Pediatric Occupational Therapy in the Home

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This article discusses the challenges and implications for pediatric practice in the home. Pediatric occupational therapists are moving the treatment setting from the clinic to the home. Working within the home environment requires occupational therapists to adapt their roles, functions, and treatment styles. Intervention frequently involves practical and relevant treatment, using activities and objects from the child's world. Thus, functional goals may be more realistically achieved in the child's living environment. Involvement with family members also offers opportunities to develop collaborative relationships with parents and, therefore, to integrate the intervention program into the child’s home life.

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Occupational therapy intervention is shifting out of the clinic and into the home. Home-based occupational therapy is growing, yet little research has been done on this area of practice (Short-Degraff, 1987). Although some issues related to providing home-based treatment for physically disabled adults (Trossman, 1984) may be similar to those related to treating children at home, there are specific differences. The purpose of this paper is to discuss issues specific to providing occupational therapy to children in their homes.

Current clinical practice reflects the trend that children with disabilities receive rehabilitation services at home. Until recently, most children treated at home were treated as private patients after the therapist's workday in the clinic. The enactment of maternal child care legislation and the development of early intervention programs, private practice, and contract services with agencies, have spurred the development of a home delivery model. Changes in reimbursement sources also have contributed to the increase in delivery of pediatric occupational therapy services in the home. Home health agencies such as the Visiting Nurse Association now provide occupational therapy services to children whereas, in the past, they had been primarily concerned with home care for adults.

Physicians, psychologists, home health agencies coordinators, educators, and therapists in other fields are among the varied sources of referrals for home treatment. Reasons for referrals are equally varied. However, the four groups most frequently referred are (a) children who have been discharged after an illness or after surgery or who are at high risk (e.g., premature infants discharged from a neonatal intensive care unit); (b) children whose parents are unable to transport them to a clinic or educational facility for treatment; (c) children whose parents find treatment in the home more convenient; and (d) children from programs that philosophically support home treatment as most beneficial to the child (e.g., early intervention programs).

Literature Review

The home environment is considered to be a critical variable in the effectiveness of early intervention (Marfo & Kysela, 1985; Simeonsson, Cooper, & Scheiner, 1982). Much of the current literature on pediatric therapeutic services within the home involves early intervention programming (Brooks-Gunn & Hearn, 1982; Carlyle, 1980; Marfo & Kysela, 1985; Woods, Corney, & Pryce, 1984). Brooks-Gunn and Hearn (1982) determined that both home- and center-based early intervention programs were effective. Carlyle (1980) found that home
treatment was suited for those families that had difficulty using clinic or center programs but were receptive to therapists providing treatment to their children at home. Disabled infants, whose parents were unable to acknowledge a need for intervention or to accept an association with a center, received needed services until their parents were receptive to using clinic services. A home-based program provided support for the family and treatment for the child during a period of 2 to 3 years (i.e., from the initial diagnosis to the time when parents were able to accept center help for their child). Additional advantages of working in the home appeared to be that the parent and child were more at ease and that practical environmental problems were solved more easily (Carlyle, 1980).

Mueller and Leviton (1986) compared home-based and clinic-based intervention with developmentally delayed children. They concluded that a match between family and agency goals was important in determining the most suitable mode of service delivery for a family. One benefit of home-based services was the establishment of a mutual problem-solving relationship that facilitated the use of clinic services.

Home treatment can also help resolve parents' feelings regarding their child's disability (Carlyle, 1980; Woods, Corney, & Pryce, 1984). In a study of severely disabled infants, Burden (1980) found a general decrease in the level of depression in mothers whose babies received home therapy. Regular home visits by a developmental therapist appeared to relieve some of the burden of care on the family and resulted in improved maternal mental health. Ross (1984) assessed the effects of a home intervention provided by an occupational therapist to preterm newborns of low-income families. Ross matched these infants with a control group of preterm newborns who did not receive intervention. Mothers visited at home showed a higher degree of involvement as indicated by a greater emotional and verbal responsiveness to their infants. At 1 year postterm, these infants were tested on the Bayley Scales of Infant Development. They achieved significantly higher scores on the Mental scales subsection and attained a higher average on the Psychomotor developmental index. However, no difference was found between the two groups in the Motor scale.

To assess the impact of intervention in the home, Sandow, Clarke, Cox, and Stewart (1981) compared three groups of severely mentally retarded children. Two groups received intervention; one group was seen every 2 weeks and the other every 8 weeks. The third group received no intervention. Analysis of IQ scores using the Cattell Infant Intelligence Scale showed that the children visited every 8 weeks made the greatest progress after 2 years. The nontreated group made the fewest gains. The authors concluded that the parents visited every 8 weeks were less dependent on the home visitor than the parents visited every 2 weeks and may have invested more effort in working with their children.

Some parents with available resources may prefer home treatment for their child because of convenience (Goldberg, Faure, Vaughn, Snarski, & Seleny, 1984). Such treatment may also reduce parental stress. Difficulties related to transportation may be yet another reason why home-based treatment is preferred over clinic-based treatment. These difficulties include (a) too great a distance from home to the clinic, (b) a medically fragile or severely impaired child who requires complex technical medical care, and (c) other parental responsibilities such as the care of other siblings and employment.

Home Versus Clinic

Working with a child in the home is different from working with a child in a clinic setting. To a certain extent, intervention is influenced by the environment in which it takes place. By its nature, the home includes the child within the family system with its values, socioeconomic status, and idiosyncratic adaptations. Areas of concern for occupational therapists in this work context are (a) therapist's roles, (b) involvement with the family, (c) specific challenges of the home environment, and (d) values and sociocultural issues.

Therapist's Role

Changing from a clinic to a home practice requires the therapist to adapt to the demands of the home service delivery model. One of the obvious adaptations is the difference in the roles and responsibilities of other professionals on the health care team. In clinical settings, the physician is usually the primary case coordinator and determines the course and direction of the habilitative process. Other professionals may coordinate the various services a particular child may receive. In contrast, when home-based occupational therapy is provided, treatment methods and priorities are determined by the therapist.

Home treatment frequently offers a realistic, relevant perspective not readily available in the clinic environment. This perspective is seen most clearly with activities of daily living (ADL) treatment goals, which are effectively and practically dealt with in the home. For example, at home a 13-year-old girl with severe spastic quadriplegia was able to develop the sequence, routine, and skills for personal hygiene and dressing that she had not been able to develop during clinic treatment. At the clinic, she tended to be manipulative and resistive and avoided participation in
therapy. Working closely with the girl’s mother, the
home-based therapist developed a self-care routine
for the daughter and helped the mother set limits for
her daughter.

An important advantage of working in the home
environment is that it provides the occupational ther­
pist with opportunities to observe what goes on
within the home. This often means meeting and work­
ing with extended family members, friends, and sig­
nificant others and providing supportive information
and management strategies. For example, the mother
of the 13-year-old spastic girl had chronic back pain.
The therapist was able to instruct her on the proper
use of body mechanics so that she would not injure
her back while helping her teenage daughter transfer.

Discharging a client from a home treatment pro­
gram may be more difficult. Without imposed dis­
charge procedures or collaborative support of the
health care team, therapists with a strong attach­
tment to the child and/or the child’s family may have diffi­
culty initiating discharge plans. Conversely, the fam­
ily with a strong attachment to the therapist may resist
terminating home treatment. However, when prog­
ress is no longer evident, when treatment goals have
been achieved, or when another service model is in­
dicated, discharge planning must be initiated.

Involvement With the Family

Maintaining the professional role can be problematic
in the home setting. Because the therapist is a visitor
in their home, parents may try to relate to the therapist
more as a guest than as a professional. They may offer
food and beverages, social conversation, and invita­
tions to family affairs. Occasionally, families will also
give therapists personal gifts not related to any partic­
ular holiday or event. These social gestures can com­
plicate the professional role and may at times require
the setting of professionally appropriate limits.

Family difficulties and conflicts affecting the
treatment process are immediately apparent during
home treatment. Therapists may be confronted with
these problems or with unanticipated family crises.
For example, during the treatment of a child with
cerebral palsy, the therapist became indirectly in­
volved with the mother’s frustration over her hus­
band’s drinking. Before she could treat the child, the
therapist had to spend time exploring the mother’s feel­
ings and offering support. At times like this, thera­
pists may have difficulty separating themselves from
family situations and may directly or indirectly be­
come involved in family dynamics.

Communication between the therapist and the
parents may be facilitated by working within the
home because it is easier for parents to express their
real feelings at home than in the impersonal clinic
setting. Relaxed ongoing dialogue between parents
and therapists is encouraged by opportunities to in­
teract. Thus, parents may express anxieties about
visits to physicians or seek the therapist’s advice and
opinions on medical, developmental, educational,
and even personal issues. When the occupational
therapist is the main treatment provider, the role of
counselor can be extensive. This role requires skills
in dealing with the parent’s feelings and reactions as
well as knowledge of the child’s disability and avail­
able community resources and programs. Traditional
services easily available in the clinic setting, such as
social services and counseling, may not be as readily
available to these families.

An intervention plan that involves the family may
be easier to develop and monitor in the home. Dis­
cussing the child’s treatment program with family
members offers opportunities for instruction on home
management. Whereas some therapists recommend
family involvement in treatment (Moersch, 1985;
Nelson, 1985; Wendl, Ekenberg, Dogis, & Janlett,
1984), others do not (Anderson & Hinojosa, 1984;
Tyler, Kogan, & Turner, 1974; Wilson, 1984). Before
deciding whether or not the family should be in­
volved in a home treatment program, the therapist
considers characteristics of the family and home envi­
noment, family interaction styles, and the willing­
ness of family members to participate in the treat­
ment. Expectations of parental participation in home
treatment may vary from treatment session to treat­
ment session and from case to case. Therapists should
consider the potential impact of family participation
on the entire family unit. The child’s progress should
not be at the expense of the rest of the family (Ander­
sen & Hinojosa, 1984). Parents should be able to use
the treatment time as an opportunity to interact with
their other children, to do housekeeping, or to ob­
serve their child’s treatment.

Specific Challenges of the Home Environment

Therapists working in the home may have less control
over and influence on the changing elements of the
environment than therapists working at the clinic.
The clinical environment, specifically set up and ar­
ranged for patient treatment, requires only minimal
modifications for treatment such as positioning small
equipment and selecting play materials. The home
environment often requires major adjustments to ac­
commodate treatment. It may be necessary to curtail
the use of the television or radio, limit the presence of
siblings or pets, or move furniture. Most parents are
amenable to making adjustments when they are aware
of the therapist’s treatment goals and objectives.
Some homes may be rat-infested, unclean, and not
conducive to performing treatment activities on the
floor. In these cases, therapists may choose to treat the child on their lap or on the surface of furniture.

Lack of equipment, lack of supplies, and limited space require that home-based therapists be flexible and adaptive. The success of treatment may depend on developing treatment goals in accordance with these limitations. Activities and functional goals may be achieved through problem solving and creative adaptations. For example, an obstacle course was created with kitchen furnishings and household items for a 5-year-old developmentally delayed child to meet treatment objectives. The integration of the child's own play materials in treatment may be more meaningful than the use of the clinic's equipment. The challenge of using the child's environment to meet therapeutic goals may be rewarding and stimulating to home-based therapists.

Working in homes may require the occupational therapist to purchase a basic inventory of equipment and have the means to transport it. Alternatives to purchasing equipment include (a) forming a network of therapists who can pool and share equipment and (b) making an arrangement with a local occupational therapy clinic to borrow equipment. It may be less cost-effective, however, to spend an hour traveling to and from a clinic to borrow an evaluation tool than to purchase it.

Values and Sociocultural Issues

Being in the client's home allows therapists more opportunities to become aware of how family values, that is, individual feelings about activities and disabilities, may vary with culture and personality. The athletic father of a boy with mildly involved cerebral palsy was disappointed by his son’s difficulty participating in competitive sports. Another family whose child had similar disabilities put more importance on intellectual activities and was able to accept their child's limitations with regard to competitive sports.

Home treatment with the parents present also allows the children to share their concerns and views. One child whose family frequently dined in restaurants would not consider the use of adaptive equipment for self-feeding because she felt it reinforced her “difference,” already defined by her need to be in a wheelchair. Instead of a rocker knife, the therapist suggested she use a steak knife to cut her food and worked with the family on various cutting techniques.

Choosing appropriate toys may be more difficult in the home than in the clinic where more play materials may be available. Sensitivity to the child's socio-economic status and culture is heightened in the child's natural environment. Choice of appropriate toys and activities must be consistent with the cultural values of the family. For example, the activity selection for a pre-school-age child with developmental delays was influenced by the family's Hassidic values and norms. Audiotapes of religious stories and songs available in the home were integrated into treatment sessions. (The use of television programs and cartoon characters would have conflicted with the family's values.)

To bring expensive toys into an economically deprived home for a treatment session can alienate the parents and contribute to their sense of not being able to provide what is "best for the child." One needs to be resourceful and creative in adapting and making toys from household goods or in making suggestions for the purchase of less expensive commercially available toys. Family involvement in the making or modifying of a toy is an important therapeutic goal. For example, the poor mother of a young child with cerebral palsy was encouraged to make a rattle from a toothbrush box and beans and a pull toy from an oatmeal container that was filled with macaroni and had a string attached to its sides. Until the suggestion was made the mother was unaware that she could use household goods to stimulate her child’s development. Additionally, parents may be asked to help the therapist by collecting household objects that will be used during the child's treatment. This provides opportunities for the therapist to model specific behaviors for the parents and allows parents to contribute to the child's treatment.

Working with a wealthy family may raise other concerns. Since these families are paying for their child's treatment, they may have special expectations. The wealthy parents of a child with sensory integrative dysfunction purchased all the required equipment and play materials necessary for their son's treatment. The quality and appearance of the equipment in the home was important to this family as they put great value in achieving a normal appearance for their son. Collaborative efforts and mutual problem solving regarding their concern about his dressing skills and appearance resulted in minor modifications of the stylish clothes they wanted him to wear. An individualized dressing program was also developed for his school. For this family, the child's more normal appearance was more important than his self-care independence.

Limitations of Home Treatment

Providing treatment in the home has its limitations. The home environment may not be appropriate for certain treatment methodologies or techniques used in the clinic. For example, using sensory integrative techniques with the learning-disabled child may be difficult because of the nature of the treatment, space restrictions, and extended equipment needs. For ex-
ample, a very small, one-bedroom apartment was deemed inadequate for the sensory integrative treatment of a 9-year-old child with developmental dyspraxia. Therefore, arrangements were made with a private school for appropriate equipment and space. In such cases, alternative settings such as a clinic, school, or church can be explored.

Complex splinting that requires specialized equipment or treatment modalities that require large areas may not be appropriate for home treatment. A child who requires splinting, extensive adaptive or medical equipment, and specialized services may be better served by referral to a clinic or a private practitioner with an appropriate office. In cases like these, a knowledge of the quality of services and types of resources available in the community is an asset.

Because of family dynamics, not all children may optimally benefit from occupational therapy in the home. Intervention may be directly affected by the parent-child relationship. In the case of a 6-year-old learning-disabled boy with behavioral problems who was referred for home therapy, the therapist had the initial impression that the home was very disorganized, controlled and dominated by the child, and therefore questionable for treatment. The child’s control over the household was demonstrated by his turning over all the dining room chairs, letting his pet snake loose in the dining room, building a fort around the fireplace with his toys, and occupying the only private bedroom. To discuss the session with the mother, the therapist had to sit on the kitchen floor. Consultation with the child’s psychologist confirmed the initial impression that the parents were unable to control the child and that this inability adversely affected the quality of family life. An alternate setting more appropriate for development of a therapeutic relationship was found.

Related Professional Issues

Shifting treatment from the clinic to the home also necessitates changes in the way professionals communicate with each other. In most clinic settings, case conferences in which a client’s progress is evaluated are routine. In home settings, communication is often less structured and informal. Contact with other health care providers is made by telephone, through notes, and sometimes at team meetings. Efforts to communicate with team members can become time-consuming and may involve using telephone answering machines, taking concise notes, and making telephone calls in the late evening.

The home-based therapist may have to deal with irregular work hours, lack of a centralized working environment, lack of supervision, reduced peer interactions, and feelings of isolation. The lack of such benefits as medical coverage, vacation time, and sick leave may be of concern to therapists pursuing home treatment full-time.

Consultation should be sought when the therapist is attempting to deal with specific problems affecting a child’s treatment. For example, the parents of a 5-year-old child with learning disabilities questioned the value of therapy and had difficulty communicating with each other and setting limits for their son. They involved the therapist in a negative method of reinforcing the child’s behavior by rating his cooperativeness after each session. The therapist’s assessment of the child’s behavior during a treatment session would determine whether or not the child received a new toy. Consultation with a family therapist clarified that the parents were using the therapist as a tool to deal with their marital difficulties. The therapist then stopped rating the child’s behavior and developed a therapeutic approach that dealt with the child’s behavior during treatment. In this case, recognizing the family dynamics allowed the therapist to be more directive with the parents.

Strong management and organizational skills are necessary for the home therapist. The effective structuring and coordination of all aspects of a workday becomes a major task. Calling to discuss referrals and patient progress, documenting treatments, arranging schedules, keeping financial records, and traveling to the clients’ home are all time-consuming activities. Since some of these tasks may not be formally integrated into the therapist’s daily structure, the therapist must consider the time required for each and the costs involved when analyzing total income. Many fee-for-service agencies account for administrative costs and travel time.

Therapists and clients must be somewhat flexible when making appointments. Scheduling appointments may be difficult because therapists need to consider home location, commuting time, and family schedule. However, the time spent traveling can be used fruitfully. The occupational therapist who travels by public transportation can plan activities, write notes on patients, and review treatment goals. By recording notes in a portable tape recorder, therapists commuting by car may salvage time potentially lost.

To work under the autonomous conditions of home treatment requires a solid knowledge base, considerable clinical experience, self-confidence and trust in one’s professional judgments, and the ability to substantiate efforts without the backing of the rehabilitative network readily available to the clinician. Reviewing recent literature and research, maintaining professional contacts, and attending special interest group meetings and continuing education courses will provide the home-based therapist with opportunities for peer support and upgrading clinical skills.
Conclusion
Home treatment offers a work environment in which occupational therapists can have more control over and flexibility in their practice. Therapists in the home environment adapt treatment styles and adjust to the conditions of the environment. The challenge of finding creative, relevant solutions to meet the child's developmental needs can be exciting and rewarding. Relationships with family members can also be personally and professionally satisfying.

Home treatment, an expanding area of practice for occupational therapy, will continue to be affected by governmental, philosophical, and sociological changes. This article identified treatment issues of importance to occupational therapists working in the home-based practice of pediatrics. Therapists' awareness of these issues will enable them to respond to the demands of this service delivery model.

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References


Related Readings
