

10-1-2009

Family Caregivers: Psychosocial Impacts and Clinical Needs

Andrew P. Daire

Jennifer Torres

Nivischi N. Edwards

Follow this and additional works at: <https://mds.marshall.edu/adsp>

Recommended Citation

Daire, Andrew P.; Torres, Jennifer; and Edwards, Nivischi N. (2009) "Family Caregivers: Psychosocial Impacts and Clinical Needs," *Adultspan Journal*: Vol. 8: Iss. 2, Article 1.

Available at: <https://mds.marshall.edu/adsp/vol8/iss2/1>

This Practitioner Focused Article is brought to you for free and open access by Marshall Digital Scholar. It has been accepted for inclusion in *Adultspan Journal* by an authorized editor of Marshall Digital Scholar. For more information, please contact beachgr@marshall.edu.

Family Caregivers: Psychosocial Impacts and Clinical Needs

Keywords

family caregivers, psychosocial impacts

Family Caregivers: Psychosocial Impacts and Clinical Needs

Andrew P. Daire, Jennifer Torres, and Nivischi N. Edwards

The authors describe how 3 groups of family caregivers (spouses, daughters, and sons) are affected by the caregiving role. In addition, clinical considerations and interventions for mental health professionals working with these different groups of family caregivers are discussed. A clinical case example is also presented.

The aging process for most individuals is accompanied by some loss of cognitive and behavioral functions. For some, significant cognitive impairments develop in response to various etiologies. According to the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.; American Psychiatric Association, 2000) *dementia disorders* “are characterized by the development of multiple cognitive deficits (including memory impairment) that are due to direct physiological effects of a general medical condition, to the persisting effects of a substance, or to multiple etiologies” (p. 147). The decline in functioning stemming from dementia symptoms leads to an increased need for physical and emotional assistance, which is usually provided by a family caregiver. The purpose of this article is to describe three subgroups of family caregivers (i.e., spouses, daughters, and sons) of individuals experiencing dementia and discuss clinical considerations and interventions to use with these individuals. Identifying the positive and negative aspects of caregiving for the different caregiver groups provides greater opportunities for caregivers and mental health providers to better understand all aspects of this valuable role.

Providing care to a family member experiencing dementia can be very demanding for spouses and adult children, who often provide the majority of care within the family context (Robertson, Zarit, Duncan, Rovine, & Femia, 2007). Family caregivers provide much needed emotional and physical support that plays a significant role in the health and adjustment of persons with dementia (S. Cohen & Wills, 1985). Additionally, family members provide the majority of care for older adults with functional impairments (Robertson et al., 2007). However, this role comes with the additional challenge of managing one’s own personal care needs and affairs while managing the personal needs and affairs of a loved one. This challenge presents the caregiver with a significant amount of psychological strain and burden. Whether the person with dementia resides independently or in an assisted-living facility, the caregiver is at risk of psychological distress and depression (Levesque, Ducharme, & Lachance, 1999; Schulz & Martire, 2004).

Andrew P. Daire, Jennifer Torres, and Nivischi N. Edwards, all at Counselor Education Program, University of Central Florida. Correspondence concerning this article should be addressed to Andrew P. Daire, Counselor Education Program, University of Central Florida, PO Box 161250, 4000 Central Florida Boulevard, Orlando, FL 32816-1250 (e-mail: adaire@mail.ucf.edu).

© 2009 by the American Counseling Association. All rights reserved.

Meuser, Marwit, and Sanders (2004) suggested that grief is a primary reaction to providing care for a person with dementia. With expectations that the number of Americans age 65 and older experiencing dementia will grow to nearly 3 million by the year 2015 (U.S. General Accounting Office, 1998), mental health counselors will likely experience an increase in the number of clients who must address issues related to family caregiving.

FAMILY CAREGIVERS

Family members meet the caregiving needs of an overwhelming majority of dementia patients (Alzheimer's Association and National Alliance for Caregiving, 2004; Clark & Standard, 1996). Despite popular myths (e.g., patients with dementia cannot be cared for at home or most dementia patients are relegated to nursing homes), the majority of patients with dementia have a spouse or child as their primary caregiver (Zarit, Stephens, Townsend, & Greene, 1998). According to the Alzheimer's Association and National Alliance for Caregiving, 22% of the approximately 44 million American caregivers provide substantial and unpaid care to a family member. Compared to family caregivers for patients with other diseases, individuals who care for a person with dementia are twice as likely to be providing the highest level of home care (more than 40 hours of direct care each week) and are also more likely to be living with the person (Alzheimer's Association and National Alliance for Caregiving, 2004). Keating, Fast, Frederick, Cranswick, and Perrier (1999) reported that approximately 90% of the care and support given to older adults living at home is provided by family members. In two independent studies using national data sets, family members accounted for more than 85% of caregivers, with spouses accounting for 38% to 60% of primary caregivers (D. Cohen, Luchins, Eisdorfer, & Paveza, 1990). Family caregivers identified safety in the home, lack of time for themselves, and lack of meaningful activities for people with dementia as primary caregiver concerns (Bank, Arguelles, Rubert, Eisdorfer, & Czaja, 2006). Thus, the caregiver role comes with a cost. Large cross-sectional studies of the caregiving role have shown that it was associated with stress and depression (Epstein-Lubow, Duncan-Davis, Miller, & Tremont, 2008; Schulz & Beach, 1999).

Although caregiving has a specific meaning for each caregiver, many of these individuals report enjoyable aspects of the caregiving role, including the relationship itself and the desire for positive outcomes (C. A. Cohen, Gold, Shulman, & Zuccherro, 1994). These aspects were related to the quality of the caregiver's past relationship with the care receiver, satisfaction with social supports, and how the caregiver reacted to the care receiver's behavior problems. However, this role oftentimes results in the caregiver experiencing psychological and emotional strain, such as chronic fatigue, anger, or depression (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Colantonio, Cohen, & Carlett, 1994; Epstein-Lubow et al., 2008; Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998). Because of the high demands on their time and energy, family caregivers often neglect their own physical health needs, resulting in negative health outcomes (Stevens, Lancer, Smith, Allen, & McGhee, 2009). Table 1 provides a summary of caregiver effects for the spouse and the child.

TABLE 1
Caregiver Effects for Spouses and Children

Spouse	Child
Male Caregiver	
<ul style="list-style-type: none"> • Reports poorer health than child caregivers • Has fewer individuals in his secondary helping network than child caregivers • Reports significant psychiatric distress, but seeks counseling less often than all other caregiving groups • Experiences greater challenges to his traditional attitudes • Adopts a more problem-solving and task-oriented approach to caregiving than wives • Experiences heightened social isolation because of the traditional role of the wife in forging and maintaining social relationships • Reports lower levels of life satisfaction than caregiving children • Was found to be more objective and realistic in the caregiving role than the wife 	<ul style="list-style-type: none"> • Is more likely to have help with caregiving responsibilities from the spouse than caregiving daughters • Provides less overall assistance than caregiving daughters • Reports high attachment feelings for his parent with dementia and significant levels of psychological and emotional strain • Reports having an especially difficult time with role reversing (providing care that the parent provided to him as a child) • Often deals with conflict with siblings over caregiver issues • Often plans a smaller number of tasks at a time and accomplishes them in a linear manner • Often deals with role conflict (e.g., parent, employee, spouse, caregiver)
Female Caregiver	
<ul style="list-style-type: none"> • Is most often the caregiver • Reports greater burden and psychological and psychiatric symptoms than other caregiving groups • Sees doctors more than any other caregiving group • Has the highest frequency of hospitalization • Usually receives less caregiving help from others than caregiving husbands • Experiences more depressive and anxious symptoms than male spouses and caregiving sons • Relinquishes the caregiving role later than do men • Reports health behaviors (e.g., taking care of herself physically through sleeping, eating right, exercising) are more negatively affected than for male caregivers • Often attempts to be a "supercaregiver," taking on multiple tasks at a time • Reports lower levels of life satisfaction than caregiving children 	<ul style="list-style-type: none"> • Reports experiencing role demand overload (e.g., caregiver, mother, employee, wife) most often • Seeks counseling more often than other caregiving groups • Is more likely to coreside with care receiver than caregiving sons • Generally provides a higher level of service (e.g., household tasks, shopping, bathing) to the parent with dementia than do caregiving sons • Has a greater frequency of visits to the parent with dementia • Reports a higher level of psychological and emotional strain than caregiving sons • Experiences more depressive and anxious symptoms than male spouses and caregiving sons • Often deals with conflict with siblings over caregiver issues • Relinquishes the caregiving role later than men • Reports health behaviors (e.g., taking care of herself physically through sleeping, eating right, exercising) are more negatively affected than for male caregivers • Often attempts to be a "supercaregiver," taking on multiple tasks at a time

Spousal caregivers oftentimes maintain the heavy and relentless responsibility of being the primary caregiver (Monahan & Hooker, 1995). In addition, their role as primary caregiver becomes more challenging because they bear witness to the intellectual and psychological deterioration of their life partner. Spouses

have fewer individuals in their secondary helping networks and report poorer health than other caregivers (Mui & Morrow-Howell, 1993). Spousal caregivers, who are usually older, many times have preexisting health problems that may be exacerbated by the frequency and intensity of their caregiving situation (Franzen-Dahlin, Larson, Murray, Wredling, & Billing, 2007). They exhibit higher levels of depression and stress and lower levels of life satisfaction and participation in social activities than any other family caregiving groups. In part, this is because spousal caregivers usually provide the most comprehensive care for dementia patients, maintain the caregiving role for longer periods of time, care for the most impaired individuals, and spend the most hours per week on caregiving tasks (Connell, Janevic, & Gallant, 2001).

Second only to caregiving wives, the segment of the population most affected by the caregiving role for dementia patients is caregiving daughters (Armstrong & Armstrong, 2004; Doty, Jackson, & Crown, 1998; Fingerman, 2001; Lynch, 1998; Ward-Griffin, Oudshoorn, Clark, & Bol, 2007). Caregiving daughters comprise a sizable percentage of family caregivers, and considerable research has been conducted with regard to caregiving effects. Similar to spouses, daughters in Narayan, Hepburn, and Lewis's (2004) study experienced negative effects on their health, family life, and work life. Ward-Griffin et al. (2007) found that daughters engaged in "putting themselves in their mothers' shoes" (p. 15) and devising ways of protecting themselves from the hurt inflicted by their mothers as a consequence of the disease. Caregiving daughters also experienced considerable challenges in managing labor force participation along with informal elder-care roles (Barr, Johnson, & Warshaw, 1992; Fromme et al., 2005; Stone & Short, 1990).

Although daughters reported some of the highest levels of caregiver strain and sons constituted a smaller fraction of caregivers (Fromme et al., 2005), sons did hold the primary caregiver role. Studies indicated that between 10% and 12% of primary caregivers were sons, who accounted for 52% of secondary caregivers (Stone, Cafferata, & Sangl, 1987; Tennstedt, McKinlay, & Sullivan, 1989). In a study by D. Cohen et al. (1990), 22% of the caregiving sons lived with the care receiver. These men were also committed to their caregiving responsibilities (Harris, 1998; Harris & Bichler, 1997). Unfortunately, research regarding caregiving sons is very limited, especially in light of the potential impact of the knowledge that would be gained from such research.

Despite the paucity of research for this caregiver group, some research is available offering information on sons' caregiver role, role acquisition, and caregiver effects (Crawford, Bond, & Balshaw, 1994; Daire, 2002; Harris, 1998). In Daire's study, the Parental Bonding Inventory (Parker, Tupling, & Brown, 1979) was used to examine parental bonds and caregiver distress. This research found that primary caregiving sons who reported greater levels of care in childhood bonds with their parent with dementia attributed less distress to the caregiving role. Conversely, those who reported receiving less care in the childhood bond attributed greater distress in their primary caregiving role. Although caregiving daughters experienced more psychological and emotional strain, studies have shown that caregiving sons were not exempt from the stress

and burden of this role (Crawford et al., 1994; Harris, 1998; Harris & Bichler, 1997). Mitrani, Feaster, McCabe, Czaja, and Szapocznik's (2005) findings support the relevance of family interactions in caregiver distress and suggest that a treatment approach aimed at supporting family closeness and conflict resolution and reducing negativity might enhance caregiver well-being.

CLINICAL CONSIDERATIONS FOR MENTAL HEALTH PROFESSIONALS

The U.S. Department of Health and Human Services and the U.S. Department of Labor (2003) predicted that there will be an 85% increase in the number of family caregivers between 2000 and 2050. This will increase the number of persons challenged by and in their caregiver role along with the demand for caregiver mental health and support services. This warrants additional thought and inquiry into clinical considerations for family caregivers.

When deciding on an intervention to use with a client experiencing caregiving issues, mental health professionals should consider expected proximate and distal outcomes. *Proximate outcomes* are clinical outcomes that result directly from the intervention, whereas *distal outcomes* are generally contingent upon achieving the proximal outcomes first (Kennet, Burgio, & Schulz, 2000). For example, a therapist may help the caregiver client to use a behavioral technique with the care recipient to decrease problem behaviors. The intended proximate outcome would be a decrease in the problem behaviors, whereas the therapist's intended distal outcome may be to reduce the caregiver's distress level. Although distal outcomes are more difficult to achieve, considering both helps the mental health professional assess the effectiveness of the intervention.

The stage of the care recipient's disease is also important when determining appropriate clinical interventions. There is some evidence that early behavioral and environmental interventions can reduce the impact of the disease (Hanrahan, 2001). Working with caregivers in a preventative manner may enable them to learn skills to deal effectively with the care recipient before they are close to feeling burned out. Table 2 provides an overview of clinical considerations and interventions for working with male and female caregivers.

Types of Interventions for Mental Health Professionals

Overall, interventions commonly focus on preventing, delaying, or reducing the negative impact of dementia caregiving on the health and well-being of the primary caregiver and enhancing the ability of family members to provide care (Connell et al., 2001). These interventions include psychoeducation, support, respite care, or adult day care; psychotherapy; caregiver competence; and multicomponent approaches delivered in individual, group, or mixed formats. However, successful interventions usually engage the care recipient and caregiver, provide services over a period of time, and use multicomponent approaches (Bank et al., 2006). Mental health professionals can work with their clients to enhance social support, teach skills for caregiving tasks, and help caregivers manage their negative emotions. It is helpful for counselors to determine whether to target knowledge, cognitive skills, behavior, affect, or a combination of these with their interventions (Schulz, 2001). The counselor should also consider whether these areas need to be targeted for the

TABLE 2
Clinical Considerations and Interventions for Working With Male and Female Caregivers

Male Caregiver	Female Caregiver
<ul style="list-style-type: none"> • Be aware of how culture affects the family structure. • Men are less comfortable with formal services than women are. • Therapists need to understand the special challenges men face as caregivers. • Many men are less emotionally and psychologically prepared for the caregiving role than women are. • Men sometimes face social discrimination when providing activities of daily living (e.g., bathing, toileting) to parents of the opposite gender. • Men request more education about dementia and the caregiving process than women do. • Men prefer to have knowledge of formal services before their care recipient needs them. • Men ask for additional support and information, especially regarding uncomfortable situations (i.e., sexual advances, personality changes, and outbursts by the care recipient). • Caregivers often need improved psychological, intellectual, and spiritual coping mechanisms. • Men express a need to talk with other men experiencing similar problems and view support groups comprised of only men as most supportive. • Men are a small minority in support groups; however, those who do attend consistently are active, comfortable, and open with their feelings. • Men especially report valuing respite care. • Caregiving sons appreciate training programs to help them deal appropriately with parents' behavior problems. • Help caregiving children balance caregiving with the other demands of their lives. • Help caregivers access appropriate community services. • Help male spouses increase social support. • Educate caregiver regarding problem- and emotion-focused coping skills. • Address role conflicts regarding siblings, spouses, children, and employment. 	<ul style="list-style-type: none"> • Be aware of how culture affects the family structure. • Female spousal caregivers may need support in facing a status change within the family (e.g., wife having to transition into the dominant person in the family handling finances and family decisions for the first time). • Caregivers often need improved psychological, intellectual, and spiritual coping mechanisms. • Evaluate for and address the common occurrences of depression and anxiety. • Help caregiving children balance caregiving with the other demands of their lives. • Help caregiving women increase social support (e.g., support groups, marital counseling, family counseling). • Help caregivers access appropriate community services. • Help women to separate tasks and view them individually if feeling overwhelmed. • Focus on increasing health behaviors in female caregivers. • Educate caregiver regarding problem- and emotion-focused coping skills. • For caregiving daughters, give special attention to role expectations, quality of the parent–daughter relationship, and work-conflict situations.

caregiver(s); the care recipient; the environment; or, again, a combination of these approaches. Considering the previously discussed concerns, the counselor can determine the most effective type of intervention needed. Generally, interventions for family caregivers of dementia patients are classified as education; individual counseling; support groups; respite care; or a combination of these, referred to as *multicomponent interventions* (Connell et al., 2001; Schulz, 2001).

Education

The family caregiver usually receives her or his first education about dementia from the care recipient's medical doctor. Unfortunately, the amount of education provided varies widely, and many caregivers express the desire for more information about the disease itself, as well as ways to handle the patient's behaviors and the resources available to them (Mui, 1992; Sanders & McFarland, 2002). Sanders and McFarland found that male caregivers, especially, believed they would benefit from having more information. The mental health professional may find it necessary to help her or his client with educational information and traditional case management services. Sanders and McFarland found that referring clients to educational workshops, when available, was very helpful, and letting the caregiver know what to expect in the future eased anxiety. It was also found that male caregivers expressed disappointment that they were only informed of community resources when they needed them, rather than in advance so that they could plan ahead.

Male caregiving sons also expressed the need for more information regarding problem behaviors (Sanders & McFarland, 2002). For example, they reported not knowing how to handle behaviors such as loud outbursts in public or sexual advances toward them by their mothers who were experiencing dementia. Again, being made aware of these common problem behaviors before they occur can help caregivers handle them appropriately when they are manifested.

Skills training is another common educational intervention (Connell et al., 2001). Skills training may teach a caregiver how to alleviate hassles in communication with the care recipient, improve the care recipient's eating and dressing abilities, and engage the recipient in cognitive stimulation. This approach is based on the thought that improvement in the care recipient's behavior will have a positive impact on the caregiver. There is some debate about whether this type of training affects caregiver depression and burden (Connell et al., 2001; Kennet et al., 2000). As mentioned earlier in this article, it is more difficult to determine the distal outcomes of an intervention than it is to determine the proximate outcomes.

Individual Counseling

Individual counseling has been found to be more effective than group counseling for influencing psychological outcomes in caregivers (Connell et al., 2001). Cognitive skills training is often provided in individual counseling. Therapists can work with clients to increase their everyday problem-solving techniques, time-management skills, and skills to combat dysfunctional thoughts. Many clients need help in developing effective coping skills (Connell et al., 2001). Mental health professionals can work with caregiving clients to increase problem-focused coping skills and to decrease emotion-focused coping skills. When addressing coping skills in a problem-focused manner, the effort is on changing a stressful situation in some way. Often, there are ways to make the situation less stressful, but even if the situation appears to be unchangeable, helping the client reframe her or his situation in a more positive light and seeking guidance and support are associated with greater caregiver well-being (Kramer, 1997). Emotion-focused coping skills center on the caregiver's internal strategies for managing emotional responses to external problems. Dysfunctional emotion-

focused coping skills include regulating emotions through the use of denial, avoidance, or suppression of feelings and are correlated with greater levels of caregiver distress (Kramer, 1997).

Mental health professionals can also help their caregiving clients by suggesting behavior training for the care recipient. Bourgeois, Burgio, Schulz, Beach, and Palmer (1997) conducted a study in which seven caregivers were instructed to use memory aids to decrease the amount of repetitive questioning by the care recipient. The caregiver used dry erase boards to display the answers to commonly asked questions. For example, the board may read, "John will be home at 5:30 p.m." This technique was found to reduce the need for answering repetitive questions. This is a useful area to target because problem behaviors, such as repetitive questioning, have emerged as the strongest predictor of caregiver distress, over and above the patient's level of cognitive and functional impairment (Mitrani & Czaja, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Mental health professionals can also show caregivers how to make modifications in their home environment to make caregiving tasks less stressful. For example, it was found that reducing visual and audio stimuli in the home and learning to break tasks down for the recipient led caregivers to feel less upset with the recipient's behavior problems (Connell et al., 2001).

Support Groups

Kaye and Applegate (1990) found that caregivers who chose to attend support groups regarded them positively; additionally, support groups increased caregivers' perception of social support and gave them the experience of universality. Kaye and Applegate also found that women predominantly attended mixed-gender support groups. Male caregivers sometimes resisted openly acknowledging strain or difficulty coping, reflecting a need to be strong or in command of the situation (Fromme et al., 2005). Conner (2000) found that male caregivers expressed a need to talk to other men experiencing similar problems and reported viewing support groups comprised of only men as the most supportive kind of group. However, male support groups are rare (Conner, 2000; Fromme et al., 2005). Men who did find the mixed-gender support groups valuable were active, comfortable, and open with their feelings in group (Kaye & Applegate, 1990). When asked for suggestions for improving the support group, these men expressed a desire to meet more frequently and to be provided with more useful information, rather than just sharing feelings (Kaye & Applegate, 1990; Sanders & McFarland, 2002). Another atypical, but potentially beneficial, option is a telephone-based group. Bank et al. (2006) examined the use of such a group with an ethnically diverse sample of caregivers for individuals experiencing dementia. They reported that participants found the support groups valuable for the emotional support obtained, the usefulness of information shared, and their social aspects.

Respite Care

Respite care provides the caregiver temporary relief from caregiving duties. Usually, communities have individuals who are trained to assume caregiving duties or other household tasks (Connell et al., 2001). Patients with dementia can be placed in short-term respite care or may attend adult day care while their family

caregiver works. Conner (2000) found that although this is an underutilized service for caregivers in general, men especially reported valuing respite care. Adult day care facilities often provide training and counseling for the caregiver as well as temporary respite from responsibilities (Conner, 2000). Mental health professionals can help clients by referring them to this service.

Multicomponent Interventions

Multicomponent interventions blanket caregivers with multiple services in the hope that a combination of components will have an impact on the caregivers' unique needs at the appropriate time. Although most programs providing the previously described types of interventions show some form of success, none of them cover all caregiver issues. Literature has suggested that interventions that are comprehensive, intensive, and individually tailored are the most effective ones (Kennet et al., 2000). Knowledge about the care recipient's disease is certainly necessary for appropriate care; however, it does nothing to relieve caregiver stress and burden or help caregivers establish support. Simply having knowledge does not make an individual an effective caregiver (Schulz, 2001).

Mental health professionals can assist the caregiver; the care recipient; and, when available, other family members with a multicomponent approach by helping them to reestablish equilibrium in their family system and adjust to their new roles, working to reduce burden and stress. The therapist can also help caregivers with social support, not only within their family, but also through a support group by connecting them to others who share their experience. Directing caregivers toward educational workshops, respite care, and other community resources in their area will help caregivers manage their caregiving responsibilities, along with their other roles (Connell et al., 2001; Schulz, 2001).

Multicultural Considerations

When working with a family caregiving system, counselors need to assess and take into consideration the culture of the family. The family hierarchy can be a very important factor in the effectiveness of counseling interventions. Culture can have an impact on the caregiving structure of the family (Mitrani & Czaja, 2000). However, there are very few intervention studies of any kind that are geared specifically toward minority caregivers.

There are some considerations that clinicians can keep in mind when working with minority caregivers. Culture strongly affects how a person constructs reality, and that reality will affect how the individual views stressful events and physical illness (Connell et al., 2001). Buchwald et al. (1994) described a specific method of eliciting an explanation of how a client from an ethnic minority group views illness. The LEARN model is a set of guidelines for fostering cross-cultural communication regarding health issues: **L**isten, with empathy and understanding, to the patient's and family's perception of the problem; **E**xplain your perceptions of the problem; **A**cknowledge and discuss similarities and differences; **R**ecommend treatments and treatment options; **N**egotiate treatments and gain agreement regarding what will be done and when (Buchwald et al., 1994, p. 120). Knowledge of how illness is perceived can help the therapist and the client develop realistic common goals.

Case Example: The LeBrues

Preston and Mavis LeBrue (a fictional composite of several clients) had been married for 25 years. Preston retired from the U.S. Army; Mavis, who was 15 years younger than her 77-year-old husband, retired from her job as a bank administrator. The couple had four adult children and eight grandchildren. After they retired, the couple moved from the Northeast to the warmer climate of the South and closer to their children. It was during this transition 3 years ago that Mavis noticed slight changes in Preston’s behavior, including memory problems, disorganized thoughts and behaviors, and a decline in his overall executive functions. She shared her concern with friends and family members and was moderately disturbed by her observations.

At the request of Preston’s sister, Mavis took Preston to a specialist where he received a diagnosis of dementia with Lewy bodies (DLB). This progressive degenerative disease or syndrome of the brain caused Preston to experience many “unexplainable” symptoms. The symptoms of DLB are similar to those of Alzheimer’s disease and Parkinson’s disease: decline in mental ability affecting the memory, thinking processes, behavior, and physical ability; mild tremors, muscle rigidity, and coordination problems; and hallucinations.

Preston’s deteriorating condition and the resulting changes in their relationship brought Mavis great distress. Her feelings of concern and frustration led to exasperation and depression. Her children noticed the change in Mavis’s mood. Oftentimes, they would find her sitting alone saying, “My husband is gone,” and “The man I married is not the same.” Mavis felt the need to do everything on her own. “I am his wife so I should be the one providing for his needs. I want help and don’t know what kind of help to ask others for. When I do get help, I feel guilty about not giving my husband primary care.” Mavis was referred to a licensed mental health professional, Ngozi Patricks (a fictional composite of several counselors), who specialized in providing treatment for family caregivers.

Intervention. Dr. Patricks began her assessment with a psychosocial evaluation, the administration of the Mini-Mental State Examination (Tombaugh & McIntyre, 1992) to screen for cognitive impairment, and the administration of the Outcome Questionnaire–45.2 (Lambert et al., 1996) as an objective measure of emotional distress. Results of the evaluation confirmed Mavis’s emotional distress. She received the following diagnostic profile: Axis I–Major depression, single episode, and without psychotic features; Axis II–Deferred; Axis III–Diabetes; Axis IV–Family stress due to primary caregiver role for husband with dementia; and Axis V–72 for her Global Assessment of Functioning. Dr. Patricks discussed treatment options with Mavis, and they decided on a multicomponent treatment approach. This would afford Mavis a comprehensive and intensive approach tailored to her emotional, situational, and cultural needs. Recommended treatment included individual therapy and participation in a dementia caregiver support group with monthly educational and informational meetings on dementia. Additionally, Dr. Patricks recommended that Mavis continue using the respite care services provided by a local community agency.

Mavis’s individual counseling addressed the negotiated goals of (a) increasing use and types of coping strategies and (b) decreasing her symptoms of depression. Preston’s participation with respite care services, which she identified as a beneficial

coping strategy within itself, also contributed to feelings of guilt and depression. The complex and paradoxical relationships among respite, coping, and depression proved to be one of the most challenging issues for Mavis. This was primarily because in Mavis's home country of Jamaica, spouses, or others brought to the home, provided help and support for ill love ones. "Leaving" her husband at a facility for the day was internalized as temporarily "dumping" Preston. On the other hand, the daily caregiving role was taking its toll on her emotional health, and the increased stress exacerbated her diabetes. This placed her at risk for a multitude of other medical problems considering her age. During the course of treatment, Mavis learned to understand and use a problem-focused coping approach. This approach helped her to understand the paradox respite care had with her coping and depression and led to a growing appreciation and emotional comfort with this service. Additionally, she learned other problem-solving and reframing skills. Mavis also bolstered the frequency and types of self-care activities, which she had earlier identified as another source of guilt.

The support group also proved beneficial for Mavis. She realized that others experienced similar challenges and emotional responses. It gave an additional social outlet, affording her opportunities to connect with others who shared similar experiences. The support group developed into one of her favorite coping strategies and helped her to develop other approaches to meet the changing emotional demands of a family caregiver. The monthly educational and informational meetings taught her strategies to manage Preston's behaviors, helped her learn ways to assist Preston in his activities of daily living (e.g., dressing, grooming, bathing, eating), and provided information on what she might expect as his dementia progressed.

Case example discussion. Mavis continued individual therapy for 4 months, and she followed up with Dr. Patricks every few months. Although she stopped going to the weekly support group after 2 months, she consistently attended the monthly educational and informational sessions and maintained friendships with some of the group members. The treatment plan for Mavis, which considered her cultural background, successfully met her treatment goals through a multicomponent approach that afforded focus on educational needs, respite care, support groups, and individual counseling. Mavis possessed strong cultural beliefs that influenced her expectations, resulting in feelings of guilt when using respite care services and engaging in self-care activities. These feelings of guilt exacerbated her caregiving burden and stress, thereby worsening her feelings of depression. Individual counseling helped her to understand this dynamic and develop effective coping strategies, which significantly decreased her depression symptoms. Participating in the support group and the knowledge she gained from the educational workshops reinforced the insights Mavis garnered from counseling and also provided her with additional coping strategies.

DISCUSSION AND CONCLUSION

Mental health professional are poised to provide needed services to the ever-growing population of family caregivers for patients with dementia. Nevertheless, are they ready? Recommended areas to increase readiness include training, community connection and integration, and clinical experiences. Counselors would benefit from additional education and training on dementia, the medical and psychosocial impact on the patient who has dementia, and the psychosocial and emotional impact on

caregivers. Unfortunately, the amount of time patients spend with their physicians and the amount of information provided continue to decrease. This is not to suggest that counselors should provide medical information out of their professional range. However, they can integrate some medical knowledge (i.e., diagnosis, progression, treatment, medications, and medication side effects) with mental health knowledge to better assist family caregivers.

Connecting and integrating with community services and resources is another area of counselor readiness. Additionally, these connections will be critical for private practice success. Counselors should identify and connect with community resources that provide services to patients with dementia. These agencies and individuals will best articulate needs for such patients and their family caregivers specific to the counselor's community. Second, counselors should identify and connect with community resources that provide services to caregivers of patients with dementia. Individuals affiliated with these community resources can also articulate caregivers' needs. Interfacing with these two community resource areas helps counselors to identify service gaps that can be met through their practice and provide networking opportunities for potential bidirectional referrals. Additionally, counselor and community service providers can cross-disseminate best practices in providing caregiver support services.

Finally, the education, training, and community connections come together in clinical service delivery to family caregivers. However, it is critical for counselors to remain a consummate student throughout the treatment process. Dementia retains a syndrome-like quality with commonly shared symptoms or causes that manifest themselves in unique ways with each patient. Additionally, the caregiver experience can depend on earlier relationships with the care recipient and the caregiver's own emotional or psychological factors (Daire, 2002). As demonstrated in the aforementioned case study, cultural factors can also play an integral role in treatment. Learning from each client while providing quality and ethical care can lead to successful clinical outcomes and a more successful practice.

With the increase in the number of Americans developing dementia or impairing disorders, the number of family caregivers will rise as well. The population of family caregivers is very diverse, with each member experiencing the caregiving role uniquely. Although mental health professionals must keep the caregiver's individuality in mind, there are common characteristics of caregiving groups that can help the mental health practitioner understand the issues more readily. Men and women appear to experience caregiving somewhat differently and, therefore, may have different needs from counseling. Also, the experiences of caring for an ill spouse and that of caring for an ill parent are distinct.

With advanced knowledge of what the family caregiving client will confront in the future, the mental health professional can prepare the client with skills and knowledge to ease the stress and burden as the care recipient's disease progresses. Awareness of the community resources available for family caregivers is suggested for appropriate treatment of these clients. Because there are many different types of caregiver interventions, in varying intensities, it will be the therapist's task to tailor an intervention that is most appropriate for her or his client.

REFERENCES

- Alzheimer's Association and National Alliance for Caregiving. (2004). *Families care: Alzheimer's caregiving in the United States*. Retrieved March 7, 2009, from <http://www.caregiving.org/data/alzcaregivers04.pdf>
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- Armstrong, P., & Armstrong, H. (2004). Thinking it through: Women, work and caring in the new millennium. In K. Grant et al. (Eds.), *Caring for/caring about: Women, home care, and unpaid caregiving* (pp. 5–43). Aurora, Ontario, Canada: Garamond Press.
- Bank, A. L., Arguelles, S., Rubert, M., Eisdorfer, C., & Czaja, S. J. (2006). The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *The Gerontologist*, *46*, 134–138.
- Barr, J. K., Johnson, K. W., & Warshaw, L. J. (1992). Supporting the elderly: Workplace programs for employed caregivers. *The Milbank Memorial Fund Quarterly*, *70*, 509–533.
- Bourgeois, M., Burgio, L., Schulz, R., Beach, S., & Palmer, B. (1997). Modifying repetitive verbalization of community dwelling patients with AD. *The Gerontologist*, *37*, 35–92.
- Buchwald, D., Caralis, P., Gany, F., Hardt, E., Johnson, T., Muecke, M., & Putsch, R. (1994). Caring for patients in a multicultural society. *Patient Care*, *28*, 105–120.
- Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, *43*, 230–241.
- Clark, M., & Standard, P. L. (1996). Caregiver burden and the Structural Family Model. *Family and Community Health*, *18*, 58–66.
- Cohen, C. A., Gold, D., Shulman, K., & Zuccherro, C. (1994). Positive aspects in caregiving: An overlooked variable in research. *Canadian Journal of Aging*, *13*, 378–391.
- Cohen, D., Luchins, D., Eisdorfer, C., & Paveza, G. J. (1990). Caring for relatives with Alzheimer's disease: The mental health risks to spouses, adult children, and other family caregivers. *Behavior, Health, and Aging*, *1*, 171–182.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*, 310–357.
- Colantonio, A., Cohen, C., & Carlett, S. (1994). Support needs of elderly caregivers of persons with dementia. *Canadian Journal of Aging*, *17*, 330–346.
- Connell, C., Janevic, M., & Gallant, M. (2001). The costs of caring: Impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology*, *14*, 179–187.
- Conner, K. (2000). *Continuing to care: Older Americans and their families*. New York: Falmer Press.
- Crawford, L. M., Bond, J. B., & Balshaw, R. F. (1994). Factors affecting sons' and daughters' caregiving to older parents. *Canadian Journal of Aging*, *13*, 454–469.
- Daire, A. P. (2002). The influence of parental bonding on emotional distress in caregiving sons for a parent with dementia. *The Gerontologist*, *42*, 766–771.
- Doty, P., Jackson, M. E., & Crown, W. (1998). The impact of female caregivers' employment status on patterns of formal and informal eldercare. *The Gerontologist*, *38*, 331–341.
- Epstein-Lubow, G., Duncan-Davis, J., Miller, I., & Tremont, G. (2008). Persisting burden predicts depressive symptoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*, *21*, 198–203.
- Fingerman, K. (2001). *Aging mothers and their adult daughters: A study in mixed emotions*. New York: Springer Series.
- Franzen-Dahlin, A., Larson, J., Murray, V., Wredling, R., & Billing, E. (2007). Predictors of psychological health in spouses of persons affected by stroke. *Journal of Clinical Nursing*, *16*, 885–891.
- Fromme, E. K., Drach, L. L., Tolle, S. W., Ebert, P., Miller, P., Perrin, N., et al. (2005). Men as caregivers at the end of life. *Journal of Palliative Medicine*, *8*, 1167–1175.
- Hanrahan, M. (2001). New paradigms for guiding research, interventions and policies for family caregivers. *Aging & Mental Health*, *5*(Suppl. 1), S52–S55.
- Harris, P. B. (1998). Listening to caregiving sons: Misunderstood realities. *The Gerontologist*, *38*, 342–352.
- Harris, P. B., & Bichler, J. (1997). *Men giving care: Reflections of husbands and sons*. New York: Garland.
- Kaye, L. W., & Applegate, J. S. (1990). *Men as caregivers to the elderly: Understanding and aiding unrecognized family support*. Lexington, MA: Lexington Books.
- Keating, N., Fast, J., Frederick, M., Cranswick, K., & Perrier, C. (1999). *Eldercare in Canada: Context, content and consequences*. Ottawa, Ontario, Canada: Statistics Canada.
- Kennet, J., Burgio, L., & Schulz, R. (2000). Interventions for in-home caregivers: A review of research 1990 to present. In R. Schulz (Ed.), *Handbook on dementia caregiving: Evidence-based interventions for family caregivers* (pp. 61–125). New York: Springer.

- Kramer, B. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia. *The Gerontologist*, 37, 239–249.
- Lambert, M. J., Hansen, N. B., Umpruss, V., Lunnen, K., Okiishi, J., & Burlingame, G. M. (1996). *Administration and scoring manual for the OQ45.2*. Stevenson, MD: American Professional Credentialing Services.
- Levesque, L., Ducharme, F., & Lachance, L. (1999). Is there a difference between family caregivers of institutionalized elders with or without dementia? *Western Journal of Nursing Research*, 21, 472–497.
- Lynch, S. A. (1998). Who supports whom? How age and gender affect the perceived quality of support from family and friends. *The Gerontologist*, 38, 231–238.
- Meshefedjian, G., McCusker, J., Bellavance, F., & Baumgarten, M. (1998). Factors associated with symptoms of depression among informal caregivers of demented elders in the community. *The Gerontologist*, 38, 247–253.
- Meuser, T. M., Marwit, S. J., & Sanders, S. (2004). Assessing grief in family caregivers. In K. Doka (Ed.), *Living with grief: Alzheimer's disease* (pp. 170–195). Washington, DC: Hospice Foundation of America.
- Mitrani, V., & Czaja, S. (2000). Family-based therapy for dementia caregivers: Clinical observations. *Ageing & Mental Health*, 4, 200–209.
- Mitrani, V. B., Feaster, D. J., McCabe, B. E., Czaja, S. J., & Szapocznik, J. (2005). Adapting the Structural Family Systems Rating to assess the patterns of interaction in families of dementia caregivers. *The Gerontologist*, 45, 445–455.
- Monahan, D. J., & Hooker, K. (1995). Health of spouse caregivers of dementia patients: The role of personality and social support. *Social Work*, 40, 305–314.
- Mui, A. C. (1992). Caregiving strain among Black and White daughter caregivers: A role-theory perspective. *The Gerontologist*, 32, 203–212.
- Mui, A. C., & Morrow-Howell, N. (1993). Sources of emotional strain among the oldest caregivers. *Research on Aging*, 15, 50–69.
- Narayan, S., Hepburn, K., & Lewis, M. (2004). Spouses and adult daughters: A comparison of perceptions of dementia caregiving. *The Gerontologist*, 44, 89–90.
- Parker, G., Tupling, H., & Brown, L. B. (1979). A parental bonding instrument. *British Journal of Medical Psychology*, 52, 1–10.
- Robertson, S. M., Zarit, S. H., Duncan, L. G., Rovine, M. J., & Femia, E. E. (2007). Family caregivers' patterns of positive and negative affect. *Family Relations*, 56, 12–23.
- Sanders, S., & McFarland, P. (2002). Perceptions of caregiving role by sons caring for a parent with Alzheimer's disease: A qualitative study. *Journal of Gerontological Social Work*, 37, 61–76.
- Schulz, R. (2001). Some critical issues in caregiver intervention research. *Ageing & Mental Health*, 5(Suppl. 1), S112–S115.
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association*, 282, 2215–2229.
- Schulz, R., & Martire L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*, 12, 240–249.
- Schulz, R., O'Brien, A., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effect of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist*, 35, 771–791.
- Stevens, A. B., Lancer, K., Smith, E. R., Allen, L., & McGhee, R. (2009). Engaging communities in evidence-based interventions for dementia caregivers. *Family & Community Health*, 32, 83–92.
- Stone, R., Cafferata, G., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist*, 27, 616–626.
- Stone, R. I., & Short, P. F. (1990). The competing demands of employment and informal caregiving to disabled elders. *Medical Care*, 28, 513–526.
- Tennstedt, S. L., McKinlay, J. B., & Sullivan, L. M. (1989). Informal care for frail elders: The role of secondary caregivers. *The Gerontologist*, 29, 677–683.
- Tombaugh, T. N., & McIntyre, N. J. (1992). The Mini-Mental State Examination: A comprehensive review. *Journal of the American Geriatric Society*, 40, 922–935.
- U.S. Department of Health and Human Services and U.S. Department of Labor. (2003). *The future supply of long-term care workers in relation to the aging baby boom generation: Report to Congress*. Washington, DC: Author.
- U.S. General Accounting Office. (1998). *Alzheimer's disease: Estimates of prevalence in the United States*. Washington, DC: U.S. General Accounting Office, Health, Education, and Human Services Division.
- Ward-Griffin, C., Oudshoorn, A., Clark, K., & Bol, N. (2007). Mother-adult daughter relationships within dementia care. *Journal of Family Nursing*, 13, 13–32.
- Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology*, 53B, S267–S277.