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Abstract

Occupational therapy home programs are a common approach used to provide interventions for children with cerebral palsy, but there is little evidence to demonstrate the effectiveness of such programs. This singlegroup pretest–posttest design pilot study evaluated the impact of an occupational therapy home program implemented with 20 children who had spastic hemiplegic cerebral palsy (ages 2–7 years, mean 3.8). We measured impact using Goal Attainment Scaling (GAS), the Pediatric Evaluation of Disability Inventory (PEDI), and the Quality of Upper Extremity Skills Test (QUEST). We measured participation amount through a parent self-report log. Significant changes following intervention occurred in scores on the GAS, the PEDI Functional Skills and Caregiver Assistance Scales, and the QUEST, but has found no relationship between participation amount and outcome using the same measures. These promising results suggest that further investigation of the impact of occupational therapy home programs is warranted.

Keywords

palsy, cerebral, pilot, programming, study, home, children, therapy, young, occupational, impact

Disciplines

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BRIEF REPORT

A Pilot Study on the Impact of Occupational Therapy Home Programming for Young Children With Cerebral Palsy

Iona Novak, Anne Cusick, Kevin Lowe

KEY WORDS

- cerebral palsy
- home program
- parents
- pediatrics

Occupational therapy home programs are a common approach used to provide interventions for children with cerebral palsy, but there is little evidence to demonstrate the effectiveness of such programs. This single-group pretest–posttest design pilot study evaluated the impact of an occupational therapy home program implemented with 20 children who had spastic hemiplegic cerebral palsy (ages 2–7 years, mean 3.8). We measured impact using Goal Attainment Scaling (GAS), the Pediatric Evaluation of Disability Inventory (PEDI), and the Quality of Upper Extremity Skills Test (QUEST). We measured participation amount through a parent self-report log. Significant changes following intervention occurred in scores on the GAS, the PEDI Functional Skills and Caregiver Assistance Scales, and the QUEST, but has found no relationship between participation amount and outcome using the same measures. These promising results suggest that further investigation of the impact of occupational therapy home programs is warranted.

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One common approach to providing occupational therapy intervention to children with cerebral palsy is a home program. Within the gold standard of family-centered approaches for children with disabilities, this approach views families, rather than health professionals, as being the best placed to make decisions, prioritize interventions, and plan their child's health care (Bazyk, 1989). Parents are considered team members who provide specialized help to their child (Thompson, 1998). Home programs recognize the expert caregiving of parents and aim to enhance the caregiving competency of parents to improve their child's health and development (Washington & Schwartz, 1996). Currently, however, evidence addressing the effectiveness of occupational therapy home programs is inconclusive.

The term *home program* refers to therapeutic activities that the child performs with parental assistance in the home environment with the goal of achieving desired health outcomes (Bazyk, 1989; Gajdosik, 1991; Hinojosa & Anderson, 1991; Law &

King, 1993). In the past, home programs were thought of as follow-up exercises supervised by parents "between treatment sessions" to support expert care provided by health professionals (Gajdosik, 1991). In the 1980s, the "parent training" trend expanded the parental role to include that of "therapist at home" (Bazyk, 1989).

Currently, the daily caregiving parents perform is viewed as an opportunity for therapy (Thompson, 1998): "The treatment of a child with cerebral palsy is a 24 hour a day process. . . . Home programs are an essential part of the treatment process" (Howison, 1988, pp. 683–684). Home programs are used extensively in occupational therapy practice with children (Hinojosa & Anderson, 1991; Hinojosa, Sproat, Mankhetwit, & Anderson, 2002). Therapists report that working with parents optimizes the impact of intervention on children (Hinojosa et al., 2002), and mothers of children with cerebral palsy consider home therapy to be an important aspect of home programs (Hinojosa, 1990).

Home programs are frequently substituted for hands-on therapy because of funding shortages (Law & King, 1993). Professionals consider home programs an important tool for transforming newly learned skills into functional change within daily routines (Howison, 1988), but no empirical home program research supports this belief. Instead, the focus of home program research has been on parental compliance with prescribed home programs (Gajdosik, 1991; Law & King, 1993) and qualitative analysis of mothers' experiences of home programs (Hinojosa, 1990; Hinojosa & Anderson, 1991; Thompson, 1998; Tyler & Kahn, 1976). In the absence of conclusive evidence, therapists select treatment on the basis of tradition, and both therapists and parents adopt the view that more is better (Hinojosa, 1990). There is thus a need for evidence regarding the efficacy of occupational therapy home programs to determine whether home programs help children with cerebral palsy reach desired outcomes. We sought to explore the impact of an occupational therapy home program on young children with spastic hemiplegic cerebral palsy.

Method

We obtained approval to conduct the study from the human ethics research committees of The Spastic Centre, Sydney, New South Wales; South Eastern Area Health Service, Sydney New South Wales; and the University of Western Sydney, Sydney, New South Wales. All families gave full informed consent to participate.

This pilot study used a single-group pretest–posttest design to evaluate intervention effect. We chose this design for pragmatic reasons. It has inherent limitations as to the strength and generalizability of findings, including lack of a control group and small sample size. However, a pilot study provides a way to explore sample recruitment, intervention design, and measurement issues and can indicate whether further investigation is warranted.

Sample

Participant inclusion and exclusion criteria are presented in Table 1. Recruitment

Table 1. Screening Criteria for the Pilot Study

Inclusion Criteria	Exclusion Criteria
Diagnosis of hemiplegic cerebral palsy	Diagnosis other than hemiplegic cerebral palsy
Age between 2 and 8 years	Mild motor signs evident on unaffected upper limb during fine-motor tasks
Associated upper limb spasticity of at least Grade 2 measured by the Ashworth (1964) scale	Scheduled for a medical procedure to treat upper-limb function during study duration (e.g., surgery, botulinum toxin A)
Active use of the affected upper limb observed by the investigator during a functional task	Participation in an alternative therapy intervention focused on developing upper-limb use (e.g., conductive education)
Response to light touch and pain sensation with vision occluded	Parental refusal to carry out any form of home program intervention

strategies targeted self-identified parents of a child with spastic hemiplegic cerebral palsy in the most populous state of Australia, New South Wales, and included recruitment advertisements in 79 specialist cerebral palsy provider locations and 400 pediatrician's offices, recruitment advertisements in a cerebral palsy newsletter with a circulation of 4,000, information seminars for cerebral palsy service providers (140 participants), and a recruitment advertisement at a hemiplegic cerebral palsy parent support group (12 members). These recruitment sources led to 89 telephone inquiries from potential participants, to whom we mailed participant information and consent forms. Fifty-seven potential participants met the inclusion criteria and were offered a screening assessment to be performed by the occupational therapy chief investigator (the first author) and a physician (the third author). The first 20 children who met the inclusion criteria and whose families volunteered to participate in the screening assessment were included in the sample; we chose a sample size of 20 on pragmatic grounds relating to study resources.

Procedure

We collected demographic data, clinical profiles, clinical indicators, and baseline data at the initial session before intervention commencement. An independent instrument-trained occupational therapist scored videotaped data, which we supplied in random order. The rater, who received 8 hr of QUEST scoring training, achieved acceptable ($r = .98$) correlation with the trainer's score. Parents provided the information and observations to complete the PEDI.

Instruments

We collected demographic and clinical profile data using an investigator-designed questionnaire that included age, diagnosis, social context, history of occupational therapy participation, and major life occupations. We collected the following clinical indicators at baseline: range of motion (measured using a goniometer), muscle strength (measured using Medical Research Council Scale; Mendell & Florence, 1990), and resistance to movement (measured using the Ashworth Scale; Ashworth, 1964). We used three outcome measures:

1. Goal Attainment Scaling (GAS; Kiresuk & Sherman, 1968) is an individualized evaluative tool designed to measure clinical change using goals.
2. The Pediatric Evaluation of Disability Inventory (PEDI; Haley, Coster, Ludlow, Hattiwanger, & Andrellos, 1992) is a discriminative and evaluative tool designed to measure functional independence in children with disabilities. This instrument has strong psychometric properties for children with physical disabilities, including cerebral palsy. The CareGiver Assistance Scale is inversely constructed so that an increasing score indicates reduced caregiver assistance.
3. The Quality of Upper Extremity Skills Test (QUEST; DeMatteo et al., 1992) is a criterion-referenced outcome measure that evaluates quality of upper-extremity function. We administered only the dissociated movement and grasp domains and videotaped the results for scoring by the blinded rater. According to the test developers, use of selected subscales is psychometrically

acceptable (DeMatteo et al., 1993), and validity and reliability of the instrument for children with spasticity are good (Hickey & Ziviani, 1998) and applicable to this population.

In addition to these outcome measures, we developed a home program log to measure home program participation. Parents were instructed to estimate the total amount of time per day (in minutes) that they spent on home program activities (also referred to by parents and therapist as "giving therapeutic help") and to record their perceived total time per day on the log. Parents were told that they could carry out activities within their usual daily routine. Law and King (1993) recommended this type of calendar for recording participation because it is more accurate than clinician estimates and interviews.

Intervention

The children and parents were seen three times by the occupational therapist chief investigator for intervention. The first visit, lasting about 1.5 hr, was devoted to devising the home program, providing instruction and training as appropriate, and constructing splints or casts when indicated. The other two visits, at 1 and 3 months, were home program support follow-up sessions lasting 45 min each. A final follow-up and measurement session occurred at 6 months and lasted about 45 min.

The occupational therapist sought to establish a collaborative relationship with the parents, identify mutually agreed-on goals for the home program, and discuss possible therapeutic activities and interventions, such as splinting or casting, using a resource file of suggested activities as a stimulus for conversation. In consultation with the occupational therapist, parents selected the activities they wanted in the home program, and the occupational therapist prepared a home program document for use at home. The program was then implemented, and outcomes were evaluated.

A typical home program document included a list of therapeutic activities and agreed-on splint or cast wearing times, often with accompanying illustrations or photographs to help parents remember the information and training they received in

the home program development session. The 30-min initial training session, part of the first visit, included discussion of the child's strengths, demonstration of areas for development, explanation and illustration using the therapist's limb of what improvement would look like, a demonstration by the therapist of the program's activities, and a discussion to provide clarification. At follow-up sessions, parents asked questions, demonstrated program activities, and received feedback; the therapist also modeled how to grade the activities to track the child's improvements and stimulate more progress.

Results

We used descriptive statistics, Pearson product-moment correlations; paired *t* tests; and, where data did not meet parametric assumptions, the Wilcoxon rank sum test. Significance was set at $p < .05$.

Demographic Data

All child participants lived at home with one or more birth parents (16 lived with both parents and 4 with a single parent). Participant ages ranged from 2 to 7 years (mean 3.8 years); 16 were boys and 4 were girls, and 11 had right-sided hemiplegia and 9 left-sided hemiplegia. Twelve of the children had conditions associated with their primary diagnosis of cerebral palsy (60%), most often epilepsy and asthma. All children ambulated independently, used verbal speech as their primary form of communication, sat without assistance, and transferred independently to a chair and table to participate in the assessments.

In the 6 months immediately before the study began, 10 had seen an occupational therapist for one-on-one intervention. Sixteen child-parent participant pairs had used a home program in the 6 months before the study; mean parent-estimated weekly participation time was 2.3 hr. Ten children had worn an upper-limb splint (resting, functional wrist cock ups, and thumb loop splints); mean parent-estimated weekly splint-wearing time was 21.3 hr. The daily life occupations and activities of the child participants varied by age; 6 were enrolled in a mainstream school, and 14 attended a day care or a preschool facility.

Families reported that they provided these educational facilities with a copy of the study home program for informational purposes only; the activities were written for a home context, and they included no special interventions for educational settings. The philosophical stance of the program was that the purpose of educational settings was academic development, not provision of therapy. These educational settings did not provide segregated one-on-one therapy time, so no therapeutic activity arising from the home program was anticipated for use in the educational setting, and no log times were recorded for these settings.

Goal Attainment Scaling

A total of 47 goals were developed for the 20 individualized scales. Goals were grouped into descriptive categories according to the intervention focus areas found in literature: Independence in self-care activities and use of the affected arm were the most common goal types. At 6 months, we calculated participants' mean level of attainment for each goal. A raw score of 0 reflected a goal attainment outcome as expected; -2 indicated the most unfavorable outcome and +2 the most favorable outcome. We used Kiresuk and Sherman's (1968) original method of weighting goal areas by ranking them and applying this priority in *t* score calculation. The mean total GAS weighted *t* score at baseline was 29.86 (range 22.0-48.0, *SD* = 8.21) and at follow-up was 50.12 (range 30.0-96.9, *SD* = 12.87), a mean change of 20.26 points. Because of the distribution skew, we analyzed this difference using the Wilcoxon rank sum test, which showed that the change in mean scores was significant ($p < .000$; Figure 1).

Pediatric Evaluation of Disability Index

The PEDI self-care functional skills mean score at baseline was 44.15 (range 18-69, *SD* = 14.15) of a possible total score of 73 and following the intervention was 52.1 (range 26-71, *SD* = 11.69), a significant mean change of 7.95 points ($p < .002$; Figure 2). On the caregiver assistance dimension, the mean baseline score was 22.30 (range 4-40, *SD* = 12.16) of a possible total score of 40, and at follow-up it was 27.40 (range 13-38, *SD* = 9.08), a mean change

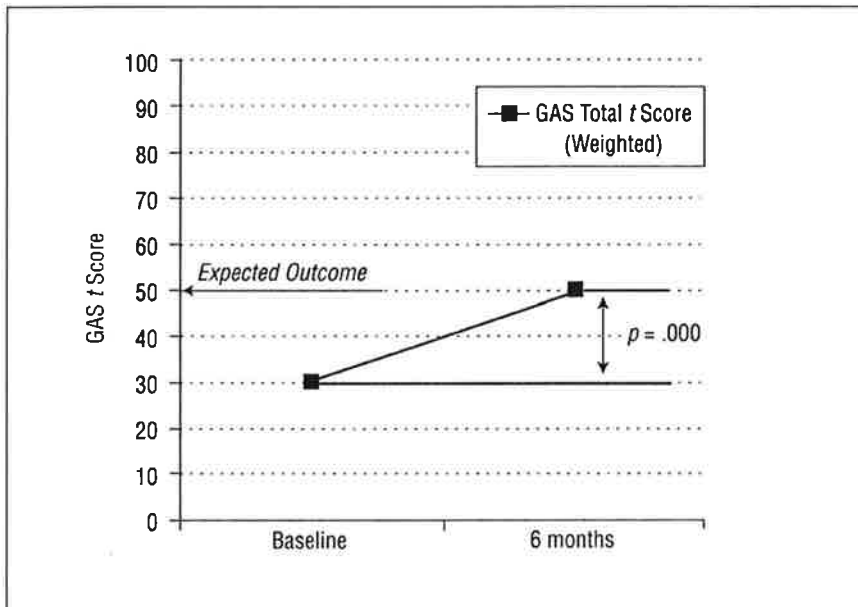


Figure 1. Change in Goal Attainment Scale (GAS) total weighted score means.

of 5.1 points. Analysis of the difference using paired *t* tests indicated that it was significant ($p < .003$; Figure 3).

Quality of Upper-Extremity Skills Test

The mean baseline QUEST total score was 33.83 (range 16.25–53.44, $SD = 12.20$) of a maximum potential score of 100, and this score increased 5.98 points over 6 months to a mean of 39.81 (range 16.25–64.59, $SD = 13.29$). Analysis of this difference using paired *t* tests indicated statistically sig-

nificant change ($p < .004$; Figure 4).

Home Program Participation

Table 2 presents the results of the participation analyses. The mean frequency of home program participation was 0.90 times per day (range 0.63–1.00, $SD = 0.11$)—that is, less than once a day, but approximately 27 times per month. No outcome was significant. The mean intensity of home program daily session participation was 14.22 min (range 5.00–43.33, $SD = 8.53$, skew 2.19).

One family had high participation: The intensity of 43.33 minutes per session was more than three standard deviations above the sample mean. With this outlier removed, the mean intensity of home program daily session participation was 13.39 minutes (range 5.00–24.0, $SD = 5.06$, skew 0.22).

We found one significant relationship: between the intensity of home program participation and upper-limb quality of movement as measured by the QUEST ($r = -.54$, $p = .02$). Duration (minutes per day) was another variable we developed to capture participation. It was calculated by multiplying frequency (number of occasions per day) by intensity (time in minutes). The mean duration of home program participation over the 6 months of the study was 13.82 min per day (range 5.00–40.24, $SD = 7.99$, skew 2.19). With the outlier removed, the mean duration of home program participation over the 6 months of the study was normally distributed at 12.27 minutes per day (range 5.00–20.31, $SD = 4.66$, skew 0.12). The outlier was removed before the Pearson product-moment analyses to enable a normal distribution (mean 11.51, $SD = 4.95$, skew = 0.21). There was little, if any, correlation between home program participation duration and final GAS scores ($r = .00$), PEDI functional skills scores ($r = -.10$), or PEDI caregiver assistance scores ($r = .01$), but there was a low correlation with QUEST total score ($r = -.38$).

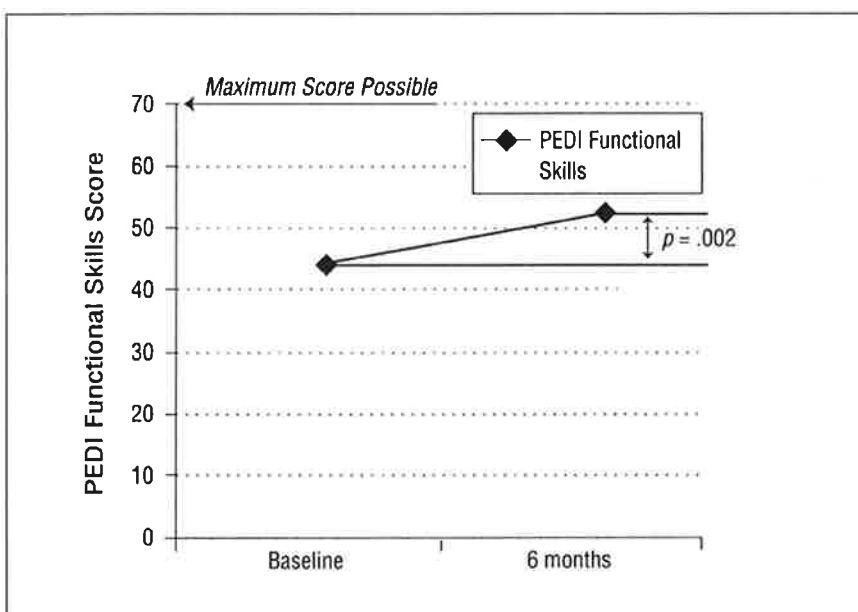


Figure 2. Change in Pediatric Evaluation of Disability Inventory (PEDI) functional skills score means.

Discussion

Occupational therapy home programs are considered important for children with cerebral palsy, yet little is known about the effectiveness of this intervention approach. This pilot study found promising differences between participants' baseline and postintervention scores on all three outcome measures, suggesting that the home program may have been effective. The design limitations of the study, however, mean that conclusions regarding program impact are tentative. The changes over time may have resulted from the home program, but it also is possible that the children's maturation over the 6-month study period or other factors, such as preschool or family

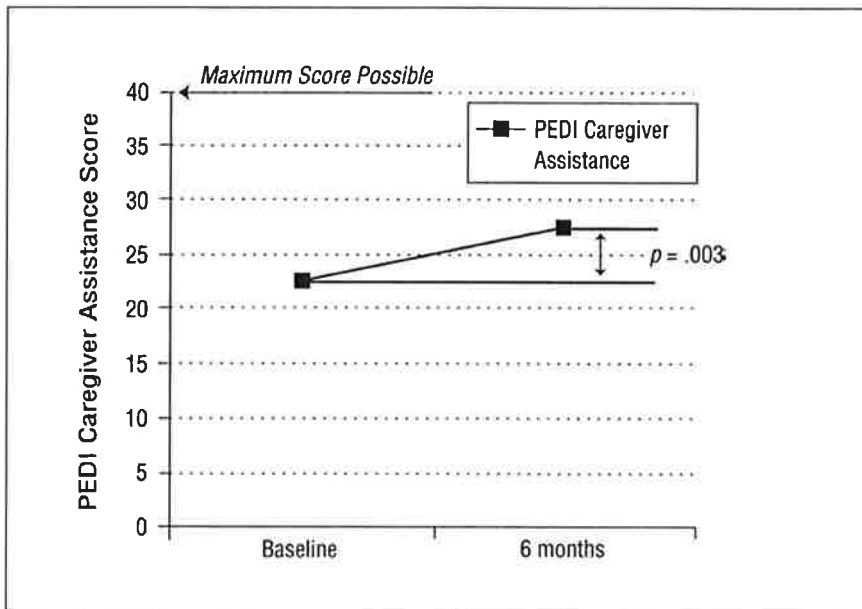


Figure 3. Change in Pediatric Evaluation of Disability Inventory (PEDI) caregiver assistance score means.

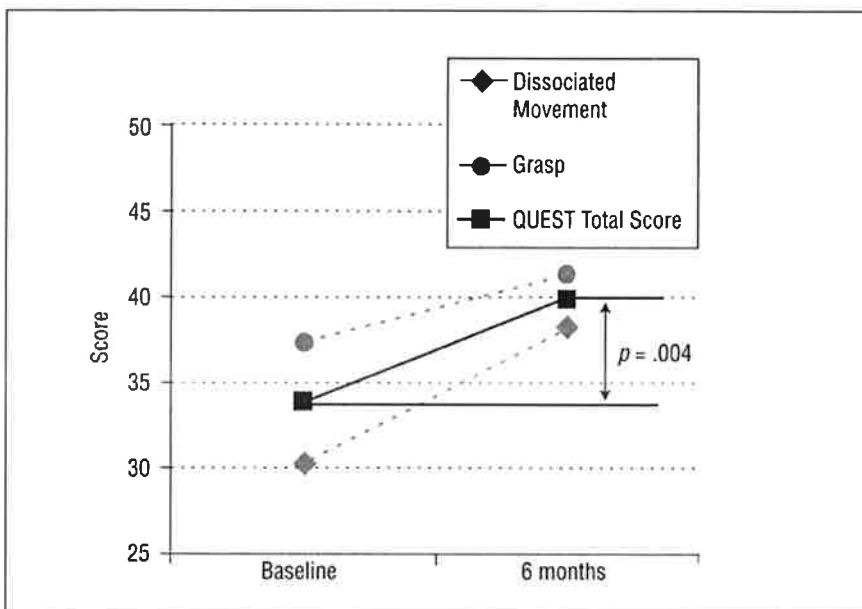


Figure 4. Change in Quality of Upper Extremity Skills Test (QUEST) total score means.

Table 2. Participation Outcomes

Outcome Measure	Home Program Intensity (r^a)	Home Program Frequency (r^b)	Home Program Duration (r^b)
Goal Attainment Scaling (t score)	+0.14	-0.06	+0.00
Pediatric Evaluation of Disability Inventory functional skills	-0.30	-0.03	-0.10
Pediatric Evaluation of Disability Inventory caregiver assistance	-0.22	-0.22	+0.01
Quality of Upper Extremity Skills Test total score	-0.54 ^b	+0.07	-0.38

^aThe outlier score was removed.

^b $p = 0.2$.

activity, may have led to the change. A control group would have helped clarify some of these issues, but given pragmatic study constraints, that was not possible. Our conclusions also are tentative, because the sample size may have been too small to detect the true effect.

As a pilot study, however, several study findings are worthy of comment. First, the multiple recruitment strategies were effective in generating a viable study sample meeting specific inclusion and exclusion criteria. Second, the protocol including data collection and a therapy session was workable, enabling full study participation and no dropouts. Third, the instruments were sensitive to changes in this population and were amenable to blind rating through random allocation of videotapes to the independent rater. The QUEST, in particular, appeared sensitive to changes resulting from home program participation. Fourth, we found that the intensity of participation was related to quality of upper-limb movement (QUEST) outcome, and duration may have had a low correlation with QUEST outcome. Because of the study's limitations, however, these relationships should be considered with caution. Finally, the results indicate that home programs may have a promising and statistically significant impact on outcomes in this population. Further investigation is warranted through larger, more tightly controlled studies to determine the real role that home programs play in change and the extent to which statistical change on selected measures is clinically significant. ▲

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