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Sense of autonomy and daily and scholastic functioning among children with cerebral palsy

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ABSTRACT

Background: There is growing evidence that children's sense of autonomy is an important psychological need closely linked with the development of self-esteem and motivation. Among children with physical disabilities, motor or cognitive limitations may negatively affect child's sense of autonomy (CSA) and competency.

Purpose: To examine how sense of autonomy among children with cerebral palsy (CP) directly and indirectly relates to their activity of daily living (ADL) and scholastic performance.

Methods: Seventy-three children with CP and their mothers participated in this study. Child's ADL skills and scholastic performance were assessed using the Pediatric Evaluation Disability Inventory (PEDI) and the Scholastic Skills Rating Scale (SSRS), respectively. Level of impairment was assessed using the Gross Motor Function Measure-66 (GMFM-66). CSA was established via videotaped mother–child interactions. Regression analyses were conducted to examine factors predicting child's functional level (ADL and scholastic). The overall model was tested for goodness-of-fit and test of mediation.

Results: GMFM and CSA significantly predicted child's ADL and scholastic functioning. GMFM explained 15% of the variance for CSA, 84% for PEDI, and 24% for scholastic functioning. CSA positively mediated the association between GMFM and child's ADL skills. GMFM was positively associated with CSA.

Conclusion: Motor impairment has a substantial impact on child's level of functioning. However, child's functioning is a complex construct that is also affected by her or his sense of autonomy. Therefore, sense of autonomy can serve as a potential point of intervention to improve functioning among children with CP.

What this paper adds?

The association between impairment severity (Gross Motor Function Measure [GMFM]) and functioning as evaluated by the Pediatric Evaluation of Disability Inventory (PEDI) among children with cerebral palsy (CP) is well established. However, the contribution of psychological factors to child's level of functioning and activity of daily living (ADL) skills has not been thoroughly investigated. More specifically, the influence of child's sense of autonomy (CSA) on the relationship between ADL skills and scholastic functioning has not been tested. The current study uses path analysis to examine the direct and indirect effects of sense of autonomy of children with CP on their functional level (ADL and scholastic functioning). The study reveals that both impairment severity and CSA predicted functional level among children with CP. In addition, children with a high sense of autonomy had higher functional

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levels, in both ADL and scholastic functioning, than children with lower levels of sense of autonomy. Moreover, sense of autonomy enhanced the association between GMFM-66 and ADL skills, as well as the relationship between GMFM-66 and scholastic performance. Therefore, the current study provides support for the key roles of sense of autonomy as a potential point of intervention to improve ADL skills as well as scholastic performance among children with CP.

1. Introduction

Children's healthy psychological development is a high societal priority. Developmental researchers, working from a variety of theoretical frameworks, continue to explore factors hypothesized to influence child development and the subsequent outcomes associated with these factors. Sense of autonomy is one of the key components of a child's optimal development. According to developmental theories (Bowly, 1969; Erikson, 1993; Mahler et al., 1991) and self-determination theories (SDT; Deci & Ryan, 2000; Ryan & Deci, 2000), sense of autonomy relates to the feeling that one has volition and is the origin of one's own actions. According to SDT studies (Grolnick et al., 1997; Ryan & Deci, 2000), sense of autonomy also contributes to a child's well-being and decreased feelings of ill-being (Deci & Ryan, 2008).

Throughout the life span, sense of autonomy advances and declines as changing conditions require altered behavior. During these phases, individuals develop new competencies, and previously acquired skills may decline (Baltes & Silverberg, 1994). Sense of autonomy develops through a transaction between the individual and the interpersonal environment, involving social interactions and close relationships (Bao & Lam, 2008; Kobak & Cole, 1994). More specifically, family and home environments are important supporters of the development of a child's sense of autonomy (CSA). For instance, according to family system theories (Miller et al., 2004; Minuchin et al., 2007), flexible boundaries within the family enable adolescents to move in and out of the family system, whereas rigid boundaries hinder their struggle for autonomy (Preto, 1988). Cohesive families, in which parents allow children to develop with respect to each other's autonomy, contribute to the development of CSA. In enmeshed families, by contrast, where personal boundaries are diffused and subsystems are undifferentiated, over concern for others may lead to a loss of autonomous development (Feldman, 2007; Minuchin, 1974).

Long-term disorders (i.e., physical disabilities, chronic illness) may significantly and permanently interfere with a child's emotional growth and development (Hostler et al., 1989), including sense of autonomy. Among children with cerebral palsy (CP), mobility limitations are negatively associated with level of autonomy (Bjornson et al., 2008; Dickinson et al., 2007; Janssen et al., 2010; Sparkes & Hall, 2007; Viehweger et al., 2008). Because of their motor and associated difficulties, children and adolescents with CP often fall below the typical developmental trajectory. Subsequently, they are likely to experience difficulty performing ADL tasks, which may affect their sense of autonomy. It is important to differentiate, however, between sense of autonomy and the related concepts of dependence and independence. Sense of autonomy relates to "the perceived capacity to control, cope and take personal decisions on how a person lives his/her daily life, following his own norms and preferences" (World Health Organization, 2004); independence/dependence refers to the need for support from another person to conduct various activities (e.g., ADL; Salvador-Carulla & Gasca, 2010). Therefore, even individuals with severe physical disabilities can be autonomous if they perceive their own needs and take responsibility for meeting them (Crittenden, 1990).

Children with CP also experience attitudinal barriers, such as parental overprotection. Blum, Resnick, Nelson, and St Germaine (1991), for example, reported that a third of youth with CP felt infantilized and overprotected by their parents. Furthermore, their participants reported feelings of resentment toward parental behaviors and claimed that they receive excessive assistance. Similarly, parental overprotection was associated with reduced behavioral autonomy among children with spina bifida (Holmbeck et al., 2002).

Although the interest in sense of autonomy among children with a physical disability is increasing, few studies have investigated the specific effect of sense of autonomy on different aspects of functioning among children with CP. Therefore, the purpose of the current study was to examine how sense of autonomy of children with CP directly and indirectly relates to their ADL skills and scholastic functioning. Specifically, the authors hypothesized the following: (a) sense of autonomy will predict child's ADL and scholastic skills, and (b) sense of autonomy will mediate the relationship between level of impairment and child's ADL and scholastic skills.

2. Material and methods

2.1. Participants

Participants in the current study were drawn from a larger study (Barak et al., 2017; Elad et al., 2012, 2013) and were recruited from clinics and schools throughout the country. Before the study, the principal investigator met with orthopedic, neurological, and special education staff about recruiting children with CP (all types of distribution and severity) from their educational and medical establishments. Two hundred families were informed of the study via pamphlets distributed by physicians, teachers, social workers, and advisors working at the various clinics and schools. Seventy-six mothers who were interested in participating in the study contacted the principal investigator. Of the 76 families who joined the study, three families were not interested in completing the process. Thus, 73 children (6–12 years of age) with CP and their mothers participated (response rate of 37%). The distribution of the children in our sample according to the different Gross Motor Function Classification System levels (GMFCS) was representative of that of a larger cohort from nine CP registries worldwide (Reid et al., 2011).

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