Research in Developmental Disabilities 34 (2013) 3746–3753

Contents lists available at ScienceDirect

Research in Developmental Disabilities

Discrepancies between mothers and clinicians in assessing functional capabilities and performance of children with cerebral palsy

Dina Elad, Sharon Barak *, Etzyona Eisenstein, Orly Bar, Uri Givon, Amichai Brezner

The Edmond and Lily Safra Children's Hospital, The Chaim Sheba Medical Center, Ramat Gan 52621, Israel

ARTICLE INFO

Article history:
Received 23 April 2013
Received in revised form 23 July 2013
Accepted 30 July 2013
Available online 7 September 2013

Keywords:
Cerebral palsy
Proxy-therapist agreement
Function
Proxy assessments

ABSTRACT

The current study is a cross-sectional study that aimed to investigate the concordance between health care professionals (HCPs) and mothers in rating capabilities and performance of children with cerebral palsy (CP), and the impact of CP gross motor severity on concordance. Seventy-three children with mild-to-severe CP (mean age 8.8 ± 2.10 years) and their mothers participated in this study. Two modes of Pediatric Evaluation Disability Inventory (PEDI) administration were used: mothers' interview by a social worker and HCPs' actual evaluation. Differences between raters were assessed by paired *t*-tests and intra-class correlation coefficients (ICCs). Agreement was defined as mean absolute difference of less than or equal to six points. The results indicated that in spite of excellent overall ICCs in PEDI (ICC > 0.8), disagreement between raters was observed in all PEDI subdomains: 38%, 56%, 72% and 59% disagreement in Functional Skills–Mobility, Functional Skills–Self Care, Caregiver Assistance–Mobility (CA–MO) and Caregiver Assistance–Self Care (CA–SC), respectively. In CA–SC and CA–MO disagreement mainly consisted of mothers rating their children lower in performance than HCPs. CP severity effected the agreement mostly in children with moderate CP severity. The implications of these results are that raters perceive child's activity differently, hence revealing hidden disability perceptions, with significant consequences for intended interventions.

1. Introduction

Cerebral palsy (CP) is an umbrella term that describes a group of heterogeneous disorders of movement and posture in terms of etiology and severity, attributed to non-progressive brain disturbances. Motor disorders are often accompanied by disturbances of sensation, cognition, perception and behavior. Consequent to the brain disorder and caused by the accompanied motor impairments, children with CP manifest difficulties in the execution of activities (Bax et al., 2005). The extent of motor disorders and activity limitations, however, are influenced by CP subtype. For instance, severely impaired gross motor function is present in 1% of children with unilateral CP, compared with 38% of children with bilateral CP; bimanual Fine Motor Function level is IV or V in 44% of children with spastic bilateral CP, compared with 1% of children with unilateral CP (Andersen et al., 2008). The assessment of activities, therefore, is of primary importance in the clinical evaluation of children with CP.

* Corresponding author at: The Edmond and Lily Safra Children's Hospital, Chaim Sheba Medical Center, Pediatric Rehabilitation Department, Zip code-52621, Israel. Tel.: +972 3 530 2684; fax: +972 3 530 2045.
E-mail addresses: sharoni.baraki@gmail.com, dina.elad@sheba.health.gov.il (S. Barak).

0891-4222/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ridd.2013.07.036

The term "activity" includes three constructs: capacity, capabilities and performance. "Capacity" describes what a person can do in a controlled, standardized environment. The Gross Motor Function Measure-66 (GMFM-66) is an example of a widely used capacity measure. "Capability" is defined as what a person can do in his/her daily environment, and "performance" describes what a person actually does in his/her daily environment (Holsbeeke, Ketelaar, Schoemaker, & Gorter, 2009). Two modes of capability and performance assessment are common: evaluation by a health care professional (HCP) or reports by family members. Studies in children with juvenile idiopathic arthritis have shown, however, that parents and HCPs may disagree on the assessment of children's capabilities and performance (Palmisani et al., 2007; Ravelli et al., 2001).

A well known capabilities and performance assessment tool is the Pediatric Evaluation Disability Inventory (PEDI). It was designed to assess children with disabilities from six months to 7.5 years of age (Berg, Aammodt, Stanghelle, Krumlinde-Sundholm, & Hussain, 2008; Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992). It is appropriate for use among older children with functional limitations as well (Haley et al., 1992). The PEDI includes three sets of measurement scales: Functional Skills (FS), Caregiver Assistance (CA), and Modifications. The FS scale can be used to assess capabilities, whereas the CA scale is used to establish performance. Recently, Vargus-Adams, Martin, Maignan, Klein, and Salisbury (2011) used the PEDI to explore the relationship between subjective ratings in several functional domains, made by HCPs, parents and children with CP. The authors reported significant correlations between parents and HCPs in rating PEDI's FS self-care (SC) (0.83, 95% confidence interval = 0.76, 0.88). However, this study investigated PEDI-FS scale only and did not examine the impact of gross motor function severity on the agreement. Furthermore, agreement between HCPs and parents was examined via correlations, without implementing other acceptable measures of agreement and statistical graphical methods.

Understanding the perceptions of different informants is an important aspect of HCPs–parent interaction, as disagreement between parents and HCPs may cause conflicts. For instance, the ability to set goals according to parents' needs and expectations may be impaired. Moreover, substantial disagreement between parents and HCPs over child's function may lead to difficulty in assessing the efficacy of interventions (Ravelli et al., 2001).

The primary aim of this study, therefore, was to investigate the concordance between HCPs and mothers in rating capabilities and performance using the PEDI in children with CP. Furthermore, the impact of gross motor function severity on concordance between mothers and HCPs was also examined.

2. Method

This study was part of a larger clinical study and was approved by the Institutional Review Board of Sheba Medical Center. All children and their caregivers gave their informed consent to the research and to publication of the results.

2.1. Participants

The participants were recruited from clinics and schools throughout the country (north, central and the south of Israel). CP diagnosis was confirmed via a medical record chart review or via confirmation from the child's primary care physician. Prior to the beginning of the study, the principal investigator met with orthopedics, neurologists and special education schools' staff, regarding the recruitment of children with CP (all types, distribution and severity) from their educational and medical establishments. Two hundred families were informed regarding the study via pamphlets that were distributed by the physicians, teachers, social workers and advisors who work at the various clinics and schools. Seventy-six mothers who were interested in participating in the study contacted the principal investigator. Out of the 76 families that entered the study. Three families did not complete the study, due to the father's or child's disinterest in completing the procedure. A total of 73 children (6–12 years) with CP participated (response rate of 37%).

2.2. Measures

2.2.1. Capability and performance-PEDI

The PEDI was chosen as a widely employed and well-regarded measure in CP research and in clinical settings (Vargus-Adams & Martin, 2009). The PEDI includes three sets of measurement scales (FS, CA and Modifications). Each scale is divided into three domains: SC, MO and Social Function (SF). The FS scale assesses capability to conduct components of daily activities in the three domains, and consists of 197 items (SC-73, MO-59 items and SF-65 items). The CA scale reflects the extent of routine required assistance in performing daily activities, and consists of 20 items (SC-8 items, MO-7 items and SF-5 items). The Modifications section of the PEDI is a categorical scale (Haley et al., 1992). Consequently, in the current study we used the FS and CA domains only. The FS–SF and CA–SF scores were excluded because most of the items relate to interactions with others in the community. It is hard for the HCP to obtain this kind of information in a medical setting. Accordingly, four domain raw scores were obtained as follows: FS–SC, FS–MO, CA–SC and CA–MO. PEDI FS was used to assess capability, whereas PEDI CA was used to establish performance. The Hebrew version of the PEDI was used. It was found to be valid and reliable in children with CP aged 6–12 years (Cronbach's alpha > 0.845) (Elad et al., 2012).

2.2.2. Severity of gross motor function – Gross Motor Function Classification System (GMFCS)

The GMFCS has been widely employed internationally to group individuals with CP into one of five levels, based on functional mobility or activity limitation (Holsbeeke et al., 2009). Level I represents the highest level of gross motor function