting education to girl child are financial constraints, early marriages, submissiveness, motherhood and parents' narrowed perceptions about women education. Educating a girl child is deliberately denied that affects the future opportunity for her total development.

	Tribal	Overall
North Arcot, Tamilnadu <sup>20</sup>	5%	1.1%
Saharia,Madhya Pradesh <sup>16</sup>	16.9%	3.6%
Car Nicobar Island <sup>22</sup>	16.4%	2.4%

#### Table 1: Annual risk of TB infection among tribals



Year	То	tal populatio	n	ST				
-	Male Female Tot		e Female Total Male F		Female	Total		
1961	40.40	15.35	28.30	13.83	3.16	8.53		
1971	45.96	21.97	34.45	17.63	4.85	11.30		
1981	56.38	29.76	43.57	24.52	8.04	16.35		
1991	64.13	39.29	52.21	40.65	18.19	29.60		
2001	75.26	53.67	64.84	59.17	34.76	47.10		

#### Table 2: Literacy among tribals

Source : Educational Statistics 2002-2003, Ministry of HRD

Some research studies have demonstrated strong links between girls' education and their health. Schooling is associated with lower blood pressure, reduced obesity and a lower risk of disability, and it reduces the mortality among adults.<sup>24,25</sup> Maternal education reduces the incidence of low birth weight and premature birth of children.<sup>26</sup> Women's health related knowledge strengthens their children's health.<sup>27</sup> It was observed that the mothers who spent time in primary schools reduced the death risk of their children before their fifth birthday by 8%.<sup>28</sup> In Egypt, the child mortality rate among families where the mother had no education was 89 per 1000 live births compared with just 38 per 1000 live births in the families where mothers had completed their secondary schooling.<sup>29</sup> According to Amartya Sen, female literacy is a more important determinant of child mortality than the male literacy and poverty reduction. Worldwide, UNAIDS reports that women currently know less about HIV transmission than men. Education

creates awareness among women for their protection against unsafe sex which may lead to infection. By empowering them educationally, they are enabled to negotiate and advocate for safe sex confidently.

#### **Social Capital**

'Social capital' refers to the connections and networks among individuals and the norms of reciprocity and trustworthiness that arise from them. Such networks support and contribute in empowering the women to work together to face their problems. Such networks can guide individuals for important health issues/threats, precautions/preventions, access to health services and give them all necessary assistance and emotional support during the treatment. This was tried by the Veshya Anyay Mukti Parishad (VAMP) group in India and it helped in increasing the usage of condom among sex workers.<sup>30</sup> World Health Organization recommended that health services can contribute in promoting the social capital by encouraging the civic participation in



their programmes/management.<sup>31</sup> Such networks need to be developed in tribal areas to empower women for their health improvement.

#### Knowledge Empowerment

The mass media plays a significant role in shaping the health beliefs and behaviors. The NFHS reported that among the tribal women, 57% were not regularly exposed to any media (Graph-3), whereas only a small proportion of tribal women were exposed to television (30%), radio (21%) and newspaper (10%). Media is the most powerful tool of communication and provides exposure to the mass audience about what is correct or incorrect. It helps to inform people about the realities of social issues including poverty, violence, corruption and bribery, suppression of human rights, discrimination and crime. There is an association between the development of mass media and social changes. Besides exposing tribals to new ideas and expanding their world view, the media is instrumental in bringing about changes in their attributes and has led them through the path of modernization. Thus, communication plays a vital role in their all around development.

#### **Political Empowerment**

Across the world, political mobilization by women has contributed to huge improvements in health and quality of life. It has led to the expansion of family planning services that have given women greater freedom regarding their choice over fertility and better protection against sexually transmitted diseases. Decline in fertility has given countries a 'demographic dividend' whereby smaller

numbers of young dependents have allowed working adults to invest more time and resources in economic activity with large benefits to economy.<sup>32</sup> Legalization of abortion in many countries has significantly reduced the abortion related mortality and morbidity. Lobbying by women groups and female politicians has eliminated diseases that affect women such as breast and cervical cancer closer to the objective of health policy and research; the consequent advancements in the prevention and treatment technologies have saved millions of lives and averted significant anguish among both women and men. Appropriate education and training can prepare tribal women to mobilize politically and to have greater involvement in policy making.

# Violence against Women and Empowerment

Regarding violence against women in the socioeconomic and political contexts of power relations, tribal women are particularly vulnerable to violence, exploitation, discrimination, unequal economic and social status and lack of secure/suitable atmosphere etc.<sup>33</sup> It often becomes a tool to socialize family members according to prescribed norms of behavior with an overall perspective of patriarchal social structure. Due to complexity of the social and cultural issues combined with the stigma and fear of disclosure, only a small proportion of the crimes of sexual assault, child abuse and physical assaults have been reported.<sup>34</sup> However; due to their strict social norms, the violence in the form of female foeticide and infanticide seems to

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be absent among tribals.

#### Wealth Empowerment

The links between wealth and health are well established. Financial resources enable individuals to protect themselves against health threats by consuming better food, drinking pure water, living in safe environment, accessing sanitation facilities and having health related awareness. In case of illness, wealthier people are able to afford effective health care and strong social support.<sup>35</sup> The World Health Organization has estimated that people living in absolute poverty (that is, earning less than \$1per day) are five times more likely to die before the age of 5 and two and a half times more likely to die between the ages of 15 and 59 years.<sup>36</sup> Economic position of an individual influences his/her health and risk taking behaviors, environmental exposures and access to resources for maintaining good health. The inverse stepwise relationship between economic position and health status generally affects people at all levels of society.

NFHS-3 used an index of the economic status of households, called the 'wealth index'. This wealth index has been developed and tested in a large number of countries in relation to inequalities in household income, use of health services and health outcomes. It is an indicator of the level of wealth of an individual in relation to his/her expenditure and income. The wealth index was constructed using household asset data and housing characteristics. According to it, each household is assigned a score for each asset and scores are summed for each household; and individuals are ranked according to the scores of their household. The sample is then divided into quintiles, i.e., five groups with equal number of individuals in each. It showed that the percent distribution of the tribal sample population by wealth quintiles is half to the persons in the lowest wealth quintile. Since the majority of tribes were poor (Graph-4),<sup>37</sup> the health impacts associated with lower socioeconomic position accumulate and persist throughout their lifespan.

#### Empowerment for Health Care Seeking

Health service utilization has been associated with several sociodemographic factors such as age, gender and socio-economic status. A study on the health seeking behaviour and acceptability of provided health facilities among the tribals of West Godavari district in Andhra Pradesh showed that despite the socio-economic background of the tribals, their attitude towards health and health facilities leaned towards modern medicine and 96% of the respondents were of the opinion that there was a difference in the present day health seeking behaviour as compared to that of their ancestors. However, NFHS-3 reported that the likelihood of having received any antenatal care and care from a doctor is lowest among the tribal mothers. Only 18% of births among scheduled tribe are delivered with health facilities. The common beliefs, customs, practices related to health and diseases in turn influence the health seeking behavior of the community. The



necessary behavioural changes and managerial control of women can significantly contribute to utilisation of health care.<sup>38</sup> Hence, there is a need to educate tribal women for making necessary changes regarding their health care seeking behaviour.

#### Women Empowerment and Health Outcomes

Due to variety of reasons, tribal health is less optimal as compared to the health of general population. And, women need to be empowered to bridge the gap in different spheres. The empowerment of women has been widely acknowledged as an important goal for better health status and development (Box-4). It is also an important factor that influences health and social outcomes, yet only few studies have examined this.

Women are the prime targets of programmes that aim at improving maternal and child health and achieving other desired demographic goals. An understanding of the status and empowerment of women in society and within their households is thus critical to promoting changes in reproductive attitudes and behaviour especially in patriarchal societies.<sup>39,40</sup> Notably; the National Population Policy, 2000 specifically identified the low status of women in India as an important barrier to the achievement of population and maternal and child welfare goals.<sup>41</sup> The World Bank has identified empowerment as one of the key constituent elements of poverty reduction, and as a primary development assistance goal. The Bank has also made gender mainstreaming a priority in development assistance, and is

in the process of implementing an ambitious strategy to this effect. The promotion of women empowerment as a development goal is based on the argument that social justice is an important aspect of human welfare and is intrinsically worth pursuing, and that women empowerment is a means to meet other needs.

#### CONCLUSION

The women empowerment proxy indices such as education, economic participation in non-agricultural sectors, exposure to media and wealth are inadequate among tribals. Thus, they remain largely marginalized, poor and socially excluded, and their health outcomes are not optimal. Working with these imbalances is of further importance for the researchers, policymakers, programme managers and civil society groups. There is also a need to monitor the impact on women empowerment and their health, so concentration on the barriers to girls education, i.e, familial resistance, cost of education, school drop-out rates etc, exposure to media, early marriages and pregnancy are crucial. Education or health related knowledge about reproductive, communicable and non-communicable diseases etc. empower women to gain benefits for their overall health development. School education needs to emphasize on the importance of gender equality and greater need and role of women's participation in family's health. The primitive way of women's living in tribal areas requires urgent actions in all these aspects to empower them, which is one of the greatest challenges of

#### Box 1: Definitions of empowerment

- ? Empowerment is the process that allows an individual to gain knowledge, skills and attitude needed to cope with the changing world and circumstances.
- ? Empowerment is an active and multidimensional process that enables women to realize their identity and power in all aspects of life.
- ? Empowerment is t he process of increasing capacity of individuals or groups to make choices and transform those choices into the desired actions and outcomes to build individual and collective assets and to improve the efficiency and fairness of the organizational and institutional contexts which govern t he use of these assets. (World Bank)
- ? The key to empowerment is the removal of formal or informal barriers and the transformation of power relations between individuals, communities, services and governments.
- ? Woman empowerment is considered to take place wh en a woman challenges the existing norms and culture of the society in which she lives, to effectively improve her well being.

#### Box 2: Measures used to define women empowerment

- ? 'Gender equality', which is defined in terms of equality under the law, equality of opportunity (including equality of rewards for work and equality in access to human capital and other productive resources that enable opportunity), and equality of voice (the ability to influence and contribute to the development process). It impl ies equivalence in life outcomes for women and men, recognizing their different needs and interests, and requiring a redistribution of power and resources. (World Bank 2001)
- ? 'Gender equity' recognizes that women and men have different needs, preferences, a nd interests and that equality of outcomes may necessitate different treatment of men and women. (Reeves and Baden 2000).

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Box	Box 3: Health profile of tribal population									
		Adults								
?	At least one ST	D syndrome								
	Women	17.6%								
	Men	8.4%								
?	STD in the age	group								
	30-34 years	16.2%								
	35-39 years	14.7%								
?	Commonest syr	ndrome in								
	Women: vagi	nal discharge	e 16.0%							
_	Men : dysu	rea	1.8%							
?	Hypertension									
	Males	31.8%								
	Females	42.2%								
	c	hildren								
?	Acute respirator	y infections	25.5%							
?	Acute diarrhoea	l diseases	5.8%							
?	Conjunctivitis		1.5%							
?	Skin infections		1.2%							
?	Infant Mortality	Rate	84/1000							
?	Under 5 Mortalit	ty Rate	119/1000							
	Elder	rly persons								
?	Number of illnes	sses per	3.0							
	person									

# Box 4 : Women empowerment and improvement in health outcomes

- ? Women spend their money and time for maintaining better health and quality of life of their children and family.
- ? Education of women regarding health status is a great health benefit to their children and families.
- ? School attendance of children is high among female headed households.
- ? Education of women increases the age of marriage and child birth.
- ? Highest birth rates for women with less education.
- ? Inverse relationship between economic status & infant m ortality rate (IMR).
- ? Strong correlation between IMR, MMR and Female Literacy Rate.
- ? 51 million unintended pregnancies in developing countries occur every year.
- ? 42 million abortions performed annually are unsafe and 68000 die each year due to abortion
- ? Higher ages of women and better education have lower chance of physical assaults.
- ? Women's cash contribution to their family income is more than 50%.



Graph 1: Tribal population in India (Census 2001)





Level of education (Years completed)





Graph 3: Exposure of tribal women in India to mass media

Source: National Family Health Survey 2005-2006. International Institute for Population Sciences, Mumbai, India, 2007



Graph 4: Distribution of wealth quintiles of tribal population in India

Source: National Family Health Survey 2005-2006. International Institute for Population Sciences, Mumbai, India, 2007

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### PUBLIC HEALTH ISSUES OF HEREDITARY HEMOLYTIC ANEMIA IN UNDER-PRIVILEGED RURAL COMMUNITIES OF A CENTRAL AND A COASTAL DISTRICT OF ODISHA, INDIA

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Abstract: Inherited erythrocytic hemoglobin disorders of blood are important public health concerns in India including in Odisha. The state of Odisha is inhabited by a large number of general caste, scheduled caste, backward caste and indigenous people. These people face several public health challenges including sickle cell anemia, -thalassemia and G6PD deficiency that cause hemolytic anemia. Detailed screening for these hemolytic disorders in under-privileged vulnerable communities was carried out in Anugul and Ganjam districts of Odisha for three months during the year 2004 and 2005. Among all castes, 30.3% and 15.1% prevalence of sickle cell disorders was recorded in Anugul and Ganjam districts, respectively along with high occurrence of hemolytic anemia in both Anugul (96.4%) and Ganjam (45.3%) districts. Hereditary hemolytic disorders are quite common public health issues in vulnerable caste populations of Odisha. Hemolytic anemia is also dependent upon the nutritional status, parasitic infestations, parasitic infections, intake of iron-folic acid containing foods and, hygienic and sanitary conditions of the people. The sickle cell gene was commonly encountered in both general castes (21.4%) and scheduled castes (5.4%) but not so frequently among the indigenous people of Odisha. In general, the consumption of iron-rich foods was low. Moreover, nutritional status of women in Anuqul district was poor leading to high prevalence of anemia. To prevent these hereditary hemolytic health problems, screening for the carrier detection is an important option. Marriage between the two carriers should be discouraged to reduce the prevalence of hemoglobinopathies specifically the sickle cell anemia in the affected population.

**Key words:** Hemoglobinopathies, Sickle cell disease, Hemolytic anemia, Public health, Anugul district, Ganjam district, Rural Odisha.

#### INTRODUCTION

The population of India consists of people of several general castes (GC), scheduled castes (SC), other backward castes (OBC) and scheduled tribes (ST) inhabiting diverse geographical and ecological niches of the country. The state of Odisha has 93 scheduled castes and 62 scheduled tribes that constitute 15.2 % and 22.4% of the state population. The Ganjam district is located at coastal region whereas the Anugul is a central district of the state. Both these districts fall within the high malaria endemic zones and are inhabited by mixed population; hence, can be considered as representative of the state population. The inhabitants of both the districts belong to



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endogamous communities and do not marry outside their own territory or caste.

Hemoglobinopathies are important genetic and public health challenges in Odisha. A large number of people of the state are vulnerable to the abnormalities of hemoglobin such as sickle cell disease causing hemolytic anemia, enhanced morbidity and mortality in the affected communities.<sup>1, 2</sup> Common symptoms of sickle cell anemia<sup>3</sup> are: recurrent fever, joint pains, swelling of abdomen, poor appetite, vomiting, enlarged liver and spleen, mild to moderate clinical jaundice, etc. Some of the physical appearances are thin limbs and long protuberant abdomen, height and weight below average for the age and head is frequently large and of abnormal shape.4 The sickle cell gene is prevalent not only among the tribal or scheduled caste population, but has also penetrated the general caste population.<sup>5-7</sup> Thus, sickle cell disease has assumed a major public health issue in Odisha, causing hemolytic anemia, high morbidity, maternal and fetal mortality and reproductive wastage affecting general health, psychosocial behavior and economy of a large number of tribal as well as non-tribal communities.8

The present study is focused on the ecological and geographical diversities with respect to the prevalence of hemoglobinopathies specifically the sickle cell disease and hereditary hemolytic anemia among the three major under-privileged communities of rural Odisha. This public health study aims to focus on the health related issues concerned particularly with the vulnerable communities and general population at large.

#### **MATERIALS AND METHODS**

The present study was carried out at the Division of Human Genetics, Regional Medical Research Centre (ICMR), Bhubaneswar (Odisha) during May to July 2004 (SKS) and April to June 2005 (PKD). At random, 2-3ml intravenous blood of 109 individuals was aseptically collected in EDTA coated vials after taking informed consent from each individual at Primary Health Centre (PHC) in Ganjam (53 samples) and Anugul (56 samples) districts of Odisha for the screening of hemoglobinopathies and -thalassemia. Blood samples were transported under wet ice cold conditions within 24 hours to the laboratory of Human Genetics at Bhubaneswar, where all the standardized tests were performed. Laboratory investigations were carried out following the standard procedures after cross checking for the quality control from time to time. Hematological parameters were studied using an automated Blood Cell Counter (Model-MS4, Melet Schloesing Laboratories, Cergy-Pontoise Cedex, France).

The sickling test was performed by using 2% freshly prepared sodium metabisulphite solution as a reducing agent for the presence or absence of sickle cell hemoglobin.<sup>9</sup> The routine hemoglobin lysate electrophoresis was carried out on cellulose acetate membrane (CAM) in Tris-EDTA-Borate buffer at pH 8.9 and quantification of A<sub>2</sub> fraction of adult hemoglobin was done by elution method.<sup>9,10</sup> The value more than 3.5% of A<sub>2</sub> fraction of adult hemoglobin



was taken as the cut-off point to determine the -thalassemia trait. Estimation of fetal hemoglobin was done according to technique described by Weatherall.<sup>10</sup>

The diagnosis of sickle cell- thalassemia was based on the findings of hemoglobin (Hb) A, F, S and  $A_2$  on electrophoresis under alkaline pH, elevated HbA<sub>2</sub> levels (>3.5%). All the doubtful cases were further subjected to hemoglobin variant analysis for detecting discrepancy, if any (Bio-Rad Diagnostics, Hercules California, USA).

Test results were given to patients or their relatives for the treatment and further clinical management by the PHC doctor. All the carrier/affected persons were imparted genetic/marriage counseling by the PHC doctor and subsequent follow ups were done.

#### RESULTS

Age and sex-wise distribution of 109 individuals screened for hemoglobinopathies and hereditary hemolytic anemia from Anugul and Ganjam districts of Odisha is presented in Table 1. It is apparent from the table that the distribution of males (46.4%) and females (53.6%) is nearly similar in Anugul; whereas in Ganjam district, males (83%) were comparatively in higher number than the females (17%). This difference was probably due to conservative attitude and hiding nature of the people especially of the women who generally avoid going to a primary health centre for the treatment.

Table 2 shows the sex-wise distribution of the subjects in broader caste groups. It may be noted from the table that it is the general caste community (58.9%) in Anugul district which utilizes the medical health care facilities better than the scheduled caste (23.2%) or other backward caste people (17.9%). This pattern of attendance at PHCs is different from Ganjam district's. In contrast, backward caste people (54.7%) use medical heath care facilities better than the general castes (39.6%) and scheduled caste (5.7%) in Ganjam district.

 Table 1: Age, sex and district-wise distribution of the subjects studied of

 Odisha

Age	Αηι	igul Di	istrict	(Cent	ral Oo	disha)	Ganjam District (Coastal Odisha)					
groups	Μ	ale	Fer	nale	T	otal	Male		Female		Total	
(in years)	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
0-10	4	7.1	1	1.8	5	8.9	1	1.9	0	0.0	1	1.9
11-20	3	5.4	3	5.4	6	10.7	2	3.8	3	5.7	5	9.4
21-30	3	5.4	9	5.4	12	21.5	20	37.7	1	1.9	21	39.6
31-40	6	10.7	5	8.9	11	19.6	13	24.5	2	3.8	15	28.3
41-50	6	10.7	6	10.7	12	21.5	7	13.2	2	3.8	9	17.0
51-60	2	3.6	3	5.4	5	8.9	0	0.0	1	1.9	1	1.9
61+	2	3.6	3	5.4	5	8.9	1	1.9	0	0.0	1	1.9
Total	26	46.4	30	53.6	56	100.0	44	83.0	9	17.0	53	100.0

	Anugul District (Central Odisha)							Ganjam District (Coastal Odisha)					
Caste	M	ale	Fer	Female		Total		Male		Female		Total	
Groups	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
General Castes	16	28.6	17	30.3	33	58.9	13	24.5	8	15.1	21	39.6	
Other Backward Castes	5	8.9	5	8.9	10	17.9	20	37.7	9	17.0	29	54.7	
Scheduled Castes	5	8.9	8	14.3	13	23.2	2	3.8	1	1.9	3	5.7	
Total	26	46.4	30	53.6	56	100.0	35	66.0	18	34.0	53	100.0	

Table 2:Major caste, sex and district-wise distribution of the subjects studied

Anemia is one of the major indicators of health status (Table 3). It has been observed in Anugul district of Odisha that anemia is a major health problem among the women. Severe anemia was found to be around 10.7% followed by mild anemia (71.4%) and moderate anemia (14.3%) in the subjects studied from Anugul district. However, in Ganjam district, mild anemia (35.8%) was frequently observed. Inhabitants of two districts can be distinguished on the basis of occurrence of anemia amongst them. The highest frequency of sickle cell disorders (30.3%) was observed in Anugul district of Odisha where 3.6% cases were of the homozygous sickle cell disease. However, the disease was more frequent among males than the females in Anugul district (Table 4). In Ganjam district, sickle cell disorders account for 15.1% in the studied population with homozygous sickle cell disease at the frequency of 5.7%. However, the disease was more frequent among females in Ganjam district of Odisha.

	An	Anugul District (Central Odisha)							Ganjam District (Coastal Odisha)				
Grades of Anemia	Male		Female		Total		Male		Female		Total		
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
Severe (<7.0g/dl)	1	1.8	5	8.9	6	10.7	0	0.0	2	3.8	2	3.8	
Moderate(7.1- 10.0g/dl)	7	12.5	1	1.8	8	14.3	1	1.9	2	3.8	3	5.7	
Mild (10.1-12.0g/dl)	16	28.6	24	42.9	40	71.4	17	32.1	2	3.8	19	35.8	
Normal(>12.1g/dl)	2	3.6	0	0.0	2	3.6	26	49.0	3	5.7	29	54.7	

Table 3: Different grades of anemia as well as sex and district-wise distributionof the subjects studied

	An	ugul D	istrict	(Centra	al Odis	Ganjam District (Coastal Odisha)							
Hemoglobinopathies	Male		Fer	Female		Total		Male		Female		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
Sickle Cell Trait	10	17.9	5	8.9	15	26.8	3	5.7	2	3.8	5	9.4	
Sickle Cell Disease	1	1.8	1	1.8	2	3.6	2	3.8	1	1.9	3	5.7	
Sickle Cell Disorders	11	19.6	6	10.7	17	30.3	5	9.4	3	5.7	8	15.1	
Normal	15	26.8	24	42.9	39	69.6	39	73.6	6	11.3	45	84.9	

#### Table 4: Different sickle cell disorders and sex and district-wise distribution of the subject studied

Table 5 shows interesting facts about sickle cell disease in Odisha. The table shows that it is the general caste people (21.4%) who suffer from the sickle cell disorders more than the people of the other castes or marginalized people. This finding is contrary to the generalized concept and understanding that the sickle cell disease is the disease of the tribals and does not affect the people of elite community. Next to the general castes, it is the scheduled caste (5.4%) people who harbor the sickle cell gene, followed by the other backward castes people (3.6%).

#### DISCUSSION

It is surprising to note from the results of the present study that there is a wide gap between the population diversity, geoecological setting, climate fluctuations, socio-cultural traditions, lifestyles behavioral attributes and nature of the

 Table 5: Different caste groups, sickle cell disorders and district-wise distribution of the subjects studied

Caste Groups	Anugul District (Cen	Ganjam District (Coastal Odisha)			
		Tot	tal	То	tal
	Diagnosis	No.	%	No.	%
General Castes	Sickle Cell Trait	12	21.4	1	1.9
	Sickle Cell Disease	0	0.0	0	0.0
	Sickle Cell Disorders	12	21.4	1	1.9
Other Backward	Sickle Cell Trait	1	1.8	4	7.5
	Sickle Cell Disease	1	1.8	0	0.0
Casies	Sickle Cell Disorders	2	3.6	4	7.5
Schodulod	Sickle Cell Trait	2	3.6	2	3.8
Castes	Sickle Cell Disease	1	1.8	1	1.9
Casies	Sickle Cell Disorders	3	5.4	3	5.7
	Sickle Cell Trait	15	26.8	7	13.2
All Castes	Sickle Cell Disease	2	3.6	1	1.9
	Sickle Cell Disorders	17	30.4	8	15.1

people, concept of reproductive health and hygiene, mating pattern, food habits etc. of the people of two districts, i.e. Anugul and Ganjam of Odisha. Apart from the listed non-genetic variables, genetic inflictions such as sickle cell disease, -thalassemia or glucose-6-phosphate dehydrogenase (G6PD) enzyme deficiency also play a major role in public health attributes and emerging disability disorders in Odisha.

The subjects studied from Anugul district of Odisha showed a marked high degree of anemia (Table 3). Apart from the iron and folic acid deficiency, parasitic inflictions like hook worm, round worm, and malarial infections are most common which might have reduced the level of hemoglobin among them. Nutritional status of women in this district was poor that might have led to the high prevalence of anemia among them. In general, the consumption of iron-rich foods at the household was lower than the required. The average daily consumption of green leafy vegetables, a good source of micronutrients, was found lower than the recommended level in this area. This is the prime cause of iron deficiency anemia in Anugul and Ganjam districts of Odisha.

The sickle cell gene is wide spread throughout the Oriya society in Odisha.<sup>11</sup> The prevalence of sickle cell disorders was high in central-western Odisha.<sup>12</sup> The present study revealed the high prevalence of sickle cell disorder being around 30% of which 3.6% contributed by the homozygous sickle cell disease, and 26.8% by the sickle cell carrier cases in Anugul district of Odisha (Table 4). However, the disease was more frequent among males than in the females in the district. For the first time, the present study has been carried out in a rural PHC of Ganjam district pertaining to hemoglobinopathies in different major caste groups of Odisha. In this study, the 15.1% prevalence of sickle cell disorders (9.4% sickle cell trait and 5.7% sickle cell disease) without any -thalassemia was detected in Ganjam district of Odisha (Table 4). From the present study, it is apparent that people of all the caste groups in Odisha are at high risk of hemoglobinopathies specifically for the sickle cell disease.

We encountered a strange finding in the present study which is contrary to the generalized misconception that the sickle cell disease is a disease of the tribal people and not of the elite people. It has been seen in the present study that it is the general caste people (21.4%) in Odisha who suffer more from the sickle cell disorders than the other marginalized people (Table 5). In other words, the defective sickle cell gene is commonly encountered in general castes (30.3%) and scheduled castes (5.7%) and not so frequently among the indigenous people in Odisha. These findings are consistent with our previous studies reported from the state of Odisha.<sup>13</sup>

To prevent this hereditary health problem, screening for the carrier detection is an important aspect. Carrier screening can be done at neonatal stage, at school level, college level, before marriage, and before pregnancy.<sup>14</sup> Marriage between the two carriers should be discouraged. Introduction of neonatal and prenatal screening with the establishment of all the infrastructural requirements and the adequately trained





staff at the localities of vulnerable people will help in lowering the incidence of these diseases in Odisha.

#### CONCLUSIONS

Hereditary hemolytic disorders like sickle cell trait and disease are quite common public health issues in vulnerable caste populations of Odisha. Hemolytic anemia is also dependent upon the nutritional status, parasitic infestations, parasitic infections, intake of iron-folic acid containing foods and hygienic and sanitary conditions of the people.

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