



Research on Supportive Approaches for Family and Other Caregivers

Background Paper

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Prepared by:
Stephanie Hughes, MPP
Sari B. Shuman, MPH, MSW
Joshua M. Wiener, PhD
Elizabeth Gould, MSW, LCSW
RTI International

Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

Introduction

More than 5 million Americans live with dementia, and the number of people with Alzheimer's disease, the most common cause of dementia, is projected to increase to 13.8 million persons by 2050 (Hebert, Weuve, Scherr, & Evans, 2013; National Institute on Aging [NIA], 2016). Dementia affects a person's cognitive function, behavior, and ability to perform everyday activities such as shopping, paying bills, and managing medications (Alzheimer's Association, 2016; NIA, 2016). Most individuals with dementia live at home and are cared for by a family member or friend--typically a spouse or adult child. More than 15 million unpaid family and friends care for people with dementia, and as the baby boomer generation ages, those numbers will increase.

People with dementia generally need more support from their caregivers than those with other illnesses (Pinquart & Sorensen, 2003; Spector & Kemper, 1994). In addition to arranging health care visits, participating in medical decision-making, and coordinating support services, caregivers of people with dementia must take steps to keep the person safe and to address the behavioral and psychological symptoms experienced by 80-90 percent of people with dementia (Black et al., 2013; Lyketsos et al., 2002). Dementia caregivers also experience challenges in performing nursing tasks and helping the person with dementia with activities of daily living, such as eating, bathing, and meal preparation (National Alliance for Caregiving and AARP, 2015).

This paper examines how caring for a person with dementia affects the caregiver and what is known about effective ways to support caregivers, including examples of effective interventions, common elements of these interventions, and areas where more research is most needed.

Caregiver Demographics

The overwhelming majority of help provided to people with dementia comes from family members, friends, or other unpaid caregivers (Schulz & Martire, 2004). Over half of dementia caregivers provide more than 21 hours of care per week (National Alliance for Caregiving and AARP, 2015). About two-thirds of caregivers are women (Kasper, Freedman, & Spillman, 2014), and a 2014 survey commissioned by the Alzheimer's Association found that female caregivers are twice as likely as male caregivers to report spending 21 to 60 hours of caregiving per week. The same study reports that about one-third of dementia caregivers are 65 or older, about two-thirds live with the person with dementia, and one quarter are "sandwich" caregivers who take care of both a parent and children under 18 (Alzheimer's Association, 2014). Current trends toward smaller families, more divorce, and more geographic dispersion mean that the number of available family caregivers is expected to decrease over time while the number of people with dementia is growing (Roth, Fredman, & Haley, 2015).

Impacts of Caregiving on Caregivers of People With Dementia

Many variables affect the experiences of caregivers, including cultural norms, family relationships, financial resources, living arrangements, and coping skills (Montgomery & Kosloski, 2009). Some aspects of caregiving can be positive and bring families closer together, but caregiving can also exact a toll on caregivers' mental, emotional, physical, and financial health (Samia et al., 2014). Caring for someone with dementia appears to create a greater

burden than caring for persons with other illnesses--for example, rates of depression are twice as high among caregivers of people with dementia as they are for other caregivers (Black et al., 2013; Family Caregiver Alliance, 2016). Caregivers' physical health is often affected as well, with higher medical costs, more doctor visits, and greater medication use (Zhu et al., 2015).

The financial impact of caregiving can also be significant. The 2014 Alzheimer's Association survey found that 15 percent of caregivers had to take a leave of absence from their jobs, 13 percent went from full-time to part-time work, and 9 percent had to quit their jobs. The same survey found that many caregivers reduced the amount of money they saved, used money from their own retirement accounts, and decreased spending on their children's education to fund the person with dementia's care (Alzheimer's Association, 2014).

As the needs of the person with dementia affect the caregiver, so too does caregiver well-being affect the care recipient. Lack of caregiver coping skills may result in more behavioral symptoms in the person with dementia, including increased irritability, agitation, and wandering. When the caregiver is angry or frustrated, the person with dementia is more likely to become similarly upset (Yuhas et al., 2006). Caregiver depression is also associated with more behavioral symptoms in the person with dementia (Mausbach et al., 2006) and is a major predictor of institutionalization (Karon et al., 2015). Finally, the support that caregivers receive can directly affect their ability to help follow doctors' recommended care plans and to ensure the person with dementia's safety (Black et al., 2013; Family Caregivers Alliance, 2006).

Effective Approaches for Supporting Family Caregivers

Numerous nonpharmacological interventions have been developed to address the many needs of caregivers, people with dementia, and the dyad of caregiver/care recipient. At least 44 have reported positive results in randomized control trials (RCTs) (Maslow, 2012).

Many positive outcomes have been demonstrated by supportive caregiver interventions, particularly those that combine multiple elements such as training, respite, support, and referral to other resources. Reported improvements include a reduction in caregiver burden and depression (Nichols et al., 2014; Teri et al., 2005), a decrease in behavioral symptoms of people with dementia (Gitlin et al., 2015; Nichols et al., 2014), and a decrease in negative reactions to behavioral symptoms by caregivers (Gaugler et al., 2016; Gitlin et al., 2009; Teri et al., 2005). Other research has demonstrated an increased use of healthy coping strategies, caregiving skills, and confidence (Gallagher-Thompson et al., 2003; Gitlin et al., 2008; Hepburn et al., 2005; Ostwald et al., 1999) and increased quality of life and well-being (Belle et al., 2006; Mittelman et al., 1996, 2006). Although effect sizes are generally modest, the results are better than those of pharmacological treatments, and often, both the care recipient and caregiver benefit (Brodsky et al., 2003; Gitlin et al., 2015). Fewer studies have examined the impact of these studies on outcomes such as hospitalizations, emergency department use, institutionalization, and cost.

Some caregivers may be more likely to benefit from interventions than others. Two studies examined the factors that affect caregivers' readiness to participate in or adhere to interventions. They found that caregivers with better health, greater financial resources, lower levels of depression, and who reported more behavioral symptoms in the person with dementia were more likely to benefit from caregiver training. Some of these factors may need to be addressed to help increase caregivers' ability to try new strategies (Chee et al., 2007; Gitlin &

Rose, 2013). Caregivers with higher self-efficacy, defined as confidence in their abilities, or more constructive coping behaviors, such as seeking out information or social support, may also be in a better position to benefit from interventions (Mausbach et al., 2006; Rabinowitz et al., 2009).

Common Elements of Effective Caregiver Interventions

Certain elements are common to interventions targeting caregivers of people with dementia: assessment, education and skills training, care coordination, counseling and support groups, respite, and referral to other resources. Each of these elements is described below, along with findings or related recommendations.

Assessment

Assessment and referral are related activities that are used to identify the needs of caregivers and to find ways to meet those needs, either through direct provision of services or by linking caregivers to other resources. The great majority of caregivers have unmet needs for resource referrals and caregiver education, and many also need mental health care. Being nonwhite, depressed, or less educated puts caregivers at even greater risk for having unmet needs (Black et al., 2013).

Expert guidelines recommend that caregiver assessment should be standard practice and should be family centered, culturally competent, result in a care plan with clear outcomes, and be repeated regularly. Comprehensive assessments include information about employment status, family relationships, home environment, health of the care recipient, caregiver values, caregiver physical and mental health and quality of life, knowledge and skills related to caregiving, finances, and available social supports and resources (Family Caregiver Alliance, 2006). Despite these recommendations, the practice of assessing caregivers is not common, and when it does occur, the information considered varies widely (Black et al., 2013).

Education and Skills Training

Caregivers need not only a basic understanding of dementia, but appropriate skills for managing these symptoms and providing increasing levels of care over the course of the disease (Samia et al., 2014). Many evidence-based interventions are designed to address these needs. Most interventions are delivered in the participant's home or in a group setting; often, sessions are supplemented with telephone calls that reinforce learning and provide additional support. A small number of researched programs deliver training online or through videos (Karon et al., 2015; Maslow, 2012). Social workers, nurses, psychologists, or other health care professionals may deliver the training, which is often part of a multicomponent intervention. Effective educational programs actively involve caregivers through activities like discussion, take-home assignments, and role play (Samia et al., 2014).

Care Coordination

Care coordination brings together a multidisciplinary team of health care or community service providers to assess the needs of and provide care to people with dementia and their caregivers. It relies on enhanced communication among care providers, generally overseen by a care manager, and often supported by technology (AHRQ, 2016). Dementia care coordination programs are primarily aimed at improving quality of care and health outcomes for the person with dementia, but because they provide a needed service to caregivers in helping manage the complex web of medical and social supports available, they may also be of benefit to

caregivers. Examples of these programs include Partners in Dementia Care (Bass et al, 2013; Bass et al, 2014), Maximizing Independence (MIND) at Home (Samus et al., 2014), Aging Brain Care Medical Home (ABC MedHome) (Wiener et al., 2016; LaMantia et al., 2015), and Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS) (Lines et al., 2013).

Counseling and Support Groups

To help address potential mental health impacts and relationship strain caused or exacerbated by caregiving, some programs incorporate individual or family counseling. Many others conduct or refer participants to peer support groups, which may meet in person or over the phone. Support and counseling activities are typically only one part of a multicomponent intervention. At least one intervention reported benefits to caregivers from a support group-only intervention (Winter & Gitlin, 2006-2007), but a meta-analysis of other studies found that support group participation was not correlated with improved caregiver outcomes (Brodaty et al., 2003). The same review found no relationship between caregiver counseling and improved caregiver outcomes.

Respite

Respite care provides supervision to people with dementia, either in the home or at another site, to give caregivers time away from care duties (ADEAR, 2012). Adult day centers, which provide planned activities for the person with dementia, and often meals and transportation, are one common source of caregiver respite. In-home respite may involve companion services or help with personal care such as bathing and eating.

There is less research on the effectiveness of respite than on other types of caregiver interventions, but one earlier meta-analysis of existing research found that respite was effective in improving caregiver burden, depression, and well-being for caregivers of older adults, but the results were not dementia-specific (Sorensen et al., 2002).

Examples of Successful Interventions

Of the many interventions that have reported positive results from RCTs, several have been translated to community settings. Although not widely available, they provide good examples of the types of services that can meet caregivers' needs.

- *Savvy Caregiver*--This educational and skill-building training is delivered via six weekly 2-hour sessions in a group format. Topics include dementia basics, cognitive changes and how they impact behaviors, establishing realistic caregiving goals, gauging the care recipient's abilities, designing appropriate activities for the person with dementia, and using a problem-solving approach to manage behavioral symptoms. Outcomes include improved caregiver competence and coping and reduced depression and distress related to behavioral symptoms (Kally et al., 2014; Samia et al., 2014).
- *BRI Care Consultation*TM--Through this intervention, trained care consultants--usually social workers or nurses--provide an initial needs assessment, help the person with dementia and caregiver develop an action plan, and provide ongoing support, which includes monitoring and follow-up with reassessment, as needed. Progress is tracked through a care consultation information system. Initial contacts occur three times per month, with the frequency decreasing over time. Contacts take place via telephone, mail, and e-mail, with occasional in-person meetings (Wiener et al., 2016). Caregiver outcomes include reduced caregiver depression, increased use of support services, and reduced number of unmet needs (Bass et al., 2003, 2013).

- *REACH II*--This intervention assesses caregivers' needs and provides in-person training and counseling over a 6-month period. Training topics include self-care, healthy behaviors, and assessing and managing problem behaviors. Action steps are practiced through role-play, as are strategies for managing stress and increasing pleasant events. Caregivers are also linked with community resources and given skills related to social support and communication. Outcomes include reduced caregiver depression and burden and increase in self-care and social support (Belle et al., 2006; Nichols et al., 2008).
- *Skills2Care*--This intervention is designed to reduce behavioral symptoms through an environmental modification approach. In-home sessions take place over 4 or 6 months (two models exist). Occupational therapists train caregivers on reducing confusion and increasing safety for the person with dementia through changes to the living space, communication skills, simplifying tasks for the person with dementia, and engaging them in meaningful activities. They also refer caregivers to other community resources. Outcomes include reduced caregiver burden and reduced distress with behavioral symptoms (Gitlin et al., 2003, 2010).
- *New York University Caregiver Intervention*--This program provides one-on-one counseling sessions to the primary caregiver and group sessions for the family. Six sessions take place over 4-6 months and address challenges that the primary caregiver or family is encountering, emphasizing communication skills and encouraging caregivers to seek support from family and friends. Outcomes include reduced caregiver depression, reduced distress with behavioral symptoms, and increased satisfaction with social support (Gaugler et al., 2016).

Research Gaps

More research is needed to better understand where to direct resources and which caregiver programs are most effective and for whom. For example, caregivers' needs change over the course of the disease, but the types of services that are most effective at each stage are unknown (Montgomery & Kosloski, 2009; Samia et al., 2012). This is especially true of the early and late stages of the disease, which have received less research attention. Forms of dementia other than Alzheimer's disease have also received considerably less attention in terms of caregiver needs. Another significant challenge is the lack of a standardized taxonomy that could make it easier to categorize interventions and compare results (Gitlin et al., 2015; Maslow, 2012).

Caregivers may benefit from different programs depending on their sex, race/ethnicity, cultural differences, relationship to the care recipient, living situation, urban versus rural locale, and many other factors. Several studies have demonstrated different needs, adherence to programs, and outcomes based on race/ethnicity, sex, and relationship (Belle et al., 2006; Gitlin et al., 2001; Kally et al., 2014), but more research is needed to confirm findings and determine how to best use this information. There are also gaps in knowledge related to specific demographic groups of dementia caregivers, including men, minorities, rural, and long-distance caregivers (Gitlin et al., 2015). Another concern is that many studies have relied on convenience samples that have skewed to spousal caregivers with higher income and more education; these results may not be generalizable to other caregivers (Pruchno et al., 2008).

Another important question is whether results from randomized controlled trials translate to success in “real world” community settings. The Administration on Aging/Administration on Community Living has funded translation studies in recent years, but additional research is needed to test other interventions and strengthen conclusions (Gitlin et al., 2015; Hughes et al., 2016). Enrollment and attrition are also issues; even when free, effective programs are introduced to the community, it is not unusual for caregivers to decline to participate or to drop out mid-course (Mavandadi et al., 2016). More study is needed to understand how and why caregivers decide to participate in and complete interventions, and if programs are not meeting their needs, whether there are better ways to offer support.

Conclusion

As the number of caregivers increases, so too does the importance of understanding how to meet their needs for education, skills training, support, respite, and connection to resources. Caregivers can benefit from better health and quality of life and may even delay institutionalization of the care recipient using programs and services that help them cope with the disease and its effects. Many effective programs exist, but more study is needed to understand whether they can be translated to the community setting and how they can meet the needs of diverse caregivers at different stages of the disease.

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