Educating Caregivers About Caregiving: An Evaluation of the Council on Aging Learning Advantages Program for Informal Caregivers

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Executive Summary

Informal caregivers provide 80% of all U.S. home care with an estimated value of at least $250 billion annually. Caregiver depression, stress, health problems, and injuries make caregiving problematic, often resulting in premature nursing home placement of the care receiver.

Council on Aging of Southwestern Ohio (COA) and the Area Agency on Aging District 7, Inc. (AAA #7) collaborated on this project to build on COA's successful Council on Aging Learning Advantages (COALA) program by providing in-home training for informal caregivers. COA and AAA #7 hired staff to conduct these trainings in their combined 15 county service area in Southern Ohio. The goals of the project were to reduce caregiver stress, burden, and injury, and increase caregiver knowledge of appropriate care strategies, thereby allowing caregivers to continue in their role and to improve the quality of the care they provide.

Results show that over a three-month time period, after receiving training, caregiver burden decreased, self esteem and competence improved, and objective knowledge of caregiving issues improved. The number of hours of care provided by the primary caregiver declined, while a larger proportion of caregivers reported using formal services such as personal care, homemaking, and respite. More caregivers were making time for themselves, and injuries such as back strain were reduced. Our findings indicate that the program is worthy of replication in other area agencies on aging.

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Background

Informal caregivers -generally family members or friends- are commonly defined as individuals who provide care recipients with unpaid assistance such as food preparation, transportation, and bathing. The National Alliance for Caregiving and AARP (2004) estimate that there are nearly 44 million informal caregivers 18 or older in the United States. Typically, informal caregivers are female, in their mid-40s, working full or part-time, and caring for someone over the age of 50 (National Alliance for Caregiving & AARP, 2004). On average, caregivers provide 21 hours of care per week; the average duration of caregiving is four years.

The type, amount, and duration of care provided by informal caregivers are nearly 80% of all long-term care in the United States, resulting in an estimated economic savings of over 250 billion dollars per year to our nation's long-term care system (Friss Feinberg & Newman, 2004). Similar to national estimates, about three-fourths of long-term care in Ohio is provided unpaid by caregivers. In 1999, the economic value of Ohio's informal care was estimated to be approximately 5 billion dollars (Mehdizadeh & Murdoch, 2003).

Impact of informal caregiving

National studies have evaluated the impact of care on caregivers' physical, emotional, and financial circumstances. The National Alliance for Caregiving & AARP (2004) found that 15% of caregivers reported high levels of physical strain. Other findings estimate that 11% of caregivers report that their health has declined as a result of caregiving (Mack, 2005). Findings also show that 35% of caregivers have poor levels of emotional health (NAC/AARP, 2004). Finally, approximately 14% of caregivers report financial strain (Thompson, 2004). Significant differences in financial strain were noted when the caregiver lived with the care recipient; 24% of caregivers in such circumstances felt more financially strained compared to 10% of those who did not share the household (Thompson, 2004).

Most studies investigating the impact of caregiving find that the physical, emotional, or economic strain placed on caregivers is directly related to the concept of caregiver burden. Caregiver burden has been defined by Zarit, Todd & Zarit (1986) as "the extent to which caregivers perceive their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (p. 261). Caregiver burden impacts the care recipients' ability to continue being cared for in the community. A recent study of Ohio PASSPORT (Ohio's 2176 Medicaid home and community-based waiver program) clients who entered nursing homes found that the need for 24-hour care and caregiver problems were two of the top three reasons for nursing home placement (Kunkel, Murdoch, Straker, & Applebaum, 2001). Another study that examined a national representative sample of care recipients found that higher levels of caregiver burden led to a greater likelihood of nursing home placement for the care recipient (McFall & Miller, 1992).

Training Caregivers

Caregivers rarely receive information about the care recipients' conditions, or training about medication, equipment, and transferring, or about other kinds of care they may have to provide. A factor that may contribute to this lack of or insufficient caregiver training could be found in the hospital discharge process. In an attempt to move the care recipient into the community, hospitals have little time to provide information and training to caregivers (Weaver, Perloff, & Waters, 1998). Similarly, home care agencies have little time to prepare for incoming patients, so they have little positive effect on informal caregiver training. In addition, home care nurses focus interventions mainly on acute conditions, not chronic, long-term conditions. Even when care recipients are enrolled in long-term home and community-based services, the formal care provided is limited in frequency so a majority of the burden and responsibility still remains with the primary caregiver.

Training: Impact on Caregivers

Research into caregiver interventions has shown that training interventions increase caregivers' knowledge of diseases and disease management, improve physical and mental health, decrease caregiver burden, and delay institutionalization of care recipients. One study found that families and caregivers "who reported receiving information about how to care for their relative at home and information about symptoms and side effects were more likely to report lower burden than caregivers who did not recall this." (Weaver, Perloff, & Waters, 1998, p. 39).

Mittleman, Ferris, Shulman, Steinberg, Ambinder, Mackell & Cohen (1993) found that limited educational and supportive counseling interventions reduced spousal caregivers' depressive symptoms in response to the troublesome behavioral symptoms displayed by the care recipients. The study concluded that the intervention lowered the risk of nursing home placement when compared to the group that did not receive the training intervention. Further studies replicated the findings. The results showed that psychosocial interventions did delay nursing home placement (Whitlatch, Zarit, Goodwin, & Von Eye, 1995).

Another study found that an intensive training program decreased caregiver burden and made beliefs about the caregiver role more realistic (Ostwald, Hepburn, Caron, Burns, & Mantell, 1999). In their study, caregivers for relatives with Alzheimer's disease were asked to attend two-hour trainings twice a week for seven weeks. During training caregivers were taught about Alzheimer's disease and its progression through the use of videocassettes and lectures. Caregivers learned that they could not stop the progression of the disease; they learned to set more realistic goals. They were also trained to focus more on their own needs as caregivers and given tools to cope. Family members that could provide support to the caregiver were also included in the training. The training ended with caregivers reporting to the trainers how they put what was taught into practice.

COALA^{SM}

During the past five years, COA has trained over 200 individuals in the skills needed to become a paid homemaker or personal care worker through their Council on Aging Learning Advantages (COALA) program. Through the recognition of the importance of the involvement of informal caregivers who may provide many types of care ranging from minimal assistance to 24-hour assistance, the Council on Aging (COA) and the Area Agency on Aging District 7 (AAA#7), through an AoA grant, expanded the COALA project to include informal caregivers interested in receiving individualized training in their own or in the care recipients' homes.

The goals of the training were as follows:

- Improvement of caregiver competence. Trained caregivers will demonstrate an increase in knowledge, skills, and confidence in their duties.
- Improvement in the quality of life for caregivers. By reducing caregivers' mental and physical burden, care may continue longer than without the

intervention. After receiving training the caregivers will report lower levels of caregiver burden, depression, and fewer injuries due to caregiving activities.

Intervention

The formal caregiver manual from COA's COALA program was adapted for use with informal caregivers. Some topics that were added to the manual include assessing the care recipient and caregiver's situation (physical, mental, social, medical, and environmental); planning for meeting the needs of the recipient and caregiver; balancing personal and caregiving responsibilities; discussing financial issues; maintaining one's physical and mental health; planning for the future; introducing community resources including support groups; and providing Internet and print resources on caregiving.

Two nurse trainers, one in COA (PSA 1) and one in AAA #7 (PSA 7), were hired to provide training to informal caregivers. Both of these registered nurses had previous experience with home care and caregiving.

Caregivers were recruited to participate in the training using a variety of strategies. These included:

- Exhibitions and presentations at local conferences and health fairs;
- Presentations to physicians, hospital discharge planners, hospital social workers, service provider organizations, nursing homes, adult protective services workers, caregiver support groups, and senior centers;
- Distribution of approximately 90 posters to churches, senior centers, caregiver support group meeting places, senior housing buildings, nursing homes, community centers, grocery stores, physician offices, health clinics, assisted living facilities, and adult day care centers;
- Placement of brochures promoting the program in physician offices, hospitals, senior centers, and other organizations where caregivers might be found;
- Distribution of press releases to newspapers and radio;
- Placement of monthly stories in the Area Agency Caregiver Newsletter; and
- Participation in local coalition meetings by nurse trainers and project managers.

After caregivers expressed interest in the training program, the COALA nurse trainers made from one to three home visits with each caregiver; the average number of visits for both sites was two. An assessment of the caregiver and care recipient was completed. The nurse trainer identified individual needs and tailored the training program (i.e. bathing, proper transfer techniques, disease specific care, mobility issues, medical equipment and medications) to the caregiver/recipient's individual circumstances. Each caregiver was given a COALA Caregiver Training Manual as well as appropriate informational materials. Intervention topics for caregivers included the following:

- Respite services;
- Problem solving with family issues, finances, and medical coverage for the care recipient;
- Stress management/ preventing burnout;
- Long-term care planning;
- Body mechanics- teaching about lifting and transfers;
- Depression and caregiver well being;
- Purchasing equipment;
- Referrals for services to assist caregiver in caring for care recipient at home/ community resource linkage;
- Fall prevention/ safety at home; and
- Nutrition information.

Many of the caregiver interventions were specific to the unique situation of each caregiver/receiver dyad and to the disease process they were managing at home. In PSA 7, a family caregiver division provided services directly such as equipment or respite service. A visit by the nurse trainer might include help in choosing equipment from a catalog. The nurse would then follow-up by having it sent to the caregiver's home. In PSA 1, caregivers were referred to existing service programs such as the Elderly Services Program (county tax-levy funded homecare) or PASSPORT, which sometimes had waiting lists. Caregivers also received information about how to obtain a prescription to have some types of durable medical equipment provided through Medicare. The service delivery structure in PSA 7 allowed the nurse trainer to directly affect the services and equipment received by the caregiver.

The researchers observed and recorded two nurse trainer training programs in order to capture the methods used for caregiver training. The COALA training program has the unique benefit of being molded to the needs of each caregiver. In order to meet the needs of each caregiver, the training sessions were guided by a general outline of specific items to be addressed with the intention of identifying the particular needs of each caregiver. In addition to individualized content, the training sessions were less structured, with the trainers deciding how long the interviews should last, how many should be conducted, and which items should be emphasized.

The training sessions that were observed took place in the participants' private residences. The primary caregiver was of central focus. While the sessions were designed with a certain amount of structure, they were also designed for flexibility and the ability to adjust or customize in order to address the specific needs of each participant and their unique situation. One training program was completed in one session (referenced as Training #1), while the other was completed over three sessions (referenced as Training #2).

Training #1 was more intense and required more focused attention than Training #2. During the observation of this session, the caregiver seemed to lose concentration and interest towards the end of the training. The benefit, however, was that the caregiver did not have to find time in her schedule to meet a second or third time, and could still telephone the trainer with additional questions. Training #2 involved three short training sessions, and each subsequent session had the benefit of being a follow-up and acted to address specific challenges identified during a previous session or to address additional questions. For example, during the first session, the trainer pointed out that a wheelchair ramp would be a help in transporting the care recipient. At the start of the second training session, the caregiver told the trainer that she had made several phone calls for quotes to have one installed. This had not previously been a concern to her, and since the first training session she had given a lot of thought to how dangerous it was not to have a ramp: “My gosh, what if I had a fire, there would be no way to get her [my mother] out of here.”

During both training sessions, certain topics were covered and investigated, with the first part devoted to assessing the primary caregivers’ needs and continuing with other topics relevant to effective caregiving. These introductory assessments were based on the caregiver/care receiver assessment tool. The start of each training session was dedicated to going over various forms including the assessment. After examining the assessment form that was completed prior to the arrival of the trainer, the trainers went over any specific questions or concerns associated with that information. This process helped clarify the kind of caregiving tasks that were being performed and the dynamics of the particular caregiving situation. Specifically, the training went over the following points:

- Medical conditions/appointments- caregiver self-care;
- Formal services- which ones were being received, which ones were needed;
- Stress/respite- whether there was someone to relieve the caregiver and how often someone was available;
- Emergency plans- whether there was a living will or power of attorney, and whether other family members were nearby in case of an emergency;
- Safety- whether appropriate equipment was available and whether other relevant safety precautions were being taken;

- General information and discussions- fall prevention, nutrition, and infection control;
- Other specific problems that needed to be discussed.

These specific areas of training were discussed in-depth and modified based on the particular needs of the caregivers. The training also included an inspection of the home environment to ensure that the house was furnished with safe and helpful equipment. Finally, a copy of the COALA training manual was distributed and discussed.

While the assessment form provided a helpful guide for identifying specific concerns and challenges faced by the caregivers, the most important aspect of the training sessions seemed to be acknowledging and problem solving regarding caregiver burnout and stress issues. These discussions led to the identification of specific services and behaviors that could provide respite or reduce stress. For instance, one caregiver talked about how she and her husband “never get to do anything anymore.” She said that “he goes to church in the morning, I go to church at night.” In training # 2, the trainer told the caregiver about the National Family Caregiver Support Program, and that by signing up, she could receive respite services. In another situation, the caregiver spoke of concerns about her father (who suffers from Alzheimer’s disease), who often gets out of the house and wanders only to be identified by neighbors and returned by the police. The trainer suggested that she replace the locks so that they are lower on the door; people with Alzheimer’s disease often cannot figure out how to use a lock when it is placed in a different location. As a result, the care recipient cannot get out, but other users are still able to open the door during emergencies. This provided a solution to one of the most challenging and stressful parts of this caregiver's role—preventing her father from wandering.

The COALA training sessions provide an effective mechanism for pinpointing specific challenges and concerns faced by caregivers, and providing resources and encouragement to address them. The trainers who were observed in the training sessions gave immediate feedback and ideas for addressing safety issues, caregiver well-being, and general burnout prevention. [Also, in these training sessions, caregivers were observed not only as sources for identifying problems but they often acted as their own problem solvers.] Our observations suggest that the caregiver intervention was implemented effectively in both training approaches (Training #1 and Training #2), although they varied content and format appropriately given the goal of individualized training for every caregiver. The impact of the training program on the caregivers who participated is discussed in the following section.

Methods

The informal caregivers were evaluated three times- once prior to training (Time 1), once immediately following training (Time 2), and again 3 months after completing the training (Time 3). The survey completed prior to training was called the "Caregiver Self-Assessment" and was used, in part, by the nurse trainers to review the caregivers' situations and needs. Three months after training the same assessment was completed again to see if changes had occurred as caregivers implemented some of the things they had covered in their training sessions. A number of scales were used to examine caregiver social support (Sherbourne & Stewart, 1991), self-esteem (Picot, Youngblut, & Zeller, 1997), competence (Shyu, 2000), burden (Zarit & Zarit, 1990), economic strain, feelings about caregiving knowledge, physical health status, mental health status (Ware, Kosinski & Keller, 1996), depression (Radloff, 1977), and objective knowledge of caregiving issues (See Appendix A for the Caregiver Self-Assessment). Items included on the objective knowledge portion of the assessment were based on the topics that the nurse trainers agreed should be covered with all caregivers regardless of the individualized needs of the caregivers or care recipients.

Immediately following the completion of the training a second assessment of the caregiver's objective knowledge of caregiving issues was made. Caregivers completed the same 20-item questionnaire that was included in the caregiver self-assessment (a "knowledge assessment" included in Appendix A) and returned it by mail to the evaluation team. The three-month follow-up questionnaire was almost identical to the pre-training survey without some of the demographic information that was initially collected. The nurse trainers mailed the survey to the caregivers along with a return envelope to Scripps Gerontology Center. Two weeks after each Time 3 questionnaire was mailed, the nurse trainers made follow-up reminder phone calls to those who had not returned their questionnaires.

Results

Despite the fact that this program was provided free-of-charge in caregivers' homes and at their convenience, recruiting caregivers to participate in the research posed a challenge. In PSA 7, comprised entirely of rural counties, 187 caregivers participated in the training program with only 55 agreeing to participate in the research data collection activities for a full participation rate of 29.4%. In PSA 1, comprised of largely urban counties, 363 caregivers participated in the training program and 123 participated in the research for a response rate of 33.9%. One-hundred and seventy-eight participants completed the Time 1 survey. One-hundred and eight completed Time 3 for a 61% study completion rate.

For some caregivers who left the study we could identify a reason; 16 care recipients died and three went to a nursing home. The remaining 50 participants simply did not return their surveys, or returned them with a note saying they didn’t want to complete them. A comparison of those who completed the Time 3 survey with those who dropped out showed no significant differences at Time 1 in depression, burden, hours of weekly care, physical health status, mental health status, caregiver injury incidents, care recipient injury incidents, and the number of caregiving activities (such as attending support groups, making home modifications) the caregivers had completed prior to enrollment. Because the groups are similar on many of the outcomes of interest it is unlikely that the dropouts had an effect on the results obtained at Time 3.

Caregiver demographics

As shown in Table 1, the average age of caregivers in this study was 59.5 and the average care recipient is 79.5. Caregivers ranged in age from 19 to 86; care recipients ranged in age from 46 to 100. An overwhelming majority (80.8%) of the caregivers enrolled in this program were female. Over one-quarter (26.9%) are employed at least part-time. Overall, three-quarters were white, while in the urban area only two-thirds were white. Most had a limited education with over-half (58.3%) having a high school education or less. Most were married (59.8%) and lived with their spouse (58.7%). More than three-quarters (81.6%) shared their homes with a parent or other care recipient and one-quarter (26.3%) had children in their homes. If they did not share their homes

Table 1. Caregiver and Care Recipient Characteristics at Enrollment

Demographic Characteristics	**Urban Care Recipient**	**Rural Care Recipient**	**Total Care Recipients**	**Urban Caregiver**	**Rural Caregiver**	**Total Caregivers**
Average Age	80.8	76.6	79.5	62.6	58.3	59.5
Gender (% Female)	62.4	50.9	58.7	83.8	74.5	80.8
Race						
White	65.8	96.4	75.6	66.7	98.2	76.7
African-American	32.5	3.6	23.3	31.6	1.8	22.1
Asian	0.9	--	0.6	--	--	--
Other	0.9	--	0.6	1.7	--	1.2
Education						
Less than high school	46.2	40.7	44.4	15.7	16.4	15.9
H.S. Diploma	35.9	40.7	37.4	39.1	49.1	42.4
Some College	12.8	14.8	13.5	28.7	21.8	26.5
Bachelor’s Degree	3.4	--	2.3	7.8	3.6	6.5
Some Graduate	0.9	--	0.6	0.9	1.8	1.2
Advanced Degree	0.9	3.7	1.8	7.8	7.3	7.6
Marital Status						
Married	34.1	57.1	43.0	53.7	73.2	59.8
Widowed	48.0	32.1	44.8	7.3	19.6	5.0
Divorced/Separated	11.4	8.9	11.0	23.6	--	22.3
Never Married	1.6	--	1.2	10.6	5.4	8.9
Household Composition						
Care Recipient				81.6	81.5	81.6
Spouse	3.3	14.3	6.7	53.7	69.6	58.7
Mother				28.5	1.8	20.1
Father				9.8	1.8	7.3
Children over 18	--	7.1	2.2	10.6	7.1	9.5
Children under 18	--	--	--	18.7	12.5	16.8
Another care recipient				3.3	7.1	4.5
Other person	2.4	5.4	3.4	8.9	7.1	8.4
Sibling	1.6	--	1.1	3.3	1.8	2.3
No one else in household	13.8	7.1	11.7	4.1	5.4	4.5
Employment						
Not employed				66.4	87.3	73.1
Employed more than 30 hrs. weekly				20.7	7.3	16.4
Employed less than 30 hrs. weekly				12.9	5.5	10.5

with the care recipient they are likely to live nearby—nearly three-quarters (71.4%) lived less than 20 minutes from the care recipient (see Table 2).

Reasons for caregiving

As shown in Table 2, caregivers in our sample provide care for a variety of reasons. Physical illnesses (64.2%) were cited in over one-half the cases, while one-half of the caregivers reported general frailty (49.2%) and/or dementia and confusion (52.0%) as reasons for their caregiving. Nearly one-third (32.4%) mentioned the care recipient's need for reassurance as a reason for providing care.

Activities of training

As our observations of training illustrated, caregivers use the information provided in training sessions to carry out activities on their own or to accomplish tasks during the training sessions. Table 3 illustrates the proportion of caregivers who reported that they had done the listed activity during the previous three months. As shown, these caregivers had accomplished a number of activities prior to enrollment (Time 1). But, after completing the training (Time 3) the proportion that had done each activity increased in all but five activities. After training, nearly 20% more of the caregivers had read books or watched videos about caregiving. This suggests that the training manual and video resources provided were used in many cases. Large increases were also shown in the proportion of caregivers who had used formal services such as respite or homemaker, and in the proportion of caregivers who had made changes to their homes. However, the percentage of caregivers who asked family or friends for help or sought professional help to deal with emotions declined. Perhaps the training in self-care and

Table 2. Care Recipient Information at Enrollment

Characteristic	Urban CR	Rural CR	Total
Relationship to Caregiver			
Spouse	24.1	55.1	33.6
Mother	45.5	22.4	38.5
Father	13.4	4.1	10.6
Son	--	4.1	1.2
Aunt	3.6	2.0	3.1
Brother	2.7	--	1.9
Sister	--	2.0	0.6
Step-father	0.9	--	0.6
Cousin	0.9	--	0.6
Uncle	0.9	--	0.6
Daughter	0.9	--	0.6
Other	7.1	10.2	8.1
Reason for Needing Care			
Physical Illness	60.2	73.2	64.2
General Frailty	49.6	48.2	49.2
Dementia/Confusion	55.3	44.6	52.0
Other	25.2	21.4	24.0
Mental Health Issues	21.1	21.4	21.2
Reassurance	33.3	30.4	32.4
Distance from Caregiver's Home			
Less than 20 minutes	64.0	90.0	71.4
Between 20-45 min.	32.0	--	22.9
Between 1-2 hours	4.0	--	2.9
More than 2 hours	--	10.0	2.9

Note: Multiple reasons for providing care could be chosen so responses sum to more than 100%.

Table 3. Caregiving Activities Undertaken at Time 1 and Time 3

Caregiving Activity	**% Yes Time 1**	**% Yes Time 3**
Ask for help from family/friends	77.7	75.7
Use special equipment	69.9	71.4
Made changes to home	69.9	81.9
Purchase equipment/ assistive devices	69.6	72.6
Used homemaker/ home health	47.6	60.6
Sought help from family/ friends with emotionsl	47.6	44.3
Read books/ watched videos about caregiving	47.1	68.2
Used personal care services	46.6	63.6
Made lifestyle changes for self	46.5	56.1
Used respite services	28.0	36.8
Made a plan for future LTC needs	22.5	28.3
Investigated nursing homes	18.6	17.9
Sought help with family relationships	18.6	24.0
Used adult day services	17.6	24.0
Sought professional help with emotions	17.5	16.0
Attend support groups	16.5	19.4
Sought help with time mgt.	15.4	12.4
Average number of Activities Undertaken	6.65	7.83***
N=108		

Note: Only those who completed both time 1 and time 3 are included.
*** $p \leq .001$

burnout prevention assisted caregivers in self-management of the caregiving stress. Training information about programs to assist with home adaptations and funding were likely an impetus for some of these changes such as home modification and formal service use. Declines in the proportion of caregivers who sought help with time management and with emotional issues may be due to training that helped with time management and provided coping skills for managing burden and stress. Also, time management may be much less of an issue for those caregivers who are receiving formal services at Time 3 that they did not receive at Time 1.

Further examination of the changes in caregiving activity was done by examining tasks that were “active caregiving activities” (e.g. relying on formal services, using assistive equipment, and “psychological-emotional changes” such as attending support groups and seeking help with emotional issues). As previously mentioned, the rural area agency had the advantage of being able to directly enroll their caregivers in programs and services as a result of receiving funding from the National Caregiver Support Program. Comparing urban and rural elders on the mean number of active and psychological activities showed that the rural elders, on average, had undertaken 4.7 active caregiving activities at Time 3 compared to 2.85 active caregiving activities among the urban elders. These differences were also statistically significant (p=.000). The groups were similar in the number of psychological activities undertaken with an average of 1.2 psychological-emotional activities for urban elders and 1.8 among the rural elders although the difference between these averages also proved statistically significant (p=.02). The average number of changes between Time 1 and 3 for urban and rural elders also reached significance for active changes in both groups, and for psychological changes among the urban elders. These results suggest that the training alone, as received by the caregivers of the urban elders, produces increased caregiving activity and resource use, but when coupled with the direct provision of resources and services, the changes made among the caregivers of rural elders were even larger. The effect that these changes have on their physical and psycho-social functioning is discussed in the next section.

Outcomes

Knowledge and Mastery

As shown on Table 4, a number of statistically significant changes were shown between the Time 1 and Time 3 caregiver assessments. Self esteem increased, competence increased, burden decreased, economic strain increased slightly, and the hours of weekly care provided decreased. Knowledge of caregiving issues increases significantly between Time 1 and Time 2, and between Time 1 and Time 3. Only social support, injuries, mental health status, and depression showed non-significant changes. Our hypothesis that injury and depression could be significantly changed with training is not borne out by these group scores, but as shown in Table 5, over half of the caregivers improved from Time 1 to Time 3 on every measure except economic strain and physical health status. The fact that an overwhelming majority (91.5%) of caregivers improved on the caregiver burden score suggests that training can provide relief for some kinds of problems but not others.

Physical Health, Injuries, Self-care

After the training intervention the caregivers' physical health status (higher score is worse health status) and the average number of illness and injury incidents declined slightly. We also looked at utilization of hospitals, emergency rooms, and physician services. A positive change is noted in an increase in the proportion of both caregivers and care recipients who had seen a physician in the previous 3 months. It may be that the training intervention, which emphasized caregiver maintenance of health and well-being,

Table 4. Caregiver Outcomes at Time1 and Time 3

<table>
<tr><th>Measure</th><th>N</th><th colspan="6">Time1 Mean</th><th colspan="6">Time 3 Mean</th></tr>
<tr><td>MOS Social Support [1]</td><td>104</td><td colspan="6">20.51</td><td colspan="6">19.9</td></tr>
<tr><td>Picot Self Esteem Score[2]</td><td>86</td><td colspan="6">20.0</td><td colspan="6">18.67*</td></tr>
<tr><td>Caregiver Competence[2]</td><td>97</td><td colspan="6">3.34</td><td colspan="6">2.97**</td></tr>
<tr><td>Zarit Burden Score[1]</td><td>82</td><td colspan="6">30.41</td><td colspan="6">16.18***</td></tr>
<tr><td>Economic Strain[1]</td><td>83</td><td colspan="6">5.18</td><td colspan="6">5.59**</td></tr>
<tr><td>Hours of Weekly Care Provided</td><td>92</td><td colspan="6">81.01</td><td colspan="6">58.33*</td></tr>
<tr><td>Number of activities caregivers are assisting with:</td><td></td><td colspan="6"></td><td colspan="6"></td></tr>
<tr><td><i>ADLs</i> (out of 6)</td><td>178</td><td colspan="6">3.17</td><td colspan="6">2.00***</td></tr>
<tr><td>IADLs <i>(out of 15)</i></td><td>178</td><td colspan="6">10.83</td><td colspan="6">7.06***</td></tr>
<tr><td>Subjective Knowledge[2]</td><td>95</td><td colspan="6">8.09</td><td colspan="6">7.28***</td></tr>
<tr><td># of Caregiver Injuries/Illness Days in Previous 3 Months (excludes those with no injuries)</td><td>50</td><td colspan="6">36.79</td><td colspan="6">34.44</td></tr>
<tr><td># of Care Recipient Injuries/Illness Days in Previous 3 Months (<i>excludes those with no injuries)</i></td><td>50</td><td colspan="6">15.46</td><td colspan="6">18.72</td></tr>
<tr><td>Physical Health Status (SF-12)</td><td>60</td><td colspan="6">48.53</td><td colspan="6">46.70*</td></tr>
<tr><td>Mental Health Status (SF-12)</td><td>73</td><td colspan="6">44.50</td><td colspan="6">45.07</td></tr>
<tr><td rowspan="2">Knowledge Assessment Score <i>(out of 20)</i></td><td rowspan="2">116
82
83</td><td colspan="4">Time 1</td><td colspan="4">Time 2</td><td colspan="4">Time 3</td></tr>
<tr><td colspan="4">15.95***</td><td colspan="4">17.68***</td><td colspan="4">16.84***</td></tr>
<tr><td rowspan="2">CESD Depression Scale <i>(greater than 16 indicates depression)</i></td><td rowspan="2">78</td><td colspan="6">Time 1</td><td colspan="6">Time 3</td></tr>
<tr><td colspan="6">14.76</td><td colspan="6">15.10</td></tr>
<tr><td rowspan="4">Knowledge Assessment Score</td><td rowspan="4">83</td><td colspan="3">% Scoring</td><td colspan="3">Time 1</td><td colspan="3">Time 2</td><td colspan="3">Time 3</td></tr>
<tr><td colspan="3">0-50</td><td colspan="3">3.9</td><td colspan="3">--</td><td colspan="3">--</td></tr>
<tr><td colspan="3">51-75</td><td colspan="3">36.1</td><td colspan="3">4.5</td><td colspan="3">25.8</td></tr>
<tr><td colspan="3">76-100</td><td colspan="3">60.0</td><td colspan="3">95.5</td><td colspan="3">74.2</td></tr>
</table>

Note: Only those who also completed Time 3 are included in Time1 scores.
[1] Higher score indicates higher level or higher incidence
[2] Lower score indicates higher level or higher incidence
*** p= .001, ** p=.01, * p=

Table 5. Proportion of Caregivers Who Maintained or Improved from Time 1 to Time 3.

Location	N	Urban	Rural	Total
MOS Social Support	104	56.9	62.5	60
Picot Self-Esteem	86	45.6	57.1	55.8
Caregiver Competence	97	60.3	54.5	58.8
Zarit Burden	82	94.7	91.7	91.5
Economic Strain	83	38.2	51.9	42.2
Subjective Knowledge	95	80.3	81.8	81.1
Objective Knowledge	83	86.3	49.4	72
CESD	78	56.4	54.6	56.3
SF-12 Physical	60	48.8	33.3	41.7
SF-12 Mental	73	56	50	53.4

encouraged some participants to take steps to maintain health or prevent future health problems. It may also be that caregivers had experienced serious health problems of their own that required physician intervention. The proportion reporting their health as good, very good, or excellent declined over the three months from 72.4% at Time 1 to 66.7% at Time 3.

Another aspect of the training program emphasized the importance of caregivers maintaining activities that they enjoy and taking time for themselves. We asked them to report how many times in a typical week they got together with friends, talked to friends on the phone, went to a place of worship, left their home for any reason, and took quiet time for themselves. None of these changed in a significant way, although the number of days in a typical week that they took quiet time for themselves to do something they enjoyed increased from 3.8 to 4.2. The proportion who took no days for themselves decreased from 16.4 to 12.2, suggesting that an increased number of caregivers were attempting to make some time for themselves.

As shown in Table 6, certain kinds of injuries/illnesses increased while others were reduced. Back strain was the most prevalent caregiver injury at Time 1; by Time 3, the proportion of participants reporting strains declined. A similar change was shown for sore muscles. These trends may suggest that participants had learned and successfully integrated proper handling techniques into their daily tasks. Headaches, falls, and scrapes and abrasions all increased. The increase reported in minor things such as

Table 6. Proportion Reporting Injuries and Health Service Utilization among Caregivers and Care Recipients at Time1 and Time 3

Injury/Service	**Caregiver Time 1 (%)**	**Caregiver Time 3 (%)**	**Care Recipient Time 1 (%)**	**Care Recipient Time 3 (%)**
Back strain	35.2	30.6	12.0	9.3
Sore Muscles	28.7	25.9	14.8	11.1
Stress/Tension Headache	31.5	36.1	7.4	8.3
Physician Visits	19.4	26.9	58.3	62.0
Falls	1.9	12.0	34.3	34.3
Hospital Admission	3.7	3.7	26.9	28.7
Cuts, scrapes, abrasions	6.5	10.2	22.2	18.5
N=108				

headaches and scrapes suggests that increased caregiver vigilance regarding their own health may have led to increased reporting of injuries.

The fact that caregivers did not significantly decline in physical health status and that about 40% of them maintained or improved their physical health over three months of caregiving can be viewed as a measure of the program's success. It is also possible that training caregivers in self-care and in issues concerning their own health sensitized and made them more attentive so that they reported worse health at Time 3. Because of the retrospective self-report nature of the injury and illness data, it is unclear which of these assumptions is correct.

Depression

Because caregiver depression was viewed as an important outcome that failed to achieve significance, further analyses identified some important differences between those who are depressed and those who are not. (Depression was identified as a CESD score of 16 or above. This is a score that indicates that depression is likely to be present.) As shown on Table 7, depressed caregivers are more likely to be caring for a mother or husband and more likely to be sharing a home with the care recipient. They are also more likely to be women; about 44% of the female caregivers are depressed compared to 29% of the men. The depressed caregivers provide nearly 25 more hours of care per week than the non-depressed caregivers, although this difference is not statistically significant. They also report about twice as many illness/injury incidents for themselves and three times as many care recipient illness/injury incidents. The incidence of care recipient illness/injury is the only statistically significant difference between those with and without indications of depression. Interestingly, depressed caregivers report higher

Table 7. Depressed and Non-depressed Caregivers at Time 3

Characteristic	**Depressed**	**Not Depressed**
Average Age	58.8	58.0
Relationship to CR		
Mother	45.5	32.0
Husband	27.3	16.0
Father	12.1	10.0
Wife	9.1	16.0
Other	6.0	26.0
Living with CR	83.3	74.0
% Employed		
No	72.2	71.7
Yes, full-time	16.7	17.0
Yes, less than 30 hours per week	11.1	11.3
Length of time caregiving	5.28 yrs.	3.74 yrs.
Caregiver Illness/Injury Incidents	37.58	19.36*
Care Recipient Illness/Injury Incidents	18.58	6.15*
Physical Health Status (SF-12)	50.05	45.66
Mental Health Status (SF-12)	58.44	38.80***
Avg. Hrs. of Care Provided per week	65.28	59.96
Reason for Providing Care		
Physical Illness	66.7	50.0
General Frailty	60.5	65.4
Dementia/Confusion	51.4	62.7
Reassurance	40.5	33.3
Mental Health Issues	35.1	26.9
Geographic Location		
Urban	71.1	64.2
Rural	28.9	35.8
N=108	N=38	N=53

physical health status and significantly higher mental health status as measured on the SF-12 than their non-depressed counterparts. It is likely that the physical and mental demands of caring for a heavy need care recipient outweigh any short-term assistance that can be provided in a training program. Despite increased knowledge and resources, providing care to someone whose health is declining will inevitably lead to feelings of sadness and loss in the caregiver. In this case, depression might be seen as a normal response to a loved one's illness.

Economic Strain

As previously noted, economic strain increased over the three-month time period for the caregivers in this study, although the proportion showing a reduction in economic strain was much greater among the caregivers of rural elders than among their urban counterparts (51.9% compared to 38.2%). This may be because the rural caregivers were provided services and equipment through the Family Caregiver Support Program. We asked caregivers about their employment status and also how caregiving had affected their work. As shown in Table 8, urban caregivers were more likely to be employed and were also more likely to have made adjustments to their jobs that would have negative economic impacts. The fact that so few rural caregivers were employed when they began caregiving may indicate that loss of income from employment changes had a much smaller impact.

Caregiver Burden

On average, caregiver burden decreased by nearly one-half, from an average burden score of 30 at Time 1 to 16 at Time 3. As previously mentioned, caregivers' feelings of burden have been linked to nursing home placement of care receivers and to physical illness of caregivers. Directly or indirectly, any intervention that can reduce feelings of burden may allow caregivers to maintain caregiving longer, as well as improve the quality of life for both caregivers and care recipients.

Table 8. Employment and Work Changes Among Urban and Rural Caregivers at Time 3.

Work Item	Urban Caregivers	Rural Caregivers	Total Sample
Employed at least part time	38.2	12.%	28.9**
Stopped pursuing employment opportunities	20.6	12.5	31.5**
Stopped working	23.5	17.5	21.3
Retired early	13.2	15.0	13.9
Took a less demanding job	10.3	2.5	7.4
Reduced Hours	13.2	5.0	10.2
Lost some fringe benefits	4.6	--	4.6*
Used vacation to provide care	22.1	5.0	15.7**
Used sick time to provide care	7.4	5.0	6.5
Took time off without pay	11.8	7.5	10.2
Reduced overtime, changed to lower-paying shift	5.9	5.0	5.6
Came late/left early	11.8	7.5	10.2

*p=.10; **p=.05

Summary

COALA individualized training was provided to over 500 caregivers by Area Agencies on Aging in Planning and Service Areas 1 and 7 in Southern Ohio. One-hundred and seventy-eight caregivers enrolled in a research evaluation to examine the effects of training on caregiver burden, social support, self-esteem, competence, subjective knowledge, physical health status, mental health status, and objective knowledge of caregiving issues. The training program was provided in individuals' homes, with some common issues covered with all caregivers, it was also tailored to address the individual needs of particular caregivers and care recipients.

Three months after training, caregivers showed significant improvements in self-esteem, competence, burden, subjective knowledge of caregiving, caregiver and care recipient injury/illness incidents, and objective knowledge of caregiving. Depression increased slightly, as did the average number of care recipient injury/illness incidents, but both of these increases could have been due to chance since they were not statistically significant. Physical health status of the caregivers declined slightly over the three-month period.

On all measures except physical health status and economic strain, over one-half of the caregivers maintained or showed improvement over the three-month period. Since caregiving can be costly on a financial as well as a physical and mental health level, these results are not surprising. Caregivers in the rural PSA actually showed slightly improved economic strain, this is most likely because the National Family Caregiver Support Program allowed them to receive services and other resources in addition to the training program.

Between the time the participants enrolled in the program and the three-months post training, significant differences were shown in the number of ADLs and IADLs they were assisting with, the number of caregiving activities such as planning for long-term care, and in learning more about the care recipient's illness, etc. Between Time 1 and Time 3 the number of caregivers who said they made time for themselves every day increased as well. In order for caregivers to continue in their roles, they must learn to make time for themselves, take care of themselves, and ask for help when they need it. The fact that an overwhelming majority of participants reported decreased feelings of burden after 3 months suggests that they may be heeding the advice of nurse trainers. In addition, the number of caregiving activities undertaken increased over time, suggesting that caregivers may have become more proactive about seeking solutions and resources to help with the challenges they face.

Conclusions

The COALA program provides a valuable model for replication by other organizations wishing to provide supportive services for caregivers. The training manual could easily be adapted for use by other organizations by changing the resource lists to reflect what is available in each community. In some cases, the gains shown by caregivers in the rural area agency were greater than those shown in the urban agency. Training, coupled with direct provision of services and funds for such things as home improvements and medical equipment, may produce better outcomes for caregivers than either services or training alone. Caregiver training could become an integral part of assessing older adults for home and community-based services. Such a model would require agencies to accommodate both the needs of the care recipient and the caregiver. As the National Family Caregiver Support Program continues to have an impact on how agencies think about caregivers as clients, a training program such as COALA will likely find greater acceptance among care managers and others who have previously focused only on the care recipient.

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Appendix A

Caregiver Assessments

Date____________________________ **AAA ID#**_______________

COALA^{SM} Caregiver Self-Assessment

A. We are interested in knowing about the caregivers we are serving in the COALA program. First, we would appreciate it if you would provide the following information about the person you are caring for (the Care Recipient or CR). All of the information you provide will be kept confidential. Place a check "√" in the box to the left of your answer or fill in the blank.

1. What is the care recipient's relationship to you?___________________________________

2. Does the care recipient live with you?

☐ **Yes → (Skip to Question #6 below)**
☐ **No**

3. Where is the care recipient's home located? Would you say in….

☐ A city or town ☐ The suburbs, or ☐ A rural area

4. How far away does the care recipient live?

☐ Less than 20 minutes away
☐ Between 20 and 45 minutes away
☐ Between 45 minutes and one hour away
☐ Between 1 and 2 hours away
☐ More than 2 hours away

5. Who else lives with the care recipient? <u>CHECK ALL THAT APPLY</u>

☐ No one else; they live alone
☐ Spouse (Husband or wife)
☐ Sibling (s) (Brother or Sister). How many?_____
☐ Child(ren) under 18. How many?____
☐ Child(ren) over 18. How many?_____
☐ Other persons. Their relationship to the care recipient?________________________

6. What is the care recipient's date of birth?______________

7. What is the care recipient's gender? ☐ Female ☐ Male

8. What is the care recipient's highest educational level?

☐ Less than high school diploma
☐ High school diploma
☐ Some college, including associate's degree
☐ Bachelor's Degree
☐ Some post-graduate work
☐ Advanced Degree

9. What is the care recipient's race? (Check all that apply.)

☐ White or Caucasian
☐ Black or African-American
☐ Asian
☐ Hispanic or Latino
☐ Other. What?____________

10. What is the care recipient's Marital Status?

☐ Married
☐ Widowed. How long?______________________________
☐ Divorced or separated. How long?___________________
☐ Single, Never Married

11. What is (are) the main reasons you are providing care to the care recipient? CHECK ALL THAT APPLY

☐ Physical illness (e.g. heart attack, stroke, Parkinson's, diabetes, emphysema, recent surgery)
☐ General Frailty (e.g. dizziness, fear of falling, weakness, shortness of breath)
☐ Mental health issues (e.g. depression, mental illness or developmental disability)
☐ Dementia/confusion (e.g. Alzheimer's, cannot make complex decisions, etc.)
☐ Reassurance (e.g. afraid to be alone, wants to be checked on, etc.)
☐ Other. What reasons?____

12. When did you become a caregiver for the care recipient? __________________________
month/year

B. We are also interested in knowing about the characteristics of the caregivers we are serving in the COALA program. We would appreciate it if you would provide the following information <u>about yourself</u>. Place a check "√" in the box to the left of your answer or fill in the blank.

1. Where is your home located? Would you say in….

☐ A city or town ☐ The suburbs, or ☐ A rural area

2. What county do you live in? _________________________________

3. Who lives in your household? <u>CHECK ALL THAT APPLY</u>

☐ No one else; I live alone
☐ Spouse (Husband or wife)
☐ Mother
☐ Father
☐ Mother-in-law
☐ Father-in-law
☐ Siblings (brother or sister). How many?______

☐ Child(ren) under 18. How many?____
☐ Child(ren) over 18. How many?_____
☐ Another person for whom I am caring. Their relationship to you?_______
☐ Other persons. Their relationship to you?________________________

4. What is your date of birth?______________

5. What is your gender? ☐ Female ☐ Male

6. What is your highest educational level?
☐ Less than high school diploma
☐ High school diploma
☐ Some college, including associate's degree
☐ Bachelor's Degree
☐ Some post-graduate work
☐ Advanced Degree

7. What is your race? (Check all that apply.)
☐ White or Caucasian
☐ Black or African-American
☐ Asian
☐ Hispanic or Latino
☐ Other. What?______________

8. What is your Marital Status?
☐ Married
☐ Widowed. How long?__________________
☐ Divorced or separated. How long?___________________-
☐ Single, Never Married

9. What county and state were you born in?____

10. Are you employed outside the home?
☐ Yes, full-time.
☐ Yes, less than 30 hours per week.
☐ No.

C. Now that we've learned about your background, we'd like to learn some basic information about your health status and your levels of activity. Please answer every question. Although many questions look like others, they are all different. Please take time to read and answer each question carefully and place a check "√" in the box or column that is closest to your response.

1. In general, would you say your health is:

☐ Excellent
☐ Very Good
☐ Good
☐ Fair
☐ Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	YES, limited a lot	YES, limited a little	NO, not limited at all
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf			
3. Climbing several flights of stairs			

<u>During the past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health?</u>

	YES	NO
4. Accomplished less than you would like		
5. Were limited in the kind of work or other activities		

<u>During the past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

	YES	NO
6. Accomplished less than you would like		
7. Didn't do work or other activities as carefully as usual		

8. <u>During the past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?

YES, limited a lot	YES, limited a little	NO, not limited at all

These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks:</u>

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. have you felt calm and peaceful?						
10. did you have a lot of energy?						
11. have you felt down-hearted and blue?						
12.has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting friends, relatives, etc.)?						

How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
13. I seem to get sick a little easier than other people.					
14. I am as healthy as anyone I know.					
15 I expect my health to get worse.					
16. My health is excellent.					
17. I have a regular physician that knows me and my health issues.					

D. The next set of questions asks about the support you get from others, and how you've been feeling emotionally.

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available if you need it?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. someone you can count on to listen to you when you need to talk					
2. someone to give you good advice about a crisis					
3. someone to give you information to help you understand a situation					
4. someone to help with daily chores if you were sick					
5. someone to share your most private worries and fears with					
6. someone who understands your problems					

Please check how often, in the past week, you have felt…	Less than one day	1 – 2 days	3 -4- days	5 – 7 days
7. That you were bothered by things that don't usually bother you				
8. That you did not feel like eating; your appetite was poor				
9. That you could not shake off the blues even with help from family and friends				
10. That you were just as good as other people				

11. That you had trouble keeping your mind on what you were doing				
12. Depressed				
13. That everything you did was an effort				
14. Hopeful about the future				
15. That your life had been a failure				
16. Fearful				
17. That your sleep was restless				
18. Happy				
19. That you talked less than usual				
20. Lonely				
21. That people were unfriendly				

Please check how often, in the past week, you have felt…	**Less than one day**	**1 – 2 days**	**3 -4- days**	**5 – 7 days**
22. That you enjoyed life				
23. That you had crying spells				
24. Sad				
25. That people dislike you				
26. That you could not “get going:”				

E. We are interested in the activities you participate in during a typical week. Please answer each question by recording the number of times you usually perform the activity. If you do not perform the activity, please answer with a zero “0”.

1. During a typical week, how many times do you get together socially with family, friends or neighbors? __________

2. During a typical week, how many times do you talk with family, friends or neighbors on the telephone? __________

3. During a typical week, how many times do you go to church, temple, or another place of worship for services or other activities? __________

4. How many days in a typical week, do you leave your home for any reason? __________

5. How many days in a typical week do you take quiet time for yourself to do something like read a book or magazine, take a nap, do something you enjoy, or just relax? __________

F. We would now like to find out some of the things you do to help the care recipient. Please rate the care recipient’s level of dependence or independence on each of the

following activities by placing a "√" in the column underneath your answer. For each activity, in the last column, indicate whether YOU are helping the care recipient with this activity by circling YES or NO. If the activity does not apply to the care recipient, leave the item blank.

How independent is the care recipient in:	**Completely Independent**	**Some Help is Required**	**A lot of Help is Required**	**Completely Dependent**	**Do YOU help the care recipient? Circle YES or NO Below**	
1. Taking a bath or shower?					***YES***	***NO***
2. Grooming?					**YES**	**NO**
3. Eating?					**YES**	**NO**
4. Getting to the toilet, using a bedpan, or other toileting functions?					**YES**	**NO**

How independent is the care recipient in:	**Completely Independent**	**Some Help is Required**	**A lot of Help is Required**	**Completely Dependent**	**Do YOU help the care recipient? Circle YES or NO Below**	
5. Medical matters, such as changing bandages, injections, colostomy/catheter?					**YES**	**NO**
6. Planning or following a diet?					***YES***	**NO**
7. Preparing a meal?					**YES**	**NO**
8. Taking the right medications on time?					**YES**	**NO**
9. Transferring to or from the bed or a chair?					**YES**	**NO**
10. Walking?					**YES**	**NO**
11. Getting around in a wheelchair?					**YES**	**NO**
12. Using the telephone?					**YES**	**NO**
13. Writing checks and paying bills?					**YES**	**NO**
14. Completing forms like taxes, Medicare, Social Security?					**YES**	**NO**
15.Banking and finance matters?					**YES**	**NO**
16. Legal matters?					**YES**	**NO**

17. Making appointments?					**YES**	**NO**
18. Washing and drying clothes or bed linens?					**YES**	**NO**
19. Housework?					**YES**	**NO**
20. Transportation?					**YES**	**NO**
21.. Shopping or errands?					**YES**	**NO**

22. On average, approximately how many <u>hours per day</u> do you help with these activities? (Include only the time when you actively help, supervise, or do things for the care recipient) # of <u>hours per day</u>: __________

23. On average, approximately how many <u>days per week</u> do you help with these activities? (Include only the days when you actively help/supervise/or do things for the care recipient) # of <u>days per week</u>: __________

24. How many other family members or friends provide unpaid care for your care recipient? # of family members or friends ___________

☐ **25. Thinking about all of the family members or friends who provide care for the care recipient, about what proportion of the care do YOU provide? Would you say:**
A little
☐ More than a little, but less than half
☐ About half
☐ More than half, but not nearly all
☐ Nearly all
☐ All

26. Thinking about the amount of care YOU provide, is it too little, enough, or too much?

☐ Too little. I would like to do more for the care recipient.
☐ Enough. I can manage to meet the needs of the care recipient.
☐ Too much. The care recipient needs more care than I can manage to give.

G. The following is a list of questions that reflect how people sometimes feel when taking care of another person. Each question asks about "your relative"; answer about <u>your care recipient</u> even if they are a friend or neighbor. After each question, indicate how often <u>you</u> feel that way by placing a "√" in the column underneath your answer.					

HOW OFTEN:	**Never**	**Hardly Ever**	**Sometimes**	**Usually**	**Always**
1.do you feel that your relative asks for more help than he/she needs?					
2. do you feel that because of the time you spend with your relative that you don't have enough time for yourself?					
3. do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?					
4. do you feel embarrassed over your relative's behavior?					
5. do you feel angry when you are around your relative?					
6. do you feel that your relative currently affects your relationship with other family members in a negative way?					
7. are you afraid of what the future holds for your relative?					
8. do you feel your relative is dependent upon you?					
9. do you feel strained when you are around your relative?					
10. do you feel your health has suffered because of your involvement with your relative?					
11. do you feel that you don't have as much privacy as you would like because of your relative?					
12. do you feel that your social life has suffered because you are caring for your relative?					
13. do you feel uncomfortable about having friends over because you are caring for your relative?					
14. do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?					**Almost Always**
15. do you feel that you don't have enough money to care for your relative in addition to the rest of your expenses?					
16. do you feel that you will be unable to take care of your relative much longer?					

17. do you feel you have lost control of your life since your relative's illness?					
18. do you wish you could just leave the care of your relative to someone else?					
19. do you feel uncertain about what to do about your relative?					
20. do you feel you should be doing more for your relative?					
21. do you engage in unhealthy behaviors such as overeating, drinking too much alcohol, or other things, because of stress about your relative?					
22. do you have enough money left at the end of the month for necessities like groceries and medicine?					

H. The following questions ask about changes in your work situation and your standard of living. Place a "√" in the box next to your answer.

1. Because of providing care have you: **<u>CHECK ALL THAT APPLY</u>**

☐ I did not work before I began providing care.
☐ Stopped pursuing new employment opportunities
☐ Stopped working
☐ Retired early
☐ Taken a less demanding job
☐ Reduced working hours from full-time to part-time
☐ Lost some of your employment fringe benefits
☐ Used vacation time to provide care
☐ Used sick leave to provide care
☐ Taken time off without pay to provide care
☐ Lost or turned down a promotion
☐ Reduced overtime, changed to a lower paying shift, or otherwise reduced your wages
☐ Came in late or left early. How many hours did you miss last month?_________________
☐ Had other changes in work not related to caregiving. What?________________________________

2. Since becoming a caregiver has your financial situation improved, stayed about the same , or gotten worse?

☐ Improved
☐ Stayed about the same
☐ Gotten worse

3. Thinking about the average month, are there things that the care recipient needs that you cannot afford to buy?

☐ **Yes. What?____**
☐ **No.**

I. The next items ask you to think about injuries and accidents over the past three months. Place a "√" in the box next to each thing that has happened to you in Question 1 and to the care recipient in Question 2 and record the number of times it has happened.

<u>1. During the past three months</u>, have any of these things happened to you <u>as a result of caregiving</u>?

☐ Back strain. How many times? ______________________
☐ Sore muscles. How many times? ______________________
☐ Twisted wrist or arm. How many times?______________________
☐ Twisted ankle. How many times? ______________________
☐ Broken bones. How many times? _________________________________
☐ Cuts, bruises or scrapes. How many times? ______________________________
☐ Scalds or burns. How many times? _________________________________
☐ Tension or stress headaches. How many times? ______________________
☐ Falls. How many times? ____
☐ Admission to the hospital. How many times?________________-
☐ Outpatient visits to the hospital. How many times?____________________
☐ Visits to the emergency room. How many times? _________________
☐ Visits to a physician. How many times? _______________________________
☐ Other injuries. What?____

<u>2. During the past three months</u>, have any of these things happened to the care recipient?

☐ Back strain. How many times? ______________________
☐ Sore muscles. How many times? ______________________
☐ Twisted wrist or arm. How many times? ______________________
☐ Twisted ankle. How many times? ____________________________________
☐ Cuts, bruises or scrapes. How many times? __________________________________
☐ Skin tears or bedsores. How many times? ___________________________________
☐ Scalds or burns. How many times? ______________________________________
☐ Tension or stress headaches. How many times? _____________________________
☐ Falls. How many times? ________________________________
☐ Broken bones. How many times? ___________________________________
☐ Admission to the hospital. How many times?________________-
☐ Outpatient visits to the hospital. How many times?____________________
☐ Visits to the emergency room. How many times? _________________
☐ Visits to a physician. How many times? _______________________________
☐ Other injuries. What?____

J. The next questions ask you to think about how well you know the needs of the care recipient. For each item, place a "√" in the box below your answer.

How well would you say you know about:	Very Well	Pretty Well	Not Very Well	Not at all
1.The physical conditions of the care recipient?				
2.What things affect the condition of the care recipient?				
3.Things in the house that can cause problems for the care recipient?				
4.Things that influence the emotional state of the care recipient?				
5. The care recipient's physical needs?				
6. Ways to keep the care recipient comfortable?				

K. Here are some things that people do from time to time to make caregiving easier for themselves. How often do you do each of these things? Please place a "√" in the box below your answer.

How often do you:	Very Often	Fairly Often	Just a Little	Not at all
1. Try to be firm in directing your care recipient's behavior?				
2. Do the things you really have to do and let the other things slide?				
3. Try to find ways to keep your care recipient busy?				
4. Try to learn as much as you can about the illness (e.g. read books, talk to doctors, go to lectures)?				
5. Attend support groups to talk to other caregivers?				
6. Ask for help from family and friends?				
7. Rely on in-home services like homemaker or home health?				
8. Use special equipment to help manage the care recipient's needs?				
9. Use adult day care services?				

Since becoming a caregiver have you:	YES	NO
10. Sought professional help in dealing with emotional issues?		
11. Sought help from friends or family in dealing with emotional issues?		
12. Sought help in dealing with time management?		
13. Made a plan for the care recipient's future long-term care needs?		
14. Made changes in your (or the care recipient's) home to make caregiving easier?		
15. Purchased special equipment or assistive devices to make caregiving easier?		
16. Investigated nursing home placement?		
17. Sought help in improving family relationships?		

18. Read books, watched videos, or taken other steps to learn about caregiving?		
19. Made lifestyle changes to take better care of yourself as a caregiver?		
20. Received in-home services such as personal care for the care recipient?		
21. Received respite services to give you a break from caregiving?		

L. The next set of questions asks about some of the ways people feel about caregiving. Please answer how you feel now about caring for your care recipient compared to when you first began as a caregiver. Please place a "√" in the box below the best response.

	A Great Deal	**Somewhat**	**Just a Little**	**Not at All**
1. I feel better about myself.				
2. I feel I have become a stronger, tolerant, and/or patient person around persons with sickness or handicaps.				
3. I feel I have a closer relationship with my care recipient.				
4. I feel I have become a better person by learning new information.				
5. I feel I have become a better person by learning new ways to care for the elderly.				
6. I feel more important.				
7. I feel I have the freedom to make decisions that matter.				
8. I feel that caring for my care recipient has made our family grow and work closer together.				
9. I feel that my family members look up to me now because of my efforts under difficult circumstances.				

M. How much does each statement describe your thoughts about caregiving? Please place an "X" in the box below your answer.

How much do you:	**Very Much**	**Somewhat**	**Just a Little**	**Not at all**
1. Believe that you've learned how to deal with a very difficult situation?				
2. Feel that all in all, you are a good caregiver?				

N. This last section covers your knowledge on issues related to caregiving. Circle "T" if the statement is true and "F" if the statement is false. This is the last section.

T F 1. Fatigue can be caused by a weakened immune system.

T F 2. Caregiver burnout rarely affects care recipients.

T F 3. Smoke detectors should be tested once a year.

T F 4. Any type of fire extinguisher can be used for household fires.

T F 5. When moving a heavy object it is better to push, pull, or roll it.

T F 6. Regular physical activity can aid in preventing falls.

T F 7. If a person begins to fall you should not try to break the fall as you may cause them more injury.

T F 8. Caregivers and care recipients have very few rights regarding their care at home or in a facility unless they are paying privately.

T F 9. A Durable Power of Attorney (DPOA) is NOT a legal document.

T F 10. A Durable Power of Attorney (DPOA) for a care recipient may be.
prepared even if they have become incompetent.

T F 11. A "Do Not Resuscitate" (DNR) document does not need to be discussed or signed by a doctor.

T F 12. If a care recipient has a "Do Not Resuscitate" (DNR) document cardiopulmonary resuscitation (CPR) may still be done in an emergency.

T F 13. Infection can be present in a person's body without causing illness.

T F 14. When you are caring for someone at home it is not to necessary to use gloves.

T F 15. A person can contract an infection from the air, skin, or from common household surfaces.

T F 16. If you are bathing someone in a hospital bed, it is best to lower the entire bed to its lowest position.

T F 17. Some home medical equipment can be paid for by Medicare with a prescription from a doctor.

T F 18. If a care recipient is eligible for Medicare they are automatically also eligible for Medicaid.

T F 19. Personal care aides hired privately through a home health agency would be able to administer medications to a care recipient.

T F 20. When a caregiver hires help privately from the community there are many legal and financial matters to consider.

THANK YOU FOR YOUR TIME!!! THE NURSE WILL REVIEW THIS WITH YOU AT HER VISIT.

Date____________________

AAA ID#________________

COALA^{SM} Caregiver Knowledge Assessment

(Survey 2)

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Thank you for your participation! Please fold and place this knowledge assessment in the postage-paid envelope addressed to:

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