Reducing Psychosocial Distress in Family Caregivers

Ann M. Steffen, Judith R. Gant, and Dolores Gallagher-Thompson

Background

Families remain the most common source of assistance for older adults with physical and/or cognitive limitations (National Alliance for Caregiving and the American Association of Retired Persons, 1997; Schulz & Martire, 2004). A national phone survey found that nearly one in four US households included at least one self-identified caregiver who gave unpaid assistance to an impaired or physically frail relative over the age of 50 (NAC/AARP, 1997). The term “caregiving” encompasses a wide range of activities, from management of medications and appointments to bathing, dressing, and toileting the individual. Typically, tasks change over time as the conditions in question either become more stable, deteriorate, or in some instances, improve. Family and friends often experience considerable stress when trying to provide extensive caregiving in addition to the other demands of their everyday lives – they are often referred to as the “sandwich generation” since many are caught in the middle between employment and the responsibilities of caring for their husbands and children (and perhaps grand-children), as well as the responsibilities of caring for an impaired parent or parent-in-law. Spouses also experience considerable distress, typically focusing on their sense of loss as changes occur in the marital relationship (Davidson, 2006). Although it is true that caregiving can occur in the context of any significant physical and/or emotional disorder, most of the intervention research has been conducted with relatives of older adults with Alzheimer’s disease or another form of dementia. In addition, studies have found that these dementia family caregivers are generally more distressed than caregivers of physically impaired elders (Ory, Yee, Tennstedt, & Schulz, 2000). Given space limitations, this chapter will focus on interventions with dementia family caregivers.

Overview of Caregiver Distress: Why Do We Need Interventions for Caregivers?

Multiple studies over the past 20 years have reported significant negative psychosocial impacts from long-term dementia caregiving. These include high
rates of clinical depression and/or depressive symptoms (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Schulz & Martire, 2004; Schulz, O'Brien, Bookwala, & Fleissner, 1995), high rates of other negative emotions such as anger, frustration, burden, and fear (Ory et al., 2000), and other indices of distress, such as family conflict over caregiving, significant emotional strain, financial hardship, and reduced time for leisure pursuits (Ory et al.; Pinquart & Sorensen, 2003). In addition, studies have reported negative effects of caregiving on the physical health of the primary caregiver. For example, Vitaliano et al. (2002) and Vitaliano, Young, and Zhang (2004) found that male caregivers had a greater prevalence of heart disease than noncaregiving men of the same age. Greater risk for high blood pressure and the metabolic syndrome were also reported. Others have found complaints of bodily aches and pains and greater prevalence of diabetes, allergies, and use of nonprescription pain medication to be common in dementia caregivers (Coon, et al., 2004; Pinquart & Sorensen, 2003).

Numerous interventions have been developed to address these problems, and new psychosocial interventions are continuing to be tested (Steffen, 2006). In the past decade, there have been multiple reviews published as to their efficacy (Bourgeois, Schulz, & Burgio, 1996; Brodaty, Green, & Koschera, 2003; Schulz, Martire, & Klinger, 2005; Sorensen, Pinquart, & Duberstein, 2002). It is difficult to compare results across reviews, however, because different criteria have been used at different times to establish treatments as “evidence-based.” A recent review by Gallagher-Thompson and Coon (2007) that used strict criteria for identifying interventions as evidence-based found that three categories could be so considered at the present time: psychoeducational skill-building programs (e.g., Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003); psychotherapy (e.g., Gallagher-Thompson & Steffen, 1994); and multicomponent interventions (those using several distinct types of treatment such as support groups plus family meetings and case management; e.g., Mittleman, Roth, Coon, & Haley, 2004; Zarit & Zarit, 2007). Psychoeducational interventions, which derive from behavioral and cognitive theories and therapies (cf. Beck, Rush, Shaw, & Emery, 1979; D'Zurilla, 1986; Lewinsohn, 1974; Lewinsohn, Munoz, Youngren, & Zeiss, 1986) are often preferred by family members. The term is used to distinguish this kind of intervention from both traditional psychotherapy and from community-based support or educational programs. Most family caregivers, including the majority of those with diagnosable mental health conditions, do not identify themselves as candidates for psychotherapy or counseling. To appeal to these individuals, treatments are typically not labeled as individual or group psychotherapy; instead, such programs are often presented to caregivers with titles such as “skill training sessions” or “stress management classes” (Burgio, Hardin, Sinnott, Janosky, & Hohman, 1995).

That said, it would also be well to add a note of caution here: most clinical researchers in this field recognize that there is no “one size fits all” intervention that will be successful. What type of intervention to use in a clinical setting, with a given caregiver, depends on the presenting problem, the care-recipient’s stage of dementia, caregivers’ coping strategies and general psychological and physical health, and available resources in the community. On a national level, attempts have been made