Effect of Educational and Supportive Strategies on the Ability of Caregivers of People With Dementia to Maintain Participation in That Role

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KEY WORDS
- Alzheimer disease
- caregivers
- consumer health information
- health education
- patient education
- social support

A systematic review of evidence of the effectiveness of educational and supportive strategies for enabling caregivers of people with Alzheimer’s disease (AD) or related dementias to maintain participation in that role was conducted as part of the American Occupational Therapy Association’s Evidence-Based Literature Review Project. Forty-three articles met inclusion criteria. Results suggest that interventions that jointly engage people with AD and their caregivers in education and training in the home setting are more successful than strategies that focus solely on people with AD. Greater carryover is noted when education and training are implemented at the time that the caregiver identifies concerns. Interventions should provide caregivers with problem solving, technical skills, support, simple home modification strategies, and referral to community resources. Interventions mediated by technology have a positive effect on the caregiver and are especially important for those who live in rural areas.


The number of Americans living with Alzheimer’s disease (AD) is expected to increase from an estimated 5.3 million in 2008 to 13.2 million by 2050 (Alzheimer’s Association, 2009a; Hebert, Beckett, Scherr, & Evans, 2001). This increase is a serious societal concern because the need for care of people with AD will also rise. Although trained health professionals will continue to provide care for people with AD, nearly 10 million caregivers will be unpaid lay workers, most commonly family members. About 60% of these caregivers are women (wives, daughters, daughters-in-law, granddaughters, and other female relatives; friends; and neighbors of the person with AD). About 6% of caregivers are spouses of the person with AD. At any one time, 39% of unpaid caregivers have provided help for 1–4 yr, and 32% have provided help for ≥5 yr.

In 2009, >8.5 billion hr of unpaid care was provided, a contribution valued at $94 billion. Care is predominantly provided in the home (Alzheimer’s Association, 2009b). People with AD on average require more hours of help than other older people. Caregivers may be able to initially provide care and maintain a part- or full-time job outside of the home. However, as the disease progresses, the caregiver may no longer be able to maintain employment and supervise the person with AD.

Caring for people with AD is often complicated. As memory loss; decline of cognitive functions and judgment; disruption of sleep and eating patterns; disorientation to person, place, and time; and loss of the ability to understand and communicate effectively progress, the person with AD requires closer and more frequent supervision to remain safe (Alzheimer’s Association, 2009b). This need contributes to high rates of caregiver anxiety, stress, burnout, depression, and reduced life expectancy (Adams, 2008; Quinn, Clare, & Woods, 2009).
As the disease progresses, the demand for care can become too much for caregivers to handle by themselves. Some families hire home care workers, but the person with AD is more likely to be placed in a nursing home or assisted living residence, even though that can be quite costly (Wimo, 2010). A salient predictor of institutional placement of people with dementia is caregiver depression and poor health (Coehlo, Hooker, & Bowman, 2007). The relationship between the psychological and physical health of caregivers of people with dementia has been amply documented. Although caregiving can be fulfilling, caregivers themselves are often at increased risk for depression and illness, especially if they do not receive adequate support from family, friends, and the community (Kuipers, Onwumere, & Bebbington, 2010; Lavela & Ather, 2010). Issues of loss and grief play a significant role in a caregiver’s ability to cope with the stressors of caregiving (Noyes et al., 2010). Depressive symptoms significantly predict the decline in health status of caregivers of people with dementia (Campbell et al., 2008) and are associated with amount of time missed from work and loss of wages, which further contribute to caregiver stress and poor health (Wilson, van Houtven, Sterns, & Clipp, 2007). As many as 90% of caregivers report sleep disturbances (Rausch, Baker, & Boonmee, 2007), nearly 50% develop mobility disorders, and 20% die from cardiovascular problems potentially exacerbated by stress (Fredman et al., 2008).

Caregiving stress influences the overall quality of in-home caregiving. Caregivers’ reduced perceived self-efficacy results in reduced functional abilities of people with dementia (Ablitt, Jones, & Muers, 2009). Caregivers feeling stress and experiencing mental health problems are at risk for engaging in abusive acts against older care recipients (Macneill et al., 2010). Although caregiver health status is significantly influenced by where the person with AD resides, total burden does not significantly differ between caregivers of community-dwelling patients and caregivers of institutionalized patients (Fredman et al., 2008). People with AD whose caregivers are in poor health may be at risk for not benefiting from intervention, suggesting that efforts, including instruction in preventive care and allocating time to attend to their own health care needs, must be directed toward caregivers as part of a comprehensive AD service program (Campbell et al., 2008; Chee, Gitlin, Dennis, & Hauck, 2007; Zarit & Femia, 2008).

Occupational therapy practitioners recognize that “health is supported and maintained when clients are able to engage in occupations and activities that allow desired or needed participation in home . . . and community life” (American Occupational Therapy Association, 2008, p. 629). Thus, the target outcome of occupational therapy intervention is engagement in occupation to support participation in context. Caregivers are essential to helping people with AD remain in their home or community contexts (Haley & Bailey, 1999). Occupational therapy practitioners are familiar with the needs, functional limitations, and disruptive behaviors associated with AD. Greater emphasis must be placed on developing services that address caregivers’ high level of burden and distress. Therefore, occupational therapy practitioners need to be familiar with the evidence that supports interventions that take the patient and caregiver into account as one unit.

Method for Conducting the Evidence-Based Review

This review addresses the focused question, “What is the evidence for the effect of educational and supportive strategies for caregivers of people with dementia on the ability to maintain participation in that role?” Detailed information about the methodology for the review can be found in Arbesman and Lieberman (2011; this issue). An initial review was completed in 2007 and later updated in 2008 and in 2010 in preparation for this article.

Results

A total of 7,445 titles and abstracts were reviewed, and 172 reports that appeared to be related to the focus question were retrieved. On the basis of this review, 98 studies were eliminated because they did not meet inclusion criteria for level of evidence. An additional 31 studies were eliminated because they had been included in more recent systematic reviews retained for appraisal. The 43 remaining reports (35 Level I, 3 Level II, and 5 Level III) were first analyzed in an evidence table and finally appraised in a Critically Appraised Topic format. Supplemental Table 1, available online at www.ajot.ajotpress.net (navigate to this article, and click on “supplemental materials”), includes information about the objectives,
design, procedures, outcomes, and limitations of the studies. Findings are summarized in the following sections according to eight major categories of interventions that emerged from the studies.

**Occupational Therapy Interventions**

Five reports on occupational therapy interventions for caregivers were located for review. Evidence from these studies suggests that occupational therapy sessions that provide caregivers with education, problem-solving and technical skills (task simplification, communication), and simple home modifications improve patients’ skills, decrease their need for assistance, and reduce behavioral occurrences (Gitlin, Hauck, Dennis, & Winter, 2005; Level I, N = 127). Occupational therapy intervention enhanced caregiver skills and resulted in greater mastery and self-efficacy, although subjective appraisal of burden was not affected (Pinquart & Sörensen, 2006; Level I, N = 27). Primary caregivers who received occupational therapy felt significantly more competent than those who did not (Graff et al., 2006; Level I, N = 135), and the effect remained significant beyond 12 wk after intervention (Graff et al., 2007; Level I, N = 135). Moreover, an economic evaluation of these occupational therapy services suggested that they are a highly cost-efficient intervention (Graff et al., 2008; Level I, N = 135).

**Direct Interventions With Caregivers**

Twelve studies concluded that strengthening caregivers’ knowledge of AD and of strategies to better undertake their caregiving role staves off growing distress as the illness progresses and improves caregiving attitude. Studies consistently showed that a focus on problem solving specific challenging situations resulted in a greater sense of control and ability to absorb new information, strengthened the belief that caregivers could successfully handle the many stressful events involved in caregiving, and minimized anxiety associated with caregiving (Devor & Renvall, 2008, Level III, N = 300; Farran et al., 2007, Level I, N = 143; Hepburn et al., 2006, Level I, N = 215; Pinquart & Sörensen, 2006, Level I, N = 127; Smits et al., 2007, Level I, N = 25; Tompkins & Bell, 2009, Level II, N = 367). Caregiver interventions based on a stress and coping theory framework showed a modest but positive association with caregivers’ having less emotionally enmeshed beliefs about caregiving roles and responsibilities, but they inconsistently improved burden and depression (Pinquart & Sörensen, 2006). This inconsistency may have occurred because caregivers measured success by the care recipient’s well-being rather than their own. Therefore, they preferred individualized training that focused on their ability to identify the care recipient’s needs, and such ability was associated with a trend toward reduced nursing home admission (Fortinsky, Kulldorff, Kleппinger, & Kenyon-Pesce, 2009; Level I, N = 84).

Social skills training to aid caregivers in interacting with the patient had a significant effect on delaying nursing home admission but not on decreasing caregiver burden (Brodaty, Green, & Koschera, 2003; Level I, N = 30) because the responsibility for care may not decrease even though the care recipient’s acceptance of care may improve. Programs that provided concrete knowledge and skill building were therefore more likely to be accessed by caregivers and to be effective than programs that offered only emotional support (Charlesworth et al., 2008; Level I, N = 236).

Psychoeducation strategies that combined caregiving skill building with stress management and coping skill development had a moderate effect on caregiver scores of depression, anger and hostility, fatigue, confusion, physical symptoms, anxiety or mood disorder, and suicidality and depression (Cooper, Balamurali, Selwood, & Livingston, 2007; Level I, N = 24). Cognitive–behavioral therapy appeared to have the most positive effect because it builds on success (Cooper et al., 2007). No evidence was found that stress reduction programs focused solely on the caregiver had an effect on caregivers’ sleep disturbances, depressive symptoms, or appraisal of caregiving situation (Rose, Taylor, & Bourguignon, 2009; Level I, N = 38). Lectures, readings, and discussion groups were effective in increasing caregivers’ knowledge about AD but had limited effect on caregivers’ depression or care recipient behavior if not accompanied by skill development (Kuhn & Mendes de Leon, 2001; Level III, N = 58).

**Joint Interventions With Caregivers and Patients**

Interventions that focus solely on the behavior of the person with dementia without addressing caregiving issues may not be adequate for reducing caregiver distress. Caregivers who were educated in behavior management and skills for coping with their own stress in joint sessions with the care recipient had better outcomes for general well-being and depression (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003, Level I, N = 167; Logsdon, McCurry, & Ten, 2007, Level I, N = 39; Onor et al., 2007, Level I, N = 16). Joint care recipient and caregiver education and support groups that dealt with coping with memory problems; social and family relationships; daily living skills; self-esteem; planning for the future; legal, financial, and health considerations; and stress management resulted in reduced family conflict.
during the early stages of dementia (Logsdon et al., 2007). Joint multimodal programs slowed functional decline of care recipients while increasing caregiver knowledge and confidence (Burns et al., 2003; Onor et al., 2007).

**Family Interventions**

Caregiver counseling and support groups that involve the caregiver and the whole family have been shown to have a positive effect on caregiver depression and reaction to troublesome behavior, which are significant predictors of patient institutional placement. Such programs may delay institutionalization by nearly 1 yr (Curry, Walker, & Hogstel, 2006, Level III, N = 35; Mittelman, Brodaty, Wallen, & Burns, 2008, Level I, N = 158; Mittelman, Haley, Clay, & Roth, 2006, Level I, N = 406; Mittelman, Roth, Clay, & Haley, 2007, Level I, N = 406; Mittelman, Roth, Haley, & Zarit, 2004, Level I, N = 406; Peacock & Forbes, 2003, Level I, N = 36; Pusey & Richards, 2001, Level I, N = 30; Spijker et al., 2008, Level I, N = 13). This type of intervention has also been associated with improved caregiver subjective sense of health (Mittelman et al., 2007). Caregiver education programs alone may not significantly improve caregiver psychological well-being, but one study found that caregivers participated in family support groups more if the programs also provided case management; the three content topics ranked highest by value to support group attendees were normal aging and disease, respite voucher information, and practical ideas and help with legal forms (Curry et al., 2006).

**Combination of Strategies**

Evidence is limited but has generally suggested that a combination of supportive and educational strategies tailored to specific needs is of most use to caregivers (Acton & Kang, 2001, Level I, N = 24; Belle et al., 2006, Level I, N = 642; Schulz, et al., 2002, Level I, N = 43; Spijker et al., 2008, Level I, N = 13). Caregivers were more likely to consider multimodal interventions (e.g., addressing the patient and caregiver individually but also then including family support) as having greater social validity (the degree to which an intervention is helpful in an immediate social situation; Schulz et al., 2002). Multimodal interventions were also better received across ethnic and cultural groups (Belle et al., 2006). In addition, multimodal interventions significantly decreased the odds of and increased the time to institutionalization (Spijker et al., 2008).

**Interventions in the Home**

Patient–caregiver dyad interventions conducted in the care recipients’ homes rather than in institutions had a modestly positive effect on caregivers’ sense of self-efficacy and ability to manage agitation (Huang, Shyu, Chen, Chen, & Lin, 2003; Level I, N = 48). Such interventions were also associated with reduced mortality of people with AD or related dementias, although they may have had a limited impact on their behavior as the disease progressed (Dias et al., 2008; Level I, N = 81; Gitlin et al., 2008; Level I, N = 60). Given the importance caregivers place on interventions tailored to their specific situation, more research is needed to compare outcomes of caregiver interventions that take place in the home and those that take place in the community.

**Technology-Mediated Interventions**

Technology-based interventions permit caregivers and patients to remain at home while providers interact with them through a remote system. Technology-mediated support groups had a positive, although inconsistent, impact on caregiver psychological morbidity (Powell, Chiu, & Eysenbach, 2008, Level I, N = 6; Thompson et al., 2007, Level I, N = 44). Telephone network interventions with social components were those most likely to result in caregiver improvements on measures of psychological well-being, although they presented obstacles in scheduling several caregivers at one time (Cooke, McNally, Mulligan, Harrison, & Newman, 2001, Level I, N = 40; Winter & Gitlin, 2007, Level I, N = 103). Weekly telephone conversations between caregivers and professionals providing monitoring and advice were relatively more effective if measured by frequency of use. Respite calls, in which a professional maintained a conversation with the patient while the caregiver had free time to attend to personal matters, also had relatively high use, although most caregivers preferred in-person meetings (Powell et al., 2008). Cognitive–behavioral intervention was effectively carried out over the telephone and resulted in significant improvement in perceived self-efficacy in caregiving and in resolving problems (Glueckauf et al., 2007; Level I, N = 36). Video-based caregiver education was no more effective than telephone- or Internet-based interventions (Gant, Steffen, & Lauderdale, 2007; Level I, N = 32). However, frequency of use of Internet-based psychoeducation via informative Web sites and e-mail exchange was associated with a greater reduction in the caregiver’s experience of burden (Chiu et al., 2009; Level III, N = 28). Strengths-based telephone health counseling programs that focused on caregiver skill building and
helped coordinate caregiver interaction with community agencies or other resources improved caregiver sense of efficacy (Engelhardt et al., 2008; Level II, \( N = 181 \)). Telephone-based support groups appeared to be as effective as in-person groups for ethnically diverse caregivers (Powell et al., 2008). Preliminary evidence showed that spirituality-based (mantram) meditation training can be carried out effectively over the telephone and resulted in a reduction of caregiver distress and an improvement in quality of life (Bormann et al., 2009; Level III, \( N = 36 \)).

**Respite Care**

Current evidence has not demonstrated significant long-term benefits or adverse effects from the use of respite care for people with dementia or their caregivers (Lee & Cameron, 2004; Level I, \( N = 3 \)). Use of adult day care was somewhat helpful in alleviating care-related stress, especially in regard to compatibility of family, job, and caregiving responsibilities. Moreover, it enhanced caregivers’ opportunity to take part in social and recreational activities (Schacke & Zank, 2006; Level II, \( N = 77 \)). Respite care provided short-term relief of caregivers’ anxiety and depression (Tompkins & Bell, 2009; Level II, \( N = 367 \)). Overall, however, it did not relieve caregiver burden because caregivers remained concerned for the care recipients’ well-being during their time away from them.

**Discussion and Implications for Practice**

Occupational therapy practitioners are committed to supporting engagement in meaningful occupations and activities. This engagement is most meaningful when done in the most natural context. Caregivers are essential in supporting people with AD to stay in their home and communities longer. Occupational therapy interventions focused only on the person with AD have the potential to benefit both caregivers and patients by helping them remain longer in their roles and contexts. However, interventions that focus only on care recipient behavior without addressing caregiving issues may not be as adequate in reducing caregiver distress (Burns et al., 2003). Although the quality of evidence is limited, a combination of supportive and educational strategies appears to be of most use to caregivers. Occupational therapy practitioners must keep in mind that interventions for caregivers may affect some of the tasks or time spent in caregiving, but the caregiver remains responsible for the care, and thus the intervention is unlikely to change his or her perception of responsibility. Therefore, burden may not be the best outcome to demonstrate the effectiveness of caregiver interventions (Burns et al., 2003).

Combined programs may improve some, but not all, aspects of functioning for caregivers and the person with AD (Smits et al., 2007). Rather than blanketing caregivers with a variety of interventions, these interventions should be implemented at the times they are needed, thus increasing the likelihood of better outcomes (Acton & Kang, 2001; Thompson et al., 2007). Collaboration with the caregiver in targeting present problems is more likely to result in a greater sense of self-efficacy than when caregivers follow only prescribed home programs (Huang et al., 2003). Intensive programs that involve patients and their families and that are modified according to caregivers’ needs not only tend to be more successful in enhancing patient function but also are likely to reduce the objective burden of caregivers as measured by time spent in caregiving (Brodaty et al., 2003).

Therefore, a basic occupational therapy plan for people with AD and related dementias should include interventions for caregivers. Such interventions should encompass education about the progression of the disease, emotional support, problem solving, referral to community resources, and development of strategies to help caregivers manage their reactions to behavior challenges (Kuhn & Mendes de Leon, 2001). An understanding of how the caregiving role is different from other family roles is essential (Curry et al., 2006). Individualized strategies that show immediate results increase caregivers’ sense of mastery and success in their role and reinforce long-term participation in caregiver support groups (Gitlin et al., 2008; Graff et al., 2007), which can, in turn, have a favorable impact on caregiver depression and patient placement in a nursing home (Mittelman et al., 2004).

In addition to the focus on traditional caregiving skills, occupational therapy practitioners should support caregivers’ appraisal of their own situation and skills (Gitlin et al., 2005; Hepburn et al., 2006). Inclusion of social components is effective in improving caregivers’ psychological well-being (Cooke et al., 2001). Encouraging caregivers to strengthen their social support system for the long term should be a basic component of occupational therapy intervention (Mittelman et al., 2007). Occupational therapy practitioners’ psychosocial training prepares them to serve as cofacilitators of emotional support, stress management, and problem-solving groups, which are effective in reducing caregivers’ psychological morbidity, increasing family cohesiveness, and delaying institutionalization. A combination of direct patient care and caregiver support is highly effective and...
cost-efficient therapy for community-dwelling older adults and their caregivers (Graff et al., 2008). Therefore, it should be advocated as a service included in all community health, primary care, and outpatient services for people with AD.

Finally, occupational therapy practitioners should provide caregivers with information regarding the range of services available in the community. Current evidence is limited and does not demonstrate any long-term benefits of or adverse effects from the use of respite care for people with AD or their caregivers (Lee & Cameron, 2004). Use of respite programs and adult day care is significantly effective in alleviating care-related stress, especially in regard to compatibility of family, job, and caregiving responsibilities (Schacke & Zank, 2006). At the same time, occupational therapy practitioners should recognize that use of day programs may alleviate some, but not all, aspects of caregiving stress (Mittelman et al., 2006). Occupational therapy practitioners should also be alert to circumstances in which placement should be recommended to protect caregivers’ health and well-being.

Occupational therapy practitioners should consider enhancing their services with telephone-based support for caregivers as a follow-up to in-home therapy. This type of brief support has been moderately effective for caregivers as a follow-up to in-home therapy. This type of program at Creighton University. Telesupport groups appear to provide benefit mostly to older caregivers (265 yr; Winter & Gitlin, 2007), and therefore occupational therapy practitioners may consider inclusion of such intervention as part of an overall program if the caregiver appears to be relatively isolated and has a greater need for social contact.

As indicated in Supplemental Table 1, reviewed studies were frequently limited by sample size and overreliance on subjective measures. In addition, caregiving burden was defined in many different ways, making comparison of interventions’ effectiveness on this particular outcome difficult. These limitations point to the challenge of research with caregivers, for whom participation in research may add yet another task to attend to in an already overbusy life. Further research specifically measuring changes in caregiver skill, the time and effort caregivers expend in providing assistance to people with AD, and the improvement in functional skills of people with AD is needed. ▲

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References


*Studies included in the review.


