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Mary A. Corcoran
Thomas Jefferson University

Laura N. Gitlin
Thomas Jefferson University

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Dementia Management: An Occupational Therapy Home-Based Intervention for Caregivers

Mary A. Corcoran, Laura N. Gitlin

Key Words: Alzheimer's disease • caregivers

This paper describes an occupational therapy intervention designed for family caregivers of persons with dementia. The intervention, based on the framework of a competence-environmental press model and the principle of collaboration, was implemented during 5 home visits. Each visit was designed to build caregiving skills through collaboration in identifying problem areas, developing and implementing environmental strategies, and modifying management approaches. A case vignette illustrates the therapeutic process and outcomes. The theoretical rationale and structure of the intervention and innovative documentation for evaluation of the theoretic process are also presented.

Mary A. Corcoran, PhD, is Assistant Professor, Thomas Jefferson University, Department of Occupational Therapy, 130 South 9th Street, Suite 820, Philadelphia, Pennsylvania 19107.

Laura N. Gitlin, PhD, is Associate Professor and Research Coordinator, Thomas Jefferson University, Department of Occupational Therapy, Philadelphia, Pennsylvania.

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National estimates indicate that 4 million Americans have Alzheimer disease and that this number will rise as the older population increases. Extensive research has documented the profound consequences of Alzheimer disease for the person as well as for family and friends who continue to provide more than 80% of the long-term care and management of the disease process (Pepper Commission, 1990; Select Subcommittee on Aging, 1987). Such daily management issues as wandering, agitation, violence, aggression, and difficulties with self-care activities have been shown to have dramatic physical and psychological consequences for informal caregivers. This paper presents a home-based occupational therapy intervention designed to improve caregiver skill in the management of the behavioral or secondary symptoms exhibited by a spouse with dementia. The rationale for the intervention, a description of each therapeutic visit, an innovative documentation form, and a case to illustrate the intervention process are provided. Presented elsewhere are the detailed explanation of the conceptual components of the intervention (Corcoran & Gitlin, 1991), the study methods and outcomes (Gitlin & Corcoran, 1991a), and a program used to train occupational therapy students in the delivery of the intervention (Gitlin & Corcoran, 1991b).

Background

The intervention presented in this paper addresses three critical issues that have emerged from caregiver and health services research: (a) the need for theory-based treatment approaches, (b) the importance of developing strategies to manage the behavioral outcomes of Alzheimer disease, and (c) the importance of developing home-based service strategies that reflect the needs of caregivers.

Need for Theory-Based Treatment Approaches

Although caregiver interventions have recently proliferated, they still lack a theoretical base (Gallagher, 1985; Haley, Brown, & Levine, 1987). Reported interventions have included stress management, education, group support programs (Whitlatch, Zarit, & von Eye, 1991; Zarit, Anthony, & Boutsetts, 1987), personal and group counseling programs (Gallagher, Rappaport, & Benedict, 1985; Lovett & Gallagher, 1988; Toseland, Rossiter, & Labrecque, 1989), relaxation and meditation (Gendron et al., 1986), respite care (Burdz, 1988; Lawton, Brody, & Saperstein, 1989), and problem-solving groups (Silven et al., 1986). These interventions have evolved in response to a body of literature that identifies stress as a major contributor to the health and well-being of caregivers. Although these programs provide critical support to caregivers, they do not reflect the complexity of the experiences and the breadth of issues that caregivers indicate as

problematic. Furthermore, research by Dura and Kiecolt-Glaser (1990) suggests that caregivers who choose not to participate in on-site training and educational programs may differ greatly in their needs and care approaches from those who require home-based services. Alternative interventions that are founded in concepts broader than stress and that are sensitive to caregivers' concerns are evidently necessary.

Need to Develop Management Strategies

Because dementia is irreversible and progressive, caregivers' needs often change and expand over time. Recent studies have identified the development of caregivers' management abilities as a meaningful approach for addressing diverse caregiver needs encountered over time (Clark & Rakowski, 1983; Corbin & Strauss, 1988; Corcoran & Gitlin, 1991; Crossman, London, & Barry, 1981; Gallagher, 1985; Pinkston & Linsk, 1986; Smith, Smith, & Toseland, 1991; Toseland et al., 1989). Ethnographic research has also revealed that caregivers create meaningful, effective solutions to daily care problems, but seek reinforcement and additional skills to refine their efforts (Hasselkus, 1988). These findings underscore the importance of helping caregivers develop effective problem-solving skills to manage the diverse behavioral manifestations of dementia.

Need for Personalized Interventions

An extensive body of literature indicates that the emotional, physical, and social consequences of caregiving differ based on gender, familial relationship, and cultural background (Anthony-Bergstone, Zarit, & Gatz, 1988; Brody, 1981; Hasselkus, 1988; Pruchno, Michaels, & Potashnik, 1990; Rodeheaver & Datan, 1988; Sherman, Ward, & LaGory, 1988; Wilson, 1990; Young & Kahana, 1989). These differences influence approaches to managing care, especially problem-solving skills, use of formal and informal supports, degree of upset experienced with dementia-related behaviors, and sense of personal efficacy derived from caregiving (Barusch & Spaid, 1989; Young & Kahana, 1989). Furthermore, the group education and counseling format used in most interventions may be inappropriate for male caregivers and others from diverse cultural backgrounds who traditionally have not participated in such groups (Barusch & Spaid, 1989; Edwards & Baum, 1990; Kaye & Applegate, 1990; Miller, 1987; Wilson, 1990).

This literature suggests that health services for caregivers must be flexible to address each caregiver's specific needs, style of care, and values. Services that are client driven and derived through working with a health care provider may effectively support caregivers (Gitlin & Corcoran, 1991b; Hasselkus, 1988; Perlman, 1973). Home-based services, in particular, must reflect the caregiver's

perceptions of need and support his or her values and style of care (Hasselkus, 1988; Levine, Corcoran, & Gitlin, in press). Treatment strategies that incorporate caregivers' values and personal goals have been shown to be more efficient and effective for older disabled adults (Chiou & Burnett, 1985; Perlman, 1973; Shelton, Jeppson, & Johnson, 1989).

Theoretical Framework

A competence–environmental press model (Ansello, King, & Taler, 1986; Lawton, 1989b; Lawton & Nahemow, 1973) provides the conceptual framework for developing the therapeutic strategies within the intervention described below. This model suggests that many behavioral manifestations of dementia may be controlled or minimized by environmental manipulations that lower the press for persons with declining levels of competence. *Press* refers to the external forces of the environment that influence the functioning of a person with a specific level of competence. The model suggests that enhancing a caregiver's ability to modify environmental press may have two consequences. First, it may minimize difficult behaviors manifested by the person with dementia. Second, the incorporation of environmental strategies may expand caregiver problem-solving abilities and thus improve the caregiver's sense of efficacy in managing daily problems.

Research findings from studies that used theories of person–environment fit have underscored that the environment can promote or restrict independent behavior and positive affect (Barris, Kielhofner, Levine, & Neville, 1985; Lawton, 1989a; Parmalee & Lawton, 1990; Pynoos, Cohen, David, & Bernhardt, 1987). Evidence from studies on institutional settings suggests that specially designed environments may reduce behaviors such as wandering, agitation, or restlessness (Corcoran & Barrett, 1987; Hall & Buckwalter, 1987; Hiatt, 1982; Kiernat, 1982; Levy, 1987; Paire & Karney, 1984; Parmalee & Lawton, 1990). Environmental strategies to control behavior of the person with Alzheimer disease have included removing clutter to reduce agitation and promote cue finding, placing clothing out to decrease confusion and promote independent dressing, and simplifying daily tasks to facilitate participation (Kiernat, 1986; Levy, 1987). Although publications tell caregivers how to eliminate environmental barriers (Pynoos, Cohen, & Lucas, 1988), caregivers have not traditionally received hands-on training in using the environment to control secondary symptoms of dementia.

Therapeutic strategies derived from a competence–environmental press framework are designed to alter press and thus realign the competence of the care recipient with environmental expectations. As in Barris et al.'s model (1985), the environment is defined as four hierarchically arranged, interacting layers: (a) objects (physical

tools or objects in the home), (b) tasks (activities that compose daily routines such as meal preparation and eating), (c) social groups and organizations (family, friends, and neighbors), and (d) culture (values and beliefs that shape care provision in the home). Therapeutic strategies involve manipulating the properties of these layers to achieve a balance between the competence of the person with Alzheimer disease and the pressing environmental forces (Corcoran & Gitlin, 1991).

Within this theoretical framework, the intervention uses a collaborative therapeutic structure in which the occupational therapist and caregiver develop and implement environmental strategies that address the secondary symptoms of dementia. Collaboration requires that the health professional listen actively and involve the caregiver in identifying problems, planning treatment, and implementing treatment. Within a collaborative framework, treatment becomes contextualized and is shaped by the caregiver's unique needs, goals, preferences, and resources. This approach to treatment enables families to function proactively to manage the influence that chronic illness exerts on their life-style (Corbin & Strauss, 1988; Hanft, 1989). Occupational therapy efforts respond to, and are shaped by, each caregiver's needs, management style, and environmental resources. This approach to intervention has been identified as a critical step in the development and testing of meaningful services for this population (Haley, 1991; Smith et al., 1991).

Description of Intervention

The intervention, which involves five home visits in 3 months by a registered occupational therapist, is targeted for caregivers who assist with self-care activities for a spouse with moderate to severe dementia from Alzheimer disease. It was designed to meet caregivers' demonstrated need for instruction in care techniques (Hasselkus, 1988; Smith et al., 1991), major risk of physical and psychological decline (American Association of Retired Persons, 1988), and high probability of institutionalizing their spouses (Pruchno et al., 1990; Stone, Cafferata, & Sangl, 1987).

During each visit, the occupational therapist and caregiver work together, first to identify behaviors that present difficult management issues for the caregiver, then to determine appropriate environmental solutions. This problem-solving activity gives caregivers new strategies to change and control behavior of the person with dementia by manipulating the objects, tasks, or sociocultural components of the environment (Barris et al., 1985; Kiernat, 1982).

In each session, the occupational therapist provides ongoing support and education about dementia and its secondary behavioral symptoms and the availability of support groups and community resources. This ongoing education is contextual in that it responds to the needs of

each caregiver and his or her level of knowledge as it emerges during therapeutic exchange. As the intervention progresses, the therapist redirects the caregiver's attention and problem-solving approaches to the elements in the environment that may be exacerbating the behavioral symptoms of dementia. The focus of each visit and the basic activities that occur are described below.

Visit 1. The focus of this visit is to build rapport and establish goals. First, the therapist begins to build a collaborative relationship by facilitating the caregiver's attempts to (a) share his or her perspectives about providing care, (b) identify problems to be addressed, and (c) set goals for the subsequent visits. Second, the therapist reviews current care strategies by observing the interactions between caregiver and care recipient and begins to identify environmental influences on problem behaviors. Although the problem behaviors identified by the caregiver as particularly difficult are the target of Visit 1, the therapist also attempts to observe other care strategies to assess the caregiver's general problem-solving approach and use of the environment.

Visit 2. This visit has three objectives, in addition to the continuation of observations and dialogue to build a collaborative relationship. First, the therapist indicates specific environmental influences on the problem behaviors identified in Visit 1. Second, the therapist introduces information regarding dementia, role modeling of specific care activities, and use of the environment as a treatment modality. Third, the caregiver and therapist develop a plan to address specific problem behaviors and identify the initial steps to be implemented by the caregiver. An example of such behavior would be a care recipient's inability to choose appropriate articles of clothing and don them in the correct sequence. The plan may involve working with the caregiver to eliminate extraneous articles of clothing from sight (objects layer), match the physical assistance provided in dressing with the care recipient's fluctuating needs (task layer), and provide verbal cues regarding socially appropriate clothing for the events of the day (social and cultural layers).

Visit 3. During this visit, the therapist and caregiver review their plan and the initial steps implemented by the caregiver between Visits 2 and 3. They examine the caregiver's perceptions and recollections of the plan's effect on the frequency and severity of problem behaviors and explore how the caregiver felt about the modifications. On the basis of this review, the caregiver and therapist further refine the plan, use it to develop detailed environmental strategies for managing other problem behaviors, and agree on a time frame for implementation.

Visit 4. During this visit, the therapist assists the caregiver in further refining specific care strategies. The therapist continues to engage in role modeling and education but begins to release ownership of management decisions to the caregiver. To facilitate the caregiver's skills and sense of efficacy, the therapist encourages the

caregiver to make more independent, informed management decisions. Finally, the problem-solving process used to develop the plan is identified and generalized to other problems.

Visit 5. An important task of the final intervention visit is the review of the problem-solving process that the caregiver has used to approach specific problem behaviors. Other tasks may include final modifications of specific strategies and refinement of caregiver's techniques. Closure includes confirmation of the caregiver's skills and a discussion of the application of environmental strategies to future problems. The following case illustration shows the progression of the intervention from building rapport, collaboratively identifying problem areas, and developing and implementing environmental strategies to reevaluating, modifying, and supporting management approaches.

Case Illustration

For several years, Mrs. C. has been caring for her husband, who is moderately impaired because of Alzheimer disease. Mrs. C. is an anxious person who has frequent asthma attacks as a result of stress. She expresses fear of her husband because he has a tendency to become paranoid and suspicious. For this reason, Mrs. C. scheduled all the initial intervention appointments for times when her husband would be away from home.

Mrs. C. and the therapist spent most of Visit 1 exploring Mrs. C.'s perspectives on the demands of her caregiving role, her response to those demands, and the goals of the intervention. Mrs. C. reported that three major issues troubled her: her husband's tendency to repeat questions, his resistance to bathing, and her own uncertainty about Alzheimer disease and its management. The therapist explored with Mrs. C. how she managed each problem area. Mrs. C. explained that her solutions to the first two problems involved either yelling at her husband or ignoring him to avoid a fight. Either way, she was ineffective in managing his problem behaviors, as evidenced by her high stress levels and his lack of personal hygiene. The therapist suggested several possible environmental influences on Mr. C.'s behavior, such as lack of an established bathing routine (task layer) and absence of visual cues in objects needed for bathing (objects layer). These were confirmed or refuted by Mrs. C. The two agreed to establish a regular routine, identify sources of information about Alzheimer disease and its management (social groups layer), and develop an atmosphere of calm in the home (task layer). Mrs. C. instructed the therapist to meet with her in her husband's absence for the next visit.

During Visit 2, Mrs. C. and the therapist developed a plan based on the discussion from Visit 1. With the therapist's guidance, Mrs. C. decided to place a written schedule on the dining room table each morning and to direct her husband to the kitchen sink for bathing at the same

time each day (task layer). She also agreed to try to answer his repetitive questions promptly, but just once and in a calm voice (task layer). Instead of responding to a repeated question, Mrs. C. decided to redirect her husband (task layer) and to leave the room when she felt aggravated. The therapist role-played these techniques with Mrs. C. to clarify them and gave her a copy of *The 36-Hour Day* (Mace & Rabins, 1981).

During Visit 3, Mrs. C. and the therapist reviewed their plan and the initial steps that Mrs. C. had implemented. Mrs. C. reported that she had shouted at her husband much less during the interim between visits. She had decided to direct her husband to the sink for bathing only on Sundays, after he shaved, because this had been his normal routine for years (task layer). The daily schedule was not only in place, but Mrs. C. had taken the initiative to write it in large print on a bright piece of paper (objects layer). In this way, Mrs. C. modified the therapist's suggestions to reduce the possibility that Mr. C. would misinterpret her verbal instructions. A final objective of this visit was to refine and expand Mrs. C.'s management techniques, so the therapist began to help Mrs. C. explore how the environment around the sink could be adapted to encourage her husband's independent bathing.

By Visit 4, Mrs. C. had independently set up the sink with a towel hanging nearby and had placed the soap in a bright container to increase visibility (objects layer). She happily reported that she had not needed to give her husband instructions after she calmly reminded him to remove his shirt for bathing (task layer). By this time, Mrs. C. had eliminated her ineffective solutions of yelling at her husband or ignoring him. Her ability to remain calm had improved and she had established the habit of leaving the room when upset. During this visit, the therapist and Mrs. C. discussed the success of a regular routine and calm atmosphere, refined her environmental modifications, and began to generalize these techniques to emerging problems such as incontinence. Mrs. C. had purchased her own copy of *The 36-Hour Day* (Mace & Rabins, 1981) and had called her physician for a referral to a dementia specialist (social groups layer). Because the physician had refused to make a referral, Mrs. C. requested more information about community resources from the therapist.

During Visit 5, Mrs. C. reported that she had contacted a local hospital about caregiver education classes and listed four other community resources of which she was aware (social groups layer). Her husband's emerging incontinence had not been a problem during the past week, but Mrs. C. was uncertain about why it had abated. The therapist reviewed Mrs. C.'s problem-solving approach and explored how Mr. C.'s incontinence might have been positively influenced as a result of the regular routine and approving attitude. By Visit 5, Mrs. C. and the therapist had addressed the three identified problem areas, accom-

plished the goals established in Visit 1, and developed a problem-solving approach that Mrs. C. could generalize to other emerging issues such as incontinence.

Intervention Documentation

Documentation of therapeutic practice and client benefit becomes increasingly critical as occupational therapists must account for their activities and service effectiveness. Figure 1 shows a form that documents intervention for Mrs. C. in one problem area, that of Mr. C.'s repetition of questions. In a research study, we developed and tested this form for documenting the planning and implementation process within each intervention visit. The form provides the therapist with a graphic delineation of five aspects of treatment: (a) each problem behavior addressed during the intervention, (b) the number and range of management approaches used by the caregiver and an indication of effectiveness, (c) the range of environmental strategies introduced by the caregiver and therapist, (d) the time frame in which strategies are accepted by the caregiver, and (e) the time frame in which ineffective strategies are eliminated. The form also provides an on-going treatment record to discern those problem areas that are effectively addressed across cases and those that

necessitate additional effort or alteration in the therapist's strategy.

The research study in which this document was used evaluated intervention strategies developed during treatment and the extent to which these strategies were accepted by caregivers and continued over the five intervention visits. Table 1 lists 17 distinct solutions, arranged in descending order of frequency of use, that were implemented by 17 caregivers in the study. These solutions involved modification or manipulation of one or more environmental layers and were identified as effective by the therapist because a desired change in the care recipient's behavior was achieved. Effectiveness was determined on the basis of the caregiver's self-report and the therapist's observation in each visit. Development and implementation of these effective solutions occurred through independent problem solving by the caregiver, a direct suggestion by the therapist, or collaboration by the caregiver and therapist. As shown in Table 1, such solutions as graded assistance (12%), encouragement of simple work and leisure tasks (10%), use of formal supports (10%), and preparation of the area with needed objects (10%) were the most frequently used solutions; solutions such as eliminating clutter (3%) and identifying objects with visual cues (3%) were used less frequently. These

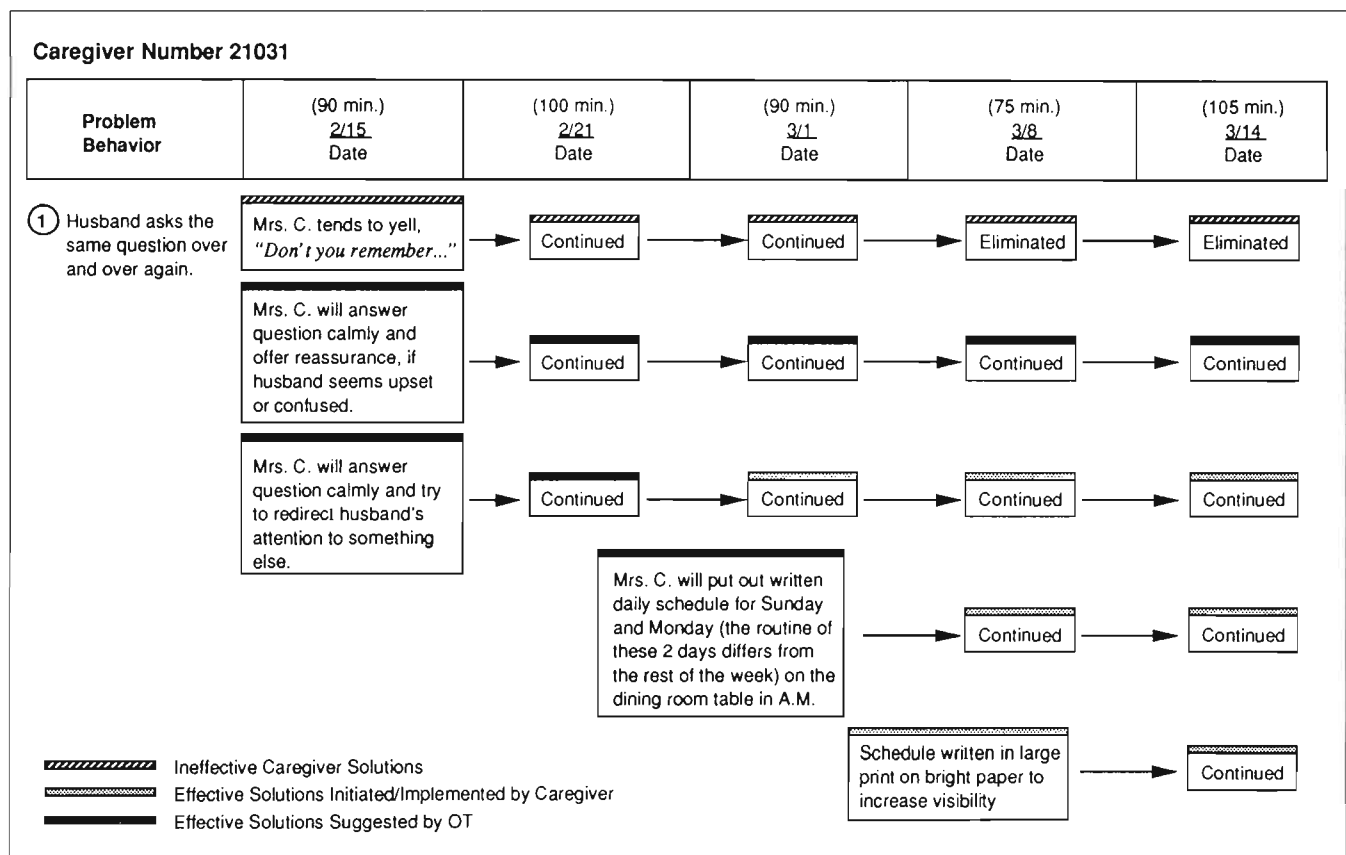


Figure 1. The treatment documentation sheet. Patterned boxes differentiate between effective and ineffective care strategies and their continuation or elimination over the intervention period. *Note.* OT = occupational therapist.

Table 1
Effective Caregiver Solutions and Frequency of Use
(N = 17)

Solution	Number of Times Used ^a	% of Total Solutions Implemented
Use graded assistance	33	12.0
Identify/encourage simple work and leisure tasks	27	10.0
Use formal supports	27	10.0
Prepare area with needed objects	27	10.0
Use safety precautions (e.g., locked doors, nightlight, ID bracelet)	18	7.0
Use tactile guidance/demonstration	18	7.0
Use clear verbal instructions	18	7.0
Convey calm and approving attitude	17	6.5
Establish and communicate a regular routine	15	6.0
Use commode/adaptive equipment	12	4.0
Use energy conservation and pacing (caregiver and care recipient)	12	4.0
Use informal supports	11	4.0
Use caregiver education opportunities	9	3.0
Identify objects and their use through visual cues	9	3.0
Eliminate clutter	9	3.0
Use mattress pads/absorbent pads	5	2.5
Control fluid intake	3	1.0
Total	270	100.0

^aAs reported by therapist during Visits 1 through 5.

approaches to behavioral problems may be more difficult for caregivers to incorporate into their routine or may not be viewed by caregivers as effective. Future clinical studies are needed to fully describe how caregivers select problem-solving approaches and to develop and test occupational therapy strategies for assisting caregivers in using a greater range of effective solutions. Furthermore, determining the comparative effectiveness of each management approach and examining the relative effect of the therapist's suggestions, caregiver-initiated approaches, and joint solutions would provide important insights from which to guide occupational therapy practice.

Practice Considerations

Occupational therapists offer a unique and critical contribution to helping caregivers maintain elderly persons with dementia in the home. Working with caregivers in their home offers a new consultative model of practice and presents three challenges to the profession. The first challenge is to establish a mechanism for payment for such services. A critical limitation to this intervention approach is that to date, occupational therapists cannot be reimbursed by third-party payers for these services; therefore, such services must be developed in tandem with other types of hospital or community-based programs that can absorb the costs. Hospitals experimenting with diversification of services in geriatric long-term care may endorse such an approach as part of a broader com-

petitive marketing campaign to capture the geriatric consumer (Capitman et al., 1988). Although current congressional discussions and legislative hearings may expand reimbursable services to this population, there is currently no mechanism in place to do so. Home care therapists are perhaps in the best position to adopt these intervention principles and may receive Medicare reimbursement for documenting improved functioning of the care recipient. In addition, therapists in private practice can market this service model to clients who pay their own expenses and can maintain treatment documentation that supports expanding reimbursement at the state and federal levels.

The second challenge to the profession is to develop innovative educational models to train therapists to use this framework. Intervention effectiveness depends on the therapist's ability to assume and understand the caregiver's perspective, creatively adapt the principles of competence-environmental press to specific household arrangements, and suspend a medical model framework while collaborating with persons from diverse socioeconomic and cultural backgrounds. Such treatment assumptions necessitate the development of educational models that emphasize team assessment and treatment approaches, expose therapists to treatment in the home, and orient therapists on assuming a caregiver or insider perspective to jointly derive meaningful and relevant care management strategies.

The third challenge to the profession is to further develop and refine therapeutic strategies that address the multiple needs of caregivers as identified by caregivers. The intervention methods described here may work for one group of caregivers but not for all. These methods may have to be extended, modified, and adjusted to enhance the well-being of other caregiver groups. An evaluation of the relative effectiveness of specific environmental solutions for particular caregiver groups warrants further research. Future studies must also examine the interactive effects of time, experience, and caregiver stress on the ability of a specific caregiver to benefit from this or any other type of intervention.

Conclusion

This paper presented an intervention approach designed to enhance caregiver use of the environment to solve behavioral problems associated with a person with dementia. The intervention is grounded in a competence-environmental press framework and the principle of collaboration. The documentation form developed for the intervention provides an ongoing evaluative tool to determine therapeutic effectiveness, rate of caregiver change, and those problem areas that pose a particular challenge to the therapist and caregiver.

This intervention approach offers three potential benefits. First, the effective application of principles of the competence-environmental press model may lead to

decreased caregiver stress and an improved sense of efficacy in the caregiver's ability to manage daily behavioral problems. Bandura's (1977, 1982) study of association between efficacy and competence demonstrates a strong positive relationship between sense of efficacy and one's actual performance or ability to accomplish tasks. Conversely, experiences of mastery or achievement reinforce expectations of efficacy (Bandura, 1977).

Second, the intervention may have long-term benefits. The expansion of a caregiver's ability to solve problems may enable him or her to generalize environmental strategies introduced during the intervention phase to new problem behaviors that emerge over time. Thus, one carryover effect of the intervention may be to prolong caregivers' ability to manage progressive behaviors of the person with dementia. Telephone interviews with selected caregivers after 3 months of participation in this service model indicated that their understanding of environmental influences was enhanced and that they were able to apply the skills developed during the intervention to other problem situations several months after the intervention had ended (Gitlin & Corcoran, 1991b). The long-term benefits of the service for both the caregiver and care recipient need to be systematically tested.

Third, the concept of collaboration is especially compelling in a community-based service model that requires caregivers to develop skills to adapt their physical and social environments. The concept of a client-centered and collaborative approach to care has emerged in the occupational therapy and health care literature as a pivotal factor to assure treatment efficacy (Peloquin, 1990; Shelton et al., 1989). However, these relationships and the effectiveness of collaboration need continued testing. Such research will also provide the necessary evidence to support development of a payment structure and health service provision system that includes the critical perspective and skills of occupational therapists. ▲

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