

IMPLICATIONS AND CHALLENGES OF GENETIC COUNSELLING OF TRIBAL FAMILIES WITH DOWN'S SYNDROM IN CENTRAL INDIARajesh Dehankar¹, Sanjay Walulkar², D. D. Ksheersagar³, V. M. Paikrao⁴**HOW TO CITE THIS ARTICLE:**

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ABSTRACT: The recent discoveries in genetics give us a wide area of Gene Therapy. However, the treatment is still far away from the tribal population of India. Most of the Indian populations undergo counseling for genetic diseases. Genetic counseling in tribes unlike metropolitan population is a difficult task due of their traditional believes lower literacy and poor socio-economic status. The present article deals with our observations and experiences in counseling of traditional tribal families for Genetic disorders. Here we reveal the stepwise process of genetic counseling used to convince and agree them to give sample for testing. We also discuss the challenges of genetic counseling of tribal population.

KEYWORDS: Genetic counseling, tribal families, chromosomal disorders.

INTRODUCTION: At present there is very less scope for treatment of the genetic diseases. Most genetic disorders, unfortunately, cannot be cured the available treatments only helps to manage the diseases caused by abnormal genes, while the treatment itself and its efficacy vary from one type of disorder to another, though Human Genome Project (HGP) and recent discovery in genetics give us a wide area of Gene Therapy.

However, the treatment is still far away from the Indian people. In India whenever a patient suffering from genetic disorder or couple who is at risk, already having a defective child, they are advised to consult with genetic counselor.

As in most of the genetic disorders, treatment is not available or out of reach of people of developing country^{1,2} like India, we often counsel them how to prevent or reduce the disorder. The main tribes in Vidarbha region of central India are the Gonds, Korkus, Kolams, Andhs, Pardhans etc.³

In this tribal population due to their traditional believes, lower literacy and poor socio-economic status, many times, it is difficult task to counsel them about genetic diseases and agree them to give sample for testing. In this article, we try to explain our observed experiences, challenges and the counseling process used over tribal parents and its outcomes.

METHODS:

Participants: Participants were recruited from the tribal area of Vidarbha region of central India. The study-included counseling of 19 parents belongs to common tribal community of Vidarbha among which 14 have Down's syndrome, 3 have unknown mental disorder and 2 have Autism. The ages of their children ranged from 2 to 20 years.

Counseling Process:

Data Collection: We record the data regarding the family history and patients' medical history to find the identical cases in the family.

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Pedigree Analysis: If identical cases were found in the family, we have to show them the pedigree chart and explain mode of inheritance of disorder, chances of having normal or abnormal child from next pregnancy.

The pedigree chart was build using collected data. We have to show them the pedigree chart and if the identical cases found in the pedigree, we explain the presence of genetic disorder within their family. We also explain how genetic test could help them to give information about possible chances appearance of disorders in their future generation.

Introduce to Identical Cases: We show them some photographs of patients with identical disorder sometime we advise them to visit these patients. By knowing that their child is not only one who is suffering from this disorder, they begin to trust us.

Mode of Inheritance: We explain the possible mode of inheritance of disorder whether autosomal/X-linked/Y-linked/dominant/recessive is present. We explain the possible mode of inheritance of disorder and chances of having normal or abnormal child from next pregnancy.

Rejection of Testing: In spite of all our efforts of counseling and convincing the tribal parents for testing some parent reject the further testing and treatments. In that case, we just provide them all information, risk and available option regarding the disorder so that it becomes helpful to them in future.

Sample Collection: After the proper counseling most of the parents, agree to give consent for sample collection. For the genetic testing, we generally need to take the blood, bone marrow, buckle scrub and/or amniotic sample.

Post Testing Counseling: The Cytogenetic and/or DNA analysis confirm the syndrome. Then we predict the exact mode of inheritance we explain them the actual percentage of having normal or abnormal child from next pregnancy.

We guide them about the necessary medical care of the patient and advise them regular heart and respiratory checkup, as these diseases more often associated with the chromosomal abnormality, which may increase survival rate of patient's. In case of speech problem we advise them to consult the logopaedic until speech was well established. We also give them the information about special school for mentally handicapped children and tell them that how could they become employable with this education.

OBSERVATION:

Experience during Genetic Counseling of Tribes: In the tribal people of India, the patient with the common mental retardation from chromosomal syndrome/Mental diseases/Autistic etc. some-time treated as Avatar of God, and child supposed to have the supernatural power. People thought that the child could treat the people's diseases, solve their problems, treated as a good luck charm, could see the future or even guess the number of lottery ticket.⁴

ORIGINAL ARTICLE

Parents Religious Credence: The parents belong to common tribal communities of Vidarbha were interviewed, some perturbing reply of the parents as follows:

“...If he could treat people’s disease, how could you treat him?” replies the mother of 7-year-old son with Down’s syndrome.

Father of the 12-year-old son with Down’s syndrome say “...The homes where such children live, they get very good luck and God bestows a lot on such a child...”

“...I got lot of success in hunting and perhaps it is because I take such good care of my child...” tribal father say.

Tribal father believes that his 14-year-old daughter goddess of wealth of she could guess the lucky draw number. Village people ask her about ticket of Daily lotteries, by using their own methods they guess the number by her babbling and sign.

Mother of 9-year-old mentally retarded child says, “...His child could identify the gender of prenatal child...”

The mother of 17-year-old says, “...It is because of him, our village is prevented from getting the epidemic Swine Flu disease”, she also says, “He can cure the diseases like leprosy and vitiligo”.

If the parents of that child came or sent to the genetic laboratory for genetic diagnosis or counseling, it is very difficult to counsel and convince them to give sample for testing. For these types of parents at first, we have to listen their all believing and show trust in them then counsel in local language according to explained counseling process.

DISCUSSION: Genetic counselor often faces the difficulty in the genetic counseling of the people having lower literacy and poor socio-economic status. In India, the traditional believe of tribal population make it more difficult.

Traditional Believe with reference other workers problem regarding believe: According to Danquah et al both good and bad health can have some spiritual implications for the African. “When x-rays and laboratory tests are not conclusive, the African is left in a state of doubt, and solutions are sought from outside sources. If orthodox medicine doesn’t work and the African uses his belief system, that he has sinned against God, in which case he will use a priest, ”explains Professor Danquah. “If he has sinned against the lesser gods, he consults spirits and shrines. If he believes the cause to be witchcraft, he also sees the shrine.”

It is generally explained in a behavioral context where rituals and other related symbolic activities (e.g., meditations, prayers, fasting, reading religious scripts, attendance at services, etc.) are practiced by individuals according to their specific beliefs and modes of social organization^{3,5}. These activities have been noted to strengthen the faith of people and assist them with decision making in health-related practices.

A strong law against the Superstition: In India, tribal people thought that inborn mentally challenged person thought to be having the miraculous healing power. The relatives of the mentally challenged person offend use them as for beguile the believer. According to the Maharashtra State Ant superstition law (Black Magic law), the use of mentally retarded person for the purpose of the superstitious activity like treating people by the secret power and/or as beguiler person is illegal the, Bill is still pending before Maharashtra State Assembly (April, 2013).

ORIGINAL ARTICLE

Rejection of therapy with other workers with same Problem: According to the Christian Science community, healing of physical and mental illnesses and disorders is possible only by prayer. They do compromise somewhat in the case of broken bones. Here they suggest that members might consider having broken bones set by a physician and then seek healing from a Christian Science Practitioner.

Most have no objection to the use of glasses and canes. Many Christian Scientists do not use medicine or go to doctors; they choose prayer when faced with a personal medical problem, in themselves or their children. They base these beliefs on the passages in the Christian Scriptures, which describe Jesus Christ or the apostles healing sick people in the first century CE. Rita Swan co-founded Children's Healthcare Is a Legal Duty (CHILD) in 1983.⁶

She had documented deaths of children in Christian Science families due to meningitis, diabetes, diphtheria, measles, kidney infection, septicemia, cancer, and appendicitis; she has found outbreaks of polio and measles at Christian Science camps and schools; she has interviewed adults who, because of diseases and injuries that went untreated during childhood, became profoundly deaf, or lame, or suffered permanent organ damage.⁵

The Watchtower Society of Christian denomination teaches that blood transfusions, even if needed to save a person's life, must not be accepted. This teaching is based upon passages in the Bible⁷, which prohibit the consuming of blood: According to the Watchtower Society, an adult Jehovah's Witness who willingly and knowingly accepts a blood transfusion is committing a sin and might forfeit his or her eternal life.

Some counter-cult sources imply that the church teaches that all who have had a transfusion (even if given against their will or at an age or situation when they cannot give informed consent, or given without their knowledge) will lose eternal life. This is not true.

This happened not only in India: Some patients would risk not taking their medications while anticipating divine healing outcomes. The observation is in line with spiritual causal theories strongly underlining chronic conditions in Ghana (de-Graft Aikins).⁸ In a related study on medication adherence among persons with mental illness in Ghana, a similar trend was observed. Patients and their families sought spiritual interventions for their mental illness because they perceived the conventional antipsychotic medications failed to achieve a complete cure Read U.⁹

Religion, spirituality, and kinship ties may have an important role in older adults' understanding and treatment of illness. Some older adults may view illness and death as a natural part of life, or believe illness is a result of natural causes, improper diet or eating habits, exposure to cold air or wind, the will of God for improper behavior, or a lack of spiritual balance. Some older adults may delay seeking medical care, preferring self-treatment and giving god a chance to heal, or may seek care from folk healers, lay advice, home remedies, and prayer to treat illness.¹⁰

For example, the Latino older adult may see illness as an imbalance between internal and external forces, and may seek medical care from folk healers (University of Washington, 2005).¹¹

Many American Indians believe that harmony among the body, heart, mind, and soul contributes to one's overall health (University of Washington, 2005),¹¹ and that illness may be caused by the breaking of sacred tribal taboos, unhealthy relationships with humans or nature, or by witchcraft.¹² The person may turn to Western medicine for treatment of the symptoms of illness, but may also seek traditional healers to address the disharmony that caused the illness (University of Washington, 2005).¹¹

ORIGINAL ARTICLE

In Hinduism the law of cause and effect (*karma*), which one creates through thoughts, words, and deeds, may result in illness or accidents as a means to purification. Karma is believed to accrue over many lifetimes; hence, an illness may be seen because of actions in this life or a past life. Acceptance of one's karma may influence a person's attitude toward medical intervention (University of Virginia, 2003).¹³

In the Chinese culture, health may be viewed as finding harmony between complementary energies called yin and yang, such as cold and hot, or dark and light (University of Washington, 2005)¹¹. Cultures following Chinese or Ayurvedic health beliefs may try traditional approaches to treating illness first, such as using foods and herbs to restore yin/yang balance, and will seek Western medical care if these treatments fail. The traditional systems of medicine are believed to remove the cause of the illness, and therefore, some Asian ethnic groups rely on traditional remedies for long-term treatment (Institute for Safe Medication Practice, 2003).¹⁴

Counseling of the tribes carried through establishing a positive, supportive, trusting relationship with the parents. Seek an understanding of the causes of illness from the parents' cultural point of view. Elicit information about use of nontraditional therapies in non-judgmental way. Determine their preference regarding group learning or individual, private instruction.

In providing information, councilor have to consider whether primary importance is placed on the individual or on the community, what roles for women, men, and children are generally accepted in the community and whether the preferred family structure is nuclear or extended, one generation or multigenerational, and who receives the information.^{15 16}

Acquire the skills and competencies necessary for quality cross-cultural care.

CONCLUSION: Genetic counseling in tribes is difficult, as most of the tribal peoples in India are having lower literacy and poor socio-economic status. The traditional believe about miraculous healing, supernatural power, fortune hunting etc. of mentally retarded person make it more challenging task. The stepwise process of genetic counseling, introduction to identical cases may useful to convince and agree them to give sample for testing. However, the needful steps have to take to irradiates the genetic disorders from the tribal population.

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ORIGINAL ARTICLE

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