



Developmental Disabilities in Children: Medical and Social Challenges in Central India

Jenisha Jain¹, Shikhar Jain¹

Financial Support: None declared
Conflict of Interest: None declared
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How to cite this article:

Jain J, Jain S. Developmental Disabilities in Children: Medical and Social Challenges in Central India. Natl J Community Med 2017; 8(8):451-455.

Author's Affiliation:

¹Consultant, Department of Pediatrics and Neonatology, Choithram Hospital and Research Centre, Indore

Correspondence:

Dr. Jenisha Jain
mayank4670@rediffmail.com

Date of Submission: 02-03-17

Date of Acceptance: 28-08-17

Date of Publication: 31-08-17

ABSTRACT

Background: There is paucity of facilities and social supports available for help of patients with developmental disabilities, especially in developing countries like India

Aim: The present study was done to determine the profile of children presenting with developmental disabilities, social support available to their families and common problems encountered by them

Materials and methods: This questionnaire based study was done by interviewing and examining consecutive patients with different developmental disabilities over a six month period at a tertiary level centre in western India

Results: We noted that most of the cases were detected late, especially hearing impairment. Most parents faced depression and guilt on detection of such disabilities which improved later. Social and financial problems plagued most of the respondents. Most patients were nutritionally deprived

Conclusion: The study highlights the problems in detection, treatment and social support to children with developmental disabilities and their families in Western Madhya Pradesh. There are gaps in the medical, educational and integration services for disabled children in our area and we need to make specific measures to address them.

Keywords: Disability, medical challenges, Social challenges

INTRODUCTION

Any restriction or lack of ability to perform an activity in a manner or within the range considered normal for the human beings, resulting from impairment is termed as disability. Impairment concerns the physical aspects of health; disability is the loss of functional capacity resulting from an impairment organ; handicap is a measure of the social and cultural consequences of an impairment or disability.¹It is estimated that nearly 10-15% of the world population is living with some form of disability.²⁻³The prevalence all types of disability is 6.3% in India and mental disability is the most common type of disability.⁴

Various stresses and problems are faced by families of children with developmental disabilities. There is paucity of facilities and social supports available for their help, especially in developing countries like India. The present study was done to study profile of children presenting with developmental disabilities, social support available to such families and common problems encountered by the patients and their families.

MATERIALS AND METHODS

This observational study was done at Choithram Hospital and Research Centre, Indore. A total of 50 children with different developmental disabilities attending Paediatric services and Special Clinics at

our centre formed the study group. The study period was 6 months (January to June 2014). A detailed questionnaire was prepared for the study. All the data was collected by a single observer (JJ) using the questionnaire. The questionnaire covered the following aspects- details of history and examination with special attention to delays, deficits and disabilities; family support, social support and medical support systems available to them at 1 year, 3 years, 5 years, 10 years or 15 years of age (as applicable) and at the time of contact; problems and difficulties faced by the parents and families and parental reaction to their child's disability at diagnosis and at present.

We included the following type of disabilities:

Cerebral palsy (CP): Any child with disorders of movement and posture caused by a non-progressive injury to immature brain.

Mental retardation (MR): Child with IQ < 70.

Hearing impairment (HI): Child with loss of 60 dB or more in better ear.

Visual impairment (VI): Child with visual acuity of < 3/60 in better eye or inability to count fingers in day light at a distance of 3 meter.

We excluded children below 1 year and above 18 years of age, those with learning disabilities and those where authentic information was lacking.

The data so collected was tabulated in Microsoft excel sheet and analysed using appropriate statistical tests.

RESULTS

A total of 50 children were recruited for the study. Males (31) outnumbered the females (19) and majority of the children were above 5 years of age (36/50, 72%)

Demographic profile of study group: Among the enrolled cases, 16(32%) had cerebral palsy while mental retardation (13, 26%), hearing impairment (12, 24%) and visual impairment (9, 18%) were noted in descending order of frequency. Among cerebral palsy cases, ten had spastic quadriplegia while dystonic CP, spastic diplegia and hypotonic cerebral palsy were noted in two cases each. Table 1 shows the age and sex distribution among the cases and socioeconomic status of their families at the time of contact. Only 5 (10%) cases belonged to class IV (lower class) suggesting that lower class is possibly least likely to utilize hospital or institutional services.

Suggested interventions and its implementation among cases: We enquired regarding the suggested interventions by doctors for all the children and how well they had been implemented. Out of

the total 16 patients with CP, 14 were suggested physiotherapy at diagnosis. Ten (71.5%) could implement it on a regular basis while the rest reported lack of facilities in rural areas and difficulty in transport as the reasons for non compliance. The remaining two patients were informed that no form of medical help could improve the condition of the child. In MR category (13), 3 were advised physiotherapy and all of them could implement it. 4 were advised special education and they were attending such schools. Two children were advised for oil massage which they did and 4 i.e. 30% were told that nothing can be done, and the child will remain the same. Among HI children, 7 were advised ear surgery costing around 3 lacs to 6 lacs, which only one of them could afford. 3 were advised hearing aids, which were being used. 21 (16.6%) were told that the disease is not curable. In VI category (9 cases), 8 had undergone single/multiple surgeries. One child (11.11%) was told that nothing can be done.

Table 1- Age, sex distribution and socioeconomic status of cases

Parameter	Cases (%)
Age distribution	
1-5 years	14 (0.28)
5-12 years	26 (0.52)
12-18 years	10 (0.2)
Sex distribution	
Males	31 (0.62)
females	19 (0.38)
Socioeconomic status*	
Class I	11 (0.22)
Class II	15 (0.3)
Class III	19 (0.38)
Class IV	5 (0.1)

* According to modified Kuppuswamy grading

Age of detection of disability and associated risk factors: The age at diagnosis of CP was varied ranging from at birth to a maximum of 18 months. More than half of the cases (10/16) were diagnosed within one month of age. All children were born in hospital. Birth asphyxia (10/16) and prematurity (2/16) were the major risk factors for CP. On the contrary, mental retardation was diagnosed beyond 6 months of age in majority of the cases (Range - 1 month to 4.6 years). Down's syndrome (3/13) and prematurity (3/13) were the major risk factors noted. The age at diagnosis in hearing impaired children had a wide range of 6 months to 3 1/2 years.

Seven cases were detected by parents themselves and the rest were detected by family members other than parents. The possible etiological factors noted were- strong family history (4), prematurity (2), neonatal hyperbilirubinemia (2), seizures (3)

and ear infection(1). Among the visually impaired, 4 out of 9 cases (44.4%) were diagnosed at birth by doctor, two each at 3 months and 6 months, and one was diagnosed at 9 months. The etiological factors included- retinal disease(4), congenital glaucoma(2), retinopathy of prematurity(2) and sequelae of meningitis(1).

Nutritional status of cases: On clinical examination, 15 (30%) were wasted, 4% were stunted alone and 28% (n=14) were wasted as well as stunted. 34% children had normal or mildly low nutritional status as per WHO classification. Children with cerebral palsy had poor nutritional parameters compared to the other three subgroups.

Financial aid and support: 7 children (HI-3, VI-4) out of 50 i.e. 14% were receiving aid from government in form of scholarships. Three children (MR-1, HI-2) were receiving aid from private trusts. Three cerebral palsy patients were financially supported by extended family members. None received or took financial help from friends. One HI child was adopted by a family and being given aid in form of school fees and books, uniform.

Parental reaction at diagnosis, family problems and psychological issues: Majority of the parents of children with CP were depressed at diagnosis and eventually half of them had recovered from it. A few (6/16) reported guilt but with time the feeling had resolved in four such parents. Some (3/16) had feelings of denial and anger. Anger was directed either at God, partner or doctor who did not guide them. In MR category, guilt (10/13) was a major reaction to child's illness but most of them coped up with the feeling. Few (4/13) denied the diagnosis initially. In HI and VI category, most of the parents (16/21) reported feeling depressed at diagnosis and as the child grew older, fear of being dominated or maltreated was the major concern (18/21).

During the phase of diagnosis and early years, most of the parents (in all categories) suffered loss of work hours as they had to visit hospitals and rehabilitation centres repeatedly which also increased financial stress. Out of 50, 40 (80%) parents reported financial concerns as their main problem. Parents of 5 children (3CP and 2HI) reported lack of availability of facilities. Family support was good for almost all parents except for one parent (HI child) who were not supported by their family.

Problems parents/ children faced: The concern of safety of the child increased as the age of the child increased. A total of 17 parents had this fear when the child was in 5-12 years of age group and 7 had this feeling when child reached in 12-18 years age group. This was more pronounced in hearing and vision impaired groups. Social isolation was reported by 11% of the parents of child age group 1-5

years, 20% in 5-12 years group, and 6% in 12-18 years group parents. 20% parents of CP children had fear to conceive next time.

Though majority of CP (13/16) children received supportive treatment from neighbourhood children, few parents (3/16) reported that the children did encounter humiliating behaviour at times.

Eleven MR children received supportive treatment from neighbourhood children, whereas others had to face humiliations (2) or sympathetic attitude (3). The humiliating behaviour was received more often (5/13, 37%) during social outings. Vision impaired children however received supportive treatment by neighbouring children and during social outings.

DISCUSSION

The present study was undertaken to know the common problems encountered by disabled children and their families in western Madhya Pradesh. This was a hospital based study where children attending outpatient services were recruited. This study is an effort to get an insight into the problems of developmentally disabled children and their families, their social environment and the support systems available to them in western Madhya Pradesh. As children in the age group of 1-18 years have been included, the data gives a composite picture of past 18 years. As the study has been conducted in hospital setup; the study has a bias towards urban areas and those families who were able to attend hospital or institutions. The true picture in the rural and tribal areas and very low socioeconomic groups is likely to be different and may be much worse given their limited resources.

In our study, male children (62%) constituted the majority and most of the cases were above 5 years of age. Some studies have shown more disability among males⁵, while others among females.⁴ Majority of our cases belonged to Class I-III. This is different compared to the study by Mathur et al⁶ who reported that majority of their cases belonged to the poorer classes. This difference could be related to the fact that this is an institution based study and not representative of the community in general. Most of the disabled children were wasted or stunted or both, which is in accordance with the study by Stevenson R.⁷

Majority of the parents, across all disabilities, implemented the medical advice and treatments suggested to them. We noted that MR cases were generally detected later compared to CP and HI was most commonly first detected by parents or other family members. Majority of the cases with VI had

a potential cause and underwent multiple medical treatments for the same. Severity of mental retardation, lack of thoroughness in diagnosing or treating a child and education of parents are possible factors that may affect the age at diagnosis for MR. The age at diagnosis of HI beyond 3-6 months is considered late by current standards, thus practically all cases in our study were diagnosed late. This is because there is no facility or protocol for hearing screening for newborns and infants in most hospitals and healthcare facilities including apex hospitals like medical colleges in our area. Only very recently some institutions as ours are making efforts in this direction. Further, all cases were detected by parents or family members. This is a dark comment as primary care physicians and pediatricians who are not fully aware and are not utilizing clinical hearing, screening methodologies like history and behavioural hearing tests in young ages during their routine clinical practice. In contrast to HI, we found that VI gets detected comparatively early. Paramleen et al have also reported that the mean age of the developmentally disabled children attending the clinics was 4 years.⁸ This highlights the point that either these children are referred late or that parents other measures before bringing a child to a special institute. On the contrary, in the west children are referred for early intervention at an average age of 1.2 years.⁹ Disability limitation at early stage when they are amenable to preventive and rehabilitative measures, so that progression to severe disability can be minimized is a vital component in rehabilitation of disabled. It has been noted that very few disabled people gets benefit from rehabilitation services in India.^{5,10}

Only a handful of children and their families received help from government and private trusts. Majority had to mobilise their own financial resources for regular schooling and medical treatment. Though numerous plans and schemes have been made for betterment of disabled individuals in our country, a very large proportion only get access to scanty help / aid. To get monetary aid for surgery of CP child, or concession for train reservations, parents have to fill a number of forms and still for years, the money is not reimbursed. The Government has decided to set up District Disability Rehabilitation Centres (DDRCs) to provide comprehensive services to the persons with disabilities at the grass root level. The services would include awareness generation, survey, identification and early intervention, counseling, assessment of need for assistive devices, provision/fitment of assistive devices, and their follow up/repair, therapeutic services like Physiotherapy, Occupational Therapy and Speech Therapy, referral and arrangement for surgical correction through Government and Charitable Institutions, facilitation of

issue of Disability Certificates and bus passes, sanction of bank loans, and promotion of barrier-free environment.¹¹

We studied the parents feelings and problems encountered during and after diagnosis if disability in the child. The various reactions of the parents at diagnosis included depression, anger, guilt, denial and disappointment. With support of family, passage of time, better understanding of the disability, progress of child with physiotherapy and special education, these feelings improved over a period of time. Safety of the child and behaviour of fellow children and neighbours remained a significant concern for many parents. 90% parents faced loss of work hours and financial problem especially during early age group 1-5 years. 10% had problem of lack of availability of facilities at their work place. Family support was good for 98% of the study population. Recurrent admission to hospitals, stigmata of having a child with disability, difficulty in carrying a disabled child along with were the factors responsible for social isolation. Psychological support to patients and family members may play an important role. A recent study among mentally disabled adolescents showed that psychosocial intervention improves the quality of life and reduces the disability severity.¹² Social segregation of disabled is common in India, mainly due to cultural and religious factors. Recruitment of disabled individuals into the mainstream via vocational education and rehabilitation would improve the emotional and physical wellbeing, and reduce burden on their families.¹³

CONCLUSIONS

Majority of our cases were males and above 5 years of age. Majority of the parents reported following and implementing the medical treatments suggested to them. MR and HI were detected late in our case cohort, suggesting that special measures need to be taken to ascertain early detection and timely interventions. Majority of the children, especially CP, were malnourished. Financial support was lacking to most families. Children and their parents faced numerous psychological and social issues. The need of the hour is to recognise these important deficiencies and develop multidisciplinary approach to rectify them and assure better quality of life to developmentally disabled children.

REFERENCES

1. Barbotte E, Guellimin F, Chan N Lorhandicap Group. Prevalence of impairments, disabilities, handicaps and quality of life in the general population: A review of recent literature. Bull World Health Organ. 2001;79:1047-55.

2. World Report on Disability. Geneva: WHO; 2011. World Health Organization
3. Geneva: WHO; 1989. The World Health Organization. Training in the community for people with disabilities
4. Ganesh KS, Das A, Shashi JS. Epidemiology of disability in a rural community of Karnataka. *Indian J Public Health*. 2008;52:125-9.
5. A report on disabled persons. New Delhi: Department of Statistics, Government of India; 2003. National Sample Survey Organization
6. Mathur GP, Mathur S, Singh KP, Kushwaha KP, Lek SN. Detection and prevention of childhood disability with the help of anganwadi workers. *Indian Pediatrics* 1995;32:773-77.
7. Stevenson R, Conaway M, Chunela N. Growth and health in children with moderate to severe cerebral palsy. *Pediatrics* 2006;118(3):1010-8
8. Paramleenkaur, Chavan BS, Snehlata, Amandeep Kaur, Sophia, Yashwant Arora, Vani Ratnam. Early intervention in developmental delay. *India J Pediatrics*. 2006;75(5):405-408.
9. Bailey Jr. DB, Hebbeler K, Scarborough A, Spikes D and Mallik S. First experience with early intervention. A national perspective. *Pediatrics* 2004;113(4):887-896.
10. Kumar SG, Das A, Soans SJ. Quality of rehabilitation services to disabled in a rural community of Karnataka. *Indian J Community Med*. 2008;33: 198-200.
11. District Disability Rehabilitation centers sanctioned. [Last accessed on 2015 Aug12]. Available from <http://pib.nic.in/release/release.asp?relid=64681>.
12. Ganesh Kumar S, Avinash S, Unnikrishnan B, Kotian MS. Effect of psychosocial intervention on quality of life and disability grading of mentally disabled adolescents. *Curr Pediatr Res*. 2011;15:127-31.
13. Kumar SG, Roy G, Kar SS. Disability and Rehabilitation Services in India: Issues and Challenges. *Journal of Family Medicine and Primary Care*. 2012;1(1):69-73. doi:10.4103/2249-4863.94458.