



Counselling Parents with Intellectually Disabled Children - South Indian Scenario

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ABSTRACT

Intellectual disability is a major public health problem today particularly in paediatric population. When a child is affected it is most vital to counsel the entire family. In the current genomics era both pre-diagnosis and post-diagnosis counselling are of prime importance. Medical and paramedical teams have to be well trained to effectively counsel the affected families. Intellectual disability due to both treatable and preventable causes results in socio economic stigmata. The need of the hour is to develop strategies at primary, secondary and tertiary levels. Sustained efforts are required to instil self confidence in the patients and it is very important to involve the affected family for the successful outcome. The evolution of genetic counselling programs must suit the needs and, must be cost effective and socio-culturally acceptable. The concept of “will to implement and evaluate” must be imbibed in all concerned with the care of the intellectually disabled children. Future genetic research programs will be able to create a stronger platform to effectively manage the intellectually disabled children.

Keywords: Intellectual Disability, Genetic Counselling, Rehabilitation, Speech therapy.

1. INTRODUCTION

Genetic Counselling is a communication process, which deals with the human problems associated with the occurrence or the risk of occurrences of a genetic disorder in the family. This process involves an attempt to train one or more personnel in a family to help the intellectual disabled individual [1]. Counselling requires thorough knowledge, skills in teaching the personnel with medical facts, including the diagnosis, the probable course of the disorder and the available management [1,2]. The counsellor should appreciate the way heredity the risk of recurrence in specified relatives, also dealing with the

risk of recurrence. Choosing the right course of action in view of the risk and family situation. Make the best possible outcome to the disorder in an affected family member, reported by American Society of Human Genetics.

2. GENETIC COUNSELLING

Genetic counselling is required for the parents whose first child is affected with a inherited disorder and they wish to have another child; Family history with the Genetic disorder; Advanced maternal age; Consanguineous marriage and looking for the normal

child birth; Known history with one or both partners are carriers of an inherited disease [3].

The educational level of the parents plays a vital role in helping them understand the reality of the situation. Arriving at a diagnosis is important but in most instances the family cannot afford molecular diagnostic testing which is not going to offer a cure [1,3]. So it is explained in detail that the need for testing in the proband is mandatory if they are planning to have another child. According to the Department of Medical Genetics at The Tamilnadu Dr MGR Medical University, Chennai caters to a large population of patients from the lower socio-economic strata of society. During the period from 2008 to 2013, a total of 1084 patients with developmental delay and intellectual disability were seen and counselled (134 children with Down syndrome, 28 children died due to various complications and 106 of them had congenital heart disease). Counselling is done to the parents of the child and/or to the legal guardians. It is first important to ascertain the relationship of the adults accompanying the proband [4]. If it is an extra person like the aunt, uncle, neighbour, friend or mother in-law/father in-law, I'll politely ask them to leave the room due to confidentiality. There were 994 children were accompanied by the mother, 20 children with both parents, 34 children were brought by their grandparents or caregivers as mother had an infant to take care or unwell and 14 new-borns were seen in NICU with mother in postnatal ward. Totally 1084 children were seen.

2.1 Acceptance of a special child

The genetic aspects of the disease should be clearly explained because the educational level of parents is only up to high school/school dropouts. Most of the times the parents are perplexed that they are normal but have an abnormal child. The pedigree chart helps in making them understand the real situation. Most of the times, the mother refuses or unable to accept that her child has a delay in cognitive functions and she pretends that her child is able to perform tasks eventhough delayed. Hence, a lot of time has to be spent in convincing her to accept the reality. In many cases, the father may be not available because he will be working and living elsewhere, had deserted the family or remarried. The burden of taking care of the affected child is completely borne by the mother. The gravity of the situation, long term care, possible complications that can arise due to the phenotypic abnormalities are all very difficult for the mother to understand in the first session. School dropouts ranging from STD V to IX amongst mothers formed

the majority. There were only 20 women were completed school education, 2 were engineers (software) and the rest had vocational training. The occupation of the fathers ranged from agricultural worker, mason, painter, carpenter, welding/lathe operator, courier personnel and petty shop owner.

Age appropriate counselling is required for the parents. For example a 2 year old child not able to sit without support should receive therapy to improve muscle tone and strength, and the other motor milestones has to be achieved. Puberty and other long-term issues should not be discussed for the same age group. Mother will say that baby turns to sound and makes some noise. Hearing assessment is mandatory and child should be referred to SLP (speech language pathologist) by the age of one year [5,6]. Speech therapy is another important area that is lacking focus.

2.2 Importance of Nutrition

Repeated infections can set them back considerably as the child is struggling to convalesce and recuperate. Feeding and swallowing difficulties along with choking must be explained and diet must be altered accordingly [7]. It is always better to provide regular home cooked food and avoid processed packaged food. High protein and low fat diet is always stressed upon with good servings of easily available fruits and vegetables. This will help prevent constipation and obesity. Greens, ragi, banana, papaya locally available nuts like groundnuts, fried gram are a good source of high protein that are available throughout the year. Economic constraints will be easier to handle if we give them these choices. Always stress on the nutrition to the mother/the caregiver so that they will be prepared to take care of her special child. In the case of Inborn Errors of Metabolism (IEM), diet plays a major role in preventing neurological damage. Delay in diagnosis, access and affordability of enzyme replacement therapy put the family in a difficult situation. Parents are encouraged to participate in the awareness programmes like Rare diseases day on 28th of February, Autism day on 2nd April and Down syndrome day on March 21st.

2.3 Early Intervention Therapy

This forms the back bone of the entire rehabilitation programme [9]. The earlier they start, the better the results. Patients are brought in late, usually by 2 years of age. Parents are usually waiting for them to achieve some motor milestones before they seek help. 3-6 months is a good time to start physiotherapy

which is taught to the mother. If the involvement is complete, bonding is established and outcomes are better. It is always better to send patients to centres that cater to paediatric age groups rather than adults. The staff will be more supportive in handling babies gently and patiently teach mother. It is also important to provide medications to treat the hypothyroidism to prevent further damages to brain and follow up is mandatory [8]. A project was proposed between the State Health Society-Tamilnadu (SHS-TN) a part of Government of Tamilnadu and the Department of Health and Family Welfare acting as the Nodal Agency for National Health Mission (NHM) to implement the Reproductive and Child Health (RCH) program through MNC (Madhuram Narayanan Centre) for these paediatric groups. This project aims to strengthen and expand preventive services by establishment of Early Intervention Centres in all districts in Tamilnadu for the management of screened cases of newborns, infants and children with birth defects. They facilitate referral services after detection of disabilities to Institute of Child Health and Hospital for Children (ICH&HC), Egmore. Sarva Shiksha Abhiyan (SSA) is an attempt to improve capabilities of all children through provision of community owned quality education in a mission mode. SSA will facilitate and train the mainstream school teachers to coordinate with the Special Educators in evolving the Individualized Education Program (IEP) for children with special needs.

2.4 Speech Therapy

Hearing assessment is mandatory for all the Newborn and they have to repeat after 6 months or 1 year of age. Appropriate referrals to an ENT specialist is done in the case of Sensory Neural Hearing Loss (SNHL). Children with normal hearing are advised speech therapy by 1 year of age to get good results. Mother and other family members are encouraged to keep talking in their vernacular tongue to stimulate the baby. Music is another important tool to help these children calm down. It is a well-known fact that children with Down syndrome enjoy music thoroughly.

2.5 Ophthalmic Examination

Eye is a window to Genetic diseases and Malformation syndromes [10]. Parents are told by elder family members that squint is lucky so they ignore the importance of eye examination. No counselling is complete without a detailed examination of the eye. The treatment options like Correction of Squint, Prescription of glasses and Periodic review for preterm babies (Retinopathy of Prematurity) should be emphasised. If required,

immediate surgical intervention for the Coloboma and congenital cataract are given and their vision is improved.

2.6 Special School

Parents are anxious to know about the academic capabilities of their children. Mobility, speech, hand coordination and life skills like indicating toilet needs and completing the process without help are some of the important criteria for the child to attend a regular school. Awareness of special schools, accessibility to them and affordability are some of the major problems faced by parents from rural areas. Special educators play a major role in shaping these children to handle their Activities of Daily Living (ADL) and help them to achieve the set goals for the academic session.

2.7 Life Skills

Daily Routine activities like brushing teeth, combing hair, bathing and toilet training should be started depending on the child's capabilities. Disposable diapers are a boon but in many cases toilet training gets delayed because effort is not made to get the child to the toilet. In the case of severely disabled children the question of toilet training does not arise; but others who can perform simple tasks should be encouraged with supervision.

2.8 Vocational Training:

Children who can perform simple tasks must be given vocational training like office assistant, telephone operator, kitchen helper, etc. Parents are happy and the child as he grows into an adult can be kept occupied. Government has made it mandatory to recruit differently abled people in all organisations. Hence it is important to stress to the parents about the Disability card which is given by the local collector's office or the Regional centre of The Department of Social Empowerment and Justice. This card entitles the child and family to travel at subsidised rates in Government transport, monthly maintenance grant from Government of India and other Government subsidies can be availed by the family.

2.9 Adolescent Age related Issues

Both boys and girls have a stormy period during adolescence. It becomes more difficult in special children because of their inability to communicate. Mood swings, anger, depression, addiction and anti-social behaviour are some of the problems faced. Menstrual cycle in girls can give parents a hard time. Medical menopause can be suggested after consulting

a Gynaecologist [7,8]. Weight gain is another important issue that has to be addressed. Quiet, obedient children during puberty turn stubborn, rebellious and become a nightmare for parents. Parents need reassurance and counselling. Marrying teenagers with intellectual disability is only going to worsen the situation more. Common statement by the parents - "Who will take care of my child after me and my wife are deceased?" -is a dilemma faced by many couples. Residential long term care for these individuals is not available. Few centres scattered in different states. Several NGOs have been working towards this problem under the surveillance of the Department of Social Empowerment and Justice. The numbers are very few and a large number of these children are neglected due to ignorance and poverty.

3. CONCLUSION

Parents of intellectual disabled children definitely need counselling. Sympathetic and patient hearing, will help them come to terms with reality. Improving antenatal, perinatal and postnatal care will reduce the rate of intellectual disability. Early identification of hypothyroidism will help in preventing neurological damage. Keeping the child healthy with available seasonal food is required. Rehabilitation through Early Intervention Therapy (EIT) requires more attention for this type of children. Many support systems are available, parents and caregivers have to take advantage of it. Acceptance of their child with disability is often required. Gaining importance of disability cards and other government subsidies has to be utilised.

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Conflicts of Interest

No conflicts of interest.

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