Translation of Two Evidence-Based Programs for Training Families to Improve Care of Persons With Dementia

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The need for evidence-based non-pharmacological community programs to improve care of older adults with dementia is self-evident, considering the sheer numbers of affected individuals; the emotional, physical, and financial toll on affected individuals and their caregivers; the impact on our health care system; and the growing availability of evidence regarding the potential for psychosocial interventions to enhance care and decrease costs. To address this need, the Administration on Aging has begun funding translation of evidence-based programs into community settings. Two programs, Reducing Disability in Alzheimer’s Disease and STAR-Community Consultants (STAR-C), were selected by the Ohio Department of Aging (in collaboration with the Alzheimer’s Association Chapters in Ohio) and the Oregon Department of Health Services (in partnership with Area Agencies on Aging and the Oregon Chapter of the Alzheimer’s Association) to be implemented by their staff. Both programs are designed to improve care, enhance life quality, and reduce behavioral problems of persons with dementia and have demonstrated efficacy via randomized controlled trials. This article addresses the developmental and ongoing challenges encountered in the translation of these programs to inform other community-based organizations considering the translation of evidence-based programs and to assist researchers in making their work more germane to their community colleagues.

Key Words: Alzheimer’s disease, Behavioral treatment, Caregiver training, Depression, Physical activity, Behavioral problems, Exercise

The need for translation of evidence-based programs into real-world clinical and community settings has been identified as a long overdue and critical priority by funders, clinicians, researchers, and consumers alike: “... there is a 20-year gap
between knowledge generated from our best clinical research and the utilization of that knowledge in our health and mental healthcare sectors” (Brekke, Ell, & Palinkas, 2007). Indeed, this gap is so detrimental to effective care that major professional groups, such as the Institute of Medicine (Institute of Medicine, 2001), Joint Commission on Accreditation of Hospitals (Feldstein & Glasgow, 2008), and others, have joined the call, and the National Institutes of Health and the Administration on Aging have provided a significant infusion of funding opportunities to stimulate such translational endeavors (National Institutes of Health, 2011; National Institutes of Health & Administration on Aging, 2011).

For older adults and their care providers, this emphasis is well timed. In the United States alone, more than 3.4 million adults, aged 71 or older, are suffering some form of dementia (Plassman et al., 2007). An additional 10 million adults, many of whom are themselves elderly adults, are providing care to these cognitively impaired older adults (National Alliance for Caregiving & American Association of Retired Persons, 2005). This represents a tremendous burden on the emotional and physical health of those affected as well as a significant economic toll on our health care system (Alzheimer’s Association, Thies, & Bleiler, 2011; Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008; Luppa et al., 2008). Dementia is a disease of epidemic proportions.

Successful evidence-based non-pharmacological treatments to improve care, decrease problems experienced by older adults with cognitive impairments, and assist their caregivers have emerged in recent years (e.g., Belle et al., 2006; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010; Logsdon et al., 2010; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Teri et al., 2003; Teri, Huda, Gibbons, Young, & van Leynseele, 2005). Some have also been successful in reducing the strongest predictors of institutionalization—behavioral disturbances, depression, and caregiver burden—suggesting the potential of these non-pharmacological treatments to reduce health care costs associated with such problems. Unfortunately, a recent comprehensive review of this research concluded: “Despite the growing availability of . . . psychosocial interventions that are . . . helpful to people with dementia and their caregivers, the majority of older adults with dementia do not receive appropriate treatment” (Chapman, Williams, Strine, Anda, & Moore, 2006, p. 1).

In response to this need, the Administration on Aging has funded an initiative to move evidence-based interventions into communities, through the Alzheimer’s Disease Supportive Services Program. This article provides an overview of two evidence-based interventions: Reducing Disability in Alzheimer’s Disease (RDAD; Teri et al., 2003) and STAR-Community Consultants (STAR-C; Teri, McCurry, Logsdon, & Gibbons, 2005) that have been selected for translation by community agencies in Ohio and Oregon. The discussion focuses on the strategies that were incorporated throughout development of the interventions to facilitate community-based translation and elucidates the challenges and opportunities faced by the agencies and investigators in working together to facilitate translation.

**Methods**

**Seattle Protocols**

**Overview.**—RDAD and STAR-C are two of a series of treatment protocols for training caregivers to improve care and reduce the behavioral problems of persons with dementia that have been developed via an iterative process of discussion with key stakeholders, clinical application, and empirical investigations in home or community settings, employing trained clinicians to deliver care culminating in randomized controlled clinical trials (e.g., Teri et al., 2003; Teri, Logsdon, Uomoto, & McCurry, 1997; Teri, McCurry, Logsdon, & Gibbons, 2005). Collectively, these programs have come to be called the Seattle Protocols. The theory, clinical framework, and empirical evidence for the Seattle Protocols have been reported elsewhere (Teri, Logsdon, & McCurry, 2005). Briefly, each Seattle Protocol teaches the caregiver and person with cognitive impairments (to the extent they are able) to alter their interactions in ways that result in decreased problem behaviors, improved mood, and enhanced quality of life. Treatment is systematic yet individualized, person centered, and focused on current observable interactions of direct relevance to the problem under consideration and the unique psychosocial context.

In STAR-C, community consultants are taught behavioral problem-solving strategies, and they, in turn, train family members to use these strategies to reduce depression and anxiety in the person with dementia (Teri, McCurry, et al., 2005). Consultants conduct eight weekly sessions in the participant’s own home for more than 2 months, followed by
four monthly phone calls. In RDAD, this training is augmented by teaching family caregivers to help their care recipient engage in regular physical activity to increase flexibility, endurance, and strength with the goal of decreasing the behavioral and physical disability common among persons with dementia (Teri et al., 2003). In this program, 12-hr-long sessions are conducted for more than 3 months: two sessions per week for the first 3 weeks, followed by weekly sessions for 4 weeks; biweekly sessions for 4 weeks; and three monthly sessions for the final 3 months. All sessions are conducted in participant’s own home.

**Developmental Strategies Incorporated to Facilitate Translation**

Throughout development and empirical evaluation of these protocols, attention was paid to all aspects of study and treatment design that would facilitate their eventual translation to community settings; including initial rationale for the intervention; identification of appropriate candidates for treatment; development of systematic and standardized manuals for treatment; use of clinically relevant and psychometrically sound measures of outcome; standardized procedures for assessing ongoing treatment fidelity; and methods for selecting staff and providing initial training and ongoing support (Bellg et al., 2004; Glasgow, Klesges, Dzewaltowski, Bull, & Estabrooks, 2004).

**Initial Rationale for the Intervention and Population of Interest.**—The Seattle Protocols were initially developed in response to observed clinical needs. Their origins in a geriatric clinic by practicing clinicians (Teri, Logsdon, & McCurry, 2002) led to an understanding of the challenges faced by persons with dementia and their caregivers, particularly in regard to behavioral problems that often overwhelmed both individuals. Thus, the protocols were molded over time by clinical experiences with providers, caregivers, and those with dementia. Consequently, the interventions are pragmatic, reasonable yet theoretically grounded, and scientifically sound. Each intervention was developed in an iterative fashion, incorporating clinical observations and input from patients and caregivers, building sessions step by step, and integrating standardized approaches with clinical flexibility.

**Identification of Appropriate Candidates for Treatment.**—The original randomized controlled clinical trials used tightly defined eligibility criteria for subject recruitment in order to control as many sources of outcome variance as possible. Gradually, the protocols were extended to more diverse and heterogeneous samples to more accurately reflect real-life clinical populations. Initially, highly trained interdisciplinary research teams and clinicians conducted the trials. Over time, community clinicians were trained to conduct treatment within the broader clinical settings. Thus, these programs became increasingly generalizable, more and more integrated into the community, and translational by their very nature.

**Development of Systematic and Standardized yet Flexible Treatment Manuals.**—Treatment manuals were developed that provided all the materials necessary to conduct the interventions, including an overview of the conceptual and clinical basis of treatment; issues to consider when conducting treatment; specific, systematic, and standardized agendas for each session including guidelines for dealing with unexpected clinical situations; and detailed session-by-session information, participant handouts, and data tracking forms. The manuals were meant to insure treatment fidelity for the research and to be as detailed, clear, and comprehensive as possible to facilitate the adoption by other care providers. Thus, they are now used to provide agencies with consistent and clear information regarding protocol initiation and maintenance in real-world care environments.

**Use of Clinically Relevant and Psychometrically Sound Measures of Outcome.**—Although any scientifically valid study relies on psychometrically sound, well-established measures of outcome, it is particularly important to insure that the measures for community interventions are clinically useful and meaningful to agencies, clinicians, caregivers, and persons with dementia. Assessment procedures for the Seattle Protocols included recommendations regarding data collection, responses to common questions, and instructions on how to insure minimal missing data while also minimizing respondent burden.

**Procedures for Assessment of Treatment Fidelity.**—Each Seattle Protocol includes structured methods for assessing treatment fidelity—both adherence (the degree to which the trainers followed treatment procedures) and compliance (the degree to which caregivers completed behavioral “assignments”). These same procedures, which are consistent with
national recommendations for monitoring treatment fidelity in efficacy and effectiveness trials (Bellg et al., 2004; Glasgow, Lichtenstein, & Marcus, 2003), were employed by the agencies to insure that staff were accurately delivering the core content fundamental to RDAD and STAR-C.

Selection of Staff and Methods for Initial Training and Ongoing Support. — The Seattle Protocols were originally developed and tested by researchers with extensive clinical experience and over time were studied with clinicians practicing in community-based settings. Consequently, when it came time to train interventionists for the translational programs, a set of clinical skills and/or professional background necessary to conduct the interventions had been identified, and a method for providing initial training and ongoing case-specific consultation was already established. This helped community agencies identify staff and establish procedures for training and case consultation, in which the developers provided the first wave of training and the agencies later assumed these responsibilities.

Translation Sites

STAR-C/Oregon Department of Human Services. — The Oregon Department of Human Services, Seniors and People with Disabilities Division, partnered with two Area Agencies on Aging (AAA) (Rogue Valley Council of Governments Senior & Disability Services; Multnomah Aging & Disability Services) and the Oregon Chapter of the Alzheimer’s Association to implement STAR-C in three counties.

Program selection. STAR-C addressed a need that the AAA and the Alzheimer’s Association had identified—family caregivers needing more help due to their struggles with dementia-related challenging behaviors. Existing programs (such as Powerful Tools for Caregivers, Alzheimer’s Association Helpline, etc.) were helpful but the agencies thought the structured and systematic skills training available through STAR-C would augment and strengthen these offerings. The availability of a clearly structured manual and willingness of the program developers to work with the agencies to help train existing staff were an added incentive.

Trainers. Staff were initially recruited from among existing case managers at the two participating AAA. Most had at least a bachelor’s degree and experience working with diverse low-income older adults and people with disabilities, but prior dementia-specific training was not required for participation. Consultants completed a 1- and 1.5-day training on STAR-C with University of Washington (UW) trainers (Drs. Logsdon, McCurry, and LaFazia) after which they provided audiotaped sessions of STAR-C cases for review by UW trainers to ensure protocol fidelity and quality of program implementation. In addition, they received local supervision from a regional coordinator at each AAA. Six consultants were trained initially (January, 2010) with five additional personnel trained the next year (February, 2011). These 11 consultants include nine AAA case managers, two private geriatric case managers, and two regional coordinators.

Client base. Participants in the STAR-C program have included existing case-managed clients of the AAA, community members who were recruited via promotional materials, and referrals from other community organizations. Fifty family dyads were enrolled in the first year. Unlike the original research, a documented diagnosis of Alzheimer’s disease is not required, given the logistics of confirming such a diagnosis and concerns about this creating a barrier for some participants. However, screeners inquire the nature of the dementia and most report having Alzheimer’s disease, vascular dementia, or dementia (undifferentiated). As in the original research, STAR-C-Oregon excluded participants with dementia due to complications of active substance abuse, traumatic brain injury, and less common forms of dementia.

Dissemination. A variety of methods are being used to reach out to the community, including presentations and reminders to other case managers to refer clients, referrals from the Alzheimer’s Association, presentations to clinical groups and other social service organizations, and development and distribution of promotional flyers and brochures at community events.

RDAD/Alzheimer’s Association—Ohio.—The Ohio Department of Aging partnered with the Alzheimer’s Association Chapters in Ohio and the Benjamin Rose Institute on Aging to offer RDAD. Initially, the Alzheimer’s Association, Northwest Chapter, served as the core implementation site; subsequent to the success achieved at
that site, staff at three additional chapters (Central Ohio, Greater East Ohio, and Miami Valley) were trained and have implemented the program. The Benjamin Rose Institute on Aging serves as an independent program evaluator.

**Program selection.** RDAD was selected because of its “fit” with other programs already provided in Ohio, as well as its unique focus on both the person with dementia and their family caregiver. The caregiver education and behavioral training aspects of RDAD were compatible with groups already offered at the Alzheimer’s Association, but RDAD included additional skills to help staff extend services to family caregivers living with various stages of dementia and their concomitant behavioral problems. The exercise component of RDAD was novel and enabled the chapters to offer a new service, therefore increasing the scope of their support services.

**Trainers.** Staff are bachelor’s and master’s prepared clinicians (primarily nurses, social workers, and gerontologists) and average 18 years’ experience in the field (range 5–36 years). All RDAD staff participated in a 2-day training program conducted by UW trainers (Dr. Teri and Mr. Houle) followed by regular group supervision sessions to discuss and problem solve implementation strategies and challenges with offering the program and to celebrate treatment successes. Eight staff were trained initially (March, 2009), with an additional 15 individuals trained the next year (February, 2010). Although the initial training was conducted by the developers, the second training was conducted by site trainers in conjunction with the developers so that ongoing training and supervision can now be sustained by agency staff.

**Client base.** Clients were referred from other Alzheimer’s Association programs, other local community organizations such as the AAA, local community paper press releases, and other aging-related service providers. To date (between May, 2009 and September, 2011), 405 families have participated.

**Dissemination.** Each Alzheimer’s Association chapter is responsible for the promotion of RDAD. Promotional efforts include methods such as press releases, features in local stories and television programs, articles in chapter newsletters, presentations to outside agencies and organizations, and distributions of flyers describing the program to senior centers and physician offices.

**Research and Community Partners Working Together**

**Initial Training and Ongoing Consultation.**—Because the translation of RDAD and STAR-C was initiated and led by community agencies, UW developers followed their lead in responding to requests, suggesting modifications and providing guidance, while recognizing the need for the community partners to shape and direct the translation to meet their needs and those of their clients. Both sites have established ongoing dialog with the developers, including on-site in-person training and long-distance consultation between the developers, the initial trainers, the new community-based trainers, and agency administrators.

**Treatment Fidelity.**—The STAR-C and RDAD interventions were designed to meet the demands of rigorous randomized controlled trials while also being responsive to the needs of clinical or community settings. Treatment protocols include guidelines to address myriad complex clinical issues that caregiving dyads can bring to any given session. Thus, although well-established and clear procedures exist, they allow a degree of freedom and clinical judgment. In moving from research to community implementation, this flexibility was both an asset and a challenge. The agencies had their own skilled and experienced staff with diverse clinical experiences that provided invaluable feedback regarding what needed to be changed, adapted, adjusted, and amended (and thus “translated”). Establishing clear guidelines about what aspects of intervention could and could not be altered was challenging but essential. The rationale and the methods of the core strategies were discussed in detail to ensure they would be respected and conducted accurately. Developers had to provide clear client eligibility criteria and explain the potential limitations of including other clients in the treatment groups. For example, prior research focused exclusively on persons with Alzheimer’s disease, and yet, the agencies served older adults with other forms of dementia and those without dementia. A common question was: can we do this program with caregivers of non-demented or non-Alzheimer’s dementia? Although the agencies certainly could
implement the programs with other groups of older adults and their caregivers, it was essential that they understood that such extension went beyond the evidence base and therefore the same level of efficacy could not be assumed. This give-and-take created a healthy and productive adaptation of established materials to suit the specific needs of the partners while also maintaining the integrity and fidelity of the original approach.

**Program Evaluation.** — In the initial studies, evaluations included the person with dementia and their caregiver; key domains of interest were assessed using well-established measures of outcome (such as frequency and severity of behavioral problems in the person with dementia, level of caregiver depression and burden, reasons for institutionalization). Although community partners wanted to replicate the initial study results, concern emerged about the time and costs associated with the assessment. Eventually, the method and nature of evaluation developed and employed for the translation sites varied depending upon their individual needs. Both agencies adhered to the original assessment protocols used in the randomized controlled clinical trials but modified data collection procedures to be more consistent with their other programs and reasonable given staffing considerations. For example, neither site conducts blind assessments; both mail outcome measures directly to the caregivers who complete them and return them, independent of the consultants. Ohio also has trainers complete the original battery of cognitive and physical performance assessments and has further augmented treatment compliance and intervention checklists by developing surveys for the trainers and interviews for chapter leadership to assess satisfaction with program delivery.

**Discussion**

This article provides an overview of two evidence-based programs that have recently been translated by two different community agencies. STAR-C is a psychosocial support and skill training program designed to teach caregivers how to identify and increase pleasant events, improve communication, and use behavioral problem-solving skills to reduce the problems experienced by their family member with dementia while improving care and life quality. RDAD incorporates training in these caregiving skills while also training caregivers and persons with dementia to engage in exercises designed to improve strength, flexibility, balance, and general physical function. Both STAR-C and RDAD were designed to be conducted in the home of the person with dementia and their caregiver.

STAR-C was adapted by the Oregon Department of Human Services to increase the capacity of AAA in three counties to provide care to older adults with dementia and their caregivers. To date, 13 individuals have been trained and 70 dyads (caregivers and their family member with dementia) have successfully participated in the program. RDAD was adapted by the Alzheimer’s Association Northwest Ohio Chapter and expanded to other chapters in Ohio to enhance their offerings to older adults with dementia and their caregivers by providing both caregiver education and support and physical exercise training. They have successfully trained 25 staff who have provided RDAD to 405 family dyads; RDAD is now offered throughout the state of Ohio.

A number of aspects of initial program development were instrumental in ensuring the successful translation of these programs, including development by clinicians with extensive experience in working with dementia patients and their caregivers; systematic yet flexible approaches to training; detailed, well-developed, and well-researched training materials; experts to provide initial training to field trainers and prior demonstrated utility in community setting; and evidence from randomized controlled clinical trials.

The translation of these programs provided opportunities and challenges both for the developers of these programs and for the administrators and staff implementing them in community-based agencies. Balancing the needs of the community agencies with requirements of the funders and standards of the developers was ongoing. Establishing a true partnership was essential. Many issues could have been “deal breakers,” but by working together and focusing on our common goal of enhancing the care of older adults, there was considerable opportunity for true collaboration. Decisions made together were better than any decision that would have been made independently.

The journey of RDAD and STAR-C from initial development to randomized controlled clinical trial to translation into community-based agencies is far from over. Active consultation and support between the developers and the agencies are ongoing. The first wave of trained staff at each site has trained and supervised the second wave. Thus, both sites are well on their way to building capacity to address
these critical health care needs. How the developers' roles will evolve as the sites become more expert in delivering the programs remains an open question.

Both Oregon and Ohio are committed to continuing RDAD and STAR-C; the initial positive responses of trainers, caregivers, and those with dementia have made it clear that the programs are worth maintaining. However, a number of questions must now be answered if these programs are going to continue to be implemented and sustained over time. How can the integrity and effectiveness of the program be maintained and documented while it also evolves to meet the changing clinical and economic needs of clients being served? What are the costs and economic benefits of providing the programs? What minimum data set will be sufficient to continue tracking the integrity of the program, its effectiveness, and cost? What ongoing staff training, certification, or licensure will be necessary to maintain skills and continue providing quality services?

This is not the first partnership of researchers and community agencies to traverse the road to translation. Lorig's Chronic Disease Self-Management Program has been disseminated nationally and internationally, training peer facilitators and evaluating the impact of the program on participants (Lorig, Hurwicz, Sobel, Hobbs & Ritter, 2005). Although each evidence-based program has distinctive characteristics, can we collectively develop a consistent strategy across programs or must each program develop its own translational plan? In our case, differences in the programs themselves—the time commitment required and the focus of training—as well as differences in the agencies—time allocated to start-up and development, variability in the constituents they served, as well as the geographic region in which they are located—may well influence their short-term success and long-term viability. As more and more programs are conducted in diverse communities, only continued committed partnerships between agencies and researchers can help identify ways to increase the likelihood of success.

The true test of the success of the two programs described in this paper will, of course, be the test of time. Two critical questions will need to be answered: First, are these programs effective in their new settings? Second, if they are effective, will these agencies be able to sustain them?

Effectiveness will be relatively easily answered—both agencies are currently engaged in program evaluation activities and outcome data will be available soon. At this time, administrators, trainers, and caregivers are reporting good success and are well pleased with the program; agencies have reported significant success in both enrolling and maintaining clients in the program, trainers are excited about the improvements they are seeing, and caregivers report that they and their family members with dementia are benefiting.

Sustainability is less easily answered. Although both agencies were successful in competing for and obtaining Agency on Aging funding to initiate these translations, there is an expectation that they will develop a revenue stream to maintain these programs. How feasible that will be in the current economic climate is uncertain. Clearly, the infusion of monies from funding agencies and the interest in taking evidence-based programs to the next level of translation are helping move things forward. But how long will these monies be available and what infrastructures will survive when these initial outlays are gone? Ohio successfully trained the second wave of providers by having the first wave (in conjunction with the developers) conduct the training. Oregon is planning to follow suit. For both agencies, by integrating these programs into their portfolio of services, they are on the road to sustainability. How can these programs be linked to changes in health care, the focus on care transitions, and the interest in ensuring that state long-term care systems are dementia capable?

What can we do as researchers, clinicians, and policy makers to insure effective programs are supported and grown? Even the most effective program must evolve over time and meet the changing needs of the health care system as well as its constituents. How do we enable new programs to be developed that might offer hope to those not yet reached? How do we insure we share our knowledge and experiences so we learn from each other in as effective a way as possible—assuring that we do not repeatedly start from scratch wasting precious resources? Time and hard work—focused clinical activity, funded services, and additional research—will together determine whether these and other translational efforts are fruitful in achieving the goal of improving the care of older adults with dementia.

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