

# Use Of Pediatric Evaluation Of Disability Inventory For Functional Assessment In Prematurely Born Indian Children- A Community Based Study

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**Abstract**—India has a varied socio-economic, demographic factors and health care facilities that affect the morbidity & mortality among vulnerable children especially the preterm born children. The objective of the study was to compare the functional assessment of children of age 5-7.5 years who were born preterm with the children born at term using the Pediatric Evaluation of Disability Inventory (PEDI). This was a cross sectional, community based survey. The results showed that children of age 5-7.5 years who were born preterm were significantly low in the functional skills when compared to their peers who were born at term

**Index Terms**—Functional Assessment; Preterm; Paediatric Evaluation of Disability Inventory

## I. INTRODUCTION

Disability is defined as “difficulty doing activities in any domain of life (from hygiene to hobbies, errands to sleep) due to health or physical problem. The ongoing developmental process in children is one of the main reasons that disablement in childhood differs markedly from disablement in adulthood.”<sup>1</sup>

In India, a developing country, the brunt of the strain of health problems, is felt by the vulnerable groups, i.e. mothers and children.<sup>2</sup> In both, the number of infant & maternal mortality rate, India ranks number one in the comity of nations well below China though the later has 20% more population than India.<sup>2</sup> Morbidity is common in children and frequently involves physical, developmental, psychological, emotional, or behavioural problems. Children's health could be substantially improved if vulnerable children who are ‘at risk’ are readily identified with the help of good outcome measures. It is especially important to monitor the health of these vulnerable populations to limit health care costs.<sup>3</sup>

There are several risk factors which contribute for developmental delay in children. There is now clear evidence that prematurity and low birth weight is the most important biological risk factors for developmental delay.<sup>4</sup> Significant advances in perinatology and neonatology in the last decade have resulted in increased survivors of extreme premature

infants.<sup>5</sup> In an infant, born premature, body systems are often underdeveloped. The medical complications associated with prematurity often lead to CNS damage. The developmental outcomes of children born preterm remain a serious concern.<sup>6</sup>

Huddy et al have shown that preterm and low birth weight babies are at high risk for motor, sensory and neuro developmental problems, educational difficulties and behavioural disorders.<sup>7</sup> High incidence of learning, behavioural problems and early school failures even in pre term children who were neurologically normal has been reported by Gross et al.<sup>8</sup>

All the above factors may have long term implications on the child, causing impairments and limitation in functional activities and thus may precipitate disability.<sup>9</sup> While research is focusing on neuro motor, sensory, cognitive, & language skills, studies to date have rarely focused on application of these skills in everyday settings in children born preterm. Such skills have been called functional skills which is multi dimensional construct that includes daily living, socialization & communication. 6 Children growing, learn essential functional activities, and will be able to function more and more independently, guided by the parents or caregivers.<sup>9</sup>

The ultimate goal of pediatric rehabilitation is to integrate the disabled child into the home, the school environment and the community, in which he or she learns functional activities independently in a safe and timely manner.<sup>1</sup> Rehabilitation, like other clinical disciplines, tends to assess its impact by looking at the outcomes at the end of treatments. Outcomes measure some change from a status at one point in time to another.<sup>10</sup>

Today outcomes research is being used in medicine, increasingly in physical therapy. As noted by Relman, we are currently in the 3<sup>rd</sup> stage of this modern revolution, the era of assessment and accountability.<sup>11</sup> The limited availability of measures based on an international taxonomy to assess functional limitations among children has been recognized. There is a need for functional assessment measures for screening, clinical assessment and outcome evaluation.<sup>1</sup> In general, the development of outcome instruments is a time consuming process. Besides this, from a research point of view, a proliferation of many specific instruments for the

same conditions threatens to decrease the external validity of study findings. Therefore, it is preferable to use established instruments. The validity of an assessment however can be affected when an outcome instrument developed & calibrated for a specific culture, is used in another culture, due to translation difficulties, irrelevancy of item contents, & inappropriate norm scores.<sup>1</sup>

In the assessment of functional performance, Dunn emphasized the importance of context. Environmental and social variables have a profound effect upon the functional performance and are considered a potentially important influence on functional outcomes.<sup>12</sup>

A review of the measures indicated the comprehensiveness of the Paediatric Evaluation Disability Inventory (PEDI) developed by Haley et al, which is a parental report or structured-interview instrument used to assess the functional abilities of young children of age 6 months to 7.5 years. This instrument consists of 'Functional Skill Scale', 'Caregiver Assistance Scale' and 'Modification Scale' and has proven to be reliable, valid, and sensitive to changes in functional skills.<sup>13, 14</sup>

The present study aimed to assess the applicability of PEDI in India and establish the content validity of PEDI, if found necessary and to compare the functional status in children of age 5-7.5 years who were born preterm with that of children born at term using the Paediatric Evaluation of Disability Inventory.

## II. METHODOLOGY

### A. Study Setting

This community based study was conducted within the limits of Mangalore City Corporation in the state of Karnataka, a city along the western coastal line of India.

### B. Study Design

Cross sectional study

### C. Study Subjects

Group 1: Inclusion Criteria: Normal Children of age 5 to 7.5 years born at term as indicated by the medical records.

Group 2: Inclusion Criteria- Children of age group of 5-7.5 years with a history of Preterm birth <37 completed weeks of gestation as per the medical record

Exclusion Criteria- Children with diagnosed motor, sensory or musculoskeletal problems, Cerebral palsy, and history of deafness or use of hearing aid, severe visual acuity problems, diagnosed mental retardation and children diagnosed to have learning disability.

### D. Sampling

Group 1: Simple random sampling and Group 2: Non random sampling

### E. Data Collection

The content validity of original PEDI was established by a panel of experts after administration on a pilot sample of 23 non disabled children which showed that the cronbachs alpha and the internal consistency ranged from 0.68-0.93

and 0.6-0.7 respectively denoting poor to moderate ICC values. Approval from the Institutional Research and Ethical Committee was obtained. Written Informed consent was taken from the parent/ caregiver prior to administration of validated PEDI.

Out of the total of 60 wards within the limits of Mangalore City Corporation (MCC), 14 wards were selected by simple random sampling. 255 Normal Children between 5 to 7.5 years from the selected wards of MCC were recruited for the study and validated version of PEDI questionnaire was administered on the parents or caregivers in the language that they understood in the form of structured interview.

The validated PEDI was administered on 52 children aged 5-7.5 years who were born preterm. These children were identified through the medical records of the hospitals in Mangalore and through the schools in Mangalore.

### F. Data Analysis

Data analysis was done using the SPSS version 15. The Mean and Standard Deviation (S.D) for the raw scores for the Self care domain, Mobility domain and Social function domain of the functional skill scale and Caregiver Assistance Scale was obtained for Group 1 and Group 2.

Using the raw score mean of the functional skill scales, Group 1 and Group 2 was compared using the Independent Sample 't' test. Using the raw score mean of the Caregiver Assistance Scale, Group 1 and Group 2 was compared using the Pearson's chi square test.

## III. RESULTS

The purpose of the present study was to compare the children of age 5-7.5 years born preterm (Group 2) with the children of the same age born at term (Group 1) using the validated version of PEDI.

TABLE 1. Raw score mean and S.D of the 3 domains of Functional Skill Scale in Group 1 and 2

Age in yrs	Self Care		Mobility		Social function	
	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2
5-5.5 years	66.5±5.3	59.5±10.5	56.8±1.4	56.7±1.0	60.0±3.5	50.5±9.2
5.5-6 years	68.0±5.2	66.8±3.9	57.3±7.7	57.6±7.7	60.6±5.7	60.7±2.1
6-6.5 years	70.5±3.5	66.3±7.1	57.4±7.7	56.0±3.8	62.5±1.9	58.4±7.7
6.5-7 years	70.4±3.8	67.5±4.3	57.5±6.6	57.3±9.4	62.2±2.4	61.0±1.4
7-7.5 years	71.7±2.6	62.8±6.3	57.7±6.6	56.8±9.9	63.2±1.9	53.5±12.1
Mean±S.D						

TABLE 2. Comparison of the mean scores of FSS of Group 1 and Group 2

Group 1		Group 2		Mean Diff	't' value	'p' value	95% CI of the difference		
Domains	Group N	Mean	S.D				lower	Upper	
Self Care	1	255	69.38	4.6	3.97	3.89	0.000	1.93	6.02
	2	52	65.4	7.1					
Mobility	1	255	57.35	0.922	0.83	2.07	0.044	0.24	1.64
	2	52	56.52	2.87					

Social	1	255	61.69	3.61	3.92	3.58	0.001	1.73	6.12
function	2	52	57.77	7.73					

The Raw score mean and S.D of the 3 domains of Functional Skill Scale in Group 1 and 2 is shown in Table 1. The raw score mean of the 3 domains of FSS was compared for the Group 1 and Group 2 using the independent sample t-test as shown in Table 2,. This showed that there is significant difference in the self care and social function domains between the 2 groups where the normal children achieved higher scores in these two domains as compared to the children born preterm. However, this difference may not be clinically significant.

Caregiver Assistance Scale:- The mean and SD for the scores for the 3 domains i.e. Self Care, Mobility & Social Function in the Caregiver Assistance Scale was obtained for the Group 1 and Group 2. There was a significant difference in the scores of the Caregiver Assistance Scale between both the groups in most of the items except 'Eating' and 'Bowel Training' of the self care function domain and 'Bathroom transfer' and 'Indoor locomotion' of mobility domain indicating that in the present study, children of age 5-7.5 years born at term were more independent and required less assistance from the caregivers in performing these activities when compared to the children of the same age born preterm.

#### IV. DISCUSSION

Functional status instruments measure functional skills which are practical behaviours that enable children to interact & live within their physical & social environments. Children's increasing functional skills becomes important as they enter formal schooling. It has been reported that teachers consider independence in functional skills as a critical component of school readiness.<sup>3</sup>

Comparison of the raw score mean of the two groups showed that there was significant difference in the self care domain and social function between the 2 groups where the normal children achieved higher scores in these two domains as compared to the children born preterm. Though this is statistically significant, a difference of score '2' may not be clinically significant considering the variations in score even in the normal children in group 1. This indicates that the preterm born children do lag behind in their functional skills especially the self care & social functions which is in agreement to the numerous studies done on preterm born children.

Comparison of the scores of the 3 domains in Caregiver Assistance Scale between Group 1 and Group 2 showed that the term born children were more independent and required less assistance from the caregivers in performing the activities when compared to the preterm born children.

The functional skills are dependent on many factors such as sensory, motor, behavior, emotional, parenting styles, child rearing practices, home & school environment etc. With so many factors contributing to the functional skills, a problem in any of these areas will affect the function of the

child. Studies show that the preterm born children in spite of not having major neuro developmental problems have shown deficiency in many areas of development when compared to their peers.

Marlow performed a controlled study of motor skills on fifty three ELBW children aged 6 years old without cerebral palsy and receiving mainstream education. On the test of motor impairment, ELBW children had a wide range of minor abnormalities of motor, neurological, cognitive, and behavioural function than the controls.<sup>15</sup>

Jongmans et al showed a surprisingly high proportion of preterm children with minor neurological signs and / or perceptual motor difficulties in the absence of major neurological impairment. As the presence of these problems may affect the children's ability to function in everyday life, it is essential that they are comprehensively assessed so that meaningful intervention can be planned when necessary.<sup>16</sup>

Huddy et al concluded that preterm and low birth weight babies were at increased risk of motor and sensory neuro developmental problems, educational difficulties, and behavioural disorders and they may have multiple area of hidden disability.<sup>7</sup> The Scottish low birth weight study group in their cohort study documented that at the age of 4-5 years, the study children were poor in tests of fine motor skills.<sup>17</sup>

All the above studies show evidence that preterm and low birth weight children may have subtle & minor deficits that may affect the children's ability to function in everyday life. This was evident in our study which showed that these children have poor functional skills which is very important for active participation in day to day life. It is thus very essential that these children are comprehensively assessed and observed into adolescent age so that meaningful intervention can be planned when necessary.

#### V. CONCLUSION

The pilot study confirmed that there existed inter cultural differences while using the original Pediatric Evaluation of Disability Inventory, and hence validation was done. The present study concluded that children of age 5-7.5 years who were born preterm had lower scores in self care and social function skills when compared to the children of the same age who were born at term and they were more dependent on their caregiver for assistance in performing most of the activities in self care, mobility & social function skills.

Study Limitation: The present study did not consider the environment of the children which may have influenced the results. In addition, because PEDI depends on caregiver's reports regarding the behaviour of children, this assessment can be subject to the biases of the person supplying the information.

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