

# An Evaluation of Dementia Dialogues®: A Program for Informal and Formal Caregivers in North and South Carolina

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## Abstract

In 2019, the University of South Carolina's Office for the Study of Aging (OSA) remodeled the curriculum for the nationally registered Dementia Dialogues® program that delivers high-quality education to formal and informal caregivers of persons who exhibit signs and symptoms of Alzheimer's disease and related dementias (ADRD). This study evaluated new knowledge acquired and program satisfaction by North and South Carolina program participants ( $N = 235$ ) after completing updated modules. Pre/post module survey data were analyzed using means and percentiles, McNemar's test, and paired  $t$  tests. Results demonstrated significant positive increases in caregiver knowledge attainment, with differences in overall knowledge change in specific modules among caregivers and noncaregivers ( $p < .0001$ – $<.05$ ). Dementia Dialogues® may serve as a useful tool in providing important information that increases caregiver knowledge of persons living with ADRD. Further research is recommended to examine how knowledge improvement translates into caregiving practices.

## Keywords

Alzheimer's disease, dementia, caregiver training, health promotion

## Introduction

There are 52.5 million people in the United States aged 65 years and older, and that number is projected to rise considerably in the coming decades (U.S. Census, 2018). As of 2020, it is estimated that 5.8 million of those older adults are living with Alzheimer's disease and related dementias (ADRD; Alzheimer's Association, 2020b). As the number of older adults with ADRD continues to rise, providing ADRD-focused caregiving education becomes critical for ensuring that an adequate and competent formal and informal workforce is available to support older adults with ADRD and their families (Kovaleva et al., 2019; Zembrak & Campione, 2020).

Caregivers of older adults living with ADRD play a critical role in the U.S. health care system (Fauth et al., 2019; Sherman & Steiner, 2018). In South Carolina, for example, there are approximately 318,000 caregivers for people living with ADRD and they provide up to 362 million hours of unpaid care (Alzheimer's Association, 2020b). Growing evidence indicates that caregivers often face unique challenges when providing quality care to older adults living with ADRD (Fauth et al., 2019). Knowledge on ADRD, effective communication, and patient-centered care techniques can help

caregivers overcome such challenges (Pleasant et al., 2016). Providing ADRD-focused caregiver education may influence positive outcomes for the caregiver such as improving satisfaction with the social support network of the caregiver and decreasing the level of conflict within the family in the case of informal caregivers (Fauth et al., 2019), two outcomes that are important for the caregiver's socioemotional well-being. Caregiver education may also decrease caregiver strain and depression (Lorig et al., 2019), while significantly improving their overall knowledge of ADRD (Tomar et al., 2019). Furthermore, researchers have demonstrated success in implementing, evaluating, and interpreting evidence-based

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interventions focused on the knowledge, attitudes, and behaviors of ADRD caregivers (Pleasant et al., 2016), while improving their caregiving experiences and health outcomes (Lorig et al., 2019).

The University of South Carolina's Office for the Study of Aging (OSA) has long recognized the importance of and is committed to furthering information, education, and research on ADRD and caregiving. The OSA's core mission is to prepare communities to meet the needs of a growing older adult population and to enhance the quality of life for these individuals as they age (Guest et al., 2018). One of the ways it does this is by educating formal and informal caregivers in North and South Carolina through a nationally registered Dementia Dialogues® program, a five-module, evidence-informed, and free-of-charge training course designed to educate community members and caregivers for persons who exhibit signs and symptoms of ADRD. Dementia Dialogues® differentiates itself from other programs because it takes place in a community setting and it highlights the roll of the family in the caregiving process while also acknowledging them as true caregivers. Health care providers are generally not trained to educate family or informal caregivers on how to care for their loved ones, which leads family caregivers to have difficulties recognizing and managing the signs and symptoms associated with medical conditions in the care recipient (Sherman & Steiner, 2018), or leaves them feeling overwhelmed or ill-prepared (Zembrak & Campione, 2020). Dementia Dialogues® sets itself apart by making such training accessible (e.g., free of charge) and readily available to informal and formal caregivers, including family members. Importantly, the program also provides education on how to recognize the self-care needs of all types of caregivers and integrates the family caregiver as an essential partner in the care of their loved one (Schulz et al., 2018). Dementia Dialogues® also presents participants with the opportunity to reflect on their caregiving experiences (Stajduhar et al., 2013).

### **Dementia Dialogues® Program**

**Mission and strategic goals.** The mission of Dementia Dialogues® is to provide the most current and practical evidence-based information about how to care for people living with ADRD. The target audience includes formal and informal caregivers and any other community members who are interested in learning more about ADRD caregiving. All participants complete the same modules as the information is applicable to different caregiving roles. Both participants and Certified Instructors have expressed that they prefer mixed groups as individuals provide different insights and understanding.

The OSA strives to promote the Dementia Dialogues® program in every state and to every person caring for and interacting with a person living with dementia. Specifically, the Dementia Dialogues® program aims to educate communities by (a) providing an overview of ADRD (Module 1), (b)

devising new strategies for effective communication between care partnerships (Module 2), (c) understanding the impact of the environment on persons living with ADRD (Module 3), (d) addressing challenging behaviors of persons living with ADRD (Module 4), and (e) developing creative problem-solving techniques for caregivers who provide care to persons living with ADRD (Module 5). Overall, Dementia Dialogues® assists informal and formal caregivers in learning evidence-based practices in communicating and providing quality care to persons living with ADRD.

**Course format and content.** Since 2001, more than 21,000 individuals have been trained in at least one module and more than 10,000 individuals have completed the entire course. Dementia Dialogues® is offered in-person nationwide by Certified Instructors. The 6-hr course consists of five modules in a lecture format, which are presented in Table 1. The program is mostly lecture-based, though, it does include videos to aid in further understanding of concepts. Certified Instructors are encouraged to bring their professional expertise into activities to have participants experience what a person living with dementia may experience. This expertise may be from current or past nursing, social work, teaching, administrative, caregiving, or other related ADRD roles.

Instructors have flexibility in how they present the program's content and how many individuals participate. Modules may be offered individually, a few at a time, or all five at once, and may be presented to a group or to an individual. It is recommended the program is presented in small groups to allow for personal interactions, discussions, and understanding. This allows for a cohort model of learning. Learning cohorts are groups of people with a shared interest or common purpose who progress through an educational experience together (Off et al., 2019). Such an approach to the delivery of educational interventions is based on people's interactional support, teamwork, and shared resources. Most Certified Instructors offer one module a week in a 60- to 90-min lecture format. Individuals who attend and complete all five modules of the training course are awarded a Dementia Dialogues® Specialist Certificate. The Office of Research Compliance, on behalf of the Institutional Review Board, determined that the referenced program is not subject to the Protection of Human Subject Regulations in accordance with the Code of Federal Regulations 45 CFR 46 et. seq.

There are several other caregiver trainings specific to dementia, such as the Certified Dementia Practitioner® Certificate through the International Council of Certified Dementia Practitioners (International Council of Certified Dementia Practitioners, 2020), essentiALZ Certification through the Alzheimer's Association (Alzheimer's Association, 2020a), CARES® Dementia Basics program (Pleasant et al., 2016), and REACH (Schulz et al., 2003). However, Dementia Dialogues® is the only program that is free of charge. Individuals also seek out this training

**Table 1.** Module Title, Description, and Pre/Post Survey Questions.*Module 1—The Basic Facts: An Overview of Alzheimer's Disease and Related Dementias.*

This module is an overview of Alzheimer's disease and related dementias. Specifically, this module defines dementia and the types of dementia, and identifies the prevalence of the disease around the world, in the United States, and provides a resource to identify individual state prevalence. This module also reviews warning signs of dementia, identifies risk factors for developing the disease, treatment options, and highlights expected changes as the disease progresses.

*Pre/Postmodule Questions:*

1. Dementia represents the loss of a person's ability to use his or her intellectual capacity.<sup>a</sup>
2. Dementia is considered a normal part of aging.<sup>a</sup>
3. Dementia is a progressive condition that may be further compromised by depression.<sup>a</sup>
4. The inability to perform familiar tasks can be an early sign of dementia.<sup>a</sup>
5. Individuals with middle to later stage of dementia require assistance.<sup>a</sup>

*Module 2—Keep the Dialogue Going: Strategies for Effective Communication*

This module discusses the importance of effective communication between care partnerships. It identifies barriers to communication as the disease progresses, and communication strategies to these barriers.

*Pre/Postmodule Questions:*

1. Nonverbal communication is as important as verbal communication for a person with dementia.<sup>a</sup>
2. Later stage communication difficulties include increased vocabulary.<sup>a</sup>
3. It is important to always correct a person with dementia when they are confused.<sup>b</sup>
4. A person with dementia does best with simple instructions giving one step at a time.<sup>c</sup>
5. Communication abilities do not change over time for a person with dementia.<sup>a</sup>
6. When a person with dementia repeats the same question or story several times, it is helpful to remind them that they are repeating themselves.<sup>c</sup>
7. A person with dementia does not need praise as they do not understand what it means.<sup>d</sup>

*Module 3—It is a Different World: Understanding the Impact of the Environment and Ways to Promote Independence*

This module discusses environmental barriers for a person living with dementia and how to make the environment safe, as well as providing strategies for successful activities of daily living.

*Pre/Postmodule Questions:*

1. A person with dementia can become agitated in an environment with noise and unnecessary clutter.<sup>d</sup>
2. To help a person with dementia make a decision, give as many choices as possible.<sup>d</sup>
3. A person with advanced dementia will not generally respond to changes in their physical environment.<sup>e</sup>
4. Daily care for a person with advanced dementia is effective when it focuses on providing comfort.<sup>e</sup>
5. Changing the environment (e.g., putting on a CD, opening or closing the blinds) will make no difference to a person with dementia.<sup>b</sup>
6. Having the same caregiver schedule each day can make life easier for both the caregiver and the person with dementia.<sup>a</sup>

*Module 4—It is Nothing Personal: Addressing Challenging Behaviors*

This module addresses challenging behaviors for the person living with dementia. Specifically, this module defines what a challenging behavior is, identifies the most common challenging behaviors, and addresses strategies for overcoming these behaviors.

*Pre/Postmodule Questions:*

1. Uncharacteristic behaviors in a person with dementia can indicate a need.<sup>f</sup>
2. If a behavior is irritating to the caregiver, it must be stopped.<sup>a</sup>
3. To immediately reduce dementia-related behavior, some use of medication should be your first response.<sup>g</sup>
4. Sundowning means that a person with dementia tends to become more alert and cooperative toward the end of the day.<sup>a</sup>
5. It is alright to make up a story (or lie) to a person with dementia to help reduce dementia-related behaviors.<sup>g</sup>
6. One of the easiest ways to reduce dementia-related behaviors is just to slow down while providing care.<sup>g</sup>
7. Exercise can help reduce restlessness and have other benefits for a person with dementia.<sup>a</sup>

*Module 5—Now What Do We Do? Creative Problem-Solving*

This module focuses on developing a care team and problem-solving techniques for caregivers who provide care to persons living with dementia. This module also reviews caregiver stress, identifies national resources and warning signs of adult maltreatment, and how to locate individual state reporting statutes and reporting procedures.

*Pre/Postmodule Questions:*

1. Once a person has Alzheimer's disease, she or he is no longer capable of making informed health-related decisions.<sup>a</sup>
2. Everyone can benefit if family and friends are involved in the care for a person with dementia.<sup>a</sup>
3. Often, dementia-related behavior is a reaction to something that is bothering the person.<sup>g</sup>
4. It is not important for a caregiver to attempt to determine the underlying cause of a dementia-related behavior.<sup>a</sup>
5. Setting time aside for yourself as a caregiver is vital to the care you provide to a person with dementia.<sup>a</sup>
6. Adult Protective Services is in every state and is required to investigate allegations of adult maltreatment.<sup>a</sup>

<sup>a</sup>Author developed. <sup>b</sup>Dementia Knowledge Assessment Tool Version 2. <sup>c</sup>Alzheimer's Disease Knowledge Scale. <sup>d</sup>Alzheimer's Disease Knowledge Test.

<sup>e</sup>Dementia Knowledge Assessment Scale. <sup>f</sup>25-item Dementia Knowledge Assessment Scale. <sup>g</sup>the 25-item CARES Dementia-Related Behavior Knowledge Test.

opportunity because it is nationally registered, evidence informed, approved for continuing education credits, and offered by a credible and reliable organization. Furthermore, the program is updated annually for statistics, current research, and feedback from overall course evaluations from participants.

**Certified Instructors.** Recruitment of Certified Dementia Dialogues® Volunteer Instructors is primarily through word of mouth, but also through the OSA's participation in conferences as a vendor, attendance at professional meetings, and promotion of the program on its website. Retention of these volunteers is accomplished by the Program Coordinator, housed at the OSA, through ongoing communication, interest in spreading the knowledge and skills for caregivers and community members, and the Program Coordinator being accessible to assist and troubleshoot, when necessary. Becoming a Certified Dementia Dialogues® Instructor is free of charge. Persons interested in becoming a Certified Instructor must submit an application and be approved by the OSA Program Coordinator or designee. Upon acceptance, the prospective volunteer must enroll in a required *Train-the-Trainer* course. All Certified Instructors should demonstrate a good understanding of the program curriculum, have experience or knowledge of AD/DRD, and have effective communication, presentation, and problem-solving skills. Currently, there are 129 Certified Dementia Dialogues® Instructors across four states: (1) Georgia, (12) North Carolina, (75) South Carolina, and (41) Utah. With that said, this study analyzed data obtained from North and South Carolina.

**Program remodel and update.** The Dementia Dialogues® program was updated with current statistics, references, and activities, and some content was reorganized for clarity. It was re-released on July 1, 2019, across all four participating states to include a pre- and post-survey for each of the five modules. Prior to this, Dementia Dialogues® only had a five-question survey with true/false questions administered before Module 1 and after the completion of Module 5. The program also underwent a curriculum revision to ensure that current research and statistics were presented accurately. To update the pre/post survey and to better understand how other education programs for dementia caregivers were assessing changes in knowledge, OSA team members conducted a comprehensive scoping review (Resciniti et al., 2020). This review included 35 studies which used 19 author-developed and 16 previously published tools to evaluate dementia educational knowledge among formal and informal caregivers.

Guided by these published and validated assessment tools and the Dementia Dialogues® curriculum, pre/post questions were updated for each of the five program modules. Each module's assessment of knowledge ranged from five to seven questions; all questions were true/false format (Table 1). In addition to updating knowledge questions, the pre-surveys

collects participant demographic information (sex, age, race, ethnicity, and caregiver status) from a close-ended list of options. An overall course evaluation is also administered following the final module. The overall course evaluation is a combination of closed and open-ended questions. The evaluation addresses the teaching effectiveness of the presenter through seven questions using a Likert scale of 1 – 4 (1 = strongly disagree & 4 = strongly agree), and open-ended questions that address techniques (*What are you taking away from this training in terms of working with a person with dementia?*), content (*What information was not covered that you wish had been covered during this training?*), and other (*What additional comments do you have regarding the training or speaker?*).

**Program objectives.** Dementia Dialogues® is the first free of charge AD/DRD caregiver training program of its kind. There is a need for research on dementia knowledge among formal and informal caregivers, including family members, and the validation of existing knowledge evaluation tools (Resciniti et al., 2020; Kovaleva et al., 2019). For those reasons, a formal program evaluation of the updated Dementia Dialogues® was conducted using data from North and South Carolina program participants. The following research questions guided our evaluation: (1) What are the demographic characteristics of the program participants and (2) are participants accruing new knowledge after each of the five learning models? The objective of the program evaluation was to identify its key characteristics, effectiveness, and potential areas for improvement. Program evaluations are critical for institutions, such as the OSA, that are dedicated to the advancement of knowledge. It is hoped that this program evaluation will yield knowledge about best practices within communities, insights for future program development, and opportunities for program promotion in other U.S. states.

## Method

Collection of data began when the revised curriculum was released to instructors on July 1, 2019. Prior to starting the five learning modules, the Certified Instructor provides each participant with an "Instructor Assigned Participant Number" and participants are asked to write the assigned number on each module's pre/post survey. All participants are formal caregivers, informal caregivers, or the general population and at least 18 years old that are from North and South Carolina. The program also collects participant demographic information through the pre-surveys. The "Instructor Assigned Participant Number" allows OSA to complete a program analysis and evaluation for each learning module. After course completion, each participant also completes an anonymous overall course evaluation, which does not collect identifying information to enable and encourage participants to provide honest opinions about the training program. Certified Instructors' send the completed documentation



**Table 2.** Participant Demographics per Module.

| Demographics |                                                                             | Module 1<br>(N = 237) | Module 2<br>(N = 231) | Module 3<br>(N = 233) | Module 4<br>(N = 220) | Module 5<br>(N = 202) |
|--------------|-----------------------------------------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Sex          | Female                                                                      | 78.97% (169)          | 80.00% (152)          | 79.37% (150)          | 82.56% (142)          | 82.91% (131)          |
|              | Male                                                                        | 21.03% (45)           | 19.47% (37)           | 20.63% (39)           | 17.44% (30)           | 17.09% (27)           |
|              | Transgender                                                                 | —                     | 0.53% (1)             | —                     | —                     | —                     |
| Age          | 20–39                                                                       | 19.35% (42)           | 18.44% (26)           | 22.40% (43)           | 19.21% (34)           | 19.23% (30)           |
|              | 40–59                                                                       | 32.26% (70)           | 35.46% (50)           | 32.29% (62)           | 34.46% (66)           | 34.62% (54)           |
|              | 60–79                                                                       | 36.41% (79)           | 34.04% (48)           | 35.42% (68)           | 37.29% (66)           | 19.10% (61)           |
|              | ≥80                                                                         | 11.98% (26)           | 12.06% (17)           | 9.90% (19)            | 9.04% (16)            | 7.05% (11)            |
| Race         | American Indian, Alaskan Native, Native Hawaiian, or Other Pacific Islander | 0.47% (1)             | 1.08% (2)             | —                     | —                     | 0.66% (1)             |
|              | Asian                                                                       | 0.47% (1)             | 1.62% (3)             | 1.12% (2)             | 1.21% (2)             | 0.66% (1)             |
|              | Black                                                                       | 18.48% (39)           | 17.30% (32)           | 24.02% (43)           | 24.45% (42)           | 19.08% (29)           |
|              | White                                                                       | 80.57% (170)          | 80.00% (148)          | 74.86% (134)          | 73.33% (121)          | 79.61% (121)          |
| Ethnicity    | Hispanic or Latino                                                          | 3.91% (5)             | 4.76% (6)             | 2.91% (3)             | 4.04% (4)             | 4.21% (4)             |
|              | Not Hispanic or Latino                                                      | 96.09% (123)          | 95.24% (120)          | 97.09% (100)          | 95.96% (95)           | 95.79% (91)           |
| Caregiver    | Yes                                                                         | 42.86% (84)           | 42.11% (80)           | 53.54% (93)           | 52.05% (89)           | 51.25% (82)           |
|              | No                                                                          | 57.14% (112)          | 57.89% (110)          | 47.46% (84)           | 47.95% (82)           | 48.75% (78)           |

(sign-in sheets, surveys, evaluations) to the OSA Program Coordinator or designee. Data are collected and stored in the REDCap data management system, an online database provided by the University of South Carolina.

Both the demographic survey and the pre/post knowledge instrument were author constructed. The demographic survey was created by the Program Coordinator and evaluated by the OSA team. The knowledge instrument was developed by the OSA team through an iterative process. Initially, a scoping review by (Resciniti et al., 2020) was conducted to evaluate knowledge instruments used in dementia caregiver educational programs. These instruments were extracted and reviewed to identify questions related to Dementia Dialogues® modules (Table 1). Five members were selected to oversee one module each to review and select questions from the extracted instruments related to the module topic. Questions were either selected from previously published instruments or were author constructed. Once questions were identified for each module, the OSA team reviewed and selected the most appropriate questions, which ranged from five to seven questions per module. Questions from Alzheimer's Disease Knowledge Test (Dieckmann et al., 1988), Dementia Knowledge Assessment Scale (Annear et al., 2015), Dementia Knowledge Assessment Tool Version Two (Toye et al., 2013), CARES® Dementia-Related Behavior™ Knowledge Test (Gaugler et al., 2016), Alzheimer's Disease Knowledge Scale (Carpenter et al., 2009), and the 25-item Dementia Knowledge Assessment Scale (Annear et al., 2017) were used in the knowledge instrument. Table 1 provides the selected and developed question by module.

Participants' demographic information was analyzed with means and percentiles for continuous and categorical variables, respectively, for each of the five modules. Not all

participants completed a pre- and/or post-survey (see *Limitations* section), which prevented data from being fully analyzed for individual learning from pre- to post-surveys. To account for this, a complete case analysis was conducted in which only nonmissing data were included in each pre- and post-analysis. McNemar's test was used on paired data with dichotomous outcomes (true/false) to assess knowledge changes for each specific true/false question from the five pre/post-surveys. To evaluate overall knowledge changes, a total percent was calculated for each module, and then analyzed with a paired *t* test. Finally, paired *t* tests were used to analyze overall module results stratified by self-identified caregiver status (caregivers vs. noncaregivers). All data analyzed were from July 1, 2019 to December 31, 2019. Analysis was performed in both SAS and STATA.

## Results

Means and percentiles for the demographic information from all five modules are presented in Table 2. Participants tended to be female, between 40 and 79 years, White, and non-Hispanic. There tended to be an equal number of caregivers and noncaregivers in attendance; with the majority of participants being caregivers in Modules 3 through 5 and noncaregivers in Modules 1 and 2. Module 1 had an overall sample size of 237; although, the sample decreased to 202 in Module 5.

Table 3 presents the pre/post-survey results for each module and total results, which is the percent correct from all questions combined. Significant changes in knowledge from pre-test to post-test were seen for at least one question for each of the five modules. Caregiver knowledge for each module based on the presurvey was relatively high, ranging from 74.8% to 93.1%. Overall, every module showed a significant positive increase in score for the specific knowledge

**Table 3.** Pre- and Posttest Results for each Module by Question and Overall Results.

| Question | Choices | Module 1 (n = 235)  |                        | Module 2 (n = 230)  |                        | Module 3 (n = 230)  |                        | Module 4 (n = 220)  |                      | Module 5 (n = 202)  |                        |
|----------|---------|---------------------|------------------------|---------------------|------------------------|---------------------|------------------------|---------------------|----------------------|---------------------|------------------------|
|          |         | Pre                 | Post                   | Pre                 | Post                   | Pre                 | Post                   | Pre                 | Post                 | Pre                 | Post                   |
| 1        | True    | <b>78.35% (181)</b> | <b>85.28%* (197)</b>   | <b>96.23% (204)</b> | <b>99.06%*** (210)</b> | <b>99.53% (214)</b> | <b>99.53% (214)</b>    | <b>97.95% (191)</b> | <b>98.46% (192)</b>  | 39.04% (73)         | 29.41% (55)            |
|          | False   | 21.65% (50)         | 14.72% (34)            | 3.77% (8)           | 0.94% (2)              | 0.47% (1)           | 0.47% (1)              | 2.05% (4)           | 1.54% (3)            | <b>60.96% (114)</b> | <b>70.59% (132)</b>    |
| 2        | True    | 18.22% (41)         | 9.33% (21)             | 13.21% (28)         | 13.21% (28)            | 11.63% (25)         | 4.19% (9)              | 5.13% (10)          | 6.67% (13)           | <b>97.33% (182)</b> | <b>97.68% (183)</b>    |
|          | False   | <b>81.78% (184)</b> | <b>90.67%*** (204)</b> | <b>86.79% (184)</b> | <b>86.79% (184)</b>    | <b>88.37% (190)</b> | <b>95.81%*** (206)</b> | <b>94.87% (185)</b> | <b>93.33% (182)</b>  | 2.67% (5)           | 2.14% (4)              |
| 3        | True    | <b>95.11% (214)</b> | <b>95.65% (215)</b>    | 7.08% (15)          | 3.3% (7)               | 29.3% (63)          | 21.86% (47)            | 8.72% (17)          | 10.26% (20)          | <b>84.49% (158)</b> | <b>90.91% (170)</b>    |
|          | False   | 4.89% (11)          | 4.44% (10)             | <b>92.92% (197)</b> | <b>96.7% (205)</b>     | <b>70.70% (152)</b> | <b>78.14% (168)</b>    | <b>91.28% (178)</b> | <b>89.74% (175)</b>  | 15.51% (29)         | 9.09% (17)             |
| 4        | True    | <b>94.22% (212)</b> | <b>95.56% (215)</b>    | <b>98.11% (208)</b> | <b>99.53% (211)</b>    | <b>96.28% (207)</b> | <b>95.35% (205)</b>    | 15.38% (30)         | 9.23% (18)           | 6.95% (13)          | 5.35% (10)             |
|          | False   | 5.78% (13)          | 4.44% (10)             | 1.89% (4)           | 0.47% (1)              | 3.72% (8)           | 4.65% (10)             | <b>84.62% (165)</b> | <b>90.77%* (177)</b> | <b>93.05% (174)</b> | <b>94.65% (177)</b>    |
| 5        | True    | <b>98.22% (221)</b> | <b>96.89% (218)</b>    | 3.77% (8)           | 4.72% (10)             | 4.65% (10)          | 3.26% (7)              | <b>67.18% (131)</b> | <b>77.95% (152)</b>  | <b>98.40% (184)</b> | <b>98.40%*** (184)</b> |
|          | False   | 1.78% (4)           | 3.11% (7)              | <b>96.23% (204)</b> | <b>95.28% (202)</b>    | <b>95.35% (205)</b> | <b>96.74% (208)</b>    | 32.82% (64)         | 22.05% (43)          | 1.60% (3)           | 1.60% (3)              |
| 6        | True    | —                   | —                      | 7.55% (16)          | 2.36% (5)              | <b>99.07% (213)</b> | <b>98.14% (211)</b>    | <b>93.33% (182)</b> | <b>96.41% (188)</b>  | <b>96.26% (180)</b> | <b>99.47% (186)</b>    |
|          | False   | —                   | —                      | <b>94.45% (16)</b>  | <b>97.64%*** (207)</b> | 0.93% (2)           | 1.86% (4)              | 6.67% (13)          | 3.59% (7)            | 3.74% (7)           | 0.53% (1)              |
| 7        | True    | —                   | —                      | 4.25% (9)           | 4.25% (9)              | —                   | —                      | <b>97.44% (190)</b> | <b>99.49% (194)</b>  | —                   | —                      |
|          | False   | —                   | —                      | <b>95.75% (203)</b> | <b>95.75% (203)</b>    | —                   | —                      | 2.56% (5)           | 0.51% (1)            | —                   | —                      |
| Total    |         | 88.89% (234)        | 92.23%* (235)          | 93.11% (230)        | 95.20%* (229)          | 90.43% (230)        | 92.85%* (230)          | 74.84% (218)        | 78.18%*** (220)      | 87.71% (202)        | 91.67%*** (202)        |

Note: Bolded text indicates correct response.

\*p &lt; .05. \*\*p &lt; .01. \*\*\*p &lt; .001.

**Table 4.** Overall Module Results Stratified by Self-Identified Caregiver Status.

| Module | Caregiver       |                 |           | Noncaregiver     |                  |           |
|--------|-----------------|-----------------|-----------|------------------|------------------|-----------|
|        | Pre             | Post            | p value   | Pre              | Post             | p value   |
| 1      | 90.12% (n = 83) | 91.43% (n = 84) | p = .5991 | 87.86% (n = 112) | 92.32% (n = 112) | p = .0224 |
| 2      | 90.89% (n = 80) | 94.29% (n = 80) | p = .0339 | 94.48% (n = 110) | 95.94% (n = 109) | p = .3313 |
| 3      | 88.41% (n = 92) | 92.65% (n = 93) | p = .0268 | 92.06% (n = 84)  | 93.85% (n = 84)  | p = .2741 |
| 4      | 75.00% (n = 88) | 77.53% (n = 89) | p = .0617 | 75.66% (n = 81)  | 79.44% (n = 82)  | p = .0285 |
| 5      | 86.59% (n = 82) | 92.07% (n = 82) | p = .0049 | 88.89% (n = 78)  | 91.24% (n = 78)  | p = .2765 |

**Table 5.** Overall Program Evaluation.

| Question | Evaluation question                                         | 1 |    | 2 |    | 3  |    | 4   |     | Unanswered |    |
|----------|-------------------------------------------------------------|---|----|---|----|----|----|-----|-----|------------|----|
| 1        | The presentation was organized and easy to follow.          | 4 | 2% | 0 | 0% | 18 | 9% | 186 | 89% | 1          | 0% |
| 2        | The speaker demonstrated knowledge/experience in the topic. | 3 | 1% | 2 | 1% | 15 | 7% | 189 | 90% | 0          | 0% |
| 3        | The speaker clarified content in response to questions.     | 3 | 1% | 1 | 0% | 19 | 9% | 186 | 89% | 0          | 0% |
| 4        | The presentation level was appropriate for the learner.     | 3 | 1% | 0 | 0% | 19 | 9% | 187 | 89% | 0          | 0% |
| 5        | The speaker exhibited enthusiasm for the topic.             | 4 | 2% | 0 | 0% | 12 | 6% | 193 | 92% | 0          | 0% |
| 6        | The speaker met the objectives outlined for the training.   | 4 | 2% | 0 | 0% | 14 | 7% | 189 | 90% | 2          | 1% |
| 7        | I would recommend this training to others.                  | 3 | 1% | 1 | 0% | 14 | 7% | 191 | 91% | 0          | 0% |

domain associated with the module; Module 1: 88.9% versus 92.2% ( $p = .0100$ ), Module 2: 93.1% versus 95.2% ( $p = .0204$ ), Module 3: 90.4% versus 92.9% ( $p = .0198$ ), Module 4: 74.8% versus 78.2% ( $p = .0005$ ), Module 5: 87.7% versus 91.7% ( $p = .0023$ ). Furthermore, there were differences in overall knowledge change in specific modules by self-identified caregiver status (caregivers vs. noncaregivers). Although the results showed significant improvements, the effect difference between pre- and post-results was marginal, ranging from 2.1% to 4.0%. Table 3 indicates the presence of an increase in scores from pre- to post-results for all questions for both caregivers and noncaregivers; however, Table 4 indicates that significant results per module differed by caregiver status. Modules 2 (90.89% vs. 94.29%;  $p = .0339$ ), 3 (88.41% vs. 92.64%;  $p = .0268$ ), and 5 (86.59% vs. 92.07%;  $p = .0049$ ) showed significantly increased scores for caregivers, whereas Modules 1 (87.86% vs. 92.32%;  $p = .0224$ ) and 4 (75.66% vs. 79.44%;  $p = .0285$ ) had significantly increased scores for noncaregivers. Participation in each of the modules was high, with only having missing data for 4.3% for Module 1, 7.8% for Module 2, 6.5% for Module 3, 11.4% for Module 4, and 7.4% for Module 5.

We also assessed participants' satisfaction with the program following Module five (see Table 5). Scores ranged from 1 (*strongly disagree*) to 4 (*strongly agree*). Questions 1 through 6 were related to the presenter or the presentation, Question 7 asked if the participant would recommend the program. Each of the seven questions asked demonstrated positive results, with participants selecting 4 (*strongly agree*) 89% to 92% of the time. Only 1% to 2% of the participants selected 1 (*strongly disagree*) for each question. For

example, only 2% of the participants disagreed with Question 7, "I would recommend this training to others."

## Discussion

The present study is the first to summarize the nationally registered Dementia Dialogues® program and the first to formally conduct an evaluation of the trainings administered in North and South Carolina. Not only did this evaluation reveal statistically significant positive increases in knowledge scores across all five modules, but it also demonstrated extremely high satisfaction rates among participants, with between 89% and 92% of them strongly agreeing that the program was easy to follow and appropriate for their level, that the presenter was knowledgeable and met the outlined objectives, and that they would recommend the program to others. The high satisfaction scores of participants are in line with research that suggests that caregivers are generally appreciative of educational interventions designed to better prepare them in their caregiving role. Such research indicates that caregivers acknowledge the immense value these programs bring to the formal long-term care service system by paying attention to and addressing their caregiving needs and challenges. By being targeted directly at caregivers, these programs call "attention to the essential, but often overlooked, role of the family," thereby "valuing the invaluable" (Reinhard et al., 2019), and honor them as "the real caregivers" with "their own expertise and knowledge" (Cloyes et al., 2014). In addition, the Dementia Dialogues® program can serve as a useful tool in providing persons with an association to caregiving (either formal or informal) with important information that

increases their knowledge of caregiving. The improvements in knowledge were statistically significant; however, the effect difference between the pre- and post-measures was marginal. In comparison, meta-analytic studies of caregiver interventions consistently show satisfactory effect sizes of a variety of interventions, including educational and psycho-educational programs, for caregiver burden, with smaller effect sizes for caregiver depression, immediately after implementation (Thomas et al., 2017; Jensen et al., 2014; Northouse et al., 2012; Sørensen et al., 2002).

One reason for the marginal improvements for the Dementia Dialogues® program may be caregivers' high knowledge on the presurvey, which ranged from 74.8% to 93.1%. These marginal increases highlight the importance of considering the clinical or applied significance versus the statistical significance, and also suggest that more research efforts should be geared toward improving caregiver knowledge about challenging behaviors of the caregiving recipient. Nevertheless, these findings are relevant for moving the program forward for several reasons (Given et al., 2008).

First, many caregivers experience challenges in providing care because they find it difficult to recognize and manage the signs and symptoms associated with medical conditions in the care recipient (Sherman & Steiner, 2018), often feel overwhelmed or ill-prepared (Zebrak & Campione, 2020), and wish for more resources to fill this gap (Biello et al., 2019; Piggott et al., 2017). At the same time, educational interventions aimed directly at providing caregivers with instructions on how to give end-of-life care is highly effective in increasing their confidence with caring for their loved one as well as their overall satisfaction with caregiving and reducing their uncertainty about giving care, setting priorities, solving problems, and making decisions (Given et al., 2008; Kovaleva et al., 2019). Second, health care providers are generally not trained to educate caregivers about how to care for their loved ones, and the time spent on having these conversations is not reimbursable. Therefore, making readily accessible (e.g., free of charge) educational programs available to caregivers that better prepare them on the "how to" of care provision while also providing them with information on how to recognize addressing their own self-care needs psychological and physical health needs integrates them as essential partners in the care of their loved one (Schulz et al., 2018). Finally, despite widespread consensus that educational programs offered in a community setting can prepare caregivers for their caregiving role by providing needed information, the limited research on the effectiveness of such programs makes the interpretation of findings difficult and hinders decision-making regarding which programs really work and should be used (Jensen et al., 2014; Thomas et al., 2017; Toseland et al., 2011).

Caregivers appear to prefer programs that include specific information about dementia and its management, address individual caregiver challenges, offer practical and logistical support, and can be delivered in flexible formats (Biello et

al., 2019). The positive findings of this evaluation of the Dementia Dialogues® program are in line with research suggesting that "cohort models" provide an ideal context for family caregiver interventions. This approach views caregivers as cohorts, "groups of individuals who are banded together, treated as a group, or who start and stop an experience at the same time" and who "have the potential to understand and hold genuine compassion for one another, while empathizing and identifying with each other's circumstances and struggles" (Off et al., 2019). The findings are in line with research indicating that group-based strategies directed at caregivers positively impact, among other aspects, caregiver knowledge (Pailler et al., 2015). Although the Dementia Dialogues® program is not intended to be a caregiver support program, it may in fact carry a supportive function in that it allows caregivers to share their experiences while engaged in knowledge acquisition. This coincides with evidence suggesting that caregivers learn, among other processes, by reflecting on their own situations (Stajduhar et al., 2013).

### Limitations

Limitations of the Dementia Dialogues® evaluation are worth noting. Although the program has existed since 2001, the current study only analyzed data from the remodeled curriculum from July 1–December 31, 2019, as previously stated. Also missing are data from Utah (the state did not begin using the remodeled program curriculum until January 1, 2020) and Georgia (has yet to initiate the program in the state). Our results are only generalizable to participants of the remodeled curriculum in North and South Carolina. In addition, our evaluation focused solely on caregiver knowledge, not caregiver self-efficacy, given the focus of the current modules.

Missing data are a further limitation of the knowledge evaluations of the program. Not all participants completed a pre- and/or post-survey, nor did all participants properly identify their "Instructor-Assigned Participant Number" or the Instructor did not properly assign the number to participants. These issues prevented data from being fully analyzed for individual learning from pre- to post-surveys; therefore, a complete case analysis was conducted in which only non-missing data were included in each pre- and post-analysis. Although, the missingness was relatively small with it ranging from 4.3% to 11.4%. An additional data limitation includes potential misinterpretation of the Likert-type scale on the overall course evaluation. For example, some participants selected "1" for *strongly disagree* when they may have intended to select "4" for *strongly agree*. Such issues were recognized when comparing qualitative and quantitative data from individual evaluations. To avoid such issues in the future, the Program Coordinator and lead instructor will provide a refresher training course for active Certified Instructors and will ensure proper guidance and training on the administration of evaluations is covered in-depth. Another limitation



was the lack of diversity of our sample and representation of certain demographic groups. For example, 96% of the participants were non-Hispanic. Therefore, results may not be generalizable to a fairly large sector of the American population or other states in the United States with a large proportion of Hispanic populations.

## Conclusion

Given the rise in older adults with ADRD, the critical role that caregivers play in supporting this population, and the unique challenges that ADRD patients present, there is a need to provide ADRD-focused caregiving education to create an adequate and competent formal and informal caregiver workforce. Despite limitations, this study serves as a preliminary evaluation of the newly remodeled Dementia Dialogues® program. Statistically significant improvements in knowledge following training suggests that the program is effective for informing formal and informal caregivers on issues related to persons living with ADRD. Future research could involve interviews or focus groups with different types of caregivers to learn more about their training needs and potential changes to module content moving forward. The relatively high proportion of correct responses before the program and the modest improvements in knowledge among caregivers also suggest that there may be alternative areas, such as attitudes and behaviors, that may need further research and attention. In addition, it could be useful to include a follow-up study after a few months to determine long-term effects of the training on formal and informal caregivers' knowledge. Further research is recommended to examine how the newly remodeled program fares in Utah and Georgia, in comparison with the Carolinas, and how the knowledge improvement translates into better caregiving practices. In addition, the demographic characteristics of the program may be useful in identifying key characteristics for development of future programs and creation of opportunities to promote such programs in areas where they are most needed. In addition, future research will expand outcome measures to further understand how Dementia Dialogues® affects caregivers' self-efficacy, confidence, and mental health. Finally, as the instrument used was author constructed, validation of this instrument is imperative through development and understanding of its psychometric properties.

Currently, Dementia Dialogues® is an in-person training. In light of the COVID-19 pandemic, OSA is creating an instructor-led (synchronous) and self-paced (asynchronous) online learning opportunities. OSA's goal is to have both online learning platforms available to the public by the end of 2020. Dementia Dialogues® will remain available for in-person and online learning formats post-pandemic.

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## Ethics

University of South Carolina Office of Research Compliance IRB Number: Pro00090870. (The Office of Research Compliance, on behalf of the Institutional Review Board, determined that the referenced program is not subject to the Protection of Human Subject Regulations in accordance with the Code of Federal Regulations 45 CFR 46 et. seq.).

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## References

- Alzheimer's Association. (2020a). *Curriculum Review and essential ALZ*. <https://www.alz.org/professionals/professional-providers/dementia-care-training-certification>
- Alzheimer's Association. (2020b). *2020 Alzheimer's disease facts and figures*. <https://alz.org/alzheimers-dementia/facts-figures>
- Annear, M. J., Toye, C. M., Eccleston, C. E., McInerney, F. J., Elliott, K. E. J., Tranter, B. K., . . . Robinson, A. L. (2015). Dementia knowledge assessment scale: Development and preliminary psychometric properties. *Journal of the American Geriatrics Society*, 63(11), 2375–2381.
- Annear, M. J., Toye, C. M., Elliott, K. J., McInerney, F., Eccleston, C., & Robinson, A. (2017). Dementia knowledge assessment scale (DKAS): Confirmatory factor analysis and comparative subscale scores among an international cohort. *BMC Geriatrics*, 17(1), Article 168. <https://doi.org/10.1186/s12877-017-0552-y>
- Biello, S., Tomolo, A., Abraham, C., Escoffery, C., Lang, D., Sawyer, C., & Thompson, N. (2019). A qualitative evaluation of caregiver support services offered at the Atlanta veterans affairs health care system. *Preventing Chronic Disease*, 16. <https://doi.org/10.5888/pcd16.180156>
- Carpenter, B. D., Balsis, S., Otilingam, P. G., Hanson, P. K., & Gatz, M. (2009). The Alzheimer's Disease Knowledge Scale: Development and psychometric properties. *The Gerontologist*, 49(2), 236–247. <https://doi.org/10.1093/geront/gnp023>
- Cloyes, K. G., Carpenter, J. G., Berry, P. H., Reblin, M., Clayton, M., & Ellington, L. (2014). A True Human Interaction™: Comparison of family caregiver and hospice nurse perspectives on needs of family hospice caregivers. *Journal of Hospice & Palliative Nursing*, 16(5), 282–290. <https://doi.org/10.1097/NJH.0000000000000066>
- Dieckmann, L., Zarit, S. H., Zarit, J. M., & Gatz, M. (1988). The Alzheimer's disease knowledge test. *The Gerontologist*, 28(3), 402–407. <https://doi.org/10.1093/geront/28.3.402>
- Fauth, E. B., Jackson, M. A., Walberg, D. K., Lee, N. E., Easom, L. R., Alston, G., Ramos, A., Felten, K., LaRue, A., & Mittelman,

- M. (2019). External validity of the New York University caregiver intervention: Key caregiver outcomes across multiple demonstration projects. *Journal of Applied Gerontology*, 38(9), 1253–1281. <https://doi.org/10.1177/0733464817714564>
- Gaugler, J. E., Hobday, J. V., Robbins, J. C., & Barclay, M. P. (2016). Direct care worker training to respond to the behavior of individuals with dementia. *Gerontology and Geriatric Medicine*, 2. <https://doi.org/10.1177/2333721415626888>
- Given, B., Sherwood, P. R., & Given, C. W. (2008). What knowledge and skills do caregivers need? *American Journal of Nursing*, 108(Suppl.), 28–34. <https://doi.org/10.1097/01.naj.0000336408.52872.d2>
- Guest, M. A., Miller, M. C., Smith, M. P., & Hyleman, B. (2018). Office for the Study of Aging at the University of South Carolina: Promoting healthy aging through program development, evaluation, education/training, and research for South Carolina's older adults. *Journal of Applied Gerontology*, 37(3), 332–348. <https://doi.org/10.1177/0733464816643878>
- International Council of Certified Dementia Practitioners. (2020). *Certified Dementia Practitioner® Certification*. <https://www.nccdp.org/cdp.htm>
- Jensen, M., Agbata, I. N., Canavan, M., & McCarthy, G. (2014). Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: Systematic review and meta-analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry*, 30(2), 130–143. <https://doi.org/10.1002/gps.4208>
- Kovaleva, M., Blevins, L., Griffiths, P. C., & Hepburn, K. (2019). An online program for caregivers of persons living with dementia: Lessons learned. *Journal of Applied Gerontology*, 38(2), 159–182. <https://doi.org/10.1177/0733464817705958>
- Lorig, K., Ritter, P. L., Laurent, D. D., & Yank, V. (2019). Building better caregivers: A pragmatic 12-month trial of a community-based workshop for caregivers of cognitively impaired adults. *Journal of Applied Gerontology*, 38(9), 1228–1252. <https://doi.org/10.1177/0733464817741682>
- Northouse, L., Williams, A.-I., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, 30(11), 1227–1234. <https://doi.org/10.1200/jco.2011.39.5798>
- Off, C. A., Griffin, J. R., Murray, K. W., & Milman, L. (2019). Interprofessional caregiver education, training, and wellness in the context of a cohort model for aphasia rehabilitation. *Topics in Language Disorders Journal*, 39(1), 5–28. <https://doi.org/10.1097/TLD.0000000000000171>
- Pailler, M. E., Johnson, T. M., Zevon, M. A., Kuszczak, S., Griffiths, E., Thompson, J., Wang, E. S., & Wetzler, M. W. (2015). Acceptability, feasibility, and efficacy of a supportive group intervention for caregivers of newly diagnosed leukemia patients. *Journal of Psychosocial Oncology*, 3(2), 163–177.
- Piggott, C. A., Zimmerman, S., Reed, D., & Sloane, P. D. (2017). Development and testing of a measure of caregiver confidence in medical sign/symptom management. *American Journal of Alzheimer's Disease and Other Dementias*, 32(7), 373–381. <https://doi.org/10.1177/1533317517711247>
- Pleasant, M. L., Molinari, V., Hobday, J. V., Fazio, S., Cullen, N., & Hyer, K. (2016). An evaluation of the CARES® Dementia Basics Program among caregivers. *International Psychogeriatrics*, 29(1), 45–56. <https://doi.org/10.1017/s1041610216001526>
- Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019, November 14). Valuing the invaluable 2019 update: Charting a path forward. *AARP Public Policy Institute*, 1–32. <https://doi.org/10.26419/ppi.00082.001>
- Resciniti, N. V., Tang, W., Tabassum, M., Pearson, J. L., Spencer, S. M., Lohman, M. C., & Friedman, D. B. (2020). Knowledge evaluation instruments for dementia caregiver education programs: A scoping review. *Geriatrics & Gerontology International*, 20(5), 397–413. <https://doi.org/10.1111/ggi.13901>
- Schulz, R., Beach, S. R., Friedman, E. M., Martzolf, G. R., Rodakowski, J., & Jamesill, A. E. (2018). Changing structures and processes to support family caregivers of seriously ill patients. *Journal of Palliative Medicine*, 20(Suppl. 2), 36–42. <https://doi.org/10.1089/jpm.2017.0437>
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L. N., & Mahoney, D. F. (2003). Resources for Enhancing Alzheimer's Caregiver Health (REACH): Overview, site-specific outcomes, and future directions. *The Gerontologist*, 43(4), 514–520.
- Sherman, C. W., & Steiner, S. C. (2018). Implementing sustainable evidence-based interventions in the community: A fidelity-focused training framework for the savvy caregiver program. *Journal of Applied Gerontology*, 37(12), 1450–1471. <https://doi.org/10.1177/0733464816684623>
- Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356–372. <https://doi.org/10.1093/geront/42.3.356>
- Stajduhar, K. I., Funk, L., & Outcalt, L. (2013). Family caregiver learning—How family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets. *Palliative Medicine*, 27(7), 657–664. <https://doi.org/10.1177/0269216313487765>
- Thomas, S., Dalton, J., Harden, M., Eastwood, A., & Parker, G. (2017). Updated meta-review of evidence on support for carers. *Health Services and Delivery Research*, 5(12), 1–132. <https://doi.org/10.3310/hsdr05120>
- Tomar, R., Jha, A., Gale, T., & Huzzey, L. (2019). Benefits of attending a 'Dementia First Aid' course for family caregivers of people with early dementia: Findings of a pilot evaluation. *British Journal of Medical Practitioners*, 12(1), a008.
- Toseland, R., Smith, T., & McClive-Reed, K. (2011). Evaluating the effectiveness of caregiving education and support programs. In R. W. Toseland, D. H. Haigler, & D. J. Monahan (Eds.), *Education, training and support programs for caregivers: Research, practice, and policy* (pp. 125–147). Springer Science & Business Media. [https://doi.org/10.1007/978-1-4419-8031-1\\_9](https://doi.org/10.1007/978-1-4419-8031-1_9)
- Toye, C., Lester, L., Popescu, A., McInerney, F., Andrews, S., & Robinson, A. L. (2013). Dementia Knowledge Assessment Tool Version Two: Development of a tool to inform preparation for care planning and delivery in families and care staff. *Dementia*, 13(2), 248–256. <https://doi.org/10.1177/1471301212471960>
- U.S. Census. (2018). *Population quick facts*. <https://www.census.gov/quickfacts/fact/table/US#>
- Zebrak, K. A., & Campione, J. R. (2020). The Effect of National Family Caregiver Support Program Services on Caregiver Burden. *Journal of Applied Gerontology*. Advance online publication. <https://doi.org/10.1177/0733464819901094>