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**THE IMPLICATIONS OF DEMENTIA DIALOGUES ON HEALTH CARE WORKERS
AND CARE TAKERS**

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ABSTRACT

More than 5.5 million people have Alzheimer's Disease or a related dementia in the U.S., yet public awareness about the disease is low, with many basing their belief off of fears and myths. Dementia Dialogues is a 5-session educational program, aimed at teaching caregivers (formal and informal) about what dementia is and how-to best support patients with dementia. Upon evaluation of the Dementia Dialogues program in Utah, it was determined that the program is effective. Results support prior literature and indicate a positive relationship between the education and public awareness that Dementia Dialogues provides. The sample included 1198 individuals from 67 separate sessions held between August 2016 to September 2019. A survey was administered to all participants and a pre- and post-test was used to examine whether there was a knowledge change in participants; the majority increased on average 7.06 points between the two. This study provided evidence that individuals are able to participate in this program and leave more knowledgeable about dementia and the symptoms, how to assist patients with the disease, and how-to manage caregiver stresses in relation to caring for dementia patients. Continued exploration of the Dementia Dialogues program and positive effects it has for caregivers and patients will add to the broad range of literature on this subject and may lead to state or nationwide interventions that increase public awareness and knowledge about Alzheimer's Disease and dementia.

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Introduction

As individuals age, the risk of developing dementia increases. This can lead to memory loss, impaired judgement, and an overall reduction in an individual's ability to achieve everyday tasks and activities. It is often unknown that Alzheimer's Disease is only one form of dementia. Dementia is also caused from vascular cognitive impairment, dementia with Lewy bodies, frontotemporal dementia, Parkinson's disease, Huntington's disease, HIV, and traumatic brain injury.

Currently, there are more than 30,000 individuals in Utah and 5.5 million persons in the United States (U.S.) that have Alzheimer's Disease (Utah Health Department, 2019). Alzheimer's Disease is one of the top causes of death in the U.S., and those with Alzheimer's Disease typically live with the symptoms of cognitive decline for approximately 5-10 years. Alzheimer's Disease patients, in both the early stages of diagnosis and throughout their decline, require long term care management from various health professionals including at-home nursing care, medical assistants, geriatricians, and family members. Most adults with Alzheimer's Disease are unable to take care of themselves during the later stages of the disease, relying on these healthcare professionals and family members to manage their symptoms and daily activities. Although, caregivers are not always informed on the best methods to provide care and to assist the patients with Alzheimer's Disease. The caregivers are often unaware of the specificity of dementia and how to assist the for patients that have Alzheimer's Disease. Without proper knowledge and the necessary education, it is impossible to provide effective care to the ever-growing population experiencing Alzheimer's Disease and related dementias.

In this paper, I will first outline the prevalence and history of Alzheimer's Disease, and then discuss the public awareness about the realities of Alzheimer's Disease. Next, I will describe Utah's approach to increasing awareness of Alzheimer's Disease as a public health

priority, and how they are committed to improving the knowledge of Alzheimer's Disease among the public and the private workforce responsible for caring for patients with dementia. As part of Utah's State Plan, they have invested in a specific program called Dementia Dialogues that provides unbiased education about Alzheimer's Disease for persons who are providing care to patients with Alzheimer's Disease. Dementia Dialogues is a work-force education and training program, which is an intervention used within the health care industry to improve the efficacy and compassion of care provided by health care professionals to patients. Dementia Dialogues has also been used to educate family caregivers, and other community members who want to learn more about Alzheimer's Disease and dementia. After reviewing this literature, I will present a systematic evaluation of the Dementia Dialogue program administered by the Utah Department of Health from 2016 to 2019. This report is important because it provides a comprehensive review and discussion of one state's approach to increasing awareness of Alzheimer's Disease and to improving the quality of care for persons with Alzheimer's Disease and related dementia.

Literature Review

Alzheimer's Disease and Related Dementias

Since the late nineteenth century there have been a multitude of changes in the studies of dementia. What once was viewed as a normal part of aging has shifted to be seen as a distinct disease (Ballenger, 2017). Dementia was largely studied in the beginning of the twentieth century by German psychiatrists, Emil Kraepelin and Alois Alzheimer. These psychiatrists were passionate in trying to define "dementia" as a mental disorder for which a pathological basis was the underlying cause. However, in 1910 Emil Kraepelin created the category of Alzheimer's Disease. This finding distinguished an early onset of senile dementia that occurred later in life from the cases that were occurring before age 65. Before this instigation, dementia was solely

associated with aging. Kraepelin changed this stigma of Dementia with the new entity of Alzheimer's Disease (Rosato, Leavey, Cooper, De Cock, & Devine, 2019). This new motion set way for dementia even though it was allegedly related to the same brain and clinical pathology and symptoms, this suggested that Alzheimer's was a sort of disease.

Alzheimer's Disease is a specific type of dementia that causes an irreversible, progressive brain disorder that slowly destroys memory and thinking skills. The disease usually appears in patients in their mid- to late 60s and only worsens as the patient continues to age. The causes of Alzheimer's are unknown but, likely include a combination of lifestyle, environmental, and genetic factors alike. Each one of these factors has the risk of increasing or decreasing the cognition in the Alzheimer's patient but differs from person to person (Kernisan, 2013). Alzheimer's Disease is hard to diagnose because there is no blood test, brain scan, or physical exam can definitively and exclusively diagnose Alzheimer's disease. Many conditions can produce symptoms that can be mistaken for those of early Alzheimer's, making reaching the correct diagnosis is complicated and often requires Alzheimer's Disease to continually progress (Alzheimer's Association, 2018). There is a lot of research that has been done surrounding the causes and the search for cures on Alzheimer's Disease; however, little information is available about hands-on care.

While Alzheimer's Disease is the most common form of dementia, it is not the only cause for dementia. A host of other related dementias exist including vascular cognitive impairment, dementia with Lewy bodies, frontotemporal dementia, Parkinson's disease, Huntington's disease, HIV, and traumatic brain injury. These forms of dementia are commonly referred to as Alzheimer's disease and related dementia's, ADRD. These are caused by damage to or loss of nerve cells and their connections in the brain. Depending on the area of the brain that's affected

by the damage, dementia can affect people differently and cause different symptoms (Centers for Disease Control and Prevention, 2019).

Prevalence & background

Currently, 44 million people worldwide suffer from Alzheimer's Disease, and this number has been doubling every 5 years (Utah Health Department, 2019). In the United States alone, 5.5 million Americans are living with ADRD making it the 6th leading cause of death. By 2050 this number is projected to rise to nearly 14 million Americans. With this high diagnosis, more than 16 million Americans provide unpaid care for people with Alzheimer's or other dementias. These caregivers provide an estimates 18.5 billion hours of service valued at nearly 234 billion dollars (Alzheimer's Association, 2019). Patients with Alzheimer's Disease usually need high levels of care in activities of daily living, which is often provided by family members, friends, or informal caregivers (Isik, Soysal, Solmi, & Veronese, 2019). Individuals that provide care for Alzheimer's Disease patients have to cope with the stressful age-related conditions and dementia-related factors accompanying the disease. As Jerome Kaplan, an advocate for social programs for the elderly, argued in 1953, "with the number of people who are over 65 increasing significantly each year, our society is today finding itself faced with the problem of keeping a large share of its population from joining the living dead—those whose minds are allowed to die before their bodies do" (Ballenger, 2017, p.715).

Dementia affects patients in their everyday life events. Not only is the patient's cognition and emotional well-being affected, but also a side-affect to the memory loss is decrease in ability to take on everyday activities (Robinson, 2018). With there being so many different kinds of dementia, the symptoms are often specific to the individual patient. With cognitive deterioration being the one common factor in all types of dementia. Dementia is challenging not only for individuals suffering, but also those who are taking care of these patients. While dementia is still

an incurable disease at this time, the aim of treatment is to slow the deterioration of the mind and to manage symptoms while educating others about the disease.

Public awareness & fear

Dementia is often a difficult topic for discussion between both those aging and those providing care. There is often a lack of knowledge about dementia, which evokes fear in both individuals suffering from dementia and those that are caring for these patients. Many individuals in society are unaware of the difference between dementia and Alzheimer's Disease making the stigma high. Many studies have made a strong case in the necessity of informing the public in an effective way about the dementia risks and protective factors for caregivers (Heger et al., 2019). By providing information to the public about the risks and symptoms of dementia it has lowered the fear and stigma factor in individuals especially those of old age. Many older individuals do not believe they are at risk for dementia. This leaves them blinded to the signs and symptoms of the disease (Haapala, 2018). "The Lancet Commission on Dementia Prevention, Intervention, and Care underscores that society as a whole has a responsibility to not only provide information about dementia prevention, but also implement low-level interventions in society" (Heger et al., 2019).

Yet, there seems to be a relative lack of dementia risk awareness in the general public, resulting in major gaps of knowledge on dementia in general, and on the relation between lifestyle and brain health in particular (Heger et al., 2019). Stigma about dementia can discourage a person from seeking diagnosis, hinder a patient's quality of life, discourage participation in Alzheimer's disease research, and inhibit members of the public from adequately educating themselves (Stites et al., 2018). Raising the public awareness of dementia lowers the associated stigma. A public health campaign prevents a one-size-fits-all approach which in turn leads to a dropping fear of dementia (Page, Hayslip, Wadsworth, & Allen, 2019). Many older

respondents believe that there is nothing one can do to lower the dementia risk, and that dementia is an inevitable and non-preventable part of living. In order to make sure that people are aware of the symptoms and risk factors associated with dementia there need to be a health priority that aims at educating individuals about dementia, which will lower the fear and stigma factors inversely.

Making Alzheimer's Disease a Public Health Priority

Making Alzheimer's Disease a public health priority can lower the struggles for both caregivers and decrease the drain of emotions Alzheimer's Disease patients feel. A public health campaign would assess the dementia literacy and knowledge concerning dementia risk and protective factors in middle-aged and older individuals living in the community (Heger et al., 2019). Meeting the emotional and health needs of caregivers is supported and needed to lessen the health risks. Often times dementia can cause catastrophic consequences and stress to those that are providing care to dementia patients. A public health concern addressing these needs would be beneficial for caregivers and provide need specific resources. Dementia patients exhibit unique needs and have more specific tasks that they need assistance with when compared to patients with other types of conditions (Han et al., 2019). Having the knowledge and support of a health campaign would allow caregivers to reach out and increase their capacity to handle dementia related challenges. When caregivers have knowledge and access to support services it allows them to be more resilient with the patients. Caregivers that are supported by family members and have utilized relief care and education on dementia and associated diseases are more likely to push through (Robinson, 2018).

Utah's state Alzheimer's plan

The state of Utah has developed a plan to fight the increasing risk of Alzheimer's spreading throughout the state, and to increase public awareness and knowledge about ADRD. The newly revised state plan for 2018-2022, revised from the 2012-2017 state plan, addresses the requirements for the caregivers and the person who is diagnosed with dementia. Utah's State Plan for Alzheimer's and Related Dementias includes the following three guiding directives that have been set into place:

- 1) To combat the stigma and increase awareness of Alzheimer's disease and related dementias,
- 2) To emphasize person-centered care that responds to individual needs and strengths, and
- 3) To emphasize person-centered care that responds to individual needs and strengths (Alzheimer's Society, 2019).

Alongside these three guiding directives, the plan represents four all-encompassing goals which are reinforced by suggestions and specific strategies set forth by the coordinating council. The goals are as followed; Goal 1, Public Awareness –Dementia Aware Utah, Goal 2: Aging Services – Dementia Competent Workforce, Goal 3: Helping People with Dementia – Supported and Empowered Caregivers, Goal 4: Research – Expanded Research in Utah (Alzheimer's Society, 2019). “These goals are to be completed through the shared efforts of private organizations, non-profit entities, local and state government agencies, as well as interested stakeholders and individuals” (Utah Health Department, 2019). The goals are set in place as achievable measures of progress for the associated organizations. While the guiding directives are an overall umbrella encompassing the goals steering towards emphasizing dementia overall.

Dementia Dialogues

A part of Utah's State Plan includes the implementation of the Dementia Dialogues program which was introduced within the 2012-2017 Utah State Plan. It provides the most current and practical information regarding how to care for and support patients that have Alzheimer's Disease and related dementias. The newest plan continues this education to caregivers within goal 1,2 and 3 of the allotted goals for 2018-2022. Dementia Dialogues is a training that certifies health care professionals and family caretakers on the care for persons who have signs and symptoms associated with Alzheimer's Disease or related dementias. Currently Utah has over 50 active "Dementia Dialogue" trainers and has trained over 10,000 health professionals and caretakers through the "Dementia Dialogue" program (Meinor, 2019).

The purpose of Dementia Dialogues is to educate individuals who care for persons who exhibit signs and symptoms associated with Alzheimer's Disease and related dementias. The Department of Health in Utah aims to develop dementia-related competencies of primary care providers and non-health workforces across the continuum of care through Dementia Dialogues, according to the goals of their state plan (goals #1 #2 and #3). Participants who have completed the training have reported "higher rates of understanding Alzheimer's disease and dementia, recognition of signs and symptoms, and effective management of challenging behaviors" (Guest, Smith, & Hyleman, 2015). The trainings have likewise been shown to lessen the stress and burden that accompanies the caregiving role by simply providing educational practices to provide care.

The Current Study

The purpose of this project is to explore the data that has been collected from the Dementia Dialogues program and to evaluate whether the training being offered is effective in increasing the awareness and knowledge about Alzheimer's Disease. This information will add to the current literature of the public awareness and education about Alzheimer's and related

dementias. The information discovered will be presented to the Utah Health Department Dementia Dialogues staff and advisory board to determine the efficiency and learning throughout the program.

Methods

The Utah Department of Health has offered a program called Dementia Dialogue to provide specific training and education about Alzheimer's Disease and related dementia, as well as the needs of patients with dementia. This training is intended for health care professionals and family members who are involved in the care and support of persons with Alzheimer's Disease or related dementia. The goal of the training is to increase awareness and knowledge about Alzheimer's Disease, including its symptoms, common trajectories of disease progression, and the typical care needs of patients with Alzheimer's Disease. The program has also been subsequently translated and presented to Spanish-speaking caregivers and community outreach workers.

Each training includes a 5-session course and is based on the curriculum originally created by researchers and clinicians at the Office on the Study of Aging (OSA), Arnold School of Public Health, University of South Carolina through funding from the South Carolina Department of Health and Human Services (DHHS) (Guest, Smith, & Hyleman, 2015). The curriculum includes 5 main modules:

Basic Facts	<ul style="list-style-type: none"> • Identify signs and symptoms of dementia • Understand various causes of dementia • Learn treatment strategies
Keeping the Dialogue Going	<ul style="list-style-type: none"> • Understand communication challenges • Identify effective communication techniques • Interpret non-verbal communication
It's a Different World	<ul style="list-style-type: none"> • Become aware of environmental factors • Learn strategies to facilitate caregiving • Understand “normalization” and the implications for caregiving
It's Nothing Personal	<ul style="list-style-type: none"> • Identify challenging behaviors • Recognize possible causes of challenging behaviors
Now what do I do?	<ul style="list-style-type: none"> • Learn effective solutions to minimize challenging behaviors • Identify non-pharmacological strategies to addressing challenging behavior.

Figure 1. Modules Covered in the Dementia Dialogue Curriculum

The 5 content modules are presented across a 3-week course, meeting once a week for 2 hours at a time. After completion of the course, the participant received a Dementia Specialist Certificate, and received up to 7.5 continuing education hours upon completion of the Dementia Dialogues course (Dementia Dialogues, 2018).

Participation in the Dementia Dialogues program is voluntary. The classes were offered free throughout Utah to anyone that wanted to gain more information about Alzheimer’s Disease and related dementias. There was not a required number of participants for each class. Classes were not held on a specific schedule, but rather held when there was a location and a trainer were available. The first session was held on August 9, 2016 and the most recent class was held September 18, 2019 with a total of 67 classes held since the beginning of the program start in Utah.

During each course of the Dementia Dialogues program, a quiz was administered to each participant to evaluate the competency and learning of each individual attending the class. The test consisted of a pre-test, which was given before the start of the first session, and a post-test, given after the completion of all five sessions. Alongside the test, a survey was also provided at the end of the program, asking each participant to provide some simple data such as: what profession they were in, whether or not they were a caregiver, the effectiveness of the teachers and curriculum, the main techniques/takeaways gained from the course, and recommendations and feedback to improve the program. The test and survey were scored and recorded by Kristy Russell and compiled into an excel worksheet for comparison of all programs held. The results presented here come from a systematic review of these data.

Results

Sessions & Attendees

There were a total of 67 Dementia Dialogues sessions held between August 9, 2016 and September 18, 2019. There was 1 session in 2016, 27 in 2017, 21 in 2018, and 18 in 2019, signaling a decreasing trend over time, in how often the program has been offered since it was first implemented in Utah.

At least 1,198 persons have attended one of these 67 Dementia Dialogue sessions during this time period; 4 of the sessions failed to record how many people participated. On average, a Dementia Dialogues class had about 18 attendees, with the smallest class being only 3 people and the largest class having over 100 attendees. [# of students per session: *Mean* = 17.8, *Min* = 3, *Max* = 106, *SD* = 18.87].

The attendees of the 67 Dementia Dialogues sessions represented a wide-variety of professionals working in the long-term care and aging-services industries, as well as community

members. There were 7 sessions that did not record the professions of the attendees; and others within each session that “failed to answer” what their profession was. However, of the 60 sessions for which this information was available, the most common type of attendee was a family member; they comprised 17% of the total Dementia Dialogue attendees. The next most common attendee included social workers, comprising about 14% of the attendees. This was followed by frontline long-term care staff such as certified nursing assistants (CNAs) and personal care assistants (PCAs), comprising about 10% of the total attendees. As shown in Figure 1 below, other attendees included administrators and admission/marketing staff from long-term care facilities, as well as other professionals that are likely working with persons with dementia and their families, such as clergy, chaplains, physical therapists, counselors, etc.

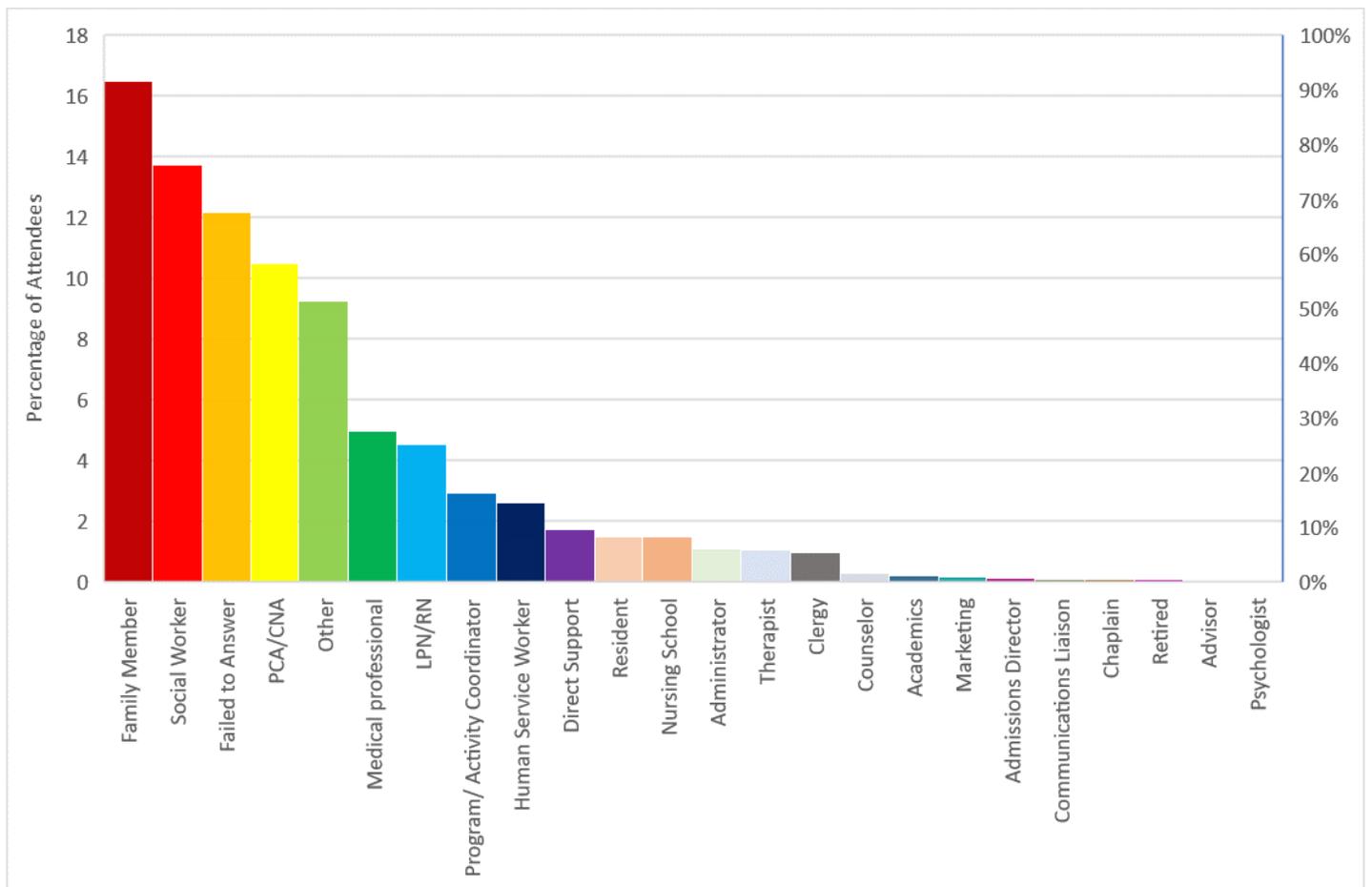


Figure 2. Percentage of total Dementia Dialogue attendees (n=1198), by self-reported profession

Teachers/Facilitators

44 different persons taught the Dementia Dialogues course. One session did not include information about who the facilitator was. Most sessions (i.e., 38 out of 67, or 57%) were taught by a single facilitator, with a number of the sessions being team-taught by two to five facilitators (i.e., 28 out of 67 sessions, or 42%, were team-taught).

One facilitator (initials, SR) taught 9 sessions; a few other facilitators (initials, JW and CS) taught 2-8 sessions; and most facilitators (n=44) only taught the Dementia Dialogues course one time. Our evaluation found that there were no significant differences in attendee outcomes, such as perceptions of program satisfaction or knowledge gain, by characteristics of the facilitator (i.e., single teacher versus team-taught, or by particular teacher). This suggests that a number of different facilitators can effectively present the Dementia Dialogue curriculum, and that the program can be presented in both a single-teacher or team-taught format.

Location

The Dementia Dialogues course has been offered across the state of Utah, with a little over a third of the classes offered in the Salt Lake County AAA district (36%) and another almost one-third in the Five-County AAA district (30%). As shown in Figure 1, the rest of the sessions were offered in the Weber 7.5%, Davis 17%, Tooele 3%, Mountainland 5%, and San Juan 1.5% AAA districts.

All Dementia Dialogue courses have been taught in-person in facilities such as government buildings (e.g., Cedar City municipal buildings), long term care facilities, and other facilities that have traditional classroom space (e.g., Weber Tech). Our evaluation found that there were no discernable differences in attendee outcomes, such as perceptions of program satisfaction or knowledge gain, by location of where the course was taught.

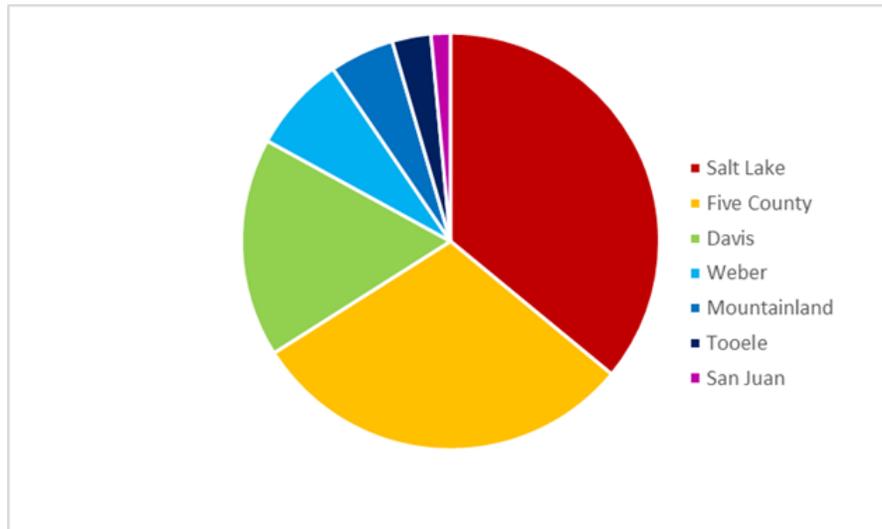


Figure 3. Area Agency on Aging (AAA) where Dementia Dialogues class was held, Aug 2016-Sept 2019

Outcomes – Knowledge About Dementia

At the start of a Dementia Dialogues course, each attendee completed a short 5-item quiz, assessing their knowledge about dementia. The quiz is scored on a scale from 0-100. This quiz is then repeated at the end of the Dementia Dialogues course to assess how much their knowledge about dementia improved as a result of the Dementia Dialogues curriculum. Of the 67 sessions offered, there was valid pre- and post-course data available for 57 sessions (i.e., 10 sessions failed to record one or both of the knowledge scores for attendees). As shown in Figure 3, the average pre-test score was 89.94%. The average post-test score was 97%. This represents a 7.06 percentage point change in scores, meaning that the average attendee scored significantly higher (7.06 points higher) on the post-test score compared to their pre-test knowledge score.

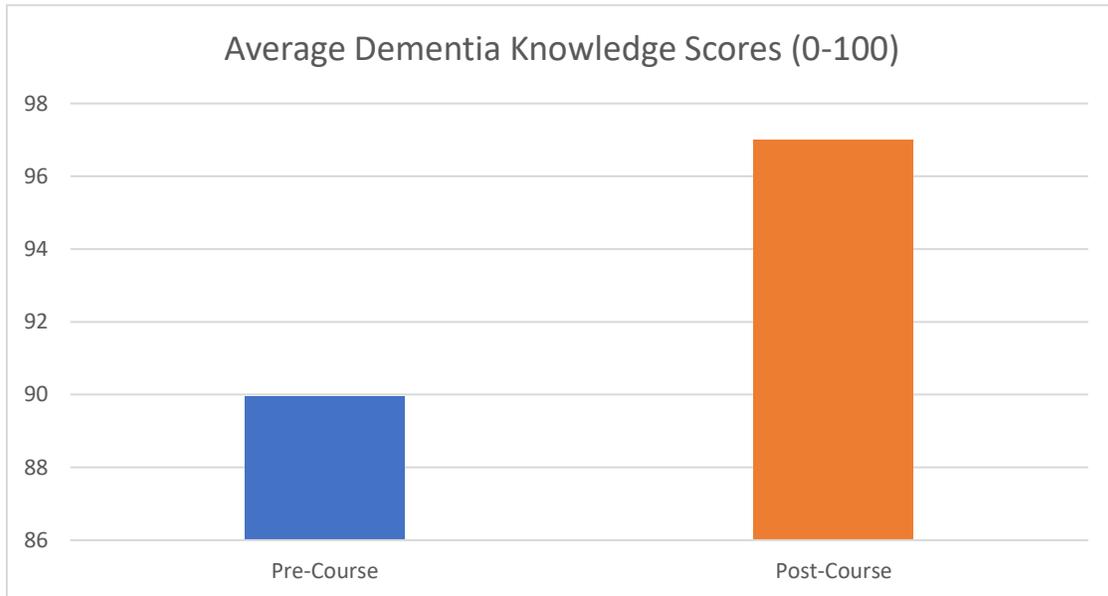


Figure 4. Average Dementia Knowledge Scores, measured before and after the Dementia Dialogues course (n=57 sessions)

Across the 57 groups for which there are data, the most significant change was recorded in a group that increased their average scores from 66.93 to 100 (i.e., a 33.07-point increase in scores). This group was fairly small, comprised of 7 participants who were PCA/CNAs at 83% with 16% failing to answer. The least significant change came from a group where attendees scored, on average, 93 on the pre-course quiz and 87 on the post-course quiz (i.e., a 6-point decrease in scores). This group was comprised of 29 persons, representing family members, medical professionals, RNs, Counselors, and others. Another group comprising of all medical professionals also saw a 6-point decrease. The negative change in knowledge scores is considered anomalous and was limited to these two groups; all other sessions reported a positive change in scores between the pre-course and post-course quizzes (from 0.9 to 33-point increase in scores).

As mentioned previously, neither the group’s average knowledge score nor the change between the group’s pre- and post-test was systematically or statistically associated with the size of the group, facilitator type, location of the session, or characteristics/profession of the attendees.

During the final session of the course, each attendee was asked to name the “main takeaway” they gained from attending the Dementia Dialogues training. Although many sessions did not record this information from attendees (i.e., 50 out of the 67 sessions), the responses received from 17 sessions provide an illustration of the most valuable parts of the Dementia Dialogues curriculum, from the perspective to the attendees. The comments were categorized into three broad themes: *Have Patience, Improve Communication, and Seek More Education*. Table 1 provides examples of the comments offered by attendees under each of these three themes, indicating the most valuable and lasting information that participants gained from the course.

Table 1. In your opinion, what was the “main takeaway” of the Dementia Dialogues course?

<i>Have Patience</i>	<ul style="list-style-type: none"> • <i>Treat patients with respect and be patient</i> • <i>Take one step at a time</i> • <i>Understanding what it’s like for patients</i>
<i>Improve Communication</i>	<ul style="list-style-type: none"> • <i>How to respond when the patient becomes aggressive</i> • <i>Recognizing and using nonverbal cues</i> • <i>Validation is very important</i>
<i>Need More Education</i>	<ul style="list-style-type: none"> • <i>Techniques to help in a long-term care environment</i> • <i>New products available to accommodate dementia</i> • <i>Caregiver education is key- both facility and family caregiver</i>

Outcomes – Attendee Satisfaction

In addition to the knowledge assessment, each attendee also answered a 7-item survey about their satisfaction of the Dementia Dialogues course during the final class period. The following data are based on the data reported from 59 sessions (8 sessions did not record this information). As shown in Figure 4, attendees had overall favorable impressions of the Dementia Dialogues course, scoring an average of about 86% on the individual items used to assess their satisfaction with the course, such as whether they would recommend the course to others, whether the course met the stated objectives, and whether the speaker was enthusiastic and knowledgeable, and whether the content was clear. These evaluation scores are akin to a solid “B” in a traditional grading sense, which suggests that the overall satisfaction was fairly high, yet there is still room for improvement.

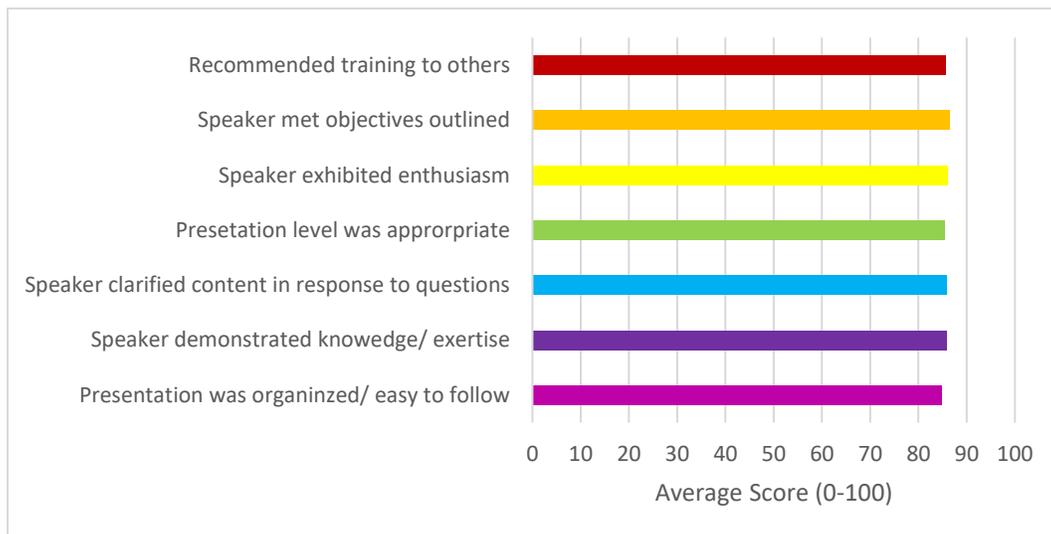


Figure 5. Average Satisfaction with Dementia Dialogues Course (n=59 sessions)

Our evaluation found that, across the 67 sessions, there was no correlation between average satisfaction scores and average knowledge-change scores. This suggests that participant

learning outcomes were not dependent on their perceived satisfaction with the course, and vice versa.

Attendees from 41 of the 67 sessions were asked whether they had any recommendations for improvement. These responses are summarized in Table 2. Individual suggestions were categorized into three thematic topics: *Alternative Techniques*, *Family Involvements*, and *Caregiver Involvement*. These recommendations provide a blueprint for future revisions of Dementia Dialogues curriculum, or for new course development to support persons interested in learning more about Alzheimer’s Disease and related dementias.

Table 2. Do you have recommendations for how to improve the Dementia Dialogues course?

<p><i>Alternative Techniques</i></p>	<ul style="list-style-type: none"> • <i>Spend more time on behavior tracking</i> • <i>Hands on practice, and more real-life examples</i> • <i>The use of validation therapy</i>
<p><i>Family Involvement</i></p>	<ul style="list-style-type: none"> • <i>When is it time to involve the family if they are unaware?</i> • <i>Communication techniques when working with families</i> • <i>How to take care of important legal matters, do you need a power of attorney or not? What assistance is available and where to go to get that help</i>
<p><i>Caregiver Involvement</i></p>	<ul style="list-style-type: none"> • <i>Caregiver health and wellbeing</i> • <i>Caregiver emotional support</i> • <i>How caregivers handle stress and frustration</i> • <i>Ways to handle/ overcome guilt as a caregiver</i>

Discussion

We explored the Dementia Dialogues program and how it has offered many caregivers throughout Utah the opportunity to learn more about how to take care of dementia patients. While this program was initially developed in South Carolina, it has impacted Utah and has

helped to make changes to the way dementia patients receive care. According to our review of the program, it has been found effective and is useful to the participants within Utah. Dementia Dialogues has achieved its outcome of educating caregivers about Alzheimer's Disease and related dementias, how to care for dementia patients, and also how to take care of themselves while providing care to someone with dementia. The increase in knowledge is evident when comparing the test scores from participants pre- and post-course, which showed an increase in almost every session.

In the literature reviewed, caregivers did not feel like they had the tools to help patients who have dementia (Heger et al., 2019). The Dementia Dialogues program has educated caregivers and family members and has focused on how to make them aware of the disease and the associated symptoms. The program focused on the relationship with caregivers and dementia patients to show that the use of public awareness and education can instruct individuals to help provide the best care. Participants stated that they learned more about the disease itself as well as how to help patients who have it

The Dementia Dialogues program was offered throughout the state of Utah, from Saint George to Weber County. By allowing family members and medical professionals alike to participate in the sessions, the Dementia Dialogues program in Utah reached both the informal and the formal workforce. Overall, these results provide evidence that the Dementia Dialogues program has been a useful mechanism to achieve the Utah state plan's goals to increase awareness and knowledge of Dementia. The increase in knowledge throughout the sessions on the pre- and post-tests shows that the goals and the mechanisms set in place have been successful in educating the informal and formal workforce. Goals 1-3 in the Utah state plan aimed to educate the caregivers that were taking care of dementia patients through public awareness.

These have been met and achieved indicating the succession of the Dementia Dialogues program as a whole.

Suggestions for Improvement

While the Dementia Dialogues course was enjoyed by most participants, and the teaching effectiveness was typically rated very high, there is room for some improvement, based on our review of the data provided by participants of the program. For example, participants suggested a couple of specific changes, such as “offering the training to caregivers through the senior centers”, “I wish it was more specific to working environment”, “depending on the presenter there seemed to be a lack of knowledge on the subject”. By addressing these comments and potentially enhancing the existing curriculum, the program has the potential to even better meet the specific needs of caregivers to persons with dementia.

Another room for improvement is regarding the scheduling of Dementia Dialogue courses. The sessions are held fairly infrequently, and do not appear to be broadly advertised in their respective areas. When a new session is held, it should be shared with all the assisted living and care centers in the surrounding areas. Family caregivers, perhaps through AAA caregiver support programs, should also be invited to participate. By allowing this to be advertised, the Dementia Dialogue’s reach in increasing public awareness and education about dementia will increase, allowing this program to meet the goals of the Utah state plan even better. It is possible that offering the sessions regularly on specific dates each month would allow participants to attend more often and share the information with others. Providing a centralized calendar and a way for interested participants to be able to sign up on the Utah Health Department website would allow sessions to reach more people. This type of active outreach may also reveal where a program is most needed, if a number of interested persons in a similar geographic area request a program.

Finally, the data collected from each Dementia Dialogues course needs to be tracked better in order to better evaluate the program as a whole. Currently, participant characteristics and evaluation data are aggregated by session, rather than recorded for individual participants. By recording the data per individual rather than per session, it would allow for greater analytic possibility, such as whether specific professions benefited most from the program, or whether informal (family) or formal caregivers gained more from the program. Furthermore, recoding more characteristics of individual participants, such as age and other demographics, would allow for an exploration of whether program outcomes differed across different demographic subgroups. This more detailed data recording would provide an even more comprehensive evaluation of the Dementia Dialogues program, and perhaps suggest specific groups to target for further education and training. These data would also provide more detail, which could be used to present to the Utah State Legislature for continued funding of Dementia Dialogues program after the 2018-2022 plan is over.

Implications & Possible Applications of Results

Due to the recent change in Utah regarding the Certified Nursing Assistant (CNA) assisted living rule change, Dementia Dialogues has the potential to spread to even more individuals. Utah has passed a rule change that allows Assisted Living Level II facilities to no longer require their employees to have their CNAs. With the new rule passed there is only the requirement for one licensed CNA to be on staff at a time. This plan was initiated in the hopes of lessening the labor shortages in the facilities caused by the lack of available CNA's. By dropping the CNA requirement, the patients are no longer going to be receiving the same level of care as they would if the care was required to come from state trained individuals.

Previously in order to obtain your CNA the individual had to complete a nursing assistant training program and pass the competency evaluation that came from the state (NATCEP). Then,

the individual would be placed on the Utah nursing assistant registry. CNAs were licensed to work under the direction of a licensed nurse and to help with patients' daily activities and care. With the rule change no longer requiring CNA's in these facilities it is not guaranteed that these individuals are knowledgeable about the patients' conditions and how to take care of them efficiently. While untrained employees are required to receive training from the facility in which they are hired, it is limited to that specific facility and cannot be transferred elsewhere.

In spite of these limitations, Dementia Dialogues has the potential to close these gaps in knowledge. As suggested above, requiring, or providing the program to all that work in the assisted living facilities would allow for these individuals to receive the education to better understand dementia patients and how to assist them best. The Dementia Dialogues program should be mandatory for all employees that are working with dementia patients to ensure the patients are obtaining the best possible care in their diminished states of mind. The current employee requirement only entails of 16 hours of documented one-on-one training with another employee. This rule should be increased to require time for the program of Dementia Dialogues to be incorporated for all new employees.

Conclusion

Dementia Dialogues highlighted the relationship of dementia with caregivers and family members. There were 1198 individuals who participated in the program from August 2016 to September 2019. After analyzing the data provided, it was found that the Dementia Dialogues program has been effective in Utah. Therefore, the program should be implemented throughout the state and offered to more individuals working in close relation with dementia patients. Individuals are able to participate in this program and leave more knowledgeable about dementia and the symptoms, how to assist patients with the disease, and how-to manage caregiver stresses in relation to caring for dementia patients.

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Appendix: Evaluation of Dementia Dialogues presented for research.

Evaluating "Dementia Dialogues" Program, Utah, 2016-2019

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I. Introduction

A part of Utah's State Plan includes the implementation of the "Dementia Dialogues" program which was introduced within the 2012-2017 Utah State Plan. Dementia Dialogues is a training that certifies health care professionals and family caretakers on the care for persons who have signs and symptoms associated with Alzheimer's Disease or related dementias. Currently Utah has over 50 active "Dementia Dialogue" trainers and has trained over 10,000 health professionals and caretakers through the "Dementia Dialogue" program.

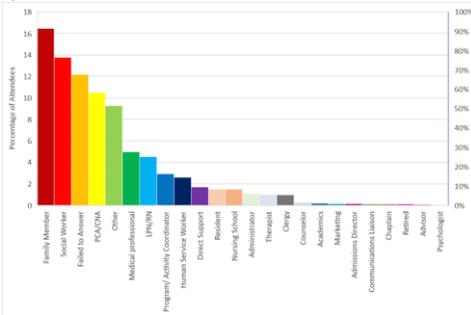
The purpose of Dementia Dialogues is to educate individuals who care for persons who exhibit signs and symptoms associated with Alzheimer's Disease and related dementias. The Department of Health in Utah aims to develop dementia-related competencies of primary care providers and non-health workforces across the continuum of care through Dementia Dialogues. Participants who have completed the training have reported "higher rates of understanding Alzheimer's disease and dementia, recognition of signs and symptoms, and effective management of challenging behaviors. The trainings have likewise show to lessen the stress and burden that accompanies the caregiving role by simply providing educational practices to provide care.

II. Methods

Participants of each of the sessions were gathered voluntarily. The classes were offered everywhere throughout Utah to anyone that wanted to gain more information about Alzheimer's Disease and related dementias. The first session was held on August 9, 2016 and the most recent class was held September 18, 2019 with a total of 67 classes held since the beginning of the program start in Utah.

At the start of a Dementia Dialogues course, each attendee completed a short 5-item quiz, assessing their knowledge about dementia. The quiz is scored on a scale from 0-100. This quiz is then repeated at the end of the Dementia Dialogues course to assess how much their knowledge about dementia improved as a result of the Dementia Dialogues curriculum.

Figure 1 – Percentage of total Dementia Dialogue attendees (n=1198), by self-reported profession



III. Results

At least 1,198 persons have attended one of these 67 Dementia Dialogue sessions during this time period; 4 of the sessions failed to record how many people participated. On average, a Dementia Dialogues class had about 18 attendees, with the smallest class being only 3 people and the largest class having over 100 attendees.

As shown in Figure 4, the average pre-test score was 89.94%. The average post-test score was 97%. This represents a 7.06 percentage point change in scores, meaning that the average attendee scored significantly higher (7.6 points higher) on the post-test score compared to their pre-test knowledge score.

Figure 4 - Average Dementia Knowledge Scores, measured before and after the Dementia Dialogues course (n=57 sessions)

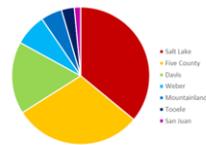
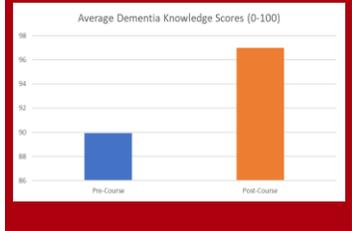


Figure 2 – Area Agency on Aging (AAA) where Dementia Dialogues class was held, Aug 2016-Sept 2019

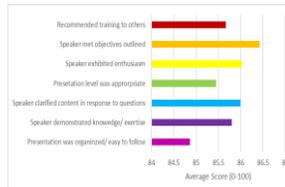


Figure 3 -Average Satisfaction with Dementia Dialogues Course (n=59 sessions)

IV. Conclusions

This study provided evidence that individuals are able to participate in this program and leave more knowledgeable about dementia and the symptoms, how to assist patients with the disease, and how to manage caregiver stresses in relation to caring for dementia patients. Continued exploration of the Dementia Dialogues program and positive effects it has for caregivers and patients will add to the broad range of literature on this subject and may lead to state, or nationwide interventions that spread awareness and knowledge of dementia throughout.



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