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## Ease of Caregiving for Children: A measure of parent perceptions of the physical demands of caregiving for young children with cerebral palsy



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### ABSTRACT

The Ease of Caregiving for Children is a parent-completed measure of how difficult it is for them to safely help their children participate in activities of daily living. The objectives of this study were to determine the internal consistency, test–retest reliability, and construct validity (known groups methods) of the Ease of Caregiving for Children and create an interval-level scale. Participants included 429 parents of children with cerebral palsy (CP) and 110 parents of children without motor delay. Children ranged in age from 18 to 60 months. Parents completed the Ease of Caregiving for Children and therapists assessed children's gross motor function. The Rasch model of item response analysis was used to create an interval-level scale. Results indicated high internal consistency and acceptable test–retest reliability. Ease of caregiving varied by children's ages for parents of children without motor delay, however there was no significant difference by age for parents of children with CP. Parents of children with less gross motor ability reported more difficulty in caregiving than parents of children with higher gross motor ability. Rasch analysis for children with CP resulted in a hierarchical ordering of items by difficulty with good fit and logical ordering. Findings support the Ease of Caregiving for Children as a reliable and valid measure of parents' perceptions of their difficulty to safely assist their children to perform activities of daily living. The measure should enable health care providers to assess and provide interventions that address families' needs in caring for their children with CP.

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## 1. Introduction

All young children require caregiving; however, to complete self-care activities, children with cerebral palsy (CP) often require additional assistance beyond that which is expected for children their age without motor delay. Cerebral palsy refers to a group of disorders of the development of movement and posture, causing activity limitations including performance of self-care (Rosenbaum et al., 2007). The Gross Motor Function Classification System (GMFCS) categorizes the gross motor

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function of children with CP into 5 levels, varying from children in level I who walk without restrictions to children in level V who have severe limitations in self-mobility (Palisano, Rosenbaum, Bartlett, & Livingston, 2008). Children with CP require more physical assistance for self-care tasks than children without motor delay (Ostensjo, Carlberg, & Vollestad, 2003). Furthermore, young children with CP in GMFCS levels I and II are able to complete more self-care activities than children in levels III–V (Ostensjo et al., 2003). Parents of children with CP are more likely to report that they need more help to care for their children than parents of children with cystic fibrosis or spina bifida (Leonard, Johnson, & Brust, 1993). Among parents of children with profound intellectual and multiple disabilities, parents of children 8 years of age and younger reported greater caregiving workload than parents children 9 years of age and older (Tadema & Vlaskamp, 2010).

The increased caregiving for children with disabilities may adversely affect physical and psychological well-being including time to engage in non-child rearing activities. The physical demands of caregiving have been reported to affect caregivers' physical health and well-being (Eker & Tüzün, 2004; Leonard et al., 1993; Raina et al., 2005) and are associated with poorer psychological well-being and poorer quality of life of the caregiver (Carona, Crespo, & Canavarro, 2013; Cramm & Nieboer, 2011; Kuhlthau, Hill, Yucel, & Perrin, 2005; Murphy, Christian, Caplin, & Young, 2007; Ray, 2003; Rimmerman & Stanger, 2001; Viner-Brown & Kim, 2005). Mothers of children with disabilities reported that they engaged in fewer occupational roles compared with mothers of children without disabilities (Crowe, Van Leit, Berghmans, & Mann, 1997). Caregivers of children with disabilities reported that they have limited time to complete daily tasks, care for other family members, or for respite activities (Murphy et al., 2007).

Improving ease of caregiving is a potentially important outcome of services for many children with CP. Understanding and measuring the construct "ease of caregiving" from the parent perspective may help service providers and researchers identify opportunities for and effectiveness of intervention to address parents' confidence, safety, physical demand, and time requirement of caring for their children. Addressing these caregiving demands is consistent with family-centered care (Dempsey & Keen, 2008) and service providers may serve a key role in fostering parents' capacity for caregiving. In this construct we intentionally refer to "ease of caregiving" rather than "burden of care." The term "burden of care" is sometimes used to describe caregiving for children with disabilities. However, the concept of "ease of caregiving" is more consistent with the International Classification of Functioning, Disability and Health (ICF), which focuses on health and functioning, rather than on disability (World Health Organization, 2002). Similarly, "ease of caregiving" is more aligned with principles of person-first language (Rothstein, 1997) and avoids the imposition of existing negative stereotypes found in published literature (Barbosa, Chaud, & Gomes, 2008; Brinchmann, 1999). Parents of children with disabilities have reported that such stereotypes negatively impact the services provided for them (Lindblad, Rasmussen, & Sandman, 2005).

### 1.1. *Measuring ease of caregiving*

There has been a call for development of valid and reliable measures that reflect parents' experiences of caregiving for children with disabilities (Meester-Delver, Beelen, Hennekam, Hadders-Algra, & Nollet, 2006; Park et al., 2003). Such measures should: (a) address the caregiving experience of parents of young children of all levels of physical ability, (b) be feasible for parents to complete, and (c) be useful for identifying needs, planning interventions, and monitoring change.

Researchers studying ease of caregiving have used self-designed tools (Leonard et al., 1993; Tadema & Vlaskamp, 2010; Tonga & Duger, 2008), regionally developed tools (Leonard et al., 1993; Roberts & Lawton, 2001), semi-structured focus group discussions (Roy, Rousseau, Allard, Feldman, & Majnemer, 2008), semi-structured interviews (Larson, 2010; Roy et al., 2008), and non-structured interviews (Barbosa et al., 2008; Brinchmann, 1999) to assess caregiving. Unless publicly available, use of self-designed, customized measures or semi-structured interviews limits the ability to replicate study designs and prohibits comparisons across studies or synthesis in systematic reviews.

Several measures exist for quantifying a child's self-care performance and the level, amount, and type of caregiver assistance needed to complete self-care tasks (Haley, Coster, Ludlow, Haltiwanger, and Andrellos, 1992; Granger, Hamilton, & Kayton, 1989; Fougeyrollas et al., 2004, 2007; Msall, 1996). One measure, the Care and Comfort Caregiver Questionnaire (CareQ), is specific to caregivers of children with CP and measures caregivers' perceived effort in caring for children in GMFCS levels III to V (Hwang, Kuroda, Tann, & Gaebler-Spira, 2011). Although these tools measure the child's performance or the amount of adult assistance required to complete self-care tasks, they do not assess parent perception of ease of caregiving for children with all levels of gross motor function. As we were unable to identify a measure applicable to parents of all children with CP, our research team developed the Ease of Caregiving for Children for use in our study of children with CP ages 18 to 60 months of age (Bartlett et al., 2010). The Ease of Caregiving for Children is a self-report measure of the level of difficulty a parent is experiencing in assisting a child to perform self-care activities safely and fulfill the child's physical needs in a confident and competent manner within reasonable time expectations. Parents are instructed to consider four aspects of caregiving in their responses to each test item: (1) safety, (2) physical demands, (3) time, and (4) confidence. The Ease of Caregiving for Children complements the Child Engagement in Daily Life measure, which assesses child participation in family and recreational activities and self-care (Chiarello et al., 2014).

The study had two primary objectives. The first objective was to determine internal validity, test–retest reliability, and construct validity (known groups method) of the Ease of Caregiving for Children when completed by parents of young children with CP. Known groups refers to the ability to discriminate ease of caregiving among parents of children of varying ages and motor abilities. We hypothesized that parents of older children would report greater ease of caregiving than parents of younger children and that parents of children with higher motor ability would report greater ease of caregiving than

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