

11-1992

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Recommended Citation

Corcoran, Mary A., "Gender differences in dementia management plans of spousal caregivers: implications for occupational therapy." (1992). *Department of Occupational Therapy Faculty Papers*. Paper 32.

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Gender Differences in Dementia Management Plans of Spousal Caregivers: Implications for Occupational Therapy

Mary A. Corcoran

Key Word: Alzheimer's disease

Occupational therapists treating older people with Alzheimer disease know that they must also consider the others who are affected by the disease, the informal caregivers. Intervention is most effective when it enables both the impaired person and the primary caregiver to manage the secondary symptoms of dementia. Unfortunately, little is understood about how caregivers approach and carry out their tasks and about why male and female caregivers respond differently to their caregiving role in terms of depression, burden, stress, and substance abuse.

This paper discusses the effects of gender on dementia management plans of spousal caregivers. Husbands and wives have different approaches to caregiving; each approach has consequences. Male caregivers adopt a task-oriented approach to their duties and carry out their activities in a linear fashion; female caregivers use a parent-child approach and nest activities inside one another in a constant stream of work. Two cases are presented to illustrate gender differences in dementia management plans. Implications for occupational therapy include suggestions for supporting men and women in their caregiving role, modulating the negative consequences of caregiving, and conducting research to demonstrate the efficacy of an occupational therapy approach.

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This article was accepted for publication May 11, 1992.

The issue of elder care, especially for persons with Alzheimer disease, is emerging as one of the most complex personal and public policy issues of the 1990s. As the population ages, the incidence of Alzheimer disease is expected to rise proportionately. A growing network of informal caregivers provides 80% of all long-term care for persons with Alzheimer disease (Pepper Commission, 1990; Select Subcommittee on Aging, 1987). These informal caregivers are usually family members who sacrifice their own needs to provide daily care to a loved one. Most of these informal caregivers are women, although a study that considered only spouses found men and women equally likely to assume responsibility for care (Pruchno & Resch, 1989). Caregivers of spouses with Alzheimer disease are especially vulnerable to the profound effects of caregiving because the caregiver resides with the impaired spouse, the spouse is likely to require moderate to maximal levels of care, and the caregiver is usually the primary source of care (Anastas, Gibeau, & Larson, 1990).

Caregiving has been grimly described as a role that is "devoid of formal training, choice, and compensation" (Pruchno, Kleban, Michaels, & Dempsey, 1990, p. P193). Despite the proliferation of caregiving studies in the literature, little is understood about why people take on arduous caregiving duties, how they approach their tasks, and what consequences follow. For enhanced understanding of the caregiver experience, an accurate description of the caregiving context that includes gender, familial relationship, cultural background, and the illness characteristics of the care recipient is needed (Gwyther & George, 1986).

The purpose of this paper is to describe the effects of two aspects of the total caregiving context, gender and spousal relationship, on dementia management plans. A *dementia management plan* is defined as the caregiver's conscious or unconscious beliefs about which course of action will most effectively control the symptoms of dementia and promote quality of life. Thus, dementia management plans are value laden and based on the family's beliefs about illness, disability, and family roles. Described in this paper are the different approaches of husbands and wives to caregiving and the consequences of each approach, the effect of those different approaches on dementia management plans, and implications for occupational therapy.

Different Approaches to Caregiving: Linear Versus Enfolded

Many women, especially those with a traditional view of women's roles, experience difficulty balancing work and family responsibilities (Hochschild, 1989; Montgomery & Datwyler, 1990). A traditional view regards women's work as concentrated in the home sphere and less powerful than men's work; it considers that caregiving tasks fall

within the parameters of what women are socialized to do, especially because the workplace of caregiving is the home. Most current caregiving wives are traditionalists, having been socialized to their role before the sexual work revolution described by Hochschild (1989). This ongoing revolution began in the early 1980s, is based on economic and social realities of the 1980s and 1990s, and has resulted in increasing numbers of women in the work force. The sexual work revolution challenges the traditional view of women's work and promotes equal power for equal paid and unpaid work.

Despite the movement of their daughters from the kitchen to the board room, the cohort of women aged 65 years and older who are caring for a spouse with Alzheimer disease is not fully represented in the workplace. For these older traditionalists, women's work roles are centered in the home and reflect a greater sense of social obligation. Labels for this type of work, such as *social director*, *kin keeper*, and *family caretaker*, underscore the frequency of women's interaction with family members and their sense of social connectedness (Sherman, Ward, & LaGory, 1988; Spitze & Logan, 1989). Several authors identify social connectedness as the basis for women's nurturing approach to caregiving (Gilligan, 1982; Patterson, 1987). Thus a traditional perspective on women's work will influence a caregiving wife not only to highly prioritize the care of her husband, but also to focus her energies on the emotional atmosphere of the home.

Many elderly women have absorbed this traditional societal view of women's roles so completely that they have been caught in what feminists call the *comparison trap* (Wilson, 1990). The comparison trap is women's absorption of misguided societal expectations about the high level of self-sacrifice required by the caregiving role. Stressful, burdensome duties are performed as a labor of love, and personal needs must be sacrificed to provide care. Feelings of anger, resentment, and pain are wrong and cannot be acknowledged without intense guilt. The comparison trap works by reducing a social problem (caregiving crisis) to personal attributions of competence. The implication is that a person who is hard-working and competent can overcome lack of support and feeling of burden. One example of this phenomenon in a similar female role is the supermom myth of the woman on the go, organized, and efficient. When a person is unable to function as the mythical supermom (or supercaregiver) does, the comparison trap is sprung and negative consequences occur. Extension of the comparison trap to caregiving suggests that wives may be more likely than husbands to question their own competence when unable to endure the emotional and physical burdens of caregiving. This questioning diverts attention from the responsibility of adequate public policy to support informal caregivers.

Most of the specific reasons for gender differences in the approach to caregiving can be thought of as a conse-

quence of role socialization (Montgomery & Datwyler, 1990). From infancy, persons are shaped to conform to society's norms regarding acceptable attitudes and behavior. Part of this shaping process involves development of each person's gender ideology. *Gender ideology* is defined as beliefs about gender that are based on cultural notions and attached to strong emotions (Hochschild, 1989). Gender ideology defines what it means to be a man or woman in any given society. On the basis of gender ideology, persons develop gender strategies, which are plans of action for solving problems at hand (Hochschild, 1989). One example of a gender strategy is demonstrated when a man who believes that men do not do kitchen work (gender ideology) is never able to find the pots and pans.

Traditional gender ideology dictates that women must expect not only to assume caregiving duties, but also to receive minimal help from male family members (Hartman, 1990; Montgomery & Datwyler, 1990). On the basis of this traditional female gender ideology, women have been found to frequently use a gender strategy called *enfolded activity* (Bateson, 1991) in which they nest one activity inside another, or several others, to accomplish many tasks at once. Enfolded activities are tasks that can be performed while caring for a child, such as homemaking, and are therefore traditional women's work. A historical example of this is the lazy butter churn used by many early English settlers of the United States. The lazy butter churn swung freely on a wall from a wooden support. The settler woman tied a rope from the bottom of the churn to her rocking chair, then continued the rope to her baby's cradle. As she rocked and sewed, the rhythmic movements of the chair were transferred via the rope to both the butter churn and the cradle. In this way, the woman enfolded the activities of churning butter, caring for her baby, and sewing. Contrast the enfolded activity approach with the linear nature of traditional male work (Bateson, 1991). In a linear approach, tasks are initiated and completed one at a time until the job is finished. A historical example of linear work is hunting, which cannot be accomplished while one is engaged in any other activity, especially child care.

Although most people no longer churn butter or hunt for food, women continue to enfold activities and men continue to delegate work to others to proceed linearly (Bateson, 1991). Theoretically, if elderly women identify with caregiving as congruent with their gender identity and have even developed an enfolded activity strategy to enact the caregiving role, they should be highly prepared to be caregivers. However, an irony exists in the overwhelming evidence that caregiving wives pay a high physical and psychological price of depression (Pruchno & Resch, 1989), stress (Anthony-Bergstone, Zarit, & Gatz, 1988), drug use (Clipp & George, 1990; Rodeheaver & Datan, 1988), and burden (Zarit, Todd, & Zarit, 1986). Are caregiving wives using an enfolded activ-

ity approach in caring for elderly husbands, and if so, why does this approach not shield women from the negative consequences of caregiving?

One key to this question lies in the possibility that the type of emotional preparation required for an enfolded approach to child care differs from the type needed to enfold care for an adult with progressive debilities. Emotional preparation is affective work done in anticipation of assuming an arduous role or tasks. Emotional preparation for enfolded activity includes needs reduction, suppression of career ambitions, and shifts in priority of values (Bateson, 1991; Hochschild, 1989); its purpose is to ready the person mentally for the demands of caregiving work. Perhaps the conventional emotional preparations for an enfolded activity approach to child care are inadequate in a spousal situation. When the care recipient is a marriage partner who used to make decisions independently, the caregiver may require other types of emotional preparation to care for him while he deteriorates. Thus, if wives use a conventional emotional preparation that accompanies an enfolded activity approach, they may actually be less emotionally prepared for caregiving than their male counterparts. As demonstrated below, the enfolded activity approach and its necessary emotional preparation predispose women to negative effects from caregiving.

The Effects of Different Approaches From Caregiving

What is the evidence that caregiving wives typically use an enfolded activity approach with their husbands? If an enfolded activity approach is used, are the majority of caregiving wives emotionally prepared to use this approach to care for an adult? The following discussion explores these questions by reviewing three relevant topical areas: (a) the focus of caregiving duties, (b) psychosocial responses to caregiving, and (c) physical adjustments to caregiving.

Focus and Extent of Caregiving Duties

The literature suggests that men and women typically use different models for their caregiving roles. According to Fitting, Rabins, Lucas, and Eastham (1986), women tend to use a parent–infant model, whereas men use a task-oriented model found in the workplace. The contrasts between these two approaches underscore the tension between a traditional enfolded approach and its application to adult care.

The task-oriented model typically used by caregiving husbands focuses on completion of caregiving tasks in the most efficient manner. This completion is often achieved only through delegation of responsibility for everyday tasks to others. Caregiving men are likely to purchase instrumental services for housekeeping and

other physical work, usually from women (Montgomery & Datwyler, 1990; Pruchno & Resch, 1989). In contrast, the parent–infant model used by many caregiving wives focuses on the caregiver's total responsibility for the care and nurturing of the care recipient. The literature demonstrates this assumption of total responsibility in the tendency of women to perform all instrumental caregiving tasks themselves (Montgomery & Datwyler, 1990; Pruchno & Resch, 1989). Consistent with this model, women spend more time per week than men in actual caregiving tasks, usually in those involving physical assistance with self-care (Sherman et al., 1988; Spitze & Logan, 1989; Stone, Cafferata, & Sangl, 1987; Young & Kahana, 1989). Consequently, women work longer hours (called a *double day*) that amount to one extra month of work per year (Clipp & George, 1990; Hochschild, 1989). Not surprisingly, this double-day phenomenon exacerbates a preexisting leisure gap, which refers to the disparity in available free time between men and women (Hochschild, 1989).

Use of the parent–infant model, in which all the decisions and work are the responsibility of the parent, may be problematic for women who have only known their husbands as equal, even authoritative, marriage partners. A parent–infant model necessitates a permanent, difficult role transition from spouse to mother. This type of emotional preparation is not part of the conventional work done for an enfolded approach to child care. Old patterns of self-preparation are irrelevant and new ones may not be available, thus the parental caregiving wife is unprepared for the demands of enfolded care.

Psychological Adjustments

Although both men and women express a sense of affection, duty, and obligation as motivators for assuming care responsibilities, more women also report conflicting feelings of constraint and resentment toward their impaired husbands (Fitting et al., 1986). Conversely, many men report an improved relationship with their wives as a result of caring for them. In other words, despite the similar motives of affection and duty, gender differences occur in emotional responses to caregiving. These different responses to caregiving may occur because the male caregivers are assuming a new role, whereas female caregivers are returning to a former role, one they might have thought they had left behind forever. The inconsistency between the role of caregiver and a woman's vision of her golden years is likely to require emotional preparation beyond that typically associated with an enfolded approach. For instance, contrast a mother who delays her career plans in preparation for child care with a caregiving wife who must abandon her career or retirement plans as part of her emotional preparation. The emotional preparation tasks of needs reduction, suppression of career ambitions, and shifts in priority of values may be

adequate only under certain circumstances, such as time-limited child care.

Because of inadequate emotional preparation and despite traditional gender ideology, a wife may secretly resent that her life is consumed by the care of her husband. These tensions may result in frustration about workload and resentment of the care recipient. Hochschild (1989) refers to this resentment as the "toxic waste" of a relationship, which can block feelings of unambiguous love and motivation for caregiving. This is especially problematic for wives who emphasize the nurturing aspect of caregiving, as is the case in the parent-infant model.

Partly because of their designation as kin keeper, female caregivers demonstrate greater sensitivity and concern for the changed relationship with their spouse than do male caregivers. Continuity and maintenance of the status quo is important to the well-being of caregiving wives (Bearon, 1989). Disruption of life-style interacts negatively with sense of personal competence, need for achievement, and pursuit of personal aspirations (Motenko, 1989). For these reasons, wives may go to great lengths to maintain a semblance of the former productivity and life-style their husbands enjoyed. One caregiver expended a great deal of personal energy in arranging and training volunteers to unobtrusively support her impaired husband during his hospital volunteer work. Female caregivers have also been noted to stage situations in which they act confused, helpless, and frightened so that the impaired husbands can think they are rescuing their wives. Some of the strategies used to empower confused husbands may be difficult for women who have enjoyed positions of responsibility and control in the workplace or at home. Thus, the emotional preparation needed to suppress one's competence is unparalleled in child care.

Perceived benefits of caregiving and motivations for continuing in the caregiving role can spring from many sources. One source of motivation or benefit is a sense of gratitude for past favors or reparation for past mistakes. An illustration of this motivating source is seen in the statement "She stood by me while I drank too much and ran around. Now I'm going to take care of her." For husbands, other sources of motivation include fulfillment of older men's need for family orientation (Pruchno & Resch, 1989) and harmony between the traditional take-charge nature of men's work and the caregiving process (Miller, 1987). Female caregivers may also care for their husbands out of gratitude for a lifetime of financial or emotional support or a need to engage in a nurturing role.

Another benefit of caregiving stems from the social value of sacrifices associated with this time-consuming and burdensome role. Wives with Alzheimer disease are often regarded by their families as deserving of support in return for a lifetime of caregiving (Spitze & Logan, 1989). By fulfilling these obligations to their wives, despite tradi-

tional gender ideology, caregiving husbands may actually enjoy more social kudos for their work than a caregiving wife would. The advertising industry has recently become aware of the emotional appeal of nontraditional fathers depicted in loving, patient, caregiving tasks. When the television shows a father lulling his baby back to sleep in the middle of the night, the message is "Where is his lucky wife? Sleeping?"

Caregiving wives are less likely to enjoy social laurels for their work because the traditionalist view expects women to assume the caregiving role. Lack of social recognition creates an imbalance between burden and benefit, so caregiving wives have fewer rewards to offset the high costs of their role. This imbalance, in combination with inadequate emotional preparation to assume a demanding enfolded activity approach to caregiving, is a factor in women's higher incidences of mental health complaints (Anthony-Bergstone et al., 1988; Pruchno & Resch, 1989; Zarit et al., 1986). Yet despite their need for mental health services, elderly women experience considerable difficulty in accessing and using the mental health system. One factor in this phenomenon is the double jeopardy of age and gender (Rodeheaver & Datan, 1988). This double jeopardy negatively influences service use, therapist-client interactions, and diagnosis in a way that places older women at risk of being underserved by the mental health system. Caregiving wives are not only at risk for mental health problems but are also unlikely to receive the intervention they need. For the same reasons, female caregivers are unlikely to access preventative support that may assist them in the emotional preparation needed for their role.

Physical Adjustments

The relationship between physical and psychological caregiver health is underscored by Pruchno et al.'s (1990) study of the predictive power of depression for decline in health within 6 months. Although all caregivers report increased vulnerability to physical illness, female caregivers tend to report a greater degree of physical morbidity, poorer health, more frequent visits to physicians, and reduced immune functions (Barusch & Spaid, 1989; Kiecolt-Glaser et al., 1987; Schulz, Visintainer, & Williamson, 1990).

Implications for Dementia Management Plans

Gender differences may influence spousal caregivers' definition and resolution of care management problems in a number of ways, and are modified by other aspects of the caregiving context such as culture and personality. No evidence in the literature suggests that gender alone is correlated with the amount or displays of affection, or with the quality of physical care provided to the care recipient. Although not every caregiver's approach to de-

mentia care can be categorized according to gender, some trends are suggested by the above discussion.

In general, male caregivers' task orientation is likely to result in identifiable plans that allow a balance of his work, rest, and leisure while providing adequate physical care for the impaired wife. Outside supports may be engaged to help with household and caregiving duties, but the recognized care management remains with the husband. A semi-structured daily routine supports a linear progression of activities that the caregiver is likely to have planned in advance. Although few of those activities are initiated solely to enhance the emotional health of the impaired wife, if the wife is obviously upset or unhappy, the male caregiver is likely to approach this problem with the same energy that he would expend for a physical problem.

The literature review suggests that the enfolded activity approach of the caregiving wife is likely to result in dementia management plans that reflect a supercaregiver myth. The caregiving wife is inclined to voice concerns and confusion about the adequacy of her husband's care and to engage in a stream of continuous work. She may seek outside support or counseling, but she will purchase little instrumental help. Her daily routine is less defined and structured than her male counterpart's and is readily altered. These alterations may be partially due to her difficulty with directing her husband, reactions to unanticipated problems, or the importance of his input regarding the routine. Part of the day is likely to be spent in engaging the impaired husband in activities for his emotional health and in doing activities as a married couple. The wife's plans may be largely tacit; she may not even be able to identify her overall dementia management scheme. Because she is emotionally underprepared for the use of enfolded activity with an adult, the caregiving wife is likely to experience conflicting emotions of resentment and nurturance. These gender differences in dementia management plans are illustrated in the following examples of two caregivers.

A woman has been caring for her husband, who is moderately impaired due to Alzheimer disease, for 3 years. She is an organized, competent, efficient and highly informed woman who provides excellent care for her husband, but at the high cost of self-sacrifice. She rescheduled her self-care routine for the evening (after her husband is asleep) to accommodate the numerous tasks necessary to support his quality of life. The specifics of each day's routine are based on his emotional status and reflect the wife's commitment to her husband's independent engagement in self-care, work, and leisure activities. The list of tasks she must complete to act on this commitment include arranging for a friend to take him golfing, marking his golf clubs with red covers, premeasuring birdseed, discussing his performance at his volunteer job with his coworkers, playing cards or dominoes with her husband, and preparing work areas with needed items (photos and photo album, appropriate clothing, bathing items, etc.). In addition to this long list of activities, she manages the housework, finances, and social obligations. Although her day is completely consumed by her husband's care, she voices feelings of incompetence and states, "One of my big problems is trying to be creative enough to think of things for him to do." She is also concerned about how happy he is and what will happen to him in the future.

This case illustrates an enfolded activity approach to dementia management and how it involves this caregiving wife in a constant stream of work. Her primary concern is for her husband's emotional health and she fills their day with carefully arranged activities that are meaningful to him. Despite her efforts, she is concerned that she is inadequate as a caregiver. Contrast the above enfolded activity approach with a linear approach typically used by a caregiving husband.

The husband has been providing care for 3½ years to his wife, who has moderate impairment from Alzheimer disease. He has arranged for his three nieces to visit daily and perform his wife's self-care activities. He spends his day doing housework, making sure that his wife does not wander outside, and monitoring her behavior for signs of emotional or physical upset. When she demonstrates a need for his attention, he intervenes to satisfy her needs with an object of symbolic meaning, a doll. He feels satisfied when her needs are met, stating "She hugs it and smiles. That will give me a great feeling. It's just like someone gave you a million bucks." He has structured a routine that allows him the freedom to "go on with my work and keep her happy."

In contrast to the caregiving wife presented earlier, this male caregiver demonstrates a task-oriented approach in which one task proceeds linearly after another. His family's help with his wife's care lightens his total workload. He does not express concern for his wife's emotional health, nor does he initiate any activity until she indicates a need. Even at that point, he provides her with an activity that does not require interaction with him, so that he can complete his work while she distracts herself. Of particular interest is the contrast between his expression of satisfaction with the results of his efforts and the concerns voiced by the caregiving wife in the first case illustration. The differences between these two approaches to caregiving are largely gender-related and have implications for occupational therapy practice and research.

Practice and Research Considerations

The literature review exposed a dichotomy between women's socialization for caregiving and their negative responses to enactment of that role in elder care, along with evidence that suggests that women transfer their gender strategy of enfolded activity from child care to spousal care. Yet an irony exists in that use of enfolded activity does not shield women from profound consequences of caregiving. One factor in this irony may be found in the fundamental differences between the type of emotional preparation needed for enfolded activity with children and the type needed for adult care.

This discussion raises two compelling issues to be addressed by health care providers and researchers. First, as a basis for effective and relevant intervention programs, occupational therapists and other health care providers must understand how men and women approach their caregiving roles and the consequences of those approaches. Working with caregiving husbands requires the

occupational therapist to identify and support the husband's task-oriented approach. When this identification is made, the husband may be able to generalize his approach to emerging caregiving issues that may develop after therapy has been discontinued. The occupational therapist should help the husband recognize and act on the influence he has on the emotional health of his impaired wife. If the caregiving husband is willing, he may benefit from learning recommended techniques for eliminating excess disability. In this way, whether he performs the caregiving duties himself or purchases instrumental help, he will have the information he needs to successfully manage the flow and content of care provision. In addition to the above information, the caregiving husband illustrated in this article would have benefitted from tips on environmental modifications to make his monitoring tasks simpler, such as placing a bell on the door leading outside.

Occupational therapists working with caregiving wives may begin by helping them to recognize their own limitations and set boundaries for self-sacrifice. Efforts should include assisting each caregiver to establish some time for herself, teaching energy conservation, and encouraging a predictable daily routine. The occupational therapist should support the caregiving wife's efforts to improve her husband's emotional health, but only at a reasonable emotional and physical cost to the wife. Techniques that may assist the caregiver in this goal include environmental adaptations and the correct choice and adaptation of activities (Levy, 1986). For example, the caregiving wife in the case illustration would have benefitted from suggestions about gross motor, repetitive activities that require little preparation and supervision and allow her more time for herself.

A second issue raised by this discussion is the need for clinically based studies to describe the caregiving experience. Although the literature suggests that caregivers use gender-related approaches to their role, this hypothesis has not been tested. It is likely that several aspects of the caregiving experience, in interaction with gender, have predictive power for dementia management plans. Future clinical studies could describe whether and how the enfolded activity approach to caregiving is used and the nature of any emotional preparation for its use. Occupational therapists can address this need for research by gathering and analyzing case material describing how caregivers define and approach their caregiving duties. Occupational therapists who base their interventions on gender differences must document and publish their specific techniques and catalog the conditions for success, such as home-based versus clinic-based and spouse versus nonspouse. Further, clinical research can be conducted to test the effectiveness of documented occupational therapy interventions that are sensitive to the different caregiving needs and approaches of men and women.

Conclusion

The importance of the informal caregiver to successful dementia management is widely recognized in current occupational therapy literature (Corcoran & Gitlin, 1992; Dybwad, 1989; Hasselkus, 1987). Evidence indicates that the emotional and physical consequences of caregiving differ, especially between men and women. These differences influence approaches to managing care, in particular how men and women define, carry out, and respond to their caregiving duties. Compared with male caregivers, women spend more hours involved in care provision, provide more physical help with self-care, and focus more on the quality of their relationship with the care recipient (Barusch & Spaid, 1989; Hochschild, 1989; Wilson, 1990). These tendencies are partially responsible for the fact that female caregivers are likely to experience negative consequences of caregiving, such as depression, stress, and drug use.

Despite growing evidence that male and female caregivers manage care differently, few guidelines are available to help health care practitioners design intervention programs that are sensitive to gender differences. The literature review presented in this article catalogs the gender differences in caregiving, the consequences of each approach, and implications for occupational therapy practice and research.

Discussion of gender-related different approaches to caregiving is important to the occupational therapy profession for three reasons. First, occupational therapy interventions that are sensitive to individual caregiving management issues and style are likely to be more effective. Such client-driven services may directly and efficiently address issues of genuine concern to each caregiver. Second, occupational therapy interventions designed to build relevant caregiving skills may also be cost-effective if institutionalization can be delayed for even a short period of time. In a time of widespread cost containment and service reductions, any intervention that can save health care dollars would be highly valued. Third, discussion of gender-related approaches gives the opportunity to expand reimbursement for dementia intervention to caregivers. At this point, caregivers who directly receive intervention must pay for the service themselves or enroll as a subject in a research project. Neither of these opportunities is available to most caregivers, so needed services are not provided. These benefits suggest that the challenge of designing and testing occupational therapy interventions that account for gender differences in caregiving is well worth the effort. ▲

Acknowledgment

Case material for this paper was gathered as part of a research project funded by the American Occupational Therapy Foundation.

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