

1-1994

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Corcoran, Mary A., "Management decisions made by caregiver spouses of persons with Alzheimer's disease." (1994). *Department of Occupational Therapy Faculty Papers*. Paper 56. <https://jdc.jefferson.edu/otfp/56>

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Management Decisions Made by Caregiver Spouses of Persons With Alzheimer's Disease

Mary A. Corcoran

Key Words: caregivers • occupation

Objectives. As the incidence of Alzheimer's disease increases, so does the effect on families and friends who assume caregiving responsibilities. Despite the proliferation of caregiving studies reported in the literature, little is known of the day-to-day management styles and preferences of caregivers. To develop, implement, and test interventions designed to sustain caregivers in their role, more information is needed about the caregiving experience. Results of a descriptive study are presented as a first step in understanding the complex process of choosing, organizing, and implementing everyday caregiving tasks.

Method. Subjects of the study were 26 persons who provide care for a spouse with moderate impairment from Alzheimer's disease. Interview data were analyzed with grounded theory techniques to isolate the purposes behind the management decisions of spousal caregivers.

Conclusion. Implications are presented for occupational therapy intervention to assist caregivers in gaining the knowledge and skills necessary for effective and efficient management of problem behaviors associated with Alzheimer's disease.

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This article was accepted for publication May 10, 1993.

Americans are facing a caregiving crisis, fueled by such demographic trends as the rapid growth in the oldest segment of our population, increase in incidence of Alzheimer's disease, and reduction in the birth rate resulting in fewer children to care for aging parents (Blazer, 1990; Evans, Scherr, Cook, Albert, & Funkenstein, 1990). In addition, economic necessity has prompted more women to enter the workforce, thereby further eroding the pool of available caregivers. The term *caregiving crisis* reflects the profound negative physical and emotional consequences of caregiving experienced by family members, who provide 90% of the long-term care in the United States (Pepper Commission, 1990). Especially at risk in this crisis are spousal caregivers of a person with Alzheimer's disease, because these caregivers (a) reside with the care recipient, (b) care for a moderately to maximally impaired person, and (c) are usually the primary source of care (Anastas, Gibeau, & Larson, 1990). For these reasons, the caregiving crisis has emerged as one of the most complex personal and public policy issue of the 1990s.

A foundation of descriptive data has been established concerning who engages in caregiving and the work requirements of that role (Corbin & Strauss, 1988; National Survey of Caregivers, 1988; Stone, Cafferata, & Sangl, 1987). Our present level of understanding about the characteristics and needs of caregivers indicates the direction of a next-step in caregiving research—a systematic exploration of the caregiving experience, especially the decision-making processes guiding daily management choices. The study presented in this paper is a fundamental description of the daily care decisions made by spousal caregivers in their effort to shape the way dementia affects the impaired person and the family. Thus, findings will provide a groundwork for future directions taken in occupational therapy practice and research.

Overview

The basis for examining the daily care decisions of caregivers was informed by the limited body of literature currently available on this topic. Corbin and Strauss's (1988) catalog of work performed by caregivers provided an initial glimpse of what caregivers do on a daily basis, and Bowers' (1987) analysis of the purpose underlying caregiving tasks furnished a conceptual basis for the study presented here.

The Structure of Caregiving Work

Corbin and Strauss (1988) asserted that management of a chronic illness is best understood from a sociological rather than a medical perspective. They argued that the affected person and family envision and actively modify the influence of chronic illness on their lives. In this way,

symptoms, level of disability, and the eventual outcome are shaped by those who are most affected. For instance, families make daily choices that manage the way chronic illness unfolds, such as whether to use outside services or how to distribute responsibility for care among family members. The shape of a course of illness, called an *illness trajectory*, is dependent on the interplay of many variables, including the nature of the illness, the beliefs and responses of people affected by the illness, and the actions of health care personnel (Corbin & Strauss, 1988, 1991). The variability of this interplay is notable in the case of dementia, where the shape of the dementia trajectory is particularly influenced by the interrelationships among the caregiver's approach to care provision, the family structure, and the family's cultural perspectives on disability and quality of life (Corcoran & Gitlin, 1991).

Shaping a trajectory can involve a formidable amount of work for the chronically ill person and his or her family. In the case of dementia, the work necessary to shape a trajectory, termed *illness trajectory management* (Corbin & Strauss, 1988) may be entirely assumed by one or two caregivers. This process of actively shaping an illness trajectory involves the players in a spiral of work to be done throughout the course of illness. Corbin and Strauss (1988) described this work spiral as consisting of three lines of work: illness work, biographical work, and everyday work. Trajectory management requires the players to balance the demands for attention among and within the three lines of work briefly described below.

Illness work refers to the process and tasks of directly managing the illness itself. Illness work has the effect of diagnosing and medically managing the disorder or preventing secondary problems, as illustrated by seeking second opinions or trying experimental drugs.

Biographical work is observed in the family's efforts to define and maintain individual and family identity. Biographical work may be carried out toward many ends, such as incorporating limitations into one's identity or reconceptualizing oneself in light of the illness. This type of work is important in dementia and difficult to accomplish because of the dynamic nature of the symptoms. When a decline is noted in cognitive abilities, the person and family must incorporate this change into a new image of self and family. For instance, an impaired person who is no longer considered able to drive safely will need other outlets for exercising independence. Likewise, the spouse of this person will take another step in the transition from equal partner to caregiver (Hasselkus, 1988).

Everyday work refers to routines of daily chores necessary for care provision and home maintenance. Everyday work may be influenced by illness work or biographical work, as in situations where a caregiver spends time engaged in certain household tasks, such as constantly tidying up, to eliminate confusing stimuli and promote productivity by the impaired spouse (Corcoran & Gitlin, 1991).

These three lines of trajectory management work exist in a state of tension because all cannot be equally addressed at the same time. Focus shifts among the three lines of work in response to dynamic circumstances in the illness, biographical, and everyday work demands. Each day, the caregiver must prioritize the workload and decide on a course of action by choosing which work tasks and processes fit his or her vision of the dementia trajectory. For example, a caregiver may choose to spend time preparing a tempting meal (focusing on physical health) instead of helping the impaired spouse to engage in a valued pastime (focusing on emotional health). By cataloging what work is performed by caregivers and the interrelationships among those work lines, Corbin and Strauss' (1988) analysis served as a solid beginning for further investigation of the caregiving experience.

The Purpose of Caregiving Work

Another key to understanding the caregiving experience was offered by Bowers (1987), who conducted a grounded theory analysis of the intended purpose, or meaning, of work performed by intergenerational caregivers. In that study, women caregivers caring for an institutionalized parent with cognitive or mental disability or both were interviewed about the work they performed as caregivers. Analysis of those in-depth interviews isolated five categories of work, according to purpose, as anticipatory, preventative, supervisory, instrumental, and protective (Bowers, 1987).

As suggested by Bowers, any given behavior may have one or more tacit purposes that supersede the overt reasons for the behavior. For instance, dressing someone in his or her favorite clothes is simultaneously instrumental care and protective of the care recipient's self-esteem. This dual purpose is illustrated in the following statement: "After he [care recipient] gets dressed, he looks like a million dollars and he's very pleased with himself. I take him down to the dining room to eat and he loves it." In this way, the act of dressing someone is performed not only to don clothing, but also to influence that person's self-image and to perform important biographical work. Thus, categories of work performed by caregivers overlap, although they are conceptually distinct.

Bowers suggested that tensions normally associated with caregiving are unrelated to task performance, but may result from the caregiver's unfulfilled commitment to the purposes of caregiving. For instance, the caregiver quoted above may help her father to dress quite appropriately, but is likely to agonize over whether he truly feels pleased with himself as a reflection of his appearance.

Although useful for understanding the intent of several caregiving management strategies in that particular population of caregivers, the generalizability of Bowers' results to other groups of caregivers cannot be assumed.

Spouses caring for a person in the community demonstrate several important differences from the sample in the Bowers study. First, challenges in the community are different from those in an institution. Although the physical environment in an institution may contain fewer confusing stimuli than the home does, it is unfamiliar and may not support engagement in former valued roles. This suggests that caregivers of institutionalized elderly persons must develop different strategies to retain the care recipient's connections with activities that support self-image. Second, it is likely that the spousal caregiver is the primary caregiver, if not the only caregiver. Contrast this arrangement with that of an institution, where several (sometimes unfamiliar) caregivers rotate through the impaired person's daily routine. Third, because the spousal caregiver resides with the care recipient, their lives are intertwined. As in any family system, changes in one spouse will prompt changes in the other. Fourth, the sources of stress and societal expectations about caregiving differ for intergenerational caregivers when compared with spousal caregivers (Brubaker, 1990). Because of these important differences between intergenerational and spousal caregiving, and between caring for an institutionalized and a community-dwelling impaired person, it is compelling to examine the relevance of Bowers' concepts to actual data from spousal caregivers.

Method

Subjects were 26 persons, each of whom was the primary caregiver for a husband or wife with moderate impairment from Alzheimer's disease. Data originally gathered as part of a 2-year efficacy study (Gitlin & Corcoran, 1991) were analyzed *ex post facto* for this spousal caregiving study. Eligibility criteria required the caregiver to provide assistance with two or more self-care tasks, such as dressing or bathing, on a daily basis. Potential subjects were recruited through a network of agencies providing evaluation, referral, and support services.

Of the 26 subjects available for inclusion in this study, 11 were men and 15 were women. Subjects were predominantly elderly (mean age = 72 years), white (2 subjects were black) persons from a middle-range socioeconomic status (mean income = \$1944 per month), and had at least a high school education. Most of the caregivers were retired, although two worked part-time and two worked full-time, and had been providing care to an impaired spouse from 26 to 45 months. Twenty households consisted of the caregiver and care recipient only. In those six households with residents other than the caregiver and care recipient, five consisted of one other person only, usually an adult child.

Data were collected by an independent interviewer as part of the larger efficacy study and proceeded in the following manner. During a 2-hr interview, subjects were read three vignettes dealing with common caregiving is-

suues and asked to give as many solutions as possible for the problems in the vignette. Based on an outcome measure developed by Lovett and Gallagher (1988), the vignettes asked the subjects to suggest management strategies to address three problem behaviors: repetitive questioning, forgetfulness, and difficulty with dressing. An example of one vignette is offered in the Appendix. The subjects' responses to the vignettes were recorded on tape and transcribed by the interviewer. The subject was revisited by the interviewer 3 months later and again asked to suggest solutions for the problems depicted in the vignettes. Both sets of interviews were analyzed by the author with grounded theory techniques.

Grounded theory is particularly relevant to this study because the subject matter has not been comprehensively studied and deals with the caregiver's perceptions and actual decisions about trajectory management. Because this topic has been previously unexplored and theories about care management decisions do not exist, it is appropriate that "one begins with an area of study and what is relevant to that area is allowed to emerge" (Strauss & Corbin, 1990, p. 23). In grounded theory analysis, concepts in the data are identified, then extensively compared and contrasted. From this *constant comparison* method (Strauss & Corbin, 1990) emerges a taxonomy of meaning that tells a story of the caregiving experience. Presented in this paper is one chapter in that caregiving story, the daily management strategies used by spousal caregivers to shape their dementia trajectories. This is a complex story, reflecting the intricacies of the caregiving role, in which management strategies overlap and serve several purposes simultaneously.

Assuring Credibility in Grounded Theory Analysis

In naturalistic studies, including grounded theory analyses, methods of assuring accuracy and rigor in data collection and analysis are different from criteria used to evaluate experimental studies. Despite the differences in methods, however, the underlying concern of both naturalistic and experimental investigators is with enhancing the credibility of the study's findings and interpretation (DePoy & Gitlin, 1993). Following are several criteria traditionally used to judge naturalistic studies, and the application of these criteria to the spousal caregiving study.

Saturation

Saturation refers to the point in the study where all new data can be integrated into the investigator's understanding of the phenomenon (DePoy & Gitlin, 1993; Strauss & Corbin, 1990). Saturation has been achieved when new data do not provide additional insights; at that point, data collection is complete (DePoy & Gitlin, 1993). In this spousal caregiving study, gathering data from three vi-

nette responses at two different times added to the likelihood of saturation by expanding the investigator's immersion in the phenomenon of interest, caregivers' management strategies.

Audit Trail

Naturalistic investigators must be prepared to substantiate their findings with a trail of thoughts and actions that reveal the reasoning behind data analysis and interpretation (DePoy & Gitlin, 1993). This trail is referred to as an *audit trail* (Guba, 1981). Although several systems are available for creating an audit trail, this investigator used a process known as *memoing* (Strauss & Corbin, 1990). When memoing, the investigator records how his or her theoretical consideration of the data evolved over time. In this way, the investigator can achieve a level of analytical distance from the data (Strauss & Corbin, 1990) and provide extensive records of how the results were obtained.

Reflexivity

Although investigator bias cannot be eliminated entirely, it can be reduced through a process of self-examination termed *reflexivity* (DePoy & Gitlin, 1993). This reflective process is an examination of the investigator's thinking process and how his or her interpretations may have been influenced by personal perspectives on the phenomenon of interest. The *memoing* technique described earlier was used by this investigator to consistently identify and examine the factors influencing how management strategy categories emerged in data analysis.

Results

Bowers' (1987) conceptualization of the purpose of caregiving work as consisting of five conceptually distinct but overlapping categories can be extended to caregiving spouses. Overall, these categories (anticipatory, preventative, supervisory, instrumental, and protective) were supported in the data from caregiving spouses, although some important differences can be noted and are presented in the following discussion.

Anticipatory Care

Bowers defined anticipatory care as "behaviors or decisions that are based on anticipated, possible needs" of a care recipient (1987, p. 25). Likewise, the subjects of this study placed a high value on anticipating the needs, responses, and wishes of the impaired spouse. For instance, one caregiver noted proudly that he was able to guess his impaired wife's thoughts, thereby making it possible for him to "know exactly what to do with any

motion she makes. I just know how to correct it, I've been around her that long." Caregivers in the sample offered few strategies for anticipatory care but implied this knowledge was obtained through years of association as a married couple. One caregiver did note that this type of care was facilitated by assessing "the makeup of the patient and how you will handle him and what he will do."

The intergenerational caregivers in Bowers' (1987) study intentionally hid this form of caregiving because they feared insulting their parents through obvious anticipatory care. In contrast, spousal caregivers were vocal about this type of care and mentioned correct anticipation of the care recipient's needs with notable pride. Successful anticipation was a valuable skill that came with experience and, at times, represented affection between the spouses. Caregivers often noted that their role in anticipating and satisfying their spouse's needs resulted in perceptions of happiness, such as "feeling like a million bucks" or being glad of an opportunity to show love for the spouse.

Preventative Care

This type of caregiving involves active monitoring to prevent physical injury or illness and mental deterioration (Bowers, 1987). Spousal caregivers in the sample were firmly committed to the need for preventative care, especially to avoid physical injury. Preventative care was often suggested to "prevent a fall" or avoid serious medical complications by taking the care recipient "to the doctor and find out the reason."

A few caregivers used mental exercise ("Name each of the United States") to prevent mental deterioration, but for the most part, caregivers in the sample did not suggest any attempts to stave off the spouse's inevitable mental deterioration. Any strategies to prevent mental deterioration were usually performed in the context of other care tasks, such as instrumental care, and centered on reinforcing reality ("Just argue with him that he did eat: 'You did eat, you just don't remember'"; "Point out to him that you only wear one pair of pants at a time"; "Just say quietly, 'Hey honey, you have your bra on the outside, put it on the inside'").

Although Bowers (1987) described the tactics of preventive caregiving as including alterations to the physical environment, this was not the case with spousal caregivers in this study. The major activities suggested to prevent harm included good nutrition and use of formal supports ("It would be worthwhile asking the doctor. [I would do] what the doctor would tell me and we would work it out together") to prevent problems and complications. Although spousal caregivers did advocate modifying the environment, this was primarily done to protect the impaired spouse's emotional health (discussed in section on Protective Care).

Supervisory Care

Bowers described supervisory care as highly active, direct monitoring of the care recipient for difficulty during activities. Numerous statements from spousal caregivers, such as "Watch that he puts on the right clothing," "Check to see if she has underwear on," "Just being nearby to see what she is doing wrong and assist her," and "Keep an eye on her and make sure she goes to the bathroom," underscored the value of supervisory care and recommended amount of time devoted to it. As noted, and in keeping with levels of overlap among the caregiving lines of work noted by Corbin and Strauss (1988), supervisory care is often carried out in conjunction with instrumental, anticipatory, supervisory, or protective caregiving. For example, one caregiver gave his wife a doll to hold when she got restless. She enjoyed the doll tremendously and treated it like a real child, thereby recreating a highly valued former role. When her attention was focused on the doll, her husband's need to monitor her closely was reduced, and he was able to prepare dinner. In this way, this caregiver carried out supervisory, instrumental, anticipatory, and protective care simultaneously.

One management strategy, limited access, has application to several lines of care but is often used to carry out supervisory care. Limited access requires the caregiver to restrict the freedom of his or her spouse to access certain objects or areas of the home. Caregivers in the sample recommended locks ("Lock up the things and he will forget about them"; "Lock her clothes up"; "Put locks on the door"), hiding and storage places ("Hide the food"; "Put away inappropriate clothing for the season"), and other restrictions ("Keep him out of the room where the clothes are"; "Keep her out of the kitchen") to limit access. These strategies made supervising the care recipient's movements easier.

Instrumental Care

Instrumental care is the set of tasks that traditionally come to mind when caregiving is considered. Instrumental care includes dressing, meal preparation, bathing, grooming, and other related tasks. Bowers (1987) asserted that caregivers consider instrumental care to be the least important type, and her conclusion is supported in this study. Although spousal caregivers often discussed their instrumental care, it was usually presented as the context for other types of care, especially protective caregiving ("Put your arm around her shoulder and tell her, 'Come on sweetheart, let's get you changed'"). One caregiver demonstrated her combined preventative and instrumental care when she stated, "In order to get the nutrients in him that he needs, she's going to have to feed him." In this statement, the purpose of feeding the spouse supersedes instrumental care and targets good nutrition (prevention).

When instrumental care was mentioned in isolation, the strategy most often suggested to implement it was physical assistance by the caregiver ("Prepare her clothes every day and get [the area] ready and help him get dressed"; "I have to get her clothes out every day"). A second strategy for implementing instrumental care centered on instructing the impaired spouse to perform instrumental work ("I make him take off a pair"; "I just talk him into it"). Caregivers recognized the importance of appropriate instructions to success of the plan ("I always take special care with instructions") and advocated a wide range of methods from commands to gentle persuasion. Almost all caregivers used verbal instructions, ignoring other avenues of communication such as hand-over-hand guiding.

An instrument strategy that was less frequently used, but still notable, involved role modeling ("She watched me and I'd have a portion of whatever it is and she'd have the same thing"). Again, these strategies usually were mentioned with the purpose of demonstrating other types of care, such as protection ("Make light of it and say 'Honey, wasn't that a funny thing that you did? Isn't it funny to wear your bra on the outside?'").

Protective Care

The purpose of protective care is to shield the impaired spouse from "consequences of that which was not or could not be prevented" (Bowers, 1987, p. 26). Consequences can be thought of as threats to self-esteem, sense of well-being, and dignity. For instance, if an impaired husband's deterioration cannot be prevented and he is no longer able to work outside the home, the caregiver may protect the spouse's self-image by engaging him in productive, adult-oriented work activities. Consistent with Bowers' conclusion that protective care was considered by caregivers to be the most important and most difficult to implement, the spousal caregivers in this study were highly concerned with protecting the impaired spouse and offered many suggestions for carrying out this important work.

Protective care is conducted by spousal caregivers during other daily activities. For instance, how instrumental care was approached often implied the more fundamental protective care that was being performed. One caregiver engaged his wife in the instrumental care of the home (drying dishes) so that "She feels better about herself. At the end you say 'Thank you very much' even though you could do fifty times as much." Apparently, this caregiving husband was less concerned about getting the task done than about protecting his wife's self-image.

Five categories of management strategies, specifically intended to protect the self-image of care recipients while conducting other caregiving work, were suggested by spousal caregivers in this study. They are engagement in productive activities, distraction, error-proofing the en-

vironment, strategic time use, and maintained involvement with friends and family. These strategies were not emphasized by Bowers' (1987) intergenerational sample, possibly reflecting a different constellation of tasks necessary to care for an adult residing in an institution.

Engagement in productive activities. Spousal caregivers are especially inclined to protect the care recipient's self-image by maintaining that person in as much productive activity as possible. Particularly popular suggestions are highly familiar, gross motor, repetitive activities that have a predictable effect on the environment. Productive activities that meet these criteria and were recommended by the sample included washing dishes, sweeping the floor, picking the grass out of the garden, folding laundry, making the bed, washing windows, dusting, and polishing the furniture. Interestingly, these are precisely the types of activities recommended by Levy (1986) for persons at a midpoint in their cognitive decline.

Distraction. Although some caregivers valued distraction to get the impaired spouse "out of my hair," most suggested this strategy to divert attention from difficult topics ("Walk out of the room for a couple minutes and maybe by the time I get back, she will have forgotten"). The implied intent of distraction for this reason was to preserve the harmony in the home and the impaired spouse's emotional well-being.

Although all caregivers in the sample valued distraction, suggestions for use of this management strategy ranged from distraction with socially interactive activities to distraction with objects that leave the caregiver free to pursue other tasks. Those caregivers who recommended distraction with objects usually suggested items with symbolic meaning ("I go grab the baby doll and give it to her. She hugs it and kisses it and forgets everything"). Caregivers who preferred socially interactive activities usually used themselves or another person to divert the impaired spouse's attention ("Go to the market with her or something"; "Take him to the park"; "Invite someone in to entertain him"; "Tell her funny stories, get her laughing"). A third method of distraction involved attempts by the caregiver to have the impaired spouse distract himself or herself with an activity that involved minimal interaction with the caregiver ("Go sit down and watch TV or do something to amuse yourself"; "Tell [him] to go take a walk somewhere, not outside because he won't go out. I mean, he will but I have to go with him"). Thus, distraction is a flexible tactic that has application to a number of purposes and management styles.

Error-proofing. Error-proofing is suggested by spousal caregivers to adjust the objects or tasks in a way that eliminates the possibility of error by the care recipient. When successful, error-proofing allows the care recipient to complete a task independently or with minimal assistance. Error-proofing is a useful, often necessary way to engage in protective work because it allows opportunities

for productive activity by the care recipient and is therefore beneficial for self-esteem. However, this management strategy increases the caregiver's workload because he or she must identify and modify objects and tasks. Error-proofing usually requires the caregiver to set out all necessary items, sometimes in sequence, and eliminate all extraneous objects from view ("the dresser is free of all objects"; "I wouldn't put everything on the table. I would just give him one serving at a time"). Error-proofing may also involve presenting the objects in a compelling way ("You have to cut and slice it so she will eat it") or in planned portions ("Cut the portions in half"; "Then the plate looks full, and it is not full of fattening foods").

A second form of error-proofing requires the caregiver to complete several steps in the activity to support the impaired spouse's competencies. One wife explained, "[I will say] 'Suppose you wipe the dishes for me? Listen, don't put them away, just put them over here on the counter for me and I'll put them away later' because I know he doesn't know where they go." A third form of error-proofing requires the caregiver to relax the rules typically associated with an activity, thereby eliminating the possibility of error ("I would just let him mix everything together").

Strategic time use. As part of protective care and in an effort to avoid boredom or anxiety, caregivers will often try to stretch activities to fill as much of the day as possible. One caregiver described her efforts at avoiding her husband's repetitive questions about his dead mother, which upset them both. She relied on a sequence of planned activities performed slowly with waiting periods between each, as she observed was done in her husband's adult day care program. She commented that stretching time is successful because "Before you know it, the day is done, that's how I solve it." However, even during unplanned activities in the home, caregivers note that they stretch the time taken for the impaired spouse to perform activities ("That way he'll sit and eat it slowly"; "Stretch out the meal for an hour or so—let it take up some time"). These strategies were offered as one tactic for avoiding problem behaviors and upset for both spouses. Thus, it appears that stretching time may have some protective function for the caregiver as well as the care recipient.

To a lesser degree, caregivers in the sample used time to provide cues about expected behavior to the care recipient. This was done by planning the events of the day and creating a routine. Even within the temporal boundaries of a given task, a routine was beneficial for promoting independence and self-image ("Have a period for dessert and have a period for salad and have a period for the main meal").

Maintained involvement with friends and family. When one caregiver noted that "they have to remain part of the family," she spoke to the belief of many caregivers that maintained social ties are beneficial. These care-

givers appear to be responding to their spouse's need to remain part of the family and community, thereby promoting a healthy self-image. At times, this can be a difficult undertaking, especially if physical distance or fear of judgment separates social networks. Suggestions for maintaining social ties were diverse. Several caregivers recommended getting out of the home to "intermingle with other people" and suggested a good tactic would be to "go walking in the mall, let her see the store windows and the lights." Other caregivers focused their efforts on involvement with the family to engage the impaired spouse in a productive activity ("Get a member of the family or maybe a neighbor that he confided in to get the photos out and start putting them in; Insist on going with friends and neighbors"). Spousal caregivers in this study appear to value maintenance of the impaired person's place in the family and are sometimes willing to expend considerable energy to do so.

To summarize, spousal caregivers in this study made decisions about daily management practices that reflected an effort to anticipate the care recipient's needs, prevent harm, supervise actions, perform instrumental tasks, and protect self-esteem. Further, the caregivers appeared to advocate strategies that simultaneously satisfied two or more purposes for caregiving. These findings suggest that caregivers make management decisions based on a personal vision of a dementia trajectory, regardless of whether the individual caregiver had consciously specified the shape of such a trajectory.

Implications for Practice and Research

Although reimbursement for occupational therapy intervention in Alzheimer's disease is severely restricted, the demographics of this disease suggest that occupational therapists will increasingly encounter clinical situations that include a family unit dealing with dementia. It is critical that occupational therapists are prepared to enhance the occupational functioning of family caregivers by supporting, refining, and further exploring the strategies used by caregivers to shape their dementia trajectory. To empower the family to effectively engage in the important work of caregiving, two treatment dimensions should be added to the overall approach.

First, the occupational therapist and caregiver need to understand the caregiver's preferences for certain management strategies. They can do so by labeling strategies as they are observed or mentioned and reflecting on the frequency with which they are used. These preferences, once understood, will provide the basis for further discussions to clarify the caregiver's overall approach and desired outcomes. For instance, if a caregiver prefers to manage problem behaviors through distraction and error-proofing, he or she may place these strategies at the center of an overall management plan. On the basis of that plan, he or she may decide on specific outcome

measures that include care recipient engagement in productive activities and less caregiver upset with problem behaviors. Hasselkus (1990) advocated use of ethnographic interviewing to discover the caregiver's preferred management style. Ethnographic interviewing includes probes, such as "Tell me more about how you handle this problem," that can facilitate dialogue between caregiver and occupational therapist about management preferences and goals.

Second, occupational therapists may help to emphasize gratifications from caregiving such as those found as a result of anticipatory care. As was seen in this sample, caregivers expressed satisfaction when the needs of their family member were correctly guessed. By encouraging caregivers to recognize and act on their own intuitions about care recipient needs and desires, occupational therapists may tap a previously unrecognized source of caregiving satisfaction.

The study presented here also has implications for future research directions, including theory building about the caregiving experience. Through systematic exploration of the occupations of caregivers, caregiving models can be developed and refined. Based on those models, principles for supporting and refining naturally occurring management styles will provide a foundation for new occupational therapy treatment approaches to Alzheimer's disease. Clinical research is also indicated to test the effectiveness of treatment approaches for both caregivers and their impaired family members.

Although the study presented here is only an initial step in understanding the caregiving experience, it represents a necessary direction for occupational therapists who work with the caregivers of elderly persons with dementia. As a consequence of the profession's commitment to occupation, occupational therapists have an obligation to empower caregivers to shape their own and their family member's lives in meaningful and relevant ways. ▲

Acknowledgment

I thank the American Occupational Therapy Foundation for its financial support of the data collection.

Appendix: Problem-Solving Vignettes

Read the following to the participant:

"We are interested in finding out how caregivers approach caregiving problems. I am going to read a story in which the main character has a problem. Then I am going to ask you some questions about what the main character might do to resolve his or her problem. I would like to tape record your answer so that I don't miss anything you say. Is that all right with you?"

If the participant is concerned about the taping, remind him or her that the answers are held in confidence. (All the re-

sponses are given a code number instead of being identified with a name, and this data is seen by the principal investigator only.)

"OK, here is the story:

Mrs. W. is taking care of her elderly husband with dementia. Her husband had always worked hard all his life, but now he really can't do very much. He follows Mrs. W. around the house all day asking 'What can I do now?' This is driving Mrs. W. crazy. Tell me as many things as you can think of that Mrs. W. can do to solve this problem."

Prompt: Can you think of any other things Mrs. W. might do?"
Use this prompt only twice.

"What obstacles might get in the way of Mrs. W.'s attempts to solve this problem? Tell me as many different obstacles as you can think of."

Prompt: "Can you think of other obstacles?" *Use this prompt only twice.*

Go on to the next story

Source: Modified from instrument in Lovett, S., & Gallagher, D. (1988). Psychoeducational interventions for family caregivers. Preliminary efficacy data. *Behavior Therapy, 19*, 321-330.

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