The Caregiver Toolbox:
Evaluation of a Workshop for Informal Caregivers

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EXECUTIVE SUMMARY

The Caregiver Toolbox is a face-to-face group workshop designed for informal caregivers of older adults. The stated goals of the Caregiver Toolbox are to increase caregivers' knowledge of available resources, caregiving skills, and confidence in their role.

The Caregiver Toolbox is offered in seven sessions, lasting two hours each, once a week. The workshop sessions are facilitated by two trainers employed by the Central Ohio Area Agency on Aging (COAAA) who also share responsibilities for creating the curriculum, promoting the workshop, and recruiting participants. Both trainers have personal caregiving experience and serve caregivers in their professional roles within COAAA.

Workshop participants are recruited through mailing lists, email listservs, television advertising, the local County Office on Aging, and organizations that partner with COAAA such as the local chapter of the Alzheimer's Association and local health systems. During recruitment, free respite services are advertised and COAAA staff makes respite arrangements for caregivers who request that service.

This evaluation is the result of a request from COAAA and the trainers to assist them in building an evidence base for the workshop. Specifically, they wanted to know if the workshop met the needs of participating caregivers, increased their knowledge of available resources, helped them develop their caregiving skills, and increased their confidence as caregivers. The trainers were also interested in caregivers' suggestions for improving the content and structure of the workshop.

This evaluation utilized a pre-post design to observe changes in caregiver knowledge, reported behaviors, and stress ratings as a result of workshop participation. The evaluation included two workshops—one held in 2015 and the other in 2016. Where possible, the results from both workshops are combined. The caregivers were evaluated at three times using a combination of qualitative and quantitative methods - once prior to the beginning of the workshop (pretest), once immediately following the conclusion of the workshop (posttest), and again two - three months after the conclusion of the workshop (follow-up).

Twenty-four caregivers began either the 2015 or 2016 workshop and agreed to participate in the evaluation. Fewer than half (42%) of these caregivers attended all the sessions in the workshop. Two caregivers attended the workshop, but declined to participate in the study. All 24 caregivers completed pretest questionnaires which included demographic information, a list of their expectations for the workshop, and a stress rating.

Overall, the caregivers who attended the Caregiver Toolbox received what they wanted from the workshop. They rated the sessions highly, stated that the sessions met their needs, and indicated that they are likely to use the information that was provided. High scores on the weekly quizzes indicate that the content was learned by the participants. Through both qualitative and quantitative measures, the caregivers consistently reported that they gained helpful resources, knowledge, and skills. Caregivers affirmed that the *Caregiver Toolbox Manual* is a valuable resource and one that is easily shared with others. Caregivers also provided meaningful feedback which trainers can use to make changes to the workshop structure and enhance the workshop experience.

The fact that caregiver expectations were so closely aligned with the content provided in the workshop indicates that COAAA was effective in recruiting the caregivers they hoped to reach and delivering to them what was promised.

While the small sample does not lend itself to in-depth analysis or generalization regarding caregiver outcomes, it is encouraging that over three-fourths of the caregivers who participated in follow-up reported that they have done something differently as a result of what they learned in the workshop and a majority experienced benefits from those changes. At follow-up, more than half of the caregivers reported using workshop resources after the conclusion of the workshop and half of them reported a decrease in stress from prior to attending the workshop.

Despite the logistical challenges of offering face-to-face workshops, this evaluation demonstrated that there is value in providing informal caregivers with the opportunity to interact and connect with one another while providing them with resources and concrete skills to support and enhance their caregiving. Overall, our results suggest that the Caregiver Toolbox is an effective and worthwhile approach to providing important knowledge to assist caregivers in maintaining their ability to continue to support older adults.

BACKGROUND

In 2015, the National Alliance for Caregiving & AARP Public Policy Institute estimated that approximately 34.2 million Americans had provided unpaid care to someone age 50 or older in the year prior to their survey (National Alliance for Caregiving & AARP Public Policy Institute [NAC & AARP], 2015). This means that roughly 14.3% of all American adults are a caregiver to an individual who requires assistance with daily activities (NAC & AARP, 2015).

Amid increasing warnings of the shortage of direct care workers to care for the growing numbers of older adults, the majority of whom who have expressed a desire to remain in their homes, the vital place of informal caregivers within the provision of long-term services and supports to older Americans has been well-documented. In 2015, the National Alliance for Caregiving and the AARP Public Policy Institute provided an update on their report "Valuing the Invaluable: The Economic Value of Family Caregiving" which estimates the value of the unpaid assistance provided by informal caregivers to be $470 billion (Reinhard, Feinberg, Choula, & Houser, 2015).

At the same time, some caregivers do not feel prepared for this role. A recent study of public opinions on long-term care asked respondents if they felt that an older family member or close friend would need ongoing living assistance in the next five years (Associated Press-NORC Center for Public Affairs Research [AP-NORC], 2014). Three out of 10 of the individuals polled stated that they felt this to be true (AP-NORC, 2014). When asked if they thought that they would be personally responsible for providing that care, 32% felt that they would. However, not all of them felt prepared for that role. Of those who felt that they would be responsible for providing care, 51% reported that they felt "somewhat prepared" and 17% stated that they felt "not prepared at all" (AP-NORC, 2014). This sentiment was echoed among caregivers in the NAC & AARP study when eight out of 10 caregivers stated they could use more information on or help with caregiving topics. (NAC & AARP, 2015).

Navigating the United States system of long-term care services and supports can be intimidating. The Associated Press-NORC poll found that fewer than half of their respondents had received information about long-term care in the last year and of those who had information was most often received from friends, family, or co-workers rather than professionals (AP-NORC, 2014). There is clearly a need for accurate and accessible information for informal caregivers and to increase their contact with experts who are familiar with the system and can guide them in navigating it.

Calls for more programs and supports for informal caregivers have been numerous. Most recently, in their 2016 report "Families Caring for an Aging America", the National Academies of Science, Engineering, and Medicine outlined several public policy recommendations designed for caregivers which include increased funding for programs that provide supportive services for caregivers and a recommendation for increased evaluation of caregiver interventions (National Academies of Science, Engineering & Medicine, 2016).

A recent study of the National Family Caregiver Support Program found that caregiver education was offered by 86.5% of the Area Agencies on Aging responding to a national survey. More than half of those who offered training and education did not use any of the established evidence-based programs such as “Powerful Tools for Caregivers” suggesting that custom-developed local workshops are a common model for providing information and assistance to nonpaid caregivers of older adults (The Lewin Group, 2016). The program evaluated in this study is one such program.

The Caregiver Toolbox

The Caregiver Toolbox is a face-to-face group workshop designed for informal caregivers. The stated goals of the Caregiver Toolbox are to increase caregivers’ knowledge of available resources, caregiving skills, and confidence in their role.

The workshop sessions are facilitated by two trainers employed by the Central Ohio Area Agency on Aging (COAAA) who also share responsibilities for creating the curriculum, promoting the workshop, and recruiting participants. Both trainers have personal caregiving experience and serve caregivers in their professional roles within COAAA.

Workshop participants are recruited through mailing lists, email listservs, television advertising, the local County Office on Aging, and organizations that partner with COAAA such as the local chapter of the Alzheimer’s Association and local health systems. During recruitment, free respite services are advertised and COAAA staff makes respite arrangements for caregivers who request that service.

During the workshop sessions, participants are provided with the *Caregiver Toolbox Manual*, a 114-page booklet including information on a variety of topics and resources helpful for caregivers. The content of the workshop sessions is structured around the manual and is enhanced with handouts for each session (mirroring the material provided in the manual) and PowerPoint presentations. Additionally, participating caregivers are presented with several smaller guides each relating to a particular topic of interest (e.g., Housing, Utilities, and Transportation).

The Caregiver Toolbox was originally designed to be offered in six sessions. After the addition of more content prior to the start of the evaluation, the number of sessions was increased to seven. While the sessions were designed to be run consecutively over a period of weeks, the trainers found that they often received requests from various groups to present session topics individually or to spread the sessions out over a period of months rather than weeks.

This evaluation is the result of a request from COAAA and the trainers to assist them in building an evidence base for the workshop. Specifically, they wanted to know if the workshop met the needs of participating caregivers, increased their knowledge of available resources, helped them develop their caregiving skills, and increased their confidence as caregivers. The trainers were also interested in caregivers' suggestions for improving the content and structure of the workshop. The original evaluation design was built around two identical workshops, each potentially containing 20 participants, to be held simultaneously in separate counties within the COAAA region in the fall of 2015.

Due to recruitment challenges, only one workshop was held in 2015 with 10 participating caregivers. The workshop was comprised of seven consecutive weekly sessions. The sessions were held once a week on a weekday from 6:00 – 8:00 p.m. in a local faith-based social services center. In hopes of increasing the strength of the evaluation, a second workshop was held in spring of 2016 with 14 participating caregivers. This workshop was held in the family resource center of a centrally-located hospital within the city. The sessions were held consecutively on a weekday for eight weeks from 6:00 – 8:00 p.m. (with the exception of one holiday). The health system in which the hospital is a member acted as a co-sponsor for the workshop and advertised it within their dedicated communication channels.

The preliminary results of the 2015 workshop were shared with the trainers prior to the 2016 workshop so that they could incorporate this information in their planning. Based upon the experiences of the trainers in the 2015 workshop, two changes were made to the structure of the 2016 workshop. First, the material originally covered in Week 1 was split into two sessions to accommodate the explanation of the evaluation and still cover the desired content, resulting in a total of eight sessions for the 2016 workshop. Second, the topic of "Common Family Dynamics" was moved to the last week in the 2016 workshop to allow more time for the focus group immediately following the session. The 2016 workshop also differed from the 2015 workshop in that the trainers did not provide separate handouts for participants and primarily referred to the *Caregiver Toolbox Manual* during sessions. This decision was made based on feedback from 2015 workshop participants who felt the additional handouts were unnecessary. Table 1 lists the workshop sessions for 2015 and 2016.

At both workshops, participants were provided free parking, snacks and beverages, and two $20.00 gift cards as an incentive for participating in the evaluation (distributed at four weeks and at the end of the last session).

Table 1. Workshop Sessions in 2015 and 2016

2015 Workshop	2016 Workshop
Week 1: Getting Started Week 2: Navigating the Health Care Maze Week 3: Caring in the Home Week 4: Caring in a Facility Week 5: Preventing Burnout Week 6: Common Family Dynamics Week 7: Caring for a “Difficult” Family Member	Week 1: Getting Started – Accessing Aging Services Week 2: Planning Ahead – What You Need to Know Week 3: Navigating the Health Care Maze Week 4: Caring in the Home Week 5: Caring in a Facility Week 6: Preventing Burnout Week 7: Caring for a “Difficult” Family Member Week 8: Common Family Dynamics

METHODS

This evaluation utilized a pre-post design to observe changes in caregiver knowledge, reported behaviors, and stress ratings as a result of workshop participation. The caregivers were evaluated at three times using a combination of qualitative and quantitative methods - once prior to the beginning of the workshop (pretest), once immediately following the conclusion of the workshop (posttest), and again two - three months after the conclusion of the workshop (follow-up).

In the first session of each workshop, the evaluation was explained and caregivers were given the opportunity to participate. The decision not to participate in the evaluation had no effect on the caregivers’ participation in the workshop. Those who declined to participate received the same course materials and information as participating caregivers and also completed weekly quizzes, which were not submitted to the evaluators.

RESULTS

Pretest

There were 24 caregivers who began the 2015 and 2016 workshops and agreed to participate in the evaluation. Fewer than half (42%) of these caregivers attended all the sessions in the workshop. About a third (33%) attended at least half the sessions, and a quarter (25%) attended fewer than half the sessions. Two caregivers attended the workshop, but declined to participate in the study. All 24 caregivers completed pretest questionnaires which included demographic information, a list of their expectations for the workshop, and a stress rating. Results are reported for both the 2015 workshop and 2016 workshop when comparable data were available.

Session Observation

One 2016 workshop session was observed by an evaluator with the goal of more deeply understanding the training experience of the caregivers and trainers. The observation occurred in Week 3 and the discussion topic was Navigating the Health Care Maze. The training room was arranged in a classroom style with small tables facing a screen at the front of the room. Each table was capable of seating two caregivers. There were 11 caregivers in attendance at the session and 10 of them had agreed to participate in the evaluation. Food and beverages were available to the caregivers outside the room.

The session was presented in a lecture style, and despite time constraints, trainers encouraged questions and sharing from participants. The staggered arrival of the caregivers made it challenging for the trainer to begin the session on time and some caregivers who arrived late missed the discussion about the resource guides that are available through COAAA. The trainer used humor and personal examples when presenting the material, which the caregivers responded to positively. Almost all the participants seemed very engaged and interested. This was evidenced by their body language, and the fact that all but one caregiver spoke during the session to either ask questions or share personal experiences. Of the sub-topics covered in the session, the section on hospice and palliative care services elicited the most response from caregivers and a majority of the questions and sharing occurred in that discussion.

The evaluator observed that there was very little conversation or engagement *between* caregivers during the session, but that they all seemed to be engaged with the trainer. One caregiver was accompanied by his spouse, who lives with dementia. She sat beside him and did not speak for the duration of the session. This did not seem to make the caregivers, trainer, or the spouse uncomfortable.

The quiz took approximately one - two minutes for the caregivers to complete. After the quiz, a few caregivers chatted with each other and a couple of caregivers approached the trainer to talk. Many of the caregivers stopped to pick up resource guides before leaving the room.

Caregiver Characteristics

As shown in Table 2, the average age of the caregivers was 63 years. The ages of the caregivers ranged from 45 – 84 years with a median age of 63 years. An overwhelming majority (96%) of the caregivers were female. One quarter **(**25%) of caregivers reported they were caring for more than one person at the time they started the workshop. Caregivers were given the opportunity to select multiple responses in this category, therefore, Table 2 reflects the various, and in some cases, multiple caregiving relationships of the caregivers. Primarily, the caregivers were caring for parents (54%) and spouses (46%). A small number of caregivers (8%) reported that they were also providing care to children under the age of 18.

At the beginning of the workshop, over half (58%) of the caregivers reported living with at least one of the persons for whom they care. Two of these caregivers reported that they live with the person for whom they care for a portion of the year (four months and six months respectively). For the caregivers who indicated that they were not living with a person they cared for, the majority lived within 40 miles of that person.

On average, the caregivers had been caregiving for seven years. The length of their caregiving ranged from four months - 22 years. About a third (29%) reported they were employed. Of those, 21% reported working part-time (ranging from three - 35 hours/week) and 8% reported working full-time. One quarter (25%) of the caregivers reported that their loved one was receiving formal services at the time they started attending the workshop. The types of services received varied, with the majority receiving home health nurses and home health aides. Over half (58%) of the caregivers reported that other family members or friends shared caregiving responsibilities with them. Fewer than half (42%) of the caregivers reported that at least one person for whom they cared required 24/7 supervision or care.

A small percentage (13%) of caregivers reported that the availability of free respite affected their decision to attend the workshop.

Table 2. Caregiver Characteristics at Beginning of Workshop

Demographic Characteristics	2015 Workshop [*n*=10]	2016 Workshop [*n*=14]	Total [*n*=24]
Average Age	63	63	63
Gender (% Female)	100%	93%	96%
Caring Relationships			
Caring for more than one person	60%	--	25%
Parent or Parent-in-Law	70%	46%	54%
Spouse	50%	46%	46%
Sibling	20%	8%	13%
Son or Daughter	10%	--	4%
Grandchild	10%	--	4%
Other	10%	8%	8%
Co-Residence			
Living with at least one care recipient	50%	54%	50%
Distance to Care Recipient Household*			
Next Door/Same Building	40%	--	17%
Within 1-10 miles	20%	29%	25%
Within 11-40 miles	40%	57%	50%
Within 41-100 miles	20%	--	8%
Over 100 miles	--	14%	8%
Length of Caregiving (average years)	7	7	7
10 years or more	20%	38%	29%
3-9 years	50%	31%	38%
Less than 3 years	20%	31%	25%
No response	10%	--	8%
Caring for Minor Children	10%	7%	8%
Employment	10%	43%	29%
Receiving Formal Services	40%	14%	25%
Visiting Nurse/Home Health Nurse	20%	15%	17%
Home Health Aide/Private Aide	20%	--	8%
Physical Therapy	--	14%	4%
Transportation	--	7%	4%
Day Care	10%	--	4%
Assisted Living	10%	--	4%
Sharing Caregiving With Others	60%	57%	58%
24/7 Supervision	60%	29%	42%
Free Respite Affected Decision to Attend	20%	--	13%

*Percentages sum to more than 100 because caregivers caring for more than one person chose multiple responses.

Weekly Quizzes and Session Feedback

At the conclusion of each session, caregivers were asked to complete a quiz containing four questions related to the content of the session and requesting that caregivers rate the session overall, whether the session met their needs, and how likely they would be to use the information provided in the session.

The average quiz score for participants across all 15 weeks was 95%. Because very few quiz questions were missed overall, only the questions which were missed are reported in Appendix A to assist trainers in identifying where participants may need further explanation or clarification.

The weekly session feedback from caregivers was overwhelmingly positive. Almost all (98%) of the caregivers rated the sessions as “Excellent” (77%) or “Good” (21%). The majority of caregivers reported that the sessions met their needs “A lot” (71%) or “Some” (21%). Almost all (98%) caregivers indicated that they “Definitely Will” (73%) or “Probably Will” (25%) use the information they learned in the sessions. Table 3 displays the weekly session feedback for the 2015 and 2016 workshops and the total.

Table 3. Weekly Session Feedback

Weekly Session Feedback	2015 Workshop	2016 Workshop	Total
Session Ratings			
Excellent	65%	85%	77%
Good	31%	15%	21%
Sessions Met Needs			
A Lot	65%	74%	71%
Some	20%	21%	21%
Likely To Use Information			
Definitely Will	61%	81%	73%
Probably Will	35%	19%	25%

Note. Percentages are based on only the respondents who answered each question.

Trainer Feedback

Both trainers were asked to record their thoughts about the sessions they facilitated on Trainer Feedback Forms which were shared with the evaluation team after each session. The forms captured the attendance for the session, weather conditions, whether the content scheduled for that session was covered in the time allotted, process notes (energy level of the trainer and group; areas of content that took longer than expected), what seemed to work well about the session, what did not seem to work well, and general notes.

The challenge of covering all the scheduled content within each session was a common issue related by the trainers. The size and set-up of the training room and how the physical space related to content (e.g., ability to provide demonstration of skills) and interaction between caregivers was also noted multiple times. The trainers made use of these observations when preparing for the 2016 workshop (e.g., splitting first topic into two sessions, rearranging the order of topics) Appendix A contains the trainer feedback as written on the Trainer Feedback Forms.

Posttest

Over half of the caregivers (67%) completed posttest questionnaires which asked about the degree to which their expectations for the workshop were met, whether they would use the information from the workshop, what was most helpful to them about the workshop, what changes they would suggest, and whether they would recommend the workshop to others.

Caregivers' Expectations

At the beginning of both workshops, caregivers were asked to list three things that they hoped to get from the workshop. Among the 16 caregivers who finished the workshop and completed a posttest, a total of 41 expectations were expressed. Caregiver responses were reviewed for common themes and several categories emerged:

Resources/Services (41%)
Caregiving skills/Tools (22%)
Self-Care (15%)
Education/Knowledge (7%)
Planning ahead (7%)
Navigating the system (7%)
*Due to rounding and the small size of the sample, percentages may not add up to 100.

The majority of caregivers' expectations prior to the start of the workshop were related to the categories of "Resources/Services" (41%) and "Caregiving Skills/Tools" (22%).

At the end of the workshop, caregivers were presented with customized posttests listing the specific items they had named at the beginning of the workshop and were asked to report whether those items were "definitely provided", "somewhat provided" or "not at all provided." Overwhelmingly, caregivers reported that their expectations were either "definitely provided" (78%) or "somewhat provided" (20%). Only a very small number of expectations were "not provided at all" (2%). Table 4 displays the breakdown of caregivers' expectations for the workshop and the degree to which they were provided. Appendix B contains the detailed listing of what caregivers hoped to get from the workshop and the degree to which those expectations were met.

Table 4. Caregivers' Expectations for the Workshop

Expectations for Workshop	2015 Workshop	2016 Workshop	Total
Definitely provided	57%	89%	78%
Somewhat provided	43%	7%	20%
Not provided at all	--	4%	2%

Follow-Up

Follow-up questionnaires and self-addressed, stamped return envelopes were mailed to the 19 caregivers who had attended at least half of the sessions in their workshop. The questionnaires were mailed by COAAA staff along with cover letters encouraging caregivers to complete them approximately two - three months after the completion of the workshops (three months for 2015 and two months for 2016). The questionnaires included demographics which closely aligned with the information gathered at pretest, and also included questions regarding changes made to caregiving since the end of the workshop, benefits experienced from those changes, materials reviewed since the conclusion of the workshop, resources used since the conclusion of the workshop, what caregivers found most helpful about the workshop, and recommended changes. Completed questionnaires were returned to Scripps Gerontology Center to protect the confidentiality of the caregivers' responses. A total of 14 caregivers returned follow-up questionnaires for a response rate of 74%.

What Caregivers Found Most Helpful about the Workshop

At both posttest and follow-up, caregivers were asked to report what they found most helpful about the workshop. Caregiver responses were found to relate to the following categories:

Resources/Services
Caregiving skills/Tools
Interaction with other caregivers
Education/Knowledge
Self-Care
Planning ahead
Navigating the system
Interaction with/Access to trainers

At posttest, the majority of items mentioned as most helpful fell equally into the categories of "Resources/Services" (18%), "Interaction with Other Caregivers" (18%), and "Interaction with/Access to Trainers" (18%). At follow-up, items related to "Resources/Services" made up over a third (39%) of what caregivers found most helpful, followed by "Education/Knowledge" (17%) and "Caregiving Skills/Tools" (13%). Appendices C and D contain the detailed listings of items caregivers found most helpful at posttest and follow-up.

What Caregivers Would Change to Make the Workshop Better

At posttest and follow-up, caregivers were also asked to suggest changes that they felt would improve the workshop. Caregivers' responses were reviewed for themes and were grouped into the following categories:

Content
Class structure
Time/Location
Class materials
Advertising/Outreach
Training space

At posttest, changes related to "Class Structure" (50%) and "Time/Location" (30%) made up the majority of changes suggested by the caregivers. At follow-up, changes related to "Content" (27%) were most frequently mentioned by the caregivers followed by "Class Structure (18%), "Time/Location" (18%), and "Class Materials" (18%). Appendices E and F contain the detailed listings of changes recommended by caregivers.

Recommending the Caregiver Toolbox to Others

The last question on the posttest questionnaire was "Would you recommend the Caregiver Toolbox to others?" All of the 15 caregivers who responded to this question said they would recommend the workshop to others.

Focus Group

A focus group involving 10 caregivers was held immediately following the last session of the 2016 workshop and was facilitated by one of the evaluators. To protect the confidentiality of caregivers' responses, neither of the two trainers were present during the group. With the caregivers' permission, the group was audio-recorded and later transcribed for analysis.

At the beginning of the group, several caregivers immediately commented on how they enjoyed being able to see each other's faces (the group met around one large table) and that the usual classroom-style set-up of the room made it challenging for them to get to know each other. The importance of interaction with other caregivers was also reinforced as participants shared how they valued listening to other caregivers' stories and using them to gain perspective on their own caregiving situations. During the group, the evaluator noticed a camaraderie among the caregivers that had not been present during the session observation in Week 3.

The caregivers shared that they learned of the workshop in varied ways (newspaper, Alzheimer's Association, television, internet, emails from the local Health Department, and communication from the co-sponsoring hospital health system). They also indicated varied reasons for attending the workshop (being new to caregiving role, needing help to deal with caregiving, wanting to do better for the people they care for, wanting resources, looking for something to do with their spouse, caring for a new person, and wanting to get a new perspective).

The caregivers related that the time of day and location of the workshop posed challenges which were primarily related to traffic. They also expressed some things that made it easier for them to attend the workshop (free and convenient parking, snacks and drinks provided, central location within the city, and the fact that the sessions were scheduled so they could plan ahead to attend). Several caregivers expressed appreciation for the *Caregiver Toolbox Manual* and resource guides and mentioned that they had passed along resources they learned about in the workshop to other caregivers who were unable to attend. There was general agreement among the caregivers that participating in the workshop had increased their confidence in their caregiving. The caregivers also praised the trainers as being very knowledgeable and they expressed appreciation for the personal stories trainers shared during the sessions. The questions used in the focus group are found in Appendix G.

Telephone Interviews

In the 2015 and 2016 workshops, there were six caregivers who attended fewer than half of the workshop sessions. In order to gain insight as to why these caregivers did not finish the workshop, telephone interviews were sought with four such caregivers from the 2016 workshop. The interviews took place approximately two months after the conclusion of the workshop and were audio-recorded with permission from the caregivers. During the interviews, the evaluator requested demographic information similar to that collected in the follow-up questionnaire and the questions posed to the caregivers closely resembled questions asked at posttest and follow-up. The full interview guide used for the telephone interviews is found in Appendix H.

Three caregivers willingly participated in telephone interviews. The fourth caregiver could not be reached. The caregivers relayed that they learned about the workshop through similar channels to the caregivers who completed the workshop, with the exception of one caregiver who reported she heard about the workshop from her private counselor. When asked why they stopped attending the workshop, one caregiver responded that her son was going through a divorce at the time and she was helping to care for her grandchildren. Another reported that the training site was difficult to reach from her workplace at the time of day the workshop was held (she worked on the other side of town) and that she was having car troubles at the time of the workshop. The third caregiver related that a scheduling conflict prevented her from attending.

When asked about their expectations prior to attending the workshop, two of the caregivers indicated they were looking for information about Medicare and/or benefits. The other caregiver indicated that “easing stress” was her expectation. Two of the caregivers indicated that they had used something they learned in the workshop in their caregiving. One mentioned that she had used information on planning and bringing in help, and was in the process of moving to a single-story home. Another stated that she learned tips from the other caregivers in the workshop and how to put a “buffer” between her and her loved one. Only one caregiver reported that she had used any resources or reviewed materials since attending the workshop. She stated that she has begun investigating VA (Veteran’s Affairs) options, keeps the *Caregiver Toolbox Manual* in her kitchen for easy reference, and that she picked up an extra manual for her sister.

When asked what they would change about the workshop, one caregiver indicated that offering the workshop in the morning would be helpful and another indicated that there was a lot of content and not much time for questions in the sessions. All three caregivers mentioned interaction with other caregivers as part of what they liked about attending the workshop. They also spoke about the value of hearing other caregivers’ stories and learning from them. In general, the responses of these three caregivers were similar to those provided by caregivers who completed the workshop. All three stated that they would attend the workshop again if provided the opportunity.

OUTCOMES

Caregiver outcomes were observed through self-reported changes in behavior and stress ratings gathered on the posttest and follow-up questionnaires. The tool used to record caregivers’ stress ratings was adapted from an instrument created for the “A Caregiver Respite Strategy for the State of Ohio: Implementation and Evaluation” project funded by The Ohio Department of Aging (McGrew & Heston, 2015).

Stress Ratings

Stress ratings were measured three times – prior to the beginning of the workshop (pretest) immediately following the conclusion of the workshop (posttest), and approximately two - three months after the end of the workshop (follow-up). The caregivers were asked to rate the level of their stress on a scale from 1-10 (with 1 being the lowest and 10 being the highest), to list the sources of that stress, and to indicate what they thought might help reduce their stress. The tool used to gather stress ratings at all three times can be found in Appendix I.

At the beginning of the workshop, the average stress rating reported by the participating caregivers was 7. Stress ratings reported prior to the beginning of the workshop ranged from 2 to 10 with a median stress rating of 8. Table 5 summarizes the percentage of stress ratings reported by caregivers prior to the beginning of the workshop into relatively low (1-3), moderate (4-7), and fairly high (8-10). It seems clear that at the time these caregivers decided to attend the workshop, their stress was fairly high.

Table 5. Stress Ratings Prior to the Beginning of Workshop

Stress Rating	Pretest (*n*=24)
1-3	4%
4-7	38%
8-10	58%

Nearly half (42%) of the caregivers reported stress ratings at all three times of collection. Of those caregivers for which we have stress ratings at all three times, 50% reported a decrease in stress from pretest to follow-up, 20% reported their stress as the same, and 30% reported an increase in stress. Table 6 displays the stress ratings of the 10 caregivers who reported stress ratings at all three times.

Table 6. Stress Ratings for Caregivers Who Reported at All Three Times

Caregiver #	Pretest	Posttest	Follow-Up
5	10	5	10
10	6	4	8
12	8	7	5
13	9	5	5
15	4	7	6
17	2	3	2
18	10	10	6
19	6	5	4
23	9	3	6
24	4	7	6

While no clear patterns were found among the caregivers who reported similar directions of stress ratings, some brief summary of the characteristics within each group is offered here.

Caregivers Who Reported Decreased Stress

The workshop expectations expressed by the four caregivers who reported decreased stress centered primarily on increasing knowledge and self-care. At posttest, they indicated that almost all of their expectations for the workshop were provided. For one of the caregivers, there was a change in employment (from working part-time to no employment). Three of these caregivers made changes in their caregiving based on what they learned in the workshop and two reviewed materials after the conclusion of the workshop.

Caregivers Who Reported Same Stress

The two caregivers who reported same stress levels both experienced significant changes in their caregiving situation between the end of the workshop and follow-up. One of the caregivers, who reported a reduction in stress level at posttest, lost her mother prior to follow-up and expressed concern about her father who lived 86 miles away from her. Additionally, she was still caring for her spouse and reported that his disease was "worsening." The other caregiver was caring for an individual who had hip surgery between the conclusion of the workshop and follow-up. Both of these caregivers expressed workshop expectations related to caregiving skills and service/resources.

Caregivers Who Reported Increased Stress

Two of the three caregivers who reported increased stress indicated that they were caring for at least one person living with dementia. Their sources of stress appeared to be related to the progression of disease and care needs of these individuals. Both of these caregivers were caring for a spouse and one was simultaneously caring for a parent. The other caregiver reported that she had temporarily lived with and cared for a sibling during the sibling's recuperation from a surgery. Although she was no longer providing care, this caregiver indicated that her follow-up stress rating and her sources of stress were in reference to how she felt at the time she was caring for her sibling. All three caregivers reported that all of their expectations were provided by the workshop.

The following impacts are reported only for those 14 caregivers who provided follow-up information.

Caregiving Changes As a Result of the Workshop

A majority (86%) of the caregivers reported that they have done something differently as a result of what they learned in the workshop. One caregiver did not specify changes, but the other 11 caregivers reported changes related to the following categories:

Utilizing resources/Services (25%)
Passing on resources to others (19%)
Caregiving skills/Tools (13%)
Self-Care (13%)
Financial/Legal matters (13%)
Advocacy (6%)
Using written materials (6%)
Housing (6%)
*Due to rounding and the small size of the sample, percentages may not add up to 100.

Appendix J includes the detailed listing of changes made by caregivers.

Benefits reported by Caregivers

The majority (83%) of caregivers who reported making caregiving changes as a result of the workshop also reported benefits realized from those changes. Caregivers reported benefits related to:

Financial/Legal matters (29%)
Utilizing resources/Services (21%)
Self-Care (21%)
Education/Knowledge (7%)
Caregiving skills/Tools (7%)
Interaction with other caregivers (7%)
Written materials (7%)
*Due to rounding and the small size of the sample, percentages may not add up to 100.

Appendix K contains the detailed listing of benefits reported by caregivers.

Materials Reviewed After the Workshop

Half (50%) of the caregivers reported that they had reviewed the course materials since the end of the workshop. Caregivers reported reviewing materials related to:

Financial/Legal matters (42%)
Caregiving skills/Tools (25%)
Resources/Services (17%)
Self-Care (8%)
Family dynamics (8%)
*Due to rounding and the small size of the sample, percentages may not add up to 100.

Appendix L contains the detailed listing of materials reviewed by caregivers between the conclusion of the series and follow-up.

Resources Used After the Workshop

More than half (64%) of the caregivers reported that they had used any of the resources received in the workshop since its conclusion. Caregivers reported using resources related to:

Specific resources/Services (33%)
Financial/Legal matters (17%)
Caregiving skills/Tools (17%)
Written materials (17%)
Passed on materials to others (17%)

Appendix M contains the detailed listing of resources used between the conclusion of the workshop and follow-up.

SUMMARY

Overall, the caregivers who attended the Caregiver Toolbox received what they wanted from the workshop. They rated the sessions highly, stated that the sessions met their needs, and indicated that they are likely to use the information that was provided. High scores on the weekly quizzes indicate that the content was learned by the participants. Through both qualitative and quantitative measures, the caregivers consistently reported that they gained helpful resources, knowledge, and skills. Caregivers affirmed that the *Caregiver Toolbox Manual* is a valuable resource and one that is easily shared with others. Caregivers also provided meaningful feedback which trainers can use to make changes to the workshop structure and enhance the workshop experience.

The fact that caregiver expectations were so closely aligned with the content provided in the workshop indicates that COAAA was effective in recruiting the caregivers they hoped to reach and delivering to them what was promised.

While the small sample does not lend itself to in-depth analysis or generalization regarding caregiver outcomes, it is encouraging that over three-fourths of the caregivers who participated in follow-up reported that they have done something differently as a result of what they learned in the workshop and a majority experienced benefits from those changes. At follow-up, more than half of the caregivers reported using workshop resources after the conclusion of the workshop and half of them reported a decrease in stress from prior to attending the workshop.

The recruiting challenges experienced during the evaluation and telephone interviews with caregivers who were unable to complete the series further demonstrated the barriers caregivers face while trying to balance their self-care needs with the responsibilities of caregiving. However, the varied ways in which caregivers learned of the workshop indicates that the message that resources are available is reaching them.

CONCLUSION

There is some question about whether caregiver interventions should be centered on supporting caregivers' emotional needs or focus more on building awareness of resources, knowledge, and skills. It is clear that caregivers can benefit from education, resources, and support, but it is challenging to know what balance of these aspects best serves caregivers.

Despite the logistical challenges of offering face-to-face workshops, this evaluation demonstrated that there is value in providing informal caregivers with the opportunity to interact and connect with one another while providing them with resources and concrete skills to support and enhance their caregiving.

Even in a workshop where the stated goals are more knowledge/skills-based than support-focused, setting up the physical space to encourage connection and interaction between caregivers may be one way to subtly enhance support. The simple act of hearing others' stories proved powerful for the caregivers in this evaluation. Adjusting the content of the workshops to provide more space for this sharing could prove beneficial to many caregivers.

The instruments and processes developed for this evaluation will allow COAAA to replicate and complete more in-depth evaluation in the future if they desire.

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APPENDIX A. MISSED WEEKLY QUIZ QUESTIONS AND TRAINER FEEDBACK

Week	Workshop	Missed Questions	Trainer Feedback
1	**2015** **Topic:** Getting Started	**“Medicare pays for most kinds of long-term care services that a person would need.”** Incorrect answer = True	• Not all material was covered within the allotted time. Topics not covered were: o Insurance Options – Medigap and Long-Term Care o Advance Directives/DNR/Guardianship • Group was attentive – some participants did ask questions or for clarification • Trainer in not a high energy trainer. This particular session trainer was ill. • Participants understood and responded well and appropriately with regards to the study explanation and tools. • Too much material to cover – even with summarizing rather than going into depth. • Subtopics (some of them) such as Medicaid are more “meaty” and time does not allow for depth needed. • Difficult to keep it interactive and cover material. • We need to make it clear that lead time is needed to set up respite for attendees. Late registrants cannot be accommodated due to agency assessment requirements and scheduling.
	2016 **Topic:** Getting Started – Accessing Aging Services	**“What long-term care options are available in most communities?”** Incorrect answer = Home- and Community-Based Services	• Not all material was covered within the allotted time. Topics not covered were: o Housing options including ▪ Independent ▪ Group homes ▪ Assisted Living ▪ Nursing Facilities ▪ CCRCs • We had 3 late arrivals after explanation of the study and tools. With brief introductions of participants it was 45 mins into the 2 hrs. allotted before we got started with content. • It definitely felt like splitting up the first topic into 2 sessions provided a better opportunity to cover what was covered more clearly. Not as rushed and could give more examples or say things in different ways. • We need to build in more time to complete tools/explanations. If we were to do the evaluation (COAAA), wondering how well it would work to mail some materials ahead of the classes. • [Trainer 2] will pick up where I left off at “Housing” next week.

Week	Workshop	Missed Questions	Trainer Feedback
2	**2015** **Topic:** Navigating the Health Care Maze	**“Your contact with hospital discharge planners should happen only right before your loved one goes home.”** Incorrect answer = True **“The federal law that focuses on health care privacy is called?”** Incorrect answer = Federal Privacy Act (FPA)	• All material for this session was covered in the time allotted. • Good comments/questions from the group. • One participant is a 30 year RN and she added enhanced information from the Toolbox. • More discussions than 1st session. • Less content to present than 1st session. Less hurried and so more interactive. • Many participants are very stressed in their caregiving role. The format we typically used in past would help make better use of their time. They need a support group – this *illegible* bridges that when their time is limited. • There is a trade-off between covering materials and addressing pressing needs. • One attendee had an emergency with parents and left early (no eval)
	2016 **Topic:** Planning Ahead – What You Need to Know	**“Medicare has the following parts.”** Incorrect answer = Part A Hospital Care **“What is a key legal document that appoints a person to assist in planning if a person can no longer make informed health care decisions?”** Incorrect answers = Guardianship of the Estate, Financial Power of Attorney	• All material for this session was covered in the time allotted including from last week – housing choices (AL, SNF, and ICF) • 2 people were late but weather was horrible • Good session, lots of questions and interaction • We brought fresh fruit snacks and that was a big hit • Flow of info and rhythm of material seemed to work well – very good to split first session content into two areas. • People really want the list and names of elder law attorneys – we go back and forth on this issue due to our nature as a public entity – currently we do not give out specific names – hard to know what to do. • Had many Medicare and Medicaid questions – clearly this is an area with much confusion.

Week	Workshop	Missed Questions	Trainer Feedback
3	**2015** **Topic:** Caring in the Home	**"You should always lift a wheelchair using the detachable armrests and footrests."** Incorrect answer = True **"Which of the following does not generally contribute to the development of a pressure ulcer?"** Incorrect answer = A person being in the same reclining position for several hours at a time	• All material for this session was covered in the time allotted. • Good energy level • Lots of questions about bring care into home – spent more time talking about financing care than usual. Lots of Medicaid questions. • Visuals, handouts seemed to work well. • 2 hours with a small break is good. • Room itself is not conducive to demonstration i.e., no room – this was a problem. • This was the small room as they had another group scheduled in the large room – if we do again – cannot have this room for this topic. • Some of these caregivers are really stressed – did not discuss burnout per se but did discuss the times when a caregiver might need either placement of an individual or more assistance.
	2016 **Topic:** Navigating the Health Care Maze	No missed questions	• Covered all material though could have probably spent more time on medications • Few people were late – maybe consider starting at 6:30 p.m. next time – 6:00 may be too early. • Not as much group interaction due to classroom style set up. Circle is preferable. People did ask questions though. • General flow of the materials and discussion seemed to work well. • A few people missed last week's session so I could tell they were still unclear on Medicare vs. Medicaid and different housing options when we talked about Hospice vs. Palliative Care. Not sure how to remedy this. • I think [Evaluator's] presence was pretty non-invasive which was great. • Consider classroom vs. oval set up for our next course.

Week	Workshop	Missed Questions	Trainer Feedback
4	**2015** **Topic:** Caring in a Facility	No missed questions	• Not all material was covered in the time allotted. Had lots of questions so did not get to last section on outings. • Good energy – had lots of questions about different kinds of facilities and paying for care. • Had to address some questions on dementia and resentment in families as well • Lots of interaction – one group member having a very rough time but others seem to be jumping in with suggestions. • All was good tonight. • Room still little small. • I see elements of support coming out of some members – I think a few might want to come to a support group in the future.
	2016 **Topic:** Caring in the Home	**"What should be considered when thinking about hiring in-home assistance?"** Incorrect answer: Whether to hire an agency or an individual? **"You should always lift a wheelchair using the detachable armrests and footrests."** Incorrect answer: True	• Covered all material – was not able to allow participants to practice techniques as much as usually like to. • Good – lots of questions about home modifications and programs to pay for home care. • Still not as much intergroup interaction and I feel that this is due to classroom set-up. • Redid Power Point a little to follow Caregiver Toolbox with page numbers listed and this was good. • It is good to have participants use the Toolbox but it has more info than we cover. • All worked well.

Week	Workshop	Missed Questions	Trainer Feedback
5	**2015** **Topic:** Preventing Burnout	**“Which of the following is not a helpful way to prevent caregiver burnout?”** Incorrect answer = Setting realistic expectations for yourself and your family	• All material was covered within the time allotted. • Good energy from trainer and group. • Content was easily covered in the allotted time – even with more sharing of stories, stressors, and situations. • The group was more interactive and at ease. They supported each other and did some problem-solving. • Trainer used some personal experiences to relate material to real life scenarios. Storytelling helps draw out participants and helps them recognize ways to use the material. It seems to also help them see how unique experiences and responses are but find commonalities – and reassurance and hope. • This topic in the past has been a “hard sell.” Very difficult to get caregivers to stay focused on their needs. They appreciate that someone is attending to their needs, but from a practical standpoint it keep coming back to the care receiver and their preferences/cooperation.
	2016 **Topic:** Caring in a Facility	**“Common reasons for a family to consider facility placement are that someone is wandering and/or has frequent incontinence.”** Incorrect answer = False **“When choosing a care facility, what are some steps to take?”** Incorrect answer = Locate several facilities in your area	• All material was covered within the time allotted. • Quiet group • Good questions • Difficult topic to stimulate interactions, so felt a little plodding – particularly in covering resident’s rights in a care facility. • Trainer occasionally forgets to advance the PowerPoint! Was working from the book. • Participant questions reflected experience and good insights on the general topic and subtopics. • Questions prompted discussion of some more painful realities related to care in a facility. Trainer might not have “gone there” without the direct questions. • Some feedback from participants that the time does not work well due to heavy traffic in the area. • Trainer left the office early to get to [training site] and was still cutting it close to get there on time. • A challenge to make this topic more interactive and yet limit the “horror stories.”

Week	Workshop	Missed Questions	Trainer Feedback
6	**2015** **Topic:** Common Family Dynamics	**"Families are involved in the care of most people living at home."** Incorrect Answer = False	• All material for this session was covered in the time allotted. • Nice session • Participants sharing their own experiences. The new participant shared a lot. • All was good – they participated in discussion. • Maybe need to spend a little more time discussing family meetings.
	2016 **Topic:** Preventing Burnout	No missed questions	• All material for this session was covered in the time allotted. • Good energy trainer and group. • Much more group participation for this workshop. • Very good suggestions from participants in addressing burnout. • Trainer encouraged more input on various aspects of the topic. Tried to lecture a little less. This topic is easier to present this way. • Just concerned that the caregiver who brings his wife did not attend. He has not asked for respite as he indicates his wife is more distressed away from him. Afraid he felt the content might be painful for her to hear. But he especially needed this one workshop. • Examples I provide to flesh out the topic seem to help. We ([Trainer 2] and I) probably would not cover this the same way.

Week	Workshop	Missed Questions	Trainer Feedback
7	**2015** **Topic:** Caring for a "Difficult" Family Member	No missed questions	• Material for this session was "kind of" covered in the time allotted. ○ Last section on dementia and suggestions was not covered, but realistically due to their questions, we had covered it earlier – so it was not sequential – 6 of the 7 attendees were caring for someone with a dementia diagnosis – so lots of questions earlier in other sessions. • Process/energy were good – seems like they were sad to be split up. They had bonded. They had some questions initially about caregiver services so we went back and recovered a little. • People really liked this content. They shared lots of experiences. • Room size is not ideal. Would not do in this room again – too small. Also cleaners of the room were in and out. • Referred all of them to support groups (both COAAAs and Alz. groups). Several said they would go.

	2016
	Topic:
	Caring For a "Difficult" Family Member
		No missed questions	• Covered all plus included more on dementia than in Toolbox in response to questions.
			• Not as much discussion as I would have liked until I got to dementia – then lots of question and answer and examples.
			• What worked well:
			  ○ Discussion of difficult behavior
			  ○ Discussion of dementia – even those whose family member does not have dementia were contributing.
			• All was good.
			• Still would move room into an oval next time we do it.

Week	Workshop	Missed Questions	Trainer Feedback
8	**2016** **Topic:** Common Family Dynamics	**"Which of the following is <u>not</u> a suggestion for family meetings?"** Incorrect answers: Include those family members who are in the younger generations, set ground rules for the meeting before starting	• All topics were touched on – some in more depth than others due to time constraints. • Energy level good. • Trainer did not invite as much interaction in order to cover materials. Still had some good comments. • Participants showed interest in keeping in touch with each other. We will facilitate that communication for those who are interested. • Room setup definitely needs to be change so that participants can talk and share with each other. Will use a circle or u-shape going forward. • Some content is repetitive from Preventing Burnout – need to re-work this a bit. • This was the last session. Participants shared that they had benefitted from the classes and expressed appreciation for contact information for COAAA staff for future questions/issues.

APPENDIX B. WHAT CAREGIVERS HOPED TO GET FROM THE WORKSHOP

Participant responses are reported as written with minor corrections for spelling and grammar.

“Definitely provided”
Resources/Services
- Expand my awareness of resources available in [county name].
- Services available.
- What is available in the care of my loved ones?
- Need resources.
- Information about where to look for help.
- Resources available for caregiving.
- Information related to dementia.
- Planning – resources to bring Mom home.
- At home care resources (24 hour care).
- Services available for Medicare person.
- Respite availability.
- Tapping into resources.

Caregiving Skills/Tools
- Learning how to keep loved one “calm.”
- Better ways of helping my client.
- How to care for a difficult person.
- Best ways to provide care for a loved one.
- Caregiving tips/suggestions.
- Tools for stress management.
- Tools for anger management.
- Tools for better communication.
- Sometimes resistant patient.

Self-Care
- How to take care of me in the process of caring for mother.
- Preventing burnout.
- Maintain good health for both.
- Coping skills.

Education/Knowledge
- Education.
- Learning something new.
- General knowledge.

Planning Ahead
- How to plan ahead – when to get started?
- Finding out how I can help myself when time comes.

Navigating the System

- How to work the politics.
- Navigating medical information about services.

“Somewhat provided”

Resources/Services

- Activities for my loved one.
- When I need a break who do I call on?
- What’s available?
- Legal, financial resources for best outcomes.

Self-Care

- Improve my coping strategies.
- How to accept help.

Planning Ahead

- Planning for the future.

Navigating the System

- Navigating healthcare/insurance maze.

“Not provided at all”

Resources/Services

- Home modification resources.

APPENDIX C. WHAT CAREGIVERS FOUND MOST HELPFUL ABOUT THE WORKSHOP (POSTTEST)

Participant responses are reported as written with minor corrections for spelling and grammar.

Resources/Services

- Learning about the [county name] caregiver grant.
- Resources available in the community.
- The workshop has made me aware of so many resources I will depend upon as this journey progresses.
- Resources.
- Good information about sources available to help.
- Resources are helpful and to call COAAA for ideas will be great.

Interaction with Other Caregivers

- The camaraderie developed between the students.
- Being able to respond honestly, with no judgement especially when it come to the burnout session.
- Hearing others' struggles with the behaviors of their impacted family member.
- Listening to other people that have about the same issue that I have with my family member and how they are coping with the issues.
- Meeting the others and creating empathy for all attendees and hearing their circumstances and their role and their difficulties.
- Nice to know that our problems are not so bad.

Interaction with/Access to Trainers

- The tips, stories, advice from the facilitator.
- Opportunity to ask questions and receive immediate answers.
- Good to hear of various cases and how to resolve problems that come.
- COAAA - meeting caring professionals who are so knowledgeable and offer concrete experiences to make it more real.
- [Trainer 1] and [Trainer 2] were great presenters and their compassion and expertise were so helpful.
- Both speakers were very informative, and good speakers.

Education/Knowledge

- So many of the topics were issues I was experiencing. It was so timely. I made use of 95% of the information.
- The Chapter 6 gave a lot of information regarding the medical reasons for Alzheimer’s vs. no short-term memory. It explains to some degree what my mom’s brain is doing and thinking.
- The wide parameters of the issues discussed under "Caregiver" very informative.
- Also the section on dementia, versus Alzheimer’s some great info.
- Each topic in book is very relevant. Tips on caregiving, communication, understanding differences in family dynamics all so helpful.

Self-Care

- Session 6 & 7, I am not always as up front with my Elders. I tend to suck it up - These workshops help me to learn to express myself better.
- Personal experiences of things I am going through.
- I've also learned about the "toll" caregiving can take and how carefully one must work to stay healthy.
- Knowing stress and time for self was good to talk about.

Class Materials

- The caregiver toolbox kit is very helpful organizing, and setting up a foundation for planning future steps.
- The printed material.
- The booklet - a huge resource.

Caregiving Skill/Tools

- How to deal with love ones with Alzheimer’s - things that may work in difficult situations.
- Help with getting people who are disabled getting in and out of wheelchairs, etc.

Navigating the System

- On several occasions I had issues with rehab Medicaid and other during this Workshop of classes. At every stage those specific issues were addressed in these classes. Thank you.

APPENDIX D. WHAT CAREGIVERS FOUND MOST HELPFUL ABOUT THE WORKSHOP (FOLLOW-UP)

Participant responses are reported as written with minor corrections for spelling and grammar.

Resources/Services
- Guidebook and class discussion increased awareness of available resources.
- Encouragement to retain an elder law attorney and information about same.
- What's most helpful is the fact that I know this resource exists even though I may not be in need of services right now.
- Yes it gave information on what is available when we need it.
- Help me be more knowledgeable of resources to assist man and family with caregiving.
- Respite care.
- Hospice.
- Resource lists.
- It provided information on where I can go to get help if needed. I will utilize respite in 2017 and home health care (baby-sitting). I may try adult day care services. I also learned that VA may be able to provide some funding as well as my county aging department.

Caregiving Skills/Tools
- Information about safely using wheelchairs and how to safely assist someone to stand/sit.
- How to use wheelchair.
- How to get someone out of chair.

Interaction with Other Caregivers
- Opportunity to share - group discussion.
- The fellowship of others going through the same thing.
- Feeling less isolated.

Education/Knowledge
- I learned something important in each class.
- Human explanation of different areas of benefits.
- The real honest and professional info the facilitators presented as well as those of us reaching out.
- Going through the variety of topics.

Self-Care
- The area of Preventing Burnout was most important.

Planning Ahead
- I picked up the Medicaid papers and completed them when my mom was still living - but never needed to apply for it.

Navigating the System
- The contacts made with JFS and COAAA.

Interaction with/Access to Trainers
- Everything. The leaders were very patient and gave a lot of very good information.

APPENDIX E. WHAT CAREGIVERS WOULD CHANGE TO MAKE THE WORKSHOP BETTER (POSTTEST)

Participant responses are reported as written with minor corrections for spelling and grammar.

Class Structure

- I would like to have heard more from other caregivers about their experiences and how problems were resolved.
- Perhaps asking a little more audience participation in some topic [illegible word] that allows for "hands in the air" or personal experience with limits for talking too much.
- Less reading the materials out of the text book.
- Have participants read the material in advance of the session so the material can be covered in fewer sessions.
- Don't need the computer PPTs.

Time/Location

- Different hours - 6:00 p.m. is [illegible word] with traffic.
- Time schedule of classes (traffic).
- Change the start time to 6:30 or 7:00 p.m. which would eliminate the traffic problems.

Advertising/Outreach

- I think this should be offered earlier in the health care/caregiver experience. If more people know this was available the caregiver stress could be lowered significantly.

Training Space

- Better seats, more comfortable space.

**Four caregivers indicated that they would not change anything about the Workshop.

- Nothing.
- It was all wonderful.
- Enjoyed it all - wished I'd known about this years ago - however it's great we don't know what's down the road!
- I honestly can't think of one. It was a really well thought out and executed class.

APPENDIX F. CHANGES TO THE WORKSHOP RECOMMENDED BY THE CAREGIVERS (FOLLOW-UP)

Participant responses are reported as written with minor corrections for spelling and grammar.

Content

- Talk about TOD and Survivorship Deed.
- Provide a list of legal things that need addressed before and after death.
- None except plans for group activities for caregivers and loved ones.

Class Structure

- For people who are not as outspoken maybe some index cards to write down questions.
- Have part of it be a support group, but keep that separate from the lectures/informational time.

Time/Location

- Time change - 6:00 was very heavy traffic in [city name].
- Time of classes, or have in a less congested area of time.

Class Materials

- Eliminate the duplicative handouts which basically mirror the guidebook.
- Instead of handouts which duplicate the Guidebook, provide participants with several colors of highlighters which can be used to highlight/emphasize the "high points" of the trainers' presentation.

Advertising/Outreach

- The program was promoted on Ch. [X] TV, but the information centered around [county name] and counties that border. My county, [county name], is in the Ch [X] viewing area, but no information provided was for [county name]. [Trainer 1] provided me with #'s I need for contact purposes, but expand info or don't advertise program on local TV channels.

Training Space

- On the last night for the focus group, the tables were rearranged into a large u shape. Several of us made the comment it helped to create a feel of camaraderie. It would have been positive to do that.

Three caregivers indicated that there was nothing they would change.

- None, because it was well done.
- It was wonderful - thank you.
- Can’t really think of changes that need to be made.

APPENDIX G. FOCUS GROUP QUESTIONS

1. Have any of you attended a caregiver workshop or caregiver support group before?
   What kind?

2. How did you hear about the Caregiver Toolbox Workshop series?

3. Why did you decide to attend the Caregiver Toolbox?

4. Was there anything that made it difficult for you to attend the workshop sessions?
   Was there anything that made it easier?

5. What do you feel is the most important topic that was covered in the Caregiver Toolbox?

6. Is there a topic that you think could be left out or that is not necessary to cover in the workshop series?
   Which one/s?

7. Is there a topic that was not covered that you wish would have been covered?
   What is it?

8. Has participating in the Caregiver Toolbox had any effect on the stress that you feel in your caregiving situation?
   How?

9. How has the Caregiver Toolbox affected your caregiving knowledge?
   How has it affected your caregiving skills?

10. How has the Caregiver Toolbox affected your confidence in handling the planning aspects of caregiving?
    How?

11. Is there anything that you’ve learned in the Caregiver Toolbox that you’ve already used in your caregiving?
    What?

12. In general, what did you like most about the experience of attending the Caregiver Toolbox?

13. In general, what did you like least about the experience of attending the Caregiver Toolbox?

14. Is there anything else you’d like to share about your experience of attending the Caregiver Toolbox?

APPENDIX H. TELEPHONE INTERVIEW GUIDE

Caregiver Toolbox Workshop
Telephone Interview Guide
(Participants who attended fewer than half of sessions)

Participant: ____

Date: _________________________________

Interviewer Script:
[Good morning/afternoon/evening], my name is [insert name]. I’m a researcher with Miami University in Oxford, OH. Earlier this year, you attended the Caregiver Toolbox workshop series offered by the [Area Agency on Aging] at [training site]. Miami University is partnering with COAAA to help them improve the Caregiver Toolbox Workshop and I’d like to ask you a few questions about your experience. This should take about 20 minutes of your time. Do you have a few minutes to speak with me?

If yes, inform participant that the call is being audio-recorded and proceed with questions.
If no, inquire whether you can call back at another time and what time would work best.

<u>**Demographic Questions:**</u>

1. Who are you caring for? What is his/her relationship to you? ***(Please place an “x” in the blank. If participant is caring for more than one person, you may place more than one “x”).***

   _____ Parent/Parent-in-law
   _____ Grandparent
   _____ Spouse/Partner/Significant Other
   _____ Sibling
   _____ Son/Daughter
   _____ Grandchild
   _____ Friend
   _____ Neighbor
   Other Relative (specify): ____________________
   Other (specify): ___________________________

2. Do you live with the person(s) you are caring for? **Yes** **No**

   If no, what is the distance between you and your loved one(s)? ***(Read answer choices and place an “x” in the blank.)***
   _____ next door/same building
   _____ less than 1 mile
   _____ 1-10 miles
   _____ 11-40 miles
   _____ 41 – 100 miles
   _____ over 100 miles

3. Are you raising any children under the age of 18? **Yes** **No**

   If yes, how many? _________

4. Are you currently employed? **Yes** **No**

   If yes, are you employed: full-time____ part-time (hours per week: ________)

5. Do(es) your loved one(s) receive any formal services to help with their care? For example, home health aides and/or nurses, transportation services. **Yes** **No**

   If yes, what type of services? ***For personal care and nursing services, please indicate how many hours per week the loved one(s) receive(s).***

   - ____
   - ____
   - ____

6. Do any other family members or friends share caregiving responsibilities with you for your loved one(s)? **Yes** **No**

7. Do(es) your loved one(s) require 24/7 supervision or care? **Yes** **No**

   If yes, about how much of that do you provide?

   (Read answer choice): **100% 75% 50% 25% Other amount ___________**

<u>Workshop-Related Questions:</u>

8. Had you attended any other caregiver workshops or caregiver support groups before you attended the Caregiver Toolbox? **Yes** **No** **What kind?**

9. How did you hear about the Caregiver Toolbox?

10. Why did you decide to attend the Caregiver Toolbox?

11. What were you expecting to learn or receive from the Caregiver Toolbox?

12. Was there anything that made it difficult for you to attend the workshop sessions?
    Yes **No**
    Would you share with me why you stopped attending the sessions?

13. Was there anything you learned in the sessions you attended that you've used in your caregiving? **Yes** **No** **If yes,** what?

14. Were there any resources that you learned about in the sessions you attended that you've used? **Yes** **No** **If yes,** which resources?

15. At the first session, you received the Caregiver Toolbox workbook. Have you reviewed any part of the workbook since you last attended the workshop? **Yes** **No**
If yes, what materials did you review?

16. If you had the opportunity to attend the Caregiver Toolbox again, would you do it?
Yes **No** **If no**, what would make you more likely to attend the Caregiver toolbox again?

17. In general, what did you like most about the experience of attending the Caregiver Toolbox?

18. In general, what did you like least about the experience of attending the Caregiver Toolbox?

19. What changes would you recommend to the Caregiver Toolbox?

20. Is there anything else you'd like to share about your experience of attending the Caregiver Toolbox? **Yes** **No**

APPENDIX I. STRESS RATING TOOL

Participant ID: ___________________

CAREGIVING STRESSES

Caring for a family member or friend has both challenges and rewards. Many caregivers say their caregiving situation is stressful for a variety of reasons. We would like you to think about what is stressful about your caregiving situation and rate that stress below. As you decide on your number, please consider caregiving tasks and responsibilities and also any effects caregiving has on your relationships, social activities, employment, education, finances, physical or emotional health.

On a scale of 1 to 10, with 1 being no stress and 10 being extreme stress, how much stress are you feeling about your overall caregiving situation?

Please circle the number that best describes your situation.

	Stresses
Extreme Stress	**10**
	9
↑	**8**
	7
	6
	5
	4
	3
	2
No Stress	**1**

Please help us understand why you picked this number. **What are the most stressful things about your caregiving situation?**

1) ___________________________________

2) ___________________________________

3)___________________________________

4)___________________________________

5)___________________________________

What do you think would most help you in caring for your loved one (s)?

____

____

____

____

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APPENDIX J. CAREGIVING CHANGES

Participant responses are reported as written with minor corrections for spelling and grammar.

Utilizing Resources/Services

- Explored the Family Caregiver Support Program Grant via the [County Office on Aging].
- Respite Care.
- Reaching out for respite care.
- Arranged Institutional Respite Care, plan to use it [specific dates]/ thanks to the Caregiver Tool Kit and [Trainer 1] – an angel!!

Passing on Resources to Others

- Gave family a caregiver toolbox manual for all the great resources.
- Gave COAAA phone number to others helping the elderly.
- Through information learned, I have passed on the info and assisting others.

Caregiving Skills/Tools

- Tried to develop more patience.
- Able to lift him differently and carefully.

Self-Care

- My parents (mother passed 12/24/15) don't listen to me. I'm an RN. I have learned to let it go unless there is an immediate safety issue.
- I have also found the part on coping skills was most important for me.

Financial/Legal Matters

- My editor is a paralegal - He told me to do a TOD (Transfer on Death) on Dad's care now - $17.00 instead of hundreds after he dies. He also told me that my Dad had to open up the Survivorship Deed so the house goes to him - it needs to be filed with a death certificate, a form that is notarized by the county auditor.
- Retained an elder law attorney, which I had been procrastinating. Now attending to various legal matters.

Advocacy

- Fight for his Medicaid/Medicare benefits.

Using Written Materials

- Refer to resources in Toolbox booklet.

Housing

- We are looking for different living arrangements. We've made a few visits, but finding it difficult to find what we need.

APPENDIX K. BENEFITS REPORTED BY CAREGIVERS

Participant responses are reported as written with minor corrections for spelling and grammar.

Financial/Legal Matters

- The TOD (Transfer on Death) for the car is done. Survivorship Deed is done.
- My mother's finances will be better managed and I won't have to navigate Medicaid (if/when it's necessary) on my own, thank God.
- My mother's finances will be better protected if I were to predecease her (as an only child of an only child, and of divorced parents, it's a problem).
- Proper medical paid for by Medicare instead of out-of-pocket.

Utilizing Resources/Services

- Awareness of additional resources available.
- I am more relaxed, because I get two days a week with daycare and we do a weekend every 90 days of Respite Care.
- I have called COAAA a few times to ask questions.

Self-Care

- Just knowing there is help out there and how to get it has helped me in coping with my situation. I also feel I am coping with my situation a lot better.
- Less stressful for me.
- I feel so much better mentally knowing I can reach out that there is help.

Education/Knowledge

- I feel more knowledgeable to help family when needed.

Caregiving Skills

- Being more conscious about need to be patient.

Interaction with Other Caregivers

- Opportunity to ventilate feelings and identify with other caregivers who are in/experience similar challenges.

Written Materials

- I am glad to have caregiver toolbox manual with all the resources.

APPENDIX L. MATERIALS REVIEWED

Participant responses are reported as written with minor corrections for spelling and grammar.

Financial/Legal Matters

- The legal portion regarding my mom's property.
- Benefits.
- Estate planning/will.
- Medicare.
- Advance care planning.

Caregiving Skills

- I did look at the materials about providing care in a care home setting.
- Way to lift.
- Medical equipment.

Resources/Services

- Phone numbers for programs.
- Resource lists.

Self-Care

- Preventing burnout.

Family Dynamics

- The mediations for families.

APPENDIX M. RESOURCES USED

Participant responses are reported as written with minor corrections for spelling and grammar.

Specific Resources/Services

- Contacted the [County Office on Aging] regarding the Family Caregiver Support Program grant: Not currently eligible as husband is in rehab facility - will re-connect when husband is D/C home.
- Alzheimer's Association group classes.
- Hospice care - my mother passed away July 22.
- Respite Care.

Financial/Legal Matters

- I also contacted COAAA for help with Medicare questions, after learning in a workshop that this service is available.
- Information about locating an elder law attorney in my area.

Caregiving Skills

- Staying calm.
- Finding music, painting to help in their care.

Written Materials

- "Conversations That Light The Way" booklet.
- COAAA Utilities Guide for Seniors.

Passed On Materials to Others

- I have also passed along contact information for COAAA to someone who asked for it.
- I have passed info on.