

Insight on the Issues

From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia

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The strain on family members and friends caring for people living with dementia can lead to adverse consequences for the individual and family, as well as the health care system itself. Caregiver support services can make a real difference in the daily lives of people with dementia and their family caregivers. Evidence-based programs hold promise to help caregiving families, but they are not widely available in communities. Without access to effective and practical care strategies, family caregivers do not benefit optimally from programs that help them manage and cope with the challenges they face. Advancing proven programs in community-based organizations, health care systems, and other real-world settings should be a priority to help families in need.

INTRODUCTION

Improving family caregivers' experience of care, and addressing the practical and emotional needs of families in their caregiving role, is gaining attention among practitioners and policy makers. Caregiver strain can lead to changes in a family caregiver's own health and well-being. This may, in turn, lead to burnout—and the inability to continue caring for a relative, partner, or close friend at home and in the community.

Research shows that targeted care strategies can help family caregivers cope, reduce distress, acquire skills, and improve well-being—enabling them to continue providing care at home and in the community as older adults prefer, thereby delaying or avoiding more costly nursing home care. But despite the effectiveness of evidence-based caregiver supportive services, these proven services are still

not commonplace and available to the families and friends who could benefit from them.

Barriers to scaling up effective programs include health care and social service providers' lack of knowledge about proven caregiver supportive services, limited technical assistance and guidelines to help providers understand how to identify family caregivers who might benefit from such programs, lack of integration in existing systems of care, and lack of sufficient funding and payment mechanisms for using proven caregiver supportive services in practice settings.

This paper examines what is known about effective services and programs to support family caregivers of adults living in the community, with a focus on evidence-based programs for family caregivers of persons living with dementia.^{1,2}



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It explains evidence-based caregiver supportive services, and highlights several programs that have been shown to improve one or more aspects of the quality of life of family caregivers and can be implemented in local communities. This paper also summarizes positive program outcomes and identifies common characteristics of these successful caregiver programs and services. Finally, the paper recommends ways to improve the evidence base and address identified barriers to enable families to access effective support services where they live.

The emphasis in this paper is on supports for family caregivers of persons living with dementia—known as *dementia caregivers*—because the negative impacts of caregiving are especially severe when caring for someone with dementia living at home, and because most evidence-based caregiver programs have been tested with this population.³ Nonetheless, the key attributes of the programs highlighted may be helpful to family members and friends caring for an older person or an adult with any chronic illness or disabling condition.

PART 1: THE CURRENT PICTURE

Why Focus on Family Caregivers of Persons Living with Dementia?

Addressing the needs of dementia caregivers is important because of the growing number of older people living with dementia who rely primarily on their families for help with basic tasks of daily living. These family members also commonly experience more stress than those caring for people with disabilities who do not have dementia, in part because care needs are progressive, complex, and frequently unpredictable.^{4,5,6} Research suggests that high caregiver stress is an important and highly significant predictor of an older adult's placement in a nursing home, especially when caring for someone with dementia.^{7,8,9,10,11}

Dementia is the main cause of loss of independent living in older adults, and is highly feared by most Americans.

Most people living with dementia are cared for at home by family members. Of the nearly 5 million

older adults (ages 65+) who received help from others because of health or functioning reasons in 2011, nearly three out of four (71.4 percent)—or an estimated 3.5 million older adults—received help from family members or friends because they had dementia.¹²

Dementia caregivers typically spend more hours and years in the caregiving role, and they report greater emotional upset, distress, isolation, and financial burdens than family caregivers of those without cognitive impairment.^{13,14,15}

Dementia is one of the costliest health conditions to society.¹⁶ Persons living with dementia have higher Medicare and Medicaid expenditures than those without dementia.^{17,18} The financial risks of caregiving are especially high for families of persons living with dementia, who oftentimes experience many years of care until the end of life. In one recent study, dementia caregivers reported nearly twice the average out-of-pocket costs in 2016 than those caring for someone who does not have dementia (\$10,697 v. \$5,758).¹⁹

A focal point of research has been on developing, testing, and evaluating services to lessen distress, improve well-being, and better support individuals living with dementia and their families.

Even small changes in behaviors (such as wandering, repetitive questioning, apathy, and resisting help with daily activities) can help families keep a relative with dementia living at home with improved quality of life.²⁰ Behavioral and psychological symptoms (such as depression, aggression, apathy, and sleep disturbances) are nearly universal in dementia and associated with multiple negative outcomes for the individual and the family. Behavioral and psychological symptoms of dementia, rather than core cognitive symptoms (such as memory loss), often lead to heightened caregiver upset and strain, and earlier nursing home placement.^{21,22,23}

What Are Some of the Most Widely Tested Evidence-Based Caregiver Supportive Services?

The family caregiver's own needs for information and education, skills training, and other supportive services are often ignored in the delivery of health

KEY TERMS AND DEFINITIONS

Dementia Caregivers	Any relative, partner, friend, or neighbor who has a significant personal relationship with, and who provides a broad range of assistance for, a person living with Alzheimer’s disease or other dementia.
Evidence-based Programs	Service interventions that have been proved effective through outcome evaluations. In this paper, the term refers to caregiver supportive services and programs that have been developed, tested, and evaluated in one or more randomized controlled trial in the United States.
Implementation of Tested Models	The process by which an effective program, innovation, intervention, or practice is put into use in real-world settings.*
Long-term Services and Supports (also referred to as <i>long-term care</i>)	The broad range of day-to-day help needed by people with longer-term illnesses, disabilities, frailty, or extended health conditions. This can include help with housekeeping, transportation, paying bills, meals, personal care, and other ongoing social and health care services outside the home. Long-term services and supports also include supportive services provided to family members and other unpaid caregivers.
Meta-analysis	A method of statistical analysis that uses and combines results and other information from multiple separate but related research to draw a conclusion. A meta-analysis is a type of systematic analysis of data from multiple studies.
Nonpharmacological Interventions	A commonly used term to describe services and care practices that do not involve the use of drugs.
Psychosocial Interventions	Describes a variety of nonmedical, supportive services and strategies that aim to change behavior, develop personal coping strategies, improve well-being, and support people living with dementia and their families. These services may include education and skills training, counseling, support groups, and family meetings. These service interventions are often based in the community.
Randomized Controlled Trial (RCT)	The “gold standard” for rigorous scientific research and evaluation of service interventions. A main feature of an RCT is the random assignment, meaning assignment in a chance or unbiased way, to a <i>treatment group</i> that receives the supportive services, or to a comparison or <i>control group</i> that does not receive the supportive services, in order to measure the effects of the service intervention.
Social Supports	A term meaning access to help from other family members or friends, or from community services.
Translation of Research into Community Practice	The implementation or transfer of an effective service intervention into everyday practice by a community-based organization, medical practice, or health plan.

* Eric Lindland et al., “Just Do It” *Communicating Implementation Science and Practice*. (Washington, DC: Frameworks Institute, 2016).

care and long-term services and supports (LTSS), even if the care plan depends on the family caregiver. Yet the needs of family and close friends who take on a caregiving role—especially dementia caregivers—are often central to and intertwined with the care of the person living with dementia who may rely on their family caregiver for everyday help.

Caregiver supportive services for families of persons living with dementia—also known as *service interventions*—can include one or more care practices or strategies including but not limited to the following:

- Psychoeducation (such as education about a disease, stress reduction techniques, community resources, and how to ask for and access help);
- Behavior management/skills training (such as coaching on particular ways to handle activities and adaptive equipment, or the use of environmental modifications and cueing to reduce and manage behavior symptoms in the person with dementia);
- Counseling (such as individual counseling, family counseling, or training in cognitive reframing or other positive coping techniques);
- Self-care activities (such as yoga); and
- Social support groups.^{24,25}

The term *evidence-based programs* in this paper refers to caregiver supportive services that have been developed, tested, evaluated, and proved effective in one or more randomized controlled trial (RCT) in the United States. (See also “Key Terms and Definitions.”)

The body of evidence for effective dementia caregiver supportive services is growing.

Scientific reviews of tested dementia caregiver interventions have generally found that both the person living with dementia and the family caregiver value supportive services, and are helped by these programs. These reviews, known as *meta-analyses*, highlight the positive effects of nonpharmacological programs that include a combination of education, counseling, cognitive behavioral therapy,²⁶ environmental modification in the home, skills training, and other supportive services to improve

caregiver well-being, reduce caregiver strain, and ease the psychological distress common for family members caring for someone with dementia.^{27,28,29,30} Some evidence-based programs also enable the family member to remain in the caregiving role longer, thus avoiding or delaying costly nursing home placement for individuals living with dementia.³¹

Over the past 15 years, a number of evidence-based dementia caregiver programs originally evaluated in RCTs have been further tested in the United States in what are known as *translation studies*. These studies have examined whether these evidence-based programs can be successfully implemented in everyday practice by community-based organizations or health care systems and show similar positive outcomes that were achieved in the original research.^{32,33}

What Is the State of Evidence-Based Program Growth and Usage?

Despite the proven value of some caregiver programs, few are well known or have been expanded into everyday practice to help caregiving families.

In one national study of the Older Americans Act’s National Family Caregiver Support Program, over half (52 percent) of Area Agencies on Aging reported that they did not offer any evidence-based caregiver training and education interventions to family caregivers in the community.³⁴ Another recent study found that while nearly half (45.5 percent) of family caregivers providing substantial assistance to older adults living in the community do so for someone with dementia, the caregivers’ use of supportive services was low.³⁵

PART 2: THE CURRENT EVIDENCE

Evidence-Based Services for Family Caregivers of Persons Living with Dementia: Six Selected Examples

A number of dementia caregiver services show positive outcomes, including improvement in caregiver well-being. They represent an array

of approaches using multiple strategies and care practices to educate and support dementia caregivers.

Appendix A highlights six selected examples of effective dementia caregiver programs and services. It includes the name of the service/practice model, key citations describing the service intervention and the results in peer-reviewed journals, and a description of the tested program. It also features key findings and outcomes, including information on the implementation of the tested intervention in community organizations and other settings.

These programs were selected based on the following criteria:

- The persons with dementia are living at home and in the community.
- The program is a supportive service, not a drug (pharmacological) intervention.
- The service intervention has been shown to have positive outcomes in at least one RCT conducted in the United States.
- Outcomes are positive for persons living with dementia and their family caregivers.
- The intervention has been replicated or translated in a community setting at least once.

Selected programs include the following:

Benjamin Rose Institute (BRI) Care

Consultation—A telephone-based program using comprehensive assessments of both the person living with dementia and family caregiver to identify needed services and supports; then through personalized coaching, the program works to find solutions to address identified problems and unmet needs.

Care of Persons with Dementia and Their

Environments (COPE)—A home-based program designed to support the person living with dementia's abilities by reducing environmental stressors in the home, and improving the family caregiver's skills as well as problem-solving and coping strategies.

New York University Caregiver Intervention

(NYUCI)—A program for dementia caregivers offering individual and family counseling, support groups, and phone consultation to manage stress and improve problem-solving, manage problem behaviors

of the person living with dementia, and promote communication and support among family members.

Resources for Enhancing Alzheimer's Caregiver Health (REACH II)—An in-home and telephone-based program for dementia caregivers using a structured assessment to identify problems and help the family caregiver understand and learn ways to manage unmet needs through education, support, and skills training. Such services are aimed to improve caregiver health, social support, depression, and handling of problem behaviors.

Savvy Caregiver—An education and skills training program for dementia caregivers to improve caregiver knowledge, confidence and skills in managing caregiving tasks, and carrying out the caregiving role effectively.

Home-Based Counseling with Family Caregivers

(STAR- C)—A home-based counseling program for dementia caregivers using skills training to identify, reduce, and manage behavioral symptoms of the person living with dementia, improve family caregiver communication with the person with dementia, and improve quality of life for the individual and the family caregiver.

Evidence-based programs can be provided by a range of practitioners with various methods of service delivery.

In addition to in-home sessions and telephone support, some of the effective programs have also been delivered through group meetings, videophone, or web-based service delivery. Dementia caregiver programs are provided by a range of health care and social service professionals, including nurses, social workers, occupational therapists, community health workers, and care managers. Although evidence-based caregiver interventions have generally been implemented by community-based agencies and outside of medical settings, some dementia caregiver programs have more recently been effectively integrated into health systems.^{36,37}

Evidence-based programs show multiple positive outcomes for family caregivers.

The selected caregiver interventions have been shown to provide multiple benefits to help alleviate

the negative consequences of caregiving, and improve quality of life for dementia caregivers and those for whom they care. When studied, all the selected programs were shown to enhance family caregivers' sense of well-being and reduce perceptions of distress (burden) for the intervention group compared with the control group of family caregivers. All programs also showed improvements in caregiver knowledge about the disease, and in caregivers' abilities and confidence to deal more effectively with problem behaviors in the person living with dementia.

Five of the six selected programs decreased caregiver depression for substantial proportions of the dementia caregivers. Three of the six programs increased social support, including better communication among family members and friends, having a professional to talk to when a problem arises, or learning about other resources in the community. Two programs were shown to delay or reduce nursing home placement, and one program reduced hospital admissions and return emergency department visits for a vulnerable subgroup of persons living with dementia (see exhibit 1).

What Are the Common Features of Successful Caregiver Support Programs?

In general, effective dementia caregiver programs that lead to better caregiver outcomes

- Target family members or friends most at risk,
- Tailor the intervention to the family caregiver's specific concerns and unmet needs—as identified by the family caregiver through a systematic assessment,
- Ensure a combination of culturally appropriate support strategies, and
- Utilize specially trained health care or social service professionals who understand the principle of person- and family-centered care.^{38,39,40} (See exhibit 2.)

Successful programs for dementia caregivers begin with a caregiver assessment.

Trained service providers aim to build a trusting relationship by first asking questions of the family

caregiver. Examples of such questions are what is a daily routine like, what is the biggest worry, what tasks does the family caregiver feel he or she can and cannot do safely, does the family caregiver work at a paying job outside the home, and what types of assistance may be needed to maintain the caregiver's health and well-being.

Programs typically offer from 4 to 10 sessions in the home tailored to the identified unmet needs of the family caregiver—based on a caregiver assessment—using multiple strategies over three to six months, with periodic follow-up by telephone. Support services that proactively engage the family caregiver by using *teach back* methods, practicing new skills, receiving feedback, and developing a plan to utilize new skills to address the types of activities the family caregiver may encounter also seem to be the most useful.^{41,42}

PART 3: GOING FORWARD

What Needs to Be Done to Improve the Evidence Base and More Rapidly Implement Proven Programs in the Community?

Despite research demonstrating the positive benefits of dementia caregiver supportive services—and the important need to help these caregiving families cope better—implementation of these effective programs in community settings has been limited. Gaps remain in the research conducted, and in the translation of successful caregiver services from research to real-world settings.

The recommendations below should be a high priority for action to ensure a broader reach and wider impact for improving the lives of family caregivers and those for whom they care.

Recommendations

- 1) Support more research on effective care practices and programs for diverse caregiving families and situations.**

More research is needed to design and test effective caregiver interventions specifically with diverse family caregivers in mind. These interventions

EXHIBIT 1

Improved Quality of Life Associated with Selected Caregiver Support Programs for Family Caregivers of Persons Living with Dementia

Outcome Measures

Program	Improved Caregiver Well-Being	Improved Caregiver Knowledge and Skills	Reduced Caregiver Burden	Reduced Caregiver Depression	Increased Access to Social Supports	Delayed/Reduced Nursing Home Placement of Person with Dementia	Reduced Hospital Admission/Emergency Department Visits of Person with Dementia
Benjamin Rose Institute (BRI) Care Consultation	X	X	X	X	X	—	X*
Care of Persons with Dementia and Their Environments (COPE)	X	X	X	—	—	X**	—
New York University Caregiver Intervention (NYUCI)	X	X	X	X	X	X	—
Resources for Enhancing Alzheimer's Caregiver Health (REACH II)	X	X	X	X	X	—	—
Savvy Caregiver	X	X	X	X			
Home-Based Counseling with Family Caregivers (STAR-C)	X	X	X	X	—	—	—

Source: AARP Public Policy Institute analysis of statistically significant improvements in outcome measures from reviews of published journal articles as of March 2017. None of the selected programs utilized all of these outcome measures as part of the development and testing of the caregiver interventions in these randomized controlled trials.

— Indicates the outcome measure was either not used or reported in the study, or that a positive result for the outcome was not obtained.

* Results were significant for a subgroup of subjects receiving BRI Care Consultation, namely those who are most vulnerable with greater needs. Persons living with dementia who received the service intervention and whose cognition worsened over the one-year study had fewer hospital admissions and emergency department visits than control group subjects whose cognition worsened.

** At nine months, more family caregivers who received COPE compared with those in the control group perceived greater benefits including keeping the person living with dementia at home.

EXHIBIT 2

Ten Common Attributes of Successful Caregiver Support Programs

- 1. Adopting the principle of person- and family-centered care**
- 2. Targeting family members/friends most likely to benefit from the program**
- 3. Building a trusting relationship with the person and the family**
 - Having a consistent staff contact
- 4. Ensuring appropriate language access and cultural sensitivity in working with multicultural families**
- 5. Assessing the family caregiver's unique needs, problems, strengths, and resources, as identified by the caregiver**
 - Discussing goals of care as part of assessment and care planning
- 6. Providing the family caregiver with a combination of education, skills training, counseling, and problem-solving strategies to address multiple areas of unmet needs**
 - Proactively involving the family caregiver in the service delivery process
- 7. Tailoring services to the family caregiver's specific concerns and needs in keeping with the program's protocols**
 - Recognizing the heterogeneity of caregiver needs and circumstances
 - Ensuring programs are not "one size fits all"
- 8. Utilizing specially trained providers with the necessary abilities, knowledge, and skills to build rapport with the family caregiver, provide personalized coaching, and deliver other program components to improve coping and teach self-care skills**
 - Having trained staff who understand the concepts of person- and family-centered care, and working with family systems
- 9. Offering periodic follow-up (booster) support as needs change over time**
- 10. Evaluating caregiver outcomes to continuously improve the program**

Source: Adapted from Laura N. Gitlin and Nancy Hodgson, "Caregivers as Therapeutic Agents in Dementia Care: The Context of Caregiving and the Evidence Base for Interventions," in Family Caregiving in the New Normal, edited by Joseph E. Gaugler, and Robert L. Kane (London, UK: Academic Press, 2015), 305–53; and National Academies of Sciences, Engineering, and Medicine, Families Caring for an Aging America (Washington, DC: The National Academies Press, 2016).

would address caregivers' most pressing concerns for groups such as LGBT caregivers and multicultural families, and other subgroups including long-distance, male, and rural caregivers.^{43,44,45} Because both home and community are set in a cultural context, it is important to consider the family's culture, primary language, and other main concerns and resources when providing home-based services and supports.⁴⁶ In addition, different methods for delivering programs and services may be appropriate at different stages in the life course of the family. An example would be millennial caregivers who may prefer different ways of receiving help or want other types of support than older spouse caregivers do, such as technology-based support services that may offer effective innovations to reach and help more family caregivers.

Further, since most caregiver intervention research has focused mainly on improving outcomes for dementia caregivers, future research should address family caregivers of persons with other chronic conditions or disabilities. Dementia caregiver supportive services should also be adapted to include skills training, counseling, and problem-solving strategies that address the individual's other chronic conditions, such as diabetes or arthritis, or with issues concerning sensory impairment, such as hearing or vision loss.

To date, most caregiver services have been psychosocial interventions to reduce caregiver distress and improve caregiver knowledge and coping strategies. New care models should also be tested to address practical issues of family care, including financial and physical strain, the need for appropriate respite and a break from ongoing care tasks, the challenges of balancing caregiving with employment responsibilities, and improving communications and interactions with health care and LTSS providers.^{47,48} There is also a growing need to provide skills training to family caregivers in performing complex medical/nursing tasks (e.g., wound care, operating medical equipment, and giving injections) in addition to help with daily activities.⁴⁹ Such skills training and better overall care preparation for family caregivers could lead to fewer hospital readmissions and fewer trips to the emergency room with the person with dementia.

2) Create a registry of evidence-based programs and train service providers to deliver caregiver support services effectively and more broadly.

Health and social service professionals—as well as consumers and their families—should have the best possible information about the effectiveness of supportive services. Thus there is growing recognition among stakeholders of the need to create a classification system and registry for evidence-based dementia caregiver programs. Such a registry would identify what services and care practices can be offered, who the programs target, how the services are delivered and paid for, what kind of staff and training are needed, and the outcomes the service intervention can achieve.^{50,51} In response, efforts are underway to develop a web-based resource to assist organizations to compare proven dementia caregiver programs and to encourage adoption of these services for the family caregivers they support.⁵²

To implement proven services effectively and make the programs more available to the families who need them, service providers should have access to training and technical assistance. Such training would include understanding how best to provide care that is person- and family-centered, learning how to identify and reach family caregivers who might benefit, mastering how to implement programs with sufficient fidelity to their original procedures and intent, and determining how to pay for the service intervention.^{53,54}

Such a system could be a model for other emerging, evidence-based caregiver support services. Technical assistance is especially needed to assist providers, health plans, and other agencies to more rapidly scale up and adopt proven programs in their organizations and integrate them into existing systems of care.

3) Conduct cost analyses and develop payment mechanisms for caregiver interventions.

Few studies have examined the cost-effectiveness of dementia caregiver supportive services, posing a barrier for these proven programs to be adopted more widely by community-based organizations and health care systems.⁵⁵ The few cost analyses that have been done do show that dementia caregiver

supportive services can be low cost and result in cost savings to the family caregiver by lessening the time spent carrying out caregiving tasks.^{56,57}

Some experts suggest that more work is needed to show cost savings for evidence-based caregiver services, in order to provide incentives for implementing these programs into routine practice in community agencies, health care systems, and publicly-funded LTSS programs. Information on the cost-effectiveness of proven programs would help inform federal and state policy and health plans concerned with delaying or avoiding Medicaid costs for LTSS and Medicare costs for hospitalizations.⁵⁸

There is also a lack of adequate funding of evidence-based programs for family caregivers, as well as limited payment mechanisms to allow service providers to get reimbursed for delivering proven caregiver services.⁵⁹ In practice, payment policies for Medicare and Medicaid are largely designed to address the needs of the eligible, individual beneficiary only—not the “unit of care” that includes the family caregiver. As the main public payers of health care and LTSS, Medicare and Medicaid do not yet fully embrace evidence-based practice that is both person- and family-centered.⁶⁰

4) Encourage adoption of effective caregiver programs in managed long-term services and supports (MLTSS) and other settings.

With the growing movement toward managed care, Medicaid MLTSS programs have strong financial incentives to identify what supports the member’s

family caregiver needs, especially when the care plan of a member with dementia depends on having a family caregiver. As more managed care plans adopt a person- and family-centered approach to assessment, care planning, and service delivery, plans can be early adopters of evidence-based dementia caregiver services. They can also partner with community-based organizations that serve older adults to deliver these proven programs for their members’ family caregivers. These value-added services can make a difference in the lives of their members living with dementia and their family caregivers, who are among the most vulnerable people.⁶¹

CONCLUSION

Despite a growing evidence base that dementia caregiver supportive services are effective, few proven programs have been implemented into everyday practice. Experts suggest that there is a 20-year gap between knowledge gained from sound clinical research and the translation of that knowledge in practice settings in the community.⁶² Family caregivers can ill afford to wait this long.

Advancing proven programs to reach families who need help should be a priority at the federal, state, and local levels. Caregiver supportive services already known to be successful at improving quality of life for people living with dementia and their family caregivers should be scaled up and made available, accessible, and affordable to the families who need them.

APPENDIX A.

Selected Examples of Effective Programs for Family Caregivers of Persons Living with Dementia

Benjamin Rose Institute (BRI) Care Consultation		
Practice Model/Citations	Program Description	Key Findings/Outcomes
<p>David Bass et al., “The Cleveland Alzheimer’s Managed Care Demonstration: Outcomes after 12 Months of Implementation,” <i>The Gerontologist</i> 43 (2003): 73–85.</p> <p>David Bass et al., “Caregiver Outcomes of Partners in Dementia Care: Effect of a Care Coordination Program for Veterans with Dementia and Their Family Members and Friends,” <i>Journal of the American Geriatrics Society</i> 6 (2013): 1377–86.</p> <p>David Bass et al., “A Controlled Trial of Partners in Dementia Care: Veteran Outcomes after Six and Twelve Months,” <i>Alzheimer’s Research and Therapy</i> 6 (2014): 9, doi: 10.1186/alzrt242.</p> <p>David Bass et al., “Impact of the Care Coordination Program ‘Partners in Care’ on Veterans’ Hospital Admissions and Emergency Department Visits,” <i>Alzheimer’s & Dementia: Translational Research & Clinical Interventions</i> 1 (2015): 13–22.</p> <p>David Bass et al., “Reflections on Implementing the Evidence-Based BRI Care Consultation with RCI in Georgia,” <i>Generations</i> 39 (2016): 49–56.</p>	<p>This program aims to assist older adults with dementia and their family members or friends who help the older adult with everyday care tasks and care management. It offers personalized coaching and information, assists clients in locating appropriate community services, provides care coordination between health and community services, strengthens the network of family/friends in assisting with care tasks, and provides ongoing emotional support to the family caregiver and older adult through regular phone contact with a care consultant.</p> <p>The program was first developed in 1996 by a team of applied researchers at the Benjamin Rose Institute on Aging in Cleveland, Ohio, and staff from the Cleveland Chapter of the Alzheimer’s Association.</p> <p>The program is delivered by trained care consultants (such as social workers or nurses) by telephone and e-mail targeted to both the older adult with dementia and the family caregiver. The services can also be provided to people with other chronic conditions (such as diabetes, heart disease) and their family caregivers.</p> <p>The program includes an assessment of the family caregiving situation, the development of an action plan of specific and achievable tasks to address identified problems, personalized coaching following a standardized protocol, and ongoing monitoring and reassessment for the duration of enrollment in the program.</p> <p>A full-time care consultant, with part-time administrative support, can serve about 125 families.</p> <p>Program Information: http://www.benrose.org/research/EBP_Care_Consultation.cfm https://nadrc.acl.gov/</p>	<p>Reductions in family caregiver strain and depression, reductions in unmet needs of the family caregiver, and increased access to and use of support services for the family caregiver and older adult.</p> <p>A subgroup of intervention subjects, that is those persons with dementia whose cognition worsened over the one-year study, experienced decreased hospital admissions and emergency department visits compared with those in the control group whose cognition worsened. This suggests that the intervention was effective in reducing hospitalizations for those older people with greater cognitive impairment and more behavioral symptoms.</p> <p>The initial implementation of the program was in 2009, at the end of five controlled research studies. The program has been tested in a managed care organization, health care system, a U.S. Department of Veterans Affairs’ (VA) outpatient setting, and community-based organizations.</p> <p>The program has been translated in practice settings in Ohio, Georgia, and five VA medical centers in Boston, Massachusetts, and Houston, Texas.</p> <p>About 30 organizations in the United States are licensed by the Benjamin Rose Institute on Aging to deliver BRI Care Consultation.</p>

Care of Persons with Dementia and Their Environments (COPE)

Practice Model/Citations

Richard H. Fortinsky et al., "Translation of the Care of Persons with Dementia in Their Environments (COPE) Intervention in a Publicly-Funded Home Care Context: Rationale and Research Design," *Contemporary Clinical Trials* 49 (2016): 155–65.

Laura N Gitlin et al., "A Biobehavioral Home-Based Intervention and the Well-Being of Patients with Dementia and Their Caregivers: The COPE Randomized Trial," *Journal of the American Medical Association* 304 (2010): 983–91.

Laura N. Gitlin et al., "Interventions to Address Functional Decline in Persons with Dementia: Closing the Gap between What a Person 'Does Do' and What They 'Can Do,'" in *Neuropsychology of Alzheimer's Disease and Other Dementias*, 2nd ed., edited by Randolph W. Park et al. (New York: Oxford University Press, in press).

Nancy Hodgson et al., "Caregiver's Perceptions of the Relationship of Pain to Behavioral and Psychiatric Symptoms in Older Community Residing Adults with Dementia," *Clinical Journal of Pain* 30 (2014): 421–27.

Nancy A. Hodgson et al., "Undiagnosed Illness and Neuropsychiatric Behaviors in Community-Residing Older Adults with Dementia," *Alzheimer's Disease and Associated Disorders* 25 (2011): 109–15.

Program Description

This home-based service is designed to improve the well-being of the person with dementia and the family caregiver. The program provides dementia education, problem-solving, and specific strategies, including environmental modifications, communication, and task simplification techniques, to improve home safety and activity engagement and reduce functional dependencies for the person with dementia. It also teaches family caregivers how to manage and cope with behavior symptoms and to care for themselves.

Focusing on caregiver-identified problems, the person with dementia and the family caregiver receive up to 10 in-home visits from an occupational therapist and 1 in-home visit and 1 telephone call with an advanced practice nurse over a four-month period.

The program unfolds in 3 phases:

Phase 1

- An occupational therapist conducts an initial assessment to evaluate the interests and abilities of the person with dementia, the family caregiver's daily routines and care challenges, and the physical home environment.
- The advanced practice nurse reviews the number and types of medications the person is taking and potential drug interactions, assesses for pain, and obtains blood and urine samples from the person with dementia to rule out underlying medical issues or infections that may be contributing to behavioral symptoms or functional decline.

- The advanced practice nurse also meets with the family caregiver to provide education about the importance of taking care of self, how to detect pain, manage medications, and other aspects (hydration, constipation) that can affect daily function.

Phase 2

- The occupational therapist provides an assessment report to the family caregiver and begins to address his or her top three care challenges. Caregivers are shown and practice various strategies, including communicating differently, setting up tasks, and using activities to prevent and manage behavioral symptoms.

Phase 3

- The occupational therapist helps family caregivers learn how to generalize strategies and prepare for future changes in the person with dementia's cognition, function, and behaviors.

Key Findings/Outcomes

Improved functional status and increased activity engagement for the person with dementia, improved caregiver well-being and confidence in the caregiving role.

Increase in ability of family caregivers to keep person at home (at nine months), no change for problem behaviors of the person with dementia.

COPE is being translated and integrated into care plans in a Medicaid waiver and state-funded program in Connecticut to help home care beneficiaries at risk for nursing home admission remain at home with their families caring for them.

The replicability of COPE is high and it has the potential of saving Medicaid costs because all states offer similar home care waiver programs.

In Australia, COPE is being translated and evaluated for delivery via telephone and also in various health care settings, including physician offices, clinics, and home care agencies.

A project to implement COPE in PACE and other community-based programs in the United States is being planned. (PACE is a Medicare and Medicaid program, and stands for Programs of All-Inclusive Care for the Elderly).

New York University Caregiver Intervention (NYUCI)

Practice Model/Citations

Joseph E. Gaugler, Mark Reese, and Mary S. Mittelman, "Effects of the NYU Caregiver Intervention-Adult Child on Residential Care Placement," *The Gerontologist* 53 (2013): 985–97.

Joseph E. Gaugler, Mark Reese, and Mary S. Mittelman, "Effects of the Minnesota Adaption of the NYU Caregiver Intervention on Depressive Symptoms and Quality of Life for Adult Child Caregivers of Persons with Dementia," *American Journal of Geriatric Psychiatry* 23 (2015): 1179–92.

Kirsten H. Long et al., "Estimating the Potential Cost Savings from the New York University Caregiver Intervention in Minnesota," *Health Affairs* 33 (2014): 596–604.

Mary S. Mittelman et al., "An Intervention That Delays Institutionalization of Alzheimer's Disease Patients: Treatment of Spouse-Caregivers," *The Gerontologist* 33 (1993): 730–40.

Mary S. Mittelman et al., "A Family Intervention to Delay Nursing Home Placement of Patients with Alzheimer's Disease: A Randomized Controlled Trial," *Journal of the American Medical Association* 276 (1996): 1725–31.

Mary S. Mittelman et al., "Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer's Disease," *Neurology* 67 (2006): 1592–99.

Mary S. Mittelman and Stephen J. Bartels, "Translating Research into Practice: A Case Study of a Community-Based Dementia Caregiver Intervention," *Health Affairs* 33 (2014): 587–95.

Program Description

This program supports family caregivers through individual and family counseling provided by trained counselors (such as social workers or nurses), coupled with ongoing support, to address caregiver depression and manage stress. A main emphasis is on involving family members and friends to support the primary family caregiver.

Based on an assessment of caregiver needs, services include four components:

- Individual counseling tailored to each caregiver's specific situation (two sessions)
- Family counseling within four months of enrollment with the primary caregiver and other family members or friends selected by the caregiver (four sessions)
- Continuous availability of counselors by telephone to help family caregivers deal with crises and changes over time
- Weekly support group participation.

Counselors also provide resource information and referrals to each primary caregiver and family as needed.

The NYUCI program was developed by clinicians at the New York University Alzheimer's Disease Center in the mid-1980s. It was tested and evaluated with spouse caregivers in the New York metropolitan area from 1987 to 2010.

Program Information:

About the NYUCI

<https://ttdc.hcinteractive.com/content/about-nyuci>

<https://nadrc.acl.gov/>

<http://www.rosalynncarter.org/UserFiles/NYUCI%281%29.pdf>

Key Findings/Outcomes

Improved caregiver competence and self-confidence, greater satisfaction with support from family and friends, and improved coping with problem behaviors of the person with dementia.

Other outcomes included decreased depressive symptoms and related caregiver distress for more than 3 years after baseline, improved caregiver self-reported physical health and number of physical illnesses, and reduced nursing home placements 1.5 years longer than usual care.

An adaptation of the NYUCI model for adult child caregivers of persons with dementia in Minnesota—called Minnesota Family Memory Care—also showed delays in nursing home placement, underscoring the potential cost savings associated with this program.

Consistent with the original research trial, the Minnesota program showed a decrease in caregiver depression and stress, and reductions in the severity of family caregivers' reported reactions to problem behaviors of the person with dementia. Family caregivers also experienced improved quality of life and greater social support from others.

The NYUCI has been translated and implemented in a number of states (Minnesota, Florida, Georgia, California, Wisconsin, and Utah). It has also been replicated in other countries (such as Israel, Australia, and the United Kingdom). The intervention allows for flexibility, and can be tailored to different cultures and ethnicities.

Resources for Enhancing Alzheimer’s Caregiver Health (REACH II)

Practice Model/Citations

Steven H. Belle et al., “Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups: A Randomized Controlled Trial,” *Annals of Internal Medicine* 145 (2006): 727–38.

Louis D. Burgio et al., “Translating the REACH Caregiver Intervention for Use by Area Agency on Aging Personnel: The REACH OUT Program,” *The Gerontologist* 49 (2009): 103–16.

Leisa R. Easom, Gayle Alston, and Ryan Coleman, “A Rural Community Translation of a Dementia Caregiving Intervention,” *Online Journal of Rural Nursing and Health Care* 13 (2013): 55–91.

Amanda F. Elliott, Louis D. Burgio, and Jaimie DeCoster, “Enhancing Caregiver Health: Findings from the Resources for Enhancing Alzheimer’s Caregiver Health II Intervention,” *Journal of the American Geriatrics Society* 58 (2010): 30–7.

Linda O. Nichols et al., “Translation of a Dementia Caregiver Support Program in a Health Care System—REACH VA,” *Archives of Internal Medicine* 171 (2011): 353–59.

Linda O. Nichols et al., “REACH VA: Moving from Translation to System Implementation,” *The Gerontologist* 56 (2016): 135–44.

Alan B. Stevens et al., “Implementing an Evidence-Based Caregiver Intervention within an Integrated Healthcare System,” *Translational Behavioral Medicine* 2 (2012): 218–27.

Program Description

This program combines education, support, and skills building (in the home and by telephone) to improve dementia family caregivers’ quality of life and reduce depression. The training and counseling focuses on ways to manage the behavior symptoms of the person with dementia, reduce the family caregiver’s negative emotional response to the behaviors, manage the caregiver’s stress, and increase support for the caregiver from other relatives and friends.

Family caregivers participated in 12 individual sessions (9 at home and 3 by telephone) and 5 structured telephone support group sessions over a six-month period. Trained staff provided family caregivers with the following:

- Educational materials on dementia, caregiving, and local resources
- Problem-solving techniques to identify and address problem behaviors and role-playing exercises on managing difficult problem behaviors
- Skills training for improving self-care by managing caregiver stress, emotional well-being, and social support
- Stress-management techniques (such as breathing and stretching exercises, or listening to music).

REACH II was implemented in five U.S. cities in 2004. It provided supportive services and training to a diverse group of family caregivers, including White, African American, and Hispanic family members. REACH II is now being delivered in the original program model and two adaptations.

Program Information:

<http://www.rosalynncarter.org/UserFiles/ReachOutActionGuide.pdf>

http://www.rosalynncarter.org/rci_reach/

<https://nadrc.acl.gov/>

REACH VA:

https://www.caregiver.va.gov/CAREGIVER/REACH_VA_Program.asp

Key Findings/Outcomes

Improved quality of life in Hispanic and White family caregivers, and African American spousal caregivers. Prevalence of clinical depression among all racial groups of family caregivers was lower in the intervention group than in the control group at the end of the study period.

REACH II has been adapted for service delivery in the community, and implemented in a number of states, localities, and care settings using a shorter number of sessions. It can be offered in the home, in a facility or clinic, by telephone, or by telehealth modalities.

Organizations using the modified program have found results similar to those in the original research trial.

The modified program has been implemented within the U.S. Department of Veterans Affairs, and other organizations including hospital systems; state aging agencies; area agencies on aging; and social service programs in Hong Kong, Germany, and South Korea.

Savvy Caregiver Program

Practice Model/Citations

Patricia C. Griffiths et al., “Development and Implementation of Tele-Savvy for Dementia Caregivers: A Department of Veterans Affairs Clinical Demonstration Project,” *The Gerontologist* 56 (2016): 145–54.

Kenneth W. Hepburn et al., “Dementia Family Caregiver Training: Affecting Beliefs about Caregiving and Caregiver Outcomes,” *Journal of the American Geriatrics Society* 49 (2001): 450–57.

Kenneth W. Hepburn et al., “The Savvy Caregiver Program: Developing and testing a Transportable Dementia Family Caregiver Training Program,” *The Gerontologist* 43 (2003): 908–15.

Kenneth W. Hepburn et al., “The Savvy Caregiver Program: The Demonstrated Effectiveness of a Transportable Dementia Caregiver Psychoeducation Program,” *Journal of Gerontological Nursing* 33 (2007): 30–6.

Zina Kally et al., “The Savvy Caregiver Program: Impact of an Evidence-Based Intervention on the Well-Being of Ethnically Diverse Caregivers,” *Journal of Gerontological Social Work* 57 (2014): 681–93.

Sharon K. Ostwald et al., “Reducing Caregiver Burden: A Randomized Psychoeducational Intervention for Caregivers of Persons with Dementia,” *The Gerontologist* 39 (1999): 299–309.

Linda W. Samia, Kenneth W. Hepburn, and Lynne Nichols, “Flying by the Seat of Our Pants: What Dementia Family Caregivers Want in an Advanced Caregiver Training Program,” *Research in Nursing and Health* 35 (2012): 598–609.

Program Description

An education and skills-training program to help dementia family caregivers to manage stress and carry out their caregiving role effectively by strengthening caregivers’ knowledge, skills, and outlook for caring for someone with dementia.

Savvy Caregiver is a 12-hour program delivered to family caregivers by trained group leaders, usually in six 2-hour sessions over a 6-week period. The program’s curriculum includes teaching points and learning objectives for each session, and is designed to educate family members about the unfamiliar role of caregiving.

Savvy Caregiver is available in a range of formats (classroom, telephone, online), making the program accessible and responsive to family preferences for training and support.

Savvy Caregiver was originally developed and tested by researchers at the University of Minnesota.

Program Information:

http://www.rosalynncarter.org/caregiver_intervention_database/dementia/savvy_caregiver/

<https://nadrc.acl.gov/>

<http://www.hcinteractive.com/>

Key Findings/Outcomes

The program demonstrated positive benefits for family caregivers, including reducing burden and depressive symptoms, negative reactions to behavior problems, and overall caregiver distress.

The program has been replicated in several states. In California, the program was targeted to ethnically diverse families including African American, Asian/Pacific Islander, and Latino family caregivers. In Maine and Michigan, the program was replicated statewide, including for rural family caregivers.

The replication of the original education and skills-training program demonstrated improvements of caregiver competence and mastery of tasks, and reductions in distress comparable to the original program in the RCT.

A modified version of Savvy Caregiver has also been tested in rural Minnesota, Colorado, and Alaska with positive reactions from the family caregivers and the health and social service professionals who offered the training.

The program can be offered by a wide variety of organizations or groups in a range of community settings (including rural areas).

An online version, Tele-Savvy, is being tested and evaluated in an RCT.

Home-Based Counseling with Family Caregivers: STAR-C

Practice Model/Citations

Rebecca G. Logsdon, Susan M. McCurry, and Linda Teri, "STAR-Caregivers: A Community-Based Approach to Teaching Family Caregivers to Use Behavioral Strategies to Reduce Affective Disturbances in Persons with Dementia," *Alzheimer's Care Quarterly* 6 (2005): 146–53.

Susan M. McCurry et al., "Adopting Evidence-Based Caregiver Training Programs in the Real World: Outcomes and Lessons Learned from the STAR-C Oregon Translation Study," *Journal of Applied Gerontology* (2015): 1–18, doi:10.1177/0733464815581483.

Linda Teri et al., "Training Community Consultants to Help Family Members Improve Dementia Care: A Randomized Controlled Trial," *The Gerontologist* 45 (2005): 802–11.

Linda Teri et al., "Translation of Two Evidence-Based Programs For Training Families To Improve Care of Persons with Dementia," *The Gerontologist* 52 (2012): 452–59.

Program Description

This program is designed to help family caregivers identify, reduce, and manage difficult behavioral symptoms of their relative with dementia. It also aims to decrease depression and anxiety in individuals with Alzheimer's disease and related dementias and their family caregivers.

The program is delivered to the family caregiver by a trained community health professional (such as a social worker), in eight weekly in-home visits, followed by four monthly phone calls to sustain the approaches adopted during the program.

Using structured and systematic skills training, the trained health professional works with the family caregiver to do the following:

- Understand that dementia is a brain disease and learn what is realistic to expect
- Learn skills to address challenging behaviors of the person with dementia
- Develop individualized behavioral plans to reduce challenging symptoms
- Improve caregiver communication with the person with dementia
- Increase use of pleasant events to improve mood and quality of life in the person with dementia and the family caregiver.

STAR-C was originally developed and tested by clinicians and researchers at the University of Washington, School of Nursing, and Northwest Research Group on Aging.

Program Information:

http://www.rosalynncarter.org/caregiver_intervention_database/dementia/star-c_intervention/

<https://nadrc.acl.gov/>

<http://depts.washington.edu/roybalnw/>

Key Findings/Outcomes

For the family caregiver, quality of life, depression, burden, and reaction to behavior problems improved. The person with dementia experienced significant reductions in the frequency and severity of targeted problem behaviors. The results were maintained at six-month follow-up.

STAR-C has been implemented and tested in one urban and two largely rural counties in Oregon with similar positive outcomes for the family caregiver and the person with dementia.

STAR-C has also been translated for community agencies into a shorter, six-week program consisting of four home visits and two check-in telephone calls once the program is completed.

The modified version of the STAR-C program is currently being implemented in five Washington State Area Agencies on Aging and two in Oregon.

NOTE: All selected service interventions were tested through a randomized controlled trial (RCT).

- 1 This paper focuses on psychosocial interventions to support dementia family caregivers. It does not examine the effectiveness of respite care programs that can be provided in the home, adult day centers, or other residential care facilities, or other services such as assistive technologies. It also does not address evidence-based practices specifically intended for use in assisted living facilities, nursing homes, or hospitals. Some of the care practices for family caregivers utilized in these settings are emerging and are in various stages of development, implementation, and evaluation.
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