

CarePRO: Care Partners Reaching Out
Translating a Psychoeducational Skill-building Intervention for
Family Caregivers of People with
Alzheimer's Disease or a Related Dementia

Translation Report

Submitted to the
Arizona Department of Economic Security,
Division of Aging & Adult Services

September 2013

David W. Coon, PhD
Arizona State University
500 N. 3rd Street, MC3020
Phoenix, AZ 85004
david.w.coon@asu.edu

Funded by the U.S. Administration on Aging

CarePRO: Care Partners Reaching Out Translating a Psychoeducational Skill-building Intervention for Family Caregivers of People with Alzheimer's Disease or a Related Dementia

BACKGROUND

Please note that CarePRO (Care Partners Reaching Out), a psychoeducational skill-building intervention for caregivers of people with Alzheimer's Disease or a related dementia (ADRD) was conducted simultaneously for several years in Arizona and Nevada. However, the Initial Period of the project began one year earlier in Arizona through ADSSP funding to support the beginning of the project only in Southern Arizona. This project began in Southern Arizona as *REACH Out!*, but was renamed CarePRO and was folded into the overall CarePRO project when Arizona received additional ADSSP funding to expand the project across the state and Nevada received its ADSSP CarePRO project grant. This report envelops both Reach Out and CarePRO in Arizona, but only discusses the project under the name of CarePRO. It is also important to note that the overall project, as opposed to the intervention, was named NevadaCare in Nevada, while Arizona and its partners referred to the overall project only by the intervention's name (CarePRO). Separate but coordinated reports were submitted to the U.S. Administration on Aging given the strong spirit of collaboration between the partners in the two states as well as the overlap in some key partners (i.e., the Desert Southwest Chapter of the Alzheimer's Association and the intervention's developer, Dr. David W. Coon at Arizona State University). The project's overarching goal and related objectives were developed within the RE-AIM framework (Glasgow, Vogt, & Boles, 1999) to help develop and implement CarePRO as a cost effective organization friendly adaptation of an evidence based treatment for family caregivers. The RE-AIM framework was also used to organize this translation report. The following key points discussed more fully below were similar across both states; however, this report provides details related to the state of Arizona.

Partners. CarePRO (Care Partners Reaching Out), funded by the Administration on Aging through an Alzheimer's Disease Supportive Service Program, is a collaboration among partners and investigators from the Arizona Department of Economic Security, Division of Aging & Adult Services, Arizona State University, the Desert Southwest Chapter of the Alzheimer's Association and local area agencies on aging in Arizona. The project's partners are described below.

State Unit on Aging: David Besst, Family Caregiver Support Programs Specialist, ADES-DAAS, served as the Project Director. ADES DAAS was the fiscal agent for the project and responsible for its overall management, including preparing and submitting required budgetary and programmatic reports, managing project timelines, monitoring progress, documenting outcomes, and monitoring collaboration with key partners. Project management entailed the close coordination of activities between the ADES-DAAS and its partners.

Arizona State University: Dr. David W. Coon, Professor in the College of Nursing and Health Innovations Arizona State University (ASU), has extensive work developing, implementing, and evaluating both individual and group evidence-based family caregiver interventions (e.g., Coping with Caregiving, REACH II, EPIC or Early-stage Partners in Care and others). Dr. Coon provided the initial training for interventionists in all three regions of the state served by the Desert Southwest Chapter of the Alzheimer's Association, conducted the

first round of CarePRO interventions for co-leaders in the three Chapter regions, and implemented a train-the-trainer model for ongoing dissemination. To help ensure treatment fidelity, Dr. Coon provided group bi-weekly and ad hoc consultation for Chapter interventionists during their first independent CarePRO intervention and monthly supervision afterwards. Experienced CarePRO interventionists then co-led a CarePRO series with new staff as they joined the Chapter. He conducted a formative evaluation with project leaders and staff through project meetings and supervision activities in all three regions incorporating feedback to enhance the project's effective integration into community partnerships. Dr. Coon served as the program's primary evaluator and the key person supervising the analysis and subsequently reporting the project's key outcomes and findings. Dr. Coon trained and supervised staff on a daily basis to conduct telephone screening, baseline interviews and 3 month, 6 month and 12 month follow-up interviews as well as data entry and management activities. Dr. Coon also helped to manage IRB submissions, and consult with staff on screening and interview issues, and/or data management questions or concerns. Dr. Coon's ASU staff also provided initial telephone interviews in Nevada when staffing challenges emerged unexpectedly in Nevada due to health related concerns. Dr. Coon through numerous community presentations each year also helped provide outreach and recruitment support to the project.

Alzheimer's Association Desert Southwest Chapter (AA-DSW): Key personnel from AA-DSW involved in CarePRO were Deborah Schaus, Executive Director, as well as her Director of Program & Advocacy and the three regional directors in Arizona. The Chapter covers the entire state of Arizona as well as Southern Nevada and provides personalized guidance and support to families struggling with dementia; raises the level of knowledge and skill of family members and community professionals who provide care; offers an array of programs designed to deliver accurate and comprehensive information about the disease; and, reaches out to serve even more of the affected populations through an increase of consistent and equitable services and support to diverse, multicultural and rural populations. AA-DSW was actively engaged in project outreach and recruitment. Thirty-one staff (including replacement staff due to staff transitions) were trained and delivered CarePRO served a wide range of communities and clientele across the entire state. Staff participated in bi-weekly supervision with Dr. Coon during their first independent delivery of a CarePRO 10 week series and then monthly thereafter with the opportunity for ad hoc consultation as needed.

Area Agencies on Aging (AAA's): Five AAA's were involved in the CarePRO project: Area Agency on Aging Region One, Inc. (AAA-R1) in Maricopa County, Pima Council on Aging (PCOA) in Pima County, Pinal/Gila Council for Senior Citizens (PGCSC) in Pinal counties, Northern Arizona Council of Governments (NACOG) in Yavapai and Coconino counties, and Western Arizona Council of Governments (WACOG) in Mohave County. All five agencies advocate, plan, coordinate, develop, and deliver services for seniors (60 years and older), adults (18-59 years) with disabilities and long-term care needs, persons of any age who are HIV positive, and family caregivers. The AAA's worked to ensure their staff participated in early-stage trainings provided by AA-DSW in their regions, worked with AA-DSW to develop a smooth referral process for the CarePRO program, disseminated CarePRO program information, and provided assistance to help promote the CarePRO program. AAA case managers also coordinated with AA-DSW Chapter staff to review if any other available services were necessary to help the families being served. As part of the CarePRO partnership, the AAA's also discussed and facilitated respite options and opportunities for caregivers who wanted respite assistance while they attended CarePRO group meetings.

PROJECT RATIONALE, PURPOSE & GOALS

Project Rationale. The decision to move forward and embed the CarePRO intervention into the Alzheimer's Association Chapters and strengthen the relationship among CarePRO partners to facilitate recruitment, implementation and evaluation of CarePRO in Arizona rested on several factors. A number of recent meta-analyses and reviews of the caregiver intervention literature (e.g., Coon & Evans, 2009; Coon, Keaveny, Valverde, Dadvar, & Gallagher-Thompson, 2012; Gallagher-Thompson & Coon, 2007) show that psychoeducational skill-building, psychotherapy (cognitive behavioral, in particular), and multicomponent interventions that combine skill training with other intervention approaches are effective in reducing caregiver distress and enhancing caregiver well-being. CarePRO partners in both Arizona and Nevada recognized that Coping with Caregiving (Gallagher-Thompson, Coon, Solano, Ambler, Rabinowitz, & Thompson, 2003), Savvy Caregiver (Hepburn, Tornatore, Center, & Ostwald, 2001; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999), NYU Caregiver Intervention (Mittelman, Haley, Clay, & Roth, 2006; Mittelman, Roth, Coon, & Haley, 2004), and REACH II (Belle, Burzio, Burns, Coon, Czaja, Gallagher-Thompson, et al., 2006) have been identified as meeting the evidence based treatment criteria of the American Psychological Association and other recognized entities (Coon et al., 2012; Gallagher-Thompson & Coon, 2007). However, Dr. Coon had already developed a working relationship with Long Term Services and Support (LTSS) partners in Arizona as well as both Chapters, and the partners were interested in the potential cost effectiveness of CarePRO's group based approach. Chapter leadership and staff expressed that individual in-home interventions would prove particularly challenging for them to sustain long term. The CarePRO project model was adapted to meet the differing LTSS systems in the two states. For example, respite options and opportunities were discussed and facilitated by Arizona's local area agencies on aging for caregivers who wanted respite assistance while they attended CarePRO group meetings. However, Nevada does not have local area agencies on aging, and therefore the Chapters served in this capacity in the state of Nevada.

Purpose & Goals. The overarching goal was to translate the core components of Coping with Caregiving (CWC) and its related tools and strategies into a community-based program (CarePRO), and to ensure that the intervention is accessible to diverse populations of caregivers across Arizona. Dr. Coon drew from CWC's cognitive behavioral theoretical framework and its original components and incorporated feedback from community partners and family caregivers to adapt and enhance CWC into CarePRO. CarePRO's partners collaborated to accomplish the project's goal through the following objectives:

- **Objective 1:** Expand the reach of empirically-based caregiver interventions in Arizona, by ensuring that CarePRO is available and accessible to eligible Arizona families suffering from the effects of Alzheimer's Disease and Related Disorders (ADRD), including diverse, underserved populations.
- **Objective 2:** Ensure CarePRO effectiveness by faithfully rendering the core elements of CWC used in REACH and other subsequent randomized controlled trials, while making the intervention more accessible and practical for both providers and family caregivers.
- **Objective 3:** Improve the delivery and adoption of CarePRO within the community by utilizing formative evaluation techniques to obtain ongoing feedback from caregiver participants and grant partners.
- **Objective 4:** Assure the consistent delivery of the intervention through implementation of standardized training, focused workshop site selection, and supervised workshop delivery in all service settings.

- Objective 5: Maintain and expand delivery of the CarePRO intervention to allow Arizona caregivers an opportunity to learn the coping skills afforded.

RATIONALE FOR THE CarePRO INTERVENTION APPROACH

CarePRO is a psychoeducational skill building group based intervention for family caregivers of people with Alzheimer's disease and related dementias. CarePRO, developed by David W. Coon, PhD, at Arizona State University, is based on Coping with Caregiving (CWC), a 10 session psychoeducational skill building class based intervention designed, implemented and evaluated by Dolores Gallagher-Thompson, Larry Thompson, David W. Coon and their colleagues at the Older Adult & Family Center at Stanford University School of Medicine and the Palo Alto VA Health Care System.

CWC grew out of several prior family caregiving projects with staff and students at the Older Adult & Family Center led by Dr. Gallagher-Thompson and Dr. Thompson including *Controlling Your Frustration: A Class for Caregivers* and *Increasing Life Satisfaction Class*. A number of these classes meet the American Psychological Association's criteria for evidence based treatments (e.g., Coon & Evans, 2009; Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003; Coon et al., 2012; Gallagher-Thompson & Coon, 2007; Gallagher-Thompson, Lovett, Rose, McKibbin, Coon, & Futterman, 2000). CWC was tested against an Enhanced Support Group condition (ESG) in a clinical trial as part of the 5-year NIH-funded REACH (Resources for Enhancing Alzheimer's Caregiver Health) project at the Palo Alto, CA site. In the REACH trial with 91 Latinas and 122 Non-Hispanic White women, CWC was compared to an Enhanced Support Group (ESG) patterned after traditional caregiver support groups found in community settings. Both Latinas and Non-Hispanic White CWC participants when compared to their ESG counterparts reported statistically significant improvements including reductions in depressive symptoms, negative coping strategies and negative interactions with people in their social networks, as well as increases in positive or adaptive coping strategies. Both CWC and ESG participants showed reductions in caregiver bother associated with care recipient behavior problems as well as increases in caregiver satisfaction with support received from their social support systems (Gallagher-Thompson et al., 2003).

Key components of CWC, its goals and related homework are included in Figure 1.

Figure 1. Coping with Caregiving (CWC) classes, goals and related homework.

	Coping with Caregiving (CWC) Class Goals	Homework
Class 1	Overview of dementia, understanding frustration, and practicing relaxation.	Daily relaxation diary.
Class 2 - 4	Identifying unhelpful thoughts about caregiving, changing unhelpful thoughts into adaptive thoughts or more helpful ways of thinking, and linking to behaviors.	Relaxation diary, daily thought record.
Class 5 - 6	Understanding types of communication and practicing how to be more assertive in caregiving situations and with others.	Practice assertive communication.
Class 6 - 9	Identifying pleasant events and activities, understanding and overcoming personal barriers to increasing pleasant events.	Daily mood rating, pleasant events tracking form.
Class 10	Review of major skills taught.	

Theoretical backdrop for CWC and CarePRO. Both CWC and CarePRO are grounded in several complementary theoretical frameworks and their related assessment and intervention tools and strategies. CWC and CarePRO were derived from the Lazarus and Folkman's (1984) Stress and Coping model that has been successfully applied to caregiver distress by Pearlin, Mullan, Semple and Skaff (1990); as well as cognitive and behavioral theories that map out the role of cognition and behavior and their impact on affective states (e.g., depression, anxiety, and anger). Stress and coping models incorporate both cognitive and behavioral aspects in terms of appraisal and response. However, Beck and colleagues (e.g., Beck, Rush, Shaw, & Emery, 1979) and Lewinsohn and colleagues (Lewinsohn, 1974; Lewinsohn, Muñoz, Youngren, & Zeiss, 1986) more fully develop these concepts and apply them to people experiencing affective distress. Cognitive behavioral approaches help people develop the requisite skills needed for improved function. CWC and CarePRO were designed to teach a limited number of skills to manage mood through two overall approaches: 1) reducing negative affect by learning to relax in stressful caregiving situations, to appraise the care recipient's behavior more realistically, and interact with others more assertively; and 2) increasing positive mood through acquiring skills such as recognizing the contingency between mood and activities, developing strategies to engage in additional everyday pleasant activities, and learning to set self-change goals and reward oneself for accomplishments (Gallagher-Thompson et al., 2003). The CWC and CarePRO interventions were also informed by Bandura's work in self-efficacy (Bandura, 1979, 1982, 1989). Change in self-efficacy perceptions is the cornerstone of how psychosocial interventions work, and the opportunity to learn from modeling and performance-based feedback that one can effectively handle situations like those that arise in family caregiving.

These theoretical perspectives clearly helped drive the following approaches to CarePRO and its delivery. **Education** about AD/RD is typically a basic component of psychosocial interventions for caregivers (Bourgeois, Schulz, & Burgio, 1996; Coon, Ory, & Schulz, 2003; Gallagher-Thompson & Coon, 2007). CWC and CarePRO begin with an overview of AD/RD and family caregiver stress and its impact. Of course, each group meeting provides education about a key intervention topic and related skills, tools and techniques for enactment

(For example, see Figure 1). **Support** is a key component of many effective interventions, and while the CWC is referred to as a “class” the emphasis on interactive discussion and skill-building provides ample opportunity for information, suggestions and support from other caregivers as well as the group co-leaders. Yet, evidence indicates that education and support alone are typically not enough to foster behavior change. People need to develop skills to help them identify and effectively manage stressful caregiving situations. **Skill training** appears to help solidify the foundation of effective interventions (Acton & Kang, 2001; Coon & Evans, 2009; Coon et al., 2012; Gallagher-Thompson & Coon, 2007; Schulz, Martire, & Klinger, 2005; Sörensen, Pinquart, & Duberstein, 2002). Several evidence-based behavior change strategies derived from cognitive behavioral theory (e.g., relaxation skills, communication skills, pleasant-activity scheduling) shown to be effective in reducing stress and distress with caregivers as well as other midlife and older adults (Belle et al., 2006; Coon, Shurgot, Gillespie, Cardenas, & Gallagher-Thompson, 2005; Coon et al., 2003; Gallagher-Thompson et al., 2003; Scogin & Shah, 2012). CWC and CarePRO assign home practice to encourage caregiver participants to integrate the intervention skills into their everyday caregiving situations. Home practice is critical in skill translation and fosters successful outcomes (Coon & Gallagher-Thompson, 2002; Coon & Thompson, 2003; Coon, Thompson, Rabinowitz, & Gallagher-Thompson, 2005). Both CWC and CarePRO combine education and skill training in a supportive environment to help caregivers effectively manage their stress, their distress, and their stressful situations.

CarePRO INTERVENTION & ITS GOALS

CarePRO, like CWC, draws on cognitive behavioral intervention strategies and techniques to help reduce negative and increase positive mood states. Tailored to be culturally responsive, CarePRO teaches caregivers relaxation skills, assertive communication to improve interactions with providers and others in their social networks, daily pleasant event scheduling to bolster mood and activity, ways for caregivers to appraise their loved ones behavior more realistically and intervene more appropriately, and strategies to change how caregivers think about their caregiving situations. Dr. Coon refined CWC into CarePRO through feedback from both caregivers and community providers including CarePRO partners who expressed an interest in reducing the number of group sessions and providing individual coach calls to help caregivers directly apply the skills to their daily caregiving situations. Dr. Coon pilot tested CarePRO with diverse groups of men and women in both San Francisco and Phoenix and achieved positive outcomes very similar to those from the original REACH CWC trial in Palo Alto (citations).

In contrast to CWC’s 10 session group format, CarePRO combines 5 workshops or group sessions with 5 alternating weeks of individual coach calls to each group participant. CarePRO begins with a group session in Week 1 and ends with a final coach call in Week 10. The Coach calls focus on the caregiver participant’s particular situation and are designed to apply and reinforce the skills into the caregiver’s everyday situations. Just as in the group sessions, coaches are encouraged to do role plays and other interactive practice on the phone to enhance skill acquisition. Other CarePRO changes from CWC include: 1) substitution of CWC’s general relaxation strategies with a modification of the Signal Breath technique used in REACH II. In CarePRO, Dr. Coon developed Mindful Breathing techniques that are similar to CWC and REACH II techniques, but focus on caregivers experiencing changes beyond just tension to include stress and tension as well as other types of upset and ask caregivers to use their breath to clear their minds and bodies and to be mindful of changes in their bodies, their minds, and how they emotionally feel. Mindful Breathing is also combined across the five group sessions with Stretching, Music, and Imagery relaxation approaches; 2) the incorporation of

Trigger, Behavior, Response strategies to help manage care recipient behavior problems; 3) the addition of IDEAL communication (a strategy developed by Dr. Coon for REACH II) as part of CWC's assertive communication component; and, 4) the addition of a planning for the future component that describes options for care and tips for future planning. CarePRO's Leader Manual was expanded with weekly Take Home Messages and Session Tips for Leaders. Moreover, CarePRO provides some basic training and reinforcement in group process skills and uses "Home Practice" instead of "Homework" to foster treatment enactment.

The CarePRO intervention goals include the following:

- 1) Increase participants' understanding that how caregivers think about caregiving (and about their relatives or friends with dementia) strongly affects how they themselves feel and how they respond to their own caregiving situations;
- 2) Increase their understanding that what caregivers do also strongly affects how they feel and respond;
- 3) Teach a variety of specific skills to help caregivers change unhelpful thoughts and behaviors to help them better manage caregiving stress and other types of upset;
- 4) Learn ways to help manage and cope with challenging behaviors that their loved ones exhibit due to their dementia (for example, repeating the same question over and over, wandering, or shadowing).
- 5) Improve communication skills to help caregivers interact more effectively with others, including their loved ones with dementia as well as health care and social service providers, family and friends.
- 6) Create a supportive environment that fosters skill acquisition in a group workshop setting.
- 7) Foster translation of workshop skills into participants' daily lives through individual coach calls tailored to meet their own caregiving situations.
- 8) Improve the caregivers' well-being and quality of life through acquisition and translation of these workshop skills into their caregiving situations.

The CarePRO Leader manual describes each session, including the session's major goals and objectives and the method for reaching those objectives. Caregivers were provided their own manuals in a 3-ring binder format; however, the material for each session was provided and added to the binder at the beginning of that particular session meeting. The back of the manual provides additional home practice sheets and other resource material tailored for the particular geographic and service area. The basic structure of the sessions is as follows:

- Review of Last Workshop and Today's Session (Agenda)
- Relaxation Practice (Mindful Breathing)
- Review and Reinforcement of Home Practice
- Today's Session Material

- Break
- More of Today's Session Material
- Relaxation Practice (Mindful Breathing alone or with Stretching, Music, Imagery)
- Summary of Workshop and Review of Take Home Messages
- Home Practice Assignment

Figure 2. CarePRO workshops, goals and related home practice.

	CarePRO Workshop Goals	Home Practice
Workshop 1	Overview of dementia and caregiving. Understanding frustration and stress. Mindful breathing.	Daily Relaxation Log.
Workshop 2	Understanding difficult behaviors and developing an individualized plan to change behaviors. Mindful breathing plus stretching	Relaxation Log and Behavioral Log.
Workshop 3	Identifying unhelpful and changing unhelpful thoughts into adaptive thoughts. Understanding types of communication and practicing IDEAL communication. Mindful breathing plus music.	Relaxation Log, Thought Record, and IDEAL Communication Sheet.
Workshop 4	Communicating with care recipients. Monitoring our moods, identifying pleasant events and activities and overcoming personal barriers to increasing pleasant events. Mindful breathing plus imagery.	Daily Mood Rating, Pleasant Events Tracking Form.
Workshop 5	Planning for the Future and TIPS (Talk, Inform, Prepare and Share) for the Future. Review of workshop skills and ways to use the skills to address future problems.	Preparing for the Future to discuss on last Coach Call. Relaxation and other relevant logs and sheets.

REACH: PARTICIPANTS & PROGRAM ELIGIBILITY

The CarePRO intervention is designed for family and other informal caregivers of people with ADRD. CarePRO and its tools, techniques and strategies focuses on reducing stress, distress and other upset for caregivers who are providing regular consistent caregiving and/or experiencing at least moderate levels of stress. It was not designed nor has it been tested as

primary prevention intervention focused on caregiver stress prevention. Consequently, there are limitations to who can benefit from the program. CarePRO screeners at ASU were responsible for determining eligibility into the study.

The CarePRO screen was built on the national REACH and REACH II project's standardized telephone-screening tool encompassing a common set of inclusion and exclusion criteria designed to identify an appropriately diverse yet well-defined group of distressed or stressed family caregivers (Belle et al., 2006; Gallagher-Thompson et al., 2003; Wisniewski, Belle, Coon, Marcus, Ory, & Schulz, 2003). CarePRO like the CWC and REACH II interventions was designed for caregivers experiencing at least some stress or distress as a result of their caregiving role and its responsibilities. Ineligible or uninterested early-stage dyads were referred to other appropriate Chapter or aging network services.

1. Caregivers. To be eligible for the study, caregivers needed to be at least 21 years of age and providing 4 or more hours of care (i.e., directly care or supervision) each day for at least the last 6 months. Caregivers needed to report distress or stress associated with caregiving by endorsing that at least 2 of the following 6 items occurred within the past month: a) felt overwhelmed; b) felt angry or frustrated as a result of caregiving; c) felt cut off from friends and family; d) had crying spells or felt like they often needed to cry; e) felt their health had declined; and f) reported a current level of stress of at least 6 or higher on a 1 (not stressful) to 10 (extremely stressful) point scale.
2. Care recipients. Care recipients were not screened or interviewed for CarePRO. Care recipient information was provided by the caregiver. Caregivers needed to report that their care recipient had experienced at least one of the following in the past month: a) memory problems; such as asking the same question over and over, forgetting what day it is, or losing or misplacing things; b) behavior problems, such as arguing, being irritable, verbally aggressive or waking people up at night; or c) needed help with daily activities like bathing, change clothes, brushing teeth. Caregivers needed to confirm that their loved one had memory problems, a decline in memory in the past year, and/or told by a professional their loved one had Alzheimer's disease or a related dementia. Care recipients could be excluded if they had a history of Parkinson's disease, stroke, a severe mental illness before the age of 45 or if their memory problems were due to a past head injury. Screeners consulted with Dr. Coon in these cases to determine final eligibility. Although the Mini-Mental Status Exam (Folstein, Folstein, & McHugh, 1979) was used in the CWC REACH trial to help characterize care recipient level of impairment, CarePRO administered screens and interviews via telephone which precluded an MMSE administration. Moreover, the Chapters strongly expressed that they would not exclude caregivers in their programming based on a care recipients MMSE score.
3. Kin relationship. Eligible caregiver-care recipient relationships include spouse and adult-child relationships (daughters, daughters-in-law and sons) and other close friends and family members who were "considered family". In contrast to the CWC REACH trial that focused on Latinas and Non-Hispanic White women, CarePRO was open to both men and women of all races and ethnicities.
4. Community-dwelling. In keeping with the reality of the clients served by the Chapters, CarePRO did not require they live together. Upon entry into the project, both the caregiver and the care recipient must reside in a community setting, either in the same or separate households. Caregivers were encouraged to continue in CarePRO if they placed their loved one before completing the project. Similarly, caregivers whose care

recipients died were also encouraged to continue, as CarePRO skills are considered “skills for life” applied to caregiving situations, but highly transferrable to other situations and settings.

RECRUITMENT & ENROLLMENT

Enrollment for the study began Fall 2009 with the goal of enrolling a total of 410 caregivers (60 proposed in ADDSP *REACH Out!* plus another 350 through ADSSP CarePRO) across 51 CarePRO groups. By the end of June 2013, CarePRO and its partners had exceeded expectations by providing services to a total of 532 caregivers. Referrals were obtained through community organizations, media contacts and health centers/research centers, throughout the state of Arizona. The vast majority of project outreach and recruitment was accomplished through the two Chapters and their partnerships with members of the LTSS system in the state, particularly the AAA's. This partnership proved to be especially strong in Central Arizona, the Area Agency Region One. Yet, it is very difficult to determine the initial point of contact for community based projects, as many organizations referred potential participants to the Chapters prior to screening by ASU. Across time, all partners contributed to the recruitment efforts which focused on use of IRB approved material (flyers, handouts, etc.) at health fairs, conferences, and other community events, as well as outreach presentations that included CarePRO at organizations throughout the states. Partners speaking at local caregiver and professional education conferences and meetings seized the opportunity to market CarePRO at the end of their presentations; and, CarePRO recruitment materials were widely distributed at health and aging related conferences whether or not partner staff were invited to speak. ADES-DAAS utilized an internal Health Promotion and Disease Prevention Coordinator and a network of participating senior centers to facilitate community recruitment, and recruitment efforts were combined with other federally funded programs (e.g., SHIP/MIPPA, CDSME, ADRC). Later in the grant project, a statewide Caregiver Resource Line was launched as part of Arizona's Lifespan Respite Program, providing a single entry point for caregivers seeking supportive services, and this new resource would be a primary resource for future recruitment. Each community experienced different types of “tipping points” for recruitment, some of which came through word-of-mouth by former CarePRO participants who were benefitted from the program. In addition, project leadership adopted the HIPAA compliant and IRB approved fax referral form process Dr. Coon used in previous projects to facilitate recruitment. This process permits caregivers either in person or over the phone to give their contact information to providers/community professionals for release to project partners (e.g., the Chapters, the AAA's and/or ASU), thereby enabling screeners and interviewers to contact potential participants directly and reduce lag time for enrollment.

Initial Period: In the Initial Period of the Project, a total of 55 CarePRO groups enrolled 448 participants in divergent areas of the state. Group enrollments ranged in size from 2 (never recommended) to 12 caregiver participants with a median of 8 members per group (and an average of 8.2 per group). Potential participants were referred to ASU for telephone screening. Those identified as eligible by the screen were then administered a baseline interview by telephone after obtaining verbal informed consent. Final lists of eligible and interested participants were then provided to the AA-DSW so that CarePRO co-leaders could contact the caregivers prior to the first CarePRO workshop. Written informed consent was administered by co-leaders at the beginning of the workshop. Approximately 3 months after baseline assessment, ASU staff scheduled and conducted telephone follow-up interviews after completion of CarePRO's 10-week Intensive Phase (5 workshops alternated with 5 telephone coach calls). Additional follow-up interviews were conducted at 6 months and 12 months after

baseline assessment as part of the Maintenance Phase of the project. Participants were paid \$25 for each follow-up interview completed as a “Thank you” for their time and small incentive to provide essential feedback on project effectiveness and acceptability. Only trained ASU staff conducted the project telephone screens and interviews. All CarePRO screeners, interviewers and co-leaders were CITI certified for research with human subjects.

Transition and Sustained Periods: Early on in the project, both Arizona and Nevada realized the need for an extension to balance the required service delivery with the program evaluation, which includes the three follow up evaluation interviews. This extension allowed for the transition from the evaluation model, involving at least three full follow-up evaluation interviews conducted by ASU, to the final sustainability model fully embedded in the Chapters, which does not include the full screen, baseline and follow-up evaluations. Both Arizona and Nevada, reduced the evaluation period and follow-up interviews from the initial three (3), six (6), and twelve (12) month follow up to a three (3) and six month (6) month follow-up to close out all CarePRO enrollees between 7/1/12 and 9/30/12 as part of the Initial Period of the CarePRO project.

- 1) **Transition Period.** Dr. Coon worked with the Chapters in both states to develop a brief screen and pre-post survey based on the CarePRO screening and assessment tools used in the Initial Period of the project. These new tools collected critical comparable data useful as part of the project translation process. Dr. Coon trained Chapter staff to administer these tools with both the participant screen and initial interview being administered via telephone before the first workshop and a self-administered post survey provided at the final workshop for participants to complete and return via mail. The Transition Period covered enrollments for participants between 10/1/12 and 3/31/13, and allowed for the transition from a 12 month project period to a 3 month period that included only the Intensive Phase of the Intervention (the first 10 weeks involving 5 workshops and 5 coach calls) and pre-post only assessment. The Chapters reviewed their staffing patterns and wanted to rely on data from the Initial Period of the project’s Maintenance Phase for insights into maintenance of intervention gains. The Transition Period provided critical information about screening and evaluation tool options as well as training steps and staffing needs for organizations including those outside the current CarePRO partnerships that may be interested in implementing CarePRO in the future. Another 84 participants enrolled in 10 CarePRO groups during the Transition Period covering all a wide range of locations including Florence, Payson, Sun City, Phoenix, Sierra Vista, Saddlebrook and Tucson.
- 2) **Sustained Period.** Participants in all CarePRO groups initiated after 3/31/13 were not evaluated by ASU. Dr. Coon again worked with the Chapters to determine a screen and intervention assessment tool that met their needs. Feedback indicated that staffing concerns prohibit the use of more than a brief screen and post only anonymous survey. Key among the concerns were a lack of staff that could do data entry and analyses for longer and more sophisticated assessment tools. During the Sustained Period and moving into ongoing Sustainability, CarePRO has been conducted fully by Alzheimer’s Association staff, utilizing a brief screen to identify appropriate participants and a brief post only survey following the 10 week intervention since April of 2013. During the Sustained Period, another 80 participants entered 9 different CarePRO groups (34 participants each in the Southern and Central Regions and 12 in the Northern Region). Another 21 CarePRO groups are planned across the state for the rest of the Chapter’s fiscal year ending 6/30/14.

Outreach beyond an organization’s own client base is often a challenge in any project. Concerns persist across organizations about the quality of care or level of expertise that staffs in other organizations possess. These concerns are often unfounded and based on a lack of

knowledge or understanding of organizations' programs and staff skill sets. These concerns can be magnified when organizations are competing for limited funding pools or provide what they perceived to be similar programming. Unfortunately, these challenges do little to help serve caregivers who need a variety of programming to address different caregiving situations and settings. CarePRO as a new offering by the Chapters did face these challenges and it took some time to establish trust, mostly through word-of-mouth from CarePRO participants who perceived that they derived substantial benefit from the group based skill-building program- a program that is unique in its approach and delivery. In addition, many families can remain isolated when health care providers rely solely on pharmacological interventions instead of recommending psychosocial interventions to alleviate caregiver stress and distress. The CarePRO partners remain committed to increasing outreach to health care and human services providers to increase awareness of the needs of caregiver needs. Research continues to demonstrate that ethnic and racial minority families often enter the service arena and receive diagnoses much later in the disease process (Cooper, Tandy, Balamurali, & Livingston, 2011), highlighting the need for additional outreach and education in these communities to help dispel myths about ADRD and to increase the availability, accessibility and acceptability of caregiver interventions to meet the needs of these populations. CarePRO was designed with input from diverse groups of professionals and family caregivers. It is currently available in both English and Spanish.

ADOPTION

Project sites. The project partners wanted to implement CarePRO in urban, suburban and more rural settings to serve the diverse population of caregivers across the state. A total of 65 different CarePRO groups enrolling a total of 532 participants were conducted during the Initial and Transition Periods. The breakdown of these groups by region encompassed urban, suburban and rural communities and included the following: 17 groups in Southern Arizona, 11 groups in Northern Arizona, and 27 groups in the Central Arizona Region. Examples of communities served ranged from the largest Arizona cities (i.e., Phoenix, Tucson, Flagstaff, and Yuma) to smaller cities and suburban areas (e.g., Prescott, Gilbert, Apache Junction, Sierra Vista) to the smaller rural communities (e.g., Cottonwood, Snowflake, Payson and Show Low). In all cases, CarePRO group sessions were held either at the regional offices of the Chapters or other convenient community based organizations. The Chapters were successful in securing free space for the group meetings.

Staffing. *Screeners and interviewers* do not necessarily need to have a college degree; however, attention to detail combined with excellent interpersonal skills and the ability to quickly establish rapport is a must. These interpersonal skills need to be transferable across baseline to follow-up interviews due to staff turnover. The ability to adhere to a protocol while communicating naturally with participants is highly desirable. Experience with older adults and knowledge of ADRD is a plus.

Each CarePRO group is designed to be conducted by 2 *Group Co-leaders*, particularly for larger groups. All CarePRO group leaders held at least an undergraduate degree and some held a Master's degree as well. Experience with older adults and working with caregivers, attention to detail combined, excellent interpersonal skills and the ability to quickly establish rapport is a must. These interpersonal skills need to be transferable between phone work and group workshops. The ability to adhere to an intervention protocol while communicating naturally with participants is also required. Experience in behavior change management and group facilitation skills is highly desired. For CarePRO project, the group leaders were drawn from existing Chapter staff.

Training and supervision. Initial training included 4 total hours overview and instruction on CarePRO goals, purpose, format and coach call activities. Ideally, these would occur in person, but telephone overviews are acceptable, given CarePRO's train-the-trainer format. The intervention is manualized with scripts and leader tips for ease of administration. Of course, telephone sessions help to reduce travel costs for staff outside a particular region. In addition to the initial training, Dr. Coon conducted the first CarePRO group with staff members in each region attending and observing and leading repeat activities (e.g., Mindful breathing) under his supervision. Dr. Coon met bi-weekly with CarePRO trainees to debrief and review group activities and coach call progress. For the remaining waves Dr. Coon conducted bi-weekly telephone supervision with co-leaders as they implemented their initial CarePRO group series independently. He subsequently held monthly and ad hoc supervision sessions thereafter as part of the project's treatment fidelity procedures to enhance adherence to the CarePRO protocol. Supervision often focused on key challenges and challenging cases to reinforce transferability of skills to a wide variety of caregiving situations and settings. Moreover, supervision also reinforces how CarePRO skills are skills for life as caregivers transition from caring for loved ones at home to caring for loved ones in facilities or experiencing bereavement when their loved ones dies. These supervision activities are critical depending upon the staff education, training and relevant work experience prior to implementation of the CarePRO intervention. The staff in health and human services settings are often trained in case management frameworks with limited behavior change and group facilitation experiences. Their individual education and information and referral skills may be strong; however, education, implementation, and facilitation of behavior change strategies in individual and group settings may be underdeveloped and require both initial training as well as ongoing supervision. As a critical mass of trained and supervised CarePRO leaders existed within the Chapter, these experienced leaders helped train and consult with new co-leaders. Dr. Coon's ongoing supervision activities were driven primarily by treatment fidelity and treatment implementation needs, especially given the amount of staff turnover in both Nevada and Arizona (in total 42 staff were trained across the two states and the five regions of the Alzheimer's Association represented by the two Chapters).

IMPLEMENTATION

Many issues related to implementation of CarePRO across the state as well as challenges and ways to address those challenges are described under "REACH: PARTICIPANTS & PROGRAM ELIGIBILITY" as well as "RECRUITMENT & ENROLLMENT" and "ADOPTION". Monitoring of treatment is also described under "Training and supervision" within "ADOPTION". The following provides additional information on challenges to implementation and steps to address them.

Partnership challenges and opportunities. As mentioned earlier, challenges did emerge from what might be called a scarcity agency model versus an enterprise model involving cooperative competitors. The latter would work toward reducing the barriers to caregiver service by finding ways to minimize the perceived and real competition regarding clients (caregivers), funding streams, and in-kind contributions. In addition, there appeared to be some need from time to time to reinforce the difference between the AoA's former ADDGS approach versus the ADSSP spirit and approach.

Staff Turnover. Staff changes are often a challenge for translation projects in nonprofit, government, and not-for-profit organizations where salaries can be lower than the private sector. Thirty different staff were trained in the CarePRO intervention across the Initial, Transition and Sustained Periods. During the Initial and Transition Periods of the project, the

AA-DSW experienced two turnovers in the director of one of the regions. In addition, eight additional staff transitions out of the organization occurred chapter-wide during these periods. Moreover, AA-DSW also identified a staff member for a chapter-wide position (covering all of Arizona and Southern Nevada) to interface with Dr. Coon in terms of supervision and treatment fidelity monitoring and the person holding this position transitioned three times across the project. During the Sustained Period, there were three more staff transitions out of the Chapter. Nevertheless, the necessary training was available to train the new staff via in a train-the-trainer format through the remaining staff with solid CarePRO experience. Each of these transitions carries not only re-training in terms of the nuts and bolts of the project, but also the philosophy behind the CarePRO model- a philosophy built on providing caregivers skills for behavior change that can generalize into their world of caregiving.

Staff Training and Intervention Delivery: Early in the course of training and supervision, the differences between the current project staff versus staff involved in CWC's original work as well as Dr. Coon's pilot work became readily apparent. The differences were notable in terms of theoretical underpinnings, relevant training, and relative interest in behavior change models and related skills of the REACH trial staff versus those associated with education and care/case management models of the Chapter staff. The philosophy of these two frames of reference and their approaches and related activities are clearly distinct with the former focused on ongoing skill development and coaching of behavior change for caregivers and the latter focused on information, referral and care coordination. Rather than take an either/or approach, Dr. Coon worked to blend the two in supervision placing greater emphasis on the behavior change components of CarePRO, but seizing opportunities to bridge these components with education and care coordination activities. These changes in philosophy can only be fostered, and not forced from the outside. These issues arose repeatedly throughout supervision, and feedback was consistent regarding the emphasis on behavior change. Within the first year, Chapter staff began to embrace the behavior change activities and gave regular feedback about the benefits of time well spent in supervisory activities with Dr. Coon and one another. Given the large recruitment and implementation efforts that rested with the Chapters, Dr. Coon chose to add questions into supervision to help with the formative evaluation, since any additional meetings were perceived as negatively impacting staff time and thereby casting perceived burden of the project on staff.

Caregiving participants. Dr. Coon was an investigator for both the REACH (CWC) and REACH II trials. Moreover, he conducted preliminary pilot work regarding the blending of CarePRO's workshop and coach call approach as requested by community partners and delivered the initial CarePRO workshops and provided ongoing supervision in all regions of the Chapters in both states. Through these experiences, it Dr. Coon's opinion as CarePRO's developer, trainer, supervisor and evaluator that CarePRO is experiencing increasingly complex caregiver participants in comparison to those in the original REACH trials. Several factors might contribute to this: 1) caregiver education and support programs and activities (even though the vast majority are not evidence based) have proliferated over the last decade, providing other options for caregivers, particularly "good copers," to find relief for some distress; 2) Chapter staff in all the regions typically started CarePRO with their existing cases, most of which were drawn from family care consultation cases that often consist of more complex cases than other caregiving situations; thereby enrolling caregivers with challenging personality styles and chaotic family situations; and, 3) in today's world, care recipients are often released from hospital, rehabilitation settings or other situations more quickly than ever before, exacerbating caregiving scenarios for participants. While these may well represent the caregivers that future CarePRO partners will enroll, they do create additional challenges for interventionists leading this group based model. As a result, supervision has led to reinforcement of CarePRO's behavioral skills training that can complement but does not serve as a substitute for more in-depth counseling or psychotherapy needed by some of these caregivers.

Follow-up assessments. One key observation is that even though the project reduced subject burden in terms of both a much briefer interview battery and conducted the battery over the phone, Dr. Coon (an investigator on the REACH I and REACH II projects) and his staff experienced more difficulty in getting caregiver participants to schedule and then complete both pre and post interviews. Speculations about this issue are still ongoing across the CarePRO regions in the two states, but some initial thoughts are that participants received multiple calls from at least two and sometimes three or four different agencies as part of the project (e.g., the evaluation team, the chapter staff delivery the intervention, and respite providers). In the initial REACH trials, the importance of caregiver participation in the evaluation was consistently reinforced by intervention staff throughout the intervention process. Evidence of this is more difficult to obtain across the various entities involved in CarePRO as a collaborative project. While this does not impact ADSSP definitions of a “completer” (i.e., caregivers who completed at least 7 or more of the first 10 contacts), it does impact traditional definitions of dropouts as those without follow-up assessments. As part of the Transition and Sustained Periods described elsewhere, Dr. Coon worked with the Chapters to develop briefer screening and assessment tools grounded in both science and practice. The Transition Tools were successfully capturing pre/post outcomes related to effectiveness and acceptability. However, Chapters have no one to conduct the necessary statistical analyses, so Dr. Coon worked with them to develop a post only evaluation to capture caregiver perceived changes related to their CarePRO participation that are similar to outcomes and acceptability variables collected in the Initial and Transition Periods.

EFFECTIVENESS

CarePRO draws on its theoretical underpinnings from Stress and Coping theories (Lazarus & Folkman, 1984; Pearlin et al., 1990) and cognitive behavioral theories (e.g., Beck et al., 1979; Lewinsohn et al., 1986) and translates those underpinnings into behavior change approaches, techniques, and strategies to address caregiver concerns and impact key outcomes (e.g., the reduction of caregiver distress and enhancement of quality of life). More specifically, enhances CWC’s evidence-based behavior change strategies (e.g., relaxation skills, communication skills, pleasant-activity scheduling) that have been shown to be effective in reducing stress and distress with caregivers and other midlife and older adults (Coon et al., 2003; Gallagher-Thompson et al., 2003; Belle et al., 2006; Coon et al., 2005; Scogin & Shah, 2012) by infusing telephone coach calls into the overall intervention to help reinforce workshop content and help caregivers transition skills into their everyday lives. CarePRO’s group format is also likely to be more cost effective than one-on-one in-home interventions by reducing staffing, travel, and other costs.

Sample characteristics for Initial and Transition Periods: The sociodemographic background characteristics of the sample are summarized in the sponsor’s data collection table attached with this report. The majority of CarePRO’s caregivers in the Initial and Transition periods were women (76.9%); lived in urban or suburban areas (75%); and described themselves as the spouses or partners (61.1%) of their care recipients. Almost 70% (69.5%) were over the age of 60. In addition, the majority self-identified as non-Hispanic White or Caucasian (84.8%); and, in terms of ethnicity, 10.3% self-identified as Hispanic or Latino. Veteran status was added later by the ADSSP partners, so of the 363 caregivers surveyed only 10.2% were veterans. In addition, caregivers reported their care recipients’ demographic characteristics: roughly half (52.3%) were men; 97.2% of the care recipients were age 60 or older; 61.1% were the spouse of the caregiver; and, 75.1% lived in urban or suburban areas. In terms of race, the vast majority were described by their caregivers as White Non-Hispanic

(83.5%); and, in terms of ethnicity, 9% were identified as Hispanic or Latino. Of the 363 caregivers surveyed regarding the veteran status, 38.8% reported that their care recipients were veterans.

Key findings: Outcomes. Project outcomes focused solely on the Initial Period, since the Transition and Sustainability Periods used different assessment tools developed in cooperation with the Chapters. The demographic characteristics for the 448 enrolled during the Initial Period are very similar to those described above: The average age of the caregivers was just over 65 ($M=65.29$; $SD = 11.33$) with 69.3% age 60 and over. Caregivers were predominately female (76.3%); well over half were spouses or partners of the care recipients (60.5%); and, half (50.2%) reported an annual household income of below \$40,000. The majority self-identified as non-Hispanic White (84.4%) and 10.1% described themselves as Hispanic or Latino. Just under 10% (9.6%) of the caregiver participants identified themselves as veterans. Care recipients on average were over a decade older ($M = 78.63$; $SD = 8.75$) than caregivers and almost all were age 60 and older (97.5%). Half (51.6%) of the care recipients were men; the majority were non-Hispanic white (83%) with 8.6% identified as Hispanic or Latino; and, over a third (37.9%) held veteran status.

The outcomes below provide evidence of CarePRO's effectiveness both in terms of statistical significance as well as a range of very respectable effect sizes (from .15 – 1.21). Analyses include those who placed their loved ones in a long term care facility or whose loved ones had died, since many CarePRO skills (e.g., stress management, challenging unhelpful thinking, increasing simple everyday pleasant events, and effective communication skills) are applicable to life in general. Moreover, the numbers of caregivers reporting placement or bereavement was relatively small and removing them from the analyses produced no substantive differences in the findings. Findings were similar across both states.

Analyses conducted on the entire sample of Initial Period participants completing follow-up interviews immediately after the Intensive Phase of the intervention (after completion of the 5 group meetings and 5 coach calls or approximately 3 months after baseline assessment) yielded the following in terms of statistically significant improved key outcomes: a) *reductions* in depressive symptoms ($p<.001$; $d = 1.17$, use of negative coping strategies ($p<.001$; $d = .26$), bother or upset associated with care recipient memory and behavior problems ($p<.001$; $d = .46$) and negative interactions with others in the caregiver's social support system ($p<.001$; $d = .18$); and b) *increases* in caregiver use of positive coping strategies ($p<.001$; $d = .25$) and caregiver satisfaction with received social support ($p=.008$; $d = .17$)

Partners were also interested in a variety of additional quality of life indicators. These analyses yielded a number of significant findings including: a) *reductions* in overall memory and behavior problems ($p<.001$, $d = .26$); stress associated with target complaints ($p<.001$; $d = 1.21$); vigilance to "be there" or "on duty" to care for their loved one ($p=.007$; $d = .15$); and b) *increases* in leisure time satisfaction ($p<.001$, $d = .46$), positive aspects of caregiving ($p<.001$; $d = .22$), self-efficacy for caregiving ($p<.001$, $d = .45$) and caregiver preparedness to take care of their loved one's physical, emotional and social needs ($p<.001$; $d = .51$); as well as their own similar needs ($p<.001$; $d = .48$); and, knowledge of formal care services ($p<.001$; $d = .79$). The CarePRO partners were interested in examining the maintenance of these gains over time and provided 2 additional coach calls before a 6 month evaluation and another coach call before a 12 month evaluation. Follow-up assessments at both 6 and 12 months showed improvements in the vast majority of outcomes were maintained.

Key findings: Feasibility & Acceptability. In terms of acceptability, CarePRO used the REACH II project evaluation tool and well over 95% of CarePRO participants described not only overall benefit from their CarePRO participation, but also specific benefits in terms of an increased understanding of memory loss and its effects on people; more confidence in dealing with their loved one's problems; making their lives easier; and enhancing their ability to provide care. Close to 90% also felt CarePRO helped improve their loved one's life.

Additional evidence of the acceptability include numerous CarePRO groups reporting to Chapter staff that they continued to meet on their own after the end of their CarePRO workshop and coach call series, using their manuals to guide their discussions. Other groups have formed teams to participate in their local Walk to End Alzheimer's™ sponsored by the Chapters. In addition, caregivers have frequently shared their contact information with one another to stay connected after CarePRO. The proportion of participants who complete an intervention can serve as yet another measure of its feasibility and acceptability. Completers in the CarePRO project were those who completed 7 of the first 10 contacts in the Intensive Phase of the intervention. Of the 532 Initial and Transition period participants, 479 or 90% were completers. Of the 448 caregivers who participated in the Initial Period of the project, 404 or 90.2% were completers. CarePRO discontinuation was often associated with serious physical illness, serious personal problems.

Acceptability information was also gathered from Chapter staff during supervision sessions and those staff delivering the intervention reported very high levels of satisfaction and increasing confidence in delivering the intervention. The coach calls can be viewed within the Chapter model under family care consultation activities; however, some staff did express the desire for less coach calls or more flexibility in the number of coach calls, particularly for participants that were less engaged in the process. Staff also frequently reported challenges in motivating participants to fill out sheets associated with their home practice activities. It is important to note that many more participants reported integrating the skills into their lives in comparison to those reporting both integration and monitoring their progress. Unfortunately, the evidence in behavioral science research clearly supports monitoring to enhance behavior change. Therefore, additional home practice tips were incorporated into the revised manual to help facilitate this process. Even with challenging participants, staff often reported seeing positive changes through their CarePRO participation. Moreover, many staff expressed that CarePRO provided them an additional skill set applicable to other job roles and responsibilities, as well as an increased sense of self-efficacy in working with caregivers and their families. This skill set includes not only CarePRO's content, but also its group facilitation and behavior changes activities and strategies.

Our findings provide evidence of the effectiveness of CarePRO on a variety of outcomes encompassing positive changes in mood, stress and other types of emotional well-being, adaptive coping strategies, and enhanced social support as well as other quality of life indications (e.g., leisure time satisfaction, caregiver self-efficacy, etc.). The dissemination of CarePRO across both states also provides excellent evidence to support its feasibility and acceptability. The staff and the CarePRO participants who self-identified as either Hispanic/Latino, African American/Black or other minority rated the intervention as highly as their non-Hispanic white counterparts. However, the current project's predominantly non-Hispanic white, English speaking sample is a key limitation. The manual has been translated into Spanish and many of CarePRO's behavior change strategies have been successfully implemented through other work with diverse populations including CWC and REACH II (Coon et al., 2012; Gallagher-Thompson et al., 2003; Gallagher-Thompson et al., 2007; Gallagher-Thompson et al., 2008; Gallagher-Thompson et al., 2010).

MAINTENANCE

As part of CarePRO, the partners in Arizona and Nevada worked together to create a plan to transition the project's screening and assessment activities to the Chapters as well as CarePRO's intervention delivery. In the Transition Period, Dr. Coon and his team at ASU transferred additional responsibilities to the Alzheimer's Association Chapters and CarePRO's

other community partners by developing a reduced screen and assessment battery that was administered by the Chapters. Outcomes were similar for participants in the Transition Period. Finally, after successful completion of these activities with multiple CarePRO groups across both states, the Chapters worked with Dr. Coon to create a “sustainability” screen and evaluation tool for ongoing administration as part of the project’s Sustained Period and ongoing sustainability for CarePRO.

The additional CarePRO groups conducted during the Transition and Sustained Periods have pushed the delivery of CarePRO to just over 800 family caregivers across the two states. The CarePRO partnerships remain very strong, and the project lives on with both the Desert Southwest Chapter identifying CarePRO as one of their signature programs and incorporating it into their program plans. With regards to CarePRO’s sustainability after the end of the project, another 80 participants have already enrolled in 9 different groups across the three Chapter Regions; and, another 12 groups are planned for the remaining part of the fiscal year including 2 in the Northern Region, 5 in the Southern Region and the remaining 5 in the Central Arizona Region of the Chapter.

Connections across partners and with other LTSS partners are also strong with LTSS partners continuing to provide referrals and complementary resources. In Arizona, a partnership between the Arizona Caregiver Coalition and the Area Agencies on Aging has developed a new respite voucher program that will prioritize authorization of services that allow a caregiver to attend CarePRO training sessions. CarePRO manuals have been translated into Spanish and there are plans to strengthen relationships with *promotora* networks in the two states to enhance outreach into the Latino community as well. Moreover, ideas for sustainability are emerging from CarePRO graduates as well. Many participants have formed CarePRO groups that continue to meet after the end of the project and have approached Dr. Coon and Alzheimer’s Association staff with the suggestion of advertising graduation groups that participants could join that would be facilitated by former graduates. The partners are also working on opportunities for Dr. Coon and Chapter staff to train support group facilitators on the basics of CarePRO skills to help them interact more effectively with CarePRO graduates that attend their support groups.

In sum, Chapter leadership and staffs have been so pleased with CarePRO and its impact on caregivers that CarePRO has been adopted into Chapter programming. Staff at both Chapters have been trained and supervised in the delivery of CarePRO and have been implementing the train-the-trainer model. Dr. Coon has subsequently trained staff in the screening activities and worked with them in project evaluation components to meet their current needs. These activities, as well as CarePRO’s findings related to effectiveness, feasibility and acceptability will clearly facilitate the ongoing delivery of CarePRO across Arizona.

Both Chapters have been active in their pursuit of additional funding for CarePRO. For example, ADES-DAAS has taken steps to make it easier for AAA’s to fund individual AA-DSW offices to provide CarePRO classes. Further, Arizona has significantly addressed the need for respite services sometimes needed to attend CarePRO by launching a new respite voucher program that specifically targets caregivers wanting to attend evidence-based trainings or interventions. The vouchers reimburse the caregiver for up to \$300 worth of respite care, which equates to about 25 hours of care, ideal for the CarePRO intervention. The respite vouchers are exclusively available through the new statewide Caregiver Resource Line, which is operated as a collaborative between ADES-DAAS and the Arizona Caregiver Coalition. The statewide coalition is also in the process of becoming a non-profit entity and intends to compete for local and national funding to support evidence-based services like CarePRO.

Additionally, Arizona applied for and was recently awarded a federal grant to create and sustain a dementia-capable service system for people with dementia and their family caregivers. This three year cooperative agreement, which will run through September of 2016, will not only

ensure the continued provision of CarePRO in Arizona, it will allow Arizona to take the next steps to make these types of proven supportive services easily accessible to families that need them, and widely acceptable to a variety of cultural backgrounds.

Finally, the CarePRO partners in Arizona and Nevada were honored to learn that they receive the 2013 Rosalynn Carter Leadership in Caregiving Award presented by the Rosalynn Carter Institute. As noted by RCI, "This award recognizes leadership in implementing innovative partnerships between community agencies and caregiving researchers that bridge the gap between science and practice. These partnerships help move effective caregiver support programs to widespread use in the community more quickly and efficiently." The CarePRO partners will receive \$20,000 to continue to deliver CarePRO in Nevada and Arizona.

BUDGET AND COST ANALYSIS

The cost analysis provided below focuses on the specific costs associated with delivery of the CarePRO intervention. The costs of recruiting the participants in the CarePRO project described in this report are not included. These costs will vary considerably across organizations based on their prior level of involvement in family caregiver intervention development and delivery. Similarly, the analyses do not cover the costs associated with research screens and research telephone interviews conducted at baseline, 3 months, 6 months and 12 months to evaluate the CarePRO intervention's impact on caregiver outcomes. These assessments are critically important steps in the effort to evaluate CarePRO's effectiveness when translated into the community. However, many organizations cannot afford the staffing costs associated with these more in-depth assessments, and will select substantially shorter assessments tools, including brief post only assessments. For examples, both Chapters are using substantially shorter screen and assessment tools developed through the project.

Similarly, the examples do not include the three maintenance coach calls at 4, 5 and 9 months, given the feedback provided about these calls in terms of staff time and participant interest in graduation groups versus coach calls. Finally, CarePRO groups can be comfortably conducted with 2 group co-leaders for up to 12 caregivers per group. However, given the varied contexts (situations, settings, and organizational structures) faced by potential CarePRO implementers, the cost analyses are calculated through three examples below with two different group sizes: 8 participants (the median number of participants in the CarePRO ADSSP project) and 12 participants (the largest size group to be conducted comfortably). Please note that some of the project costs can be considered one-time or very infrequent costs (e.g., group leader manuals are reusable); and, CarePRO's train-the-trainer approach reduces the cost of supervision past the first group conducted independently by new CarePRO interventionists. Finally, it is possible that experienced CarePRO interventionists could conduct smaller groups with just one leader if back-up personnel were available for potential crisis situations. However, no cost analyses are provided for these scenarios.

CarePRO Cost Analyses

Three different cost analyses are provided for two group sizes (8 and 12 participants) for a total of six different analyses. However, only three tables are provided (Tables 1, 2 and 3) using 12 participants. In line with a train-the-trainer approach, the three different cost analyses for each group size incorporate different levels of training and supervision from a master trainer and supervisor across time.

- 1) Phase I includes a four hour intervention overview training, a CarePRO certified master trainer as leader and two intervention trainees as co-leaders (one Master's prepared and one Bachelor's prepared). The master trainer is the lead for the workshop and helps trainees begin to deliver intervention components. The trainees lead the coach calls. The costs also include master trainer supervision and preparation time. These initial training and supervision costs will vary depending on the number of interested co-leaders attending the initial training sessions, as well as any travel costs necessary for the master trainer. These costs will also change based on the number of trainees in the CarePRO group with the master trainer.
- 2) Phase II includes biweekly supervision with the CarePRO certified master trainer and supervision preparation time for the master trainer. However, the trainees from Phase I are leading the workshops and conducting the coach calls.
- 3) Phase III involves the two trainees from Phase I and Phase II conducting the intervention and consulting with one another. The master trainer and associated costs are not included.

Additional standard costs are described below and appear in Tables 1, 2 and 3.

Staff salary. Salaries vary across geographic regions, academic disciplines, and levels of associated work experience. In these analyses, we used the median salary in Arizona reported by the U.S. Bureau of Labor Statistics for a master's prepared counselor and a bachelor's prepared social worker.

Staffing Costs.

Intake/Evaluation: This gathers basic information on the caregiver to ensure a good fit with CarePRO including being a family caregiver for a person with ADRD, feelings of stress or other upsetting feelings associated with caregiving, and availability to participate in the 5 group meetings and 5 coach calls across the 10 weeks [1 leader per caregiver x 12 x 20 minutes = 4 hours. The amount would be reduced for only 8 participants]

Group sessions: Two group leaders for 5 group sessions lasting 2.5 hours a piece with a round trip travel time of 1 hour [2 leaders x 5 sessions x 3.5 hours = 35 hours of staff time]. Delivery time for the group sessions is the same regardless of the size of the group. Please note that travel time is not applicable if hosting CarePRO at one's own facility. The CarePRO certified Master Trainer and Supervisor costs appear only in Phases I and II.

Coach calls: One group leader is assigned to serve as the coach providing 5 bi-weekly coach calls across the 10 weeks. Many co-leaders divided the material in each group meeting, took turns presenting the material, and then each served as the coach for half of the participants. Other co-leaders chose to have one group leader deliver the material with the co-leader helping facilitate discussion and completion of in-group exercises and serving as the coach for all of the participants. [In any case, the costs associated with the 5 coach calls for 12 participants is 12 participants x 5 calls x 40 minutes per call (average) x 1 leader = 40 hours. The amount would be reduced for only 8 participants].

Session preparation/supervision/consultation: This time includes reviewing previous group sessions, coach calls, and related materials, supervision and consultation between group leaders (and with a master trainer Phase I and II) [2 group leaders x 5 sessions x 1.5 hours = 15 hours].

*Manual preparation: This involves putting the binders together for distribution at the sessions. This is estimated based on 3 hole punched copy center prepared material (1 hour is a liberal estimate). Caregivers are only provided the session material at each individual session. For example, Session 3 material is handed to caregiver at the beginning of Session 3. *Note: Group leader manuals are reusable for future groups.

Mileage. Mileage was calculated at 44.5 cents per mile with group leaders traveling together to the 5 group sessions. Mileage round trip to group sessions was calculated at 25 miles per session. Mileage costs are not applicable if CarePRO is held at one's own facility.

Supplies. The supplies outlined below are essential. In addition, groups may want to consider snacks or light refreshments or coffee, tea, or water for the breaks at the group sessions. Others may want to build the sessions in a brown bag format. While breaks are built into the group sessions and considered as part of the format, refreshments are not required or considered part of the intervention.

Group Leader Manuals. These 3 ring binder manuals cost \$33.21 per leader. Note: Group leader manuals are reusable for future groups.

Caregiver Participant Manuals. These 3 ring binder manuals cost \$33.21 per caregiver.

Session Feedback Sheets. Leaders and/or their organization may want to gather brief session feedback sheets each time or a post survey evaluation. We built in a session feedback sheets for caregiver participants at 1 page (12 participants x 5 sessions x \$.13).

Cost Example: 12 CarePRO participants

In Phase I that includes training costs with the Master Trainer/Supervisor, the total cost per CarePRO group: \$7,267. The cost per caregiver is: \$606.

In Phase II that includes supervision costs with the Master Trainer/Supervisor, the total cost per CarePRO group: \$4,831. The cost per caregiver is: \$403.

In Phase III that involves the trainees from Phase I and Phase II as co-leaders, the total cost per CarePRO group: \$3,881. The cost per caregiver is: \$323.

Cost Example: 8 CarePRO participants

In Phase I that includes training costs with the Master Trainer/Supervisor, the total cost per CarePRO group: \$6,415. The cost per caregiver is: \$802

In Phase II that includes supervision costs with the Master Trainer/Supervisor, the total cost per CarePRO group: \$3,979. The cost per caregiver is: \$497.

In Phase III that involves the trainees from Phase I and Phase II as co-leaders, the total cost per CarePRO group: \$3,209. The cost per caregiver is: \$379.

Given its group based model, initial analyses show that CarePRO costs (\$606 or \$802 per caregiver depending on size of the group) are substantially lower than those reported by REACH II (\$1,214 per caregiver) (Nichols et al., 2008) which did include supervisor and training costs (e.g., Phase I analyses). CarePRO Phase III costs (\$323 or \$379 per caregiver depending on the size of the group) are also substantially lower than the “steady state” costs associated with the New York University Counseling and Support Intervention for Caregivers (\$1,402 per caregiver) (Paone, 2009). In addition to the group based model which reduces costs, CarePRO was based on a train-the-trainer model where a CarePRO certified master trainer/supervisor co-leads the intervention with new leaders, thereby serving caregivers as part of the intervention process and reducing training and supervision costs for new interventionists.

TABLE 1. PHASE I

Activity	Participants/ Dyads	Minutes/ Event	Travel Time (minutes)	Session(s)	Hours	Master Prepared Salary/Hour \$21.28	ERE 25%	Bachelor prepared Salary/Hour \$17.79	ERE 25%	Master Trainer /Supervisor \$70	ERE 34.5%	Total Salary Expense
Overview Training		240		1	4	85.12	21.28	71.16	17.79	280.00	96.60	571.95
In Session Training		150	60	5	17.5					1225.00	422.63	1647.63
Phone Supervision		60		5	5	106.40	26.60	88.95	22.24	350.00	120.75	714.94
Supervisor Prep		42		5	3.5					245.00	84.53	329.53
Intake / Evaluation	12	20			4	85.12	21.28	71.16	17.79			195.35
Group Session	12	150	60	5	17.5	372.40	93.10	311.33	77.83			854.66
Coach Call	12	40		5	40	851.20	212.80	711.60	177.90			1953.50
Prep/Supervision/Consultant		45		10	7.5	159.60	39.90	133.43	33.36			366.28
Manual Prep		60			1	21.28	5.32	17.79	4.45			48.84
											Total	6682.66

Mileage Expense	Sessions	Avg Miles (round trip)	Cost/Mile	Total costs
Co Leader - Group Session	5	25	0.445	55.63
Trainer - Group Session	5	25	0.445	55.63
Total				111.25

Supplies	Participants	Leaders	Sessions	No. of Pages	Cost/Supply	Cost
Manual - Group Leader		2			\$33.21	\$66.42
Manual - Caregiver	12				\$33.21	\$398.52
Session Feedback	12		5	1	\$0.13	\$7.80
Total						\$472.74

Group Costs \$7,266.65
 Cost/Individual \$605.55

TABLE 2. PHASE II

Activity	Participants/ Dyads	Minutes/ Event	Travel Time (minutes)	Session(s)	Hours	Master Prepared Salary/Hour \$21.28	ERE 25%	Bachelor prepared Salary/Hour \$17.79	ERE 25%	Master Trainer /Supervisor \$70	ERE 34.5%	Total Salary Expense
Overview Training												
In Session Training												
Phone Supervision		60		5	5	106.40	26.60	88.95	22.24	350.00	120.75	714.94
Supervisor Prep		30		5	2.5					175.00	60.38	235.38
Intake / Evaluation	12	20			4	85.12	21.28	71.16	17.79			195.35
Group Session	12	150	60	5	17.5	372.40	93.10	311.33	77.83			854.66
Coach Call	12	40		5	40	851.20	212.80	711.60	177.90			1953.50
Prep/Supervision/Consultant		45		10	7.5	159.60	39.90	133.43	33.36			366.28
Manual Prep		60			1	21.28	5.32	17.79	4.45			48.84
											Total	4368.94

Mileage Expense	Sessions	Avg Miles (round trip)	Cost/Mile	Total costs
Co Leader - Group Session	5	25	0.445	55.63
Trainer - Group Session				
Total				55.63

Supplies	Participants	Leaders	Sessions	No. of Pages	Cost/Supply	Cost
Manual - Group Leader						
Manual - Caregiver	12				\$33.21	\$398.52
Session Feedback	12		5	1	\$0.13	\$7.80
Total						\$406.32

Group Costs \$4,830.88
 Cost/Individual \$402.57

TABLE 3. PHASE III

Activity	Participants/ Dyads	Minutes/ Event	Travel Time (minutes)	Session(s)	Hours	Master Prepared Salary/Hour \$21.28	ERE 25%	Bachelor prepared Salary/Hour \$17.79	ERE 25%	Master Trainer /Supervisor \$70	ERE 34.5%	Total Salary Expense
Overview Training												
In Session Training												
Phone Supervision												
Supervisor Prep												
Intake / Evaluation	12	20			4	85.12	21.28	71.16	17.79			195.35
Group Session	12	150	60	5	17.5	372.40	93.10	311.33	77.83			854.66
Coach Call	12	40		5	40	851.20	212.80	711.60	177.90			1953.50
Prep/Supervision/Consultant		45		10	7.5	159.60	39.90	133.43	33.36			366.28
Manual Prep		60			1	21.28	5.32	17.79	4.45			48.84
Total												3418.63

Mileage Expense	Sessions	Avg Miles (round trip)	Cost/Mile	Total costs
Co Leader - Group Session	5	25	0.445	55.63
Trainer - Group Session				
Total				55.63

Supplies	Participants	Leaders	Sessions	No. of Pages	Cost/Supply	Cost
Manual - Group Leader						
Manual - Caregiver	12				\$33.21	\$398.52
Session Feedback	12		5	1	\$0.13	\$7.80
Total						\$406.32

Group Costs \$3,880.57
 Cost/Individual \$323.38

CONCLUSION

The following are the significant conclusions that can be drawn from this project:

- 1) The partners demonstrated CarePRO's effectiveness, acceptability and feasibility. Effectiveness was shown through significant reductions in depression, negative coping strategies, negative interactions with support network members and bother related to care recipient memory and behavior problems as well as increases in positive coping, social support satisfaction, and a number of other quality of life indicators. Effect sizes were very respectable as well. The evidence of acceptability and feasibility is demonstrated by the high proportion of completers (i.e., those that completed at least 70% of the Intensive Phase of the intervention) and by the very high perceptions of benefit reported by caregivers on the project evaluations, and ongoing positive feedback from both participants and staff.
- 2) As another indicator of acceptability, Chapter staff and Dr. Coon (when serving as the master trainer/supervisor) received feedback that many CarePRO participants wanted to keep meeting beyond the intensive intervention phase and sometimes exchanged phone numbers to stay connected and/or keep meeting on their own. The Chapters have begun to explore ways to support graduation groups or some type of ongoing activity to help CarePRO participants stay connected; these could serve as boosters for maintenance of gains. The CarePRO project incorporated booster coach calls at months 4, 5 and 9 to explore maintenance of gains after the close of the intervention's intensive phase of 5 workshops alternating with 5 coach calls over 10 weeks. However, participants seemed much more interested in an ongoing group activity as boosters than individualized coach calls.
- 3) Clearly, an array of interventions is needed to meet the needs of our diverse community of family caregivers. Group based interventions provide a welcome opportunity to learn from professionals as well as fellow caregivers. Individualized in home interventions can be more easily personalized, provide more flexible scheduling, and meet the needs of caregivers that are homebound or where the development and delivery of groups prove prohibitive. CarePRO's success may be due in part to the combination of the two approaches. Participants regularly relayed the positive experience of learning skills with other caregivers and hearing their caregiving stories as well as the opportunity to speak one-on-one with professionals through coach calls to help tailor the intervention material to meet their needs.
- 4) Outreach and recruitment successes in caregiver interventions vary in the literature, and typically vary across geographic regions (e.g., Coon, Ory & Schulz, 2003; Nichols et al., 2004). This occurred in Arizona as well as CarePRO's companion state of Nevada. The "tipping point" for recruitment is not always immediately evident and the strategies to reach that point can be impacted by the demographics of the region, the availability of current services and perceived competition, and the strength of partnerships and existing relationships.
- 5) Recruitment is challenging for the reasons stated in this report; however, this is particularly true for ethnic minority families who may face additional barriers related to the availability, accessibility and acceptability of services and as a result tend to reach

services (dx, intervention) later in the disease progression. Previous work (e.g., Belle et al., 2006; Coon, Robinson Shurgot, Mausbach & Gallagher-Thompson, 2004; Gallagher-Thompson et al., 2003; Gallagher-Thompson et al., 2007) as well as ethnic and racial minority caregivers in the current intervention demonstrate that underrepresented caregivers benefit from psychoeducational skill training interventions. However, additional work is needed to foster recruitment of underrepresented groups into caregiver programs.

- 6) CarePRO's costs appear to be substantially lower than those reported by individualized in-home interventions such as REACH II (Nichols et al., 2008) and the New York University Counseling and Support Intervention for Caregivers (Paone, 2009). CarePRO's group-based model and its train-the-trainer approach where a CarePRO certified master trainer/supervisor co-leads the intervention with new leaders appears to help keep costs lower while generating positive well-being and other quality of life indicators as well as high perceptions of overall benefit.
- 7) A key take home message for caregivers and potential implementers of CarePRO lies in the flexibility of a psychoeducational group based intervention with skills that can be applied to a variety of caregiving situations, settings and contexts. Its group base creates an opportunity to connect with others facing the journey of Alzheimer's disease and related dementias; and, its coach calls help caregivers readily apply the skills to their caregiving worlds. Moreover, these skills have application beyond the caregiving to their lives in general. As a result, CarePRO participants reported very positive outcomes and derived high levels of benefit in a variety of domains.

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