SHORT COMMUNICATION

Utilization of Rehabilitation Services by Rural Households with Disabled Preschool Children

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We conducted this study to find the extent of utilization of services and, identification of factors which determine the use of such services in rural families with disabled preschool children. Participants included disabled children in a Unicef supported cross sectional survey conducted in a rural ICDS block. The overall proportion of non-utilization of services was found to be 52.1% with the maximum non-utilization among the households with speech and hearing disability. The important explanatary variables predicting non-utilization were low socioeconomic status (OR 4.6; 95% CI 1.27-17.68), poor educational level of father (OR 5.95; 95% CI 1.50-23.59) and poor acceptability of services (OR 36.2; 95% CI 8.73-150.2). This study has implications for planning and organization of easily accessible, quality rehabilitation services in the community.

Keywords: *Disability, Preschool children, Rehabilitation, Rural household, Utilization.*

Impairments in young children have to be viewed as the initial phase of the disability process, which if not addressed, will lead to added secondary disabilities and handicaps as the child grows. A nation wide survey conducted by the National Sample Survey Organisation has estimated that the population with disability in India is approximately 1.9% of the total population and 5.3% and 3% of 0-14 year age group are suffering from physical and mental disabilities, respectively(1). It is generally accepted that early interventions can alter the natural history of an impairment especially in childhood, preventing secondary disabilities and handicaps(2).

Rehabilitation services in the context of childhood disability encompass a wide range of interventions ranging from medical service to educational service depending on the type and extent of the disability. Institutions providing these services are situated in the urban areas, while a significant proportion of disabled children are in rural areas(3,4). There is a real need for reliable information on the extent of utilization of rehabilitation services. The Child Development Centre (CDC), Thiruvananthapuram with the support of Unicef had conducted a survey in a rural block in Kerala to estimate the prevalence of childhood disability in pre-school children and found that 2.5% of 0-5 year olds had delay, deformity or disability in one form or other. The present study is a follow-up of these children to determine the extent of utilization of rehabilitation services by the disabled preschool children and to identify factors which determine the use of such services.

METHODS

The baseline cross sectional survey conducted by CDC in the Pattanakkad ICDS block in Kerala, surveyed 12520 children in the 0-5 years age group and those with delay, deformities and disabilities were identified. From these, 105 children with disabilities were identified as per Persons with Disability (PWD) Act definitions for the purpose of this study(5). After obtaining the clearance from the

institutional ethical committee, these children were followed up and examined by a specialist in rehabilitation medicine and a pediatrician, to know about the rehabilitative services availed by them. The households of the disabled children were identified with the help of Anganwadi workers. An interview schedule was prepared for the purpose of the study and this was finalized after pre-testing. The parents were explained about the study and consent obtained before completion of the interview schedule. In order to get the overall picture of the severity of the problem, it was important to understand the patterns of disabilities that prevailed among children. Therefore the data collected was supplemented by perusal of all previous medical records relating to the child, available with the parents.

RESULTS

Of 105 children with disability identified from the earlier survey, 98 children were included in this study. One child had expired, 2 children had moved away out of the study site and four children could not be traced due to change of address. Among the total of 98 participants, 63.3% children had locomotor disability including 25.5% children with multiple disabilities. 19.3% children had speech and hearing disability, 15.3% had mental retardation and 2.3% had visual disability. The median age of diagnosis of speech and hearing disabilities was 30 months, while locomotor and mental disabilities were identified at the median age of 8½ and 6 months, respectively.

Children on follow-up treatment and those not in need of treatment were considered as utilizers for the study (n=47; 48%). Rest of the children (n=51; 52%), who discontinued treatment or those who has not gone for treatment at all were considered as non-utilizers. The proportion of non-utilization varied with the type of disability, with the highest proportion of non-utilization in speech and hearing disability (84.2%; 95% CI: 62.8-95.8), followed by locomotor disability (53.2%; 95% CI: 40.8-65.4) and lowest in mental retardation (13.3%; 95% CI: 2.3-37.5). The proportion of non-utilization was high in district and medical college level compared to 20% at the taluk level. The proportion of utilization in private hospitals was 50% and increased further when the services were sought by private consultation. It was observed that 28.6% children were on follow up. One-fifth of the children discontinued treatment due to different reasons. 27.5% of parents have not gone for any type of treatment.

In order to get further insights into the reasons for this non-utilization we conducted a univariate analysis to explore the various risk factors and confirmed it with a multivariate analysis. The most important determinants of utilization of services by univariate analysis are depicted in ***Table* I**. On multivariate logistic regression analysis, low socioeconomic status, poor perceptions about the disease and disability, low educational level of parents, and poor acceptability of services were identified to determine lower utilization of services.

DISCUSSION

The prevalence of non-utilization was found to be 52% among households with preschool disabled children. The highest proportion of non-utilizers was found in children with speech and hearing disability. This indicates that hearing disability was detected much later than others, leading to an accumulated morbidity of this disability. This pattern in the case of hearing disability has also been reported in other studies(6). Most of the children with disabilities have permanent disabilities and the basic aim of rehabilitation is to improve functional ability. Lack of intervention and improper utilization of services can lead to many secondary disabilities apart from the primary disability. It is to be noted that 31.1% of children were diagnosed at the Primary Health Centre (PHC) and referred to higher centers and the proportion of non-utilization was high at district level and Medical College level compared to 20% at the taluk level. Even though the strategies for intervention suggested by World Health Organization is PHC based, it was observed that no child was being followed up at the PHC. Hence, there is a need to create more awareness for early detection at PHC level and also for more decentralization of rehabilitation services. Private consultation was often the preferred choice of parents of disabled children. The increased compliance to utilization of private sector services at

TABLE I UNIVARIATE ANALYSIS OF DETERMINANTS OF NON-UTILISATION OF REHABILITATION SERVICES

Variables	Non-Utilizers (*n*=51) No. (%)	Utilizers (*n*=47) No. (%)	Odds Ratio (95% CI)	*P* value
Maternal education <High school	19 (34.3)	10 (21.2)	2.20 (0.89-5.40)	0.86
Father's education <High school	32 (62.7)	13 (27.7)	4.40 (1.87-10.35)	<0.001
Low socioeconomic status	36 (70.6)	16 (34.0)	4.65 (1.98-10.90)	<0.001
Expenditure >Rs 50 per visit	31 (60.8)	20 (42.6)	3.61 (1.44-7.59)	<0.001
No perceived economic access	49 (96.1)	05 (10.6)	205.8 (37.9-1116.7)	<0.0001
Expenditure (% of per capita income >12.9%)	33 (64.7)	16 (34.0)	1 (1.54-8.17)	<0.005
Proximity of center (geographical access) >10 km	48 (94.1)	33 (70.2)	6.79 (1.81-25.49)	<0.005
No perceived geographical access	32 (62.7)	02 (4.2)	37.89 (8.23-174.28)	<0.001
Acceptability measure No (≥2)	41 (80.4)	08 (17.0)	–20(7.15-55.85)	<0.001
Disability severity	39 (76.5)	12 (25.5)	1.11 (0.44-2.80)	0.82
Perceived severity	36 (70.6)	19 (40.4)	3.54 (1.53-8.17)	<0.005
No family support	06 (11.8)	02 (4.2)	3 (0.57-15.67)	0.17
No community support	06 (11.8)	04 (8.5)	1.43 (0.37-5.43)	0.59
Nuclear family	24 (47.1)	15 (31.9)	–1.90 (0.83-4.32)	0.13
Age group (in months) >59	34 (66.7)	15 (31.9)	4.27 (1.83-9.94)	<0.001
Knowledge score ≤8	25 (49.0)	22 (46.8)	1 (0.84-4.39)	0.12
Negative attitude	37 (72.5)	14 (29.7)	1.12 (0.46-2.69)	0.80

the user level shows that it is necessary to also co-opt this component into a rehabilitation service program.

Psychosocial factors have an important role in explaining utilization of services or health seeking behaviour. In this study, information about perceived benefit, satisfaction and adequacy of services provided, presence or absence of contradictory belief about treatment, and presence or absence of rapport with the providers were taken into account to obtain a measure of acceptability of the interventions provided. Based on this, it was found that parents who were not really convinced about the benefits of treatment and not satisfied with the services were found to become non-utilizers. This belief is strengthened by the fact that when childhood disability presents itself, the aim of intervention is not complete cure but habilitation. This truth is often emotionally not acceptable to parents and thus they tend to be lured towards unscientific treatment methods existing in the community. This is an important point in favor of creating awareness on disability and rehabilitation among not only the community, but also among medical professionals, so that proper guidance can be given to parents even at the primary care level. The coping strategies for parents with disabled children have been extensively studied and all of them indicate the importance of parental involvement or partnership in the rehabilitation process(6).

The study findings clearly indicated the need for establishing easily accessible community based services incorporating existing social welfare and heath service infrastructure for children with disability. Priority should be given to the prevention of childhood disabilities by early diagnosis and interventions especially in the case of speech and hearing disability. Creating community awareness regarding childhood disability and need for proper utilization of rehabilitation services is necessary for increasing the utilization of services available. The need for clear concepts about disability and its management among the medical profession by incorporating the same into the curriculum and also by continuing education programs would help much

WHAT THIS STUDY ADDS?

- The prevalence of non-utilization of available services was 52% among households with preschool disabled children and the highest proportion of non-utilizers was in children with speech and hearing disability (84.2%).

in reducing the burden of disability care at the user level and the caregiver level. Planning at the local level should consider the difference in quality and quantity of care required for different types of disability.

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REFERENCES

1. NSSO. Report on Disabled Persons. 47th Round Report No. 393, July-December, 1991.
2. Nair MKC, Mathew S, George B. Early stimulation – CDC Trivandrum Model. Indian J Pediatr 1992; 59: 767-772.
3. World Health Organization. CBR and Health Care Referral Services, Geneva: WHO; 1994. p.4.
4. Sarva Siksha Abhiyan. Available from http://s24pgseducation.org/finalind/IED.htm. Accessed on 19 November, 2007.
5. The Persons With Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. The Gazette of Government of India; January 1, 1996.
6. Parving A. Hearing screening – aspects of epidemiology and identification of hearing impaired children. Int J Pediatr Otorhinolaryngol 1999; 49: 287-292.