



Problems of Families with Cerebral Palsy- Strategies and Recommendations for Interventions in Rural India

KEYWORDS

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Introduction:

Cerebral Palsy

Cerebral palsy describes a group of chronic disorders impairing control of movements that appear in the first few years of child's life. There are many diseases, and few disabilities that a child develops during first few years of growth. The children below one year are more susceptible to infections due to low resistance. Therefore, they easily become victims to several infections, and chronic disorders. Children normally get digestive and respiratory disorders. The diarrhea diseases like gastroenteritis dysentery and cholera affect the Children. They tend to occur at least once in a year. The respiratory infections that affect children include small pox, chicken pox, diphtheria, whooping cough, measles, mumps, rubella meningitis, influenza, tetanus and tuberculosis. These infections affect children between 6 months and 3 years of age. The other infections like poliomyelitis, jaundice, typhoid, hook worm and skin infections also affect the children.

scenario

Studies over the years have provided the following. The incidence of C.P is 2-2.5 cases per 1000 live births. There are estimated 25laks children and people in India with Cerebral palsy.

Current scenario:

The incidence in a developed world is 2-2.5/1000 live birth. During delivery one out of fifty children are affected by Neuro motor disorder in India. Approximately 75% case out of 1000 loco motor disabilities evaluated by Dr. Deepak were found to be due to Cerebral palsy.

Definition

Cerebral palsy (CP) is an umbrella term encompassing a group of non-progressive, non-contagious motor conditions that cause physical disability in human development, chiefly in the various areas of body movement. (Beukelman, R. David and P. Mirenda, 1999)

Causes of Cerebral Palsy

Cerebral palsy results from damage to certain parts of the developing brain. This damage can occur early in pregnancy when the brain is just starting to form, during the birth process as the child passes through the birth canal, or after birth in the first few years of life. In many cases, the exact cause of the brain damage is never known. At one time, problems during birth, usually inadequate oxygen, were blamed for cerebral palsy. We now know that fewer than 10% of cases of cerebral palsy begin during birth (perinatal). In fact, current thinking is that at least 70-80% of cases of cerebral palsy begin before birth (prenatal). Some cases begin after birth (postnatal). In all likelihoods, many cases of cerebral palsy are a result of a combination of prenatal, perinatal, and postnatal factors. Risk factors linked with cerebral palsy include the following:

Infection, seizure disorder, thyroid disorder, or other medical problems in the mother. Birth defects, especially those affect-

ing the brain, spinal cord, head, face, lungs, or metabolism. R h factor incompatibility, a difference in the blood between mother and foetus that can cause brain damage in the foetus (Fortunately, this is detected and treated in prenatal medical care). Premature birth. Low birth weight (especially if less than 2 pounds at birth) Severe jaundice after birth Multiple births (twins, triplets) Lack of oxygen (hypoxia) reaching the brain before, during, or after birth Brain damage early in life, due to infection (such as meningitis), head injury, lack of oxygen, or bleeding.

Problems Of families with Cerebral Palsy:

Family is a very important social institution in society which contributes to overall the development of the child. The major role of the family is upbringing and nurturing of their off springs. Children play a vital role in the society . Thus the well being and healthy development physically, mentally, socially, emotionally has to be balanced to see a better future of the society . Because of the Health condition of the child the family fails to perform its role in nurturing. The following problems of the child are obstacles.

Medical Problems

While specific therapies help a child develop specific skills and abilities, the overall goal of treatment is to help the individual with cerebral palsy to reach his or her greatest potential physically, mentally, and socially. This is accomplished with a variety of different approaches managed by a team of professionals. Care for people with cerebral palsy is complicated, requiring a number of different services and specialists. In some areas, care is available through a single multidisciplinary clinic that oversees all aspects of the child's therapy.

Occupational therapy

The occupational therapist helps the individual learn physical skills he or she needs to function and become as independent as possible in everyday life. Examples are feeding, grooming, and dressing.

Speech/language

This therapy helps the child overcome communication problems. Many children with cerebral palsy have problems speaking because of poor tone or uncontrolled movements in the muscles of the mouth and tongue. Speech therapy helps develop those muscles, improving speech. Speech therapy also benefits children with hearing loss. Children who cannot speak may be able to benefit from communication technologies such as a computerized voice synthesizer.

Visual problems

An ophthalmologist is consulted for children who have strabismus and visual problems.

Seizures

Seizure disorders are common in people with cerebral palsy. These are usually well controlled with medication. A specialist in conditions of the nervous system (neurologist) may be consulted for help in selecting an appropriate regimen.

Feeding and digestive problems

Individuals with cerebral palsy often have gastroesophageal reflux or GERD (severe heartburn and related symptoms caused by regurgitation of acid from the stomach) as well as swallowing and feeding problems. A team consisting of a doctor who specializes in digestive diseases (gastroenterologist), a nutritionist, and a feeding and swallowing therapist can assess nutritional status and treat problems. Swallowing therapy helps the child eat and drink independently and help prevent aspiration. The child's diet must be customized to accommodate limitations in swallowing. Children with severe swallowing problems require feeding through a tube.

Breathing problems

People with cerebral palsy may have been breathing problems because the muscles that control expansion and contraction of the lungs are disabled. A specialist in lung disorders (pulmonologist) should be consulted for management of the resulting lung disease.

Medical therapy

This encompasses treatment for all medical problems, whether related to CP or not. Various specialists may be called upon to deal with specific problems.

Educational Problems

Many children with cerebral palsy, even those of average or above-average intelligence, are challenged in "cognitive" processes such as thinking, learning, and memory. They can benefit from the services of a specialist in learning disabilities. Such specialists can identify the child's specific learning disabilities, direct early interventions and preparation for school, and monitor his or her progress.

Statement of the Problem

Problems of Families with Cerebral palsy Patients; A study in Hyderabad.

Objectives of the Study

1. To ascertain the demographic features of the children with cerebral palsy with reference to their age, sex, caste, religion, type of family, size of family.
2. To examine the process of onset of cerebral palsy with reference to mother's recognition of the symptoms,
3. To learn the process of diagnosis and the extent of cerebral palsy with reference to the place of diagnosis, age at the time of diagnosis, extent of cerebral palsy; and the associated problems;
4. To examine the status and characteristics of the families living with the children of cerebral palsy with reference to the type family, income levels.
5. To find out the services available to the children of cerebral palsy.

Methodology of the study

A sample of 283 subjects was taken from eight Organizations in Hyderabad.

Demographical Features of the families with cerebral palsy in the Study

The study reveals that 79.9 percent children were in the age Group of above six years. 58.00 percent are belongs to male 43.5 % found in Forward caste. 94.7 Percent are from Urban Areas. 91.2 Percent were deprived of Special Education as they have no access to special schools.

It is Occurring all in all categories of the society without any Discrimination. Hence it is not only Health, Economical problem of the society, but also it is a social Problem.

The Process of onset of cerebral palsy

Our objective is to examine the process of onset of Cerebral Palsy with reference to mother's recognition of the symptoms, duration of onset, and the age of the child at the onset

of the C.P.

S.No.	Indicators	Number (N=283)	Percentage
1	Loss of Head Control	253	89.4

The study reveals that 89.4% of mothers are identifying head control is symptom, which is occurring in development of early milestones of the child. The intensity of the problem may vary at different ages. The physical endurance, confidence level of the families of these children will worsen as the age of the child is increased. Because the Demands of the children needs will be increased as age increases.

Diagnosis and Associated Problems of families with Cerebral Palsy;

The study highlighted that Majority was diagnosed at the age of 2-4 Years. 82 Percent of mothers Reported that they have diagnosed at NGO's. 80 percent cases were severely immobilized. 83 Percent was associated with Mental Retardation.

Associated Conditions / Problems with Cerebral Palsy

S. No.	Indicators	Number (N=283)	Percentage
1	Mental retardation	235	83.0
2	Seizures / Epilepsy	119	42.0
3	Visually Impaired	29	10.2
4	Speech & Language Deficits	186	65.7
5	Other Disorders	10	3.5
	Total	283	100.00

The second problem reported by caregivers was Speech and Language. The third and more important was Seizures/ Epilepsy. This is to be addressed by the parents at the early ages to prevent further damages to the brain.

Status of families having children with cerebral Palsy

The study shows that majority families were found to be low income group and average monthly income was found to be at Rs 7,033/. 79.10 percent of the respondents belongs to the income level ranges from Rs.6,000/- to Rs.10,000/- per month

Family Income per month

S.No.	Family Income per month	Number (N=283)	Percentage
1	Below Rs.6,000 to 10,000	224	79.1

Services available

The service that were availing by the families were given hereunder. 99 percent were availing Physiotherapy. 94 percent were availing Occupational therapy. 24 percent were availing vocational training. 93 percent speech therapy. 79 percent Medical interventions. It shows the need and importance of multidisciplinary approach in Rehabilitation of C.P.

Different services availed by children with Cerebral palsy

S. No.	Therapeutic Availing Services	Number (N=283)	Percentage
1	Physiotherapy	279	98.6
2	Occupational Therapy	266	94.0
3	Vocational Training/Therapy	70	24.7
4	Speech Therapy	264	93.3
5	Medical Intervention	226	79.9
6	Alternative Therapies	8	2.8

Recommendations

Self-report questionnaires must be constructed in local languages for collection of data from all family members separately so that comprehensive view about the problems faced by care givers of children with cerebral palsy is possible.

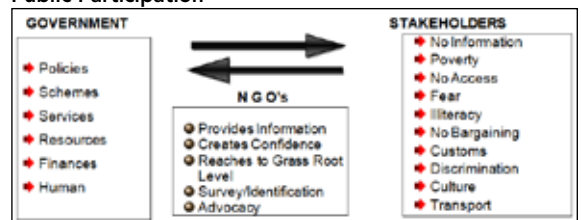
- 1) Separate parameters need to be defined and developed to evaluate the efficacy and effectiveness of the rehabilitation services available for children with cerebral palsy.

- 2) Intervention services for families of children with cerebral palsy are needed to be decentralized. This will help in providing such families with as many skills as possible to deal with their children. The support system of these families can be enhanced by organizing self-help groups, which can serve as vehicles for communication. Families can share their feelings and discover means to deal with their problems. Support groups can also diminish the feeling of isolation experienced by some families of children with cerebral palsy.
 - 3) Associated factors should be addressed in planning services for both the child and the family. The economic burden on families, social stigma associated, non-availability of services, special schools must be addressed properly and cost effective analysis and evaluation studies need to be conducted.
 - 4) Interventions aimed at improving adaptive behavior functioning, motor functions along with behavioral management programs are needed for persons with cerebral palsy and studies need to be conducted, so that effective interventions can be techniques can be designed to cater to the needs of persons with disabilities.
 - 5) In addition, informal sources of support need to be sought for the families. This would allow more time available for the child with cerebral palsy, either because the mother gains help in completing family chores, or through other family members' involvement in helping the child to become more self-reliant.
- 2) Ensuring anti-natal and post –natal checkups By Existing System
 - 3) Registration of PREGNANT Woman and encouraging institutional deliveries.
 - 4) Registering Risk Babies.
 - 5) Co-ordination between medical Para medical and rehabilitation workers.
 - 6) Clear information regarding availability of services.
 - 7) Medical professionals should disseminate correct information to mothers regarding risk factors and risk babies.
 - 8) Programme should be linked with appropriate scheme.
 - 9) Special incentives should be given for the families with identified risk babies.
 - 10) Linkages with all departments.
 - 11) Advocacy.
 - 12) Empowering the stake holders for their full Participation.
 - 13) Evaluation studies.
 - 14) Man power development

Suggestions:

- 1) Awareness to the mother regarding information at the time of pregnancy.

Model of Empowering Stakeholders through Private and Public Participation



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