Ease of Care giving for Children: parent perceptions of the physical demands of care giving for children with cerebral palsy in Indian context

Abstract

Care giving for children with cerebral palsy engages the complete parenting measure of how difficult to safely manage and help their children with cerebral palsy to complete the activities of daily living skills. The aim of the current study was to examine the consistency and test-retest reliability and construct validity of the group methods on the ease of parenting for children with cerebral palsy and 10 parents of children without motor delay in the age group of 18 to 60 months were included and parents were instructed complete the ease of care giving and have to be present with the therapist assessed gross motor function. The Rasch model of item response was used to develop interval level scale. Results declare the high internal consistency and test retest reliability. It has been identified that ease of care giving varies with different ages for parents with cerebral palsy children. Parents of children with gross motor defects reported more trouble in care giving than parents of children with intact gross motor skill. Rasch analysis was used to hierarchical ordering of items with logical sequence. Findings of the current study suggested that ease of care giving for children with cerebral palsy as a reliable and valid measure of parent's perception of their trouble to safely help their children perform their ADL skills in Indian context. There is a need for health care professionals to evaluate the family needs in parenting their children with cerebral palsy

Keywords: Cerebral palsy, Indian context, Activities of daily living skills, gross motor skill, caregivers burden

Introduction

Care giving is required for all children and children with cerebral palsy require additional assistance and proper care giving for the growth and wellbeing. Cerebral palsy children necessitate extra support and care which more than the expected range is for normal children[1]. Cerebral palsy includes a group of disorder in the development of movement and posture and the result is activity limitation which causes negative performance in self care. The gross motor function classification system evaluates the gross motor function of children with cerebral palsy in five levels[2].

Children in level 1 walk without any restrictions and those in level 5 have severe limitations in self care and mobility tasks. Those children with cerebral palsy require additional assistance in executing self care tasks than children without motor delay in their developmental years[3].

However young children with cerebral palsy in gross motor function classification system level I and level II were able to complete self care activities than children in level 3 to 5. Parents of cerebral palsy suffer more likely to report that they need timely help to care for children with cerebral palsy than the parents of children with cystic fibrosis or spina bifida[4].

Among parents of children with multiple intellectual disabilities, parent of 8 years old children with cerebral palsy reported greater care giving and workload than parents of children who handle 9 year old child. Previous researchers documented that handling children with cerebral palsy requires maximum effort and workload[5]. The amplified care giving for children with gross motor difficulty will have an impact on emotional well-being. Care giving burden reported to have permanent impact on the caregiver's health and mental wellbeing[6].

There is a need to incorporate the child participation in family and in other recreational activities as well as self care. The study has two primary objectives; initially there is a need to evaluate the internal validity and test retest reliability as well as constructs validity of the ease of care giving for children as compared to parents of children with cerebral palsy. Groups refer to the ability in discrimination of the ease of care giving in parents of children with motor coordination disorder. The second objective of the study was to evaluate the hierarchical ordering in items.

Methodology

To evaluate the internal consistency and test retest reliability we have used a methodological design and the construct validity was used to evaluate the group methods by comparing children with cerebral palsy and typically developing children. Rasch item analysis was used to evaluate the measures in interval level. Written informed consent was signed by the parents of children and they were willing to participate in the study with complete interest. Parents of typically developing children require completing the form and approving their consent to publish. Sample of 10 children with cerebral palsy and their parents participated in the study. Descriptive statistics was tabulated and to generalize the characteristics of sample, data was collected from urban, suburban as well as rural areas.

Age group of children included in the study was of age group 18 to 60 months and they found to have five levels of GMFCS. Children with level 1 category were found to walk without any restrictions and children in level II can walk independently, children in level III can walk with the assistive device and the children with level IV and V have severe restrictions in mobility by self and they depend on wheelchair support. To compare the children with CP, they were divided into three groups and group A is with GMFCS I, Group B composed of GMFCS II and III, Group C is with GMFCS IV and V. parents included in the study were mothers of children with CP as previous researchers stated that Indian mothers spend maximum time with their children and the caregivers responded were only mothers and they were with the mean age of 28years.

As the caregivers were completed high school education and only 50% were employed. Reliability sample included in the study was about 10 boys across GMFCS level and the samples included in the study were low and the results of the study were not generalized and the parents of children with typical development included in the study were recruited from snowball sampling. Children with CP and typical development were compared using Chi-Square and t-test analyses. The children with CP and without motor delay didn't differ predominantly in demographic profile. But however the parents of children with CP were found to have lower education and lower household income than parents of children without motor delay.

The ease of care giving is a 12 item questionnaire that adapts items from PPT-OMS, it composes the 10 expert's opinion on the validity and it evaluates the parent's perception of how difficult is to evaluate the children in their everyday activities of daily living. Each item was scaled in 1 to 5 levels of difficulty. Score 1 dictates very difficult and score 5 denotes no help needed. The results of higher score indicate the greater ease of care giving. The questionnaire was completed in less than 5 minutes and it is appropriate for Indian children. Parents reported that it is feasible and most appropriate for use.

Palisano et al designed gross motor function classification system to classify children with cerebral palsy from the age group of 2 to 18 years. This classification system divides the children based on their performance in activity of daily living skills. GMFCS is the five level system and this classification is based on the gross motor function in activities of daily life which emphasis on mobility as well as sitting. Age bands were divided into 5 range and children of age 2 to 4 years and 4 to 6 years were segregated. GMFCS and ease of care giving were having good reliability and validity. After instructions received in GMFCS and therapist collected data with parents of children with CP completed ease of Caregiving for children at their homes or therapy centers.

Results

Table1: Mean value of Ease of Care giving for Children with and without cerebral palsy.

Age group	TD children	GMFCS Level I	II and III	IV and V
17 to 30 months	4.1	3.9	3.8	3.2
31 to 42 months	4.2	4.0	3.7	3.0
43 months and older	4.5	4.1	3.6	3.1
Total	4.5	4.2	3.7	3.2

Discussion

Mothers of children with cerebral palsy were reported to get engaged in less occupational roles as compared to mothers of children without neurological impairment. Caregivers spend their maximum time with their children and they left with limited time to complete the daily tasks and they fail to care the other family members and fail to complete other activities. Enhancing the ease of care giving is an important outcome for many children with cerebral palsy[7].

Understanding patient perspective may help the therapists and researchers to analyze opportunities and plan effective treatment interventions to target the parents of children with cerebral palsy. Effective intervention schedule will gain the parents confidence and majority of the parents look for safe, efficient, less time requiring care for their children[8]. Addressing the demands of care giving with family centered care plays a key role in promotion of mental well being of the parents of children with cerebral palsy. Rather than referring as burden of care giving, ease of care giving can be used and burden of care giving is described as a difficulty in handling a child with disability[9].

However the International Classification of Functioning, Disability and Health (ICF) are more consistent with the terminology ease of care giving and which focus on the health rather than the disability. The term ease of care giving avoids the negative stereotypes in published literature[10]. Parents who found difficulty in helping their children to execute the activity of daily living tasks will face a negative impact on the therapy sessions provided for them. There is a need for a gold standard measure to evaluate the care giving burden for children with disability. Leonard et al identified the factors that were predominant for the development of a reliable and valid measuring tool for the evaluation of the caregiver's burden[11].

The factors which were considered primary includes the feasibility of the emolument, address the experience of parents of children helps in planning the appropriate intervention for children and the reliable and valid measure helps to monitor the change[12]. Tadema et al in 2010 identified that researchers studying the caregiving burden were used self designed tools and regionally developed tools. Robert et al in his research study concluded that semi structured group discussions and interviews were used in assessment of caregiving. The use of self designed and interview designs were used to replicate the study designs and limits comparison between research findings[13].

Fougetrolls et al identified the self care performance and the type of assistance needed for parents of children with cerebral palsy to enable practice their children with day care tasks. CareQ is the questionnaire used by majority of the researchers and this care and comfort caregiver questionnaire evaluates the perceived effort of the parents of children with CP in GMFCS level III to V. however these measures were used in the documentation of the childs performance level and it also describes the degree of assistance needed to complete the self care tasks[14].

But the limitation of the tool is it fails to document the parent perception of ease of caregiving for all levels of gross motor function. Barlett et al in 2010 developed ease of care giving tool for children with CP and it evaluates the parent's perception of the care giving burden and this tool evaluates the children of age 18 to 60 months[15]. The care giving assessment demands a self reported measure of the level of difficulty a parent experience in growing the children with cerebral palsy. Parents were questioned four aspects of care giving that includes safety, demands from physical activity, time and confidence. The caregiving for children complements the daily life activity and child engagement.

The suggestions of the study didn't have significant difference based on Childs age and several internal as well as external attributions of factors were not controlled. Parents perceived ease of caregiving skill incorporates their expectation of caregiving, promotion of childs independence, childs ease in participation in sports. Ostensjo et al documented that as the child grow, there is a increased size and weight of the child will place increased demands on the physical task execution. Chiarello et al.suggested that child's age will influence their participation in self care tasks.

Conclusion

The results endow with confirmation that the Ease of Caregiving is a valid parent accomplished gauge of parents' observation of how complicated it is to securely support their youngster with CP to execute self-care activities. It is also suggested from the study that parents of children with greater score in motor disability in CP child suffers and strive hard to care for the children than the parents of children with lower motor difficulties. However in order to provide a comprehensive evaluation, there is a need for the assessment of children in free environment without any constraints. With a better understanding of parents perception in ease of care giving, therapists and researcher will make clinical decisions and provide interventions to meet the demands of children with cerebral palsy. Further research is needed to validate the findings of the current study and children with different age group and children with other disabilities needs evaluation.

Availability of data and other materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request. Please mail and reach us in

Competing interests

Authors declare no conflict of interest

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