

## HEALTH CARE REFORM

# Translation of a Dementia Caregiver Support Program in a Health Care System—REACH VA

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**Background:** Based on the National Institute on Aging/National Institute of Nursing Research Resources for Enhancing Alzheimer's Caregiver Health (REACH) randomized controlled trial (REACH II), REACH VA (Department of Veterans Affairs) was the first national clinical translation of a proven behavioral intervention for dementia caregivers, running from September 2007 through August 2009. This article describes the population and outcomes of the REACH VA translation of REACH II into the VA.

**Methods:** Clinical staff members from 24 VA Medical Center Home-Based Primary Care programs in 15 states delivered the intervention to stressed caregivers of patients with dementia. Like REACH II, the 6-month REACH VA intervention, structured through a protocol and individualized through a risk assessment, targeted education, support, and skills training to address caregiving risk areas of safety, social support, problem behaviors, depression, and health through 12 individual in-home and telephone sessions and 5 telephone support group sessions. Staff members of the Memphis VA Medi-

cal Center, Memphis, Tennessee, collected data on burden, depression, health and healthy behaviors, caregiving frustrations, social support, dementia-related behaviors, and time spent providing care and on duty.

**Results:** From baseline to 6 months, caregivers reported significantly decreased burden, depression, impact of depression on daily life, caregiving frustrations, and number of troubling dementia-related behaviors. A 2-hour decrease in hours per day on duty approached significance. Caregivers (96%) believed that the program should be provided by the VA to caregivers.

**Conclusions:** This clinical translation achieved outcomes similar to the REACH II randomized controlled trial, providing clinically significant benefits for caregivers of a veteran with a progressive dementing disease. This model of caregiver support can inform public policy in providing assistance to caregivers.

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**I**N THE UNITED STATES, ALMOST 11 million caregivers provide 12.5 billion hours of care yearly to persons with Alzheimer disease, at a value of almost \$144 billion.<sup>1</sup> The unpaid value of their care is in addition to long-term care costs, which were \$178 billion in 2006.<sup>2</sup> In its 2008 report *Retooling for an Aging America: Building the Health Care Workforce*, the Institute of Medicine argues that family members are

## See Invited Commentaries at end of article

an integral part of the health care workforce and must have the essential data, knowledge, and tools to provide high-quality care.<sup>3</sup> Currently, caregivers frequently lack the skills to manage patient behaviors and their own stress, both of which are critical to caregiving in the home. Their lack of skills can lead to adverse physical and psychological consequences such as de-

pression, anxiety, sleep disturbance, hospitalization, mortality, and increased risk of patient institutionalization.<sup>4,5</sup>

Caregiving interventions can help caregivers. Based on the stress health process model,<sup>6</sup> the multisite National Institute on Aging/National Institute of Nursing Research randomized controlled trial (RCT), Resources for Enhancing Alzheimer's Caregiver Health (REACH II), provided education, support, and skills building in home and by telephone. Caregivers showed significant improvement in burden, depression, health and self-care, social support, and management of patient behaviors and gained 1 extra hour per day not spent in caregiving tasks.<sup>7,8</sup> There was a strong call to implement REACH II nationally.<sup>9</sup>

Although the goal of translation is to extend research findings into clinical practice, translation outcomes may not match those in clinical trials.<sup>10,11</sup> In translation, there are barriers to adoption and implementation, application of interventions to

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**Table 1. Department of Veterans Affairs Medical Center (VAMC) Facilities Participating in REACH VA**

Facility
VA Northern California HCS, Sacramento
Denver VAMC, Denver, CO
VA Connecticut HCS, Newington
Atlanta VAMC, Atlanta, GA
Charlie Norwood VAMC, Augusta, GA
Ann Arbor VAMC, Ann Arbor, MI
Battle Creek VAMC, Battle Creek, MI
Minneapolis VAMC, Minneapolis, MN
Albuquerque VAMC, Albuquerque, NM
Samuel S. Stratton VAMC, Albany, NY
Bath VAMC, Bath, NY
VA New York Harbor HCS, New York, NY
Northport VAMC, Northport, NY
Syracuse VAMC, Syracuse, NY
Durham VAMC, Durham, NC
Cincinnati VAMC, Cincinnati, OH
Butler VAMC, Butler, PA
Philadelphia VAMC, Philadelphia, PA
VA Pittsburgh HCS, Pittsburgh, PA
Memphis VAMC, Memphis, TN
James H. Quillen VAMC, Mountain Home, TN
Michael E. DeBakey VAMC, Houston, TX
Salt Lake City VAMC, Salt Lake City, UT
Huntington VAMC, Huntington, WV

Abbreviations: HCS, health care system; REACH, Resources for Enhancing Alzheimer's Caregiver Health.

inappropriate populations, intervention drift, and risk of unexpected adverse events as the population receiving the intervention expands.<sup>10,11</sup> These problems can be more difficult in behavioral interventions, which involve more time, personnel, training, and preparation than pharmacological interventions.

To investigate the feasibility of extending caregiver assistance into the Veterans Health Administration (VHA), VHA Patient Care Services, National Caregiver Support Program, through Public Law 109-461, funded a clinical translation of the REACH II RCT from September 2007 through August 2009. Although an evaluation was included, funding for the evidence-based translation did not include the components of an RCT design (eg, control group), the intervention's effectiveness having been previously established in an RCT.<sup>7</sup>

Beginning in 2007, REACH VA (Department of Veterans Affairs) was the first national clinical translation of a proven dementia behavioral intervention covering multiple states and facilities. Before this national translation, in 2004, the Administration on Aging funded 4 state-based REACH translations in California, Florida, Tennessee, and Alabama. Two were REACH II translations. The Alabama REACH II translation, with a shortened intervention series, became the REACH OUT model.<sup>12</sup> In 2008, the Alzheimer Disease Supportive Services Program of the Administration on Aging funded REACH translations in Florida, Georgia, North Carolina, and Arizona; two of these translations use the REACH VA protocol and materials. This article describes the population and outcomes of the REACH VA translation of REACH II into the VA.

## METHODS

### SETTING

Through the auspices of the VHA's Office of Home and Community Care in Geriatrics and Extended Care, REACH VA was based in Home-Based Primary Care (HBPC) programs, which provide primary and specialized care to home-bound veterans. Members of the HBPC staff from 24 facilities in 15 states (**Table 1**) were trained and certified using LiveMeeting by members of the staff of the Memphis VA Medical Center (VAMC), Memphis, Tennessee, including Memphis REACH investigators (L.O.N. and J.M.-A.) as well as other REACH site investigators (Lou Burgio, David Coon, Sara Czaja, and Dolores Gallagher-Thompson). The HBPC staff members provided the intervention in addition to their usual clinical duties. Staff training took place from February 2008 to January 2009 and recruitment from February 2008 through January 2009. Because of the short translation time frame, facilities were asked to recruit 5 patient/caregiver dyads from their caseloads.

### PARTICIPANTS

The HBPC staff members selected patients and caregivers who fit the REACH II<sup>7</sup> inclusion/exclusion criteria, including coresident family caregivers, providing 4 hours or more of care per day for at least 6 months, and endorsing at least 2 caregiving stress behaviors from a list (overwhelmed, often needing to cry, angry/frustrated, cut off from family/friends, moderate/high levels of stress, and declining health). Patient inclusion required Alzheimer disease or related dementia and at least 1 activities of daily living limitation or 2 or more instrumental activities of daily living limitations. Patients who were too ill (eg, bed bound with severe dementia, 3 hospitalizations in past year, planned institutionalization) were excluded.

### CONSENT

The institutional review boards of the Memphis VAMC and participating facilities ruled that REACH VA, as a translation of a proven intervention that was not collecting generalizable data, was not research. Caregivers gave signed permission for Memphis VA staff members to call and collect data.

### INTERVENTION

Like REACH II, the 6-month REACH VA intervention included nine 1-hour individual home sessions, three 0.5-hour individual telephone sessions, and five 1-hour monthly telephone support group sessions. The intervention included education, support, and skills training to address 5 caregiving risk areas: safety, social support, problem behaviors, depression, and caregiver health.

The intervention was structured through a protocol that specified activities to occur at each session and was individualized using a risk assessment. The interventionist taught problem solving and provided action-oriented behavioral strategies to address caregiving problems or patient behaviors identified by the risk assessment using a caregiver notebook. The notebook was written at a fifth-grade reading level, with educational information and practical strategies for 30 behavioral and 18 stress/coping topics that could be personalized for the caregiver. The interventionist also provided training on stress management (signal breath, stretching, guided imagery, pleasant events, and mood management).

The structured telephone support group sessions with 5 to 6 caregivers and a leader provided support, skills, and educa-

tion on self-care, resources, financial and legal issues, and communication with patient and service providers. The group leader used the group members' risk assessments to target examples during the sessions.

The Memphis VAMC investigators (L.O.N. and J.M.-A.) condensed voluminous REACH II materials into a manual of operations/training manual, interventionist and support group leader manuals, and a caregiver notebook, which each participating facility staff member received. Notebooks were also provided for each caregiver. Memphis VAMC staff members provided regular coaching calls to facilities and were available for consultation.

There were 3 differences in implementation from REACH II to REACH VA. First, REACH II computer-assisted screen telephones that provided information to caregivers and were used for support group calls were not used in REACH VA because of the expense of purchasing and programming telephones throughout the country. Second, in REACH II, after identification of a problem, the interventionist would return to the office to develop an individualized behavioral prescription in consultation with senior staff members, which would be delivered at the next visit. For REACH VA, because the interventionists were located at multiple facilities and would not always have access to dementia experts, all behavioral strategies were listed in a caregiver notebook. For sessions at which a new problem was identified or a problem solution modification was needed, interventionist and caregiver would discuss and highlight strategies to be tried, thus eliminating the time lag between problem identification and presentation of solutions. Third, the 21-item REACH VA risk appraisal, a component of overall risk assessment, was streamlined from the 51-item REACH II risk appraisal. After REACH VA started, a REACH II working group finalized a 16-item risk appraisal measure; this measure has a Cronbach  $\alpha$  of 0.65.<sup>13</sup> Both the REACH VA risk appraisal and the revised REACH II risk appraisal measure target education, safety, self-care and health behaviors, social support, caregiving stress, and caregiving frustrations. The VA risk appraisal asks additional questions that are important to the VHA system (eg, advanced care planning, backup for the caregiver if he or she is incapacitated, interactions with the patient's health care providers).

## VHA INTERVENTION STAFF

There were 78 staff members who were certified as an interventionist ( $n=35$ ), a support group leader ( $n=12$ ), or both ( $n=31$ ); however, only 53 staff members actually performed the intervention. For these, education ranged from associate to doctoral degrees, with 44 staff members holding a master's degree or higher. Most ( $n=51$ ) were social workers, psychologists, or nurses.

## MEASUREMENTS AND OUTCOME MEASURES

Baseline data were collected by the facility interventionist from the caregiver as part of the risk assessment during the first home visit. Memphis VAMC staff members, who had not had contact with the caregiver, collected follow-up and program evaluation data by telephone. Data collection took approximately 30 minutes. Intervention components, times, and topics were recorded by the interventionists.

Caregiver and veteran demographics included age, sex, race/ethnicity, marital status, education, relationship, and income (collected from the VHA Austin Automation Center and Veterans Benefits Administration for 107 veterans). Baseline veteran cognitive status was assessed using the facility-preferred instrument, with the Mini-Mental State Examination<sup>14</sup> used for 40.9% of the veterans. The 12-item Zarit Burden Interview<sup>15,16</sup> measured caregiver burden. Higher scores indicated greater burden. The Pa-

tient Health Questionnaire<sup>17</sup> assessed caregiver depression. Nine items were summed to characterize minimal to high/severe depression. Caregivers were also asked about the difficulty or impact symptoms caused at work, home, or with others, with higher scores equaling greater difficulty. Caregiver health from the Medical Outcomes Study Short-Form 36<sup>18</sup> was scored on a 5-point scale. Higher scores indicated better health.

The 21-question risk appraisal, adapted from REACH II,<sup>13</sup> assessed caregiving risk areas of education, advanced care planning, safety, health and healthy behaviors, social support, and caregiving frustrations. Five safety questions examined veteran access to dangerous objects, driving, wandering, smoking while alone, or being left home alone. Higher scores indicated greater safety risk. Five questions examined caregiving negative health behaviors of weight change, missed appointments, activity, eating, and medications. Higher scores indicated increased health risk. Three social support items assessed satisfaction with help and emotional support<sup>19</sup> and whether the caregiver had someone to take over care if needed. Higher scores indicated increased social support risk. Three items focused on caregiver stress or difficulty with toileting, activities of daily living, and working with the patient's health care providers. Higher scores indicated greater difficulty. Two items assessed caregiver frustrations (eg, feel like yelling at or hitting patient).<sup>12</sup> Higher scores indicated greater frustrations.

Twenty-five problem behaviors linked to caregiver notebook topics were assessed as occurring or not during the past month. For each behavior present, the caregiver was asked about bother or concern. Measures of vigilance from the Caregiver Vigilance Scale<sup>8,20</sup> included the time that the caregiver spent performing tasks for the veteran and the overall time spent "on duty" per day.

Caregiver outcomes were those used in REACH II and included differences between baseline and 6-month follow-up for measures of caregiving risk. Clinical variables included burden, depression, health, health behaviors, and number of and bother with care recipient behaviors. Caregiving variables included safety, social support, caregiving difficulties, caregiving frustrations, daily time spent on duty, and daily time spent providing actual care.

Program evaluation assessed satisfaction with individual and telephone support group sessions, quality of service, information, program components (eg, behavior management), number of interactions, and whether caregivers perceived benefit, separate from standardized measures. Caregiver comments were also collected.

## DATA ANALYSIS

Because REACH VA was a clinical translation with no control group, an RCT analysis plan (eg, sample size and power calculations, intent to treat, treatment failure analysis) was not appropriate. Data analysis used mixed-effects models with unstructured correlation to compare baseline and 6-month follow-up scores to estimate the fixed-effect parameter of change over time. Each outcome measure was treated as independent of the others. Parameters were summarized as means with 95% confidence intervals.  $P$  values less than or equal to .05 were considered statistically significant, and those between .05 and .10 were considered to document trends that approached, but did not attain, statistical significance. Outcome analysis included all participants except for 22 caregivers who were bereaved. Baseline demographic and clinical characteristics were compared between those who completed and those who were unavailable for follow-up using  $\chi^2$  tests or independent-samples  $t$  tests, as appropriate.

Clinical significance, ie, effect size, is an estimate of the findings' substantive magnitude or clinically meaningful outcomes, while statistical significance is an estimate of the rep-

**Table 2. Baseline Characteristics of 127 REACH VA Caregivers and Care Recipients**

Variable	Baseline, Mean (SD) or %
Caregivers	
Demographic variables	
Age, y	71.6 (11.6)
Female	93.7
White	78.0
Married	85.8
Education, y	12.0 (3.6)
Relationship to veteran	
Spouse	80.3
Child	15.0
Rural	19.7
Clinical variables	
Burden	17.6 (9.7)
Depression	7.8 (5.9)
Depression impact	0.8 (0.9)
General health	2.7 (1.0)
Health behaviors	2.9 (2.0)
Behaviors	11.9 (4.4)
Bother with behaviors	6.9 (5.0)
Caregiving variables	
Safety	1.3 (1.0)
Social support	1.9 (1.6)
Caregiving difficulties	1.6 (1.4)
Caregiving frustrations	1.3 (1.0)
Time per d on duty, h	20.7 (6.2)
Time per d providing care, h	9.6 (5.5)
Veteran care recipients	
Demographic variables	
Age, y	83.4 (6.2)
Female	0.9
White	78.0
Married	85.0
Income, \$	31 114 (89 378)
Clinical variable	
Mini-Mental State Examination	14.8 (8.1)

Abbreviations: REACH, Resources for Enhancing Alzheimer's Caregiver Health; VA, Department of Veterans Affairs.

licability of findings. For statistically significant comparisons, an effect size (d) of at least 0.2 SD improvement was considered clinically significant. This cut point is consistent with effect sizes reported for psychosocial interventions, which are generally small to medium.<sup>5</sup> Effect sizes were estimated as mean change relative to estimated population standard deviation.<sup>21</sup>

## RESULTS

### PARTICIPANTS

A total of 127 caregivers were enrolled at 24 facilities. Because HBPC staff members recruited caregivers of their own patients, the number who declined or were not appropriate is unknown. HBPC is patient focused, so when the veteran died or was institutionalized, the caregiver was discontinued from individual sessions but allowed to continue in support groups. Twenty-nine caregivers (22.8%) did not provide 6-month follow-up data because of placement (n=4), discontinuation (n=13), or unavailability for follow-up (n=12). There were no significant baseline differences between these caregivers and those who provided 6-month follow-up data.

As shown in **Table 2**, the caregivers were approximately 72 years old, primarily white, and wives. The veterans were approximately 12 years older than the caregivers, with a mean age of 83 years. The 52 veterans who were assessed with the Mini-Mental State Examination<sup>14</sup> had moderate dementia.

### OUTCOMES

At enrollment, the caregivers reported being overwhelmed (86%), feeling like crying (80%), being frustrated as a result of caregiving (89%), feeling cut off from family/friends (56%), being lonely (53%), and having worse health than last year (39%). On a 10-point scale, with 10 representing extremely stressed, 60% of caregivers rated stress at 6 or higher.

When outcomes were examined from baseline to follow-up (**Table 3**), the caregivers showed significant improvements in burden, depression, impact of depression on daily lives, and caregiving frustrations (screaming or yelling, feeling like hitting or slapping). The difference of almost 2 hours in the amount of time per day spent on duty trended toward significance. Clinical significance, measured by effect size (d), ranged from 0.20 to 0.33 for statistically significant findings.

At enrollment, caregivers reported that, in the past month, the veteran exhibited memory problems (87%) and behavior problems such as arguing or waking the family up at night (61%). Most (78%) reported having to help with daily activities such as bathing. From baseline to program end, caregivers reported 1 fewer troubling behavior exhibited by the veteran, which was a significant decrease (Table 3). These behaviors included difficulties with activities of daily living such as bathing and dementia-related behaviors such as repeated questions.

### CAREGIVER SATISFACTION AND BENEFIT

When subjective benefit was examined (**Table 4**), caregivers felt that the program benefited them, helped them better understand the disease and their role, and increased their knowledge and ability to provide care. The caregivers felt that the telephone support groups were a way to align with others who were in similar circumstances, while learning and teaching from experience. While both individual sessions and support groups were positively received, caregivers reported that they would like more in-home sessions.

### COMMENT

This translation was designed to demonstrate that a proven behavioral intervention for dementia caregivers could be successfully translated into clinical practice across multiple facilities with different types of staff delivering the intervention. From baseline to follow-up, the caregivers reported significantly improved burden, frustrations that could lead to abuse, depression and the effect of depression on daily life, and number of troubling patient behaviors. A decrease of 2 hours per day on duty trended toward significance. All statistically significant findings



**Table 3. Repeated-Measures Mixed-Model Analyses for Caregiver Outcomes Over 6 Months<sup>a</sup>**

Variable	Estimated Improvement (SE)	95% Confidence Interval	P Value	Effect Size
Burden	2.88 (0.86)	1.17 to 4.59	.001	.33
Depression	1.49 (0.55)	0.39 to 2.59	.009	.26
Depression impact	0.29 (0.11)	0.07 to 0.51	.01	.26
General health	0.13 (0.12)	−0.11 to 0.37	.27	.11
Health behaviors	0.20 (0.20)	−0.19 to 0.59	.30	.10
Safety	0.06 (0.13)	−0.20 to 0.32	.65	.04
Social support	0.11 (0.18)	−0.25 to 0.46	.56	.06
Behaviors	1.02 (0.49)	0.04 to 2.00	.04	.20
Bother with behaviors	−0.18 (0.63)	−1.43 to 1.08	.78	.03
Caregiving difficulties	0.12 (0.18)	−0.24 to 0.48	.51	.07
Caregiving frustrations	0.26 (0.09)	0.09 to 0.44	.003	.30
Time on duty, h	1.75 (0.92)	−0.09 to 3.58	.06	.19
Time providing care, h	0.96 (0.63)	−0.29 to 2.20	.13	.15

<sup>a</sup>The analyses included 105 caregivers. Bereaved caregivers were excluded.

also met the criteria for clinical significance (with effect sizes  $\geq 0.2$ ). The findings from this translation are similar to those from the REACH II RCT, which also reported significantly improved burden, depression, improvement in patient behaviors, and 1 extra hour per day not spent in caregiving tasks.

These findings have both clinical and system implications. One promising finding is the lessened potential for abuse shown in decreased caregiving frustrations such as yelling or hitting. An estimated 1 to 2 million older persons are mistreated each year, with approximately 16% of cases reported.<sup>22</sup> The VHA caregiving dyads had typical risk factors for abuse, eg, shared living arrangements, dementia, hostility, and dependency.<sup>22</sup> Candid caregiver comments suggest that the REACH VA intervention may help caregivers learn to manage troubling behaviors and stress before a crisis occurs.

A second important finding is the reduction of caregiver burden and depression as well as the decrease in dementia behaviors exhibited by the patient. Improving caregivers' ability to continue to provide care has significant economic consequences for society. For example, research in Minnesota has shown that a 1% decline in informal (family) care provided to seniors costs the state \$30 million per year in long-term care.<sup>23</sup> Having a family caregiver can reduce nursing home placement.<sup>24</sup> Dementia caregivers' stress and burden predict institutionalization,<sup>25</sup> and reducing caregiver stress may delay or avoid nursing home placement.<sup>26</sup>

Despite a clinical and policy need for behavioral approaches to dementia caregiving, translations of randomized clinical trial interventions into effective real-world applications with durable findings<sup>9</sup> are infrequent. As far as we know, REACH VA is the first translation of an evidence-based dementia caregiving behavioral intervention into a health care system. The importance of behavioral interventions is that the skills and knowledge taught to caregivers can continue to be used after the formal intervention is ended to problem solve caregiving difficulties as they arise. We have seen this pattern in caregivers from REACH II, which ended 6 years ago. Caregivers have contacted us informally to report that they continue to use behavioral strategies, stress reduc-

**Table 4. Caregiver Reported Benefits for REACH VA**

Program Component and Area of Benefit	% of Caregivers Reporting Benefit (95% Confidence Interval)
Overall intervention	
General benefit	97.8 (94.7-100.0)
Better understanding of disease and caregiving role	92.1 (86.5-97.7)
Increased confidence in dealing with veteran behavior problems	93.3 (88.1-98.5)
Improved ability to care for the veteran	91.0 (85.1-97.0)
Improvement in veteran's life	82.0 (74.0-90.0)
Individual sessions, home visits	
Improved skills	96.6 (92.9-100.0)
Increased knowledge	96.6 (92.9-100.0)
Telephone groups	
Improved skills	79.6 (68.9-90.4)
Increased knowledge	81.5 (71.1-91.8)

Abbreviations: REACH, Resources for Enhancing Alzheimer's Caregiver Health; VA, Department of Veterans Affairs.

tion exercises, and problem solving to take on new challenges. This model, which was structured through a protocol and targeted to individual risks, is workable for closed staff model health care systems, such as VHA, where ongoing contact between providers and caregivers provides a sounding board and support as caregivers continue to practice the intervention's principles.

REACH VA is also appropriate for primary care, particularly geriatrics primary care, in which there is an ongoing relationship between patient, family, and provider. With rising interest in patient-centered medical home concepts of ongoing care coordination, REACH VA could provide a tool for primary care providers to help caregivers manage their family members at home. The intervention is designed to be staff user friendly, with scripts, talking points, and all caregiver materials collected in 1 place, and is currently being implemented in community settings by hospitals, universities, area agencies on aging, and other organizations. The intervention is also being developed for use in a facility or office setting, rather than in the home, and for delivering all ses-

sions over the telephone. The number of Americans with dementia is projected to increase during the next several decades. Because the caregiving role generally falls to the family,<sup>27</sup> caregivers will be searching for answers and assistance in managing both their family member's behavioral concerns and their own responses.

There were limitations that should be mentioned. The number of dyads (n=127) was relatively small, partly because of the short amount of time for the demonstration project, the inclusion of intervention duties in addition to regular duties, and the difficulty in assigning workload credit in a system that was prohibited from treating nonveterans. Also, many interventionists were in newly created HBPC psychology positions and were learning new jobs as they took on the REACH VA intervention. During this time, there was an increase in staffing to work with returning Iraq and Afghanistan veterans, and several interventionists and group leaders took these positions. Staff turnover led to repeated training sessions and a time lag in enrolling caregivers. A final limitation is that patient care costs are not yet analyzed. Adjudication of VHA utilization data and assignment of cost estimates, which is done centrally for all VA projects, can take from 6 months to more than 1 year.

This model of structured and individualized caregiver support can inform public policy. REACH VA was one of the exemplary geriatrics projects submitted by the VA and the National Institute on Aging to the Senate Special Committee on Aging and selected by the committee to be used "to inform aging policy and to serve as a catalyst for continued progress in addressing the most pressing concerns of the nation's older population."<sup>28</sup> Caregiver support through the health care system is an idea whose time has come. As health care systems have become more lean, family caregivers have taken on more demanding and complex kinds of care for longer periods, and they are the repository of the "institutional memory" of their family member's illness.<sup>29</sup> The VA is in the forefront of this movement. In May 2010, Public Law 111-163 Caregivers and Veterans Omnibus Health Services Act of 2010 was signed into law. It will allow the VA to provide unprecedented benefits to caregivers who support the veterans who have sacrificed for this nation. The VA is discussing the feasibility of implementing national options, including REACH VA, for caregivers. On a local level, several VAMCs that have not previously implemented REACH VA have requested training. This growing interest in assisting caregivers reflects the statements of a REACH VA interventionist who said, "Investment in the caregiver is a direct investment in patient care."

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Nichols. *Critical revision of the manuscript for important intellectual content:* Nichols, Martindale-Adams, Burns, Graney, and Zuber. *Statistical analysis:* Graney and Zuber. *Obtained funding:* Nichols and Martindale-Adams. *Administrative, technical, and material support:* Nichols, Martindale-Adams, and Zuber. *Study supervision:* Nichols and Martindale-Adams.

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## INVITED COMMENTARY

# Fulfilling Our Obligation to the Caregiver

## It's Time for Action

Family caregivers are relied on by health care systems, yet, at the same time, neglected. They provide the bulk of care given to the more than 5 million persons with Alzheimer disease in the United States. They are expected to take on increasing amounts of complex care in the home, a task that requires entire health care teams in institutional settings. Their work keeps people out of nursing homes, while providing high-quality care at minimal cost to public and private health care systems. In return, their efforts and their well-being too often go ignored.

Family caregivers are often thrust into this position, with no training and little support, resulting in increased prevalence of adverse physical, social, and psychological outcomes. Caregivers are at greater risk for depression and anxiety. They are less likely to engage in preventive health measures, and there is some evidence suggesting an increased risk of mortality. Although caring for those with dementia requires considerable out-of-pocket costs, many family caregivers stop working in order to care for their loved ones. In real-world settings, little has been done to decrease these risks to caregivers.

What can public and private health care systems do to foster healthy caregiving? Providing family caregivers information, skills, and support systems to help care for patients with dementia is one way to approach this prob-

lem. Several different caregiver interventions have now shown improvements in caregiver well-being in randomized control trials. One intervention took the form of a collaborative care approach led by advanced practice nurses who worked with caregivers and were integrated within primary care.<sup>1</sup> Another was REACH II (Resources for Enhancing Alzheimer's Caregiver Health), an individualized multicomponent home- and telephone-based intervention that was designed to enhance the caregiver's coping skills and management of dementia-related behaviors.<sup>2</sup> The REACH II intervention significantly improved caregiver quality of life in terms of burden, depression and emotional well-being, self-care and healthy behaviors, social support, and management of care recipient problem behaviors. It also resulted in 1 hour less per day that caregivers were required to provide direct care, giving them a much needed respite in their busy day.

A remaining question is whether these caregiver interventions can be implemented in real-world health care settings outside the randomized controlled trial environment. In this issue of the *Archives*, Nichols and colleagues show with the REACH VA (Department of Veterans Affairs) study that the answer is a resounding yes. Twenty-four Home-Based Primary Care programs within the Veterans Health Administration (VHA) were able to put into practice a modified REACH II intervention. As in REACH

II, the results improved caregiver outcomes, including reductions in caregiver frustration, burden, and depression.

Some clinicians may argue that health care systems do not have a duty to provide caregiver support, as their contractual obligation is with the patient and not the caregiver. However, if health care systems are going to increasingly rely on family caregivers to deliver complex care, then they have the obligations to aid caregivers in this task and to reduce the personal costs associated with it.<sup>3</sup> We now have compelling evidence that interventions focused on the caregivers are beneficial and can be practically implemented in existing health care systems such as the VHA. It is time that we fulfill our obligations to caregivers.

The REACH II model should not suffer the same fate as many other proven geriatric models that were not disseminated widely, and there are hopeful indications that it may not. Congress has already passed a law providing supportive services such as training, education, and counseling assistance for caregivers of veterans (Public Law 111-163). The VHA should now take the next step by ensuring that these services are universally available and based on proven multicomponent caregiver interventions such as REACH VA. Other health care systems should follow its lead.

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## INVITED COMMENTARY

# A Model Program for a Devastating Disease

## Important Content and Methods Issues in Translating Research Into Practice

In this issue of the *Archives*, Nichols and colleagues report on the clinical translation of the REACH VA (Resources for Enhancing Alzheimer's Caregiver Health/Department of Veterans Affairs) program of training and support for caregivers with family members who have Alzheimer disease and related dementia. Their article is important for both content and methodological reasons. The authors describe the results of a national dissemination effort to make this evidence-based program available to caregivers of VA patients across the country. Their encouraging results promise some relief to the increasing number of family members and patients who are coping with Alzheimer disease and dementia, chronic conditions that result in large health care costs, have an enormous impact on the quality of life of families, and are almost certain to increase in prevalence given the aging of our population.

One reason that Nichols and colleagues' work is noteworthy is that it focuses on training and providing support to family members who are caregivers, a population and a resource that are both highly motivated and often neglected by modern medicine. The sheer magnitude of

the REACH VA effort is impressive, involving training and implementation in 29 sites from 24 separate VA facilities in 15 states. There are important lessons to be learned about both program content issues and dissemination research methods. I hope that the authors will expand on these issues and methods in future publications and focus on several others that are mentioned below.

As an implementation and dissemination researcher, I infer that their success in such a challenging endeavor may be attributable at least in part to 4 program content factors. The first factor is that they have made the training materials highly accessible and the intervention replicable through the training manuals, support group leader manuals, and caregiver notebooks. Going beyond research protocols to develop easy-to-use resources such as those that address common implementation issues is one important key to success. A second factor is the mass customization<sup>1</sup> that develops through the use of their risk appraisal and caregiver notebooks, which allow caregivers to tailor the structured program to fit their unique circumstances. A third factor, common to most successful self-management and behavior change interventions, is a focus on problem solv-



ing<sup>2</sup> so that caregivers have the capacity to respond to new challenges that will arise in the future. Finally, I suspect that the fourth factor, which involves the ongoing contact that is provided through the combination of home visits and individual and group support telephone calls, is important in keeping caregivers connected to the program and to each other for ongoing support. Our understanding of how REACH VA works would be advanced if future research could support or refute these hypotheses.

The article by Nichols and colleagues is also exemplary in terms of several dissemination research evaluation features. The relatively comprehensive yet practical assessment procedures provide a good model in that they include outcomes that are important to family members, patients, clinicians, and policy makers. In particular, assessment of quality-of-life outcomes, unanticipated events, validated measures of depression and burden, patient behaviors and social support, and, finally, estimated time spent in caregiving provide an efficient yet broad battery of outcomes. Transparent reporting of results<sup>3,4</sup> is another strength: the authors characterize their results in terms of measures of effect size, criteria for clinical (in addition to statistical) significance, and comparison to earlier, more tightly controlled research studies. Finally, including the broad array of clinical sites and geographical areas helps to ensure that results will generalize across settings and local conditions.

Of course, no study is perfect, and it would have helped if Nichols and coauthors had included imputation analyses that modeled different assumptions regarding missing values, more in-depth reporting on variation and implementation across settings and caregivers, and, especially, more information on the percentage of facilities, staff, and caregivers that declined to participate as well as their characteristics and reasons for declining. These issues are likely best addressed using qualitative or mixed-methods approaches and may be reported separately. The primary factor that is missing from a policy maker's viewpoint is an economic analysis that would include intervention costs from different perspectives and sensitivity analyses reflecting different levels of intensity, scale, and other assumptions.<sup>5,6</sup> It appears that at least patient care cost data were collected and will be reported in future articles.

Many readers will likely be concerned that the study did not use a randomized or cluster randomized design. Without knowing the reasons why the authors apparently did not believe that randomization or other more rigorous designs, such as multiple baseline across settings or time series designs,<sup>7,8</sup> were possible, it is hard to judge this issue. My perspective is that while this is a limitation, the real-world aspects and replication features that were built into the evaluation by the inclusion of such a diverse group of settings, staff members, and areas of the country more than overcome it. It is exceedingly unlikely that extraneous or temporal factors would have produced improvement across the vast majority of the settings.

Like all good research, Nichols and colleagues' study also raises more questions, and I hope that the authors will

pursue the following issues in future reports. Study of caregivers, patients, staff members, and settings that did especially well (and poorly) through mixed-methods research would likely produce important directions for further program refinement. Although the 6-month data are very encouraging, longer-term follow-up data on outcomes and reports of the extent that facilities have continued, modified, or discontinued their REACH VA programs 2 years from now would be even more helpful. Finally, comparative effectiveness research comparing the outcomes, costs, and benefits of implementing the program in different ways, eg, via online minimal contact vs community health workers vs nurse or health educator implementation, would also be valuable.

In summary, Nichols and coauthors' innovative article illustrates several key points about what some leaders are beginning to call T3 and T4 research,<sup>9</sup> which involves dissemination to broad audiences and populations. It demonstrates how research can successfully be translated into practice by partnering with implementation agents, by achieving a balance between fidelity to intervention protocols and customization to local settings, and by using feasible yet broad evaluation methods. We need more such efforts to bend the cost curve, to enhance quality of life, and to improve health outcomes.

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