

Family Caregiving in Dementia

Geoffrey Tremont, PhD

There are 5.3 million people with Alzheimer's disease in the US—a number expected to grow as the baby-boomer generation enters old age, with estimates that 7.7 million people will be affected by 2030. From 65 to 75% of dementia patients are cared for at home by family members.¹ According to the 2010 Alzheimer's Association Facts and Figures report, 10.9 million Americans provide 12.5 billion hours of care per year. In Rhode Island, an estimated 39,138 individuals provide about 44 million hours of care per year.

Because dementia involves relentless cognitive deterioration, family caregivers have to manage changing demands and unexpected problem behaviors. Caregivers often sacrifice their own needs. The “caregiver burden” includes both objective aspects of providing care (e.g., time and physical aspects of providing caregiver) and subjective experience of caregiving (e.g., perceptions and emotional reactions to caregiving). Although there are strong correlations between caregiver burden and depression, they are not necessarily the same construct.² Our view is that caregiver burden represents a stressor that if not ameliorated will lead to mental health consequences such as depression. In this article, I will review the consequences of caring for an individual with dementia, briefly discuss theoretical models of caregiver stress, highlight the literature on psychosocial interventions for dementia caregivers, and identify future directions for dementia caregiver research.

MENTAL HEALTH CONSEQUENCES OF DEMENTIA CAREGIVING

There is evidence that providing care for an individual with dementia is more stressful than caring for a physically-impaired older adult.³ Dementia caregivers report high levels of depression and anxiety and exhibit elevated rates of mood disorders; about one-third of caregivers meet diagnostic criteria for depression.⁴ Correlates of depression and other aspects of distress in caregivers include care recipient behavior problems, severity of cognitive and functional impairment,

more hours providing care, greater number of caregiving tasks, and longer duration of caregiving.^{3,5} Our group has also shown that unsatisfying prior relationships and poor family functioning are associated with stronger emotional reactions to memory and behavior problems and increased burden compared to individuals with satisfying pre-dementia relationships^{6,7}

There are also moderating factors, including greater distress in spousal caregivers, older caregivers, female caregivers, and in individuals with less social support.³ Given the strong relationship between care recipient behavior problems and caregiver distress, caregivers of individuals with fronto-temporal dementia (characterized by greater behavioral abnormalities than other dementias) report higher levels of distress than caregivers of individuals with Alzheimer's disease.⁸ Similarly, early behavior problems specific to Lewy Body Dementia (e.g., hallucinations, delusions, sleep disturbances) are strongly related to caregiver strain.⁹ Even for individuals with early-to-middle stage Parkinson's disease, there is evidence that cognitive and mood symptoms are more strongly related to caregiver strain and depression than motor symptoms.¹⁰ Recent evidence suggests that *perceptions* of patient suffering are predictive of caregiver depression and antidepressant use, independent of patient characteristics, patient behavior problems, and the amount of time caring for the patient.¹¹ There continues to be some uncertainty about whether long-term caregiving is associated with increased risk for problems or some degree of adaptation. Recently, our group has shown that persisting high levels of burden are associated with a subsequent increase in depressive symptoms.² Caregivers with greater depression and burden leading up to and during the end-of-life period are at increased risk of prolonged grief (see Tuya Fulton and Epstein-Lubow in this volume).

PHYSICAL HEALTH CONSEQUENCES OF DEMENTIA CAREGIVING

Caring for an individual with dementia can also lead to increased risk for physical health problems, both in terms of perceived health and objective health measures.^{3,12} The chronic stress associated with dementia caregiving may impair immunologic and hormonal functioning, thereby increasing susceptibility to illness. Furthermore, there is evidence that dementia caregivers neglect their own health (e.g., not getting enough sleep, poor nutrition).¹² Predictors of poor health among dementia caregivers include behavior problems and cognitive impairment in the care recipient, longer duration of caregiving, low socioeconomic status and education, receipt of less informal support, older age, not being a spouse, co-residence with the care recipient, and high levels of depression/burden.¹³ Furthermore, women and minority caregivers report poorer health than men and Caucasian caregivers.¹⁴

There have been several dramatic findings related to the health of caregivers, including death and development of their own cognitive impairment. Schulz and Beach¹⁵ showed that caregiving was an independent risk factor for mortality, with caregivers experiencing a 63% increased risk of death over 4 years compared to non-caregivers. Similarly, spousal caregivers of individuals with dementia had a higher mortality rate after hospitalization of their spouse than spousal caregivers of individuals hospitalized for reasons not related to dementia.¹⁶ Finally, recent epidemiological data show a six-fold increased risk of

Table 1. Domains to Assess Risk for Poor Caregiver Outcomes

Depression and Other Mood Disorders
Burden and Stress Level
Self-Care and Healthy Behaviors
Social Support
Caregiver and Patient Safety Issues
Management of Patient Problem Behaviors

Adapted from Belle et al.²⁴

dementia in spousal dementia caregivers compared to non-caregivers.¹⁷

POSITIVE ASPECTS OF DEMENTIA CAREGIVING

Although there has been a great deal of focus on the negative consequences of dementia caregiving, not all caregivers experience distress and burden, especially very early in the caregiving process.¹⁸ In addition, the length of caregiving may result in stability or decreases in burden and may increase time to nursing home placement, suggesting adaptation to the caregiving role.¹⁹ Most caregivers report some satisfaction with providing care, including feeling needed and useful, feeling good about oneself, learning new skills, developing a positive attitude and appreciation for life, and strengthening relationships with others.²⁰ Positive aspects of caregiving are inversely related to burden and depression and have the potential to buffer against the negative consequences.²¹ Caregiver personality characteristics such as extroversion and agreeableness along with social support (especially from one's spouse/partner) are associated with higher reports of positive aspects of caregiving.²²

THEORETICAL MODEL OF CAREGIVER STRESS

The most common theoretical model applied to stress experienced by dementia caregivers is Lazarus and Folkman's transactional stress and coping model.²³ This model posits that situations or experiences are not inherently stressful but are experienced as stressful after a two-stage appraisal process by the individual. Initial appraisals are influenced by background, past experiences, culture/ethnicity, and personality. Secondary appraisals involve deciding whether an individual is capable of managing the stress and selection of a coping strategy. This secondary process is more situation-dependent than the initial appraisal and is generally the target of interventions. Among dementia caregivers, there is evidence that active coping strategies lead to lower levels of distress than avoidant coping.

INTERVENTIONS FOR DEMENTIA CAREGIVERS

Psychosocial interventions can reduce the negative consequences for family caregivers of individuals with dementia.²⁴

Many intervention studies are plagued by methodological problems, such as small sample sizes and inclusion of non-distressed caregivers. Characteristics of effective interventions include being psychotherapeutic, multicomponent, tailored to the specific needs of the caregiver, and of adequate duration.²⁵ Interventions that have more generic educational components tend to increase caregivers' knowledge about dementia, although they have less significant impact on caregiver distress and burden.²⁶ Adding a psychotherapeutic component may help caregivers apply strategies learned in the intervention and/or address barriers to making changes. Because caregiver burden is a complex, multifaceted construct, multicomponent interventions seem to be more effective than interventions targeting one aspect of caregiver functioning.²⁶ Similarly, fixed interventions are less efficacious than those tailored to caregivers' specific needs. In the recent multisite REACH-II study, caregivers completed a risk appraisal measure to assess domains related to poor caregiver outcomes and to guide intervention implementation (see Table for list of important domains).²⁴ Meta-analytic studies have also shown that interventions of 6 months or longer are more effective than briefer interventions.²⁷ In addition to caregiver burden, distress, and depression, several multicomponent interventions have shown effects on physical health, service utilization, and delayed institutionalization.²⁸ In a large multicomponent, intervention study involving equal numbers of Caucasian, Latino, and African-American caregivers, intervention effects were seen for Caucasian and Latino caregivers, but not for African-Americans.²⁴ Finally, very few studies have addressed long-term outcomes of interventions, although there is limited evidence that positive effects of a caregiver intervention can be sustained.²⁹ Overall, comprehensive caregiver interventions involving regular, individualized contact with a counselor/social worker delivered over an extended period have resulted in reduced caregiver distress compared to control conditions.

In response to the need for cost-effective and highly accessible dementia caregiver interventions, our research group developed a telephone-based, psychosocial intervention for dementia caregivers that is

theoretically driven by a model of family functioning and the traditional stress-coping model (Family Intervention: Telephone Tracking—Caregiver; FITT-C). The FITT-C involves 16 telephone contacts over a 6-month period. Each call assesses key areas (i.e., social support, mood, family functioning, health) to allow therapists to set treatment priorities and to select the most appropriate intervention strategies. In a preliminary study of an earlier version of intervention, we found that dementia caregivers who received the FITT showed greater reductions in perceived burden and less-severe reactions to memory and behavior problems than individuals in a standard care condition.³⁰ We are conducting a large-scale, randomized controlled study comparing the FITT-C to an active control condition involving non-directive support for caregivers through empathic and reflective listening and open-ended questioning.

CONCLUSIONS AND FUTURE DIRECTIONS

Dementia caregivers suffer from increased rates of depression, serious medical risks and death, yet there is also increasing recognition of the positive effects of caregiving, which may buffer caregivers against negative consequences. Future research should identify methods and interventions for enhancing the positive aspects. Several large-scale, multi-component intervention studies have demonstrated beneficial effects for dementia caregivers, including reduced burden and depression and delayed institutionalization of care recipients. Few interventions have been tested for long-term outcomes and interventions are not necessarily effective for all individuals. It is anticipated that interventions tailored to individual caregiver's needs will result in better outcomes.

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Family and Professional Caregiving of Individuals with Dementia in Long-term Care

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More than 5 million people in the United States suffer from Alzheimer's disease or related dementias; the majority are over 65. In Rhode Island, more than 24,000 individuals are currently diagnosed with dementia.¹ Although family members initially care for most patients at home, many patients eventually require **long-term care (LTC)**. In Rhode Island, 45.4% of the approximately 8,000 residents in LTC have a diagnosis of dementia.

This review describes the health effects on both family and professional caregivers in the LTC setting, including some empirically supported interventions for family and professional caregivers.

FAMILY CAREGIVER ROLE AFTER PLACEMENT

After relatives enter LTC, many caregivers will perform similar tasks as they did when their relative lived at home; this may include basic activities, like eating and dressing, although nursing home staff will be providing care round-the-clock. The majority of families continue to manage finances, complete errands, and provide transportation to appointments. While family members can play an essential role in caregiving, and regular visitation has been associated with increased staff

satisfaction,² it is important to balance the care provided by the family and that provided by the nursing home staff, to minimize stress for both parties.

FAMILY CAREGIVER BURDEN FOLLOWING PLACEMENT

Many caregivers experience an initial sense of relief following placement, but longitudinal studies suggest that many caregivers experience new stresses and challenges as they cope with placement.³ This can lead to persistent emotional burden and depressive symptoms in the caregivers, in part because they must re-adjust their expectations about care and collaborate with staff. On average, dementia caregivers will have provided home care for five years prior to placement, and at the time of placement may view themselves as experts in their family member's care. Consequently, successful renegotiation of their role following placement is vital to healthy adaptation.⁴ In fact, the quality of the family-staff relationship is associated with important caregiver mental health outcomes, including depression⁵ and burnout.⁶

In addition to role adjustment, dementia caregivers report guilt about the decision to place, perceived failure

as a caregiver, concern about worsening cognitive and behavioral problems in their family member, financial challenges, and family conflict about the family member's care.⁷ Post-placement stress appears particularly heightened for spouses, caregivers who visit more frequently, and caregivers who are less satisfied with the help they receive from others.⁸ Similarly, older caregiver age, poor physical health, and low income are significant predictors of caregiver depression following placement, regardless of whether the individual has a diagnosis of dementia; burden is even greater if the person has cognitive impairment.⁹ As would be expected, pre-placement levels of depression and burden appear to be risk factors for poor adjustment as caregivers may have limited coping resources at that time to adjust to placement and may be particularly vulnerable to the new stressors.¹⁰

INTERVENTION PROGRAMS: CAREGIVERS

Most nursing homes in Rhode Island have support programs for the residents, but only a small minority offer support groups for family members.¹¹ Similar trends exist nation wide.¹ Though caregiving support groups may be of value, there