ORIGINAL ARTICLE

The Impact of Adaptive Seating Devices on the Lives of Young Children With Cerebral Palsy and Their Families

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ABSTRACT. Ryan SE, Campbell KA, Rigby PJ, Fishbein-Germon B, Hubley D, Chan B. The impact of adaptive seating devices on the lives of young children with cerebral palsy and their families. Arch Phys Med Rehabil 2009;90:27-33.

Objective: To determine the parent-perceived effect of adaptive seating devices on the lives of young children with cerebral palsy (CP) (aged 2–7y) and their families.

Design: Baseline-intervention-baseline study.

Setting: Homes of participating families.

Participants: Thirty parents and their children with Gross Motor Function Classification System level III or IV CP.

Interventions: Two special-purpose seating devices: 1 for sitting support on the floor or on a chair and the other for postural control on a toilet.

Main Outcome Measures: Family Impact of Assistive Technology Scale (FIATS) and Impact on Family Scale (IFS).

Results: Thirty parents (29 mothers, 1 father) and their children with CP participated. Repeated-measures analysis of variance detected significant mean differences among the FIATS scores ($F_{1.4,40.6}=19.25$, $P<.001$). Post hoc testing confirmed significant mean differences in overall FIATS scores between baseline and intervention and intervention and postintervention phases. The test of within-subject effects did not detect a significant change among IFS mean scores.

Conclusions: The introduction of adaptive seating devices for young children who need support to sit had a meaningful, positive impact on child and family life. Removal of the study devices showed a concomitant negative impact on key aspects of child and family life. Environmental resources, such as seating and other assistive technology devices, may have an important role to play in the lives of young children with physical disabilities and their families.

Key Words: Cerebral palsy; Family; Rehabilitation; Treatment outcome.

ASSISTIVE TECHNOLOGY DEVICES are environmental resources that can play an important role in improving the lives of children with physical disabilities such as CP. An assistive technology device can be described as "any item, piece of equipment or product system . . . that is used to increase, maintain, or improve the functional abilities of a child with disabilities."[1] Children may benefit from using many different types and forms of assistive technology devices to communicate, ambulate, and participate in everyday activities at home, at school, and in the community.

The effects of assistive technology devices may extend beyond young technology users to their parents and other family members. For example, 2 regional surveys of parents of children with disabilities suggest positive associations between the use of devices and improved child function and reduced caregiver burden.[2,3] Although survey methodologies do not permit causal relationships to be established between assistive technology device use and child and family factors, one could argue that the positive influence of these technologies on children, their parents, and their families is self-evident, and the need to confirm the beneficial effects through more rigorous empirical research is unwarranted. However, evidence of pervasive assistive technology device discontinuance, dissatisfaction, and nonuse weakens this line of reasoning.[4-6]

In the context of scarce health care funding for assistive technology devices and associated services, it is important for assistive technology practitioners, administrators, third-party payers, and families to understand the effectiveness of existing and emerging assistive technologies. In this way, they may make informed decisions about how to make best use of their limited resources for assistive technology products and related services for children.

To explore the effect of assistive technology devices for children with functional impairments on child and caregiver function, Henderson et al[7] conducted a comprehensive literature review of intervention studies published in English between 1996 and 2006. The authors classified the rigor of the study designs and determined whether assistive technology outcomes focused on the children, their caregivers, and/or their families. Although the review team identified "overwhelmingly positive" child-focused outcomes among the 54 articles cited, most studies were of lower quality, used measures with unknown levels of reliability and validity, and/or did not report statistically significant results. Furthermore, only 1 in 5 articles focused on caregiver out-

List of Abbreviations

ANOVA	analysis of variance
CP	cerebral palsy
FIATS	Family Impact of Assistive Technology Scale
GMFCS	Gross Motor Function Classification System
ICC	intraclass correlation coefficient
IFS	Impact on Family Scale

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comes, and none explored the effect of children's assistive technology devices on their families.

Among the assistive technology devices considered in the review were interventions for seated postural control. The review team identified only 2 relevant articles[8,9] that related to adaptive seating products for postural control. The articles reported on one community-based intervention trial involving 6 school-aged children with CP who used a novel adaptive seating device for 5 weeks.[8,9] Parents and their children reported significant functional improvements in the performance of and satisfaction with targeted bimanual tasks, and parents claimed that their children required less assistance for many of these tasks during the intervention period.

Assistive technology practitioners routinely recommend adaptive seating devices for children with CP to support their trunk, pelvis, and lower extremities, thereby providing more control for volitional movement of their arms and hands.[10-12] A variety of seating devices is available to offer children the postural control needed to engage in common childhood activities at home such as playing on the floor, eating at the kitchen table with family members, and performing personal-care activities in the bathroom.[13]

Because limited empirical evidence exists regarding the effect of these devices, we proposed to explore the parent-perceived effect of special-purpose seating devices on the lives of 30 young children with CP and their families. We designed our study to answer the following research question: do adaptive seating devices used in the home improve family life as measured by the FIATS and IFS according to parents of children aged 2 to 7 years with GMFCS level III or IV CP?

METHODS

The present study involved 30 parents and was part of a larger project involving 50 parents and their children with CP. The larger study allowed us to confirm the acceptability of the internal consistency and test-retest reliability of the FIATS. We chose a repeated-measures, within-subjects design for the present study to increase the likelihood of detecting a change in child and family outcomes because of the introduction of adaptive seating devices.

We received ethical clearance for this study from the research ethics board at our institution.

Participants

We invited parents and their young children who were clients of our facility and 2 other regional children's treatment centers. Children who participated had a primary diagnosis of CP with function categorized as GMFCS level III or IV[14] and were between 2 years 6 months and 7 years 6 months of age. (Children with GMFCS level III or IV CP can sit upright independently or with support, but generally need pelvic or trunk support or an adaptive seating device to optimize hand function. Children with level III or IV function either need an assistive device to walk or have limited independent mobility in a manual wheeled mobility device.)

We conducted screening interviews to identify and recruit parents who were primary caregivers of the child with CP. We defined a primary caregiver as an adult who provided at least 10 hours of direct supervision per day as determined by self-report. Furthermore, we recruited only parents whose child did not use specialized postural control devices at home for floor sitting, chair sitting, and toileting activities. We mailed eligible and interested parents a letter to explain the project protocol and their roles as a research participant. Caregivers who agreed to participate in the 12-week long home trial provided signed consent.

We expected to have difficulty recruiting 30 families from our facility alone, so we involved 2 other children's centers to increase our participant pool. We adopted 2 different recruitment strategies: one for our facility and another for the other 2 centers. At our institution, we reviewed our electronic medical records and identified 155 children who met the initial inclusion criteria. We mailed a brief introductory letter about the study to the parents of these children and then telephoned families 1 to 2 weeks later. A randomized selection process provided each family an equal opportunity of being contacted. Of the 143 families we contacted, 85 families did not satisfy the screening requirements, 14 families declined because of scheduling conflicts, 9 families met the screening criteria but later decided not to participate after receiving the detailed study information letter, 5 children were deemed clinically inappropriate for the study devices as judged by the research occupational therapist during the first home visit, and 25 families participated in the full home trial.

To maintain the confidentiality of families at the other 2 centers, site clinicians reviewed their own medical records to identify children who met our age and diagnostic criteria and identified 46 potential families. Site administrative staff mailed these parents an introductory letter inviting them to contact our study coordinator if interested. Seventeen parents contacted our coordinator; 11 of these did not meet the initial screening criteria, 1 child was judged clinically inappropriate at the first home appointment, and 5 families participated in the trial.

Main Outcome Measures

We previously developed the multidimensional, parent-report FIATS to detect the impact of assistive technology device use on the lives of children with physical disabilities and their families. The FIATS measures this impact by the contribution of 8 related constructs (subscales) that include child autonomy, caregiver relief, child contentment, doing activities, parent effort, family and social interaction, caregiver supervision, and safety. These constructs tap into aspects of child and family life that assistive technology devices may influence, such as the degree to which a child can perform activities independently (autonomy), interacts with others (family and social interaction), and requires attention from family members (supervision).

Parents use the FIATS to indicate the degree to which they agree or disagree with items on a 7-point Likert scale. The FIATS also contains items that contribute to a ninth independent subscale (technology acceptance) to measure parents' general receptiveness to assistive technology devices for their children. We modeled this subscale as a separate moderating construct that may temper the impact of technology on family life. Overall, the 9 subscales contribute 64 items to the FIATS.

Scoring on the FIATS is calculated by the sum of the means of the 8 related subscales. Because the range of each mean subscale scores is from 1 to 7, the overall range of FIATS scores is from 8 to 56. Lower FIATS scores are associated with lower child and family functioning on these dimensions. Because we designed the measure to detect changes in important aspects of family life that could be influenced by the introduction of seating devices, higher change scores suggest an overall positive impact on child and family life as defined by these constructs, whereas lower change scores suggest a negative effect on child and family life.

The FIATS has good content validity and face validity[15] and acceptable internal consistency (α=.94) and test-retest reliability intraclass correlations (ICCs=.92; 95% confidence interval, .86–.95) for a 2- to 3-week retest period when used with families of young children with CP. Furthermore, the FIATS 9