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Original Article:

Intervention and Prevention of Hereditary Hemolytic Disorders in Two Ethnic Communities of Sundargarh District of Orissa, India: An Experience from KAP Studies

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Abstract:
Hereditary hemolytic disorders are important public health challenges in India. They cause a high degree of morbidity, mortality and fetal wastage in vulnerable communities. Tradition-bound-psychosocial influences are detrimental to the process of prevention. This study was designed to create awareness, motivate, and sensitize two major vulnerable tribal communities: Bhuyan and Kharia for hemoglobin and allied hemolytic disorders in addition to imparting prospective and retrospective genetic/marriage counseling. Bhuyan and Kharia tribal people in Orissa live in clusters practicing inter-village tribal endogamy and clan exogamy. For the present study, random sampling procedure for the selection of whole village was followed. Imparting of education, motivation and sensitization for carrier detection were carried out through IEC materials, holding interactive meetings and discussions at district, block and village levels. Both prospective and retrospective intervention and genetic/marriage counseling was done through the local PHC doctor. The pre- and post-intervention knowledge, attitude and practice (KAP) studies were conducted. Tribal people were not knowing the signs and symptoms of sickle cell disease (2.1%) and beta-thalassemia (1.0%), but after IEC, their knowledge was considerably improved (67.8%, 56.4%, respectively). Sickle cell patient needs treatment (37.6%) like folic acid, blood transfusion, etc. Beta-thalassemia is disease causes bloodlessness and is a transfusion dependent (73.2%). All patients of thalassemia major or sickle cell disease have carrier parents and carriers do not suffer from any clinical ailments. After intervention, it was known that G-6-PD is an enzyme, which helps in glucose metabolism of red cells (76.4%) and its hereditary deficiency causes hemolytic anemia, jaundice and black urination (73.8%) in malaria cases when anti-malarials are administered. Methodical and prudent intervention and preventive strategies found positive and encouraging impact on the affected people. Success of strategy showed apparent overwhelming response of the tribal people towards changing the traditional mindset and improving their health and quality of life.

Key Words: Hereditary Hemolytic Disorders; Hemoglobinopathies; Sensitization and Motivation; Carrier Detection; IEC/Intervention and Prevention; KAP Studies; Scheduled Tribes

Introduction:
There have been difficulties for the prevention and control of hereditary hemolytic disorders in the high risk communities of India. The high prevalence of genetic and hemolytic defects and their cause of related morbidity, mortality and fetal wastage drastically affect the reproductive outcome.(1) Poor health leads to productivity loss and adversely affects the economy in many ways. The tradition-bound-psychosocial influences are detrimental to the process of elimination and prevention of genetic disorders, and are further compounded by marked illiteracy and poverty.(2) Hence, there is an urgent need to find out strategies to combat the genetic health problems faced by the vulnerable communities especially in the developing countries like India.

For the prevention and control of hereditary hemolytic disorders in at risk communities for promotion of health care strategies and better quality of life of the people, bringing of awareness about genetic diseases and imparting of health education, carrier detection, and prenatal diagnosis prior to elimination through termination of pregnancy, are highly essential.

The present study was designed with the following specific objectives:

i) To sensitize, motivate and educate the vulnerable communities through audio-visual aids like posters, charts, pamphlets, interactive meetings, group discussions, etc. for detection of carriers of the hereditary hemolytic disorders such as sickle cell disease, β-thalassemia, and glucose-6-phosphate dehydrogenase (G6PD) enzyme deficiency.

ii) To provide prospective and retrospective genetic/marriage counseling to affected persons and families; and to evaluate the outcome of periodic follow up, clinical management and, intervention through local primary health centers (PHCs)/hospitals.

Materials and Methods:

This study was a part of our major project at the Regional Medical Research Centre (RMRC), Bhubaneswar carried out in two ethnic communities, namely, Bhuyan and Kharia of Sundargarh district in Western Orissa during the period from January 2000 to December 2004.

The Bhuyan and Kharia tribes although originally belonged to two separate ethnic stocks, but now each of them divided into three social groups namely, the Hill (Pahari or Paudi) Bhuyan/Kharia, Paraja (Common People) Bhuyan/Dhelki (Late Comer) Kharia and the Paik or Khandayat (Warrior) Bhuyans/Dudh (Pure) Kharias, and are distinguished from each other on the basis of three grades of primitive culture in the state of Orissa.(3) The Hill Bhuyan/Kharia, the primitive and backward section, represents the hunting and food gathering stage of economic life along with the practice of primitive culture and rudimentary shifting cultivation. The Paraja Bhuyan/Dhelki Kharia section represents the more advanced culture with habit of plough-cultivation and food production. The Khandayat Bhuyans/Dudh Kharias have the most advanced culture, which equates them with other non-tribal population of the region. The Dudh Kharias have embraced Christianity about one and half century ago, whereas, the Dhelki Kharias are hinduised group. The latter group preponders over the other two groups in population size. The inter-group marriages are not taking place at all. Reproductively and genetically, they are completely isolated from each other. The Hill Kharias who reside in Mayurbhanj district of Orissa were not studied.

Methodology:

In order to carry out the study, formal permission from the Department of Health & Family Welfare, Government of Orissa; and the District administration was taken after proper interaction and explaining the purpose, aims and objectives of the study. Ethical clearance from the Human Ethical Committee of RMRC (ICMR) Bhubaneswar was also obtained for the smooth conduct of the study. Before the start of actual work, the mobilization, sensitization and convincing of district administration was done by holding interactive meetings at district headquarters with the District Administration, Chief District Medical Officer, District Welfare Officer of Sundargarh district for their cooperation or assistance/help, if need arises during the course of study. It was ensured that at every stage of implementation and conduct of the study smoothly, full cooperation anticipated from all concerned communities/officials.

Selection of Target Population and Sampling Procedure:

The study was carried out taking into consideration the statistical component and following the random sampling procedure for the selection of villages. The tribal people in Orissa live in clusters or groups at particular place and inter-village marriages take place because of tribal endogamy and clan exogamy. In this case, the population of each tribe was representative because the incoming and outgoing married women represented their native villages. Keeping in view the practical aspects, operational feasibility and vulnerability of the people to these genetic disorders, it was planned to select most populated blocks of the Bhuyan and Kharia tribes. Out of a total 17 blocks in Sundargarh district, 5 blocks, namely, Balisankara, Subdega, Bargaon, Hemgiri and Lahunipara were selected based on each tribe's population data according to Adivasi Atlas of Orissa.(4) Based on this census data, out of several villages so identified in these blocks, the whole village of each community at random was selected. For Bhuyan tribe, for example, Hemgiri (villages, Ratansara, Gad Dwar) and Lahunipara (villages, Badjal, Budhabhuin, Kuliposh Colony) Blocks; and for Kharia tribe, Balisankara (villages, Sarbahal, Chandnimal, Dhotipada), Subdega (village, Ranpur) and Bargaon (village, Latagaon) Blocks were studied (Fig. 1).

For the coverage of two communities, a total of 422 families (195 of Kharia and 227 of Bhuyan Tribe) with 836 and 767 persons, respectively of Bhuyan and Kharia tribes were included in the study. Only five families in Kharia and six in Bhuyan tribes were either not available or did not respond to our motivational and sensitization campaigns even after conducting the census, hence were not included in the analysis (Table 1). Out of a total 767 persons belonging to Kharia tribe studied, there were overall 422 persons (196 males and 226 females) who belonged to Dudh Kharia and 345 persons (181 males and 164 females) were of Dhelki Kharia tribe. Similarly, out of a total 836 Bhuyans, there were 213 (106 males and 107 females) Parajas, 244 (117 males and 127 females) Paik or Khandayats, and 379 (184 males and 195 females) Pahari or Paudi Bhuyans (Table 1). On the whole, a total of 1,603 Bhuyan and Kharia tribals belonging to both sexes were screened for hemoglobinopathies and allied disorders.

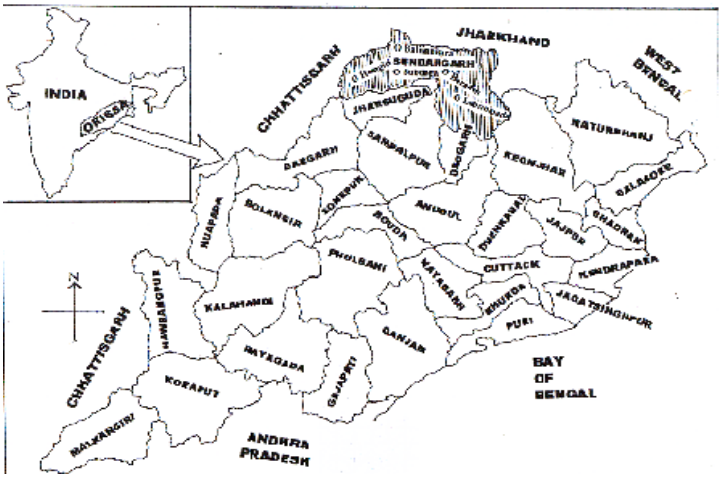

Fig 1: Map of Orissa state showing 30 districts and the study area (shaded)

Table 1: Tribe-wise data of the subjects studied in Sundargarh district of Orissa

Name of Tribe	No. of Families Census Taken	No. of Families Not Covered	No. of Families Covered	Population		
				Males	Females	Total
Kharia	195	5	190	377	309	767
Bhuyan	227	6	221	407	429	836

Study of Knowledge, Attitude and Practices (KAP):

Before starting the study, the knowledge, attitude and behavioral practice (KAP) information was collected from adult individuals belonging to both sexes in each tribe based on the semi-structured interview questionnaire prepared for the purpose. Educational levels of respondents (410) belonging to both sexes of Bhuyan and Kharia communities were recorded (Table 2). The responses were collected before the start of study as well as after the dissemination of information, education and communication (IEC)/intervention.

Table 2: Educational levels of the respondents belonging to Bhuyan and Kharia communities of Sundargarh district, Orissa

Educational Level	Bhuyan Tribe		Kharia Tribe	
	No.	%	No	%
Graduate	0	0.0	4	2.0
10+2 (Intermediate)	4	2.0	10	4.9
Matriculate	12	5.8	30	14.7
Under-Matriculate	20	9.7	34	16.7
5th Class Pass	46	22.3	54	26.5
Illiterate but knowledgeable persons	124	60.2	72	35.2
Total	206	100.0	204	100

Information, Education and Communication (IEC):

After sensitization of the District Administration and District Health Authorities and getting assurance for the support, the sensitization, motivation for carrier detection, education and awareness campaign was launched at the village level in the selected villages by holding inter-active meetings, discussions, explaining health hazards caused by genetic diseases through pamphlets, charts (easily understandable by even illiterate people), explaining the purpose of program in the local dialect and language, involving local primary health center (PHC) doctor, block development and panchayat officer (BDPO), auxiliary nurse and midwife (ANM), child development and project officer (CDPO), local community leaders (sarpanch, ward members, etc.), anganwadi workers, multipurpose health workers, laboratory technicians, prominent village leaders, etc. This cordial community participatory approach was overwhelmingly welcomed, appreciated and reasonably successful. It was also ensured that program was tribe-oriented, tribe-friendly and tribe-participatory, adjusting convenience and availability of community members, without disrupting their routine or without harming their interests under natural climate and ecological setting.

Intervention, Genetic Counseling, Clinical Management and Follow up of Affected Families through Local PHC Doctor:

Each person who had given blood for investigations was provided with investigation report card. As per the investigation report, the affected individuals were given advice to take follow up action accordingly. Regular visits to the selected localities at the interval of 2 months were done involving the local PHC doctor for giving the appropriate advice to each subject for clinical management, treatment and follow up of the affected and carrier cases, as and when necessary.

To affected individuals/families, the prospective/retrospective counseling was given for community prognostic management and future planning for these genetic disorders.(5,6) The basic idea of intervention was to bring awareness in these tribal communities about the silent/hidden killer hereditary/genetic disorders and their elimination. Interventions were effected to all carriers as well as disease cases of hemoglobin disorders like sickle cell trait and disease, Hb E trait and disease, Hb D trait, β-thalassemia trait and HPFH and the G6PD deficiency through local PHC doctor in each village by holding the interactive discussions taking them into confidence and keeping privacy of each person during the course of this study.

For prospective counseling, a carrier of marriageable age was advised to get the blood tested of the partner before finalization of the matrimonial alliance. Similarly, to young carrier children of these hereditary conditions, the parents were advised to match the blood of prospective partner of their children before finalization of the marital union. This will prevent the marriage between two carriers and eliminate the chance of getting affected or diseased offspring. The carriers were advised to marry only non-carriers of these disorders as far as possible.

For retrospective counseling, the carrier parents were given options to take prudent decision before going for a pregnancy, either to go for a child with a risk or adopt a child of a relative or a friend without a disease as per the convenience. Children of carrier parents in every pregnancy have 25% chance of being diseased, 25% chance of having normal and 50% chance of having carrier like the parents. If single partner is a carrier, then there is 50% chance in every pregnancy of having carrier or normal child, but without the disease. Those carrier parents, who already have the children, should go for testing blood of their all children and follow the prospective counseling.

Those parents who are carriers and want to have their own child were advised to go for prenatal diagnosis (within 10-11 weeks of conception), if they can financially afford to go to metro cities like Kolkata, New Delhi, Mumbai, Chennai, etc. where these diagnostic facilities are available in India.

Results:

KAP Studies and Impact on Tribals:

Before starting the awareness in the identified tribal people, the knowledge, attitude and practice (KAP) responses were studied from 200 individuals on a predesigned proforma as a measure of Pre-intervention as well as later on, after intervention (Post-Intervention) from 210 individuals. Educational levels of a total 410 respondents belonging to both sexes of Bhuyan and Kharia communities were recorded (Table 2).

In response to question of prevalent diseases in the village (Pre-intervention), the majority of them responded in the following sequence: cough (87.5%), fever (83.7%), cold (67.2%), malaria (56.6%), jaundice (43.7%), anemia (38.2%), diarrhea (loose motion) (37.3%), joint pains (35.2%), abdominal pains (33.8%), scabies (21.5%), Tuberculosis bacillus (17.6%), leprosy (10.6%), asthma (5.7%), and so on. The people had no idea (knowledge) about the hereditary health problems prevalent in their community. About the common health problems according to them were: malaria, cough, cold and asthma (breathlessness). Among the other health problems were: weakness, body ache or joint pains, but they were not aware of the cause of these symptoms. They did not feel any necessity for treatment. However, if the illness persisted, they used to go to a local quack and occasionally to PHC doctor for treatment.

Sickle cell disease:

Tribal people were not aware of the hereditary blood disorders during pre-intervention period, but after intervention they could very well tell about sickle cell disease (83.6%), β-thalassemia (56.4%), etc. They had heard about sickle cell disease, but they did not know what it causes. After intervention, they could explain that hemoglobin carries oxygen and in the absence of oxygen, sickling occurs (67.8%). After intervention they under-

stood the difference between a sickle cell disease and a sickle cell trait. Regarding the signs and symptoms of sickle cell disease (Table 3), they did not know anything about it (except 2.1%), but after intervention, their knowledge about the signs and symptoms was considerably improved (67.8%) from the illustrated booklet provided to them free of cost on the Information, Education and Communication (IEC) literature.(3,6) They could be able to suspect a sickle cell disease patient with pains in joints, anemia, jaundice, weakness, requirements of blood transfusion, increased size of spleen or liver, etc. Earlier, they did not know that it was a fatal disease. Now they know that sickle cell patient encounters a crisis and needs treatment (37.6%) like blood transfusion, folic acid tablets, soda-amine, etc.

Table 3. Pre- and post-intervention knowledge of respondents for three hereditary hemolytic disorders in Bhuyan and Kharia tribal communities of Orissa.

Knowledge about the Disease	Pre-Intervention N= 200		Post-Intervention N=210	
	Known	Not Known	Known	Not Known
	%	%	%	%
Sickle Cell Disease:				
1. Signs and symptoms of sickle cell disease	2.1	97.9	67.8	32.2
2. Inheritance of sickle cell disease	0.0	100.0	67.5	32.5
3. Mode of transmission in offspring	0.0	100.0	68.7	31.3
4. Prevention of sickle cell crisis	0.0	100.0	67.5	32.5
5. Treatment of sickle cell disease	2.3	97.7	37.6	62.4
6. Blood transfusion	0.0	100.0	73.2	26.8
7. Carrier detection	0.0	100.0	64.3	35.7
8. Precautions to be taken	0.0	100.0	75.5	24.5
Beta-Thalassemia:				
1. Signs and symptoms of beta-thalassemia major	1.0	99.0	56.4	43.6
2. Inheritance of beta-thalassemia	0.0	100.0	67.5	32.5
3. Necessity of treatment	1.0	99.0	56.4	43.6
4. Transfusion requirements of patient	0.0	100.0	73.2	26.8
5. Carrier detection of beta-thalassemia	0.0	100.0	64.3	35.7
6. Prevention of beta-thalassemia	0.0	100.0	64.3	35.7
7. Precautions to be taken	0.0	100.0	75.5	24.5
G6PD Enzyme Deficiency:				
1. Functions of G6PD enzyme	0.0	100.0	76.4	23.6
2. Signs and symptoms of deficiency	0.0	100.0	73.8	26.2
3. Identification of G6PD deficiency	0.0	100.0	73.2	26.8
4. Mode of inheritance of G6PD deficiency	0.0	100.0	37.6	62.4
5. Neonatal jaundice due to G6PD deficiency	0.0	100.0	67.8	32.2
6. Treatment of G6PD deficiency	2.3	97.7	37.6	62.4
7. Preventions against G6PD deficiency	0.0	100.0	64.3	35.7

For treatment, according to them, good food like mutton, chicken, egg, etc. was the best treatment to recover from weakness. After our intervention, they had realized that green vegetables and fruits were equally important (34.5%) along with regular medical treatment from a PHC or other qualified doctor (37.6%). They were aware of the precautions to be taken to prevent a crisis (75.5%). The IEC booklet supplied by the investigator free of cost was provided to them for future guidance and practice.

Beta-thalassemia major:

Earlier, they have not heard about beta-thalassemia syndrome (except 1.0%). Now they know that thalassemia major is a disease that causes bloodlessness (56.4%). They are well versed of the signs and symptoms of thalassemia major and know that thalassemia major is a transfusion dependent disease (Table 3). There is no permanent cure for thalassemia major (56.4%), except bone marrow transplantation. A carrier of thalassemia is called trait (67.5%) just like a sickle cell trait. All patients of thalassemia major have carrier parents and carriers do not suffer from any clinical ailments (67.5%).

When two persons with thalassemia carrier or trait marry, then there is a 25% chance of having a child with thalassemia major, 50% chance of having a child like parents and only 25% chance of a normal child (67.5%). Two carrier parents of thalassemia, sickle cell disease or having any such defect are advisable not to marry. If any one of the parents is carrier, then there is 50% chance of the defect to be passed on to the child (Table 3). After intervention, they know that persons who require repeated blood transfusions are the most likely to be suffering from thalassemia major or sickle cell disease (73.2%).

G6PD Enzyme deficiency:

After intervention, it is known that G6PD is an enzyme, which helps in glucose metabolism of red cells (76.4%). The deficiency of this enzyme causes hemolytic anemia, jaundice and black urination (73.8%) in malaria cases when antimalarial drugs/medicines are administered (Table 3). This is also a hereditary disease (76.4%).

To a question, what was your source of knowledge about hereditary diseases like G6PD deficiency, the answer was through the medical team which frequently/regularly visited us, made us aware of hereditary diseases of blood in which crisis can be prevented (64.3%). They discussed and explained in various meetings, answered our questions, gave us booklets, tested our blood, medicines distributed and reports were given, genetic/marriage counseling advice (intervention) was given individually (confidentially) in the presence of a PHC doctor for follow up.

Attitude and Practice:

Regarding their attitude towards any illness or disease was to do nothing about it, it will automatically be cured, but after intervention, they (65.7%) had realized that something should be done, it was better to go to a doctor for treatment or he/she could give advice what to do (Table 4). About 57% of the respondents were of the opinion to take illness very lightly, let the person die attitude (52.6%). A majority of the people (65.7%) knew that local made liquor was a panacea for all diseases, but 21.6% of the respondents disagreed with this notion after intervention.

Table 4. Pre- and post-intervention attitude and practices of respondents towards three hemolytic disorders in Bhuyan and Kharia tribal communities of Orissa				
Attitude and Practice	**Pre-Intervention N=200**		**Post-Intervention N=210**	
	Yes (%)	**No (%)**	**Yes (%)**	**No (%)**
Attitude:				
1. No effort to do anything	100.0	0.0	34.3	65.7
2. Local made liquor is panacea for all diseases	65.7	34.3	21.6	78.4
3. Take illness very lightly	56.9	43.1	36.1	63.9
4. Let the person die attitude	52.6	47.4	40.7	59.3
5. Generally do not go for any treatment	100.0	0.0	31.8	68.2
6. Use of traditional herbs at home	96.5	3.5	45.7	54.3
7. If illness persists, consult a village quack	84.4	15.6	27.5	72.5
8. Take magical treatment from a faith healer	83.7	16.3	34.6	65.4
9. Limited paying capacity or habit of getting treatment always free of cost	100.0	0.0	45.7	54.3
10. Prefer to go to a private practitioner for medicine/ injection	58.5	41.5	62.4	37.6
11. Go to a PHC doctor at last stage when the patient is about to die	65.3	34.7	37.3	62.7
12. Negligence/ignorance of a disease leads to unrecoverable consequences/ loss of life	23.6	76.4	84.8	15.2
13. Government provides medical facilities, we should make maximum use of them	17.9	82.1	83.7	16.3
14. Our health is our prosperity	15.9	84.1	85.5	14.5
15. A positive attitude is equally necessary so that community accepts the intervention	12.5	87.5	89.4	10.6
Practice:				
1. No treatment	79.3	20.7	43.7	56.3
2. Take delayed treatment	65.8	34.2	23.2	76.8
3. Prefer going to village quack instead of PHC doctor	74.8	25.2	37.3	62.7
4. No follow up for check up of any illness	95.1	4.9	14.4	85.6
5. Use of indigenous/traditional medicine	53.2	46.8	45.6	54.4
6. Never go to a PHC doctor for advice/suggestion	100.0	0.0	67.7	32.3
7. Doctor is God, who treats and gives medicine	23.6	76.4	79.9	20.1

Most of the people used traditional herbs (96.5%) at home, whereas, 45.7% differed from traditional use of medicine after intervention and 3.5% did not know about traditional medicine. A majority (84.4%) used to consult a village quack for treatment, but post intervention period 72.5% people knew where to go for treatment. Earlier 83.7% of the respondents were of the opinion to go to a faith healer for treatment, but then only 65.4% had the faith in faith-healer (Table 4). Tribal people in general are habitual (100%) of getting treatment always free of cost, but the post intervention scenario 45.7% differed from this conception. Earlier 41.5% of the people used to go to a private practitioner for medicine/injection but then only 37.6% of the populations went to them. There was very strong attitude to consult a doctor when there was no alternative, no hope and the patient was about to die in the last stage (34.7%) and 62.7% differed with this notion (Table 4).

A majority of the people (76.4%) did not know that negligence/ignorance of a disease leads to unrecoverable consequences/loss of life, whereas after intervention only 15.2% were unaware of such consequences. Tribal people (82.1%) did not know that government provides medical facilities so that they could make maximum use of them. However, 16.3% of the people were still there, who did not know about such facilities. About 84% of the tribal people did not know that their health was their prosperity, 14.5% of the people still did not believe in it. Tribal communities do believe that a positive attitude is equally necessary so that community accepts the intervention.

Despite of all efforts, only 43.7% of the respondents realized the practice of treatment for hereditary hemolytic disorders. However, the habit of delay in treatment still persisted among them. There was a considerable improvement (62.7%) towards their practice of going to a medical doctor rather than to a quack (37.3%). Tribal people still did not know the importance of follow up for check up (14.4%). The practice of indigenous/traditional medicine was still continuing among them. However, they (67.7%) were convinced to go to a PHC doctor for treatment and suggestion/advice for hereditary disease. About 80% of these tribals had realized and practiced that a doctor was a second God for them.

To a question, how to prevent hereditary problems in the family or community? The answer was to bring proper health awareness, education and screening for carrier detection (64.3%) and help the families or tribal communities to prevent the hereditary problems. This community participatory approach was overwhelmingly welcomed. But such testing facilities for carrier detection should be available at PHC/CHC or District Headquarters Hospital (64.3%) level (Table 3) in every affected district or region of every state in India.

Discussion:

This study has developed an intervention package model for prevention and control of hereditary hemolytic disorders in two scheduled tribes of Sundargarh district in Orissa. As a part of the intervention, a sample of two tribes (Bhuyan and Kharia communities) was screened for hereditary hemolytic disorders; awareness was created and the counseling was offered. The study was specifically designed to develop an intervention package for prevention and control of hereditary hemolytic disorders with genetic counseling as the principal intervention. Such a strategy can be successful only if the intervention is acceptable to the community. The overwhelming response (especially of incoming and outgoing married women in both communities) to screening, report card demands, active participation in interactive discussions, family counseling and coming forward for carrier detection of partners of marriageable age, seeking screening before planning pregnancy, adopting a child than going for pregnancy of carrier parents, regular follow up of affected individuals during the study period (2000-2004), etc. are the testimony of acceptance, effectiveness and success of the intervention strategies in two tribal communities of Orissa in the present study.

The impact of this study for bringing awareness, sensitization and health education would initially be expected to be slow, but it would be definite and regular in the subsequent generations due to further enlightenment and the practical experience. The

present study was an attempt to change the mindset of the tribal people.

Health is a pre-requisite for human development and concerns with the well being of a common man. Health is a function not only of medical care, but also of the overall integrated development of society: cultural, economic, educational, social and political organization. Each of these aspects influences the health status and quality of life. It was realized in this intervention program that there is a need to change the mindset of the people. To achieve the stipulated aims and objectives, we had adopted biomedical anthropological approach (7) to successfully implement and evolve eco-friendly, tribe-oriented, tribe-friendly, tribe-participatory and, health seeking behavior and cooperation model for this study. As we know that the health comes by evolution, not by revolution. Health must meet the needs of the people, as they perceive them. Health cannot be imposed from outside against people's will. It cannot be dispensed to the tribal people.(2) Adequate sensitization, motivation and proper education with sincerity for community participation are the keys for successful and effective intervention. It has been realized that imparting of relevant training to state's local health authorities for carrier detection including PHC/CHC doctor, paramedical staff, health workers, technicians, pharmacists and ANMs for preliminary tests are important component in the intervention strategies in the tribal communities for prevention of hereditary disorders.

The foregoing analysis of the available epidemiological data clearly indicates that hereditary disorders are rapidly becoming a major public health concern in the state.(8) The health care needs of most tribal populations necessitate that this challenge be addressed promptly. Moreover, great advances have been made in our knowledge of genetic disorders and scientific technology, and the principle of equity in health care demands that the gap between medical progress and health care services should be narrowed down whenever possible. The benefits of scientific progress and developments must percolate to the needy and affected sections of the society. There is an urgent need for translational research to narrow down the gap between the laboratory and the actual beneficiaries at grass root level.

On the other hand, a major proportion of the genetic disorders that are commonly encountered in the state can be prevented by basic public health measures and activities focusing primarily on education and approaches in primary health care that are applicable in most countries. While the basic genetic and diagnostic facilities should be available to deal with all aspects of prevention and care, the establishment of such facilities, if they do not already exist, may not require the sophistication and high costs that many people think. Action is, therefore, required to initiate activities to control genetic disorders in the country. The nature and sophistication of such activities will vary from one state to another, but the national programs should be established to provide basic services covering prevention, health promotion and case management activities.

To initiate interventions for the control of genetic disorders at the national level, the establishment of a vertical program for medical genetics is necessary. The strategies and public health approaches can be incorporated into the existing health care system. Integration into reproductive health program is probably the most appropriate way to achieve this objective. A multitude of prevention approaches can be feasibly integrated, at the primary health care level, within the reproductive health programs already operating in the country, such as the maternal and child health care clinics and family planning clinics. Although some additional training and resources will be required, the potential benefit is considerable in terms of reduction of suffering as well as reduction of the health and economic burden related to the care of patients with genetic and congenital disorders.

It is recommended that in order to achieve the stipulated aims and objectives, the sensitization, motivation and proper education with sincerity for community participation are the keys for successful and effective intervention. Imparting of relevant training to PHC doctor, paramedical staff, health workers and technicians for carrier detection will further enhance the prevention and control program. The approach should be eco-friendly, tribe-oriented, tribe-friendly, tribe-participatory with health seeking strategy and cooperation for the study. Peoples' participation and cooperation in every stage for these hereditary disorders are prudently essential for better health and improving the quality of life.

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