

A Rural Community Translation of a Dementia Caregiving Intervention

Leisa R Easom, PhD¹

Gayle Alston, MS²

Ryan Coleman, MBA³

¹ Full Professor, School of Nursing, Georgia Southwestern State University,

leisa.easom@gsw.edu

² Director of Community Initiatives, Rosalynn Carter Institute for Caregiving, Georgia

Southwestern State University, gayle.alston@gsw.edu

³ Data Manager, Rosalynn Carter Institute for Caregiving, Georgia Southwestern State

University, ryan.coleman@gsw.edu

Abstract

Purpose: This study explored the impact of the implementation of the GA REACH (Resources Enhancing Alzheimer's Caregiver Health) a multicomponent, evidence-based, tailored intervention, in eleven rural counties in Georgia.

Methods: Utilizing up to nine face-to-face (in the home) and three telephone sessions, tailored education and support was provided to 85 family caregivers over a six month period. A pre-post research design was utilized to measure the impact of the intervention. Data was collected on burden, depression, health and healthy behaviors, caregiving frustrations, social support, dementia-related behaviors, and plans for institutionalization. Paired sample T-tests were used to analyze the data.

Results: From baseline to six months, caregivers reported significant ($p < 0.05$) decreased depression, decreased burden, improved caregiver health, and decreased behavioral problems of

the care recipient. Caregivers expressed feeling empowered and more capable of addressing the needs of the care recipient.

Conclusions: Findings in this study indicate that the GA REACH caregiver support program can sustain the rural caregiver and improve the care environment for the care recipient. Hope for the current overburdened health care system includes the incorporation of caregiver support programs and referral to such programs by nursing and other health care providers, especially as the need for family caregivers will increase along with the number of older adults.

Keywords: Rural, Translation, Caregiving, Dementia, Aging, Evidence-based

A Rural Community Translation of a Dementia Caregiving Intervention

If family caregivers were no longer available, the cost to our healthcare system would be extremely high and burdensome. Family caregivers make up the “backbone” of the nation’s long-term care system for adults with dementia. The need is great for caregiver support for those caring for loved ones with Alzheimer’s disease. Across our nation, 1 in 8 older adults are living with this disease; especially the oldest old group - half of those aged 85 and older have the disease (Alzheimer’s Association, 2011). Georgia (GA) has one of the fastest older adult growth rates in the United States with the oldest age group, 85 and older, increasing rapidly (AOA, 2011). Correspondingly, individuals who care for these older adults, caregivers, have also increased. An estimated 11 million caregivers provide 12.5 billion hours of care each year to an estimated 5 million persons with dementia (Alzheimer’s Association, 2011; Hoch, 2009; Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). The net worth of the work performed by family caregivers has been estimated at \$450 billion annually (Feinberg, Reinhard, Houser, & Choula, 2011). These valuable family caregivers need to be viewed as targets for

health interventions as well as key participants on the caregiving team for the client with dementia.

In the US, approximately 25% of family caregivers live in rural areas which pose unique challenges to caregiving. Lack of access for rural residents is a primary concern of state units on aging who are responsible for delivery of services to older adults. Specifically, in GA, more than 56% of all counties are classified as “rural”. The Georgia Statistics System (Georgia County Guide, 2010) was used to define the rural counties in this study. Other considerations of service delivery for the rural resident include distance, transportation, understaffed agencies, high cost of services, and a fragmented service system which lacks coordination and staffing. Rural resident self-reliance has also created an attitudinal barrier to acceptance of services (Armer & Conn, 2001).

Family caregivers provide a valuable care service; however, the cost to the caregiver may be considerable. Research studies have repeatedly shown that family caregivers have an increased risk of experiencing depression, grief, fatigue, and physical health problems secondary to exhaustion and self-neglect (Albert, 2004; National Alliance for Caregiving & American Association Retired People [AARP], 2009; Nichols et al., 2011; Sullivan, 2004). The well-being of the caregiver is the key to supporting the care recipient, and also, may determine whether the care recipient can remain safely at home or must be placed in more costly institutionalized care.

Background

GA REACH (Resources for Enhancing Alzheimer’s Caregiver Health) is a 6 month, evidence-based, multicomponent caregiving intervention that targets the well-being of the caregiver. The following narrative provides a brief review of the history of the evolution of the REACH intervention.

Feasibility Study

REACH (Burgio et al., 2003) began in 1995, as behavioral research focused on a variety of multicomponent interventions at six sites designed to enhance family caregiving for Alzheimer's disease and related disorders. This first study was designed to examine the feasibility of using multiple different intervention approaches. The interventions were based on diverse theoretical frameworks, all of which are consistent with basic health-stress models. The goals of the health-stress model are to recognize the stressor, change the stressor, and/or change the caregivers' response to the stressor. Results of this first study emphasized the need for further research focusing on a tailored approach which assessed the risk or needs of the caregiver.

Randomized Control Trial

The follow-up study, REACH II, was a randomized, controlled trial sponsored by the National Institute on Aging and the National Institute on Nursing Research (Belle et al., 2006), and was implemented with caregivers of loved ones with dementia. This multicomponent intervention assessed the risk of the caregiver and based upon the results of this assessment, provided tailored, caregiver specific education, support, and enhancement of stress management skills. Delivery of this six month intervention occurred through in-home visits and telephone conversations. The findings of REACH II revealed that Hispanic and White caregivers receiving the intervention experienced improvement in burden and depression, but African American caregivers did not. However, when viewed as a group, findings indicated that caregivers demonstrated improvement in caregiver burden, depression, and management of difficult behaviors, social support and self-care, which created a better environment for care for the care recipient. None of these efforts focused solely on the rural population.

Translational Efforts

Critical is the translation of clinical research into the community setting. Translational research facilitates the movement and adoption of clinical research into community settings where families can access and benefit from the program (Woolf, 2008). Effective implementation of clinical science into service areas is critical so that good effects are achieved with consumers. The bridge from science to service is not always easy, and must continually evolve (Fixsen, Naoom, Blasé, Friedman & Wallace, 2005).

According to rural nursing theory (Long & Weinert, 1989), a primary concern of rural dwellers is the ability to work and be productive. A secondary concern may be preventive health measures. Applying these beliefs to a rural caregiver implies that the caregiver work is primary and care of self is secondary. Supports for the rural caregiver are critical. There is limited knowledge about caregiver supports in rural areas where access to care may be limited and community agencies struggling with narrow budgets to provide such supports. In 2004, the Administration on Aging funded 4 state-based REACH translations in California, Florida, Tennessee, and Alabama. Of these translational efforts, the Alabama REACH translation became the REACH OUT model with a shortened intervention series (Burgio et al., 2009). In 2007, the Department of Veterans Affairs implemented REACH VA and became the first national translation of a proven dementia behavioral intervention (REACH II) covering multiple states and facilities (Nichols et al., 2011). Results from the REACH VA study included significantly decreased burden, depression, caregiving frustrations and number of troubling dementia-related behaviors. In 2008, the Alzheimer Disease Supportive Services Program of the Administration on Aging funded REACH translations in several states, including GA.

Purpose of Research

This article describes the study and outcomes of a community translation of the REACH intervention (modeled from REACH VA) in rural GA. This translational study involved one group to examine causality in the community setting which is not conducive to experimental controls. The study was conducted by the Rosalynn Carter Institute for Caregiving (RCI) – an educational, research, advocacy, and service unit of Georgia Southwestern State University. The mission of the RCI is to provide caregivers with effective supports and make investments that promote caregiver health, skills and resilience. This study adds to the knowledge of evidence-based support for rural caregivers to sustain them in their efforts to provide care for their loved ones.

Method

Design

This study utilized a pre and post research design with baseline assessment of caregivers occurring prior to the introduction of the 6 month intervention program and follow-up assessment at the end of the program. Additionally, an overall program evaluation was conducted via telephone with each program enrollee by an independent evaluator to ensure objectivity of program success/failure.

Sample and Participant Selection

The final convenience study sample included family members (n = 85) who were caring for moderately to severely impaired individuals living with Alzheimer's disease or related dementia in the home setting. Caregivers were recruited from eleven rural counties through various means. The counties served in this study had a population density of 40 people per square mile as compared to the state of GA's 141 people per square mile. Employment and poverty levels were

less favorable than the state as a whole. The average unemployment rate for the counties served was 11.2% as compared to the state average of 9.8% (U.S. Department of Labor, Bureau of Labor Statistics, 2012). Poverty rates among people aged 65 and over ranged from 16.8% to 25.1% compared to 13.5% for the state as a whole (U.S. Department of Agriculture [USDA], 2011).

Geographical distances. We considered geographical distances when planning the recruitment process. An outreach plan was created by the investigators and recruitment was continuous over a three year period. Flyers and brochures were developed and delivered to aging agencies, faith-based agencies, the medical community, emergency responders, stores, and markets in the rural counties. Oral presentations were given at churches, civic group meetings, and health care fairs to advertise the program.

Inclusion/exclusion criteria. A convenience sample was utilized. Referral to the program occurred through self, friends, or agency referral. To be enrolled in the study, each enrollee: 1) was a co-resident caregiver or responsible for daily meal preparation for an individual with Alzheimer's disease or related dementia; 2) verbally expressed that the care recipient has memory problems; 3) provided a minimum of 4 hours of care/day; and 4) rated themselves as having stress at a level of 5 or greater on a scale of 1 to 10. The stress level rating was a verbal rating, not a formal scale. Exclusion criteria were limited to the inability to speak the English language. Although care receiver dementia severity was not an inclusion/exclusion criterion, this information was collected using the Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982). The information from this assessment scale provided the interventionists with some knowledge of the intensity of the caregiving situation and assisted them to best plan with the caregiver. Care recipients in this study had moderate to severe dementia. The University

Institution Review Board provided the human participants oversight for this project and each participant signed an informed consent form (IRB #08-019). See Table 1 for caregiver characteristics.

Table 1: Demographics of Caregivers Completing Georgia REACH

| Demographic | Frequency (n=85) | Percentage |
|------------------------------|------------------|------------|
| Marital Status | | |
| Never married | 5 | 6% |
| Married | 66 | 78% |
| Widowed | 4 | 5% |
| Divorced | 7 | 8% |
| Single | 3 | 4% |
| Race | | |
| Caucasian | 58 | 68% |
| African American | 26 | 31% |
| Not Reported | 1 | 1% |
| Gender | | |
| Male | 19 | 22% |
| Female | 66 | 78% |
| Education | | |
| Did not graduate high school | 4 | 5% |
| High school graduate | 46 | 54% |
| At least some college | 31 | 36% |
| Not Reported | 4 | 5% |
| Age (mean = 67) | | |
| <60 | 16 | 19% |
| >60 | 68 | 80% |
| Not Reported | 1 | 1% |

Procedures

Overview

The 6 month intervention program utilized an interventionist manual, a caregiver resource notebook, and a training manual for the certification process. This program included the efforts of both an Interventionist and a Group Leader. The Interventionist met with each caregiver in the

home while the Group Leader conducted a telephone support group with small groups of these same caregivers. The manuals (produced in earlier research by Nichols et al., 2011) provided scripts to guide both the interventionist and the group leader. The scripts were not read aloud, but provided a consistent base on which to begin conversations with the participants.

Interventionist. The Interventionist met face-to-face with the caregiver for up to nine in-home meetings, approximately 1 ½ hours each and conducted up to three telephone sessions of approximately ½ hour each. A total of twelve contacts, by the interventionist, with each caregiver were desired, but the type of contact could vary. Specifically, a caregiver could substitute four of the in-home visits for telephone visits. This adaptation differed from the original REACH II intervention which allowed up to two by phone visits that could be substituted for home visits.

At the initial visit, the interventionist collected baseline data on demographics, and conducted a risk appraisal assessment focused on depression, burden, health, social support, self-efficacy, desire to institutionalize and behavioral problems. Following the initial meeting, the interventionist met with the caregiver in the home and problem solved to address problems identified in the risk appraisal assessment. The risk assessment guided the focus of each interventionist meeting and tailored support to each family. Topics addressed included safety, behavioral issues, and caregiver skills and frustrations. For example, if the assessment revealed sharp or dangerous items in the home upon initial evaluation, a component of the plan for care would include removal of these items creating a less risky and safer environment for the care recipient. A Caregiver Notebook, with resources and handouts on caregiving topics such as communication and problem solving techniques, was given to each participant and used during the face-to-face meetings and served as a reference for caregivers. Educational modules in the

notebook targeted the general and specific problems experienced by families living with dementia. Each module had a different focus and helped to provide information in a specific area. For example, information dealt with “How to Deal with Driving” and “How to Deal with Repeated Questions” which are commonly cited issues with dementia. Each participant was encouraged to make notes and become familiar with every module of their Caregiver Notebook. Work performance of the interventionists was monitored through monthly audio files of their in-home sessions, weekly review of all documentation, and weekly team meetings with the program manager. Close supervision and tracking of interventionist’s interaction was warranted to assess fidelity to the intervention, especially with the staff turnover experienced. At the completion of the program, data was collected by the interventionist to compare to baseline data. While we desired for a third party to collect the post data with each family in the home, the families voiced that they would be uncomfortable with a new person and that they felt this may upset their loved one. Individuals with dementia become disturbed when the schedule and familiar routine is disrupted (Tabloski, 2010).

Group Leader. As a separate wave of support, the Group Leader was responsible for the enrollment and scheduling of caregivers, 5-6 caregivers/group, in a telephone support group over the course of the program. The Group Leader conducted a total of 5 telephone support group sessions, all of which were topic focused and scripted in regard to general information for the topic to be discussed. These calls were in addition to the three interventionist telephone sessions. The script provided a uniform way to introduce topics of general concern to caregivers, and then each group explored and shared among themselves. Topics addressed in these sessions included 1) Healthy Lifestyle; 2) Communicating With Your Loved One; 3) Communicating With Health Care Providers; 4) Community Resources; and 5) Financial and Legal Issues. The calls led by the

group leader provided verbal support and allowed caregivers to share with one another. On the telephone calls, caregivers could remain anonymous so as to encourage openness among the group. The program manager monitored fidelity to protocol by listening in on random support group calls.

Training and certification for staff. Required qualifications for the interventionist included an understanding of dementia and related caregiver issues, experience in assessment, care planning and delivery of in-home services, and a high school education. All interventionists had some college education which was above the required qualifications. Requiring a minimum of a high school education was planned to minimize the importance of formal college education for this intervention delivery. Instead, good communication capabilities and life experiences in assessment or care planning seemed more appropriate skills to the investigators. Instruction on Alzheimer's disease was included in the training process. Role play was utilized in the interview process with the scoring process heavily related to rapport building skills and ability to adhere to scripts protocol. Following hiring, each interventionist and group leader completed a training process, led by the REACH VA research team, resulting in certification. The training and certification process for the interventionist required two days of instruction followed by a third day of role play with critique and review of skills. The certification process for the group leader was a one day training followed by a day of role play and critique of role play. Mastery of learning through demonstration of skills is the goal of the certification process. We had hoped to hire two interventionists and one group leader to implement this intervention. We experienced staff turnover, and over the three year period, six interventionists, 2 African American AND 4 Caucasian, and one group leader, Caucasian, were hired. Reasons for high interventionist staff

turnover included family relocation and job transfer for better pay. The training and certification process was repeated with each new hire.

Measures

Baseline interviews included all major study variables and were conducted in the caregivers' homes. All measures were utilized pre and post intervention. Follow-up interviews occurred at the end of the six month program and also occurred in the home of the caregiver. Overall program evaluation was done by a third party via the telephone.

The *Caregiver General Questionnaire* included 16 items of general demographics with specific questions related to hours/week for caregiving duties and vigilance, as well as self-reported status of caregiver health, caregivers rated health compared to six months ago on a 5-point scale where lower scores indicated better health; and well-being, five questions on healthy lifestyles rated as never, sometimes, or often. A *Risk Appraisal Assessment* consisted of 21 items, adapted from REACH II (Czaja et al., 2009), with five questions addressing caregiver safety, five questions assessing caregiver health behavior, three questions of social support, three questions targeting stress, two items on behavioral frustrations i.e. yelling at care recipient, caregiver hitting care recipient; and three questions on advanced planning. In each of these scales, higher scores indicated higher risk in each area that was rated, with the exception of social support (2 items) where higher scores indicated better support. The *Zarit Burden Scale* (Zarit, Reever, & Bach-Peterson, 1980) measured caregiver stress and burden information, 12 item version. For this five point scale, 0 being "Never" and 4 being "Nearly Always", higher scores indicated greater burden. A score of 17 or higher indicated a "high" level of burden and stress. The Center for Epidemiologic Studies Depression Scale (CES-D), short form version

(Andresen, Malmgren, Carter, & Patrick, 1994) is a 10 item, four point scale measuring depression with score of 10 or higher indicating a “high” level of depression. The *Revised Memory and Behavior Problem Checklist* (Teri et al., 1992) is a scale of 24 items to assess memory, depression, and observable behavioral problems. Occurrence of the behavior and caregiver reaction is scored through self-report. The *Revised Scale for Caregiving Self-Efficacy* (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002) is a 15 item checklist to assess caregiver confidence in caregiving skills on a scale of 0 to 100. On this scale, higher scores indicated a higher self-efficacy. *Desire to Institutionalize* (Morycz, 1985) is a six item self-report scale regarding the caregiver intent to place. The *Program Evaluation* consisted of 40 items related to aspects of the program including helpfulness of the caregiver notebook; stress management techniques; knowledge, skills, and confidence gained as a caregiver; number length, and quality of in-home visits; value of telephone support group; and overall satisfaction with program participation. Higher ratings indicated increased satisfaction.

Data Analysis

Paired t-tests were employed for data analysis. The t-test is a statistical method for comparing differences between two groups. The two groups being compared, pre and post, were matched. Paired samples T-tests were used to determine statistical significance ($p \leq .05$) among the group from baseline to follow-up data collection. Chi-square tests were utilized to determine statistical differences among demographic segments. Frequency distributions were utilized in regard to occurrence of reported behavioral problems. Analysis utilized SPSS version 15.0.

Results

Program Participants

A total of 161 caregivers were enrolled in the program. Eighty-five caregivers completed the intervention and all data measurements within 6 months of beginning the program resulting in an attrition rate of 47%. If an enrolled caregiver missed a session: 1) not home when the interventionist arrived for the scheduled visit, or 2) the caregiver did not answer the phone, each called a minimum of twice to make appointment, the caregiver was sent a letter in the mail encouraging them to continue participation. Reasons for program drop included the failure to communicate/make appointments after multiple contacts (n = 23), lack of interest to continue program (n = 18); deceased care recipient (n = 13), the lack of time to devote to the program (n = 12), institutional placement of care receiver (n = 6), the caregiver returning to work after hiring agency personnel to provide caregiving services (n = 2), deceased caregiver (n = 1), and the interventionist felt threatened in the home environment (n = 1). Using chi-squared tests, we found no statistical differences in baseline demographics (age, education, race, gender, dementia severity of care receiver) and caregiver variables (burden, stress, depression) between participants who dropped out (n = 76) and the remaining participants (n = 85).

Caregiver Variables

Caregivers participated in nine in-home sessions and three interventionist telephone conversations. Additionally, caregivers were invited to participate in 5 telephone support groups with the group leader; however, caregivers chose to participate in an average of two group calls / caregiver. In a comparison from baseline to program end, caregivers showed significant improvements in decreasing burden and depression (see Table 2). The group mean burden score of all participants was 19.1 upon entry to the program, compared to 16.3 at program end. Fifty-

seven caregivers (67%) scored above the burden benchmark of 17, indicating risk, compared to thirty-nine (46%) caregivers scoring above the benchmark at the end of the program. The group mean depression score was 11.8 upon program entry compared to 9.9 at program end. Sixty one caregivers scored above the benchmark, individual score of 10 or higher, for depression upon program entry and only 40 (47%) caregivers above the benchmark upon program exit.

Table 2: Outcome Measures Paired t-tests

| Outcome | Pre Scores Mean (SD) | Post Scores Mean (SD) | p value |
|------------------|----------------------------|-----------------------------|---------|
| Depression | 11.8 (6.5) | 9.9 (6.1) | 0.006 |
| Burden | 19.1 (8.2) | 16.3 (3.0) | 0.004 |
| Caregiver Health | 3.1 (.7) | 2.8 (.9) | 0.023 |
| Self-Efficacy | 71.8 (16.8) | 75.3 (17.8) | 0.202 |

From baseline to program end, caregivers reported improvements in their health self-report ratings. The program entry group score was 3.1 and the program exit score was 2.8, lower scores indicated better health ratings. With the caregiver self-efficacy tool, on a scale of 0 – 100, participants rated their confidence in handling fifteen different caregiving situations, with 0 being not at all confident and 100 being totally confident. Specifically, confidence in being able to control future problems with the care recipient improved from 58.3% to 78.7% ($p = .004$). From baseline to program end, overall self-efficacy scores rose from 71.8% to 75.3%, but was not statistically significant ($p = .202$).

Caregivers reported being less troubled by problematic behaviors at program end. Caregivers responded to twenty four questions regarding occurrence of certain memory and behavior problems in the last week, and if so, how much “annoyance or bother” was experienced. On average, caregivers experienced 15 (41%) of the 24 problem behaviors with the

care receiver at the beginning of the program with the most frequently reported bothersome behavior being “forgetting what day it is”. The number of behaviors that occurred remained the same over the course of the intervention. When asked to rate how much these behaviors annoyed or bothered the caregiver on a 5-point scale (with 0 being not at all bothered, and 4 being extremely bothered), the mean fell from 1.7 to 1.5, comparison of baseline to program end. The behavior that caregivers showed the most improvement, being less bothered by, and learned to cope with better was “care receiver threatened to hurt themselves”.

Additionally, there were two caregiver frustration behavior questions in the caregiver questionnaire, administered both pre and post intervention. When asked how often the caregiver felt like screaming or yelling at the care recipient in the past six months, 1 = “Never”, 2 = “Sometimes”, 3 = “Often” due to care recipient behavior, the mean score fell from 2.1 to 1.9. When asked if they felt they had to keep from hitting or slapping the care receiver because of his/her behavior, the mean score fell from 1.2 to 1.1. These scores did not achieve statistical significance, but caregivers did report improvement.

Finally, caregivers stated they had spoken with the care recipient less often about the possibility of institutional placement after participating for six months in the GA REACH program, 28% at program entry compared to 15% at program end.

Cost analysis. Expenses for program implementation were carefully calculated. Salary of the PI, office space, telephones, and internet were not included in this calculation as we hoped that agency adoption of this intervention would already have these expenses/services and would not be additional costs. Included in the cost analysis was: 1) salaries for the program manager, the interventionists, and group leader; 2) travel expenses for mileage for service delivery, marketing / outreach activities; 3) supplies e.g. training manuals, paper, copying; 4) Caregiver

notebooks for each client; 5) teleconferencing fees for support groups; and 6) postage for letters sent regarding telephone support group sessions and to remind those clients who had missed an appointment. Analysis of the 85 participants completing the study revealed that program implementation involved a cost of \$7.00 per day/caregiver.

Program evaluation. On the overall program evaluation, which was conducted by a third party, who was not involved with the home visits, caregivers shared that the program was beneficial. Within two weeks following the completion of the intervention, each participant was contacted via telephone and asked specific questions regarding aspects of the program. Caregivers (100%) reported a better understanding of Alzheimer’s disease, the caregiving role, and increased confidence in dealing with behavioral problems of the care recipient.

Table 3: Program Evaluation

| Program Component | % Reporting Benefit |
|--|---------------------|
| Overall Intervention | |
| General Benefit | 100. |
| Better understanding of disease and caregiving role | 100. |
| Increased confidence in dealing with behavior problems | 100. |
| Improved ability to care for care recipient | 98.50 |
| Improvement in care recipient’s life | 86.70 |
| Individual sessions and home visits | |
| Improved knowledge | 100. |
| Increased caregiving skills | 97.10 |
| Telephone groups | |
| Improved knowledge | 72.70 |
| Increased caregiving skills | 77.20 |

Discussion

Georgia REACH, a caregiver support program, demonstrates a successful community translation of the REACH intervention with a rural population of caregivers caring for individuals with moderate to severe Alzheimer’s disease or related dementia. Evidence-based caregiver support programs have shown to have positive outcomes for both rural and urban communities (Burgio et al., 2009; Smith & Bell, 2005).

In this convenience study, data was collected pre-intervention and post-intervention. Positive outcomes were achieved. As with the earlier REACH VA (Nichols et al., 2011) translational study and the REACH II randomized control trial (Belle et al., 2006), caregivers experienced statistically significant improvements in both depression and burden. Caregivers expressed receiving benefit from all components of the intervention, with telephone support groups receiving a lower rating. The lower rating of the telephone support group was not surprising. This rural population did not seem to value the telephone support and shared that they “did not have time” to spend an hour on a phone call, but preferred the “face to face” contact. Perhaps this finding is related to the geographical distances, isolation, and a need for human social interaction experienced by rural caregivers.

Recruitment issues. In the first year of the project, it became clear that marketing and recruitment efforts would have to be intensified to reach and enroll rural caregivers for the program. Rural caregivers are isolated by definition and demonstrate attitudinal barriers such as a deep sense of independence and discomfort with accepting outside help. Distrust of a new program also impacted and slowed enrollment. To address this problem, accountability for enrollment was expanded to all team members. Marketing and recruitment activities held priority in weekly meetings and interventionists were also utilized to promote the program when not engaged in direct service delivery. Interestingly, outreach to social service providers, specifically senior and community centers yielded the greatest return and resulted in an increase in program enrollment. Marketing to local retail businesses, posting flyers and leaving brochures, was probably the most ineffective recruitment strategy for the number of participants recruited. For the future, rural agencies and organizations implementing a caregiver support intervention

program should begin marketing early and continuously. Budget plans should address staff and marketing costs to carry out an intense campaign to enroll caregivers.

Behavioral problems. Management of behavioral problems is a frequent complaint of all caregivers caring for individuals with Alzheimer's disease. The rural caregivers in this study were no different with all reporting care recipient behavioral problems and frustration at managing these troubling behaviors. From baseline to program end, the occurrence of behavioral problems remained consistent and caregivers reported being "less bothered" in their responses to problematic behaviors. We found this finding interesting as behavioral problems usually increase with advancing Alzheimer's disease. Caregiver frustration was also reduced after program participation. Caregiver confidence, self-efficacy, increased, perhaps indicating that caregivers felt more empowered. Through the intervention, caregivers learned new techniques to communicate and problem solve. Perhaps this new knowledge and feelings of empowerment had a positive influence on the perception of their ability to address and respond to problematic behaviors. Similarly, the REACH VA (Nichols et al., 2011) intervention study indicated significant improvement in caregiver frustration and behavior management as well. Decreasing caregiver frustration also has potential for lessening the risk of abuse. These findings may indicate that caregivers can learn to manage troubling behaviors of the care recipient before frustration rises to crisis levels.

Institutionalization. Caregiver stress and burden predict institutionalization (Gaugler, Kane, Clay, & Newcomer, 2005). Reducing caregiver stress through a caregiver support program may delay or avoid nursing home placement (Mittelman, Haley, Clay, & Roth, 2006). In this study, a change was demonstrated in the frequency of conversations between caregiver and care recipient regarding nursing home placement. Perhaps the need for such conversations decreased

as a result of better behavior management skills, decreased stress, and decreased burden. With institutionalization representing a high cost to both families and the overall healthcare system, more exploration regarding the desire to institutionalize is warranted in future studies. Collecting data in this area is clearly indicated.

Social need in rural areas. Caregivers appeared to value the “face to face” contact with the interventionist. A total of twelve contacts by the interventionist with each caregiver were desired. The flexibility of the contact allowed for a substitution of four in-home visits for a telephone visit. Most of the caregivers opted for all of the nine in-home visits. Perhaps caregiver preference and choice for in-home visits demonstrates the isolation experienced by rural caregivers living in areas where the population is sparse and geographically distanced.

Application to rural health care and nursing practice. The fabric of rural beliefs will probably not change much over the next decade. Nurses practicing in rural health must understand that rural individuals define their health by their ability to work and be productive (Long & Weinert, 1989). For rural caregivers, their work is the care of their loved one. Blending this view of work and care of self is important. As nurses, we must strive to help the rural caregiver to consider that caring for themselves will allow them to continue working and providing that care to the loved one. A seamless nursing referral system for rural caregivers to community caregiving support programs is needed. Knowing what community programs are available is an important nursing role in the rural healthcare environment.

Program cost. Analyzing the cost to implement this program was tedious, but important. Community agencies hoping to adopt the GA REACH program to support the caregivers served need to know anticipated costs. Planning well can assist with sustainability of a program. Data analysis suggests a cost of \$7.00 per day/caregiver. This finding is similar to REACH VA cost

data (L. Nichols, personal communication), which reports \$5 per day/caregiver with travel to the caregiver home limited to 50 miles, one-way. Additionally, the target population in REACH VA was identified veteran families. In our study, travel costs were higher and impacted by distances of up to 110 miles, one-way, submitted by interventionists traveling to the homes of rural participants and extensive recruitment to these participants. In comparison, the cost per day in a long term care facility is estimated at \$215 per semi-private room, inclusive of lodging and meals (Prudential Research Report, 2010).

Limitations

Limitations of this translational study include the one group and quasi-experimental design which provide a means for examining causality in situations not conducive to experimental controls. Although not the “gold-standard” randomized control trial type of research, translational research focuses on “real-world” effectiveness and thus, has value. The small sample size of mainly Caucasian caregivers and limited geographical rural area influence the generalizability of the results. Additional research is needed to examine the effect of this program with caregivers of diverse populations. Staff turnover of interventionists was a limitation requiring more time for training of new staff. Chief reasons for staff turnover were family relocation and/or returning to school. With each new hire, the training and certification process was repeated to ensure intervention fidelity, yet causing a delay or lag in enrolling new participants. Data collection in the home was conducted at baseline and program exit by the interventionist, possibly causing a response bias. While we desired to have a third party to collect the data, the families voiced being uncomfortable with a new person and causing possible upset with the care recipient.

Conclusion

Program benefit and satisfaction was reported by all caregivers in this study. Caregivers shared that the program helped them to understand dementia and increased their knowledge and skills to provide care. Caregiver support programs, such as the GA REACH program, should be an essential component of rural community agency programs. Caregiver support programs also fit well into primary care settings, especially those working with geriatric populations. Professional medical and nursing personnel need education regarding these programs and a referral process into these programs is critical. Our older adult population will continue to experience growth in coming years and the need for in-home caregiving will increase correspondingly. The findings in this study show great promise for sustaining the rural caregiver and creating an improved caring environment for the care recipient. Hope for a positive future for aging individuals demands the incorporation of caregiver support programs into the health care system, especially for rural health.

Supporting Agency

This project was supported in part by grant number 90AE0320/01, from the U.S. Administration on Aging, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their finding

References

Administration on Aging. (2011). A profile of older Americans. Retrieved http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/index.aspx

- Albert, S.M. (2004). Beyond ADL-IADL: Recognizing the full scope of family caregiving. In C. Levine (Ed.) *Family Caregivers on the Job. Moving Beyond ADLs and IADLs*. New York, NY: United Hospital Fund of New York.
- Alzheimer's Association. (2011). *Fact sheet*. Retrieved from www.alz.org
- Andresen, E., Malmgren, J., Carter, W., & Patrick, D. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *American Journal of Preventive Medicine, 10*(2), 77-84. [[MEDLINE](#)]
- Armer, J. & Conn, V. (2001). Exploration of spirituality and health among diverse rural elderly individuals. *Journal of Gerontological Nursing, 27*(6), 28-37. [[MEDLINE](#)]
- Belle, S, Burgio,L., Burns, R. Coon, D., Czaja, S., Gallagher-Thompson, D., ... Zhang, S. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine, 145*, 727-738. [[MEDLINE](#)]
- Burgio, L., Collins, I, Schmid, B. Wharton, T., McCallum, D., & Decoster, J. (2009). Translating the REACH caregiver intervention for use by area Agency on Aging personnel: The REACH OUT program. *Gerontologist, 49*(1), 103-116. [[MEDLINE](#)]
- Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L., Mahoney, D., & Schulz, R. (2003). Resources for enhancing Alzheimer's caregiver health (REACH): Overview, site-specific outcomes, and future directions. *Gerontologist, 43*, 514-520. [[MEDLINE](#)]
- Czaja, S., Gitlin, L., Schulz, R., Song, Z., Burgio, L., Stevens, A., Nichols, L., Gallagher-Thompson, D. (2009). Development of the risk appraisal measure: A brief screen to

identify risk areas and guide interventions for dementia caregivers. *Journal of American Geriatrics Society*, 57, 1064-1072. [[MEDLINE](#)]

Feinberg, L., Reinhard, S., Houser, A., & Choula, R. (2011). Valuing the invaluable: The economic value of family caregiving, 2011 update. Washington, DC: AARP Public Policy Institute. Retrieved from <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>

Fixsen, D., Naoom, S., Blasé, K., Friedman, R., & Wallace, F. (2005). Implementation research: A synthesis of the literature. Retrieved from <http://nirn.fpg.unc.edu/>

Gaugler, J., Kane, R.L, Kane, R.A., Clay, T., & Newcomer, R. (2005). The effects of duration of caregiving on institutionalization. *Gerontologist*, 45, 78-89. [[MEDLINE](#)]

Georgia County Guide. (2010). Georgia Statistics System. Retrieved from <http://www.georgiastats.uga.edu/>

Hoch, D. (2009). National Center for Biotechnology Information. *Pub Med Health*. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001748/>

Long, K. & Weinert, C. (1989). Rural nursing: Developing the theory base. *Scholarly Inquiry for Nursing Practice*, 3, 113-127. [[MEDLINE](#)]

Mittelman, M., Haley,W., Clay,O., & Roth, D. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer's disease. *Neurology*, 67, 1592-1599. [[MEDLINE](#)]

Morycz R. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. *Research on Aging* 7, 329- 361. [[MEDLINE](#)]

National Alliance for Caregiving and AARP. (2009). *Caregiving in the U.S.* Retrieved from http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf

- Nichols, L., Martindale-Adams, J., Burns, R., Graney, M., & Zuber, J. (2011). Translation of a dementia caregiver support program in a health care system -- REACH VA. *Archives of Internal Medicine*, 171(4), 353-361. [[MEDLINE](#)]
- Prudential Research Report. (2010). Long term care cost study. Retrieved from <http://www.prudential.com/media/managed/LTCCostStudy.pdf>
- Reisberg, B., Ferris, S., de Leon, M., & Crook, T. (1982) The Global Deterioration scale for assessment of Primary Degenerative Dementia. *American Journal of Psychiatry*, 139, 1136-1139. [[MEDLINE](#)]
- Smith, S. & Bell, P. (2005). Examining the effectiveness of the Savvy caregiver program among rural Colorado residents. *Rural and Remote Health* 5, 466. [[MEDLINE](#)]
- Steffen, A., McKibbin, C., Zeiss, A., Gallagher-Thompson, D. & Bandura, A. (2002). The revised scale for caregiving self-efficacy: Reliability and validity studies. *Journals of Gerontology: Psychological Sciences*, 57, 74–86. [[MEDLINE](#)]
- Sullivan TM. (2004). Caregiver strain index (CSI). *Dermatology Nursing*, 16(4), 51-54. [[MEDLINE](#)]
- Tabloski, P. (2010). *Gerontological Nursing*. 2nd edition. New Jersey: Pearson Education.
- Teri, L., Truaz, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. (1992). Assessment of behavior problems in dementia: The revised memory and behavior problems checklist. *Psychology of Aging*, 7, 622-631. [[MEDLINE](#)]
- United States Department of Agriculture (USDA). (2011). *The economics of food, farming, natural resources and rural America*. Retrieved from <http://www.ers.usda.gov/Data/povertyrates/>

United States Department of Labor, Bureau of Labor Statistics. (2012). *Unemployment rates*.

Retrieved from <http://www.bls.gov/lau/lastrk11.htm>

Woolf, S. H. (2008). The meaning of translational research and why it matters. *Journal of American Medical Association*, 299, 211-213. [[MEDLINE](#)]

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20(6), 649-655. [[MEDLINE](#)]