The Effect of Occupational Therapy Intervention on Mothers of Children With Cerebral Palsy

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Using the interviewing techniques and ethnographic methodology reported by Hinojosa, we explored the relationships between mothers of preschool children with cerebral palsy and their children's occupational therapists. Data from two interviews with five mothers were transcribed, organized into topics, and, through constant comparative analysis, formulated into themes. One theme, "Is anybody listening?" suggested that professionals often disregard information provided by the mothers; a second theme, "Not another one," revealed the importance of continuity of care and the patient hardship of frequently changing therapists. Consistent with Hinojosa's study, all of the mothers sought duplicative therapy. All of the mothers had established positive relationships with their occupational therapists and described them as skilled agents of change who were effective in helping their children and who were valuable sources of information and support.

Current practice of occupational therapy in early intervention has evolved from the child-centered medical model to a family-centered interdisciplinary model. The family, as part of the early intervention team, is to decide on the extent, type, and priorities of intervention (McGonigel, Kaufmann, & Johnson, 1991). Whereas in the past, occupational therapists were educated to address issues related to the child's developmental skills and function, these issues are now to be addressed in the context of family priorities and needs (Hanft, 1988; Stewart, 1989). Family-centered care, although widely advocated in the literature (Dunst, Trivette, & Deal, 1988; McGonigel et al., 1991), is not always realized in practice.

The family's role in deciding the priorities of intervention represents a change from the past when the types of services offered were decided by professionals (Bailey, 1991). Traditionally, the therapist has instructed the parents in home activities and adapted methods for handling and positioning their child, and the parents have then become responsible for carrying out these activities at home. As such, the parents were viewed as the recipients of services, rather than as partners in the child's intervention program.

The development of collaborative relationships between parents and therapists seems to be a critical element of family-centered early intervention. When a collaborative relationship is established, parents and therapists contribute equally to assessment, problem solving, and decision making. Parents may select the level of involvement in therapy services that best meets their needs (Bazyk, 1989). Usually, the level of involvement changes according to the age of the child, the type of services offered, and the life cycle of the family (Bailey, 1991; Case-Smith, 1991; Turnbull & Turnbull, 1990).

A recent ethnographic case study (Hinojosa, 1990; Hinojosa & Anderson, 1991) examined the relationships between mothers of children with cerebral palsy and their occupational therapists. One purpose of this research was to understand the experience of therapy from the parent's or consumer's point of view. Hinojosa reported that although most of the mothers in his sample (n = 8) did not follow through on prescribed home programs, they did value the informal support of the therapist as well as or more than instruction in specific therapeutic techniques. The mothers felt that frequent hands-on therapy was important, and that the more therapy their children received, the greater their progress. Hinojosa's study also generated themes about the mothers' daily experiences in caregiving. Although they described many additional caregiving responsibilities, they seemed satisfied with their ability to manage these daily challenges. The husbands did not assume routine caregiving responsibilities; however, their support, dependability, and understanding were important to the mothers.

We undertook an ethnographic study similar to that...
of Hinojosa (1990) to expand our understanding of the lives of mothers of young children with cerebral palsy and the effect of occupational therapy services on the lives of these mothers. Although exact replication of qualitative studies is not possible, the consistency of qualitative research results can be evaluated by implementing the same research method with other groups and settings over time (Schmoll, 1992). Using another setting with a different sample, we anticipated that our study, as a replication of Hinojosa's study, would both validate the original study and produce unique results that would contribute to our understanding of the relationships between occupational therapists and mothers of children who receive occupational therapy services.

Method
Sample
The subjects were selected according to the criteria used by Hinojosa (1990). The criteria of selection were (a) both parents were present in the nuclear family, (b) at least one child in the family was diagnosed with cerebral palsy, (c) the child was of preschool age, and (d) the child had received ongoing direct occupational therapy for the year before the study. With these criteria, five mothers were identified for the study by occupational therapists in early childhood programs of a midwest city. All agreed to participate in the interviews and to have their interviews tape-recorded. Descriptive information about the five participants and their children is shown in Table 1.

Data Collection
Each participant was interviewed twice in her home with the same interview questions and probes used by Hinojosa (1990). The interviews were completed 2 weeks apart and were tape-recorded. Transcription of the first interview was completed before conducting the second. The first interview gained information about the child and the disability, the relationship of the child with family members, daily management, and the relationship of the mother with the occupational therapist or therapists involved with the child. The second, more structured interview, provided additional in-depth information about the child's therapy, the effect of therapy on other family members, and advice for their occupational therapists and for other mothers. The primary purpose of the second interview was to clarify issues discussed in the first interview. The interviewer kept a field journal documenting appointments, descriptions of the home environment, and personal ideas and feelings (Nastro, 1992).

Data Analysis
The tape-recorded interviews were transcribed verbatim. Observations from the field journals, such as nonverbal behaviors and description of surroundings, were included in the transcription. Tentative concepts were coded from the first interviews with words taken directly from the interviews. Through constant comparative analysis (Krefting, 1989, 1991), these tentative concepts were refined and clarified as data from subsequent interviews were analyzed and organized. When the tentative concepts did not fit the data, they were modified until a congruent concept to explain the data was established (Schmoll, 1987). After all data were transcribed and organized, thematic analysis began. Emergent themes were established to explain relationships among the concepts, reducing them into the smallest number of categories that could explain the data. The result of this analysis was the formation of tentative themes that described and interpreted the participants' experiences (Lincoln & Guba, 1985; Miles & Huberman, 1984).

Trustworthiness
Guba (1981) devised a method for assessing trustworthiness, or merit, in qualitative research. He described criteria for evaluation of qualitative research that included truth value, applicability, and consistency. Truth value refers to the confidence of the researcher with the truth of the findings based on research design, informants, and context. Krefting (1991) described a credible study as one that provides descriptions of the human experience be-

Table 1
Description of Families Based on Information Provided by Mothers

<table>
<thead>
<tr>
<th>Participant</th>
<th>Family Composition</th>
<th>Ethnicity</th>
<th>Description of Child With Cerebral Palsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Husband, 5 children (aged 4-24 years)</td>
<td>White</td>
<td>4-year-old adopted daughter, verbal, &quot;intelligent,&quot; able to crawl</td>
</tr>
<tr>
<td>2</td>
<td>Husband, 4 children (aged 2½-6 years)</td>
<td>White</td>
<td>2½-year-old son, verbal, social, recently learned to walk</td>
</tr>
<tr>
<td>3</td>
<td>Husband, Twins</td>
<td>White</td>
<td>3-year-old twin daughter, verbal, uses complete sentences, walks with help</td>
</tr>
<tr>
<td>4</td>
<td>Husband, 1 son</td>
<td>White</td>
<td>3-year-old son, visually impaired, uses single words, nonambulatory</td>
</tr>
<tr>
<td>5</td>
<td>Husband, 1 son</td>
<td>Black</td>
<td>3-year-old son, ambulates with walker</td>
</tr>
</tbody>
</table>
Results

Impressions of the Early Intervention System

All five participants were knowledgeable about the early intervention services available in the community and had direct contact with the primary early intervention agencies. Overall, the participants were positive about services and about the professionals whom they had encountered.

Each of the participants also had some negative experiences with early intervention services. Each indicated that her family had incurred serious financial burden in providing for a child with cerebral palsy. All had incurred extra expenses that were not covered by insurance. Other frustrations voiced by the participants related to interactions with early intervention personnel.

Is anybody listening? The participants expressed frustration that their input was sometimes disregarded by the professionals working with them.

Participant 1: The problem that I run into, and that every mother runs into, is that the child will do things at home that they won't do in the classroom. You tell the teachers, "Oh they do that at home all the time," and they don't believe you and they won't acknowledge it until they see it in the classroom. Tests should be a guide; they shouldn't be the main thing by which you base your opinion. As home she was talking and she was saying words that no one believed she was saying and the therapist would say "until I hear it I won't believe it" and that was real discouraging.

Participant 5: We know he can repeat things like "elephant" because we read to him. The teachers were trying to tell me that he's not doing it and I said, "Honey, I know he can do it, because I read to this child." If I say he's doing something, he's doing it, I don't have to lie.

Not another one. The participants expressed dissatisfaction with how early intervention services, particularly therapy services, were arranged. Their primary concerns involved the high turnover rates among therapists within programs and the reassignment of therapists every year.

Continuity of care was important to these participants, as well as the opportunity to develop relationships with their children's therapists. When the therapist was replaced, it was difficult to say goodbye or separate from one collaborative relationship and to begin the process of developing a new relationship. Often the therapist's position remained vacant for an extended time, disrupting the child's therapy program.

Participant 1: I hate when the new year starts and you get a whole new crew of new therapists. She's had the same PT for two years... and last year, other than speech, she had a whole new battery of therapists and I found that discouraging because I didn't know the therapists.

Participant 2: They (therapists) do change every year and I feel bad because I don't have any contact with the school now, I don't really know the therapists.

Participant 4: That's something that has been kind of frustrating this year... in that they lost the speech therapist the first week of school and (she) hasn't been replaced and there was no PT until two weeks ago.

Relationships With Occupational Therapists

The children in this study had received occupational therapy since infancy, in a variety of service provision systems, including hospitals, early intervention programs, preschool programs and private home-based services. The participants described long-standing involvement with occupational therapists in these various settings, described a variety of roles that occupational therapists had played in their lives, and overall expressed satisfaction with the services that they had provided. Their descriptions of occupational therapists can be categorized into three themes: agents of change, sources of information, and sources of support.

Agents of change. The participants described, at length, the therapists' abilities to effectively work with their children and to facilitate improvement in their function. They were pleased with the ways the occupational therapists had developed rapport with their children, motivated them, and challenged them.

Participant 1: The occupational therapist showed her... how to be independent as far as living and doing and learning the basics - how to feed yourself, how to dress yourself, how to get in and out of chairs, how to hold a pencil, a crayon... I see really, really good responses from the therapists.

Participant 2: When he has therapy, I like that it is surrounded by play... and I don't know, my experience with OTs is that they just get right down into it and really work and it has to do with personality, and how much they let the kid get over on them. If this OT really makes him work and if he gets mad at her, well then, he's mad at her. You know, he gets over it and she does make it fun for him. She gets him to do things that we could never get him to do.
Written information, in the form of handouts, was valued and reused long after it was given.

**Sources of Information.** Occupational therapists provided the mothers with information about development, therapeutic activities, and community resources. Written information, in the form of handouts, was valued and reused long after it was given.

Participant 1: Well, OTs have information about other programs that other people may not know about.

Participant 5: [She] gave us lots of homework, you know... stuff to read, books to read, diagrams of positioning to put them in, all kinds of stuff, I still have lots of papers that they gave us. You know, in positioning them and stuff to do with them.

Participant 4: You know, I can’t even remember all the things that [OT] was doing with him but she gave us some handouts... too, just on positioning and things like that. He also has seen some OTs at the swallowing clinic... that was real helpful, I don’t remember, I think he was like a year and a half and he was having no oral stimulation, I mean we were trying to do it, like we were touching his face and things but they gave us more ideas.

Participant 1: The home-based person who came out would not only show me and do things. She would watch me do things and correct me if I did it wrong. She also brought me our pictures, diagrams, and she would even tell me, you know, the terminology is really hard to get down pat, she would talk about her tone and I would have to listen and say “what’s that?” because it takes a long time to get used to the language. And she would bring me out these papers. I still go back to them at times and she would write and explain things, and she left them with me in a folder. I could call at any time in between visits and she would come out and monitor.

Participant 2: So any advice that we could take...home-based was great with positioning ideas and a feeder seat and things that really helped us out. Because we would work with him a lot. When he was younger, [his OT] would show us different positions and things to do like after you change his diaper, I learned a lot.

**Sources of Support.** The participants also valued the support offered by their occupational therapists. This support was often exemplified by the therapist’s flexibility in the way services were provided and in their interest in collaboration.

Participant 1: Yeah, her [OT] is the same therapist that she’s had for years and she tends to go overboard and I’m glad of it... This year before school started, [the OT] called and asked what are your concerns for this year? I asked her: Where is she at? What has she been doing? What does she see? Then I can give her my list...I like for the OTs to share their concerns, that I’m real big on. I like for the OT to believe me when I tell them this is happening at home. And generally, they do.

Participant 3: They [OTs] seem like they’re the rock, I don’t know, of all the therapists, you know there’s a rock in the family, well they seem like they’re the rock of the therapists, the ones that I’ve all had, I don’t know, but it just seems like they’re the ones who are the rock.

Participant 1: We’ve always been lucky, using the same OT. [The OT] is always flexible and so are we. Flexibility is very important. It’s a big key in how you get along.

Participant 2: She [the OT] has done a lot for us. She hooked us up with a lot of things that we otherwise wouldn’t have known about.

One participant had advice as how therapists might be more supportive to parents by expressing hopefulness rather than pessimism about the future:

Participant 4: They’re all different... the first one who’s ever said “when” he walks, [instead of “if” he walks may have been]... a little bit too optimistic. There have been others who were, I guess, pessimistic, and I guess I would pick the optimist and then try to strive for that. Keeping in mind that we might not come to that.

**Therapy Services: More Is Better**

The participants had opinions about what constituted optimal therapy. Three of the children in this study received the maximum amount of occupational, physical, and speech therapy provided by county services and insurance coverage. The parents of these children also paid for additional home-based therapy or therapy through other agencies or programs. The belief that their children required aggressive therapy programs seemed to be based on the progress that they had seen in their children, which they attributed to the therapy. All five mothers expressed the need for intensive hands-on therapy, usually above the prescribed recommendations by physi­cians and other occupational and physical therapists. For example, the participants’ advice to others was to provide children with “as much therapy as possible.”

Participant 1: I think that any child with CP needs an aggressive therapy program. The most progress that she makes is during the summer because we have a private OT and [a private] PT who come here to work with her in addition to what she receives at summer school. And so we see the most progress at the end of summer, at the transition between summer and school.

Interviewer: I know that the [program] is free, and he does receive therapy there. Why do you choose for him to also receive private therapy?

Participant 2: Well, I guess I never really thought about it except that he really needs it and I guess we want to help him be the best that he can be. We feel it’s really necessary and that he needs it. He’s always done so much better at home, home is home I guess... I don’t think that the therapy he gets at school is enough, I don’t know, because there are eight kids in the classroom, if you get OT once a week, that’s one-on-one therapy for a half hour.

Participant 3 emphasized the importance of intense occupational therapy when her children were infants.

Participant 3: I think that [preterm infants] should be getting therapy from the time they are born. I don’t know if it’s a certain time period, but like I said, those splints, they really helped [my son], and they helped him fast... I still think that they should get therapy every day and I don’t know when that should stop but they really do need it.

The participants felt that additional therapy related to the progress that their children had made.

Participant 1: I guess what I get discouraged with is an OT or a PT or even her specialist... saying to me that I should be satisfied with what she’s getting, and I say, “no, I’m not because I can see how far she can go with more therapy.” And they’re telling me, she’s getting more than the average person, and I’m saying but she needs more than the average person. There’s so many kids on the list that don’t get as much as she gets, you know it’s real discour-
None of them felt that the therapists insisted that they do as much as they can, as often as they can, and don’t let anybody talk you out of it.

Just Want to Be the Mother.

Four participants described their own intensive work with their children when they were infants. As their children reached preschool age, they had discontinued their home program routines.

Participants: I know a lot of other mothers where the kids go much more frequently, [and] with this additional therapy, and their kids are doing better. I can’t think of anything else except that the therapy is well worth it, and you should get it for your child, as much as you can get it. I don’t think [my child] would be doing as much as he is doing now if he didn’t have the amount of therapy that he’s had. We’re real lucky that we could give it to him.

Participant: I would tell them to get as much therapy as they can, as often as they can, and don’t let anybody talk you out of it.

Discussion

The sample of five middle-class women is not representative of all mothers with children diagnosed with cerebral palsy in our geographic area. Their selection for the study by therapists in the field may have been influenced by their already active involvement in early intervention programs. The open-ended interview format afforded an opportunity to discuss general feelings and concerns related to their children. Other information gained related to the effect that occupational therapists had on the mothers, their children, and families.

Is Anyone Listening?

The participants were alienated when professionals did not attend to their concerns, did not believe their reports about their children, and did not take seriously their report about their children’s levels of functioning. These responses resulted in feelings of distress rather than a sense of collaboration in determining the child’s program. When Fine and Swift (1986) asked parents to make recommendations for early intervention programs, frequently mentioned were improved parent education, information sharing, and more personal contact between staff members and parents. The mothers in our study confirmed the importance of listening as a communication skill that contributes to forming a relationship with professionals. They reported feeling discouraged and less inclined to trust when professionals did not accept their information. Research of mothers’ preferences and priorities in early intervention services indicated that active listening and respect by professionals are highly valued (Summers et al., 1990; Whitehead, Dever, & Toccafondi, 1990).

Not Another One

The dissatisfaction with the turnover rate of occupational therapists, the time required to fill vacant positions, and the problems of adjusting to a new therapist and losing continuity of therapy are findings that suggest that therapists be mindful of the difference in perspectives between parents and professionals in early childhood programs. Parents develop relationships with relatively few therapists, whereas therapists develop relationships with many families. The need for continuity is likely to be stronger in parents who become invested in their relationships with early intervention personnel. Therapists, although invested in their relationship with families, have learned to accommodate and adapt to changes in those relationships (Healy, Keesee, & Smith, 1989). The turnover rate of occupational therapists in early childhood programs is high (Yoder, Coleman, & Gallagher, 1990). This turnover results in frequent vacancies, disruptions, and inconsistencies in the child’s program. The mothers in our study spontaneously spoke to this problem as it had affected each of them, creating hardships and limiting the child’s progress. These concerns suggest that continuity of care year to year should be a priority of therapists and administrators.

Relationships With Occupational Therapists

Agents of change. All of the participants described improvements in skills and abilities in their children,
which they attributed to occupational therapy. They described specific instances when occupational therapists were instrumental in helping them understand more about their children's conditions and effective strategies for dealing with them. Mothers in Hinojosa's (1990) study also described therapists as competent and skilled in promoting their children's skills.

Sources of information. Hands-on training, diagrams, pictures, and specific explanations were all cited as effective and appreciated methods of instruction. All of the participants reported that written sheets with specific activities and recommendations for their children were helpful; many of the mothers referred to them long after they were received. These written recommendations provided guidance when the therapist was unavailable to answer questions about specific techniques. Observation of the therapist and demonstration with hands-on instruction were mentioned as helpful in this study as well of that of Hinojosa (1990). The participants also described an appreciation of therapists seeking information from them related to planning their children's programs.

Sources of support. The participants discussed the personal relationship that they and their children had formed with the therapists. They described the trust and confidence they held in their therapists. This finding is consistent with Hinojosa's finding (1990) that close personal relationships developed between mothers and their children's therapists. He reported that “the social as opposed to the therapeutic aspect of the relationships seemed to be very important” (p. 154). The mothers reported that they had special relationships with therapists and described them as “friend,” “confidant,” and “like a member of the family” (p. 154).

Open lines of communication related to the children's treatment and being available to talk and to listen were important elements in establishing collaborative relationships between mothers and therapists. Flexibility and positive attitudes about the child's potential were also important to the participants. In both written and verbal communication, expression of optimism was viewed as important. Summers and her colleagues (1990) examined family preferences in how information was gathered from them and in how intervention planning was completed. The family members who participated in this study expressed that sensitivity was the most important element in the assessment and planning process. They felt that critical elements of parent–professional relationships were respect, honesty, individualization, and advocating for family rights and services. Optimism and positive perspectives about their children were important. They found that parents looked to early intervention practitioners for emotional support and friendship.

Our participants described solid relationships between the children and therapists as well as between therapists and themselves. Communication seemed optimal when the therapists had been working with the child on a long-term basis. The mothers who had worked with a single therapist over a long period of time indicated the importance of continuity of care for both their children and themselves.

Therapy Services: More Is Better

All of the participants felt that an aggressive approach to intervention by therapists results in the greatest progress in their children. They advocated that children should get “as much therapy as possible.” Often, the amount of therapy received was not prescribed or recommended by professionals; instead, the mothers sought it out themselves. Each child in this study had received more than the recommended therapy services. This finding may reflect selection bias, as the parents selected by their therapists would tend to be active and involved. Hinojosa (1990) found similar results in his study of mothers of children with cerebral palsy in New York City. All of the children in his study were receiving multiple occupational therapy services. These women also believed that their children's progress was evidence of the continued need for duplicate services. Although the mothers were all under the impression that additional therapy services are beneficial to their child's progress, this has not been proven in research studies. When shortages of therapists are prevalent across the country, can duplication of services be justified? Do therapists who duplicate services continue to perpetuate the parents' belief that more is better by providing these services? Similar concerns regarding duplication of services were reported by Hinojosa (1990).

Just Want To Be the Mother

When their children were infants, the participants implemented intensive home programs. As the children reached preschool age, they no longer implemented specific therapy activities at home. One participant expressed that working with the child on prescribed home programs may conflict with the role of being mother. Others expressed that their therapists did not expect formalized and specific home programs to be instituted. Our results concur with Hinojosa's; his sample tended to invest energy in home programs when the children were infants and did not participate in formal home programs when their children were preschoolers. The participants reported that this change in commitment to home programs was due to lack of time, energy, and confidence in their ability to implement home treatment programs.

Conclusion

In our ethnographic case study of five mothers, communication between occupational therapists and mothers emerged as an important issue in early childhood services. Regular communication that included active listen-
ing seemed to be important to establishing a strong relationship and to effecting change in the child. The occupational therapist’s communication included providing information about the child’s disability, therapy activities, caregiving methods, community resources, and other sources of information. Emotional support to the mother was valued, in addition to the benefits received by the child. The mothers perceived that occupational therapy during infancy was critically important and that the more therapy services acquired, the better the child’s progress. The effect of additional therapy beyond that recommended by physicians or provided through state-funded programs warrants further investigation in order to be substantiated.

References


