

Generations

Journal of the American Society on Aging



Supporting People with Dementia and Their Caregivers in the Community

Reducing the stigma
surrounding dementia

Dementia-capability
in long-term care

Care for the person,
directed by the person

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Improving Services for People with Alzheimer's Disease and Related Dementias and Their Caregivers

By Michael Lepore
and Joshua M. Wiener

Across the United States and internationally, communities and long-term services and supports systems are becoming more dementia-capable.

Approximately 5.5 million Americans have dementia, and the number of people with Alzheimer's disease, the most common cause of dementia, is projected to increase to 13.8 million by 2050 (Hebert et al., 2013; National Institute on Aging, 2016). As the disease progresses, individuals with dementia become more dependent upon others for assistance with daily activities. Ultimately, in advanced dementia, people with the disease need assistance with basic tasks, such as eating.

'Funding for Alzheimer's-specific services remains limited.'

People with dementia receive care from paid and unpaid caregivers, in some cases relying on public programs. Services for people with dementia used to be primarily institutional, such as in nursing homes, but now more community-

based services are available. However, funding for Alzheimer's-specific services remains limited. Approximately two-thirds to three-quarters of people with dementia live in the community rather than in nursing homes or residential care facilities (authors' calculations based on data from the National Survey of Residential Care Facilities and the Centers for Medicare & Medicaid Services).

Dementia Care in Context

Dementia care entails several challenges.

Identifying people with dementia is difficult because the diagnostic criteria are unclear.

Identifying people with cognitive impairment is the first step to linking these people and their caregivers to services. Numerous screening tools have been tested in the field, but no screening tool works optimally across the diverse populations of individuals with ADRD, and screening has many false positives (see Borson on page 6).

→**ABSTRACT** Most people with Alzheimer's disease and related dementias (ADRD) live at home rather than in a nursing home. Across the United States and internationally, efforts are underway to establish dementia-capable home and community-based service systems and to develop effective, evidence-based services for people with ADRD and their caregivers. Although progress has been made, additional work is needed in several areas, such as eliminating disparities in care and using technology to support well-being among people with ADRD and their caregivers. | **key words:** *Medicaid, cognitive impairment, institutionalization, dementia-friendly, dementia-capable, Administration for Community Living*

Additionally, the stigma of Alzheimer's disease complicates the identification of people with dementia. In a 47-country survey, most respondents with dementia and most caregivers identified negative associations about people with dementia (see Batsch on page 13).

The population with dementia is very heterogeneous and will become more so with its increased ethnic and racial diversity (see Lepore, Lines, and Wiener on page 22). Although ADRD prevalence differs across racial and ethnic groups, and disparities in the treatment of ADRD across these groups exist, few studies evaluate interventions to address disparities in this population or explain the reasons for the disparities. Several general interventions designed to explicitly address racial and ethnic disparities focus on cultural competency of healthcare providers and health systems, but these strategies have not been rigorously tested for people with Alzheimer's disease and their caregivers.

Promising developments in dementia-capable HCBS for persons with dementia are materializing.

Also, not all people with dementia are older: people with intellectual and developmental disabilities, especially people with Down syndrome, who are aging also are among those with dementia (see Gordon on page 30). The growth of this population increases the need for providers who understand both intellectual disabilities and dementia. Promising developments in dementia-capable home and community-based services (HCBS) for persons with dementia and intellectual or developmental disabilities are materializing, particularly through a set of grant programs funded by the Administration for Community Living (ACL).

Although paid caregivers provide important services, the majority of care is provided by family and to a lesser extent friends (see Gaugler et al. on page 37). Most people with ADRD

receive care at home by family members who live with them, mainly daughters and wives. Keeping people with ADRD at home is caregivers' primary motivation for providing care.

Dementia Care Systems

Because of the specialized needs of people with ADRD, long-term services and supports (LTSS) systems need to tailor programs to the needs of people with dementia and their caregivers (see Gould and Wiener on page 44). In other words, LTSS systems and programs need to become dementia-capable. For example, with support from ACL, the Minnesota Board on Aging is developing culturally customized training materials for ADRD service providers to align with the norms and values of different populations, and the Oregon Department of Human Services is supporting dementia training for Aging and Disability Resource Connection staff (see Mead et al. on page 57). In California, a range of dementia-capable practices, including care manager training and caregiver education and support, have helped increase access to HCBS for people with dementia and their caregivers (see Cherry et al. on page 62). Specific strategies that have been used to provide services for the American Indian population also are addressed in this supplement (see Brand on page 52).

A sign of the problems in the existing system in the United States is that, among older people residing in the community, individuals with dementia are significantly more likely to be hospitalized than those without it, both overall and for potentially avoidable conditions (see Feng on page 68). This may be attributable to the lack of primary care, specialized dementia care, other medical resources, and LTSS for community-residing people with dementia. Dementia-capable and dementia-friendly efforts to reduce hospitalizations might help improve quality of care at the end of life and reduce costs of care for people with dementia, but few programs are specifically designed to reduce hospitalizations

among people with dementia who are living in the community.

Akin to the dementia-capable systems efforts in the United States, communities around the world are striving to make their healthcare and LTSS systems more dementia-friendly by designing environments that respond to the needs of people with ADRD and including people with dementia in treatment discussions and decision making (Lin, 2017). Across Scotland, local projects are helping to shift the national culture to be more dementia-friendly and dementia-capable (see Miller on page 73).

Services for People with Dementia and Their Caregivers


High-quality services for people with dementia and their caregivers require person-centered and person-directed approaches that attend to individuals' unique strengths and needs and empower them to make decisions about their daily and long-term care (see Lepore et al. on page 78). A special challenge is serving persons with dementia who live alone because they may not have people to support them and they may not be identified until they are already in more advanced stages of illness (see Gould et al. on page 83).

Numerous technological devices have been developed to help meet the needs of people with dementia and their caregivers and have shown promise for reducing caregiver burden (see O'Keeffe on page 90). Several provider efforts and evidence-based interventions that LTSS providers can use to support family caregivers

of individuals with dementia also have been developed and evaluated (see Easom on page 96; Steiner and Sherman on page 107; and Walberg et al. on page 100).

Conclusion

People with ADRD increasingly use HCBS. Across the country and internationally, communities and healthcare systems are seeking ways to become dementia-capable, and service providers are using a wide array of evidence-based and new innovative practices to support people with ADRD and their caregivers. Although dementia stigma persists, a variety of strategies—including developing ADRD-focused policies and technologies and adopting person-centered and person-directed approaches to dementia care—suggest that a more dementia-friendly culture may be emerging.

Advancing the development of more dementia-capable healthcare systems and dementia-friendly cultures will help society meet the needs of current and future generations of people affected by ADRD. Ongoing assessment of national and state progress toward these goals can provide valuable information for designing and implementing effective services for people with ADRD. 

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Screening for Cognitive Impairment in Older Adults: A Practical Overview

By Soo Borson

Proactive testing is the key to caring for people with dementia more effectively, more efficiently, and at lower cost.

Few questions in geriatrics have generated as much controversy and misunderstanding as whether to routinely screen older people for cognitive impairment and dementia. To arrive at a meaningful answer, it is important to understand current thinking about why this has been so controversial, the goals of screening, its effectiveness in identifying unrecognized cases of cognitive impairment, and the intended and appropriate use of results. Individuals at risk of cognitive disorders associated with advancing age (the most powerful known risk factor for most dementia) may avoid screening because of fears about future dependency, social marginalization, or loss of privileges if they are found to have impairment. Physicians and other providers may fear that routine screening will uncover deficits that cause suffering in their patients against which they have limited therapeutic power, while government agencies may fear that the rising prevalence of dementia will soon bankrupt both health and social care sectors.

Proactive detection and diagnosis of cognitive impairment and dementia are, however, widely held to be key to caring for individuals

with dementia more effectively, more efficiently, and at lower cost. Improving rates of detection and diagnosis, which currently hover at about 50 percent or less, relative to actual prevalence, are principal goals of the U.S. National Alzheimer's Plan for 2017 (U.S. Department of Health and Human Services, 2016). However, while under-diagnosis is a major concern, over-diagnosis also occurs and, when a wrong diagnosis of dementia is entered into an individual's electronic health record, it is extremely difficult to remove (Skinner, Scott, and Martin, 2016). Screening is the best-studied way to improve accurate detection of cognitive impairment.

The Goals of Screening

Without effective strategies to prevent or reverse the brain disorders that cause most cognitive decline in older people, the primary goal of screening for these conditions is to identify individuals—and their family and other caregivers—who may benefit from tailored medical and psychosocial interventions to improve outcomes and mitigate harms (Borson and Chodosh, 2014; Borson et al., 2013; Cordell et al., 2013).

→ABSTRACT This article addresses the rationale for screening older people for cognitive impairment and dementia, the best methods available for doing so, false positives and negatives with various tests, and how proactive detection can promote more effective, more efficient, and less costly care for people with dementia. It also explains the difference between screening and diagnosing and talks about the new CMS-enabled, free Annual Wellness Visit. | **key words:** *cognitive impairment, dementia, dementia screening, diagnosis, Annual Wellness Visit*

In clinical settings, detection of cognitive impairment by systematic screening has three main purposes. First, it can prompt a search for medical, emotional, social, or environmental factors that may contribute to disability (e.g., certain classes of medications, unsuspected medical problems, or unmet needs for care). Second, it can lead to evaluation of the underlying causes and severity of cognitive and functional decline, both of which are important in individualizing care plans. Third, screening is the first step toward identifying care strategies at home and in healthcare settings to optimize quality of life for people with cognitive impairment and those who care for them.

Improving rates of dementia detection and diagnosis are principal goals of the U.S. National Alzheimer’s Plan for 2017.

Other purposes of screening could include improving population estimates of the prevalence, incidence, and risk factors for cognitive impairment; developing defined “trial-ready” populations for rapid recruitment into research; and improving the quality of healthcare by identifying and responding to opportunities to prevent avoidable crises. This article focuses principally on applications of screening in ongoing clinical care.

Screening Differs from Diagnosing

Screening for cognitive impairment and diagnosing dementia are distinct processes. Diagnosing the presence of dementia is based on four basic criteria: the presence of deficits in more than one cognitive domain (memory and learning, planning and execution of roles and tasks, self-regulation, communication, or social judgment, among others); a decline from an individual’s prior level of cognitive ability; sufficient severity to impair everyday functioning and full capacity for independence; and exclusion of certain other types of cognitive

impairment, especially those that may be temporary (e.g., delirium, intoxication). Simple cognitive screening tests, and a thorough history provided by someone who knows the individual well and can report accurately on past and current cognitive and functional status (e.g., a close family member), are usually sufficient to determine whether these criteria are met.

The boundary between dementia and mild cognitive impairment (MCI) (i.e., subtler cognitive deficits with minimal impairments in function) is somewhat arbitrary, and not all MCI represents an early stage of an evolving dementia (Canevelli et al., 2016). Diagnosing the cause of cognitive impairment requires a broad medical evaluation using widely available standards and guidance; the Alzheimer’s Association provides a straightforward approach that can be easily applied in clinical practice (goo.gl/XyS2VF).

Screening that detects unrecognized cognitive impairment is the first step in initiating a diagnostic evaluation.

Screening Tests

Individuals can be screened for cognitive impairment by direct testing or, when this is impossible or impractical, by administering a validated proxy reporting tool. Both types of screening tests yield an estimate of the probability that an individual does or does not have significant cognitive impairment; they cannot diagnose any particular causal condition.

All tests are subject to false positive and false negative errors, the first suggesting impairment when it is absent, the second failing to detect impairment that is present. Screening tests can be calibrated to optimize the balance between these two types of errors based on their intended use. For example, calibrating the way a screening test is scored to optimize sensitivity will pick up a higher percentage of individuals who have true cognitive impairment at the risk of over-identifying (as impaired) individuals who are unim-

paired; this strategy is well suited to epidemiological surveys of the prevalence and incidence of cognitive disorders. Conversely, calibrating a test to optimize specificity will help ensure that people classified in the “normal” group are not impaired. In most healthcare settings, high specificity is generally preferable to high sensitivity. If a positive screen is used to identify individuals who will enter a comprehensive diagnostic assessment that may include lengthy or expensive testing, high specificity (few false positives) would usually be favored over sensitivity, but at the expense of more missed mild cases.

‘Screening for cognitive impairment and diagnosing dementia are distinct processes.’

There is no perfect screening test: all have strengths and limitations. Some, containing only key indicators of memory and executive deficits (e.g., Mini-Cog, mini-cog.com), are well suited for use in primary care settings where time is at a premium and simple administration and scoring are essential (Borson et al., 2006; Kallumpuram et al., 2015; Tsoi et al., 2015), while others (e.g., Feliciano et al., 2013; Freitas et al., 2014; Montreal Cognitive Assessment; MoCA; mocatest.org; St. Louis University Mental Status Examination; SLUMS; goo.gl/TkJhEP) fit well as a second step in evaluation or in specialized clinical settings where detailed coverage of multiple cognitive domains is desirable.

Proxy-based screens such as the Functional Activities Questionnaire (FAQ; goo.gl/Qo2RML) (Kallumpuram et al., 2015), Ascertain Dementia 8-item Questionnaire (AD-8; goo.gl/tSvMU3) (Cecato et al., 2016), and Informant Questionnaire for Cognitive Decline in the Elderly (goo.gl/f7QYPB) (Harrison et al., 2014) rely on estimates of impairment in everyday cognition-based functions and are usually provided by a family member. Both direct and proxy screens have value in specific settings and can comple-

ment each other, but are subject to different sources of inaccuracy. In current clinical practice, proxy screens are most valuable in identifying everyday functional impairments in individuals already found to have probable cognitive impairment.

How Effective Is Screening?

Screening older people, using validated cognitive assessment tools, is an effective way to improve detection of cognitive impairment (Lin et al., 2013); a comprehensive list of screening tools is available from the National Institute on Aging. Screening tools differ somewhat in precision—the extent to which a test includes “signal” elements relative to “noise.” Signal elements relate to the presence or absence of cerebral dysfunction (e.g., tests of memory), while noise elements can be strongly influenced by factors other than clinical cognitive impairment, such as language, cultural experience, or education (e.g., abstract mental arithmetic tasks), and in accuracy or the extent to which a screening result correctly classifies the true cognitive status of the person screened.

Bigger differences are found in how well these tools perform in specific settings, with particular users, and in given populations. For example, most screening tests perform very well in memory clinics, where most clients seen have cognitive impairment, but less accurately in primary care and community populations, where rates of cognitive impairment are far lower. This property—the dependence of test performance on the existing prevalence of the condition being tested for—is often ignored in reports on new screening tools or new applications of older tools, leading to spurious estimations of test effectiveness. With cognitive screening tools, one size does not fit all.

Cognitive impairment occurs along a broad continuum of severities and types, and a test that works well in detecting well-established dementia may fail in early stages when impairment is



subtle. In addition, screening tests intended for use in one setting must be crafted with its unique characteristics in mind; for example, a screen for primary care must fit into the time allotted to a patient visit (Lorentz, Scanlan, and Borson, 2002) and be designed for accurate administration and scoring by individuals with little or no experience in cognitive assessment after brief training (Borson et al., 2007).

Most screening tests have been optimized for relatively well educated, English-speaking individuals living in high-income countries like the United States and the United Kingdom, where there is broad acceptance that dementia is the result of a medical condition affecting the brain. In low- and middle-income countries where fewer older adults have a high school or equivalent education (and many have never been to school), language and culture differ widely from those of populations for which such tests were developed, and dementia is generally viewed from perspectives other than that of scientific medicine. In these populations, the same tests that work well in the original population can yield high rates of false positives, which

could contribute to higher rates of “dementia” reported among populations with lower levels or differing content or quality of education (Manly and Espino, 2004; Nielsen et al., 2011). Several approaches to improving test accuracy have been developed for populations with diverse languages and cultures in low- and middle-income countries, such as the 10/66 method used in cross-national studies of dementia prevalence (Stewart, Guerchet, and Prince, 2016) and the Rowland Universal Dementia Assessment Scale (Basic et al., 2009).

Short screens designed specifically for low-literacy populations are in development but lack robust validation in peer-reviewed publications; among screening tests that have been extensively validated for use in everyday settings, such as primary care in the United States, the Mini-Cog is least affected by language, culture, or ethnicity (Borson et al., 2000; Lorentz, Scanlan, and Borson, 2002).

The search for a single, culture-neutral screening tool will likely never be fully satisfied, emphasizing the importance of harmonizing approaches to screening so that true rates of

dementia in diverse populations can be compared and evaluated in the context of population health needs. Additional differences in test performance pertain to sensitivity to milder versus more severe levels of impairment. For example, some tests designed for low-literacy groups will not identify impairment in highly literate individuals until they have moderate or severe dementia, and those designed to detect very mild impairment in college-educated individuals will find excessive rates of impairment if used in low-literacy groups.

Improving Healthcare Delivery Through Dementia Detection

Undetected cognitive impairment has important consequences for individuals, families, and healthcare systems. Under-recognition of cognitive impairment in primary care settings has been repeatedly documented in the United States and other countries, preventing a large proportion of affected individuals from entering appropriate diagnostic and clinical care pathways that meet their needs (Alzheimer's Association National Plan Care and Support Milestone Workgroup, 2016).

In 2011, the Centers for Medicare & Medicaid Services (CMS) introduced a new, free preventive service, the Annual Wellness Visit. Healthcare providers who offer this benefit to patients are required to conduct an assessment for cognitive impairment. As of 2014, only approximately 14.5 percent of older adults took advantage of this benefit (CMS, 2015); despite this low percentage, the Wellness Visit is an important opportunity to improve detection of cognitive impairment. With the availability of brief, valid, and reliable cognitive screens accessible to non-specialists, such as the Mini-Cog, research on the effect of cognitive impairment on health risks and outcomes can now be readily conducted in everyday settings. Evidence of cognitive impairment based on a Mini-Cog screening score is associated with clinically important outcomes. For example, in a retirement commu-

nity sample, individuals scoring low had deficits in knowledge of their own medications (Lakey, Gray, and Borson, 2009).


'Under-recognition of cognitive impairment in primary care settings has been repeatedly documented.'

In a population-based sample of older Italians with extremely low rates of formally diagnosed dementia, low scores were associated with high need for daily assistance (Scanlan et al., 2007). Among older people followed after hospitalization for heart failure, low scores were associated with a doubling of the rate of thirty-day rehospitalization (Agarwal et al., 2016; Patel et al., 2015), and hospitalized geriatric patients with low Mini-Cog scores are at much higher risk for delirium (Alagiakrishnan et al., 2007; Dworkin et al., 2016; Heng et al., 2016) and poor surgical outcomes (Robinson et al., 2012). These studies show that use of a low-intensity detection strategy can identify older adults at high risk for a variety of poor healthcare outcomes that could be mitigated by specifically targeted interventions.

Comprehensive Care Planning for People with Cognitive Impairment

In January 2017, CMS introduced a new Medicare benefit that reimburses clinicians for conducting a systematic multicomponent evaluation of individuals with cognitive impairment. This benefit requires assessment of nine separate elements, covering the history and current severity (stage) of cognitive and functional impairment, medical conditions and medications that could contribute, depression and major behavioral concerns, safety issues, and a basic assessment of caregiver readiness and needs for supportive services. Results of the assessment are to be integrated into a written care plan that is shared with the individual and caregiver and made available in the individual's medical record.

This new benefit creates a meaningful incentive for healthcare providers and systems to integrate cognitive impairment screening into routine healthcare of older adults. Further details about the cognitive impairment care plan benefit can be found on the Alzheimer's Association website (alz.org). This benefit has the potential, when coupled with a systematic cognitive impairment detection strategy, to produce dramatic improvements in the healthcare of individuals with

cognitive impairment. Achieving its full promise depends on collaborative solutions to educate and activate patients, families, and healthcare providers, and to engage health system leaders and managers as drivers of change. 

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Global Experiences of Dementia Stigma: Perspectives of People with Dementia and Family Caregivers

By Nicole Batsch
and Marc Wortmann

An international survey demonstrates that education, information, and awareness are key priorities for reducing the stigma surrounding dementia.

Misconceptions of dementia and the individuals who are affected by it persist and create problems in society worldwide. Such misconceptions lead to the social phenomenon of stigma, wherein an individual is classified by others in an undesirable, rejected stereotype (Goffman, 1963). Stigma prevents people from acknowledging dementia symptoms and obtaining the help they need, including the first step of obtaining a diagnosis (Koch and Iliffe, 2010; Vernooij-Dassen et al., 2005). Stigma causes individuals and organizations to emphasize the symptoms of dementia rather than to support the abilities of individuals with dementia (Bamford et al., 2004).

Alzheimer's Disease International (ADI) believes that stigmatization poses a serious barrier to improving dementia care and to developing further research. This barrier is alarming because of the impact of dementia on society, as the numbers of individuals with dementia are expected to increase from 36

million in 2010 to 115 million by 2050 (Prince et al., 2015). The global cost of dementia was calculated in 2010 at \$604 billion (Wimo and Prince, 2010). Costs will likely increase at a rate similar to prevalence. Worldwide, only one in four people with dementia are diagnosed, which means most are not accessing potentially effective medical and psychosocial treatments (Prince, Bryce, and Ferri et al., 2011).

In this article, we describe the results of a survey of individuals who cope with dementia on a daily basis, including those with dementia and family caregivers (Batsch and Mittelman, 2012). Limited research has been conducted on stigma in relation to dementia. Numerous studies cite stigma as a causal factor of patients' and physicians' fears regarding diagnosis, which may result in physicians assuming nothing can be done (Koch and Iliffe, 2010). Studies neglect a thorough analysis or questioning of the concept of stigma itself and have been conducted by measuring professional expertise, caregiver-only

→ABSTRACT This article describes results from the English-language version of an international online survey of individuals with dementia and family caregivers. The sample included 1,843 respondents (127 individuals with dementia from fourteen countries and 1,716 caregivers from forty-seven countries). Despite negative associations and experiences, respondents identified that education, information, and awareness are priorities in helping to reduce stigma and to include people with dementia in everyday life. The authors conclude that participating in social programs may also be beneficial in coping with stigma. | **key words:** *stigma, dementia, Alzheimer's disease*

experiences, or the general public's perceptions (see, e.g., Harris Interactive, 2011; Werner et al., 2012; World Health Organization, 2012).

Rarely is the input of individuals with dementia included, thereby missing an important component of the stigma conversation. The subjective experience of people with dementia has traditionally not been included because of the myth that individuals with dementia are too cognitively impaired for their opinion to be valued. This has been mitigated somewhat since the 1990s by including people with dementia in research (Downs, 1997). Furthermore, the goal of such studies often has not been to identify stigma, but to shed light on its possible consequences such as anxiety, depression, health, activity, self-esteem, and social support (Burgener et al., 2015).

'Stigmatization poses a serious barrier to improving dementia care and to developing further research.'

Stigma has been previously defined, first by Goffman (1963), as being socially discredited and classified by others as not normal. A World Health Organization (WHO) and World Population Ageing consensus statement defines stigma as occurring when people who are “unjustifiably rendered shameful, excluded and discriminated against” (Graham et al., 2003). Thornicroft's (2006) definition of stigma takes these foundational definitions and expands on them by measuring problems of knowledge, attitude, and behaviors as experienced by people with mental illness through exclusion and discrimination.

Also, dementia stigma has been identified through self-stigma, stigma by association, and public stigma (Rüsch, Angermeyer, and Corrigan, 2005; Werner and Heinik, 2008). “Self-stigma” refers to a person's adaptations to participation in society based on how they think other people will respond—for example, a person with dementia who does not share his or her diagnosis with

others, fearing their reactions. “Stigma by association” is stigma experienced as a result of a relationship with a stigmatized population, which is often experienced by family caregivers of people with dementia. And “public stigma” is the general public perception of a stigmatizing condition. In the case of dementia, or more specifically, Alzheimer's disease, a MetLife study cites people's fear of developing Alzheimer's as being greater than the fear of developing cancer, heart disease, diabetes, and stroke (Harris Interactive, 2011).

Survey Goals and Methodology

The main goals of our study were to identify how individuals with dementia and caregivers experience stigma and how they perceive others view people with dementia and caregivers, within their countries of residence. We administered an online survey through ADI's national member associations, which distributed the link through networks such as support groups and social media. A sample of 1,843 respondents participated in the English-language survey, including 127 people with dementia from fourteen countries and 1,716 caregivers from forty-seven countries.

People with dementia had mild enough dementia to respond to a survey, and a small number indicated that assistance was provided to help them complete the online survey. Both people with dementia and caregivers were found to be highly educated and to have access to a computer, and the majority of participants were connected to Alzheimer's associations or societies globally, thus limiting participation from lower-educated respondents without access to computers and who may not have been connected to known dementia service providers. People with moderate or severe dementia also were not represented in this study.

Notably, the large number of respondents was unexpected, and initially this study was not intended to be empirical research or to be quantitatively analyzed. Our purpose was to

collect quotes about stigma to include in a policy report. Only a limited timeframe was planned in which to conduct what was thought to be a small questionnaire of a few respondents. A typical survey conducted by ADI of its members results in thirty-five to forty responses; therefore, we had limited resources for collecting and analyzing data. Response quantity demonstrates the high degree of importance globally of the issue of stigma among people with dementia and caregivers, and highlights a need for more research.

Because of the volume of respondents, we decided to conduct at least a basic statistical analysis of the percentage of “yes/no/don’t know” survey responses using the Statistical Package for the Social Sciences (SPSS), in addition to conducting a qualitative thematic

analysis of the optional open-ended responses to each “yes/no/don’t know” question. For example, questions such as “Have you concealed or hidden the diagnosis of dementia?” elicited yes/no/don’t know responses and respondents were asked to “Please describe (optional).” The questions were framed as yes/no/don’t know to allow individuals with mild dementia to participate (noting their possible challenges with answering a Likert scale format).

The survey was tested with three English-speaking individuals with mild dementia from different countries. Individuals with dementia and caregivers answered the same survey tool with two additional questions for caregivers, noting their relationship to a person with dementia and how much assistance they pro-

Table 1. Survey Respondents in the English Survey

	N	Gender	Decade of birth	Diagnosis (dx)	Country of residence
People with dementia	127	F: 71 (61%) M: 46 (39%)	1920–29: 6 (5%) 1930–39: 26 (22%) 1940–49: 45 (38%) 1950–59: 31 (26%) 1960–69: 10 (8%)	Length of time since dx? No dx: 4 (3%) <1yr: 15 (13%) 1-5 yrs: 59 (51%) >6yrs: 38 (33%) Dx Type* No dx: 5 (4%) Don't know: 2 (2%) Dementia: 6 (5%) MCI: 13 (10%) AD: 70 (55%) Vas: 15 (12%) FTD: 9 (7%) PPA: (-) Other: 14 (10%)	Canada 10 (8%) UK: 13 (10%) USA: 70 (55%) Countries where numbers are not included because of limited response rate of fewer than 10 people to protect anonymity: Australia, Finland, Germany, Hungary, Israel, New Zealand, Singapore, Zimbabwe
Caregivers	1716	F: 1402 (86%) M: 227 (14%)	1920-29: 34 (2%) 1930-39: 131 (8%) 1940-49: 312 (19%) 1950-59: 500 (30%) 1960-69: 370 (22%) 1970-79: 171 (10%) 1980-89: 95 (5%) 1990-99: 29 (2%)	Length of time since dx? No dx: 64 (4%) <1yr: 128 (8%) 1-5 yrs: 835 (53%) >6yrs: 557 (35%) Dx Type* No dx: 74 (4%) Don't know: 52 (3%) Dementia: 230 (13%) MCI: 91 (5%) AD: 998 (58%) Vas: 179 (10%) FTD: 70 (4%) PPA: 11 (-) Other: 120 (7%)	Asia 85 (5%) Australia/NZ: 52 (3%) Canada: 169 (10%) Caribbean: 9 (-) Europe: 75 (4%) Middle East: 7 (-) Scandinavia: 52 (3%) South Africa: 13 (1%) South America: 5 (-) UK: 82 (5%) USA: 1090 (63%) Other: 2 (-) “Other” includes single respondents from two countries.

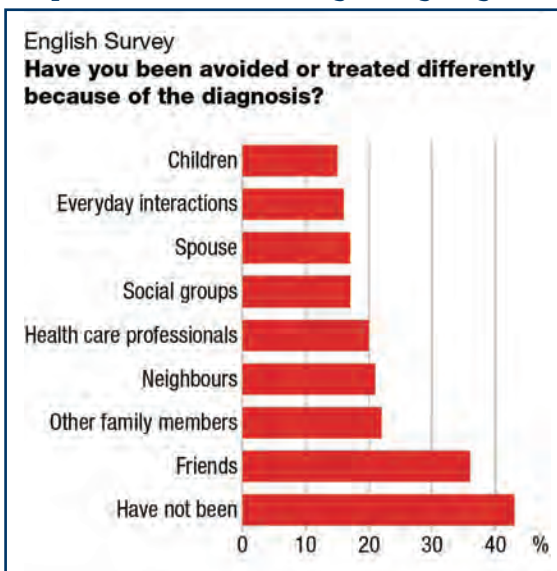
*Dx type allowed multiple choice answers and respondents could check more than one diagnosis.

vided at the time. Several questions provided only open-ended responses and were qualitatively analyzed. The thematic qualitative analysis elicited relevant categories such as “exclusion,” “marginalization,” and other categories. The number of individuals who shared each categorical response was determined to demonstrate the volume of agreement between respondents. Only English-language results are described here.

Stigma, as Experienced on an Individual Level

On an individual level, people with dementia and caregivers were asked about experienced stigma and anticipated stigma. For experienced stigma, 40 percent (n = 50) of respondents with dementia and 28 percent (n = 487) of caregivers indicated they had been avoided or treated differently because of their connection to dementia. Both respondents with dementia and caregivers cited friends as the most likely people who would avoid or treat them differently, with extended family members the next most likely,

Figure 1. English Survey: Responses of People with Dementia Regarding Stigma



Source: Batsch and Mittelman, 2012.

then neighbors. Sixteen percent (n = 21) of individuals with dementia indicated that healthcare professionals also treat them differently. (See Figure 1, this page.)

The qualitative themes indicated that individuals with dementia experienced “marginalization” or were “discounted” by being ignored, treated as children, and not valued as being human. “Social exclusion” was a major theme, as people with dementia and caregivers reported not being included in activities or social events they had previously attended. Some respondents shared the following examples of physical distancing:

Some of my friends have moved on as I can no longer be a part of what I used to do.
 —person with dementia, United Kingdom

Other teenagers did not understand and they chose to leave me because I was sad.
 —caregiver, Denmark

An unexpected finding occurred. More than 40 percent (n = 51) of respondents with dementia and more than 50 percent (n = 862) of caregivers said they were not treated differently or avoided. Later in this article, we demonstrate this as an opportunity to reduce stigma, as 54 percent (n = 832) of total respondents were highly connected to dementia programs, whereas 42 percent (n = 640) did not participate and 4 percent (n = 60) did not know about programs.

Regarding anticipated stigma, 24 percent (n = 30) of respondents with dementia admitted to concealing or hiding their diagnosis, citing “stigma” as the main reason. Most caregivers (78 percent) reported that they did not conceal or hide their loved one’s diagnosis. Although some tried to for a period of time, out of respect for the individual with dementia, at some point, the symptoms were readily observable. Caregivers also revealed that by sharing the diagnosis, they received more assistance from others.

Twenty-six percent (n = 33) of respondents with dementia and 23 percent (n = 388) of caregivers also stopped themselves from having close relationships. Individuals with dementia acknowl-

edged not wanting to be a burden on other people or worrying about people noticing their limitations. Caregivers shared that care demands required energy and time they previously devoted to their personal lives. Caregivers were overwhelmed physically, emotionally, and financially and found that others do not understand the depth of caring for a person with dementia.

I don't want people to think I am stupid.

—person with dementia, New Zealand

I believe it is important to engage as much as possible with those that understand this illness, to learn and to share for increased knowledge, appreciation, enhancing, compassion and caregiving effectiveness.

—caregiver, Canada

In the beginning, I was ashamed and didn't tell friends and neighbors. I tried to cover up my friend's mistakes.

—caregiver, Netherlands

Stigma, as Experienced on a Societal Level

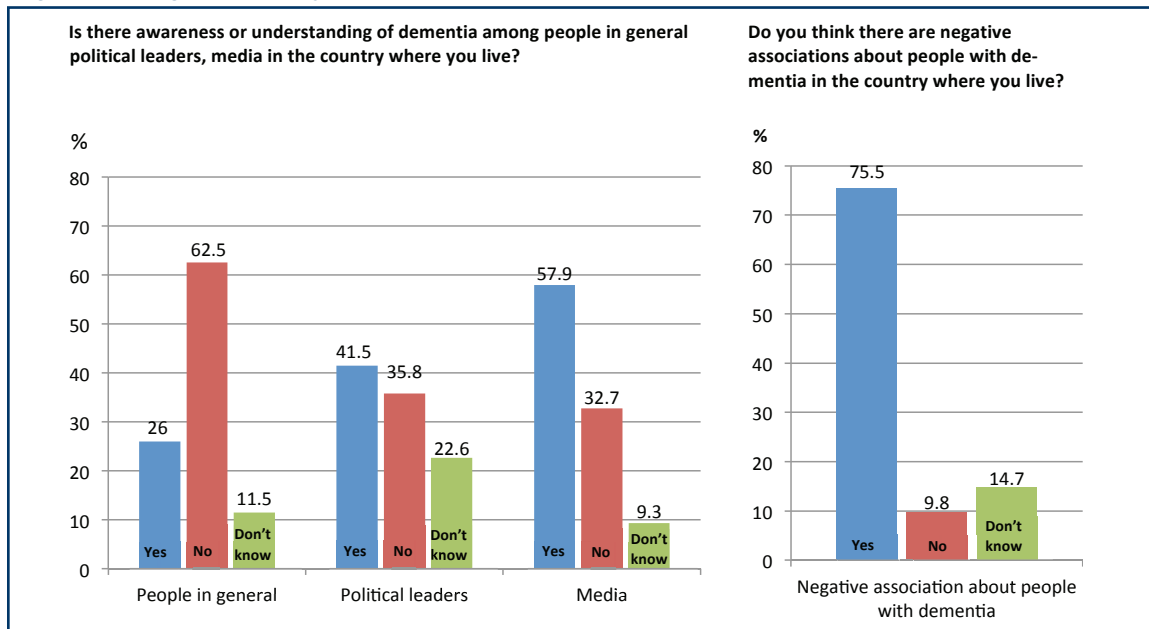
On a societal level, respondents were asked about their opinions of dementia awareness by

the public, political leaders, and the media.

Nearly two out of three individuals with dementia (n = 65) and caregivers (n = 850) said there is a lack of understanding of dementia in their country. Respondents with dementia described political leaders as being more aware (n = 44) than not aware (n = 38), and caregivers described political leaders as being less aware (n = 626) than aware (n = 509). Respondents shared that political leaders do not care unless they have a person with dementia in their family or it is an election year. The media was described as the most aware by 58 percent of people with dementia (n = 62) and caregivers (n = 828). However, most respondents with dementia and caregivers conveyed that much of the media coverage of dementia was negative and typically showed people in the later stages of the disease. (See Figure 2, below.)

The survey also assessed negative associations about dementia and inclusion in everyday life. Seventy-five percent (n = 77) of respondents with dementia and 64 percent (n = 892) of caregivers identified negative associations about

Figure 2. English Survey: Responses of People with Dementia



people with dementia in their country. Reinforcing the thematic analysis on the individual level, respondents with dementia and caregivers indicated that people with dementia were “discounted” and “avoided” by society, and the

‘In the beginning, I was ashamed and didn’t tell friends and neighbors. I tried to cover up my friend’s mistakes.’—caregiver, Netherlands

recognition of “fear” of people with dementia is pervasive. In addition, there is a tremendous lack of understanding about the experience of living with dementia or of caring for someone with dementia. Caregivers added two themes for categorization: how sometimes society perceives of people with dementia as being mentally ill or “crazy,” and the myth that dementia is a result of “old age,” not of a disease.

My cognitive abilities are still fairly high. However, when I have difficulty remembering words or am slow in my responses, I sometimes encounter impatience, people trying to find my words for me, exasperation and so forth.

—person with dementia, United States

I think a lot of people believe that people with dementia cannot function anymore in our society. [Dementia] is however a gradual process, and especially in the beginning, my mother was still able to do things and to understand what people said about her to us.

—caregiver, Netherlands

Forty percent (n = 40) of respondents with dementia reported not being included in everyday life, and 49 percent (n = 660) of caregivers agreed that people with dementia are not included. “Stigma” was cited as one of the main barriers; however “access issues,” such as lack of programs or transportation to programs, were also described. Respondents with dementia and caregivers noted that the changing stages of the disease require consideration, and that the

caregiver would be the most likely person to ensure the person’s involvement in everyday life.

Caregivers also confront societal stigma. Although most of the caregivers in this survey said there are no negative associations with being a caregiver, 24 percent (n = 336) reported that they face negative associations including being “avoided” or “discounted.” Caregivers reported a lack of understanding about the physical tasks of caring and the emotional effects, and that society expects them to give up their own lives to provide care for the person with dementia, but offers little support in return. Many caregivers described wanting the responsibility of caring for their relative; however, they do not want to be marginalized. Caregivers described being discounted by other family members for “complaining too much” about their care tasks and experienced discrimination in the workplace as compared to caregivers of young children. They were also disturbed by the societal expectations of automatically placing a person with dementia into a care home. They shared examples from relatives and from nonrelatives providing “unhelpful advice.”

Developing coping skills and reducing stigma

Respondents were asked about their coping skills in relation to dealing with stigma and most responded positively. Fifty-nine percent (n = 63) of respondents with dementia reported that they have coping skills or have developed them over time. Education about disease symptoms and progression was also recommended by respondents to help people with dementia combat stigma. Sixty-seven percent (n = 928) of caregivers reported that they have coping skills and described these skills as developing over time. Although “good days” and “bad days” exist, they reported they can cope because of friends, faith, and love for the person with dementia. Many caregivers cited previous personal or professional experiences that prepared them for this role.

Respondents were asked about how to reduce stigma and include people in everyday life. Sixty-two percent (n = 49) of respondents with dementia identified “education and awareness” as most important to reducing stigma in society. They reported that “media and diagnosed celebrities” could be useful if they demonstrate the strengths of people with dementia and not just their losses. To include people with dementia in everyday life, respondents would like to see more “community involvement” and a societal “culture change” that supports people with dementia being integrated on a more regular basis. Sixty-eight percent (n = 648) of caregivers agreed that “education and awareness” is key to reducing stigma and also cited “community involvement” as the most important way people with dementia can be included in everyday life.

The Survey’s Major Findings

Anticipated stigma prevents people with dementia and caregivers, even for a short period, from revealing the diagnosis to others. Twenty-four percent of people with dementia in this study reported concealing their diagnosis. Similarly, research carried out by the UK Mental Health Foundation for the Alzheimer’s Society (2008), which included focus groups with thirty-two people with dementia and twenty-nine caregivers, found that reactions from family and friends after revealing the diagnosis were negative, and people with dementia and caregivers expressed concern about negative media attention surrounding dementia. Both the fear of reaction and negative media attention seem to be good indicators that people might conceal or hide their diagnosis.

For people with dementia and caregivers, social exclusion remains one of the greatest challenges. Bond, Corner, and Graham (2004), discussing the sociological challenges of dementia and exclusion, describe people with dementia as being more excluded than older adults in general and cite the use of institutional care as

one of many examples of how society excludes people with dementia. Isolation from friends, family, and everyday life may lead to hastened decline of the condition of the person with dementia, and affect the caregiver’s health.

‘Twenty-four percent of people with dementia in this study reported concealing their diagnosis.’

Although the negative experiences reported are not surprising, we can draw conclusions about how best to counteract stigma and make life more manageable for people with dementia and caregivers. Respondents were asked “What do you think can be done to reduce stigma?” and they overwhelmingly reported education and societal awareness as key issues, as well as a desire to be included in community activities. Many national dementia plans include education and awareness campaigns (Alzheimer Europe, 2012). The next phase should include measuring the success of these strategies.

There may be a relationship between participants of dementia support programs and the development of skills to cope with stigma. Fifty-four percent of respondents with dementia were participants of dementia programs, and 66 percent shared they have the personal skills and abilities to cope with stigma. Dementia support programs should be recommended to people with dementia and caregivers who are not currently connected to such programs. This is supported in the findings of several studies, particularly in studies with caregivers, as studies with people with dementia are still minimal (Brodaty, Green, and Koschera, 2003; Leung, Orrell, and Orgeta, 2015; Selwood et al., 2007).


Recommendations should be made to healthcare professionals to help people with dementia and caregivers develop coping skills to deal with the social exclusion such as the encouragement and creation of support pro-

grams. Healthcare professionals should also be aware of their own biases toward stereotyping people with dementia and perhaps ignoring their needs. Often the focus is on symptoms rather than abilities or assumptions that the person with dementia can no longer understand, leading to marginalization.

Implications for Research and Policy

With the number of people with dementia around the world increasing, and no cure likely in the immediate future, we recommend that societies put more effort into effective care and support initiatives. This would necessitate communities that are inclusive, accepting of people with dementia, and giving them the chance to participate on the level that fits them. In an ideal world, every symptomatic person would be diagnosed and treated and would (as they desire) take part in support groups and other supportive programs. Caregivers would be supported as well. Governments would make strong efforts to improve healthcare programs

and increase biomedical and psychosocial research budgets to ultimately save money in healthcare.

Country-level initiatives are beginning to be created and implemented but have a long way to improve care and support for people with dementia. If we neglect this, care for people with dementia will cause unprecedented problems for global health and social systems. We believe stigma is a main barrier to advancing these initiatives. Therefore, it is essential to overcome the stigma of dementia. We can find encouragement through observing how public perception of cancer and HIV/AIDS has changed over the past thirty years. We need similar efforts to support people with dementia. 

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Alzheimer's Disease and Related Dementias: Prevalence and Racial and Ethnic Disparities in the United States

By Michael Lepore,
Lisa M. Lines, and
Joshua M. Wiener

Although disparities in AD prevalence, mortality, medication, and long-term services use are well known, effective strategies and interventions have rarely been studied.

The United States' older population is increasingly racially and ethnically diverse, as are people with Alzheimer's disease and related dementias (ADRD). As the U.S. population ages, and minorities become a larger proportion of the older population, a higher percentage of people with ADRD will be minorities. Among the

proportion that is black will increase from 7 percent to 10 percent, and the proportion that is Asian will rise from 2 percent to 6 percent (Vincent and Velkoff, 2010).

With this increasing diversity, disparities across racial and ethnic groups in the prevalence and treatment of ADRD is of mounting concern, focusing attention on cultural competency training and other interventions to reduce these disparities. This article reviews ADRD prevalence estimates for diverse populations from numerous studies, but does not provide an exhaustive review of the ADRD prevalence literature. Additionally, the article reviews information on disparities in the prevalence

'Despite a lower prevalence rate, whites have a higher overall mortality rate from AD.'

population ages 85 or older—the age group most likely to have ADRD—the proportion that is Hispanic (of any race) is projected to increase from 5 percent in 2010 to 15 percent in 2050; the

→ABSTRACT This article addresses the prevalence of Alzheimer's Disease and related dementias (ADRD) and racial and ethnic disparities among people with ADRD in the United States. Disparities among blacks and Hispanics compared with non-Hispanic whites concerning ADRD are discussed, including mortality, use of long-term services and supports, healthcare expenditures, quality of care, and caregiving. The literature suggests numerous underlying causes, including genetics, socioeconomic factors, cultural differences, lack of culturally competent clinicians, and discrimination. Although these disparities are well known, little is known about the effectiveness of various strategies, such as cultural competence training, to address these differences. | **key words:** *Alzheimer's Disease and related dementias, disparities, cultural competence, interventions*

and treatment of ADRD and in interventions to reduce these differences. In the narrative, ADRD is used when addressing Alzheimer's disease (AD) and other diseases and conditions that cause dementia, and AD is used when exclusively addressing that disease.

Prevalence of ADRD

As of 2017, an estimated 5.5 million Americans have AD, including an estimated 5.3 million people ages 65 and older, and approximately 200,000 individuals younger than age 65 who have early-onset AD (Alzheimer's Association, 2017). Overall, approximately 10 percent of people ages 65 and older have AD and show symptoms of dementia. The percentage increases with age, from about 3 percent of people ages 65 to 74, to 17 percent of people ages 75 to 84, to 32 percent of people ages 85 and older (Hebert et al., 2013).

A systematic review of the literature on dementia prevalence in the United States shows prevalence varies by race, ethnicity, age, sex, location, comorbidities, and other factors, and that the amount of evidence regarding ADRD prevalence varies across populations (Mehta and Yeo, 2017). Reported AD prevalence rates among older adults range from 14 percent to 500 percent higher among African Americans than among whites (Froehlich, Bogardus, and Inouye, 2001), although some researchers have found no significant differences in prevalence between black and white older adults (e.g., Livney et al., 2011). The most frequently cited estimates are that African Americans are about two times more likely than European Americans to have AD and Hispanics are about 1.5 times more likely than non-Hispanic whites to have AD (Alzheimer's Association, 2011, 2014).

Prevalence rates among Hispanics have been less commonly measured. Among Latinos, one study—the Sacramento Area Latino Study on Aging—that addressed prevalence of dementia, estimated that 4.8 percent of the entire study population (1,789 people older than age 60

randomly selected by census tracts in Sacramento County, California) had dementia and 31 percent of those older than age 85 (Mehta and Yeo, 2017). An earlier study found that Mexican American men had significantly higher prevalence of cognitive impairment than did non-Hispanic white men (Samper-Ternent et al., 2012). A study of Caribbean Latinos estimated ADRD prevalence of 8 percent in the ages 65 to 74 group, 28 percent in the ages 75 to 84 group, and 63 percent among those ages 85 or older (Gurland et al., 1999).

Disparities in Health Outcomes and Symptoms of ADRD

Mortality and other health outcomes among people with AD vary by race and ethnicity. Despite a lower prevalence rate, whites have a higher overall mortality rate from AD. Research on racial differences in cause of death showed that whites had ADRD listed on death certificates as the underlying or contributing cause of death slightly more often than blacks: from 1999 through 2004, the age-adjusted death rate per 100,000 was 64.7 for whites and 62.8 for blacks, a 3 percent difference (Gillum and Obisesan, 2011). From 1999 through 2008, the age-adjusted mortality rate per 100,000 was 52.1 for whites, 44.3 for blacks, 32.3 for Hispanics, 26.8 for American Indians, and 19.4 for Asians and Pacific Islanders (Moschetti et al., 2012). It should be noted that cause-of-death studies may be affected by reporting bias and inaccuracies, variations in diagnostic practices, and differences in access to diagnostic technologies. In another study, African Americans and Latinos had a lower adjusted risk of AD-related mortality than their white counterparts, whereas Asians and American Indians had a mortality risk similar to that of whites (Mehta et al., 2008).

ADRD mortality rates also vary by geographic region, with higher rates among whites than blacks in New England, the Mid-Atlantic, and in the East and West South Central census regions. In the East and West North Central, South

Atlantic, Mountain, and Pacific regions, rates were higher among blacks than whites. In six of nine geographic regions, the differences were less than 10 percent, but in the Mid-Atlantic and East and West South Central regions, white death rates were 12 to 26 percent higher than black death rates (Gillum and Obisesan, 2011).

Older African Americans with AD consistently describe themselves as more impaired, with greater need for health services, than do whites—despite a lack of measured differences in the number of recent sick days, number of reported chronic conditions, cognitive status, and mortality (Froehlich, Bogardus, and Inouye, 2001). Whether this difference is a result of unmeasured other illnesses or different types of comorbidities, cultural differences in the perception and description of cognitive disability, or some other factor is not known.

Sleep disturbances, which are common among people with AD, have been shown in a South Florida study to be more common among African American and Hispanic individuals with AD than among whites with AD (Ownby et al., 2010). In a study in Seattle, Washington, African Americans were significantly more likely than whites to report symptoms such as depression, anxiety, and sleep disturbances, even after controlling for dementia severity, age, sex, and education (Chen, Borson, and Scanlan, 2000).

Disparities in Services Use Among People with AD

AD is associated with a substantial burden in terms of negative health events, such as infections, falls, hospitalizations, institutionalization, and use of psychotropic medications (Malone et al., 2009). In a large, three-state study, Gilligan and colleagues (2013) found that, after controlling for demographics and pharmacotherapy exposure, African American Medicaid beneficiaries with dementia were significantly more likely than their white counterparts to be hospitalized.

The use of community-based social services was found to be similar across race and ethnic-

ity after controlling for dementia severity and socioeconomic status in seven separate studies (Cooper et al., 2010). However, Montgomery and colleagues (2001) found that use patterns differed by racial and ethnic group. For example, blacks tended to use small amounts of care for a longer period of time, whereas Hispanics tended to use larger amounts of care for a shorter period of time.

The provision of some services also differs by race. For example, artificial nutrition and other life-sustaining treatments—such as intensive care unit use and mechanical ventilation—have been found to be more frequently used, and decisions to continue active treatment at the end of life are more common among African Americans and Asians (Connolly, Sampson, and Purandare, 2012). Additionally, percutaneous endoscopic gastrostomy tube feeding, which is discouraged by many physicians, is more commonly used for African Americans than for whites (Braun et al., 2005).

Differences in institutional care use also have been found, including variance across states. Gilligan and colleagues (2013) found that non-white dually eligible (Medicaid and Medicare) beneficiaries with AD in Florida, New Jersey, and New York were significantly less likely than their white counterparts to be institutionalized. A study of 215 individuals with dementia in Alabama—of whom 37 percent were African American—found that whites were placed in nursing homes at nearly 2.5 times the rate of African Americans (Stevens et al., 2004). In contrast, a study in Maryland of 2,285 people newly admitted to nursing homes found that African Americans were significantly more likely to have dementia than were whites: 77 percent and 57 percent, respectively (Weintraub et al., 2000).

Sengupta and colleagues (2012) found non-whites residing in nursing homes were 4.3 percentage points less likely than whites to receive special dementia care, such as being in a dementia care unit. This difference was partly because

non-whites disproportionately lived in facilities that did not provide special dementia care.

Disparities in ADRD Medication Prescriptions and Use

Multiple studies have shown that whites are more likely than non-whites to be prescribed acetylcholinesterase inhibitors (AChEI) and other dementia medications. A meta-analysis and literature review that pooled the results of three studies found that African Americans were 30 percent less likely to be prescribed AChEIs than whites, whereas Hispanics had a likelihood of prescriptions similar to that of whites (Cooper et al., 2010). Three other studies of medication use by race and ethnicity that were not included in the above meta-analysis also found that African Americans were less likely to use or to be prescribed dementia medications (Gruber-Baldini et al., 2007; Hernandez et al., 2010; McClendon et al., 2009). However, one analysis of data using the 2000 to 2002 Medicare Current Beneficiary Survey found the opposite: community-dwelling African American and Hispanic Medicare beneficiaries were more likely to be prescribed one type of AChEI, donepezil (Aricept) than were whites (Perryman, Lewis, and Rivers, 2009).

Continuing active treatment at the end of life is more common in African Americans and Asians with ADRD.

In an analysis of four states' Medicaid populations, Gilligan and colleagues (2012) found significant disparities in medication use (AChEIs and memantine) between Hispanics and non-Hispanics in Florida and California, with greater use among Hispanics. However, in New York, non-Hispanics had greater use than Hispanics. Poon and colleagues (2009) examined medications prescribed for veterans with dementia and hypertension in the Veterans Health Administration. They found that both acetylcholinesterase inhibitors and the N-methyl-D-

aspartate receptor blocker memantine were prescribed for dementia, and African American patients were prescribed significantly less of both. Zuckerman and colleagues (2008) found that even after they adjusted for socioeconomic status, healthcare access and utilization, demographics, and other confounding variables, disparities in the utilization of anti-dementia medications persisted between non-Hispanic whites and other minority groups, with whites having a 30 percent higher usage rate. Specifically, these disparities persisted for blacks and other non-Hispanic groups, but diminished among Hispanics when these control variables were accounted for (Zuckerman et al., 2008).

Interventions Implemented to Reduce Racial and Ethnic Disparities

In seeking to address ethnic and racial disparities, the Institute of Medicine's report *Unequal Treatment* stated that matching needs to services is a more important goal than providing equal amounts of services to different groups (Smedley, Stith, and Nelson, 2003). Both undertreatment and overtreatment can be problems, and insisting that all patients are equally overtreated makes little sense. Instead, the goal should be the right care, delivered to the right patient, at the right time, in the right setting (Fowler, Levin, and Sepucha, 2011).

Although extensive research documents disparities among different racial and ethnic groups with AD, few studies evaluate interventions to address disparities in these populations. Almost all interventions designed explicitly to address racial and ethnic disparities focus on the cultural competency of the healthcare provider or health system. Implemented interventions that are not specific to the AD population include care coordination, care management, community health workers, and culturally tailored education interventions (Quinones et al., 2011).

Cultural competency is especially important in the healthcare setting, where barriers to communication and access to care can result in

delayed diagnosis or inappropriate treatment. Cultural competence involves both awareness and knowledge about other cultures, as well as skill in relating to people of other cultures. Proficiency requires acknowledging that culture guides and affects behavior (Betancourt et al., 2003).

A culturally competent healthcare environment includes a racially and ethnically diverse staff that reflects the communities served; bilingual staff or interpreters for the clients' languages; culture- and language-specific training for clinicians; and signs and communication materials that are in the clients' languages and sensitive to cultural norms (Anderson et al., 2003).

The general evidence for improved outcomes as a result of interpreter services is mixed, but a few studies suggest that patients with limited English proficiency who receive language assistance are more satisfied with their care and have better clinical outcomes (Smedley, Stith, and Nelson, 2003).

Many studies of cultural competence training not specific to AD have found that such training has a beneficial effect on the attitudes, knowledge, and skills of physicians and on patient satisfaction (Beach et al., 2005). For example, seventeen of nineteen studies of cultural competence training for health professionals found a beneficial effect in terms of knowledge; twenty-one of twenty-five studies found that such training improved attitudes; and fourteen of fourteen studies showed benefits of training in improving skills. Also, studies have found that cultural competence training of health professionals improves patient experiences. However, no definitive evidence has yet linked this training to improved health outcomes (Beach et al., 2005; Betancourt et al., 2003). One study of counseling of black female patients showed that cultural competence improved patient adherence (Beach et al., 2005).

One of the goals of the Administration for Community Living–funded Alzheimer's Disease Supportive Services Program is to provide or

expand support services for traditionally underserved or hard-to-serve AD patients and their caregivers, especially minorities and rural residents. Four grants described by Shuman and colleagues (2014) illustrate ways in which providers can address the cultural differences in the AD population. In one project, grantees engaged Chinese and Japanese communities in Southern California and Chinese and Vietnamese communities in Northern California. Georgia's project included a target population from eleven rural counties.

Almost all interventions designed to address racial and ethnic disparities focus on cultural competency.

A project in New Mexico focused on reaching veterans, particularly Hispanic and American Indian families. South Carolina's project targeted primarily the African American rural population in the southeastern part of the state. Several common themes emerged from all four grantees: recognizing cultural- and community-specific norms, building trusting relationships, finding a local champion, tailoring services to suit the needs of the community, and using outreach strategies that are meaningful to the community. An earlier Illinois grant focused on older persons who spoke Arabic, Assyrian, Bosnian, Hindi, and Urdu (Wiener and Mitchell, 2007).

A systematic review of interventions focused on caregivers of persons with AD and related disorders found eighteen studies that reported outcomes by caregiver ethnicity, of which eleven considered cultural factors in their program design. Eight of these eleven studies were from the Resources for Enhancing Alzheimer's Caregiver Health (REACH) initiative (Napoles et al., 2010). Cultural tailoring addressed family bonds, language, bicultural and bilingual staffing, health literacy, the need for advocacy, and logistical barriers.


Caregiver interventions may be more effective when delivered by staff who are bilingual and bicultural (Napoles et al., 2010). For example, the REACH and REACH II projects—multisite studies to evaluate culturally tailored interventions—were effective at reducing depression and improving quality of life among caregivers (Belle et al., 2006). Among REACH's strengths are the tailoring of intervention materials to individual caregivers and involving bilingual and bicultural staff.

Another study focusing on REACH participants, however, found inconclusive evidence for the association between racial concordance and caregiver participation rates or outcomes (McGinnis et al., 2006). In that setting, racial concordance between caregivers and interventionists had no impact on caregiver participation rates, caregiver depression rates, or caregiver burden. The study reported that African American caregivers who interacted with African American interventionists had decreased rates of depression, but the finding was statistically inconclusive.

Discussion and Conclusions

The current literature shows consistent and adverse disparities among blacks and Hispanics compared with non-Hispanic whites in several areas, including the prevalence of AD, mortality, use of medications and other interventions, and use of long-term services and supports. Although

these disparities are well known, little is known about the effectiveness of various strategies, such as cultural competence training, to address these differences within the context of AD, with almost no studies available that evaluate possible interventions. Pairing future intervention efforts with strong evaluation approaches is a key next step to effectively reducing AD- and dementia-related disparities.

Race and ethnicity are complex variables influenced by socioeconomic status, environment, diet, education, and other external factors. Moreover, because race and ethnicity are social constructs and are not biologically defined, considerable variations exist within and among ethnic and racial groups in terms of ancestral heritage. Thus, some studies have suggested that researching differences between families with and without a history of AD may be more effective than the current racial and ethnic approach (Weiner, 2008). 

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Dementia Among Individuals with Intellectual and Developmental Disabilities: Policies and Practices

By Kate Gordon

Through grants from the Administration on Aging, promising programs are emerging to address the issue of dementia in this cohort.

The onset of dementia causes people with intellectual and developmental disabilities (IDD), their caregivers, and their primary providers to navigate between two service systems developed around each specific population—Aging and

to improve home- and community-based services (HCBS) for people with IDD and dementia and their caregivers. The agencies are focusing on developing a dementia-capable and culturally competent system of care across agencies

a description of a dementia-capable system, dementia-capable policy initiatives, and promising practices that highlight examples of training efforts to build dementia-capability in HCBS serving this population.

Dementia prevalence in people with Down syndrome as they age is higher than in the general population.

IDD Service Networks (see sidebar on page 31 for IDD definition). The Administration on Aging, within the Administration for Community Living (ACL/AOA), is funding efforts

and organizations, primarily through training staff to ensure that formal services and family care supports are prepared for dementia.

This article provides a brief overview of the types of HCBS available to individuals with IDD who develop dementia,

Dementia Prevalence in People with IDD

Research shows that age-related health problems among people with intellectual disabilities are similar to those in the general population, including the development of dementia in later life (Heller et al., 2010; May and Kennedy, 2010; McCallion et al., 2013). However, the

→ABSTRACT Aging and disability service systems must build greater capacity to provide services to an increasing number of aging persons with lifelong disabilities. People living in community who have intellectual and developmental disabilities develop age-related health problems, including dementia. They and their caregivers need access to dementia-capable home- and community-based services. Through the support of public policies and dementia-specific grants from the Administration on Aging, within the Administration for Community Living, promising practices in developing dementia-capable systems of care are emerging nationwide. | **key words:** *intellectual and developmental disabilities, dementia, dementia-capable home- and community-based services, Administration on Aging, Administration for Community Living*

Defining Intellectual and Developmental Disabilities

This article makes frequent use of the term intellectual and developmental disabilities (IDD). Intellectual disability is defined as a disability that originates before age 18 and is characterized by significant limitations in both intellectual functioning and in adaptive behavior, which includes many everyday social and practical skills (American Association on Intellectual and Developmental Disabilities, 2017a). The most common syndromes associated with intellectual disability are autism, Down syndrome, Fragile X syndrome, and Fetal Alcohol Spectrum Disorder (The Arc, 2015).

The term developmental disability means a severe, chronic disability that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual reaches age 22; is likely to continue indefinitely; and results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; and capacity for independent living.

Also, developmental disability reflects the individual's needs for a combination and sequence of special interdisciplinary or generic services, individualized supports, or other forms of individually planned and coordinated assistance of lifelong or extended duration (Developmental Disabilities Assistance and Bill of Rights Act of 2000). Developmental disability encompasses intellectual disability but also includes physical disabilities, such as cerebral palsy, traumatic brain injury, and epilepsy (American Association on Intellectual and Developmental Disabilities, 2017b).

prevalence of dementia in people with Down syndrome who are in middle and early older age is higher than in the general population (Ball et al., 2008; McCarron et al., 2014). Individuals with other intellectual disabilities characterized by developmental delays and impairments in social function are also at risk for Alzheimer's disease (Strydom et al., 2009). Although some people with IDD experience neurological symptoms (e.g., seizures) more than the general population, the majority of the dementia symptoms and the stage-based losses in capacity mirror those of the general population (Ball et al., 2008).

The need for enhanced community-based support for persons with IDD and their caregivers will expand as the

overall population ages. With the aging of the population, the number of older people will increase significantly over the next twenty years, a trend that will be consistent among older adults with an intellectual disability (National Task Group on Intellectual Disabilities and Dementia Practice [NTG], 2012)

Access and Use of Home- and Community-Based Services

The services and supports needed by the general population with dementia are the same as those needed by persons with IDD with dementia. However, understanding the nature of the person with IDD's non-dementia-related, lifelong disability is necessary to provide person-centered services and supports.

Though the general population with dementia does not access HCBS until after the onset of dementia, typically in later life, HCBS support is provided within the intellectual disability system to individuals with IDD throughout their life span (Watchman et al., 2017). Individuals with IDD primarily access such HCBS as non-medical in-home support services, non-institutional residential care facilities, and adult day services.

Existing IDD services, financing, and the settings in which they are delivered, may differ from the services that older adults with dementia tend to access. IDD services for adults without dementia emphasize supporting client employment and education. When individuals with IDD



develop dementia, their caregivers and their primary service providers must learn to navigate between the two systems developed around each population. However, similar to aging services programs, many of the services available to individuals with IDD also focus on maintaining or improving functioning, such as providing assistance with basic tasks of everyday life.

Nearly a quarter of all persons with IDD live with family caregivers who are ages 60 or older (Braddock et al., 2014). Because of the stress of long-term caregiving, by the time people with IDD who are living at home reach early old age, their caregivers tend to experience adverse health impacts, such as obesity, poorer self-rated health, limitations in

their own activities of daily living (ADL), and poor health-related quality of life (Seltzer et al., 2011). Family caregivers of adults with IDD may have additional challenges in continuing to provide care at home compared to solely caring for individuals with intellectual disabilities or individuals with dementia.

Such challenges may include meeting the need for certain home modifications or caring for individuals who require assistance with a greater number of ADLs (McCallion, McCarron, and Force, 2005).

Research points to Medicaid as being the key to financing the services and supports provided to individuals with

IDD. In-home services and other community-based supports that states offer through their Medicaid program or state-only funding (through publicly funded state IDD agencies) to families of adults with IDD include: adult day services; respite services; financial services such as cash

People with IDD and dementia, and their caregivers, need access to dementia-capable HCBS in community.

subsidies, vouchers, and in-home supports such as personal assistance or homemaker services; assistive technology and environmental modifications; adaptive medical equipment; health and professional services; family counseling or training; parent support

groups; transportation and recreation activities; specialized clothing; and dietary services (NTG, 2012).

In addition, all persons with dementia who are older have the same rights to access publicly funded HCBS for which they are age-eligible, such as Older Americans Act-funded programs. For example, all caregivers of persons with dementia, regardless of co-occurring disabilities in these care recipients, are eligible to access services funded by the National Family Caregiver Support Program.

Improving the Dementia-Capability of HCBS

A dementia-capable system meets the unique needs of persons living with dementia by identifying those with a possible dementia and recommending a subsequent visit with a physician; ensuring that the staff clients encounter have appropriate training, an understanding of clients' needs and the services available; knowing how to communicate with clients; and providing quality, person-centered services that help clients remain independent and safe in their communities.

To support adults with IDD who are affected by dementia and help them to remain in their homes and communities, some parts of the aging services and IDD networks are developing a dementia-capable system

of care that is bolstered by community care programs. The focus of current efforts includes training staff in aging and dementia care about issues specific to people with intellectual disabilities, and ensuring that formal services and family care supports for individuals with IDD are prepared for dementia (Jokinen et al., 2013).

Forging Collaborative Policy Initiatives

In recent years, policy initiatives have sought to formalize dementia-focused cross-network collaboration, such as the 2017 National Plan to Address Alzheimer's Disease (2017) and the state dementia plans of Alaska, Arizona, Delaware, Georgia, Massachusetts, New Jersey, New York, Oregon, Tennessee, and Washington. The National Plan includes the development of standardized interprofessional education to address the unique needs of individuals with intellectual disabilities through cross-network collaboration (Opachan Gardner, 2016). *The Report of the New York State Coordinating Council for Services Related to Alzheimer's Disease and Other Dementias* (New York State Coordinating Council for Services Related to Alzheimer's Disease and other Dementias, 2013), recommends that the Department of Health and its partners train professionals and paraprofessionals who work with individuals with develop-

mental disabilities to be aware of the connection between Down syndrome and Alzheimer's disease, and to identify indicators of dementia.

Funding for Promising Practices

Since 2014, the ACL/AOA has sponsored projects to ensure that people with dementia of all ages and their family caregivers have access to a sustainable HCBS system that is dementia-capable. The ACL/AOA's Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS) provides grants to states in their efforts to expand the availability of community-level supportive services for persons with dementia and their caregivers. In addition, the ADI-SSS program is designed to fill gaps in dementia-capable long-term services and supports for persons with dementia and their caregivers.

More than twenty-five grantees of these programs are working on improving the quality and effectiveness of services dedicated to individuals with IDD and dementia, or those who are at high risk of developing dementia. Through the support of these dementia-specific grants, new and emerging practices in dementia-capable HCBS for persons with IDD and dementia are being implemented and evaluated.

Activities supported by ADI-SSS include the following:

- Training providers of services for individuals with IDD about dementia;
- Developing State Board for People with Developmental Disabilities dementia specialist positions to provide outreach, training, and other support for families of individuals with IDD who are at risk for dementia; and
- Conducting legal and financial planning workshops to assist adults with IDD and their caregivers with money management and future planning.

Examples of these promising practices from Rhode Island and Wisconsin are described below.

Rhode Island

A social services organization in Woonsocket, Rhode Island, called Seven Hills Rhode Island is working with several stakeholders (including the National Task Group on Intellectual Disabilities and Dementia Practice [NTG], the Alzheimer’s Association of Rhode Island, a Medicare Quality Innovation Network-Quality Improvement Organization, and a Medicaid managed care organization). It provided a statewide two-day training to advance knowledge and skills among fifty clinical leadership staff at IDD and Alzheimer’s provider organizations and the Rhode Island Developmental Disabilities Nurses Association.

Seven Hills expanded its adult day health program to include a dementia-specific special care license through the state of Rhode Island to support more than thirty-five adults with IDD and dementia with the long-term goal of incorporating older adults from the general public to lessen the segregation of the IDD population.

They developed a resource guide for 4,000 adults with IDD and their caregivers, supported by the Community Provider Network of Rhode Island (CPNRI). CPNRI represents twenty-three private providers of services and supports to people with developmental disabilities in Rhode Island; the network’s mission is to improve understanding of dementia and lead to earlier identification and acquisition of timely supportive services.

Seven Hills, a CPNRI member, designed a legal and financial planning workshop to assist 100 adults with IDD and their caregivers with money management and future care planning. It is working toward the adoption of a standardized tool to be used by organizations supporting individuals with IDD and dementia for early detection of dementia.

Wisconsin

The State of Wisconsin Department of Health Services, which houses the state unit on aging, partnered through an ADI-SSS project with the Wisconsin

Board for People with Developmental Disabilities to certify its staff as trainers through the NTG. The curriculum covers the following components: an introduction to aging with IDD; early detection of dementia; diagnosis; stages of dementia; nonpharmacologic management of difficult behaviors; how to support both professional and family caregivers; and bridging the aging and IDD networks (personal communication with Kathleen M. Bishop and Kathryn Pears, lead trainers for the NTG Education and Training Curriculum on Dementia and Intellectual & Developmental Disabilities, January 7, 2015). Trained staff provides training and outreach for individuals with IDD, families, and professional caregivers at a variety of health, aging, and IDD service provider organizations.

The project has given training to staff at Aging and Disability Resource Centers, managed care organizations, and consultant agencies that help manage an IDD Waiver program. The training covered dementia and IDD, Down syndrome and Alzheimer’s disease, early detection for dementia, differential diagnosis, healthcare advocacy, and caregiving needs. The grantee also developed an IDD and dementia toolkit for the medical community that includes diagnostic protocol guidelines and best practices,


as well as recommended diagnostic tests.

Lastly, the State of Wisconsin Department of Health Services and the Wisconsin Board for People with Developmental Disabilities have partnered with Special Olympics to

system, policy, and practice levels. Nationwide, models are emerging for developing dementia-capable and culturally competent care across agencies and organizations.

Such models include training designed by the NTG,

public through the AOA on the National Alzheimer's and Dementia Resource Center (NADRC) website (nadrc.acl.gov/) beginning in October 2017. The website includes the IDD and dementia toolkit for the medical community created and tested in Wisconsin, and the Rhode Island resource guide.

ACL/AOA also has a report and a webinar on IDD and dementia available on the NADRC website. With the support of ACL/AOA's dementia-specific grants, these resources are available to help systems address the needs of persons with IDD and dementia and their caregivers, using new and emerging practices. 

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'Nearly a quarter of all persons with IDD live with family caregivers who are ages 60 or older.'

promote dementia awareness, via family health forums, which serve to educate families and share families' stories of how they are caring for aging family members with IDD.

Conclusion

People who live in the community with IDD and dementia, and their caregivers, need access to dementia-capable HCBS. This can only be accomplished by improving the dementia-capability at the

which offers a national series of workshops on dementia and intellectual disability for staff of provider agencies, program personnel, administrators, and caregivers. The NTG is creating a network of regional trainers on dementia and intellectual disability to make this training more accessible nationwide. The resources created through the ACL/AOA programs, mentioned in the Promising Practices section above, will be available to the

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An Overview of Dementia Caregiving in the United States

By Joseph E. Gaugler,
Eric Jutkowitz, and
Colleen M. Peterson

To best meet the needs of family caregivers, who provide the most care for family members with dementia, they should be integrated into all aspects of caregiving and better supported.

The public health ramifications of Alzheimer's disease or related dementias (ADRD) are immense. There are 5.5 million Americans living with ADRD, and the prevalence of dementia increases with age (Alzheimer's Association, 2017). Approximately 10 percent of Americans older than age 65 have ADRD, with this percentage escalating to 32 percent for those older than age 85 (Alzheimer's Association, 2017). The insidious progression of ADRDs has placed

When compared to non-caregivers, twice as many dementia caregivers indicate financial, emotional, and physical challenges.

considerable pressure on an already fragmented and burdened U.S. healthcare system; Medicare beneficiaries with ADRD incur three times the healthcare costs when compared to Medicare beneficiaries without dementia (Alzheimer's

Association, 2017). The converging trends of U.S. population aging and rising healthcare costs have led some to ask: How are we going to live with ADRD (Karlawish, 2014)?

Yet with the ongoing focus on curative or preventive treatments for ADRDs, it is clear that ADRDs occur in context, specifically the family context. The brunt of dementia care is not borne by hospitals, nursing homes, or other professional providers but by families, who often navigate the course of the ADRD trajectory with a cognitively impaired relative. This article provides an overview of caregiving for people with dementia in the United States, the state of science and practice related to dementia caregiving interventions, and recommendations to better support ADRD caregivers in the United States. We rely on summary reports and articles we have recently authored or coauthored to describe dementia caregiving

→ABSTRACT The brunt of dementia care in the United States is not borne by hospitals, nursing homes, or other professional providers, but by families. As of 2017, there are 15.9 million family caregivers of people with dementia. They provide more intensive help than non-dementia caregivers, and experience greater financial, emotional, and physical challenges. Recommendations to better meet the needs of these family caregivers include enhanced integration of caregivers in healthcare encounters, increased stakeholder engagement in intervention evaluation, and an emphasis on cost-savings when evaluating and disseminating dementia caregiving support strategies. | **key words:** *dementia caregiving, family caregivers, caregiver integration, ADRDs*

in the United States (Alzheimer’s Association, 2017; Gaugler, 2016; Gaugler and Kane, 2015; Gaugler, Potter, and Pruinelli, 2014).

Prevalence of ADRD Caregiving in the United States

Ambiguity remains in how caregiving is defined (National Academies of Sciences, Engineering, and Medicine, 2016). The Alzheimer’s Association and other organizations generally define caregiving as providing help to a person because of her or his health needs; a key component of this definition is that the care is not normative (Alzheimer’s Association, 2017; Gaugler, Potter, and Pruinelli, 2014). In the dementia context, this non-normative care would refer to family caregivers providing help for symptoms such as cognitive impairment and-or behavioral issues.

Determining the number of ADRD caregivers in the United States is complicated because of how national surveys identify family caregivers. Some, such as the National Alliance of Caregiving (NAC) and AARP (NAC and AARP, 2015) ask respondents, “Are you currently providing unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person’s finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.” Those who indicate “yes” (i.e., self-identify) to this question are considered caregivers.

In contrast, the National Survey of Caregiving, which is linked to the National Health and Aging Trends Study (NHATS), surveyed individuals identified by older adult respondents of NHATS who indicated needing help with mobility or self-care, household activities, transportation, going to the doctor, or with medications (National Academies of Sciences, Engineering, and Medicine, 2016). Surveys that rely on self-identification tend to report higher prevalence estimates of caregiving than those based on older respondents identifying individu-

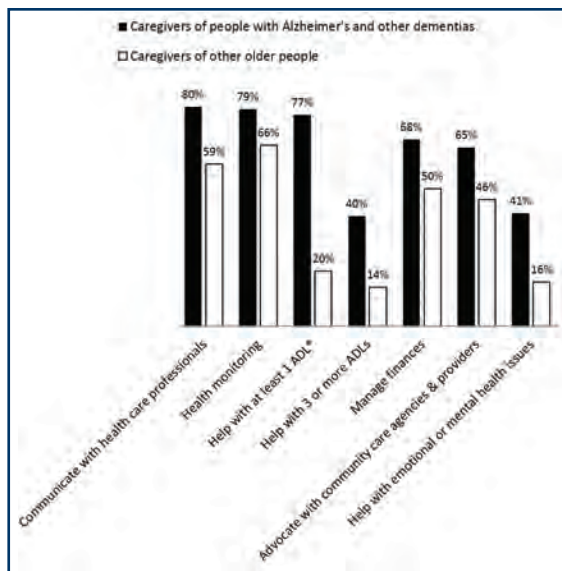
als who provide them with assistance (Giovannetti and Wolff, 2010).

In its most recent *Facts and Figures* report, the Alzheimer’s Association (2017) calculated that there are 15.9 million caregivers of people with ADRD in the United States; the Association’s approach relies on self-identification data from statewide surveys conducted by the Centers for Disease Control and Prevention and the aforementioned national NAC/AARP survey. In contrast, recent studies of caregivers derived from the NHATS survey show that there are an estimated 5.8 million family or unpaid individuals who provide care to persons with dementia in the United States (with 4.8 million providing help in the community) (Kasper et al., 2015).

Figure 1. Caregiver Background and Context

Caregiver Demographics	
Ages 65 and older	34%
Wives or Daughters	67%
Have college degree or higher	40%
Have annual income < \$50,000	41%
Caregiver Race/Ethnicity	
Non-Hispanic White	66%+
African American	10%
Hispanic American	8%
Asian American	5%
Caregiving Context	
Takes care of parents	55%
Lives with care recipient	66%
Cares for both parent and their children	25%

Figure 2. Proportion of Caregivers of People with Alzheimer’s and Other Dementias Versus Other Older People Who Provide Help with Activities, United States 2017



*ADL—Activities of Daily Living (e.g., help with bathing, housework) Source: Alzheimer’s Association, 2017.

Who Are Dementia Caregivers, and Why and How Do They Provide Care?

More than half of U.S. ADRD caregivers help parents (55 percent), but 67 percent of caregivers live with their cognitively impaired relatives at home or in the community (see Figure 1 page 38). Approximately 67 percent of ADRD caregivers are wives or daughters. Particular interest has focused on “sandwich” caregivers, meaning dementia caregivers who are engaged not only in caring for a parent with ADRD but also in childrearing responsibilities; surveys estimate that close to 25 percent of all dementia caregivers are “sandwiched” between these roles (Alzheimer’s Association, 2017).

There are several reasons family members provide care to a relative with ADRD. A majority (65 percent) of respondents to a national poll conducted by the Alzheimer’s Association indicated that the reason they assume care responsibilities is the “desire to keep (the) family

member/friend at home.” In the survey, dementia caregivers could provide multiple responses to why they provide care. Caregivers also indicated that they provide assistance to a cognitively impaired relative because of their “proximity to the person with dementia” (48 percent) and because of a “perceived obligation as a spouse or partner” (38 percent) (Alzheimer’s Association, 2017).

What tasks do dementia caregivers perform?

Current data on family dementia caregivers in the United States emphasize the added care demands associated with ADRD, as compared to caregivers of persons without ADRD. Figure 2 (this page) summarizes nationally representative findings. In general, family caregivers of persons with ADRD provide more extensive activity of daily living (ADL) tasks (e.g., bathing and dressing), instrumental ADL tasks (e.g., shopping and food preparation), and a range of other care needs (e.g., care coordination, complex care). Managing the specific symptoms of ADRD poses additional care demands for family caregivers of persons with dementia; for example, dementia caregivers are more likely than non-dementia caregivers to help with care recipients’ behavioral issues (15 percent versus 4 percent) (Alzheimer’s Association, 2017).

Dementia Caregiving: Effects, Costs, and Interventions

The adverse effects of dementia caregiving on family members are well documented in the research literature. When compared to non-caregivers, twice as many ADRD caregivers indicate financial, emotional, and physical challenges (Alzheimer’s Association, 2017). Anywhere from 30 percent to 40 percent of dementia caregivers have depression, which is approximately 10 percent greater than caregivers of persons with other chronic conditions (Alzheimer’s Association, 2017; Sallim et al., 2015). Reflecting the increasing complexity of dementia care tasks, twice as many ADRD

caregivers indicate difficulty with medical and nursing-related care tasks such as injections (22 percent) when compared to non-dementia caregivers (11 percent; NAC/AARP, 2015). More than 33 percent of ADRD caregivers in the United States indicate that their health has gotten worse since assuming dementia care responsibilities, compared to 19 percent of caregivers of someone without dementia (Alzheimer's Association, 2017). Fifty-seven percent of family caregivers of persons with ADRD had work disruptions (e.g., went in late, left early, or took time off), whereas 47 percent of non-ADRD caregivers indicated such disruptions (Alzheimer's Association, 2017).

There are 15.9 million caregivers of people with dementia in the United States.

Data from the 2016 Alzheimer's Association Family Impact of Alzheimer's Survey show that among friends or relatives who paid for dementia expenses or provided help to someone with ADRD at least monthly in the prior year, close to half (48 percent) cut back on spending and 43 percent cut back on savings because of ADRD care (Alzheimer's Association, 2017). Recent research suggests that dementia caregivers who indicate higher strain are at greater risk for death when compared to dementia caregivers who did not report high levels of strain (Perkins et al., 2013).

The costs of dementia caregiving

Dementia substantially increases the annual costs (up to \$56,000 extra) and lifetime costs (\$195,000 extra) of care to families, Medicaid, and Medicare (Hurd, Martorell, and Langa, 2013; Jutkowitz et al., 2017a). The majority of dementia costs are incurred by families because of the extent of assistance these families provided and their large out-of-pocket payments for long-term-care services (e.g., nursing homes) (Jutkowitz et al., 2017b). Declines in

function and increased behavioral symptoms among persons with ADRD drive these costs for family caregivers (Jutkowitz et al., in press; Jutkowitz et al., 2017b). Interventions that effectively support family caregivers or manage functional decline and behavioral symptoms appear to result in cost-savings to families, Medicaid, and Medicare in selected evaluations, but the effect of dementia caregiver support services on ADRD costs requires greater emphasis in future research (see below).

Interventions for dementia caregivers

As the challenges of dementia care became apparent, attention turned to developing and evaluating programs (or "interventions") for family caregivers of relatives with ADRD. The goal of dementia caregiver interventions is to implement support strategies to reduce the distress of family caregivers. Some dementia caregiver interventions also aim to help persons with ADRD avoid residential long-term care or other health service use, and reduce dementia-related symptoms such as functional decline and behavioral symptoms. Types of interventions include case management, support groups, psychoeducation, psychotherapy, problem-focused counseling, self-care and exercise, relaxation, respite, and combinations of these approaches.

Recent syntheses of the multiple systematic reviews and randomized controlled trials of dementia caregiver interventions have emphasized that programs are most effective when family caregivers are actively involved in the intervention (as opposed to receiving information passively), when content is customized to the specific needs of dementia caregivers over time, and when the needs of family caregivers and persons with ADRD are incorporated in intervention content (Gitlin and Hodgson, 2015).

An earlier report (Maslow, 2012) indicated that as of 2012, there were forty-four randomized controlled trials demonstrating positive

benefits for persons with ADRD or their family caregivers. The number of rigorous evaluations has expanded considerably since then, although an update on the total number of high-quality research studies (e.g., randomized controlled trials) is not immediately available. The Alzheimer's Disease Supportive Services Program (see <https://goo.gl/rN11Xj>) highlights several of the more notable dementia caregiver interventions that have not only demonstrated significant and consistent benefits for family members and care recipients, but also are in translation in a variety of organizations and clinical settings.

Working with Family Caregivers

A key step when providing services and support to ADRD family caregivers is to conduct an appropriate assessment. The Family Caregiver Alliance provides several principles that should underlie a caregiving assessment, including the joint incorporation of needs and preferences of the person with ADRD and the family caregiver, and inclusion of measurable outcomes that result in a care plan developed in tandem with the ADRD caregiver (Family Caregiver Alliance, 2006).

Dementia caregiver intervention programs are most effective when family caregivers are actively involved in the intervention.

Key elements that should be assessed in a family caregiver interview or questionnaire include the caregiver's background and the caregiving situation; the care recipient's medical history; the caregiver's perception of the health and functional status of the care recipient; the caregiver's values and preferences; the caregiver's health and well-being; the impacts of caregiving on the caregiver; care provision requirements; and resources to support the caregiver.

Using the assessment to see if there are gaps in family caregiver support (e.g., creating a

matrix to determine who is providing what kind of help to the person with ADRD) can then inform the recommendation of or delivery of services to the family caregiver. Using problem lists or similar tools to identify the major care issues that occur, plus their frequency and timing, also is important. Such steps can help to discover whether there are environmental or other stimuli that trigger care issues, allowing the caregiver to better manage and avoid these issues. "Failures" in attempting to support ADRD caregivers when managing care-related challenges are to be expected; creating effective strategies often entails an ongoing process of trial and error. Adopting an iterative "try it" approach helps to orient dementia caregivers to the reality that multiple care solutions are necessary throughout the course of ADRD (Gaugler, 2016).

Implications and Recommendations

In 2016, the National Academies of Sciences, Engineering, and Medicine released *Families Caring for an Aging America*, which highlighted a number of recommendations to better integrate family caregivers in all aspects of the healthcare process (i.e., a family-centered model of care). A core component of family-centered care is recognizing the existence of family caregivers during healthcare encounters and to jointly support the older person and family members with evidence-based supports, as appropriate. Specific recommendations include payment reforms in public insurance programs (i.e., Medicare, Medicaid) to reimburse professionals who deliver caregiving support programs and to more effectively train these professionals to engage with family caregivers. The report also recommended establishing data infrastructure to identify and track family caregivers over time (e.g., within electronic health records). And the report emphasized accelerating research and development (via a public-private fund) to evaluate the efficacy of emerging technologies.

Several federal organizations, such as the Alzheimer’s Disease Supportive Services Program of the Administration on Aging, the National Institute on Aging, the U.S. Department of Veterans Affairs, and others have provided funds for projects that translate evidence-based interventions into real-world settings. Despite such efforts, many evidence-based programs do not reach caregiving families in need. A major issue in translating evidence-based programs is that interventions often are tested with the goal of scientific efficacy, but key stakeholders (e.g., family members, persons with ADRD, organizational staff) are not fully engaged in such efforts.


Building best practices in translational research that highlight stakeholder engagement strategies is one recommendation that could facilitate and expedite translating promising caregiver interventions into practice (Wethington and Burgio, 2015). Incorporating evaluation strategies that extend beyond analyzing outcomes and emphasizing sustainability and utility also could accelerate the translational process (Gitlin et al., 2015).

Other recent efforts exploring the sustainability of family caregiving offer additional recommendations (Gaugler and Kane, 2015). The continuing development of “smart home” technologies that provide remote activity and health monitoring may hold potential to proactively manage the complexities of ADRD for families, but require ongoing research to better ascertain their feasibility, utility, and effectiveness.

Creating decision-making tools (e.g., via smartphone apps or similar easy-to-use platforms) that provide personalized information to meet the diverse needs of caregivers and persons with ADRD is another recommendation. But to work, such tools require effective partnerships between private-pay long-term-

care companies, state offices on aging, and federal agencies, alongside consumer-oriented efforts (e.g., ratings websites). Harnessing the power of social media and networking tools to better crowdsource ADRD caregivers’ needs and solutions could bridge the chasm between providers and scholars to enhance translation and implementation through more vibrant stakeholder engagement.

Current research on ADRD caregiver interventions and programs has largely focused on psychosocial, and, to a lesser extent, health service use outcomes on the part of family caregivers or cognitively impaired care recipients. But to drive the policy agenda forward and to make a more compelling case to payers, it is necessary to focus on how such programs result in tangible cost-savings. Incorporating family caregivers into emerging healthcare innovations, such as medical care homes or similar chronic disease management strategies, are additional approaches to consider.

Other experts have called on family caregivers to more aggressively advocate for their needs. Using the disabilities movement as a template, a national association of long-term-care reform that places family caregivers’ concerns as central to improving the delivery of care to older adults with ADRD or other chronic conditions could similarly alter the paradigm of how we view and serve family caregivers of persons with dementia in the United States. 

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Making Long-Term Services and Supports Dementia-Capable

By Elizabeth Gould
and Joshua Wiener

How do dementia-capable services work and which states and cities are succeeding in providing them?

An estimated 30 percent of people with Alzheimer’s disease and other dementias live in nursing homes, assisted living facilities, and other group residential settings, but the majority—about 70 percent—live in their own homes (Alzheimer’s Association, 2012). A substantial proportion of these people use long-term services and supports (LTSS). Model systems are dementia-capable; that is, they

‘Person-centered planning identifies the person’s strengths, goals, preferences, service needs, and desired outcomes.’

accommodate the needs of people who experience varied physical, cognitive, and behavioral symptoms of dementia by tailoring programs to the unique needs of this population and their caregivers. This article argues for the importance of dementia-capability in home- and community-based systems (HCBS) as it relates to the needs of individuals and family caregivers, describes the components of model dementia-

capable systems, and reports on how some states and local communities are becoming more dementia-capable.

Components of Dementia-Capable HCBS Systems

Many people with dementia living in the community rely on the Aging Network for information, referral, and assistance and on Medicaid and other public programs such as the Department of Veterans Affairs and services funded by the Older Americans Act to help finance LTSS services. Serving this cohort effectively involves accommodating memory loss and related physical, cognitive, and behavioral symptoms resulting from dementia, along with other medical conditions (Tilly et al., 2011). According to the Administration on Aging (2017), model dementia-capable HCBS systems do the following:

- Identify people with possible dementia and recommend they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that resemble it.

→ABSTRACT Government agencies and community-based organizations serve people with dementia and their family caregivers through the aging services network and long-term services and supports systems. Model systems are dementia-capable—they accommodate the needs of people who experience varied physical, cognitive, and behavioral symptoms of dementia by tailoring programs to the unique needs of people in this population and their caregivers. This article explains the importance of dementia-capability as it relates to the needs of individuals and family caregivers, describes the components of model dementia-capable systems, and reports how some communities are becoming more dementia-capable.

| key words: *dementia-capability, home- and community-based systems, family caregivers, Alzheimer’s*



- Ensure program eligibility and resource allocation take into account the impact of cognitive disabilities.
- Ensure staff communicate effectively with people with dementia and their caregivers and provide services that are person- and family-centered, offer self-direction of services, and are culturally appropriate.
- Educate workers to identify possible dementia and understand the symptoms of dementia and appropriate services.
- Educate the public about brain health, including information about the risk factors associated with developing dementia, signs of cognitive problems, management of symptoms of dementia, support programs, and opportunities to participate in research.
- Implement quality assurance systems that measure how effectively providers serve people with dementia and their caregivers.
- Encourage development of dementia-friendly communities.

Model dementia-capable aging services network and LTSS systems address the unique needs of people with dementia who lose their

ability to manage chronic health conditions and daily activities, and their family caregivers who progressively take on more responsibility for managing the needs of their loved ones.

Components of a Dementia-Capable LTSS System

Enumerated below are components of a dementia-capable LTSS system and examples of how states and localities are improving services to meet the needs of people with dementia and their families.

Identification and diagnosis of dementia

Agencies first need to identify which people have dementia before they can provide services that meet the needs of people with dementia and their caregivers. Individuals or caregivers may contact service providers to discuss memory problems, trouble managing finances, medical care, or behavior changes. Service providers need skills and screening and assessment tools to recognize whether the consumer may have cognitive problems or if the caregiver is describing a relative with dementia, and to refer the

individual with dementia for diagnosis. Although people with dementia use many services that other people with disabilities use, they also use services such as education and support groups that address the specific symptoms of Alzheimer’s disease and the course of the illness.

Dementia-capable agencies have adopted various strategies for identifying people with dementia and their family caregivers. Some agencies add questions on cognitive status to intake and assessment protocols. Telephone operators and other staff are trained to recognize possible cognitive impairment in their conversations with callers and during in-person meetings. Staff also are trained in the cultural traditions of various ethnic groups regarding dementia. Policies and procedures are established for referring people with possible cognitive impairment for professional assessment or support services through organizations specializing in dementia.

Entry points to the LTSS system, such as Aging and Disability Resource Centers (ADRC), create processes for referring people with possible cognitive impairment for professional assessment. The options counselors of the Tarrant County, Texas, ADRC include cognitive impairment screening questions as part of the intake process and refer individuals to the University of North Texas (UNT) Health Science Center for a geriatric assessment if he or she is experiencing symptoms of cognitive decline (personal communication with Don Smith, vice president, community development-health director, Area Agency on Aging, United Way of Tarrant County, and Janice Knebl, geriatrics professor, UNT Health Science Center, February 28, 2017).

The Washington State Department of Social and Health Services is implementing dementia-capable person-centered counseling through four of its area agencies on aging (AAA) (personal communication with Lynne Korte, program manager, Home and Community Services, Aging and Long Term Support Administration,

Washington State Department of Social and Health Services, April 25, 2017). The aim is to systematically identify people with suspected or diagnosed dementia early on in the disease process and respond with appropriate information, referrals, tracking, and follow-up. Before meeting with clients, information and assistance staff and counselors are trained in how to “listen” for cues that may indicate possible dementia, to learn what is important to each client, and to provide decision support.

Program eligibility and resource allocation

Public LTSS programs have financial and functional criteria that determine who is eligible for services. To ensure that people with dementia can participate in these programs, functional eligibility criteria need to incorporate assessments of cognitive impairment and to recognize the need for standby assistance and cueing as central to whether individuals can perform activities of daily living (ADL). Eligibility criteria that only address a need for hands-on assistance may exclude people with dementia who need verbal or written cues or monitoring to complete ADLs and instrumental activities of daily living (Garfield et al., 2015).

Person- and family-centered service provision and cultural competency

Person-centered planning identifies the person’s strengths, goals, preferences, service needs, and desired outcomes. In this model, staff, family, and other multidisciplinary team members help consumers identify and access a unique mix of paid and unpaid services to meet their individual needs. The goal of person-centered planning is to help people do what is most important to them.

Many organizations such as ADRCs and AAAs provide assistance to help people with dementia and their caregivers identify, choose, and obtain services and supports. More than with other people needing LTSS, family caregivers of people with Alzheimer’s disease and other

dementias are likely to play a central role in decision making and management regarding services because of impaired decision-making capacity.

To ensure that services meet the needs of people with dementia and their caregivers, the Illinois Department on Aging and the Alzheimer's Association, Greater Illinois, are expanding a Care Navigation program throughout the state to assist people with dementia and family caregivers to better understand dementia, answer questions, and establish individualized person-centered care plans (personal communication with Melanie Chavin, chief program officer, Alzheimer's Association, Greater Illinois, and Betsy Creamer, public service administrator, Office of Older American Services, Illinois Department on Aging, April 27, 2017). The program includes a pre-assessment completed by the family and person with dementia, an in-person meeting, a written person-centered care plan, and follow-up from the Care Navigator. Appointments and follow-up contact are in person, by telephone, or via Web services such as Skype, which allow contact with clients in rural or remote areas.

In another model, the Minnesota Board on Aging's Cultural Awareness in Dementia Care initiative is stimulating culturally responsive services among aging service providers and healthcare personnel by infusing online dementia training materials with the norms and values of specific ethnic and cultural groups (e.g., American Indian, Latino, and Somali populations) and involving expert consultants to support ongoing health equity efforts (personal communication with Nancy Lee, state program administrator principal, Aging and Adult Services Division, Minnesota Department of Human Services, April 24, 2017).

Participation in self-directed LTSS

Self-directed programs give consumers greater control over what services are provided by whom and when than does agency-directed home care. In self-directed programs, people

with dementia generally use representatives to help them make decisions. Although people with less severe levels of dementia can express their general preferences, they commonly cannot manage the more detailed and logistical aspects of care. Having the assistance of a representative who can act on behalf of the person with dementia is critical for people with cognitive impairment to participate in self-direction programs (Tilly, 2007).

'Few LTSS workers receive training on Alzheimer's disease and related dementias.'

To help facilitate use of self-directed LTSS, Rhode Island uses a shared decision-making model with individuals who have intellectual and developmental disabilities and dementia (personal communication with Sandra Fournier, LTSS oversight manager, Neighborhood Health Plan of Rhode Island, May 7, 2017). The first line of decision support for people with both dementia and intellectual and developmental disabilities is the family, in partnership with a medical team. For individuals living in a residential group home, staff are able to operate in a parallel function to the family of origin.

Worker training

Few LTSS workers receive training on Alzheimer's disease and related dementias (ADRD), including common symptoms, trajectory, and appropriate services. Federal regulations require seventy-five hours of training for home health aides and certified nursing assistants, but there are no federal requirements for training for personal care aides. States vary widely in their requirements for personal care aides, and most require fewer hours than the federal minimum (Institute of Medicine, 2010). Because of high turnover among LTSS workers, training needs are ongoing, and many trained workers leave the field (Konrad, Morgan, and Ribas, 2007; Konrad, Morgan, and Green-Royster, 2011).

To better prepare the LTSS workforce to provide services to people with dementia and their caregivers, the University of Hawaii's Geriatric Workforce Enhancement Program is providing ADRD education and training to people with dementia, family members, direct care workers, allied health professionals, medical students, residents, geriatric medicine fellows, and university faculty (personal communication with Christy Nishita, researcher, Center on Aging, University of Hawaii, April 27, 2017). The primary aim of this initiative is to better meet the needs of rural and underserved populations and address health disparities for Native Hawaiian and Pacific Islander populations. The Geriatric Workforce Enhancement Program partnered with another University of Hawaii project, funded by the Administration for Community Living, to provide short learning sessions to additional health professionals.

'Scientists continue to seek volunteers with and without dementia to help test promising interventions.'

Similarly, the Oregon Department of Human Services, in collaboration with Portland State University, is this year providing Web-based ADRC Dementia Training through a pilot program. Individuals may view trainings on their own; however, group viewing and discussion using the provided companion guides is encouraged. Topics include person-centered dementia support, communication and behavioral expression, medical and clinical aspects of dementia, and supported decision-making (Oregon Department of Human Services, 2017).

In another example, the California Department of Health Care Services and the San Francisco regional office of the Centers for Medicare & Medicaid Services in March 2017 issued an informational bulletin reminding California Medicare–Medicaid plans of contractual requirements for dementia care manage-

ment for enrollees (California Department of Health Care Services, 2017). Dementia care management staff are required to have expertise in dementia symptoms, disease progression, behavioral symptoms, and communication challenges; to have knowledge about how to address caregiver stress; and to coordinate community resources for enrollees and caregivers. Additionally, California Medicare–Medicaid plans are urged to ensure that all providers have a basic knowledge of dementia and understand the needs of enrollees and caregivers, and that plans provide regular dementia care training opportunities, given workforce turnover rates.

Caregiver support programs

Many public programs, such as Medicaid, primarily target services to the “client” (the person with dementia); thus, funding for caregiver support programs is not widespread, although it is available in some Medicaid HCBS waiver and Administration on Aging programs. Effective caregiver support programs that improve self-efficacy and empower caregivers to respond to dementia symptoms are essential to maximize the quality of life for people with dementia and their caregivers (Maslow, 2012). These programs address multiple caregiver outcomes such as reductions in caregiver depression, burden, strain, anxiety, and burnout.

The Georgia Department of Aging Services added BRI Care Consultation to its statewide menu of services after an Administration on Aging–funded demonstration showed that it was a cost-effective and efficient supplement and at times, even a substitute for traditional, in-person case management (Easom and Holloway, 2015). BRI Care Consultation is a telephone intervention with three main components: initial assessment, action plan, and ongoing maintenance and support, which includes monitoring and follow-up with reassessment, as needed. Care consultants manage a caseload of up to 150 families, with client contact varying from once every three months to a few times a week, depending

on the situation. The Benjamin Rose Institute on Aging and the Rosalynn Carter Institute provide support to the Georgia AAAs in licensing, training, and technical support (Easom and Holloway, 2015).

In another example, in 2015, the Michigan Commission on Services to the Aging adopted a new service definition for Michigan's aging network to sustain delivery of the Savvy Caregiver Program, a twelve-hour psycho-educational program designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to handle the challenges of caring for a family member with dementia. After this announcement, eight of the sixteen Michigan AAAs included the Savvy Caregiver program in their FY 2016 area implementation plans and additional AAAs are supporting the program with existing caregiver funds (Title III DE) (Steiner and Sherman, 2015).

Quality assurance

A dementia-capable quality assurance system has measures to assess whether the LTSS system and individual providers are dementia-capable and whether they provide high-quality services. Systematic and regular measurement of the experience of people with dementia and their family caregivers provide an assessment of how the service system is working from the user's perspective. Continuous quality improvement would feed back information about dementia service quality, tracking measures over time to compare performance, which could be used to improve services. Quality assessments that analyze the experience of people with dementia compared to people without dementia allows for the measurement of how providers perform on more standard measures (Konetzka et al., 2015). Overall, however, there have been few quality assurance efforts, and more attention needs to be given to developing and implementing these dementia-specific measures (Wiener et al., 2016).

Wisconsin Department of Health Services has a quality assurance plan to measure the

progress of the comprehensive Dementia Care System Redesign Plan efforts. Quality assurance strategies include taking measurements related to dementia care systems and conducting an inventory of care providers who understand dementia (Wisconsin Department of Health Services, 2016).

Since 2014, federally funded Alzheimer's Disease Supportive Services Program and Alzheimer's Disease Initiative–Specialized Supportive Services grants have reported on state- and community-level LTSS dementia-capability using an assessment that measures three areas: identification of people with possible cognitive impairment or dementia and their primary caregiver; staff training about cognitive impairment, dementia, and dementia care; and provision of specialized services for people with dementia and their caregivers (National Alzheimer's and Dementia Resource Center, n.d.). The tool's qualitative response questions are aimed at identifying aspects of the LTSS system that are dementia-capable, as well as any gaps in dementia-capability.

Participation in research

A great deal has been learned about dementia in recent years. Nonetheless, no intervention is available to prevent or cure Alzheimer's disease or other dementias, and existing non-pharmacological interventions often have modest impacts. Thus, scientists continue to seek volunteers with and without dementia to help test promising interventions around medications, caregiver support programs, and health behaviors.

A federal initiative, Recruiting Older Adults into Research (ROAR), sponsored by the Administration for Community Living, the Centers for Disease Control and Prevention, the National Institute on Aging, and their partners, promotes awareness of research participation opportunities with a focus on Alzheimer's disease and dementia (National Institute on Aging, n.d.). Some partners also have organized state-specific initiatives, such as the Illinois Cognitive Resources Network, to

disseminate information about ROAR and to support collaborative work among the Alzheimer's Association chapters, Alzheimer's Disease Assistance Centers, and organizations in the Aging, Disability, and Public Health Networks (personal communication with Raj Shah, associate professor, Department of Family Medicine, Rush Medical College, May 2, 2017).


Development of dementia-friendly communities

A dementia-friendly community is one in which the physical and social environments are responsive to the needs of people with dementia. This responsiveness includes wayfinding, a sense of safety, accessibility to local facilities, social acceptance, and understanding of dementia. Dementia-friendly healthcare settings help ensure that people with dementia receive appropriate and needed care services (Lin, 2017). The concept of being dementia-friendly has spread across the world as a way of ensuring improved quality of life for people with dementia and their families. More than thirty countries are working toward making their communities and healthcare systems more dementia-friendly.

North Carolina's Orange County instituted a Dementia-Friendly Business campaign, which provides training on Alzheimer's disease to customer-facing staff in businesses, county of-

fices, and the town offices of Chapel Hill, and to first responders and bus drivers (Dementia Friendly Orange County, n.d.). Certification is provided to organizations that meet the standards of dementia-friendliness.

Conclusion

Ensuring that the aging services network and LTSS systems are dementia-capable is critical because many expenditures are for people with Alzheimer's disease and other cognitive impairment, and dementia-capability enables these systems to effectively and efficiently provide the care that people with dementia need. In addition, caregivers of people with dementia regularly contact these systems seeking assistance in coping with their loved ones' impairments. People with dementia depend upon others for help with daily activities, short-term memory loss, decision making, behavioral symptoms, and end-of-life care issues. The types of necessary supports include assistance with care planning and care coordination, assistance with daily activities, and caregiver training. 

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Dementia Programming for American Indian Populations in Arizona

By Helle Brand

Identifying tribal cultures' common needs allows for consistency in education, while accepting distinct needs.

In the mid-1970s I began my medical career as a physical therapist in upstate New York, working initially with developmentally delayed children. Subsequently I began focusing on cognitively impaired adults, most of whom suffered from what was then known as senile dementia, or organic brain syndrome, which was viewed as an inevitable part of aging. There were no treatments, and institutional placement was common. As time progressed, the diagnosis

'If family members disabled a car or truck to discourage driving, the person with dementia was able to quickly fix the problem.'

became Senile Dementia of the Alzheimer's Type and, by 2002, when I changed careers and began working as a physician assistant, it was recognized as Alzheimer's disease. Other causes of dementia had also been identified—all of them risk factors but not norms for aging. Yet in 2006

when I moved to Phoenix and became involved with the American Indian population, tribal communities still viewed and accepted dementia as a part of aging and thus it was not recognized or diagnosed.

The following are well-quoted statistics about Alzheimer's disease, as published in the Alzheimer's Association *2017 Facts and Figures* (Alzheimer's Association, 2017), pointing to the number of those affected by the disease:

- An estimated 5.4 million people, including 200,000 who are younger than age 65, have Alzheimer's disease. That number is expected to almost triple by the year 2050. Nearly two-thirds of these people are women.
- Alzheimer's disease is the sixth leading cause of all deaths in the United States. Among people ages 65 or older, it is the fifth leading cause of death, and one in three older adults dies with either Alzheimer's disease or related dementias.
- Alzheimer's disease is the only disease in the top ten causes of death in the United States

→ABSTRACT Although the incidence of Alzheimer's disease has been well studied in Caucasian populations, the prevalence in other racial or ethnic groups, particularly in American Indians, is not well known. Through regular outreach efforts, the development of culturally sensitive educational materials and programs, and an annual conference, the Native American Program of Banner Alzheimer's Institute in Phoenix has raised the understanding of Alzheimer's disease throughout the state's American Indian communities and maintained a small, valuable cohort for a longitudinal study aimed at understanding natural aging and cognition. | **key words:** *American Indians, dementia, Alzheimer's, Banner Alzheimer's Institute, Phoenix*

for which there is no cure, prevention, or slowdown.

- Roughly one of every five Medicare dollars is spent on the care of someone with dementia.
- On a per capita basis, African Americans and Hispanics are more likely to suffer from some form of dementia than are older white populations.

Alzheimer's Research on the American Indian Population

What is not well known is the prevalence of Alzheimer's disease in other racial or ethnic groups, particularly in American Indians. The National Institutes of Health has emphasized expanding research efforts directed at women and minorities, mandating through its Revitalization Act of 1993 (signed by President Bill Clinton; National Institutes of Health, 1993) that 20 percent of subjects recruited for studies be from these groups. Early efforts with American Indians in Arizona were directed at research.

Arizona is home to twenty-two federally recognized tribes, with reservation lands representing a quarter of the state and total population—the second largest population of American Indians in the United States. Although many tribal lands are more rural or remote, Phoenix has well over 40,000 urban-dwelling American Indians, and has several tribal lands within easy traveling distance from the city, creating a potential pool of participants for research involvement.

Arizona has developed a collaborative model of Alzheimer's research through the Arizona Alzheimer's Consortium, which was founded in 1998 and capitalized on the strengths of each participating institute in genomics, brain imaging, cognitive neurosciences, and clinical and neuropathology research. The organizations involved include the University of Arizona, the Mayo Clinic, Barrow Neurological Institute, Arizona State University, and the Translational Genomics Research Institute. Specific to the American Indian efforts in which I have been

involved, the other two members of the Consortium are Banner Sun Health Research Institute (BSHRI) and my organization, Banner Alzheimer's Institute (BAI).

I moved to Phoenix in 2006 as a physician assistant to specialize in dementia care, to help launch BAI; and, as a personal and professional goal, to become part of the effort to understand the natural history of aging and cognitive changes in American Indian populations.

The Native American Project began in 2003 through the Sun Health Research Institute. The project's goals were to increase knowledge and awareness of Alzheimer's disease among Arizona's tribes and urban American Indians, and to recruit volunteers for normal aging and cognitive evaluations. A small but critical cohort (n = 60) was recruited for an Alzheimer's Disease Core Center–sponsored natural history–longitudinal study, which is ongoing.

Recruiting, maintaining, or expanding the cohort proved difficult. As noted, with twenty-two American Indian tribes represented in Arizona, each with separate governing bodies that change regularly, it was difficult to build and maintain relationships. Meeting with tribal elders or governing bodies was time-consuming and often nonproductive. Historically, those tribes closest to Phoenix have been approached most often for research but because of previous exploitation and violations of trust, they were leery when approached for this study (Davis and Reid, 1999). Equally important, the identification of Alzheimer's was not a primary concern of tribal leaders or communities, thus not a priority for tribal council meetings. Many participants in the original cohort were also lost to attrition because of difficulties in contacting them or lack of transportation to annual visits.

A key component of the early American Indian outreach and research efforts was an annual conference, *Alzheimer's Disease and Dementia in Native Americans*, designed for healthcare professionals working with American Indians and focused on traditional medical

topics. This was conducted twice in the urban setting and once rurally, with attendance of between 100 and 150 professionals. The conference expanded in 2007 because of joint discussion between BSHRI and BAI on American Indian needs related to dementia, and at the recommendation of an advisory planning committee. The expanded conference focused on diagnosis and treatment and issues of living with Alzheimer's, and was named *Weaving the Old with the New: A Four-point Discussion on the Aging Brain and Alzheimer's Disease*. Attendance was significantly higher, with 300 participants, 60 percent of whom were family caregivers and 40 percent professionals; 60 percent of the Arizona tribes were represented.

What emerged was the realization that the words Alzheimer's and dementia do not exist in many American Indian languages. The Navajo describe the dementia process as "the memory is diminishing." Many believed memory loss to be a normal part of the aging process, or to culturally reflect the closing of the circle of life, reverting back to childhood. What was painfully clear, too, was that American Indians were witnessing and struggling with a real and growing problem with dementia and its effects in their communities.

Evolving Outreach Tailored to the American Indian Cohort

The American Indian tradition is orally based, and respecting that was key in changing the American Indian outreach program, which from 2008 on was assumed by BAI in Phoenix, a sister program of BSHRI. The Advisory Council was composed of twelve American Indian community leaders who guided us in expanding and enriching the scope of the annual Native American conference and in developing culturally sensitive and appropriate materials and programs. We heard of more challenges related to lack of community resources and rural living, such as a hospital or nursing home being located four hours from home. Hearing family caregivers talk about their difficulties and needs in under-

standing and working with their loved ones with dementia shifted the focus of outreach to education.

Higher levels of alcohol use and dependence on driving to reach services presented greater difficulties behaviorally in the person with dementia and logistically for these caregivers. It was not unusual to hear that if family members disabled a car or truck to discourage driving, the person with dementia was able to quickly fix the problem. Going for morning walks presented concerns for getting disoriented and lost.

We heard frustration about knowing dementia was a real and growing problem but with little or no recognition of the issue from community leaders. We heard from adult children, particularly women, of the conflict they felt between the expectation that they would provide care for a loved one with dementia (as would be traditionally expected). Urban dwellers were concerned that they also had to work, and rural residents reported that they had little support from others and experienced burnout. Equally frustrating for all was the lack of understanding of the caregiver experience. At times, caregivers were more traditional and had difficulty understanding our teachings. Our Native advisors and families helped us realize the need for an American Indian presence and teaching at our conference.

This led to collaborative efforts with community tribal programs, physicians, and leaders, and with select tribes throughout the state. The knowledge and awareness about Alzheimer's disease and dementia in American Indians was promoted not only through our annual conference but also through participating in health fairs, workshops, and conferences offered through Native organizations such as Indian Health Services and the Intertribal Council of Arizona.

The educational programs that our Native American Outreach team offered were built from the ground up, initially focused on providing caregivers basic information on the recognition,

diagnosis, treatment, and progression of Alzheimer's disease. Daylong workshops on various tribal lands were offered, as were periodic presentations to various Native communities. These workshops were always well received and attended by thirty to fifty or more people, depending on the community. The depth of information provided grew dramatically and became more specific and more solution-oriented to the daily living challenges associated with Alzheimer's disease. These included sessions, for instance, on understanding changes in communication and how they affect behavior, on using non-pharmacologic interventions to address behaviors, on how to structure a day and provide meaningful activities for loved ones, and on general caregiving concerns.

Key to providing programs to the American Indian population was the provision of *Navigating Through Memory Loss* (Banner Alzheimer's Institute, 2017), which was modified and made culturally sensitive from a booklet we created for families seen through our Memory Disorders Clinic. Included in the booklet was basic information on the diagnosis and treatment and the cognitive and functional changes seen in the different stages of Alzheimer's disease, strategies for meeting the physical and emotional needs of a person with dementia, and a chapter on caregiver-specific issues and available resources. The booklet was made available at no cost and distributed at all outreach efforts. A CD called *Caregiver Voice*, on which American Indian caregivers shared their experiences, was produced and made available in outreach efforts.

Also integral to the education for family caregivers was the need to educate professionals who worked with families in the community, ranging from the Arizona Long Term Care System (our state Medicaid program) to case-workers and community caregivers in senior centers, nursing homes, and homecare agencies, and to healthcare workers. Daylong workshops were offered for family caregivers, as were half-day workshops for professionals, by adding

tracks for professionals at conferences, and by presenting continuing medical education talks for medical providers.

The annual Native American Alzheimer's Conference now has up to 300 participants, drawing from Arizona and other states. The conference has been held at tribal resorts and casinos at varying locations to allow equitable participation for participants. The overall theme, blending traditional ways and understandings with new teachings, remains *Weaving the Old with the New*, with a different focus offered each year. Attention to such details as having the host tribe offer the blessings to begin and end the day, and offering entertainment from host tribe members, has been important in our acceptance, as we have shown cultural sensitivity. Also in 2015 there was a national conference, put on in conjunction with key American Indian professionals throughout the country. And we had a strong presence at the American Indian and Alaska Native 2016 Long-Term Services and Supports Conference held in Minneapolis.

Ongoing Research and Future Efforts

With time, we have been able to again recruit for the Alzheimer's Disease Core Center longevity study as we increased community visibility and established trust. There are now forty-two participants enrolled in the study. Participants are offered vouchers for their participation and transportation to and from study visits, and have regular contact from American Indian outreach staff to help maintain relationships and interest in the program. The best recruitment comes from those who have had a successful experience and can speak to concerns expressed by those who might be considering enrollment.


Other activities have been developed in working with the American Indian communities, specifically memory screenings and brain wellness programs to address concerns for what the future may hold. In doing memory screenings, for which we used the Montreal Cognitive Assessment test, it was clear that scores were

consistently lower than would be expected, based on age and level of education. Working together with a Navajo neuropsychologist, a preliminary cognitive assessment tool, the Southwest Indian Cognitive Assessment (SWICA), was developed and tested in a small group but needs further testing to determine sensitivity and specificity. It is not yet available. The SWICA differs from the Montreal Cognitive Assessment in that it pairs visual and auditory registration, using five pictures of items familiar to American Indians, for registration and recall, rather than just giving five words to remember. Rather than six questions on orientation, the SWICA asks only three questions for year, month, and place.

Our many outreach programs and materials are offered at no cost to the communities. In fact, the success of our program is due to the philanthropic support of corporations, individuals, key tribes, and private foundations that are committed to assisting American Indians in the areas of education and health promotion.

Our successful connection with American Indian communities and individuals developed over time through establishing trust and building relationships. By identifying individual community needs, effective programs can be designed. Identifying common needs between all tribal cultures allows for consistency in education modalities, while still allowing for the unique needs of a given community. Our success has been in no small part due to the hiring of American Indians as outreach coordinators. Their regular presence in tribal and urban programs, and their communication with key community members, has built the necessary relationships for meeting their communities' education needs. Their understanding of American Indian cultures has helped immensely in developing culturally sensitive materials and approaches. They have been the bridge-builders, the liaisons who have listened, reported back, and responded with offers of help.

In the dementia field, we at BAI have helped to gradually change the culture and experience of Alzheimer's disease for patients and their families through offering education, providing interventions or techniques to cope with the challenges of day-to-day living, and helping people to find meaningful activities and engagement, rather than having the person with dementia and family isolate and withdraw.

We are instilling a sense of hope, and helping people to move beyond the hopelessness of the past. The message has been put forth and is well received in the American Indian communities in Arizona through consistent education at community and state levels, through ongoing communication regarding individual or community needs, and through the development of culturally sensitive and specific materials. Training of family caregivers and professionals has produced movement upward to leadership levels, such that communities are now beginning to meet the further needs for providing care for persons with dementia by developing resources—from senior and home care programs to memory care facilities. 

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ADRC Dementia Training in Oregon State

By Jennifer Mead,
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Oregon's ADRC staff training on dementia and its robust referral service are of help to people with dementia and their caregivers.

A wife who was frustrated and resentful of her husband who had Alzheimer's disease recently contacted a rural aging services agency in Oregon. She was convinced his behavior was purposeful, and their already strained relationship was increasingly tense. Staff from the agency had just completed new statewide training on dementia and so felt prepared to explain to her how Alzheimer's was affecting her husband, and could suggest strategies for how to interact with him to reduce some of his difficult behaviors. The agency referred the wife to training offered by the Alzheimer's Association and helped her make connections to additional community resources. She has since reported that the information and support made a big difference, and that her relationship with her husband is greatly improved.

Alzheimer's Is an Issue of Increasing Importance

Aging services staff face increasing questions and need for support in addressing cognitive

impairment and dementia. Getting answers to routine questions about housing, meal programs, or transportation is complicated, as individuals are confused, and families often are frustrated or angry when their attempts to help are unsuccessful. In response to recommendations for systematic dementia training in Oregon's 2012

'Aging services staff face increasing questions and need for support in addressing cognitive impairment and dementia.'

State Plan for Alzheimer's Disease and Related Dementias, in 2013 the Oregon Department of Human Services Aging and People with Disabilities applied for a three-year grant from the Administration for Community Living (ACL) to support dementia training for statewide Aging & Disability Resource Connection (ADRC) staff.

Oregon's ADRC is designed to be a highly visible source of information and support on aging and disability needs for all Oregonians. Started in 2010, the statewide ADRC includes a

→ **ABSTRACT** Aging services staff face increasing questions and need for support in addressing cognitive impairment and dementia. In response to recommendations for dementia training in Oregon's 2012 State Plan for Alzheimer's Disease and Related Dementias, in 2013 the Oregon Department of Human Services Aging and People with Disabilities applied for and received a three-year grant from the Administration for Community Living to support dementia training for statewide Aging & Disability Resource Connection staff. The trainings were a success in aiding individuals with dementia and their caregivers. | **key words:** *dementia training, ADRC, Oregon Department of Human Services Aging and People with Disabilities*

toll-free number, public website, data-tracking system, and nine ADRC regions that bring together aging, disability, Medicaid, and other partners to provide core services of information and assistance and options counseling.

Although ADRC information and assistance and options-counseling staff work with large numbers of individuals and families dealing with memory loss, no standard dementia training had previously been provided or required. The Oregon Department of Human Services Aging and People with Disabilities proposed ADRC staff training, better tracking of cognitive impairment as a challenge for clients and caregivers, and more systematic referrals to Alzheimer's support resources. Grant funds were also requested to add an Alzheimer's section to the ADRC website, to increase availability of early-stage programs offered through the Alzheimer's Association Oregon Chapter, and for statewide outreach and promotion of the ADRCs as a resource to families dealing with memory loss and dementia.

How the ADRC Training Was Developed

Oregon Department of Human Services Aging and People with Disabilities contracted with Portland State University's (PSU) Institute on Aging to develop the ADRC training based on PSU's prior training experience and role in conducting an annual ADRC consumer satisfaction survey. Early discussions with ADRC partners led to agreement on an online format. This enabled statewide access and the ability to view training as time allowed and train new staff as they came on board. In developing each of the

Figure 1. Oregon's ADRCs



eleven online modules, PSU conducted extensive interviews with staff, managers, and subject matter experts to focus training content on key issues and identify information relevant to ADRC staff. The final modules were forty-five to fifty-five minutes long and included four groupings of training, as follows:

Modules 1-4 (Tier 1), completed in late 2014, were designed for all ADRC staff and provide an overview of person-centered dementia support, communication and behavioral expression, medical and clinical issues, and information and referral resources.

Modules 5-8 (Tier 2), completed in early 2015, were designed for staff that provide more extensive and face-to-face support, including options counselors, care transition staff, adult protective services staff, and case managers. These modules address decision-support tools, person-centered planning, support for care

transitions, and support for advanced care and end-of-life planning.

Module 9, completed in early 2016, focused on issues for people with intellectual disabilities and dementia and was designed to help link aging services and services for people with intellectual and developmental disabilities. No tier level was designated.

Modules 10 and 11, completed in early 2017, focused on dementia and serious mental illness, including bipolar disorders and schizophrenia. These modules were funded in part by state funds earmarked for expanding older adult behavioral health services and bridging gaps between aging and behavioral health agencies. As with module 9, no tier level was designated.

Grant funds supported the ADRC organizations' initial time commitment to ensure staff were able to complete the training modules. Staff could view modules individually or in groups, and PSU developed Companion Guides offering additional information and discussion questions. All of the training modules are posted at goo.gl/G7WzdE.

Training Feedback and Outcomes

Online satisfaction surveys and knowledge assessments were included at the end of each of the four training groupings. Individuals received a certificate for completing the online surveys, and this allowed tracking of training completion by region and type of staff. As of February 2017, 589 completed Tier 1; 343 completed Tier 2; 104

completed Module 9; and 11 completed Modules 10 and 11. Staff who have completed the modules include information and assistance staff, options counselors, supervisors or managers, family caregiver coordinators, Adult Protective Service staff, Medicaid case managers, Medicaid eligibility specialists, support staff, care transitions coordinators, and nutrition site coordinators.

Results from the online assessments and feedback indicated an increase in self-rated knowledge for all training modules. Table 1 (below) summarizes responses to some of the questions asked on the survey.

Treat the person, not the disease. Sometimes it's hard to remember that.'

Staff said the training helped them focus more on the individual: "I will honor the person's identity. I will keep in mind that behaviors are usually expressions of unmet needs that a person cannot communicate through words," and noted that they would remember "that someone with dementia is still a person. Treat the person, not the disease. Sometimes it's hard to remember that."

Participants rated their knowledge before and after the training on a five-point scale (1 = nothing at all, 5 = a great deal). For Tier 1 modules, the largest gain in knowledge was in understanding the importance of getting a diagnosis as soon as possible. Other substantial

Table 1. Summary of Responses to Open-Ended Questions

What was most helpful?	What will you do differently as a result of this training?
<ul style="list-style-type: none"> ▪ Information or content ▪ Resources and how to make referrals to services ▪ Case examples and personal stories 	<ul style="list-style-type: none"> ▪ Identify or explore more resources for people with dementia and their caregivers ▪ Use person-centered thinking and planning ▪ Incorporate more end-of-life planning ▪ Be more patient and understanding with people with intellectual disabilities and their families ▪ Recognize early signs of dementia

Table 2. Average Level of Confidence in Ability to Use Information

	Tier 1				Tier 2					
	Module 1	Module 2	Module 3	Module 4	Module 5	Module 6	Module 7	Module 8	Module 9	Module 10 & 11
Confidence ^a	4.00	4.03	3.95	3.94	3.96	3.88	3.92	3.80	3.67	3.36

^a Confidence in ability to use the information presented in the module: 1=not confident at all, 2=slightly confident, 3=somewhat confident, 4=quite confident, 5=extremely confident.

knowledge gains were learning about resources for people with dementia on the ADRC website; understanding behavioral issues as expressions of unmet need; receiving information about dementia prevalence, early signs, and symptoms; learning about resources to assist families; and identifying person-centered approaches to address behavioral expressions.

Tier 2 gains were significant but more modest, with most participants gaining nearly one point in knowledge after completing the modules. The biggest gain was in understanding

Participants also were asked how confident they were in their ability to use the information provided in each module. In general, participants were “quite” confident, as indicated in Table 2 (above). Participants had slightly more confidence following Tier 1 modules than for Tier 2 modules or Module 9; presumably this was due to the more complex issues and situations raised in the later modules. Results from Modules 10 and 11 should be viewed with caution because few people have completed these modules to date.

‘I would not know about the resources and I would not know about respite care, so I would be doing it all myself.’

the risks of care transitions to the person living with dementia. Other areas of improvement were learning the difference between dementia, depression, and delirium; facilitating person-centered planning based on a person’s goals, strengths, and assessments; assisting families in implementing person-centered plans; and understanding common care transitions experienced by people with dementia.

Module 9 participants also made substantial knowledge gains. The greatest increase related to learning about early detection screening tools that can assist healthcare providers in assessing for cognitive impairment in people with intellectual and developmental disabilities. Participants also had more than one-point gains in their ability to describe early signs of dementia in people with intellectual disabilities.

Oregon’s Dementia Support Capability Increases

While ensuring key staff completed the training, ADRCs also used grant funds to create written protocols for referrals to the Alzheimer’s Association; to develop systems for staff to more routinely record dementia as an issue in the statewide data system; to regularly update local resources in the ADRC resource database, thereby helping individuals and families coping with dementia with easier resource access; and to actively include discussions of memory loss and dementia in ADRC outreach efforts to increase awareness about the ADRC as a community resource.

Increasing numbers of consumers and family members are dealing with confusion and memory loss, and results from the 2015 ADRC consumer satisfaction survey found that these individuals report higher needs than family members of those without memory loss and confusion. Although people and their family members who are dealing with memory loss or confusion consistently need

more support in accessing needed services, they rate ADRC staff highly as being knowledgeable and respectful, in spending enough time with them, and in helping them explore options to meet their needs. Families of individuals dealing with early memory loss are grateful for the information and support they have received. The following comments reflect their thoughts about what their circumstances would be like without the ADRC:


“I would not have continued to be a caregiver. I would have had to look at the possibilities in a caregiver situation that are outside the home. It’s allowed me to continue to help him.”

“I would not know about the resources and I would not know about respite care, so I would be doing it all myself.”

“It would be more confusing. It helps to learn about resources and it gave us a more positive outlook.”

“It would be more difficult. They helped me to find the services we needed and it just took a few phone calls to find one that fit.”

Even after the ACL grant, Oregon’s ADRCs are continuing to use the online training for new

staff and to address dementia through ongoing referrals to the Alzheimer’s Association and local resources, thereby serving a critical role in meeting the needs of Oregon’s dementia-affected individuals and families. 

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Dementia Cal MediConnect: Project Evolution and Results

By Debra Cherry,
Jennifer Schlesinger,
and Brooke Hollister

This promising project offers tools and strategies to improve dementia-care practices within health plans for the dual eligible population.

Historically, healthcare for people with dementia has been poorly coordinated with home- and community-based supports and services (HCBS). This is detrimental to quality of care because family or friend caregivers support most people living with dementia who reside in their homes. These caregivers rely on HCBS for disease education, counseling, support groups, caregiver training, respite, and additional services that have been demonstrated to ease the burden of care and improve quality of life (Logsdon et al., 2010; Stevens et al., 2012). Alzheimer's disease and related dementias (ADRD) affect more than 5.5 million individuals in the United States. Given the

high prevalence of ADRD, the many care needs of people with ADRD, the impact of the disease on caregivers, and the rising cost of healthcare for these beneficiaries, it is imperative to have high-quality and effective health systems in place (Alzheimer's Association, 2017).

In 2012, California began participating in the federal Financial and Administrative Alignment Initiative. This five-year demonstration, called Cal MediConnect, blends funding from Medicaid and Medicare and offers an opportunity to better coordinate services covered by these two programs, including medical

care, care management, in-home care, adult day services, and nursing home care. Furthermore, the demonstration

'The demonstration encouraged novel partnerships between health plans and community-based aging services providers.'

encouraged novel partnerships between health plans and community-based aging services providers to better meet the needs of these vulnerable, high-cost patients and the family caregivers on whom their care depends.

Building on the state's Cal MediConnect demonstration, the California Department of

→ABSTRACT California's Dementia Cal MediConnect Project was built on the state's Financial Alignment Initiative Pilot, which provided an opportunity for local Alzheimer's organizations to engage with health plans building more dementia-capable care systems for dual eligibles. Through advocacy, technical assistance, care manager training, and caregiver education and support, health plans improved dementia identification, strengthened care management, supported family caregivers, and built relationships with Alzheimer's organizations. These dementia-capable practices increased access to home- and community-based services for people with dementia and their caregivers. | **key words:** *Dementia Cal MediConnect Plan, dual eligibles, care manager training, dementia-capable practices*



Aging was granted funding from the Administration for Community Living's Alzheimer's Disease Supportive Services Program, and, in partnership with Alzheimer's Greater Los Angeles, co-led an effort to create a better coordinated, dementia-capable system of care. The project, called Dementia Cal MediConnect, has focused on Los Angeles, San Bernardino, Riverside, San Diego, Santa Clara, and San Mateo counties, served by ten participating health plans, numerous provider and physician groups, and Programs of All-Inclusive Care for the Elderly, three local Alzheimer's organizations, and managed

long-term services and supports (MLTSS)-contracted agencies.

Capitalizing on Opportunity

Health plans were motivated to participate in this project through the State of California and the Centers for Medicare & Medicaid Services (CMS) requirements, including requirements stipulated in three-way contracts between the health plans, the state, and CMS, and in guidance letters. Requirements mandated that the health plans conduct annual assessment surveys of all members, including questions about cognitive impairment; identify caregivers, as

needed; develop individualized care plans; convene interdisciplinary care teams, as needed; provide dementia training for care management staff, including the designation of Dementia Care Specialists (DCS); and provide care plan options, optional supports, and services for members and caregivers to avoid more costly use of services or institutionalization.

Through advocacy, technical assistance, evidence-derived care manager training, a dementia care management toolkit, and caregiver education and support provided by community-based Alzheimer's-knowledgeable organizations, the project worked with health plans, offering them tools and strategies to improve screening for cognitive impairment; developed systems to identify, assess, and support family caregivers; established protocols within the health plans to connect families to a trained DCS; and encouraged the adoption of an HCBS referral program (ALZ Direct Connect).

One deliverable from this project was a dementia care management toolkit that included a validated cognitive screening tool, a tool for identifying family caregivers, a validated caregiver stress and strain instrument, a caregiver needs assessment, standardized care plans derived from the evidence-based Alzheimer's Disease

Coordinated Care for San Diego Seniors Program, a dementia care management program (Vickrey et al., 2006), and plain language fact sheets focusing on behavioral issues prevalent in Alzheimer’s. In addition, the community-based Alzheimer’s organizations provide participating health plans with technical assistance to encourage them to incorporate tools and to establish tailored systems of care that ensure their members and family caregivers receive HCBS services and caregiver education.

Defining Dementia-Capability

Based on earlier studies and reviews, the Dementia Cal MediConnect Project identified key components of dementia-capable systems of care and sought to embed them in health plans’ systems of care (Borson and Chodosh, 2014; Clark et al., 2004; Vickrey et al., 2006). For this project, dementia-capability within Cal MediConnect systems of care included the following:

- Better detection and care management of dual eligible beneficiaries with dementia;
- Better partnerships between

health systems (managed care health plans, delegated provider groups, and MLTSS agencies) and family caregivers; and

- Stronger relationships between health systems and dementia-knowledgeable community-based organizations that can provide care manager training, technical assistance, and supports for families affected by the disease.

To achieve these dementia-capable objectives, the Dementia Cal MediConnect Project developed corresponding

Table 1. Project Objectives and Indicators of Goal Achievement

Project Objectives	Indicators of Systems Change
1. Better detection and care management of dual eligible beneficiaries with dementia	<ul style="list-style-type: none"> ▪ Health risk assessment/other assessments include cognitive impairment ▪ Adoption of AD8 or other validated cognitive screening tool ▪ Integration of cognitive assessment into e-medical record ▪ Protocol for diagnosis if screen is positive
2. Better partnerships between health systems and family/friend caregivers	<ul style="list-style-type: none"> ▪ Ability to identify family/friend caregiver ▪ Documentation of family/friend caregiver in medical record ▪ Family/friend caregiver assessment adopted ▪ Integration of family/friend caregiver education ▪ Adoption of standardized care plans ▪ Respite benefit provided by health plan ▪ Workflow processes established for use of Dementia Care Specialist
3. Stronger relationships with dementia-specific community-based organizations	<ul style="list-style-type: none"> ▪ Provision of dementia-specific professional training programs and technical assistance ▪ Provision of services and supports to patients and family/informal caregivers ▪ Adoption of ALZ Direct Connect referral program to connect to: <ul style="list-style-type: none"> - Support groups - Caregiver education - Early-stage services - Care counseling - Engagement programs

Table 2. Dementia-Capable Care Tools Used by Dementia Cal MediConnect Project

Project Tools
<p>Better Detection</p> <ul style="list-style-type: none"> ▪ Health Risk Assessment Cognitive Impairment Trigger Questions ▪ AD8 (Galvin et al., 2005)
<p>Better Partnership with Caregivers</p> <ul style="list-style-type: none"> ▪ Tool for Identifying an Informal or Family Caregiver ▪ Benjamin Rose Institute Caregiver Strain Instrument (Bass, Noelker, and Rechlin, 1996) ▪ Care Needs Assessment Tool ▪ <i>IDEA!</i> Strategy for Managing Challenging Behavioral Symptoms ▪ Plain Language Fact Sheets for Caregivers ▪ Standardized Care Plans (derived from Vickrey et al., 2006)
<p>Stronger Relationships with Alzheimer’s Organizations</p> <ul style="list-style-type: none"> ▪ In-person Dementia Care Manager Training ▪ In-person Dementia Care Specialist Training ▪ Web-based training modules for care managers ▪ ALZ Direct Connect Referral Program

indicators of systems change (see Table 1, page 64). Systems-change indicators were tangible outcomes that helped health plans and project staff assess progress toward dementia-capable systems of care. Throughout the project, health plan and project staff noted and verified systems-change indicators to highlight progress made by the health plans in building their dementia-services capability.

The Dementia Cal MediConnect Project developed or provided tools that fostered adoption of systems-change indicators (see Table 2, above). Tools were available online and disseminated to health plan staff through in-person and online care manager and DCS trainings, case teleconferences,

technical assistance meetings with health plan champions and leaders, and webinars. Educational materials and programs for family caregivers were developed to meet the linguistic and sixth-grade literacy requirements of the national Financial Alignment Initiative.

Project tools are openly accessible on the Alzheimer’s Greater Los Angeles website (www.alzgl.org/professionals).

Improving Partnerships with Home- and Community-Based Organizations

Although the Dementia Cal MediConnect Project aimed to

expand HCBS use by health plans as needed by members with dementia and their family caregivers, it emphasized improving partnerships between participating health plans and community-based Alzheimer’s

organizations. The lessons learned, however, are applicable to other aging services providers. Project goals were achieved through advocacy at the state and local levels to make the case for system change; identification and development of relationships with health plan staff champions and leadership;

Since its inception in 2014, ten health plans have been engaged in the Dementia Cal MediConnect Project.

explanation of project goals and why dementia-capability is beneficial to health plan members and to their bottom line; implementation of training and technical assistance activities; development of systems whereby identified health plan members and their family caregivers could be proactively referred to support and education services provided directly through the plans (through their contracted MLTSS providers), or by using the ALZ Direct Connect referral document to refer to community-based Alzheimer's organizations; and monitoring of system change with feedback to the state and the health plans.

The Project's Results

The project evaluation was designed to assess care manager knowledge of dementia and dementia-capable care management practices. For this preliminary evaluation, 319 care managers were trained and asked to complete surveys immediately before and after their training and again at six months, post-training.

Care manager training demonstrated multiple improvements

Evaluation of care manager training programs showed increased knowledge of available HCBS for people with dementia and their caregivers and of how to refer to HCBS. Care managers were significantly more likely to report six

months after training that they “knew what home- and community-based resources were available for members with ADRD and their informal caregivers” ($t = -10.67$, $p < .001$) and that they “knew how to

refer members with ADRD and their informal caregivers to home and community-based resources” than they had at baseline ($t = -10.70$, $p < .001$).

Additionally, care managers were significantly more likely six months after training than they were at baseline to report dementia-capable practices, such as referring members to HCBS ($\chi^2 = .005$, $p < .05$), referring caregivers to HCBS ($\chi^2 = .000$, $p < .001$), and referring members and their caregivers to an Alzheimer's organization ($\chi^2 = .000$, $p < .001$).

System changes in dementia-capability

Since its inception in 2014, eight health plans have been engaged in the Dementia Cal MediConnect Project and, in 2016, another two plans in San Diego, San Bernardino, and Riverside counties joined the project. Staff tracked changes in health plans' dementia-capability over the course of the project. They reported that since the project's start, six of the ten health plans began to use ALZ Direct Connect to


make referrals to HCBS through local Alzheimer's organizations. In addition, seven plans have offered respite

‘Care managers were significantly more likely six months after training than they were at baseline to report dementia-capable practices.’

as an optional service for caregivers. Respite is offered directly by the plan, by subcontracted MLTSS providers, or by referral to local Alzheimer's organizations. Additionally, seven health plans have directly offered or have referred caregivers to local Alzheimer's organizations for caregiver education and supports.

Promising Practices, Support, and Partnerships

The Dementia Cal MediConnect Project offers tools and strategies to improve dementia care practices within health plans serving people dually eligible for Medicare and Medicaid. Through advocacy, technical assistance, care manager and DCS training, and caregiver education and support, health plans improved processes to identify members with dementia, strengthened care management practices, provided education and supports to family caregivers, and built relationships with HCBS through partnering with Alzheimer's organizations. The

project is a promising practice with tools that can be downloaded at no cost by other organizations seeking to enhance dementia care within healthcare systems. 

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Hospitalizations Among Persons with Dementia

By Zhanlian Feng

A study demonstrates that hospitalizations occur more frequently among people with dementia, especially among elders with dementia who live in the community.

Hospitalization can be a difficult and stressful experience for anyone. For older people with dementia, a trip to the hospital is bound to be an ordeal, given the myriad problems they have to endure—severe cognitive impairment, memory loss, disorientation, poor judgment, personality and behavior changes, poor communication abilities, reduced physical functioning and self-care capabilities, and often, the burden of multiple coexisting medical conditions (Alzheimer’s Association, 2016). These problems require a special type of care that few acute care hospitals are well-versed in delivering (Galvin et al., 2010).

When people with dementia are hospitalized, not only is this disruptive to their routine care, but also this frequently leads to adverse health outcomes such as infections, complications, delirium, falls, functional decline, the imposition of physical restraints, and agitation and related behavioral symptoms (Maslow and

Mezey, 2008). It is better for people with dementia to avoid hospital visits—unless they are an absolute medical necessity.

A substantial portion of hospitalizations of people with dementia may be avoidable.

But a growing body of research shows that hospitalizations occur more frequently among older people with dementia than among those without dementia, and a substantial portion of these hospitalizations and related Medicare expenditures may be avoidable (Bynum et al., 2004; Daras et al., 2017; Lin et al., 2013).

Patterns of Hospital Use Among Older Adults with Dementia

Using the Health and Retirement Study data linked with Medicare claims from 2000–2008, a recent study (Feng et al., 2014) shed more light on the pattern of hospital use among older adult

→ABSTRACT Hospitalizations are difficult for everyone, but especially for older adults with dementia, as these admissions can lead to adverse health outcomes. Yet research shows hospitalizations occur more frequently in this cohort, especially in those living in community or in long-term-care facilities with no dementia unit. Using Health and Retirement Study data from 2000–2008, a new study shows rates of hospitalizations for people with dementia in nursing homes, in community, and toward the end of life. | **key words:** *dementia, hospitalization, Do Not Hospitalize orders, community-residing people with dementia*

Medicare beneficiaries (ages 65 or older) with dementia by where they live—in the community versus in a nursing home—and by how close they are to the end of life. The findings from that study are briefly described and discussed below.

Hospitalization among community-residing individuals

Among community-residing individuals with dementia, more than one in four (26.7 percent) had one hospitalization each year, a percentage significantly higher than those without dementia (18.7 percent). Community-residing persons with dementia were also more likely to have a potentially avoidable hospitalization (7.6 percent)—that is, hospital admission for conditions deemed by subject matter experts as preventable or manageable in the community (Walsh et al., 2012)—than those without dementia (4.7 percent). Of individuals with dementia who were hospitalized each year, approximately 28.5 percent had a potentially avoidable admission, higher than 25.1 percent of those without dementia who were hospitalized.

Hospitalization among nursing home residents

In general, hospitalizations among nursing home residents were more frequent than among community-residing individuals, reflecting the fact that nursing home residents in general are older, sicker, and frailer than are community-residing older people. However, there is little difference in the likelihood of hospitalizations between nursing home residents who had dementia (45.8 percent) and those who did not (41.9 percent). Of those residents who were hospitalized, more than half had at least one potentially avoidable hospitalization, whether or not they had dementia.

Hospitalization in the last year of life

As death neared, the likelihood of hospitalization rose sharply across residential settings and regardless of whether individuals had dementia. Among decedents who had been living in com-

munity, nearly 80 percent were hospitalized during the last year of life, and of those hospitalized in that time period, nearly half had a potentially avoidable hospitalization, whether or not they died with dementia. Among decedents from nursing homes, residents who died with dementia were hospitalized somewhat less often (65.0 percent) than those without dementia (73.8 percent) in the last year of life, but this difference was not statistically significant. Of nursing home decedents who were hospitalized in the last year of life, almost two-thirds of those with dementia and more than half of those without dementia had a potentially avoidable hospitalization.

Study Findings' Implications for Policy and Practice

The foregoing findings have several implications for policy and practice regarding the care of people with dementia.

First, it is important to recognize that the impact of dementia on hospitalization varies by residential setting. Particularly among older people residing in the community, those individuals with dementia are significantly more likely than those without it to be hospitalized, both overall and for potentially avoidable conditions. This may be attributable to the lack of primary care, specialized dementia care, other medical resources, and long-term services and supports for community-residing people with dementia. Also, few programs are specifically designed to reduce hospitalizations among people with dementia who are living in community.

In contrast, there is no significant difference in hospitalization, overall or potentially avoidable, among nursing home residents by dementia status. One possible reason is that most nursing homes are equipped to provide medical, nursing, and long-term care for many conditions that would be difficult to manage in community settings. The capacity to treat and manage complex conditions in nursing homes has grown with the increased focus on post-acute care (Tyler et al., 2013). Moreover, given

the high prevalence of dementia in nursing homes, medical staff at these facilities may be more accustomed to treating patients with dementia than are community-based physicians.

Research shows that the risk of hospitalization for nursing home residents with dementia was lower in facilities with a specialized dementia care unit or a high prevalence of residents with dementia, compared to facilities without a specialized dementia care unit or with a low prevalence of residents with dementia (Gruneir et al., 2007). Similar evidence is found in residential care facilities (assisted living facilities, board-and-care homes, personal care homes, etc.) where residents who lived in a dementia special care unit of a facility or in a facility that only serves people with Alzheimer's disease were less likely to be hospitalized, compared to similarly cognitively impaired people who did not reside in these types of settings (Wiener et al., 2014).

Second, the rates of hospitalization for people with and without dementia converge toward the end of life. In the community, people with dementia were hospitalized more often than people without it, but this difference diminished in the last year of life. One possible explanation is that dying is a difficult and complex process for all people living in community. Thus, approaching death could have overwhelmed any differences in cognitive status, resulting in similar rates of hospitalization.

Regardless of dementia, the sharp rise in hospitalizations in the last year of life among older people in the community was particularly striking, with nearly 80 percent having at least one inpatient admission. Notably, nearly half of those hospitalized in the last year of life had one potentially avoidable hospitalization. Again, these findings underline the need for and challenges of providing adequate community-based medical care, hospice and palliative care, and long-term services and supports to older

people—services that could help reduce hospital admissions at the end of life, whether or not an individual has dementia.

Third, nursing home residents who died with dementia were just as likely or somewhat less likely as those without dementia to be hospitalized in their last year of life. It is possible that in nursing homes, physicians and families are inclined to reduce aggressive end-of-life care to residents who have advanced dementia than to those who do not (Li, Zheng, and Temkin-Greener, 2013). There is increased awareness that aggressive treatments requiring hospitalization of nursing home residents with advanced dementia may amount to futile care that produces little improvement in quality of life (Goldfeld, Hamel, and Mitchell, 2013).

Efforts to reduce hospitalizations among people with dementia should target individuals who live in the community.

Furthermore, the increasing use and duration of Medicare-covered hospice care for nursing home residents, which puts a greater emphasis on comfort and pain management than on acute treatments, may have helped reduce hospitalizations of residents with dementia (Miller, Lima, and Mitchell, 2010). Nevertheless, a majority of nursing home residents who were hospitalized in their last year of life had at least one potentially avoidable hospitalization, regardless of dementia status.

In summary, the research evidence shows that hospitalizations among older people with dementia are frequent, and substantial portions of these hospital admissions both before and during the last year of life are potentially avoidable with provision of adequate care and management of conditions in non-acute settings. Every effort should be made to reduce unnecessary hospital visits for older people with dementia, who have special difficulties in transitioning across care settings (Gozalo et al., 2011). Beyond


containing costs, doing so would also improve the quality of care and quality of life for people with dementia (Maslow and Heck, 2005), especially at the end of life. For these reasons, one of the two goals related to dementia care, as set in the Healthy People 2020 initiative, aims to “reduce the proportion of preventable hospitalizations in adults aged 65 years and older with diagnosed Alzheimer’s disease and other dementias” from 25.3 percent at the baseline (measured in 2006–2008) to a targeted 22.8 percent by 2020 (National Center for Health Statistics, 2016). However, progress to date toward achieving this target could not be assessed due to lack of follow-up data.

Strategies to Reduce Unnecessary Hospitalizations

Evidence-based interventions are needed to reduce unnecessary hospitalizations for older people with dementia. One approach is advance care planning in the form of a Do-Not-Hospitalize (DNH) order that is identified as a key modifiable factor in effectively avoiding hospitalization (Givens et al., 2012). Research suggests that the presence of a DNH order has a strong influence on treatment decisions for people with advanced dementia (Maust et al., 2008). However, directives to forgo hospitalization are uncommon even among nursing home residents with advanced dementia. In 2000, only 7.1 percent of nursing home residents with advanced dementia had DNH orders, according to a study based on national data (Mitchell et al., 2007). The proportion of community-dwelling people with dementia and a DNH order in place is

unknown but presumably much lower than among nursing home residents.

It is also evident that efforts intended to reduce hospitalizations among people with dementia should explicitly target individuals who reside in the community, because these individuals are more likely to be hospitalized. Even though community-residing individuals with dementia significantly outnumber nursing home residents with dementia—there are at least three people with dementia who reside in the community for every nursing home resident with dementia (Feng et al., 2014)—they are largely invisible from existing health reform initiatives aimed at reducing hospital readmissions or potentially avoidable hospitalizations.

It is imperative to increase the focus of these initiatives on community-residing people with dementia, given the growing number of people with Alzheimer’s disease and other forms of dementia. The vast majority of these individuals will live in the community and cope daily with the difficult challenges of dementia. To meet these challenges, it is critical to further grow and integrate primary care, specialized dementia care, behavioral and mental health, long-term services and supports, and advance care planning for older people with dementia living in home- and community-based settings. 

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Supporting People with Dementia and Their Caregivers: Scotland's Ten-Year Journey

By Michelle Miller

Scotland's dementia support programs emphasize protecting the rights of individuals with dementia and ensure that they are treated with dignity and respect.

Scotland is part of the United Kingdom and has a population of 5.4 million people living in urban and remote and rural areas. There are 93,000 people living with dementia in Scotland, and numbers are set to double in the next twenty-five years. The most recent publication on diagnosed incidence was a wake-up call about the number of people who will be diagnosed each year in Scotland, with incidence reported as 16,000 per year, rising by 2020 to just under 20,000 per year (National Services Scotland, 2017).

As drug companies and researchers collaborate—and at times compete—to find a cure for Alzheimer's and dementia, there is a growing realization that this will not be a quick fix. Given the demographics of people with dementia, solely relying on finding a cure will not support people with dementia to live well now.

Because of this realization, there has been major transformational change in dementia care

and support in Scotland in the past ten years. With this comes a significant shift from the traditional biomedical model of supporting people with dementia to that of a rights-based approach that includes social citizenship (valuing people with dementia as active citizens and ensuring that their rights are respected in our society). The introduction of a Charter of Rights for People with Dementia and Dementia Standards has been significant in signaling this shift (Scottish Government, 2013).

There is a growing realization that there is no quick fix cure for Alzheimer's and dementia.

A social movement has been evolving in Scotland during the same time, as people with dementia and their caregivers now have a

→ **ABSTRACT** For the past ten years, Scotland has been on a journey of transformational change in dementia care and support. The government published its third strategy for dementia this past spring and is focused on supporting people with dementia to live well in communities for as long as possible. Focus on Dementia, Scotland's national improvement portfolio for dementia, supports the strategy's implementation in practice. People with dementia, their caregivers, and national partners also are key to supporting the development, design, and implementation of dementia strategy and improvements in Scotland. | **key words:** *Scotland, dementia, Alzheimer's, Alzheimer Scotland, dementia diagnosis, dementia care, dementia support*

stronger voice in how strategy is developed and how services are designed and delivered. Alzheimer Scotland is working in partnership with dementia policy teams and other national teams to support people with dementia and their caregivers to be involved in this work. National advocacy groups have been established (e.g., the Scottish Dementia Working Group [a group of people with dementia], National Dementia Carers Action Network [a group of caregivers of people with dementia], and Dementia Carer Voices [another group of caregivers of people with dementia that includes paid care staff]) and are part of this social movement. Part of the role of these national groups has been to challenge the status quo, including altering the language used around dementia, reducing stigma, and showing that people with dementia can live well with their disease, as long as they have the proper levels of support.

The Scottish government has emphasized care rather than cure with its first two dementia strategies.

Scotland's first dementia strategy was launched in 2007 and set key commitments in supporting people to live well with dementia. The Scottish government has emphasized care rather than cure with its first two dementia strategies, and that will continue to be a focus of the third strategy, which was published this past Summer. The emphasis is on protecting the rights of individuals with dementia and ensuring that people with dementia are treated with dignity and respect. With this comes the growing body of evidence around the effectiveness of nonpharmacological interventions to support people to live well with dementia.

Key commitments outlined in the dementia strategies include improving diagnosis and providing post-diagnostic support in the first year of diagnosis with a named link worker (the care manager who navigates care support for the

person with dementia and their family). This integrated coordination of care aims to support people to stay well at home for as long as possible and to avoid crises. Other commitments include supporting improved outcomes and experiences for people with dementia in hospitals and within specialized dementia units and supporting people with dementia in palliative care and at the end of life.

The Scottish government is now leading the coordination of “Act on Dementia,” a three-year European Union (EU) Joint Action for Dementia that was launched in 2016 (Scottish Government, 2016). This work emphasizes diagnosis and post-diagnostic support, crises and care coordination, and Dementia Friendly Communities, and provides an opportunity for member states across Europe to take a coordinated approach to sharing and implementing good practice in these areas. This collaboration will continue despite Brexit (Britain leaving the EU).

Education and Workforce

The past ten years have seen a strong emphasis on dementia education and supporting the workforce. National Health Service (NHS) Education for Scotland and the Scottish Social Services Council have developed an education framework called Promoting Excellence. In collaboration with the University of the West of Scotland, they have trained 700 members of health and social care staff and are transforming the health and social care workforce in Scotland.

National Improvement Support

Focus on Dementia is the national improvement portfolio for dementia in Scotland. Established by the Scottish government in 2014, this work is based within the Improvement Hub of Healthcare Improvement Scotland. The program works in partnership with national organizations, health and social care partnerships, people with dementia, and caregivers to improve the quality of care and experience of people with dementia.

The work supports improvements in diagnosis and post-diagnostic support, integrated care coordination in the community, specialist dementia units, acute care, and advanced care. All of the work supports the implementation of Scotland's dementia strategies and informs future policy and practice.

Focus on Dementia key workstreams

There are five workstreams within Focus on Dementia covering improvement work across the whole pathway and across a range of settings. These are detailed below:

Improving Diagnosis and Support

This work aims to improve the quality of post-diagnostic support for people newly diagnosed with dementia in Scotland.

This will be achieved by:

- Developing and testing a Quality Improvement Framework to support the delivery of high-quality post-diagnostic support. Focus on Dementia will develop and test associated measures with a focus on personal outcomes to support this work.
- Developing and facilitating a network for post-diagnostic support practitioners across Scotland to share practice to reduce variation and improve quality of care and support.
- Developing and facilitating a forum for leaders within health and social care partnerships in Scotland responsible for the delivery of post-diagnostic support across Scotland, to share practice and link with national partners to support and inform the implementation of dementia strategy.
- Testing the relocation of post-diagnostic support services within primary care, through initial testing within General Practice practices in Scotland. We will share the lessons learned from this work to inform future policy and practice.

Integrated Care Coordination in the Community

This work aims to improve coordination and quality of care and support for people with

dementia at the moderate to severe stage of their dementia, through sharing the lessons learned from testing the Alzheimer Scotland 8 Pillars Model of Community Support in practice and learning from other examples and evidence of integrated coordinated care in the community.

The 8 Pillars Model has been produced by Alzheimer Scotland with the cooperation of

Dementia-friendly communities are being locally developed through a bottom-up approach.

people with dementia and their caregivers and Health and Social Care staff. The model proposes a comprehensive integrated and coordinated approach to supporting people with dementia and their families and caregivers. This includes the introduction of a dementia practice coordinator who will perform a Health or Social Care Navigator function and ensure access to all pillars of support on an ongoing basis as appropriate to each individual. Other pillars include support for caregivers, personalized support, community connections, environment, mental health care and treatment, general healthcare, and treatment and therapeutic interventions.

This will be achieved by:

- Sharing lessons learned and evaluation from the Alzheimer Scotland 8 Pillars Model, which was tested in five Health and Social Care Partnerships in Scotland, through publications and educational events.
- Learning from other examples of integrated coordinated care models in the community to share practices.
- Learning from and informing the Crisis and Care Coordination work of Act on Dementia (EU Joint Action on Dementia) through regular progress reporting to the EU Joint Action.

Advanced Dementia Care

This work aims to improve coordination and quality of care and support for people at

advanced stages of dementia through testing the Alzheimer Scotland Advanced Dementia Care Model.

This will be achieved by:

- Working in partnership with other national improvement teams to test the Alzheimer Scotland Advanced Dementia Care Model as part of their wider work on palliative care.
- Sharing the lessons learned from this work to inform practice.

Improving Dementia Care in Hospitals

This work aims to improve the quality of care, experience, and outcomes for people with dementia in acute care general hospitals, and for caregivers and staff, in accordance with the “Ten Care Actions for Dementia” as outlined in the Dementia Strategies.

This will be achieved by:

- Understanding critical success factors in supporting positive outcomes for people with dementia in acute care settings.
- Publishing and sharing findings from this work and methodology used to inform future improvement work in acute care settings.
- Developing a national improvement approach to supporting acute general hospitals in collaboration with other acute care improvement programs and national partners.

Specialist Dementia Units

The aim of this workstream is to improve the quality of care, experience, and outcomes for people with dementia, staff, and caregivers in specialist dementia units; to improve the knowledge and understanding of improvement tools and methodology to support local improvements; and to increase the confidence and resilience in using these improvement approaches.

This will be achieved by:

- Working with four demonstration sites across Scotland to understand improvement priorities and to work in partnership with sites to support improvement activities and sharing of lessons learned.
- Developing and facilitating a network of specialist dementia unit staff across Scotland

to share practices and lessons learned to reduce variation and improve quality of care and support.

Dementia Friendly Communities

Another key emerging area for Scotland and the remainder of the United Kingdom is Dementia Friendly Communities. Scotland’s commitment to Dementia Friendly Communities fits well with the Scottish government’s 2020 vision to support individuals to “live longer, healthier lives at home, or in a homely setting” (Scottish Government, 2016).

Established in April 2013 with a £50 million (~\$65 million) endowment from the Big Lottery Fund, the Life Changes Trust has been instrumental in supporting the funding of dementia-friendly communities in Scotland. The emphasis is very much on locally driven projects rather than a top-down approach. Six monthly published reports share progress and lessons learned (Life Changes Trust, 2016). In addition, Alzheimer Scotland is providing local support through Dementia Advisors and Service Managers to provide dementia friends training and support for dementia-friendly communities. The Dementia Friends Programme has been running in Scotland for a few years and aims to improve people’s understanding of dementia in order to support people with dementia within communities (www.dementiafriendsscotland.org/).


The approach for developing dementia-friendly communities varies widely across the globe. Some countries take a nationwide approach, which is more prescriptive in design. For example, in England, the Alzheimer’s Society has developed a code of practice for the recognition of dementia-friendly communities (Bartlet, 2016). In Scotland, these communities are being locally developed through a bottom-up approach, relying on local self-appointed “champions” to drive change. Advantages of this approach are that it enables innovation, and is context specific, taking into account local needs and infrastructure. There are strengths

and weaknesses in both a national top-down approach and a grassroots approach. The national approach enables consistency and benchmarking to compare progress and quality. The bottom-up approach enables innovation and tailoring to local context but has limitations in sharing of practice and outcomes. It could be argued that having clearly articulated and agreed-upon outcomes and evaluation plans, regardless of the approach taken, would enable innovation and benchmarking.

Next Steps

Critical to success in Scotland's ten-year journey has undoubtedly been partnerships, in particular between the Scottish government's dementia policy team, the voluntary sector (including Alzheimer Scotland), national improvement and education organizations (Focus on Dementia, NHS

Education for Scotland and Scottish Social Services Council) and, importantly, the involvement of people with dementia and their families and caregivers in driving transformational change.

The next strategy was launched this past Summer, and people with dementia and their caregivers will continue to be involved in the design and delivery of strategy and improvements. The commitments will continue to be underpinned by a human-rights approach and support people to live well at home for as long as possible. We may not yet have a cure for dementia, but we will continue to invest in how we care for and support people with dementia and their caregivers in Scotland. 

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Person-Centered and Person-Directed Dementia Care

By Michael Lepore,
Lisa M. Lines,
Joshua M. Wiener,
and Elizabeth Gould

Federal policy developments and widespread service reform efforts have made significant strides in making person-centered and person-directed dementia care the norm.

Federal policies, professional consensus statements, and advocates for the rights of older adults and younger people with disabilities urge services providers for individuals with dementia to provide person-centered and person-directed dementia care. Similarly, in the general healthcare and long-term services and supports arena, patient-centered and person-directed care has broad-based support.

Time and communication are key to person-centered and person-directed dementia care.

Despite this support, confusion persists about the meaning of these concepts. This article disentangles the interrelated concepts of person-centered and person-directed care, describes their application to people who have dementia,

and reports some of the effects of person-centered and person-directed care on persons with dementia and their caregivers.

Concepts of Person-Centered and Person-Directed Care

The Institute of Medicine (IOM) described “patient-centered care” as a hallmark of high-quality care, defining it as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (IOM Committee on Quality of Health Care in America, 2001). The concepts of person-centered and person-directed care share the features of patient-centered care but they more strongly emphasize individuals’ non-medical issues (e.g., living arrangements) and coordination between acute, post-acute and long-term care. Both patient-centered and person-centered models

→**ABSTRACT** Person-centered and person-directed approaches to caring for individuals with dementia are encouraged by geriatric professional societies, consumer advocates, and policy makers, but implementation of these approaches to care remains limited. This article disentangles the interrelated concepts of patient/person-centered and person-directed care, describes their application to people who have dementia, and reports some of the effects of person-centered and person-directed care on persons with dementia and their caregivers. Also the article discusses the ability of people with dementia to engage in meaningful decision-making and describes tools for assessing the decision-making capacity of individuals with dementia. | **key words:** *person-centered care, person-directed care, Alzheimer’s, dementia, care planning*

of care promote individuals' access to their personal health information to ensure they are better informed and more active participants in their care, and value outcomes that are important to the individual (i.e., patient- or person-centered outcomes) over the technical and process measures that are often used by health-care systems. More empowering models of person-directed care preserve the characteristics of patient- and person-centered models of care described above, but enhance individuals' control over decisions about their care, emphasizing that the person, rather than the healthcare provider, is the decision-maker.

Collectively, these concepts emphasize understanding individuals and their health holistically—with attention to physical, mental, and social factors—and ensuring that individuals' preferences, needs, and values guide decision-making. Related concepts share these foci but also offer other emphases, such as the concept of relationship-centered care, which emphasizes attending to people's relationships with each other (Beach and Inui, 2006). These concepts stand in contrast to the dominant "medical model" of healthcare, wherein the focus is on medical conditions and symptoms, decision making is led by care professionals, and the role of consumers (i.e., patients, clients, long-term services and supports users) is to comply with professionals' decisions (Epp, 2003).

Person-Centered and Person-Directed Dementia Care

The shift toward person-centered and person-directed care includes care for people with dementia. Person-centered dementia care has been defined as care that is focused on the whole person (not the disease), on the individuals' remaining abilities (not on their losses), and on the person in the context of her or his social network, culture, life history, and personal identity and has been described as emerging in response to a culture of care that "reduced

dementia to a strictly biomedical phenomenon . . . was task-driven . . . relied on control techniques including chemical and physical restraints . . . and devalued the agency and individuality of persons with dementia" (Epp, 2003).

The principles of autonomy, independence, and self-determination are core to person-centered and person-directed dementia care. Key practices when working with people who have dementia include getting to know them and maximizing their abilities to make choices (Terada et al., 2013), providing them opportunities for more activities and social interactions that can compensate, in part, for their impairments (Brooker, 2007), engaging family members who they wish to be engaged in care, offering shared decision-making (Terada et al., 2013), and assessing how they see themselves rather than how they are described by others (de Medeiros and Doyle, 2013).

The need for persons with dementia to have a central voice in their own care planning is reinforced by research showing that the self-concept, values, and preferences of people with dementia may be radically different from those of their family, friends, and professional caregivers (de Medeiros and Doyle, 2013). Furthermore, people with dementia commonly assess their quality of life to be higher than do their family caregivers or their healthcare providers (Moyle et al., 2012). Therefore, directly engaging persons with dementia in processes of assessment and care planning is key to providing services that are person-centered.

Person-centered and person-directed dementia care also require that care is planned in a way that recognizes the personhood of the individual (i.e., recognizes that the individual with care needs is equally human as other persons). Recognizing the personhood of individuals with dementia can be supported by identifying significant events in their lives. For example, after learning about the life history of an individual with dementia, a support worker explained that she came to the know the indi-

vidual as a person rather than as a patient: “I’ve learned a lot about her . . . she was a patient and she was very confused . . . but when she started opening up you could see the type of person she was” (McKeown et al., 2010).

Specific approaches to supporting person-centered dementia care have been reported in the literature. For example, the VIPS Communication Skills Training—developed to advance four elements of person-centered dementia care: Valuing people, Individualized care, Personal perspectives, and Social environment (VIPS; Brooker, 2004)—has been used to increase the person-centered communication, beliefs, and attitudes among dementia care providers in a long-term-care facility (Passalacqua and Harwood, 2012). Additionally, the Care Pathway Model for Dementia aims to improve quality of life and daily functioning for individuals diagnosed with dementia and for their families or other caregivers by developing individualized recommendations focused on a person’s strengths and weaknesses that account for the individual’s living situation, social supports, life stage, and financial resources, and the individual’s and their family’s coping strategies (Morhardt et al., 2015).

Impacts of Person-Centered and Person-Directed Dementia Care

Several studies, many of them conducted outside the United States, have shown benefits of person-centered and person-directed care for people with dementia. Beneficial outcomes include higher quality of life (Terada et al., 2013), reduced falls, and better overall psychopathology (Rokstad et al., 2013), reduced aggression (Sloane et al., 2004), improved sleep patterns (Richards et al., 2001), and promise for reducing the use of antipsychotic medications (Fossey et al., 2006). In residential care settings, dementia care staff engaging in meaningful, person-centered conversations that address what is important to individuals in their care have been found to contribute to improvements in the quality of

care and quality of life of the person with dementia, and may promote the staff’s sense of purpose (Brown Wilson et al., 2013).

Person-centered care also may have benefits for care providers. The majority of randomized controlled trials and semi-experimental studies in a review of person-centered approaches to dementia care found reduced staff burnout and stress and increased job satisfaction (Barbosa et al., 2014). Additionally, in Sweden, a person-centered care intervention for individuals with dementia in a residential care facility for older adults was associated with significant reductions in staff stress (Edvardsson, Sandman, and Borell, 2014).

Engaging Persons with Dementia in Care Planning and Decision Making

One of the key aspects of person-centered care is shared decision making. Many families and service providers do not adequately incorporate the voices of people with dementia into care-planning and decision-making processes. Often, they assume people with dementia cannot contribute to these decisions because of their cognitive impairment and they are excluded from discussions about their care or their perspectives are not considered.

‘Person-centered care also may have benefits for care providers.’

Despite these practices, persons with mild to moderate dementia can participate in decisions and express preferences in areas such as their healthcare, daily care and activities, and place of residence (Menne et al., 2008). Individuals’ capacities for decision making depend on their ability to communicate, understand information about their choices, evaluate the implications of different choices, and comprehend the risks and benefits associated with different options (Woods and Pratt, 2005). A person’s ability to make decisions is recognized to vary along a continuum.


Samsi and Manthorpe (2013) characterize this continuum as ranging from supported decision-making—in which the person with dementia and the caregiver make decisions together—to substituted decision making, where the caregiver makes most of the decisions.

Several tools exist for evaluating capacity for decision making, including the MacArthur Competence Assessment Tool for Treatment, the Hopemont Capacity Assessment Interview, and the Capacity to Consent to Treatment Instrument. These instruments measure decision-making capacity in four domains: understanding information and demonstrating comprehension, appreciating the significance of treatment information, reasoning and comparing alternatives, and expressing a choice. Each instrument presents a hypothetical clinical scenario and asks individuals to show their ability to understand and appreciate diagnostic and treatment information and explain the reasoning behind choosing one treatment over another.

Conclusion

To better serve people with dementia and their families, it is important that the long-term services and supports system champion decision making that incorporates the goals, values, and preferences of people with dementia. Providing person-centered care for people with dementia requires a whole-person focus, attention to the individuals' remaining abilities, and consider-

ation of the person in the context of her or his social network, culture, life history, and personal identity. Implementation of person-directed care requires that service providers also empower persons with dementia to have control over decisions about their care.

Galvanized by broad-based support for person-centered and person-directed care by policymakers, professional groups, and consumer advocates, and by an emerging body of evidence showing beneficial outcomes of these approaches, our culture of care for people with Alzheimer's disease and related dementias appears to be shifting to be more person-centered and person-directed. However further adoption of these approaches is needed by long-term supportive service providers to make person-centered and person-directed care our new societal rule, rather than the exception, for people with dementia. 

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Serving Individuals with Dementia Who Live Alone

By Elizabeth Gould,
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Michael Lepore,
and Katie Maslow

Living alone with dementia presents a host of issues that must be carefully assessed in order to provide appropriate services or initiate a transition.

National and regional data indicate that a significant number of people with dementia live alone. According to a recent analysis of data from the National Health and Aging Trends Study, more than 30 percent of people with dementia lived alone in 2011 (Amjad et al., 2016). Lack of awareness of cognitive impairments is common in people with dementia and adds to their vulnerability (Amjad et al., 2016; Lehmann et al., 2010). Other symptoms such as impairments in vision, gait, and ability to speak coherently and understand spoken and written language compound vulnerability and unsafe conditions. Over time, a person will experience increased difficulties in the ability to plan, organize, and follow through with daily activities and personal care needs. If no one else lives in the home who can observe changes in the person's cognitive and functional abilities, the progressive decline associated with dementia may go unnoticed until an emergency occurs (Soniati, 2004).

Early intervention in a person's life requires recognizing signs of dementia and getting the

person the supports he or she will need as changes in cognitive ability occur. It is challenging to identify people with dementia who live alone and may experience unsafe conditions in their homes (De Witt, Ploeg, and Black, 2009; Harris, 2006). Meeting these people's needs also is challenging, as there is limited availability of services designed to support them, the diversity of their needs is great, and coordinating the multiple agencies necessary to meet their needs is difficult.

Characteristics of People with Dementia Who Live Alone

On average, people with dementia who live alone in the community are older than people with these conditions who live with others in the community. In a 2009 survey of a nationally representative sample of caregivers, 75 percent of respondents who said their care recipient had Alzheimer's or another dementia and was living alone reported that the person was age 75 or older, including 39 percent who reported

→ **ABSTRACT** National and regional data indicate that a significant number of people with dementia live alone; this puts them at high risk for neglect, exploitation, falls, and other safety risks. Identifying whether a person has developed dementia is the first critical step in being able to provide the necessary supports and services to help him or her adequately manage personal care needs and daily activities, while ensuring safety. This article addresses practical strategies that home- and community-based service providers can use when working with people with dementia who live alone. | **key words:** *living alone with dementia, Alzheimer's, cognitive impairment, supports and services, safety*

that the person was age 85 or older. In contrast, a slightly smaller proportion of caregivers who said their care recipient was living with them (70 percent) reported that the person was age 75 or older, including 34 percent who reported that the person was age 85 or older (Gould, Maslow, and Wiener, 2010). People with Alzheimer's and other dementias who live alone are much more likely to be female, much less likely to be married, and have somewhat lower income than people with these conditions who live with others (Edwards and Morris, 2007).

Generally, people with dementia who live alone are somewhat less cognitively impaired than those who live with others. Study findings show a 3- to 5-point difference in the average score on the 30-point Mini Mental State Examination between these two cohorts (Edwards and Morris, 2007; Lehmann et al., 2010). On average, people with Alzheimer's and other dementias who live alone also are somewhat less functionally impaired than people with these conditions who live with others in the community. One study found that those who lived alone were impaired in an average of 0.5 activities of daily living (ADL) (e.g., bathing, dressing, and using the toilet), compared with 1.5 ADLs among those who lived with others (Lehmann et al., 2010). Likewise, those who lived alone were impaired in an average of 1.9 instrumental activities of daily living (IADL) (e.g., managing medications and money, using the telephone, and shopping), compared with 3.1 IADLs among those who lived with others.

Studies conducted in California and Maryland found that 30 percent of people with Alzheimer's and other dementias who lived alone had no one providing regular assistance with personal care or other activities (Lehmann et al., 2010). A 2009 survey of a nationally representative sample of caregivers found that caregivers of people with Alzheimer's and other

dementias who lived alone were less likely than caregivers who lived with people with these conditions to be providing help with various personal care and other daily activities (Gould, Maslow, and Wiener, 2010). People with Alzheimer's and other dementias who live alone are more likely than those who live with others in the community to use social services, such as home-delivered meals, homemaker services, and case management (Edwards and Morris, 2007).

Detecting and Diagnosing Dementia

In general, people with dementia are less likely to seek medical care despite their health needs and their inability to manage their own care (Prince, Livingston, and Katona, 2007). The diagnostic process relies heavily on family members or close friends to bring concerns to the attention of a doctor and to report on changes in the person's cognitive and functional abilities. Physicians often have less access to knowledgeable informants for people who live alone and they are more likely to rely on patient self-reports, which may not be accurate (Wilkins et al., 2007). Without an accurate diagnosis of dementia, a physician may incorrectly assume that a patient has the ability to manage his or her medical conditions and follow a prescribed regimen (Wilkins et al., 2007).

In California and Maryland, 30 percent of people with dementia who lived alone had no one providing any regular assistance.

One study found that only 24 percent of people who lived alone and received a diagnosis of Alzheimer's or another dementia as part of the study had a prior diagnosis of the condition in their primary care medical record or on a Medicare claim form, or had a caregiver who reported that a doctor had said the person had Alzheimer's or dementia (Lehmann et al., 2010). In contrast, 39 percent of study subjects who



lived with others in the community had a prior diagnosis of the condition.

Identifying People with Dementia Who Live Alone

Identifying whether a person has developed dementia and the progression of the disease is the first critical step toward providing necessary supports and services to help him or her adequately manage personal care needs and daily activities, and to ensure safety. Providers such as geriatricians, case managers, or social workers attempting to identify people with dementia who live alone should be prepared to conduct a comprehensive assessment of their functional and health status (i.e., assess whether they need assistance with ADLs or IADLs) and assess their community support system (e.g., who may be included in their social network).

In some cases, identifying people living alone with dementia may start with setting up a system of “watchful waiting” for those considered to be at risk for living in unsafe situations. Watchful waiting allows providers to actively monitor a situation before intervening. Provid-

ers may not need to take major action right away (e.g., instituting home care visits), but they can be aware of a person’s situation and establish a system for reasonable monitoring that respects the individual’s preferences and needs and that may include other providers and community members.

Relying on people with dementia to self-identify as having dementia and living alone is unlikely to be successful. One strategy is to involve key community partners who have frequent contact with people in their homes, such as Meals on Wheels or the postal service, to establish an initial system of identification. Referrals from other community members, such as bankers, clergy, hairdressers, or apartment building managers, either through focused outreach or word of mouth, can expand the capacity for identifying people with dementia who live alone. Dementia Friendly America (2017), a nationwide movement to more effectively serve and support people with dementia and their family caregivers, has online tools available for various sectors of the community (e.g., local businesses, financial institutions, and

faith communities) that provide specific guidance on how to respond to these people's needs.

Understanding Risk Factors

Alzheimer's and other dementias cause impairments that can reduce a person's ability to remain safe at home, such as impairments in balance and mobility, judgment, sense of time and place, orientation and recognition of environmental cues, and sensory changes. Safety concerns for people who live alone with dementia include falls risk, unattended wandering, malnutrition, self-neglect, and accidental self-harm.

'Caregiver assessments are critical for determining ability and willingness of potential caregivers.'

Wandering is a serious safety risk because the likelihood of the person returning home safely largely depends upon others to recognize that the person is missing or that something is unusual and to report it to appropriate authorities. Dementia can impair a person's ability to negotiate the way back home and, in those instances, it is up to others to assist the person to get home safely (Gould, Maslow, and Wiener, 2010).

Other safety concerns for this cohort include medication errors, financial exploitation, and potentially hazardous living conditions (Amjad et al., 2016; Miranda-Castillo, Woods, and Orrell, 2010).

Determining Degree of Support

Assisting people with dementia who live alone requires professionals to seek the least restrictive living situation, such as remaining at home with more supportive services that account for the person's functional abilities and available supports within his or her community. It is important to note that this cohort may have varying degrees of support. Such scenarios include the following:

- A person lives alone with frequent support, visits, and monitoring from relatives and friends nearby who are looking out for his or her best interests;
- A person lives alone with some support or check-in calls from long-distance relatives and friends who are looking out for his or her best interests; and
- A person lives alone with no support and has no one dedicated to looking out for his or her best interests (Alzheimer's Association, 2009).*

*Excerpted with permission.

Determining the most relevant scenario to the person with dementia will enable providers to determine his or her level of risk and plan for the most fitting care and services.

Practical Intervention Strategies

Home- and community-based service providers can use a variety of practical strategies when working with people with dementia who live alone, including building trust, supporting safety and autonomy, involving family and friends, coordinating paid providers and formal support services, and assisting with transition to a new setting (Knowles, Lepore, and Gould, 2017).

Building trust

Building trust with a person with dementia who lives alone takes time and may require multiple contacts and meetings before community-based providers or others can ask questions about his or her needs or conduct a needs assessment. Providers can begin by asking people with dementia about their main concerns as a way of engaging them in the process and building trust (personal communication with Lisa Gwyther, director, Duke Family Support Program and Duke Employee Elder Care Consultation Service, associate professor, Department of Psychiatry and Behavioral Sciences, May 2015).

If a community-based provider is working with a third-party referral, the provider can engage the person making the referral and inquire about best methods for building trust.

Relying on family members, other known providers, or caregivers to vouch for the community-based provider can be an effective way to reassure the person that the provider is trustworthy. When engaging family members or other caregivers, providers also should watch for indicators of abuse, neglect, and exploitation.

Supporting safety and autonomy

Commitment to every extent possible to maintaining a person's autonomy is a principal concern when community-based providers work with people who have dementia and live alone. Community-based providers must support people's autonomy while addressing concerns about safety. To do both effectively, it is important for providers to understand people's capacity to make everyday decisions, weigh the associated risks involved, and carry out those decisions. Only trained health professionals should directly assess capacity.

Community-based providers can deliver the assistance needed for people to maintain their autonomy by understanding their situations and learning how to evaluate the risks and whether and how they need to be addressed. Maintaining a person's autonomy means providers must consider his or her personal values and preferences in balance with considerations of his or her safety and the safety of others.

Involving family and friends

People with dementia who live alone may have social supports and people in the community who can assist them. However, providers should use caution when reaching out to family members and friends as potential caregivers because they could be re-introducing an individual into a relationship in which there was an abusive or exploitative past. Providers also should consider the family's culture and general perceptions of aging, caring for family members, and memory impairment.

Caregiver assessments are critical for determining ability and willingness of poten-

tial caregivers. Involving more than one caregiver with assisting an individual may help prevent any one caregiver from being overburdened by his or her caregiving duties. In some cases, a family member may have a difficult time accepting that the person's level of functioning has deteriorated. Providers may need to work with caregivers over time to ensure that they understand the level of risk for people with dementia who live alone. Family caregiver support programs through local area agencies on aging can connect caregivers to community resources that can help them build the necessary skills to provide assistance to people with dementia.

Coordinating paid providers and formal support services

Coordination and communication among community-based providers are important when serving people with dementia who live alone. When coordinating care, providers should keep in mind that many community-based providers do not have a consistent and direct way to exchange information with others who are working with the same individual. A physician may not be able to easily communicate with the personal care provider who may have different perspectives on an individual's capacity, risks, and support needs. HIPAA privacy rules may also limit communication, although a person's informed, written consent to share information can lessen these barriers. The use of technology, such as shared electronic medical records, has the potential to facilitate communication and coordination across providers.

Providers also should assess the person's financial situation to determine if any assistance is needed to cover support services. Each state's Medicaid program offers home- and community-based services through its state plan or waiver programs. State and local organizations may also provide additional funding for support services for people living in the community who need more assistance.

Assistive technology can be used to help ensure that people with dementia who live alone receive adequate supports to remain in the community. Providers can monitor if an individual living alone is taking medications as prescribed using a medication tracker. However, it is important to note that assistive technology may work for some individuals and not for others, depending on the person's level of comfort using technology and his or her cognitive abilities. (For more on assistive technology, see the O'Keeffe article on page 90.)

Assisting with transition to a new setting

Many factors must be considered in determining whether a person with dementia who lives alone needs more assistance than can be provided at his or her home. Providers recommending care transitions must weigh the risks of remaining in the home, the risks of moving to a new setting, the capacity of the person to understand these risks and willingness to transition to a new setting, and the availability of new and appropriate settings for the person. If relocation becomes necessary, a provider should support the person's decision making as much as possible. For involuntary moves, providers must prove in court that a person no longer has the capacity to make decisions. Courts can appoint one person or entity as a guardian to make financial, personal, legal, and healthcare choices. Often—but not in every state—the term “guardian” refers to someone appointed to make healthcare and personal decisions, and “conservator” refers to someone appointed to make financial decisions.

When a person with dementia who lives alone transitions to a new setting, it is critical to assess his or her needs, the abilities of the new caregiver(s), and the characteristics of the new environment. If gaps are identified between what the person needs and what the new caregiver and environment can provide, it may be necessary to involve additional social services. Regardless of the type of residential setting,

having the person visit the setting before relocating is encouraged; this can help him or her feel more comfortable when the move does occur.

'Relying on people with dementia to self-identify as having dementia and living alone is unlikely to be successful.'

Right after a transition, the person is often upset or agitated in the new environment. To achieve a smooth transition, it is crucial for caregivers and family to actively communicate with the care providers in the new setting to set realistic expectations and acknowledge that the transition can be difficult. Providing access to mental health counseling also can help in adjusting to a new living environment. After relocation, it is important to maintain consistent contact with the person to make sure all the needed services are in place to his or her satisfaction.

Conclusion

Although available U.S. data on community-dwelling people with Alzheimer's and other dementias who live alone show that they are, on average, somewhat less cognitively and functionally impaired than people with these conditions who live with others, living alone creates obvious risks. Many of these people receive help from family members, neighbors, and friends, and some may not need additional help. On the other hand, Alzheimer's and most other dementias are progressive, so people with these conditions need more help over time. Impairments in judgment and ability to plan and carry out activities and lack of awareness of cognitive and functional impairments mean that many people with Alzheimer's and other dementias will not be able to recognize their own increasing need for help or be able to plan for or arrange needed services. Those who live alone, especially those who have no one visiting or checking in on them regularly, are at very

high risk for neglect, exploitation, falls, and other safety risks.

As the prevalence of Alzheimer's and other dementias continues to rise, the needs of people with dementia who live alone will also increase. Community and government agencies and others in the aging services network can test and share innovative intervention strategies in an effort to more effectively respond to this population's needs. 🌿

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Reducing Dementia Caregivers' Burden: Is There a Role for Assistive Technology?

By Janet O'Keeffe

Some AT products can help people with dementia maintain independence, reduce behavioral issues, and offer relief to caregivers, but usability depends upon the individual.

Caregiver burden, the high cost of long-term care, and the projected long-term-care workforce shortage have increased interest in the potential for assistive technology (AT) to substitute for or supplement caregiving for people with dementia. The primary goals for assistive technology for people with dementia living in their own homes—with or without a caregiver—are to help maintain independence and autonomy, ensure safety, reduce caregiver burden (thereby delaying institutionalization), and reduce care costs.

With dementia, the AT research field is in a preliminary stage of development.

The Assistive Technology Act of 1998 defines assistive technology as any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities. Such a broad

definition encompasses “low-tech” items such as grab bars and walkers for those with physical impairments, to “high-tech” items such as augmentative communication devices; sensors to turn off appliances when they pose a hazard; remote monitoring systems to determine the level of activity and safety of persons in their homes; and GPS tracking technology to enable caregivers to locate individuals who wander and become lost (O'Keeffe, Maier, and Freeman, 2010).

Hundreds of studies have been conducted on the use of AT devices for people with dementia, but two review articles found that almost all have methodological shortcomings (Fleming and Sum, 2014; Topo, 2009). The authors of these review articles and many other researchers have reached the same conclusion: for people with dementia, the AT research field is in a preliminary stage of development, with large numbers of qualitative studies, audits, and service evaluations, but few of these have been

→ABSTRACT The evidence base for assistive technology (AT) to compensate for cognitive impairment is lacking and little research has examined technologies to address common impairments of dementia other than memory loss. Nonetheless, some AT products may help to maintain independence by orienting individuals to time and place, and monitoring technologies can relieve caregivers from the need for constant supervision. However, because no product will be effective and beneficial for everyone, caregivers need to assess whether an individual can use and benefit from such products, and introduce them on a trial basis. | **key words:** *assistive technology, mild cognitive impairment, dementia, caregivers*



conducted with sufficient rigor and appropriate research design to allow for any degree of generalizability (Boger, Taati, and Mihailidis, 2016) or agreement on how to measure “success” (Olsson et al., 2012). Additional research issues include the following:

- Failing to involve persons with dementia and their caregivers in the development and design of AT devices (Zwijnsen, Niemeijer, and Hertogh, 2011);
- Using research subjects who are not comparable across studies;
- Testing AT devices with subjects who may be too impaired to use them;
- Rarely testing AT devices with those who have cognitive impairment or dementia and live alone (Topo, 2009);
- Focusing on assistive technologies that might compensate for memory loss, while failing to address other progressive impairments associated with dementia such as aphasia, agnosia, apraxia, visuospatial deficits, and executive dysfunction (Bharucha et al., 2009); and,
- Failing to consider factors that affect the adoption and continued use of assistive

technology, such as affordability, poor assessment of client needs, and lack of client and caregiver instruction and support (Bonner and Tahir, 2012).

Despite the lack of an evidence base for assistive technology that can compensate for cognitive impairment, some commercial AT products are available that may help achieve the following outcomes: maintaining independence by orienting a person with memory loss to time and place; relieving caregivers from the strain of constant supervision to help ensure safety through monitoring technologies; and improving emotional status and decreasing behavioral problems. This article focuses on a subset of AT devices—electronic or computerized devices or systems—that are intended to achieve these outcomes.

Products for Memory Impairment and Disorientation to Time

Many products are designed to address memory impairment and disorientation to time, including

- Electronic products to help people find commonly lost items, such as keys;

- Medication reminders, which range from simple electronic reminder prompts to technologically complex systems that can be programmed to alert caregivers when medications are not being taken on schedule;
- Phones with photos of family members and speed-dialing capabilities;
- Electronic devices to help orient individuals, such as clocks that display the month, day, and time, and show whether it is morning or evening; and
- Hand-held devices, such as personal digital assistants and smart phones, which caregivers can program to provide a series of reminders, verbal instructions, or messages.

A major problem with devices that provide only reminders, prompts, or instructions is that they have been designed with the assumption that memory loss is the only cognitive impairment. But memory impairment is insufficient for a diagnosis of dementia; individuals must have at least one other impairment, and the impairments must be severe enough to impair performance of activities of daily living. Deficits in executive cognitive function are common, and include the ability to solve problems and make decisions; to plan, assign priority to, initiate, and sequence tasks; and to regulate emotions and control impulses. Other symptoms of dementia include a decline in reasoning abilities; confusion; disorientation; problems with speech and understanding; and changes in mood, personality, and behavior (O’Keeffe, Maier, and Freeman, 2010).

Reminder, prompting, and instruction aids will not be effective for those who lack the cognitive capacity to use them. For many persons with dementia, completing a task requires prompting and cueing through its duration. However, reminders and prompts can be effective for individuals in the very early stages of memory impairment or mild cognitive impairment that often precede a diagnosis of dementia. Approximately 60 percent to 65

percent of persons with mild cognitive impairment develop clinical dementia in their lifetime (Busse, Angermeyer, and Riedel-Heller, 2006). Introducing a reminder and prompting product at these early stages would give individuals time to use and become familiar with the device and establish behavioral routines for using it. These routines might then persist into the early and moderate stages of dementia (Personal communication with Donald Royall, on June 28, 2010, as cited in O’Keeffe, Maier, and Freeman, 2010).

Products to Help Ensure Safety

Several AT products have been developed to alert caregivers to unsafe situations in the home, and more sophisticated technologies can both alert caregivers and prevent unsafe situations. Examples of these include devices to disable a car with a simple switch so that a person who cannot drive safely is unable to start the car; sensors that turn off a stove at specific times or in response to specific situations; and alarms to alert a caregiver when the water temperature in a faucet rises above a safe level (O’Keeffe, Maier, and Freeman, 2010). The availability of wireless technology has increased the range of products available and reduced the price of many.

One problem with reminder, prompting, and instructing devices is they are designed with the assumption that memory loss is the only cognitive impairment.

Many technologies are available to assist caregivers in monitoring persons with dementia and can provide respite, which is particularly important for those who have to provide around-the-clock supervision to ensure safety. Examples are sensors that alert caregivers when an individual gets out of bed during the night, approaches a stairway, or attempts to leave the home at unexpected or inappropriate times; and sensors that alert a caregiver, or an emergency response system, when it is likely that a fall has occurred.

Several types of assistive technologies are available to help ensure safer walking. Devices using GPS systems are designed to help individuals find their way home. However, such systems are likely beyond the capability of many—if not most—persons with dementia to operate. However, if persons with mild cognitive impairment or very early-stage dementia have the ability to recognize that they are lost and have the capacity to use devices that will help them find their way home—or help others to find them—several AT products may be useful (O’Keeffe, Maier, and Freeman, 2010).

Passive monitoring systems are available to help caregivers locate persons who have left the home and not returned; one example is a GPS device that an individual can wear, or which is attached to their clothing. These products have different capabilities, and the range of products is increasing with the introduction of new technologies for use by the general population. Caregivers who use monitoring devices to locate family members who wander need to understand that the available products help to manage risk, but do not eliminate it completely (Alzheimer’s Society, 2017).

At the same time, a system that is designed well and customized to individuals’ specific

needs, abilities, environment, and preferences—and the needs of their caregivers—can be effective in decreasing the risk of harm and reducing caregiver burden. When considering the use of any safety technology, it is important to recognize both its limitations and its potential. Such technology is not intended to serve as a complete substitute for caregiver presence or to replace caregiver supervision for a user who is not safe alone outside the home (O’Keeffe, Maier, and Freeman, 2010).

Technology to Improve Emotional States and Decrease Behavioral Problems

Few proven technologies are available to improve the emotional state of persons with dementia and to decrease behavioral problems (O’Keeffe, Maier, and Freeman, 2010). Those that have shown promise, based on preliminary research findings, include light therapy to help improve sleep patterns and technologies to facilitate exercise, entertainment, and relaxation, which might decrease emotional distress and behavioral problems (Hulme et al., 2009; Sitzer, Twamley, and Jeste, 2006). Examples include interactive computer games for physical movement and exercise, simplified remote controls for watching television, customized

Issues to Consider When Selecting Assistive Technology

- If there is definitely a need for the AT product, or whether there is another solution;
- The person’s degree of memory loss and the other types of cognitive deficits;
- The person’s needs, preferences, and ability to use devices, and how these might change over time;
- Whether the person has other conditions that may affect how they use the technology (e.g., poor sight or hearing);
- The level of support available to the person;
- How well the technology will fit in with the person’s usual routines;
- Whether the technology requires a phone line or Internet access; and,
- The cost of the technology.

Source: Alzheimer’s Society of the United Kingdom, n.d.

music playlists, and technology to aid reminiscence therapy.

Considerations When Selecting and Using Assistive Technology

To be useful, an AT product must be both effective and beneficial. A product that is effective (i.e., achieves its intended purpose) but causes distress is not beneficial. For example, an alarm that goes off when a person opens an exterior door may be frightening, or a voice recording telling the person not to leave the house may be disorienting.

To be useful, an AT product must be both effective and beneficial.


Because every individual with dementia is unique, no AT product will be useful for everyone, and it is essential to assess an individual before introducing an AT product to ensure that it matches a person's needs, abilities, and preferences. The physical and social environments also need to be assessed to help determine which types of AT products are appropriate (O'Keeffe, Maier, and Freeman, 2010).

Factors that can influence the acceptance, use, and effectiveness of assistive technology include an individual's: specific pattern of cognitive abilities and deficits; specific emotional and behavioral changes; personality characteristics and attitudes toward technology; attitude regarding AT products that appear to exert "external control"; and physical and social environment (LoPresti, Mihailidis, and Kirsch, 2004). Given the lack of research on the effectiveness of many commercially available AT products, caregivers need to determine for themselves whether they will be useful—both effective and beneficial—and introduce them on a trial basis.

Several online sources provide comprehensive information about assistive technology. Some sources that focus on assistive technology for people with memory loss, mild cognitive impairment, and dementia include www.alz.org/library, www.atdementia.org.uk, and www.alzheimers.org.uk. Other websites such as goo.gl/KXsr9Q provide information about assistive technologies for persons with all types of impairments, including physical, sensory, and communication impairments.

Conclusion

Although there is hope that technology can help to meet the care needs of persons with dementia, compared with AT products available for people with physical, sensory, and communication impairments, few products can help compensate for the cognitive deficits or address the behavioral problems common in persons with dementia (O'Keeffe, Maier, and Freeman, 2010).

The evidence base for assistive technologies that can compensate for cognitive impairment is lacking, and little research has been conducted on technologies to address common behavioral symptoms and impairments other than memory loss. However, many commercial products are available that may be helpful to persons with dementia and their caregivers. With regard to reminder and prompting products and user-operated GPS and other communication devices, introducing them when people first develop memory loss and disorientation may be more effective than introducing them when someone has been diagnosed with dementia (Royall, 2010). 

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Implementing Evidence-Based Interventions: The Development of RCI REACH

By Leisa Easom,
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Naomi Latini

Translating and disseminating the RCI REACH caregiver support program has demonstrated its sustainability.

Predictions estimate that by 2040, there will be about 82.3 million older persons in the United States, more than twice their number in 2000 (Administration for Community Living, 2016). Worldwide estimates are that by 2050, 21.1 percent of adults will be ages 60 and older (United Nations, 2013). One consequence of greater longevity is the growing incidence of dementia. Currently, more than 5 million Americans are living with Alzheimer's disease (Alzheimer's Association, 2016) and 1.4 million individuals have Lewy Body Dementia (Aging Care, 2016).

Caregivers of these individuals often go to great lengths to keep their loved ones in the home for as long as possible—

many times neglecting themselves and their own health. This article focuses on the implementation of REACH II (Resources Enhancing Alzheimer's Caregiver Health) and the subsequent development of RCI (Rosalynn Carter Institute for Caregiving) REACH. Successes, challenges faced, and lessons learned were part of the translational process. We hope our shared experience will inform future implementations of RCI REACH.

Caring for the Caregiver

Caring for the caregiver is vital to our national healthcare system because unpaid caregivers provide about \$470 billion worth of care annually (Reinhard et al., 2015). In the past

two decades, support programs have been developed to address unpaid caregivers' needs. Many of these programs have demonstrated good outcomes, such as decreased depression and decreased caregiver burden. Randomized controlled trials (RCT) and equivalent methods establish the evidence base for programs that improve caregiver outcomes (Reinhard et al., 2015). Most RCTs test program efficacy, using small non-representative samples, with implementation staff hired, trained, and supervised by researchers.

Results from RCTs, although necessary to establish efficacy, typically do not test whether or not the trials achieve positive outcomes when programs are delivered

→ABSTRACT Alzheimer's disease and related dementias strike individuals and families in the United States and worldwide. Caregivers often go to great lengths to keep their loved one in the home for as long as possible—many times neglecting themselves and their own health. This article focuses on the implementation of REACH II (Resources Enhancing Alzheimer's Caregiver Health) and the subsequent development of RCI (Rosalynn Carter Institute for Caregiving) REACH. Successes, challenges faced, and lessons learned were part of the translational process. | **key words:** REACH II, RCI REACH, dementia, caregiving

on a large scale to diverse populations (Fixsen et al., 2005); and they provide little information about the experience of day-to-day implementation, how a program fits into the menu of services for an organization, and the need for technical assistance to monitor fidelity to program protocols (Bass and Judge, 2010; Fixsen et al., 2005).

‘Caregivers were provided tailored, specific education and support to address areas of concern.’

Clinicians, researchers, healthcare providers, and policy makers are beginning to realize the need for more information to effectively translate evidence-based programs within a community, in order to make them available to older adults and their caregivers. Both public (i.e., Administration for Community Living) and private (i.e., Johnson & Johnson) sectors have provided funding to initiate and scale evidence-based programs for persons with Alzheimer’s disease or related dementias and their family caregivers.

REACH II and RCI REACH

REACH II, an RCT sponsored by the National Institute on Aging and the National Institute on Nursing Research (Belle et al., 2006), was implemented with in-home caregivers (212 Hispanic, 219 Caucasian, and 211 African American) in five

U.S. cities caring for their loved ones with dementia. This multi-component intervention entailed an initial assessment of home safety, self-care practices, self-efficacy, stress levels, and behavioral problems faced by caregivers in caring for their loved ones. Caregivers were provided tailored, specific education and support to ad-

dress areas of concern. For example, one caregiver said that her husband became very agitated in the morning when dressing for the day, and another shared that repetitive questioning was the main troubling behavior.

The coaching conversation focuses on the most troubling area of concern for each caregiver. Several organizations, including the Department of Veterans Affairs (VA), made an effort to translate the program into their community setting (Nichols et al., 2011), naming its program REACH VA. The Rosalynn Carter Institute for Caregiving’s (RCI) implementation of this caregiver support intervention (known as RCI REACH) was based on the VA model translation and implemented through a partnership with the Area Agency on Aging in Coastal Georgia.

During implementation, RCI held focus groups with caregivers and caregiver coaches to gain insight on what

was most helpful to the families served. RCI REACH (Easom, Alston, and Coleman, 2013) is a six-month-long, twelve-session intervention delivered to caregivers of people with dementia in their home and via telephone. A caregiver coach with a four-year degree in social work, nursing, or a related field conducts the intervention. An RCI Master Trainer trains the caregiver coaches, and the training includes information on dementia, use of the caregiver guide, and resources. Mastery is evaluated through skills demonstration (critiqued role playing). Caregivers receive education and information on dementia, and training in strategies and techniques for stress management, problem-solving, and self-care. RCI REACH teaches strategies to address care recipients’ behavioral changes and the attendant caregiver frustrations associated with dementia. To measure program impact, data were collected before and after conducting the program. With the support provided in this intervention, caregivers feel more empowered and able to cope with behavioral changes. By decreasing caregivers’ stress and burden, RCI anticipates the homecare environment can improve for care recipients.

Successes and Challenges

The RCI REACH implementation achieved three main

successes. First, it achieved quantitative outcomes demonstrating positive program impact. The same assessment instruments used in the original study measured this program's success, achieving statistically significant improvements similar to those of the RCT. Data were collected at baseline and at the program's end. Caregiver burden and depression decreased, caregiver self-efficacy increased, even though clients' pre- and post-data were used rather than control versus treatment data, as in the clinical trial. This is significant because dementia caregiver challenges escalate as troubling dementia behaviors increase over time (Bidzan et al., 2008; Herrmann et al., 2015). Caregivers expressed feeling empowered and being more capable of addressing care recipients' needs.

A second success was the embedding of an evidence-based program within the structure of a community-based aging agency, and seeing the program's sustainability (it is still available today). For a program to become part of the organizational identity, having buy-in from agency staff and community consumers is essential. In this implementation effort, the agency readily embraced the program with administrators and other staff attending all training sessions and becoming familiar with this program. Another element influ-

encing the embedding process is program funding. RCI REACH meets the criteria to be funded by the Older Americans Act Title IIID monies as an evidence-based program (U.S. Department of Health and Human Services, 2017).

A third success involved the production of a caregiver resource guide that offers strategies for creating a dementia-friendly lifestyle, improving caregiver self-care, and addressing difficult behaviors arising from dementia. The previous caregiver guide (based on the REACH VA guide) was a three-ring binder with materials inserts, booklets, and behavioral information. Focus group discussions with caregivers revealed difficulty in navigating the guide and material that should have been included. These conversations led to a new resource—the “Dealing with Dementia Guide” for caregivers and their families, vetted by caregivers of loved ones with dementia (the Guide is available in English and Spanish).

Challenges stemmed from integrating the new program into the landscape and culture of the existing aging agency. Discussion sessions were held with the entire staff, providing an overview of the intervention and specifics as to how each person's position would interface with the new program. Cultivating acceptance by the intake and assessment staff was

key to ensuring a healthy flow of referrals. The program and referral status were discussed in each staff meeting, as staff were encouraged to promote the program within and outside the agency. Finally, staff screened waiting list clients for dementia and those persons identified as having dementia were contacted and offered the program. The site maintained full caseloads for each caregiver coach throughout the program. Following the development of RCI REACH, RCI launched a national expansion of this program, training twenty agencies, and continues to offer training: there are now twenty-eight active RCI REACH sites across the nation, including uptake by Area Agencies on Aging, the Alzheimer's Association, and privately funded organizations.

Lessons Learned


Agencies require an initial assessment of their aptitude for implementing practices; aptitude will vary based on the intensity of the intervention, agency background, and use of evidence-based practices. For this RCI REACH translation, staff lacked knowledge of and experience with the principles of implementation science and of dementia. As well, collecting data on program outcomes and impact (as opposed to program satisfaction) is a practice new to many agencies. Supplemental training was needed so that

staff could work effectively and appropriately carry out this intervention.

Caregiver coaches require regular access to technical assistance. For an annual licensure fee, coaches receive technical assistance that includes membership in the RCI REACH online Facebook community, manual and caregiver guide updates, a refresher training session via webinar, and up to six hours of consultation for monitoring of program protocols. Annual renewal of contracts promotes a healthy exchange

between the RCI Master Trainers and RCI REACH trained coaches in the field, minimizing program disruption and ensuring efficient and effective program delivery.

RCI is privileged to have played a role in the translation and dissemination of the REACH II intervention. Testimonials from family caregivers reaffirm what the data tell us—RCI REACH is a life-changing, possibly life-saving program. Feedback from caregiver coaches in the field indicates that delivering

this program to family caregivers is a highlight of their careers. As one coach said, “It leaves me feeling so good to be a part of all the changes the RCI REACH program brings to people’s lives.” 

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New York University Caregiver Intervention Decreases Depression and Distress

By Donna K. Walberg,
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Mary S. Mittelman

Implementing the NYUCI in Minnesota benefited caregivers and aided caregiver consultants through training.

Over the past two decades, randomized controlled trials (RCT) have demonstrated that psychosocial interventions for caregivers are effective in producing clinically and socially meaningful improvements in their psychological well-being (Sörensen, Pinquart, and Duberstein, 2002). One of these interventions, the New York University Caregiver Intervention (NYUCI) also substantially delayed institution-based care of people with dementia by supporting the capacity of their family caregivers to continue to provide care at home (Mittelman et al., 2006).

Developed in the mid-1980s, the NYUCI demonstrated significant benefits for caregivers and their relatives with dementia in multiple studies in the United States, Great Britain, and Australia. The NYUCI was first evaluated in an RCT that began in 1987 and lasted for more than twenty years, with funding from the National Institute of Mental Health and the National Institute on Aging (NIA). In the original study,

participants were a spouse or partner of the person with dementia. In a new variant of the intervention, the NYUCI-AC, participants were adult children of the person with dementia (Gaugler, Reese, and Mittelman, 2013; Gaugler, Reese, and Mittelman, 2015).

The results of the original RCTs led to new RCTs in the Latino community in Northern Manhattan and in Israel and translations into community settings in eight states, all funded by the Administration on Aging. Additional community translations have been conducted in New York, Vermont and Queensland, Australia. A pilot study is currently being conducted in Paris, France. The organizations providing the intervention made it available at no cost to caregivers.

NYUCI Program Components

The NYUCI consists of two phases. The intensive phase begins with a comprehensive caregiver assessment, followed by an individual

→ABSTRACT Psychosocial services have been proven to reduce the negative emotional and physical impact of caregiving for people with Alzheimer's and other dementias. The NYU Caregiver Intervention (NYUCI) was implemented in Minnesota in more than fourteen sites and, as with the original randomized controlled trial of the NYUCI, the translation decreased depression and distress among caregivers. Greater fidelity to the original intervention was associated with delaying nursing home placement for the person with dementia. Benefits to caregivers far outweigh the challenges of translating research into practice. | **key words:** *psychosocial interventions, caregiving, Alzheimer's, dementia, NYUCI, randomized controlled trials*

counseling session, four family counseling sessions, and a final individual session, each tailored to the caregiver's specific situation. Ongoing informal counseling, generally by telephone, helps caregivers and families deal with crises and with the changing nature of the symptoms of the persons with dementia over the course of the illness. NYUCI counselors or care consultants also provide resource information and referrals for additional help such as paid care options, legal and financial planning, and information about management of behavior problems associated with dementia.

Perhaps the most important component of the NYUCI is the involvement of other family members in addition to the primary caregiver, as our research has demonstrated that the most important cause of improved caregiver well-being is greater satisfaction with social support, largely from family members and friends (Roth et al., 2005). Licensed clinical social workers, family counselors, nurses, and psychologists provide the counseling. Training in the NYUCI was originally conducted in person, but training and certification is now available through an online course that includes videos of a role play and live case presentations of the intervention.

The unifying premise of the NYUCI is that increasing social support and minimizing family conflict will improve the ability of the caregiver to withstand the difficulties of caregiving and

obviate or defer need for institutionalization of the care recipient. The focus is on diminishing the negative aspects of family involvement with caregiving while enhancing the positive, supportive aspects. Results are achieved through a process that starts by helping the caregiver to clarify the kind of help he or she would welcome and to reduce family members' unrealistic expectations.

'Our family greatly appreciates Judy's insights and input into our situation.'

Family members identified by the caregiver are then engaged in counselor-facilitated discussions in which family members express their perspectives, abilities, and inclinations to help. Over the course of four meetings, these discussions evolve into a plan of support for the caregiver, one with which every family member feels comfortable. The structure of the intervention and the initial caregiver assessment enable counselors to use many therapeutic approaches, aligned with the needs of the family and their skill set, to consistently achieve positive outcomes. The intervention not only helps caregivers understand the cause of disturbing behaviors of the person with dementia, but also reduces the impact of the behaviors on caregiver stress and well-being. The intervention also provides

Figure 1. Results of RCT of NYUCI (1987–2010: n = 406 spouse caregivers)

1. Improved support for caregivers for at least 5 years
2. Reduced caregiver depression for at least 3 years
3. Reduced caregiver reaction to behavior of person with dementia for at least 4 years
4. Improved caregiver self-rated health for at least 4 years
5. Postponed nursing home placement of person with dementia 557 days
6. Reduced caregiver depressive symptoms and burden during the transition to a nursing home
7. Effects persist through bereavement
8. Moderator of all other outcomes is social support

Sources: Drentea et al., 2006; Gaugler et al., 2008; Haley et al., 2008; Mittelman et al., 2004a, 2004b, 2006, 2007; Roth et al., 2005.

ongoing support for the primary caregiver and for other family members; this is accomplished through the relationship established with the counselor during the formal counseling sessions. Counselors routinely assure participants that they are available for further consultation, as needed.

The results of the original study of the NYUCI, which included 406 spouse or partner caregivers, demonstrated its effects on caregiver well-being, including reducing symptoms of depression (Mittelman et al., 2004a) and stress (Mittelman et al., 2004b) and improving physical health (Mittelman et al. 2007), largely through improving caregiver satisfaction with social support (Roth et al., 2005). This enabled caregivers to keep their spouses with dementia at home an average of eighteen months longer than those who received usual care (Mittelman et al., 2006) (see Figure 1 on page 101).

Why Minnesota Selected the NYUCI

The NYUCI was implemented in Minnesota from 2007 to 2014 through fourteen agencies in

four of Minnesota's six Area Agency on Aging regions, via three federal Alzheimer's Disease Supportive Service Program grants, and financial support from the Minnesota Board on Aging. The NYUCI was selected for its alignment with Minnesota's caregiver consultation model. Caregiver consultation in Minnesota is funded primarily through Title IIIIE of the federal Older Americans Act and provides individual consultation, family meetings, caregiver education, and care planning, with connections to needed resources.

Minnesota also selected the NYUCI for its documented ability to delay nursing home placement, which aligned with Minnesota's goal of reducing nursing home placements and maintaining independent community living for as long as possible.

Several approved changes were made in Minnesota's implementation of the NYUCI. Approval was given to accommodate African American and other culturally diverse families where extended family members often live with

Participant Feedback on the NYUCI Intervention

Caregiver: "I was a basket case when I first saw Jane. She listened. She cared. She was available to me by phone, by e-mail, when I needed help. She offered many helpful suggestions. She became a 'safe island' that I could go to."

Caregiver: "This has been a very positive experience for our family. It brought the AD issues 'out of the closet,' out into the open, and brought us closer together."

Family Member: "Judy had a number of ideas for us as a family to do a better job of doing our part to help her as she cares for my father-in-law. Our family greatly appreciates Judy's insights and input into our situation. This program is highly valuable to families, including ours. Most importantly, we truly realized the stress that my mother-in-law is under in dealing with her husband's need and in her own loss of how her life used to be."

Counselor: "The wife caregiver stated after the third family meeting, 'I don't know what you did during the last meeting, but my son is like a new person.' She continued to explain that her son has been more involved in helping her care for her husband, he calls more often and is more aware of the stress that she has as a caregiver. Historically, this son has been left out of the communication loop and has not played an active role, likely as a result of family dynamics that have always placed the two daughters in the 'lead roles.' By having the son participate in the family sessions and setting the stage for him to be an active participant in voicing his perspective and having his opinions validated, he has taken a more active role in the family system."

the person with dementia. Later research demonstrated that similar caregiver outcomes are achieved with non-spousal caregivers as in the original research (Gaugler, Reese, and Mittelman, 2013; Gaugler, Reese, and Mittelman, 2015). Another accommodation for implementation in a community setting was flexibility regarding the counselors' educational qualifications. In Minnesota, the NYUCI was approved to include counselors who had Bachelor's degrees (rather than Master's degrees), with additional training and clinical support to accommodate the educational qualifications of Minnesota's caregiver consultants.

Profile of Minnesota's Implementation

The caregivers in Minnesota's NYUCI implementation differed from the original study primarily by geographic location. There were more than twice as many caregivers living in rural areas as in urban areas in contrast to the original NYUCI participants, all of whom lived in a large metropolitan area. Three of the fourteen implementation sites were located in the Twin Cities metropolitan area. Five were near cities, and the rest were in rural areas of the state. The types of organizations offering the NYUCI varied from the original study as well—half were smaller nonprofit community-based organizations, two were hospital-based service programs, one was clinic-based, one was county-based, and one was assisted living-based. There were 228 participants. Similar to the original study, there were twice as many female caregivers as male caregivers. The average age of caregivers was 73. The average age of the people with dementia was 76. More than half the caregivers had completed at least some college.

Although most of the caregivers were Caucasian, 0.9 percent were Hispanic and 9.6 percent were African American. Hispanics have a 1.5 times and African Americans 2.0 times greater risk of having Alzheimer's disease than the population as a whole. Hispanic and African American caregivers also spend more time

caregiving and are more likely to experience high burden from caregiving (Alzheimer's Association, 2013). Minnesota's small numbers of ethnically diverse people, especially in rural areas, made reaching these caregivers challenging. One metro area site was dedicated to serving African American caregivers.

Key Outcome Results

At four-month follow-up assessments, caregivers reported a significant decrease in the number of their symptoms of depression and in the severity of their reaction to disruptive behaviors of the people with dementia for whom they cared (See Table 1 on page 104). At eight-month follow-up assessments, caregivers reported significantly greater satisfaction with social support, including tangible assistance (e.g., helping the caregiver with chores, staying with the person with dementia so the caregiver can go out), and emotional support from family and friends; a significant reduction in symptoms of depression; and reduced reactions to all three domains of behaviors of the person with dementia (i.e., memory problems, disruptive behaviors, and depression), although there were no significant changes in the frequency of the behaviors. At twelve-month follow-up assessments, caregivers reported significant improvements in satisfaction with general social support and tangible assistance and reduced reactions to the behavior of the person with dementia (Mittelman and Bartels, 2014).

Importantly, caregivers whose family members with dementia had more severe symptoms and more frequent disturbing behaviors at intake were more likely to participate in the entire intervention and the subsequent follow-up assessments. This suggests that families with the most challenging caregiving situations have the strongest motivation to complete all phases of the NYUCI and may thereby also receive the greatest benefit from it.

Caregivers reported a high level of satisfaction and high degree of perceived value from the counseling sessions. Eighty-one percent said that

participating in the program was very valuable to them. Another 16 percent said that participation was somewhat valuable. Responses indicated that the caregivers felt the program provided crucial education about Alzheimer’s disease, improved their understanding and ability to cope with problem behaviors, and fostered involvement by family members or others to support them in their caregiving role (Paone, 2013).

The Intervention’s Success Factors

Family commitment to the counseling sessions supported the intervention’s success, as did NYUCI developers providing training for

NYUCI consultants. Additionally, ensuring ongoing availability of reimbursement for the intervention supported sustainability.

Family commitment

Family commitment to the counseling sessions is probably the greatest success factor in achieving the outcomes of the original study. Where families fully participated and completed the four family sessions, overall caregiver outcomes were improved (Mittelman and Bartels, 2014). Skype was occasionally used to include family members who were unable to travel to meetings. Because of distance and time constraints, it was very chal-

Table 1. Outcome Changes from Intake to Follow-up Assessment Among Caregivers Who Completed a Follow-up Assessment

Outcome	Mean outcome at intake and follow-up at:					
	4 months		8 months		12 months	
	Intake	Follow-up	Intake	Follow-up	Intake	Follow-up
Caregiver’s self-rated physical health ^a	2.04	1.95	2.01	1.94	1.97	1.93
Caregiver’s symptoms of depression ^b	19.48	18.53**	19.09	17.78**	18.99	18.73
Caregiver’s satisfaction with support						
Social support in general ^c	1.91	1.75	1.92	1.6****	1.92	1.66**
Tangible assistance ^c	1.95	1.86	2.02	1.7***	2.08	1.71**
Emotional support ^c	1.66	1.57	1.73	1.49**	1.71	1.49*
Caregiver’s reaction to the person with dementia’s problem behaviors						
Depressive behaviors ^d	12.32	11.21	12.47	10.06***	12.85	8.75***
Memory problems	11.8	12.1	11.89	10.27***	12.53	9.86****
Disruptive behaviors ^d	7.48	6.27**	7.39	5.72***	7.4	5.34****
Problem behaviors (total) ^d	30.99	29.61	31.06	26.15****	31.89	24.01****
Frequency with which the person with dementia has problem behaviors						
Depressive problems ^d	14.68	13.58	14.83	14.06	15.74	13.19***
Memory problems ^d	14.33	13.87	14.42	14.58	13.29	14.4
Disruptive behaviors ^d	9.62	8.74**	9.53	8.82	10.3	8.62***
Problem behaviors (total) ^d	37.84	36.21	37.89	37.6	38.19	36.29

Table Notes: a Older Americans Resources and Services questionnaire, on which 1 is excellent and 4 is poor; b Center for Epidemiological Studies-Depression scale; c Stokes social network questionnaire, on which 1 is very satisfied and 6 is very dissatisfied; d Revised Memory and Behavior Problems Checklist. * p < 0.10; ** p < 0.05; *** p < 0.01; **** p < 0.001 (Mittelman and Bartels, 2014).

lenging to obtain the necessary involvement of family members in the family sessions. Given the importance of family involvement in the success of the service, Dr. Mittelman and a small business called HealthCare Interactive are conducting an RCT to evaluate the efficacy of telehealth as a means of delivering the NYUCI, with funding from the NIA. Access to information about the Telehealth Dementia-Care Program for Families can be found online at www.nyuci.com. Counselors are specially trained on how to conduct the NYUCI via secure video conferencing.

NYUCI training

Dr. Mittelman and her clinical colleague, Cynthia Epstein, together with Minnesota project staff, developed and delivered the NYUCI consultant training onsite in Minnesota. Ms. Epstein also

One of the NYUCI's most important components is involving family members beyond the primary caregiver.

provided clinical consultation to Minnesota's NYUCI consultants during the first years of the project. Dr. Mittelman, Ms. Epstein, and HealthCare Interactive developed a comprehensive, interactive, online NYUCI provider training and certification program, supported by a grant funded by the NIA. This training is now available to prospective providers, ensuring that the NYUCI will be widely available and that practitioners are appropriately trained (to access this training, go to www.nyuci.com).

Sustainability


Sustainability can be achieved by embedding the NYUCI as a component of usual care within Older Americans Act Title IIIIE services. Minnesota also added it as an approved Elderly Waiver/Minnesota Alternative Care service, thereby accessing stable and ongoing reimbursement.

And Minnesota added a caregiver benefit to the state expansion of the Return to Community initiative, providing additional funding opportunities for services such as the NYUCI.

Residual Benefits to the State of Minnesota

In addition to the well-documented benefits to caregivers of persons with dementia, there were several important residual benefits to the NYUCI program. The intense training needed to become an NYUCI consultant improved the talents and skills of participating Minnesota caregiver consultants; these consultants were better equipped to serve all caregivers and became quite skilled at drawing the family into the circle of care—one of the most important features of the NYUCI.

The dementia education program that was developed formed the basis of Minnesota's Dementia Capability training program, a comprehensive dementia education program that is completed not only by caregiver consultants, but also by other aging services providers whose services touch the lives of people with dementia and their caregivers.

Finally, the data resulting from Minnesota's implementation of the NYUCI documenting the impacts of the service on Minnesota caregivers were useful in obtaining funding from the Minnesota State Legislature to support dementia identification, education, and caregiver support services. 

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The Savvy Caregiver Program: Effective Implementation Through Michigan's Aging Network

By Sally C. Steiner and
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The SCP empowers caregivers and supports persons with dementia, using an effective framework that ensures program fidelity.

In 2008, Michigan's aging services network began providing the Savvy Caregiver Program (SCP), an evidence-based dementia family caregiver intervention (Hepburn et al., 2003; Ostwald et al., 1999) under a federal dementia project from the Administration for Community Living. The project team included an SCP co-developer as a training and evaluation consultant. Early on, practitioners who followed the SCP design reported observable changes among participants over the six-week program: improved grooming, posture, and social interaction. Some caregivers reported benefits from the exercises on mood and self-care, others found comfort in a better understanding of dementia and its impact. Several wrote moving testimonials on evaluations indicating relief and gratitude for their ability to connect with a family member through a new approach (Steiner and Sherman, 2013, 2015). The program not only produced short-term benefits, but also showed positive

outcomes at six months post-intervention. When implemented as designed, the program benefits caregivers and reinforces practitioners who follow the curriculum. Today, the program is provided statewide.

'When implemented as designed, the program benefits caregivers and reinforces practitioners.'

Successful implementation and continuation of a grant-funded program often are elusive yet highly desirable outcomes. This article describes the State of Michigan's efforts to consistently and sustainably provide SCP.

Evidence-based programs should be well-suited to the target population and the provider agencies' capacity (Substance Abuse and Mental Health Services Administration, 2012). Michigan's area agencies on aging (AAA) directors

→ABSTRACT The Savvy Caregiver Program is an evidence-based caregiver intervention for family members caring for a person with dementia who lives at home. It provides dementia education and caregiving skills designed to reduce caregivers' stress and improve caregivers' attitudes. The twelve-hour program shows proven effectiveness. Creating Confident Caregivers trains and supports Michigan's area agencies on aging (AAA) to provide the program as its developers intended. Practitioners receive training, data reports, and technical assistance to implement the program consistently. Michigan adopted the program as an ongoing statewide program. | **key words:** *Savvy Caregiver Program, Creating Confident Caregivers, AAAs, Michigan's Aging and Adult Services Agency*

were aware of the growing presence of persons with possible dementia in the network's home- and community-based services. Michigan's Aging and Adult Services Agency (AASA), the state unit on aging, reviewed evidence-based dementia programs and selected SCP based on several factors: the program's methods and content, AAAs' strengths, and rural caregivers' needs (Smith and Bell, 2005). SCP's format, its person-centered approach, and its proven effectiveness in rural areas matched Michigan's needs and AAA strengths.

The Savvy Caregiver Program

SCP is a program for family caregivers of persons with dementia who live at home. The program is twelve hours' duration (six weekly, two-hour sessions), the ideal group size is six to twelve participants, and more than one family member can attend. The program does not require professional qualifications for practitioners, adding flexibility in rural areas where staffing resources are thin. Although the majority of practitioners are nurses and social workers, people with various backgrounds (e.g., retired professionals, academics, and aging services staff) successfully lead the program. SCP is psychoeducation, which is a proven intervention that combines methods to teach participants new skills and interpersonal attitudes to handle challenging life situations (Authier, 1977; Lukens and McFarlane, 2004). SCP encourages caregivers to acquire problem-solving skills with the goal of reducing interpersonal stress from caregiving. This empowers caregivers and supports persons with dementia, so both can feel calm, safe, and secure. The content is effective, person-centered, and designed for replication (Hepburn et al., 2007).

Program implementation

AAAs were selected for their program-management skills and regional knowledge. Each AAA sets a regional program schedule, selects practitioners, secures host sites, and budgets program

costs. This produces variation in the number of regional SCP programs and allows AAAs to balance resources and need. Under the federal dementia grants, AAAs provided 530 SCP programs serving 4,722 participant caregivers, with an 81 percent retention rate (i.e., attendance at four of six sessions and a 98.8 percent recommendation rate) (Sherman and Steiner, 2016). From mid-2015 to date, AAAs have provided eighty-eight programs with state and federal caregiver funds, serving more than 850 caregivers. In 2014, Michigan's AASA estimated an average program cost of \$1,500 to \$2,300, not including program administration.

'AAAs provided 530 SCP programs serving 4,722 participant caregivers, with an 81 percent retention rate.'

AASA provides practitioner training, technical assistance, and data collection. In 2011, as the project expanded, concerns about consistency and fidelity arose. Program consistency is a practical concern: program implementation must be consistent across providers and over time to avoid confusion. With multiple practitioners, providing the program as intended by the program developers ensures consistency and fidelity.

Program fidelity

Providers must deliver the program with fidelity to obtain the same positive outcomes as the tested program (Breitenstein et al., 2010; Carroll et al., 2007). Few programs measure fidelity implementation (Perepletchikova, Treat, and Kazdin, 2007), yet there is a direct relationship between fidelity and positive program outcomes (Dusenbury et al., 2004). Failure to adhere to the program's core components is known as "drift." Especially in multi-site implementations, drift and fidelity criteria must be clearly defined for practitioners (Mowbray et al., 2003). Without fidelity measurements, there is no way to

determine whether or not the program was implemented as intended (Carroll et al., 2007).

Program adaptations often arise in evidence-based programs and require serious consideration (O'Connor, Small, and Cooney, 2007). AASA allows for careful review of proposed modifications, assessing whether or not the change supports program fidelity. Once approved, all practitioners receive the modification.

Service providers often rely on their own knowledge and hesitate to adopt evidence-based practices, creating tension between the tested program and individual expertise (Rahman and Applebaum, 2010). When practitioners are challenged, the response models the program: provide information, coach for skill development, and guide the practitioner to implement as trained. Not all partners made the shift from a provider-driven service to an evidence-based intervention. In a few cases, practitioner turnover or persistent agency variation concluded project participation. These difficult situations were overshadowed by the growing support for the project and for SCP. Once fidelity is defined, it is evident, as is its absence.

A Fidelity Framework: Creating Confident Caregivers®

AASA developed a framework, Creating Confident Caregivers (CCC) to support and monitor fidelity. CCC addresses three factors: practitioner adherence, practitioner competence, and program differentiation (Mowbray et al., 2003; Perepletchikova and Kazdin, 2005). Adherence is the degree to which practitioners deliver a program as intended by the program developer; competence signifies the interpersonal, group management skills used in delivering the intervention (Breitenstein et al., 2010). Differentiation captures how the intervention differs from other programs along critical dimensions (Dobson and Singer, 2005).

Adherence refers to the program's core elements, for example, programs are designed for a particular group's needs (e.g., SCP focuses



on family caregivers of persons with dementia living at home). CCC clearly defines the target group and trains to that definition. Other core elements are similarly defined and shared with practitioners (Sherman and Steiner, 2016).

Practitioner competence encompasses group and time management skills and participant engagement. Participants provide feedback about the program and practitioners on program evaluations.

Differentiating SCP from other caregiver groups proved essential, because most practitioners and participants have prior group experiences. SCP has a tested curriculum, established timeframe, and sequential activities. It is not a "drop-in" group. Publicizing the weekly format and requiring pre-registration are part of establishing CCC as distinct from other group programs.

CCC developed a cadre of Master Trainers, practitioners with a comprehensive understanding of the program, leadership skills, and mentoring abilities. Master Trainers, certified by the Governor-appointed Commission on Services to the Aging, have assumed regional program

monitoring as part of their duties. The fidelity framework is now embedded into the aging services system (Sherman and Steiner, 2016).

Program outcomes

Program effectiveness is determined by participant outcomes and is a necessary element for sustainability. The project used tested caregiver measures: depressive symptomology (Radloff, 1997), stress and effectiveness (Pearlin et al., 1990), and perceived caregiving self-efficacy (Steffen et al., 2002). Measures were collected prior to the participants’ first session and sent to participants six months post-intervention, with a follow-up mailing to non-respondents.

Cognitive changes during the six months post-program are likely. The initial data analysis of 796 rural caregivers (Steiner and Sherman, 2013) was followed by a second analysis of 835 additional statewide participants (Steiner and Sherman, 2015). Both analyses identified statistically significant increases in caregiver well-being, self-care, and confidence in their abilities to manage their caregiving situation (see Table 1, below). The rural project found a

decrease in symptoms of depression. These results meet the program’s objectives and match findings obtained by others (Hepburn et al., 2007; Samia et al., 2014; Smith and Bell, 2005).

Program sustainability

As the project’s end approached, CCC received strong support from AAA directors and became a state-approved service, allowing AAAs to use state and federal caregiving funds (e.g., Title III-D and III-E) for continuation. CCC retains all evidence-based program elements and reporting requirements, and serves caregivers of all ages and incomes, at no cost to participants. Twelve of sixteen AAAs currently provide CCC.

Conclusion

Dementia caregiving is stressful because of the person’s cognitive losses. SCP is designed to address family caregiver stress and to enhance understanding, expectations, and skills to manage the caregiving situation. Caregivers adapt their expectations of their family member, based on their understanding of dementia


Table 1. Select Descriptive Statistics and T-test Results for CCC Projects

Outcome	Project*	Pre-Test M (SD)	Post Test M (SD)	n	95% CI for Mean Difference	p
Respond appropriately to disruptive behaviors	1	2.96 (.82)	3.1 (.74)	455	-4.4-0.9	<.01
	2	2.84 (.72)	3.3 (.71)	624	-4.3-1.1	<.001
Able to be more firm	1	2.55 (.77)	2.74 (.77)	569	-.26-.16	<.001
	2	2.64 (.77)	2.78 (.80)	817	-.19-.07	<.001
Keep person with dementia more engaged	1	2.50 (.82)	2.80 (.75)	552	-.27-.13	<.001
	2	2.55 (.80)	2.73 (.82)	811	-.23-.12	<.001
Life satisfaction	1	4.2 (1.5)	4.53 (1.5)	598	-.39-.13	<.001
	2	4.2 (1.5)	4.4 (1.6)	815	-.31-.08	<.01
Depressive symptoms	1	13.0 (8.2)	12.2 (8.1)	405	.03-1.4	<.05
	2	14.0 (9.0)	13.8 (9.1)	568	-.02-.05	ns

*Project 1 = rural; Project 2 = statewide sites.

(knowledge). They learn to modify tasks, situations, and communication to meet the person's abilities (skills). They learn to reconnect with their family member (contented involvement) while caring for their own health (self-care) to make caregiving less stressful (attitude). Throughout the program, the emphasis is on helping caregivers learn to manage the tasks of caregiving, not the person, so that both can feel calm, safe, and secure.

Evidence-based programs face challenges if the replication program is to deliver the same outcomes as the original program. To obtain positive outcomes, fidelity must be defined, communicated, and measured. CCC relied on consistent training, practitioner support, and program measures to boost fidelity (Dusenbury et al., 2004). The growing emphasis on evidence-based programs adds significance to fidelity

monitoring (Mowbray et al., 2003). Funders, policy makers, providers, and practitioners share a stake in the ability to produce positive participant outcomes. SCP is effective; the CCC framework ensures that effectiveness. 

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Authors' Note

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