
Mothers' Perceptions of Home Treatment Programs for Their Preschool Children With Cerebral Palsy

Jim Hinojosa, Jill Anderson

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Data from 8 mothers of preschool children with cerebral palsy were collected through intensive interviews concerning their experience with home programs. The data were analyzed with qualitative techniques. Each mother had previously participated in or attempted to use a home treatment program with her child, but none was currently doing so. The mothers' descriptions suggest that they selected activities that were doable and that they could integrate into their daily routines and interactions. Some important characteristics of these activities were that they were enjoyable for the child and not stressful for the child, the mother, or the family.

Jim Hinojosa, PhD, OTR, FAOTA, is Associate Professor of Occupational Therapy and Director of Advanced Graduate Programs, New York University, 35 West Fourth Street, 11th Floor, New York, New York 10003-2098.

Jill Anderson, MS, OTR, is Occupational Therapy Supervisor, Step by Step Infant Development Center, New York, New York.

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Occupational and physical therapists use home treatment programs extensively in the habilitation of children with cerebral palsy (Finnie, 1975; Moersch, 1985; Parette & Hourcade, 1985; Wilson, 1984). The focus of these home treatment programs may go beyond the daily management of the child to prescriptive routines to parents on the care, handling, and treatment of their child. Although studies have supported the conclusion that home treatment by parents is developmentally beneficial for children with disabilities (Brooks-Gunn & Hearn, 1982; Brooks-Gunn & Lewis, 1984; Marfo & Kysela, 1985; Mayo, 1981; Wendt, Ekenberg, Dagis, & Jantert, 1984), the impact of home treatment programs on family members has not been examined. One intent of the present study was to explore mothers' experiences with and reactions to home treatment programs.

Home treatment programs developed by occupational and physical therapists aim to actively involve parents in their child's treatment and to increase therapeutic input. Home treatment programs vary according to the specific child's disabilities, the professionals involved, and the extent of parental involvement (Finnie, 1975; Moersch, 1985; Parette & Hourcade, 1985; Wilson, 1984). In the present study, we examined the families of children with cerebral palsy. We assumed that a study of one diagnostic group would reveal consistent issues being confronted by their families.

This article is based on the findings of a qualitative case study that explored how mothers perceive what happens in their family when a preschool child diagnosed with cerebral palsy is receiving occupational therapy, physical therapy, or both (Hinojosa, 1990). Analysis of qualitatively collected data led to the formulation of concepts, postulates, and hypotheses for the purpose of preliminary theory development. The previously published article by Hinojosa (1990) described the general finding of the entire study. The present article presents one theme, that of defining a home program, in depth.

Literature Review

Opinions differ regarding the recommended nature and extent of parental involvement in home treatment programs for the child with cerebral palsy. Some therapists, in their attempts to provide the best treatment possible for the child, may recommend extensive home treatment (Banus, 1979; Gross, Eudy, & Drabman, 1982; Moersch, 1985; Nelson, 1985; Tyler & Kahn, 1976; Wendt et al., 1984). Other therapists recommend activities that are both helpful in daily routines and easily integrated into a normal mothering role but do not specifically recommend that parents actively treat their child at home (Anderson & Hinojosa, 1984; Tyler, Kogan, & Turner, 1974; Wilson, 1984).

Some authors have expressed concern about the limited research related to parental participation in inter-

vention programs (Marfo & Kysela, 1985; Parette & Hourcade, 1985). Parette and Hourcade argued that little research supports professionals' intuitive acceptance that parental involvement is critically important to the successful implementation of a therapeutic program for young children.

Parette and Hourcade (1985) reported a significant positive relationship between parents' involvement in their child's treatment and their child's developmental gains. In the 6-month study, both an experimental group ($n = 10$) and a control group ($n = 15$) received therapy, but the parents of children in the experimental group also received instruction on treatment techniques under the direct supervision of a therapist. One question raised by the study findings was whether parental participation in early intervention programs in addition to the demands of routine care so increased the stress in the family unit that normal family interaction patterns were disrupted. Because the focus of Parette and Hourcade's study was on the outcomes of treatment related to the child's motor deficits, implications of parental involvement with the child's therapy cannot be generalized from their conclusions.

Mayo (1981) concluded that mothers of more severely disabled infants found that their involvement in home treatment made their lives more manageable. Characteristics such as the child's age, the nature of the disability, and the severity of impairment may affect a mother's perception of the helpfulness of the home intervention. Parental involvement in a home treatment program may increase the parents' knowledge of their child's condition and may facilitate parent-child interactions (Breiner & Beck, 1984; Connor, Williamson, & Siepp, 1978; Parette & Hourcade, 1985; Provence, 1985; Ross, 1984). Further, parental involvement may relieve stress and improve the family's health (Burden, 1980; Wendt et al., 1984). These studies imply that parental involvement in treatment may be perceived as an important adjunct to therapy. In addition, many parents want to become involved in their child's therapeutic program (Lipton & Savarstad, 1974).

In Kibele's (1989) qualitative study of 5 adults with cerebral palsy, 4 recalled that home therapy follow-up programs negatively affected their relationships with their mothers. Further, the subjects reported that home exercise programs and homework occupied most of their leisure time.

Despite the conflicting findings concerning the effects of parental involvement in home treatment programs, the trend is toward increased parental involvement (Hanft, 1988; Parette & Hourcade, 1985). Examination of the consequences of home treatment programs on the child and on family life is of current importance, considering the essential role given the family in intervention by the Education of the Handicapped Act Amendments of 1986 (Public Law 99-457).

With one focus of this legislation on family-centered intervention, it is appropriate that occupational therapists examine their effect on families and their daily lives.

Method

The participants in this study were 8 mothers from New York City, each with a preschool child with cerebral palsy (1 mother had two preschool children with cerebral palsy) and at least one other child (see Table 1). In each case, the child with cerebral palsy had been receiving occupational therapy, physical therapy, or both once a week for at least 1 year. The first author, using intensive interviewing techniques (Hinojosa, 1990), interviewed each mother twice.

Recorded dialogues were transcribed verbatim by the researcher (the first author) with significant nonverbal behaviors noted. These interviews were then converted to be processed through *The Ethnograph* (Seidel, Kjolseth, & Seymour, 1985), a computer program. This program, designed for managing text data, reduces the time-consuming aspects involved in the analysis of qualitative information, such as numbering lines, cutting and pasting, and sorting. An ongoing field log was kept; this contained notes on observations, communication with participant mothers, personal thoughts related to the researcher's experiences, methodological concerns, and personal reflections.

The data analysis required the first author to code the data, organize it into emerging categories, and refine themes (Bogdan & Biklen, 1982; Glaser, 1978; Glaser & Strauss, 1967; Leininger, 1985; Miles & Huberman, 1984). An analysis of the transcribed interviews and personal observations led to the identification of the following themes: "What Home Programs?" "If I Only Had 25 Hour Day," "We Together," "What Does Daddy Do?" "The Long Shadow," "Therapy, Therapy, Therapy," "The Third Parent," and "The Roller Coaster" (Hinojosa, 1990). In the present study, the data presented and discussed are those that are relevant to the mothers' experiences with occupational and physical therapy programs related to the theme "What Home Programs?"

Mothers' Themes

"But I have to be honest. I didn't work with her all the time." At the time of this study, home treatment programs as specified and designed by the therapists were not being implemented by any of the mothers, although the therapists expected all of the mothers to participate. Three mothers specifically stated that their children's current therapists strongly suggested a home treatment program as an important aspect of their overall treatment program.

When asked about their involvement in their child's therapy at home, each of the mothers tended to describe the characteristics of the individual therapists and the

Table 1
The Eight Study Participants and Their Families

Mother	Family Configuration Summary	Ethnicity	Location and Economic Class	Child's ^a Attributes
Carol	Husband Daughter, adolescent Son, school-aged Daughter ^a	Black	Bronx; Economically depressed	4 years old; spastic diplegic; verbal; uses wheelchair
Donna	Husband Son, school-aged Son ^a	Caucasian	Bronx; Middle-class	3 years old; spastic quadriplegic; does not talk
Fran	Husband, Son, 9 years old Daughter, 10 years old Son, 11 years old Son ^a	Black	Manhattan; Public housing	3 years old; right leg impaired; normal IQ
Gail	Husband Sex unknown, married Daughter, married Daughter, college-aged Son, school-aged Son ^a	Black, Jamaican	Brooklyn; Renovated area in Flatbush section	3 years old; spastic quadriplegic; blind; totally dependent
Helen	Husband (Photographer) Son, 5 years old Daughter ^a Daughter ^a Daughter, infant	Caucasian, English	Manhattan Middle-class apartment building	4 years old; spastic quadriplegic; both dependent
Irene	Husband (Administrator) Son, 3 years old Son ^a	Black	Manhattan; Public housing	2 years old; spastic hemiplegic; behavior difficulties
Jane	Husband (Art dealer) Daughter ^a Son, 8 months old	Caucasian, English, French	Manhattan; Luxury loft	5 years old; spastic diplegic; crawls; verbal
Kay	Husband (Musician) Son ^a Daughter, 8 months old	Caucasian	Queens; Middle-class	3 years old; spastic quadriplegic; mentally retarded

Note. Children are listed from oldest to youngest.

^aPreschool child with cerebral palsy.

child's treatment. Thus, their initial reactions seemed to be to avoid discussing their lack of involvement in home treatment programs.

The 8 mothers interviewed had various reactions to the home treatment programs recommended by the therapists. Only 2 of the mothers had actively participated in a home treatment program but had stopped because of responsibilities related to their other children:

I did them at the beginning. . . . You know with the other child it gets to be a little much. (Donna)

There was a time with Kane . . . before I got pregnant with [Kane's sister] when I was spending, doing therapy with him, about 6, maybe 8 hours a day. . . . And I had this schedule. . . . I kind of invented this on my own. . . . And you know it was OK for me too at that time. . . . I didn't have another child then . . . it did give time with Kane, you know, a lot of structure. (Kay)

Other mothers did not participate in home treatment programs for several reasons. Some found it too time consuming:

It's time consuming and, you know, especially when you have a family. (Donna)

She would give me an incredible amount of work to do with the children . . . There was no physical human way I could do it . . . with the children. (Helen)

Some mothers found participation to be too difficult and frustrating:

I would do it but then, as a mother, I would get frustrated. . . . I was feeling like, "Wow, what is wrong with me?" It was like I was just tired, and it's like they said, "Don't try to take an hour and do it. Do it, like, when you are changing his Pampers, or when you are doing this." But, with me, like, when I finish his Pampers, I have to move on to something else. 'Cause I have the other child here, I can't, you know, do that. (Irene)

Some mothers demonstrated a psychological block:

But I have to be honest. I didn't work with her all the time. I found it hard. . . . And I still do. I don't work a lot with her. There is some mental . . . there is a real mental block about it. (Jane)

As each mother described her involvement with her child's therapy, it became clear that each had developed her own program, in contrast to the program prescribed, by extrapolating from and often altering the suggestions made by the child's therapist. One mother with a severely

disabled child, for example, developed her program from “all the things” that she had been shown. Other mothers had adapted selected therapeutic techniques. One mother’s advice to other mothers was that

It is very important to try to do at least 50% of the things that the therapist asks you to do at home. That is very, very important—very important. I don’t care if you do it in play. They were telling me, you know, to stretch Carrie’s legs, stretch Carrie’s legs. I know that Carrie likes to hang upside down. I walk up and down the hall with her upside down, and she loves it. And that is therapy. (Carol)

Each of the other mothers also shared how she had integrated therapeutic suggestions into her own daily activities and routines with her child:

I try to use the therapy, you know, that I have been taught by them while he is playing so it will make it less painful for him. (Donna)

Sometimes I give him exercise myself. Like after bathing him, I stretch his legs, his arms. His fingers were like this [curled into a fist] and I stretch them every day and all of them [are] straight now. I worked on that. (Gail)

When I would remember and when I would see him doing something, I would work on it like that. (Irene)

Sometimes I have to try and make a game out of it with him about it. He doesn’t really know what I am doing. (Irene)

We are still doing now. . . . Actually, it is sort of automatic. It becomes built in. Hmm, speech therapy. There was a way we were supposed to feed her, the way to use the spoon. (Jane)

It appeared from these descriptions that the mothers selected activities that they viewed as enjoyable for the child and that they were physically, cognitively, and emotionally able to do (e.g., those activities that could be integrated into the mother’s routines and interactions). Three important characteristics of the activities that the mothers selected were that (a) they were pleasing for the mother to do, (b) they were not stressful for the child, and (c) they were not stressful for the mother or the rest of the family.

It became clear during the interviews that the mothers did not consider their adaptations to be a home treatment program because they did not replicate the exact methods recommended by the therapists. Each mother, however, had integrated some aspect of her understanding of her child’s treatment program into her own daily routines or interactions with her child. Play provided an opportunity for 2 mothers to do some therapy. For 3 other mothers, daily care activities such as feeding, bathing, and dressing provided opportunities for therapy:

How to hold her. How to position her. How to get her a bath. . . . There was a way to carry her so that her legs would not bend this way. And ways of easing her spasticity. . . . It is sort of automatic. It becomes built-in. (Jane)

Self-selected adapted activities became part of the home treatment programs for all of the mothers except one, the mother of a child with a mild hemiplegic impairment of the right leg. This mother’s depth of understanding about or involvement in her child’s therapy is unclear. Explanations for her lack of discussion of therapeutic

adaptations or strategies might be related to the refined treatment techniques her child required, which were difficult for her to integrate easily into a home routine; her lack of awareness of the adaptations that she had made; or the researcher’s inability to identify her adaptations.

One mother stated that there are “things that mothers do and things that therapists do.” The mothers’ responses to the therapy suggest that they believe there is a difference between their own treatment of the child and the therapist’s treatment. Each mother seemed to perceive the therapist as having unique skills and knowledge. None of the mothers said she felt adequate in treating her child through any type of formal program, but each seemed to have developed her own methods for integrating therapeutic experiences into her home life.

The nature of a home treatment program designed by the therapist seemed to be a constraint for these mothers. Their adaptations of therapists’ techniques seemed to be influenced by what they perceived as their children’s needs. The adaptations were at a skill level that the mothers could implement comfortably.

“*I’m going to let her do it!*” It is unclear whether the complexity and comprehensiveness of the home treatment programs were the only factors that led to their not being followed as suggested in the home. Considerably simpler advice by the therapists to these mothers was also not followed. The therapists had advised the mothers on other aspects of caring for the child beyond the home treatment programs, including what the mother should or should not do for the child’s benefit (e.g., not allowing the child to swallow by throwing his head back into hyperextension).

When asked what they allowed their children to do that the children’s therapists did not approve of, 7 mothers freely shared examples, including the following:

The other therapist told me, “Don’t let her walk.” I mean, that’s like saying, “Don’t let her eat,” because I can’t watch her all the time, and she wants to walk, you know. If it is going to make her become independent and this is what she wants to do, I’m going to let her do it! (Carol)

A friend of mine loaned me a walker because Carrie was trying to stand and they told me she wasn’t ready for a walker. But I knew what she used to do at home, so I disregarded what they said, and I let her do her thing at home anyway. (Carol)

He gets his knees now in a certain position that he gets in, that they called a W position. I know that it is not good for him. But it is just I can’t go over to him every time he is like that and fix him. Sometimes I let him get away with not wearing the A frames when it is extremely hot or if I feel that he has had such a tough day. (Donna)

Well, there are things that I should correct her on, but don’t. . . . She can do reciprocal crawling. . . . She decided she didn’t want to move around the house like that. So she went back to bunny hopping. . . . I know that it is bad, but I can’t stop her. . . . She can take herself to the bathroom. She can come into the kitchen. I know that she is not moving correctly as she should. But she is moving. (Jane)

I know that he is . . . not supposed to spend much time on his back. And he does spend small amounts of time on his back. Not

too long, because he is not too comfortable that way. Anyway he starts to cry. . . . Speech therapists have said repeatedly that he should be fed in his chair. . . . I find it easier holding him on my lap. (Kay)

These examples suggest that the mothers either did the best that they could with the therapists' suggestions or, if the therapist's suggestion was too difficult for them or their children, they did not follow the therapists' instructions. These mothers also reported that it was difficult to continually correct an abnormal position or movement pattern. Their responses support the conclusion that the participating mothers made many independent decisions about how they implemented their children's therapeutic program in their homes.

Importance to Mothers of Observing Therapists' Treatment

The integration of treatment techniques and strategies into the daily routines of mothers of preschoolers with cerebral palsy raises the question of how they acquired the necessary therapeutic handling skills to care for their children. The mothers universally acknowledged that they learned to care for and deal with their children by casually observing therapists' interactions with and treatment of their children.

Four mothers emphasized that therapists' demonstration of a single technique at a time was helpful. When more than one technique was demonstrated, the mothers stated that they could not manage all of the details involved and felt overwhelmed. These mothers also found that talking about their children with the therapist was valuable. Of particular importance were discussions with the therapist regarding daily life activities and issues not related to the child's therapy. Several mothers stated that sometimes these discussions were more important than the time spent in direct treatment of their children.

None of the mothers discussed formal instruction by therapists or reading materials as valuable sources for learning proper handling procedures and other child-care techniques. Only 2 of the 8 mothers commented on published literature; 1 mother found that books were beneficial in learning about cerebral palsy and 1 mother reported that a book by Finnie (1975) was helpful in the selection of equipment.

Each mother's descriptions of her own intervention suggested that the key to her action was casual observation and imitation of the therapist. The imitations were modified according to each mother's skills, routines, interactions, and experiences with her child. This supports the author's clinical finding that routine observation is an effective method for the learning of specific handling and self-care techniques.

Implications for Occupational Therapy

Occupational and physical therapists might begin to examine the effectiveness of recommending home treat-

ment programs to the families of children with cerebral palsy. On the basis of the present study's findings, therapists may want to reevaluate the value of home treatment programs and recommended activity. The mothers in this study were unable to implement home programs designed by therapists or to comply with many of the therapists' suggestions. Yet, they did benefit from observing and interacting with the therapists. Further, they appeared able to effectively adapt or extrapolate from the therapists' recommendations and to integrate these activities into their routines.

Occupational therapists may need to acknowledge their own expertise and skills in handling and treating children with cerebral palsy, as did all the mothers in this study. When given a structured home treatment program, mothers may be unable to acquire needed skills or to perform certain activities with their children. The mothers in the present study did not believe that they had adequate skills and knowledge to replicate the recommended programs or suggestions, nor did they want to assume therapist-like roles with their children.

Although mothers may not participate in formalized home programs, our findings support the belief that mothers do participate in certain home interventions. We found these self-selected interventions to have four characteristics: (a) they involved doing what the mother had determined to be doable within her daily activities, (b) they did not interrupt the family's home life, (c) they were perceived by the mother as being beneficial for the child's development, and (d) they could be done within the context of other home activities.

Therapists must recognize that mothers themselves may offer innovative interventions. We were fascinated by the mothers' creative skills in their ability to adapt home activities and routines to address their children's therapeutic goals. Most of these adaptations suggest that these mothers comprehended basic treatment principles. More importantly, we found that the therapeutic value of an activity can be enhanced by the mother who is adapting it into her daily life routine, such as in playing with her child. Thus, the home interventions selected and adapted by mothers can be therapeutic, functional, and practical.

Therapists need to select carefully those home activities that they recommend to parents. When recommending any activities, therapists should qualify when and under what circumstances the particular activity should be performed. During ongoing interactions with mothers, for example, therapists can reinforce the attitude that activities should only be done when they fit into the mother's daily routine. Additionally, therapists should choose activities on the basis of a sensitive understanding of the family's needs. Therapists can suggest methods of integrating suggested activities into play or daily routines in a way that meets the individual needs of the mother and family.

The study findings also suggest that although the mothers did not necessarily think that they were implementing a home treatment program, they did indeed implement many of the therapist's recommendations into their daily activities and routines. Accordingly, therapists can consider the following suggestions in providing input to mothers:

1. Explore maternal needs and assist the mother in developing her own interventions, thereby fostering her own creativity and reinforcing the parental role as primary care provider.
2. Provide ongoing positive support and feedback regarding the mother's solutions and actions.
3. Assist the mother in developing activities that meet the child's and family's needs and that can be realistically implemented.
4. Implement collaborative goal setting and treatment planning that is sensitive to the daily schedule of the parent, recognizing that parents may be unable to consistently perform the recommended activities.

When occupational therapists want to involve mothers in certain interventions, they should consider the importance of allowing themselves to be observed. We recommend that therapists allow the mother or parent to observe them providing therapy and to participate to the extent that they feel comfortable. Therapists may offer mothers opportunities to try handling and activities, but these experiences should not be forced. Mothers may be able to integrate only one demonstrated technique at a time. General discussion about the child may be an effective means of communication. When contact is not ongoing, for example, in a school setting, therapists can plan and encourage informal contact with mothers.

Therapists who demand parental involvement in home treatment programs may disrupt the family's ability to adapt successfully. Conversely, therapists who actively listen and provide selective guidance can foster the mother's own creative process to develop her parenting skills.

Conclusion

This study reports the feelings and perceptions of 8 mothers of preschool children with cerebral palsy who live in New York City. The findings, therefore, cannot be generalized to other mothers with preschool children with cerebral palsy. The study confirms that a mother's role and responsibilities are significantly affected if she has a child with cerebral palsy. Beyond adjusting to her disabled child's diagnosis and resultant disabilities, the mother must adjust her life-style to accommodate the special care, handling, and services her child requires. Mothers of children with cerebral palsy develop individualized problem-solving strategies to implement aspects of interventions that are recommended by their children's therapists.

The results of this study suggest that therapists should examine how they intervene with mothers about home activities. Each of the 8 mothers studied claimed that her child's therapist expected her to be involved in some aspect of home treatment. At the time of this writing, however, none of the mothers were currently participating in a home program designed by a therapist. Thus, for these mothers, home treatment programs were not an effective method of augmenting the treatment provided by therapists. More research is needed to examine the influence that therapists and their interventions have on family life. ▲

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