Bridging the Gap Between Healthcare Professionals, Families, and Alzheimer’s disease

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Abstract

The focus of this mixed methods experience was to explore the gap between healthcare professionals, families, and residents with Alzheimer's disease (AD) in order to establish meaningful connections and provide quality care. Due to the inadequate supply of healthcare professionals adequately trained to treat individuals with AD (Warshaw & Bragg, 2014) as well as nursing staff expressing difficulties when communicating with individuals with AD (Yang, 2017), it is a valuable area to address the lack of knowledge for healthcare professionals. This experience was held at Cumberland Trace memory care unit, *Cherished Memories*. Data was collected through observation hours on Cherished Memories and surveys completed by staff members and family. Surveys were developed, one for staff members and one for residents' family members, in order to address their concerns. Staff survey results indicated staff members had concerns regarding effective communication strategies, stages of AD, and caregiver burnout. Family member surveys indicated they had a basic knowledge of AD but had a desire to learn more about the disease itself as well as additional components including communication strategies, therapy options, caregiver resources, and stages of AD. These results led to an educational in-service for staff members on Cherished Memories and a family care packet for residents' family members. Sustainability was created through discussion with Cherished Memories unit manager. Findings are relevant for those who are developing educational programs for staff members working directly with elderly adults and family members who are impacted by AD.

Keywords: Alzheimer's disease, communication, healthcare, memory care

Background

As Baby Boomers enter adulthood, risks for medical illness and new diagnoses increase. The most common of these diagnoses is Alzheimer's disease (AD). Alzheimer's disease affects individuals over the age of 65 and accounts for sixty to eighty percent of dementia cases (Alzheimer's Association, 2018). Throughout this paper, Alzheimer's disease will be referred to as AD. According to Alzheimer's Association (2018), AD is defined as a type of dementia, which causes problems with memory, thinking, and behavior. There are two primary changes in the brain indicative of Alzheimer's disease. These abnormal structures are identified as tangles and plaques (Alzheimer's Association, 2018). The number of cases of AD is growing exponentially and projected to triple by 2050 (Warshaw & Bragg, 2014). Therefore, it is important for both healthcare professionals and family members to understand the disease, as well as mechanisms to effectively stay connected with individuals impacted. There is currently an inadequate supply of specialist for geriatrics or dementia, especially physicians and nurses, which indicates an even greater push for healthcare professionals to be educated on Alzheimer's disease both on site and in educational programs (Warshaw & Bragg, 2014). It has been determined by previous research that healthcare professionals experience caregiver burden when caring for individuals with AD and healthcare professionals, often nurses and nursing aides, express difficulty effectively communicating with these individuals (Yang, 2017). This creates a valuable area of study to address the lack of knowledge for healthcare professionals, as well as family and loved ones, who directly interact with these individuals.

This experience focused on providing educational training to nurses, nursing aides, and activity staff within a Memory Care Clinic as well as create a family care informative packet for potential residents families, in order to enhance quality of care, knowledge of AD, and ability to stay connected with these residents. The literature review was geared toward providing communication strategies, behaviors, and environmental modifications for healthcare professionals to utilize with individuals with AD. This disease can be a very complex condition and appears in various forms and stages. According to Alzheimer's Association (2011), healthcare professionals and families of individuals with AD have been pinpointed for lack of education. Contributing factors include: "lack of public awareness, insufficient research funding, difficulties with diagnosis, poor dementia care, inadequate treatment, unprepared caregivers, ill-equipped communities, and mounting costs" (Alzheimer's Association, 2011, p. 3). Lack of public awareness leads to negative stigmas, including the commonly used phrase, "it's a part of aging." Individuals avoid seeking medical help when experiencing these symptoms because of this hazardous mindset (Alzheimer's, 2011). As noted by an individual from Roseville, CA in the Alzheimer's Association (2011), "if we are going to get through the next 20 or 30 years – watching baby boomers with Alzheimer's increasingly burden their children with disease they cannot control – we absolutely have to invest in the research to find good treatment options" (p. 8). Insufficient research leads to difficulties diagnosing individuals with Alzheimer's disease. When individuals seek out medical attention and answers to symptoms, physicians are often challenged through serious communication barriers, which inhibits the ability to correctly diagnose (Alzheimer's Association, 2011). Individuals with AD feel unable to effectively communicate with healthcare professionals, evident by receiving insensitive or negative feeling at times (Alzheimer's Association, 2011). The majority of this miscommunication stems from lack of knowledge and specialized training. Research has proven that many facilities that these individuals end up residing are not adequately trained to handle behaviors including anxiety, aggression, or repetitive actions (Alzheimer's Association, 2011) therefore leading to a greater reason to educate families on proper care. These topics will be further investigated to examine the impact of lack of education on quality of care provided.

Literature Review

This experience focused on creating a holistic view of the resident through both the family members and healthcare professionals. This experience was conducted at Cumberland Trace, a skilled nursing facility owned by CarDon, comprised of rehab to home, assisted living, memory care, and long term care residents. This facility utilizes the Allen's Cognitive Model to determine the stage of the progression for an individual with AD. This model was developed by Claudia Allen, MA, OTR, FAOTA in the 1960's, and was mainly utilized within the mental health setting. The model has since evolved into several other practice settings, including skilled nursing facilities (Jackson, n.d). This tool is used to identify cognitive functions inhibited and still preserved in order to provide the best care possible. Allen's Cognitive Model focuses on three components including process skills, context, and analysis of activity demand (Cole & Tufano, 2008). In order to allow the individual to thrive, the clinician analyzed several components, including: task demand, task environment, extrinsic and intrinsic factors, and brain conservation. This model takes a slightly different approach to dementia, expanding on the skills an individual can still functionally perform independently and offers caregivers a way to improve quality of life and enhance quality of care (Cole & Tufano, 2008). Person-Environment-Occupation Model of Occupational Performance model, otherwise known as the PEOP, was utilized during this experience in order to further develop a holistic approach to care. This model depicts a diagram of three elements (person, environment, occupation), all of which overlap in the middle, to depict the congruency between each element (Law, Cooper, Strong, Stewart, Rigby, & Letts, 1996). The congruency in the center of the model dictates how well these three elements work together in formulating occupational performance (Law et al., 1996). For this experience, the model helps identify the gap and lack of education between the healthcare professionals, the resident, and the family members.

Understanding Alzheimer's

Alzheimer's Disease is a progressive disease, meaning it gradually worsens over time. There is currently no cure for this disease, but research still continues (Alzheimer's Association, 2018). According to Alzheimer's Association (2018), there are three stages: early, middle, and late. Characteristics that make up the early-stage include "word-finding issues, losing or misplacing valuable objects, and increased trouble with planning" (p. 5). It is important to note, individuals in the early stage may still function independently. Factors that make up the middle-stage include: "forgetfulness of personal events, unable to recall address, phone number, high school, confusion about orientation, changes in sleep pattern or bladder control, increased wandering, or behavioral/personality changes" (p. 8). During this stage, many individuals become frustrated or angry due to having difficulty expressing thoughts or performing daily routines. During the late-stage, one can identify characteristics such as need "round-the-clock assistance with daily activities and personal care, lose awareness of recent experiences, changes in physical abilities, difficulty communicating, and conversations can be extremely limited" (p. 10). In order to have an effective conversation with these individuals, it is essential to understand the nature of the disease. Having a background in the nature of the disease and the characteristics of each stage are necessary to provide thorough and effective care for these individuals.

Staff Education and Concerns

Healthcare professionals are primary hands for many individuals with Alzheimer's disease and provide constant care for those within nursing facilities. It is important to understand frustrations, desires, and concerns about knowledge regarding the care of patients. Allen's Cognitive Model is intended to offer a simplistic way to individualistically reach out. In a study completed by Ahmad (2014), it was determined that nurse participants lack knowledge in dementia care and are unaware of how to communicate, both verbal and nonverbal, and limited to no resources on methods for improving communication. Authors of "Improving Staff Attitudes to Patients with Dementia" (n.d) concluded that the following words were commonly discussed amongst nurses who work with memory-impaired individuals; upsetting, difficult, and time consuming. Wang, Hsieh, & Wang (2013) determined that nurses experienced difficulty communicating with these individuals. Nurses reported there was different dialogue between nurse and patient, suggesting the nurse did not understand patient needs. The lack of language consensus means no protocol has been developed to distinguish behavior or persuade an individual to participate in an activity. This article also noted nurses reported difficulty assessing emotions and understanding needs. The authors concluded the lack of "patient centered care" or providing holistic care appears to be a major cause of these challenges (Wang, Hsieh, & Wang, 2013). Kolanowski, Van Haitsma, Penrod, & Yevchak (2015) defined person-centered care as "emphasizing and recognizing the individual person's self-determination, choices, worth, and unique set of values, views, histories, and interests" (p 1). To perform person-centered care, it is important to see the individual behind the disease (Ericson-Lidman, Larsson, & Norberg, 2013) rather than treat them as an individual with Alzheimer's disease. Research completed by Robison & Pillemer (2007) reported coworkers on Special Care Units demonstrate a better relationship with their coworkers. This article also indicated staff members working directly with patients with dementia require social support due to increased caregiver burnout. "Caregiver burnout" is defined by Web MD (2018) as "a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude from positive and caring to negative and unconcerned" (p. 1). Burnout is a hot topic for nurses and could possibly contribute to the lack of effective communication skills and quality of care. Rating scales such as, The Maslach Burnout Inventory was created to address burnout. This scale was initially directed towards human services and educational institutions in order to address emotional exhaustion, depersonalization, and reduced personal accomplishment (Maslach, Jackson, & Leiter, 1996). This scale requires individuals to provide feedback based on a rating scale of how often they have these feelings to determine the level of burnout. When caring for individuals with AD it is crucial to demonstrate effective care communication. This process begins with fully understanding the needs, desires, and concerns of all healthcare professionals, who interact with these individuals on a daily basis.

Communication

After understanding the process and functioning cognitive level of the individual, becoming familiar with communication strategies is beneficial to remove burden from health professionals, as well as loved ones or caregivers (Alzheimer's Association, 2011). In order to effectively communicate with individuals with AD, one must have a basic knowledge of how each stage affects ability to process phrases and reciprocate conversation through word finding (Alzheimer's Association, 2018). Research has acknowledged person-centered care as a popular type of care that many facilities are striving to accomplish (Lanzi et al., 2017). Several research articles agreed that to begin communicating with these individuals, one must allow extra time for them to process the information or direction given and respond appropriately (Lanzi, Burshnic,

& Bourgeois, 2017; Dementia 4, 2016). According to Ahmad (2014), it is important to continue communicating with these individuals utilizing humanistic characteristics in order to be personable about their well being. Humanistic characteristics include being holistic, providing choice, being positive, offering acceptance, empathy, caring for the individual, and understand coping. When communicating with these individuals, utilize short sentences, familiar vocabulary, use a warm tone, and smile during conversation (Dementia, 2016; Family Caregiver Alliance, n.d). When speaking to someone in the mid-later stages of dementia, it is best to avoid questions, rather use statements (Dementia, 2016). Hopper (2011) agreed that using simple, active declarative sentences work best. For example, stating, “the physician is finished,” rather than adding adjectives and other pronouns. Hopper (2011) recognized that asking yes/no questions facilitated a better understanding than open-ended questions and being able to repeat and rephrase sentences was helpful when communicating with these individuals. According to Lanzi et al (2017) residents should be encouraged to write and draw to communicate needs in order to decrease burden of receptive language abilities and frustration. Hopper (2001) determined the success of caregiver-patient interactions depend greatly on the caregivers’ flexibility with communication skills. These findings indicated families and healthcare professionals must understand how to effectively communicate during all stages of Alzheimer’s disease.

Behaviors

The notion that individuals with AD express behaviors out of anger is a common misconception. Behaviors can be dealt with appropriately if professionals and loved ones understand how to distinguish or handle them. When communication becomes difficult and nearly impossible for many of these individuals, alternate ways must be found to express needs, concerns, and feelings, which may be represented in the form of various behaviors (Vargo, 2017). According to Dewing (2010) these behaviors can indicate an unmet need such as pain, toilet, water, food, or environment. These actions can be a response to an action done by other residents, healthcare professionals, or family members (Dewing, 2010). Behaviors such as repetitive question asking can indicate that the individual is confused or fears being abandoned by caregivers. This train of thought can be re-directed by healthcare professionals by responding to questions regarding the topic in order to distract them (Hopper, 2001). Specific movements, environments, and needs can trigger disruptive vocalizations; therefore, it is best to attempt to understand what is causing these utterances (Hopper, 2011). Healthcare professionals have a tendency to look for answers utilizing pharmacological interventions rather than seeking out alternative solutions (Vargo, 2017). Nurses may feel the agitated behavior is a direct correlation with dementia, but it can also be combined with the person's pre-dementia, current personality, coping strategies, severity of the cognitive impairment, and environmental factors (Dewing, 2010). As healthcare professionals and family members, it is impossible to change an individual's behavior. Therefore, it is a must for the professional or family to be self-aware and cognizant of behavior or modify the environment to distinguish the behavior (Family Caregiver Alliance, n.d; Ahmad, 2014). Many behaviors may be able to be distinguished or solved by environmental modifications.

Environment

An environment either allows one to thrive or leads to challenges. To facilitate successful interactions amongst residents and staff, the environment must be set up in a comforting fashion. For individuals with AD, the environment is crucial for success and ability to fully thrive. The environment can have several effects on an individual, but promoting safety, leading to greater independence, and "home-like" environments are important aspects to contribute to quality of life (Alzheimer's Association, 2009; Koren, 2010). In order to obtain safety, independence and the "home-like" atmosphere, the staff and architecture layout must be a thoroughly analyzed and planned (Koren, 2010). The physical environment features ideal for these individuals include "more privacy, silent electronic and hidden exits, and a variety of common spaces" (Koren, 2010, pg. 709) as these have been proven to correlate with decreased aggression and depression and enhance sense of freedom (Zeisel, Silverstain, Hyde, Levkoff, Laton, Holmes, 2003). Having a quiet pace of life, plenty of light, and obvious bold signs of direction and labeled common locations, such as kitchen or bathroom, are additional aspects that contribute to a safe environment (Nursing Times, 2016). Special Care Units (SCU's), are known for specialized activity programs, special care training, restrictions to those necessary, and a thriving environment (Robison & Pillemer, 2007). With these individuals, familiarity is key to understanding needs, wants, and desires based on behaviors; therefore, striving to keep the same nurses, and care team is a significant distinction for this unit (Robison & Pillemer, 2007).

Summary of Literature Review

The purpose of this experience was to explore the gap between healthcare professionals, families, and residents with Alzheimer's disease in order to establish meaningful connection and provide quality care. To accomplish that purpose, it was important to first understand the staff educational needs as well as address family members concerns through intentionally distributing surveys. After gaining a clear understanding of nurses and family member concerns, nurses were provided with educational tools and information regarding communication strategies, caregiver burnout tips, and other needs they reported were necessary while potential resident's family members were provided with a packet containing information about *Cherished Memories.* This provided both the staff and family members a better understanding of how to properly and effectively care for individuals with AD.

Methodology - Screening and Evaluation

This experience focused on addressing the lack of knowledge for both families and healthcare professionals about AD in order to decrease lack of awareness and ensure a holistic approach to care. This study utilized a mixed methods approach through a combination of both observation and surveys in order to determine the needs of the facility and the perspective of individuals, specifically family members and nursing/activity staff. First, the student set aside several observation hours of *Cherished Memories* in order to better understand the unit itself, the environment, and humanistic interactions. Next, the student surveyed the nursing and activity staff on the memory care unit in order to determine the needs and concerns of nursing staff when caring for individuals with AD, followed by analyzation of the feedback given while the second portion of the experience began. To address the second portion, the student surveyed current residents' family members in order to gain a clear understanding of their personal concerns. Nurse surveys provided feedback for personal concerns therefore allowing the student to develop educational in-services to alleviate many of those concerns. Following the feedback from the family members, topics were discussed in order to begin creating a family care packet. All portions of the methods were conducted at Cumberland Trace, a skilled nursing facility that hosts the *Cherished Memories* memory care unit.

Initiating the Experience

The speech therapist, unit manager, and director of Lifespan therapy at *Cherished Memories* initiated this experience after obtaining several observations of caregivers and families demonstrating a lack of knowledge about dementia and the skills it takes to care for these individuals. When informally interviewing and discussing this experience with both the speech therapist and the unit manager, they offered insight about their own experiences while at Cumberland Trace. They expressed the need for education about dementia and the deficits that are attached with the disease as well as communication strategies, to all staff members, specifically nursing and activities staff on the memory care unit because they directly care for these individuals daily. Both individuals reported observing nurses demonstrating frustration and agitation with their patients when completing self-care tasks, all of which most likely stemmed from poor communication skills (J. Saldana & J. Hollis, personal communication, Jan 11, 2018). As Jonathan, the memory care unit manager, said during an initial interview, "I observed just the other day one of my nurses becoming frustrated when trying to get a resident to sit down on the toilet and I had to go over and provide her a teaching moment by cueing the resident of 1, 2, 3, sit down" (J. Hollis, personal communication, Jan 11, 2018). These observations were consistent with findings in the literature. Poor communication skills with individuals with AD has led to frustration and agitation for nursing staff which can further result in decreased quality of care (Yang, 2017). The literature has also indicated that nurses in skilled nursing facilities experience caregiver burnout more often due to the level of care they provide (Yang, 2017) therefore caregiver burnout was intentionally addressed in the surveys. Based upon the students' interviews and direct observations, intentional data collection from the staff members was necessary.

Participants

Nursing staff, activity staff, and residents' family members were directly involved in this experience. Purposive sampling was used to recruit participants to complete the survey. Inclusion criteria for nursing and activity staff included being a member of the staff on

Cherished Memories. When choosing resident's loved ones to complete the survey, the student allotted one from each family due to attempting to attract a variety of feedback. The unit manager served as a guide to delegate which family members should receive the survey.

Evaluation Tools

After this informal assessment, paper surveys were distributed to the nursing and activity staff on the memory care unit to further investigate the concern. The survey consisted of 13 questions, utilizing a rating scale to verify comfort level of caring for individuals with dementia as well as level of burnout with his/her job. Questions were loosely adapted by two existing surveys, Maslach Burnout Inventory (Maslach, Jackson, & Leiter, 1996) and Sense of Competence in Dementia Care Staff (Schepers, Orrell, Shanahan, Spector, 2012). The first portion of the survey was geared towards the level of burnout staff members were currently experiencing whereas the second part of the survey was geared toward addressing staff members' comfort level and confidence when caring for these individuals. The Maslach Burnout Inventory is a rating scale for individuals to report how often he/she experiences various feelings of exhaustion, depersonalization, and personal accomplishment (Maslach et al., 1996). The Sense of Competence in Dementia Care Staff questionnaire targets the healthcare professional for how confident, on a scale of not at all to very much, they feel when communicating, caring, engaging, dealing with behaviors, etc (Schepers, Orrell, Shanahan, Spector, 2012). This questionnaire allowed staff members to anonymously be open about their comfort level when caring for individuals with AD, which in turn lead to an understanding of where the gap is when caring for individuals with dementia. See Appendix B for a select few sample questions from each section of the survey.

To address the second portion of the purpose of this experience, a separate survey was developed for resident's family members. This survey consisted of nine questions utilizing yes/no format and open-ended questions in order to gain insight of family members' knowledge of dementia/Alzheimer's as well as their knowledge of what this facility and *Cherished Memories* has to offer their loved one. These questions were formed based upon what the site mentor and unit manager wanted to know about their residents' family members knowledge of AD and their perception of their own skills regarding training and communication. Open-ended questions were chosen in order to allow family members to express their own thoughts and experiences when caring for an individual with dementia as well as provide suggestions for topics that they would have been interested to learn more about prior to enrolling their loved one in the *Cherished Memories* program.

The Goal Attainment Scale (GAS) was utilized to measure effectiveness of this experience; specifically the family care packet, nursing in-services completed, and number of activity boxes completed. The GAS is an effective form of measuring outcomes for therapeutic intervention because it allows therapist to adjust for accountability and document therapeutic change (Ottenbacher & Cusick, 1990). Therapeutic change occurs specifically through Allen's Cognitive Model for this experience by providing interventions focused on education for nurses and family members. This scale still allows measurability for success and adaptations to be made if necessary (Ottenbacher & Cusick, 1990). Hartman, Borrie, Davison, & Stolee (1997) determined that the GAS is an effective tool to use with the mental health population, specifically a special care unit. In the study completed by Hartman et al. (1997), the scale was utilized to set individualized functional client goals and keep track of the individuals progress therefore giving reason to utilize this tool during this experience to keep the students' personal goals clearly stated and allow for progress to be monitored. This outcome tool was chosen in order to effectively track the progress of the family care packet, activity boxes, and nursing in-services. This outcome tool provided clear feedback about the success of each goal. See Appendix A for GAS for this experience.

Procedure

The evaluation process consisted of observing the memory care unit and distributing surveys to the nursing and activity staff, and residents loved ones. The process began with daily observations of *Cherished Memories* in order to understand the difference between the memory care unit and a typical unit in the facility including the environment, activities, mealtime, and the program layout. In regards to the environment, observations were focused on how the unit was laid out, especially residents' rooms, mealtime, security within the unit, common area, and activity room. Observations were focused toward the activity room in order to observe interactions between the activity staff member and the residents as well as determining if appropriate activities were given to residents. When observing residents' rooms and the other architectural layout of the unit, the student focused on things such as privacy, space, lighting, noise, assistance, and security.

Other observations were geared toward certain individuals, specifically nursing and activity staff members. These observations were key in developing educational trainings due to these individuals directly caring and interacting daily with individuals with AD. These individuals were pinpointed for observations due to research and previous interviewees stating nursing staff members have a difficult time communicating with individuals with AD. These observations also gave light to possible caregiver burnout experienced by staff members evident by conversation and facial expressions. Although the focus for this experience was to discuss the family care packet and nursing in-services, providing appropriate activities for the resident's based on dementia stage was one goal added to this experience therefore consuming a big portion of the remaining observation hours.

The second portion of the process began by distributing the surveys to the nursing staff. Due to the unit only having three registered nurses and two nurse aides, not including weekend staff, and one activity staff, nine surveys were provided in a concealed binder at the nurse station. Surveys were to be completed anonymously within seven days but due to limited responses, the deadline was extended another five days. A total of five surveys were returned to the binder prior to the deadline. Data analysis began for the nurse surveys while the resident family member's surveys began to be distributed. These surveys were distributed in a slightly different manner due to convenience. Surveys were either distributed via unit manager during care plan meetings or the student when interacting with family members on the unit. Ten surveys were distributed with intentions of receiving all ten surveys back within a couple weeks however only nine were returned. The feedback and information received better-equipped nurse in-services and family care packet. The staff member questionnaire allowed the student to identify where the gap is when caring for these individuals as well as identify the level of caregiver burnout being experienced by these nurses. The family members' surveys allowed for the family care packet to be family/resident focused and include information the family finds valuable to know prior to admitting their loved one into the memory care unit. This experience solely focused on specific individuals knowledge about Alzheimer's whereas this may be not apply to other settings.

Setting Comparison

This type of cognitive approach is comparable to a variety of settings but also can be contrasted to several other settings. For this specific setting, this experience was focused toward functional cognitive performance therefore impeding ability to independently complete everyday activities, both ADL's and IADLs otherwise known as Allen's Cognitive Model. Allen's Cognitive approach looks at the role of habits and routines, the effect of physical and social contexts, and the analysis of activity demand (Cole & Tufano, 2008). Mental health is an area of practice in which occupational therapists work to address an individual's mental capability to successfully complete everyday activities. According to Castaneda, Olson, & Radley (2013) mental health incorporates any and all of the following: adapting the environment, develop leisure activities, facilitate skills for independent living, and provide ADL training. Another setting that addresses cognition through the lens of the Allen Cognitive approach is acute rehabilitation through practitioners identifying individuals deficits and attempting to return the patient back to their baseline or as functional as possible in their daily life.

Setting Contrast

Many practice settings identify cognitive impairments and further investigate how they impacted the individual's ability to independently complete their daily tasks but each facility may do so in a different manner. Acute care is a setting that addresses cognition for safety purposes but does so through the use of Toglia rather than Allen. Toglia's approach looks at cognition through the lens of restoring cognitive dysfunction (Cole & Tufano, 2008). "Disability defined in the Toglia model is defined as unable to process and organize information, lack of previous knowledge, and unable to apply performance skills in varying situations (Cole & Tufano, 2008)." Practitioners in this facility may not specifically look for dementia but certainly look at cognition in order to determine if he/she is safe to return home alone or if they require supervision during specific ADLs/IADLs. Research determined that acute care focuses on mental health and cognitive factors in addition to other physical symptoms (AOTA, 2017). Cognition plays a key role when determining if individuals are capable of returning home but not always the prime focus for all settings.

Implementation Phase

Interpreting the Needs Assessment

Knowledge gained from observation hours spent in *Cherished Memories* indicated a need for nurse in-services regarding communication strategies, differentiating stages, and handling behaviors. Observations included viewing inappropriate activities or games being given to individuals. For example, an individual in the mid-stage of dementia was provided a puzzle to complete independently. An individual in the mid-stage of dementia does not have the cognitive function to be able to complete a puzzle independently; rather, they need assistance for beginning the puzzle and several cues. Observations that involved the staff include the following: staff approaching individuals with no facial expression, staff having no intention of telling the resident the plan for where he/she is being taken, and aggressive transfers with no verbal instruction. Several staff members struggled with effectively communicating with many patients, as indicated by rarely engaging in a conversation with an individual who presented in the late stage, repeating the same phrase rather than re-phrasing, and looking at another staff member for direction. Staff members often talked to these older adults as if they were children evident by, "Roger, buddy, can you sit down" or their tone of voice would change into the "baby talk" voice. Lastly, an observation noticed was staff did not understand how to handle behaviors. For example, when a patient continuously stood up, the nursing staff repeatedly told him to sit down but never redirected him to an alternate activity. Whenever residents became upset or sad, staff often did not always take the time to acknowledge their feelings. For example, several residents would have emotional breakdowns or demonstrate a variety of behaviors and instead of addressing the behavior, staff members found a way for the resident to soothe themselves such as sitting in front of a window. Several nurses did not properly address wandering. Rather than redirecting the individual to an activity, they would allow the individual to wander or sleep for hours. Staff members' expressions indicating annoyance or frustration included eye rolling, crossing arms, and allowed the resident to continuously ask the same question over and over. On several accounts, nurses indicated frustration through side conversations with other nurses or facial expression. For example, Figure 1 depicts, an observation viewed on several accounts. Observations allowed the student to visualize interactions but the surveys would provide personal feedback from the staff.

Surveys demonstrated over half of nursing and activity staff experience some emotional drainage throughout some portion of their workday but seventy-five percent denied exhibiting these feelings when caring for residents. These surveys concluded that the nursing staff feels confident and comfortable performing their work but a small percentage indicated challenges keeping a positive behavior and engaging individuals in activities.

Although nurse surveys did not capture a large picture of where the gap was when caring for individuals with AD, the student's observations helped clarify and close in the gap. Several observations did not correlate with the results of the surveys. For example, nurses reported they felt they can effectively communicate with individuals with AD but several of the student's observations indicated otherwise. Another observation that contradicted what the surveys specifically asked was "how effectively do you feel about handling a behavior in a person with dementia." Many of the nurses indicated they can handle behaviors pretty well while the observations indicated it may lean a little more to not-so-well. The investigator found a similarity between both observation and surveys, which was the decreased positivity with several nurses when caring for residents. Nurses explicitly stated this in the survey but facial expression and side conversations were noted during observation hours to indicate decreased positivity. A second similarity that was found between the surveys and the observations was that staff members felt emotionally drained frequently throughout their workday.

Feedback given from residents' family members provided valid information pertaining to their own knowledge of AD. As the results depict in Appendix D and E, family members found it crucial to focus on what the unit and the facility has to offer regarding memory care. Due to each category showing a need, the student decided to touch upon most topics. From this information, the family care packet focused on communication strategies, resources, the process of Alzheimer's and stages, possibilities for therapy, as well as how appropriate activities will be included in the memory care unit. This information indicated that the family care packet should have a family and resident focus.

In-Service

Information gathered from the needs assessment indicated a need for nurse in-services and a family informational care packet. The student determined that the nurse in-services will be initially directed towards the staff members on *Cherished Memories* and will discuss the following topics: Alzheimer's Disease statistics, the importance to healthcare professionals, the stages of dementia and deficits, effective communication strategies, common behaviors, and tips/resources about caregiver burnout. This in-service utilized a PowerPoint in order to easily disseminate the information gathered as well as videos and scenarios to assist in the ease of learning various approaches to caring for individuals with AD. Former research by Kolanowski et al. (2015) demonstrated that individuals, particularly nursing staff, retain and learn new information quicker and more efficiently when introduced through hands on or interactive learning. The in-service was held one time for the staff members on *Cherished Memories* due to the limited number of staff members. Following the in-service, each individual completed a short post-survey in order to determine the amount of knowledge gained from the in-service and to receive feedback based on the presentation itself and content. The in-service was held one other time for other nursing staff members available to further educate society and healthcare professionals. Staff education was a large component of this DCE experience but education in general for all society is even more important. Staff was directly educated on AD, effective communication strategies, behaviors, and burnout strategies through in-services. These in-services directly facilitated staff education in order to create better care for individuals with AD.

Family Care Packet

The feedback provided by residents' family members surveys provided a sneak peek of society's knowledge of AD. The following are topics that were discussed in the family care packet: understanding memory impairment, stages of Alzheimer's Disease, why memory care, environment, daily scheduled activities, staff qualifications, activities of daily living, mealtime, behaviors, therapy options, and caregiver resources. Attached to the packet is a Life Story Questionnaire created by CPI dementia care specialist (2016) to gather previous social history, routines, and interests about the resident in order to facilitate a more person centered care residency. This family care packet remained focused on the positive treatment received at Cumberland Trace and what the memory care unit entails. This packet continued to allow family members to understand the architectural design of the unit, structured routine provided, and additional treatment the unit and staff offer to residents. The family care packet directly facilitated education on Alzheimer's Disease to society but the packet also indirectly educated the staff. This packet will continue to facilitate staff and society education therefore holding staff members to higher standards of care. Family members will have greater knowledge, possibly generating further questions for the nursing staff. The staff members may utilize this packet as a reference and to answer these upcoming questions of potential residents' family members.

Outcomes

To address the outcomes of this experience, the Goal Attainment Scale (GAS) was reviewed in order to determine if goals were met. When reviewing the GAS, all goals were accomplished at the level of more than expected. Refer to Appendix G for table depicting score correlating with the final outcome results. Although the initial plan was to only educate the staff members of *Cherished Memories*, other nursing staff members of long term care were also provided with this information. The family care packet went above and beyond the original goals due to adding the additional social history questionnaire as well as additional components, as previously stated, within the packet.

In order to achieve each goal, modifications were made regarding timeline, content, & communication style. In regard to activity boxes, the timeline was shifted due to a variety of complications. Activity boxes consisted of materials and instructions that were appropriate for each dementia stage. For example, for the yellow stage (middle), one activity box includes a matching game with pictures demonstrating correct set up and specific instructions for the staff members to use in order to know exactly how to present the activity for the resident to understand. The boxes were initially intended for group use; however, the unit manager indicated the benefits of addressing individual activities instead. With this shift came several other responsibilities including researching the stages of dementia utilized by Cumberland Trace and better grasping the deficits and needs of all three stages (green, yellow, red). This shift affected the cost, time, and number of activities required to create the boxes. Due to the increase in activities, there was an increase in instructions, therefore an overall increase in time needed to properly write out the instructions. With the modifications to the boxes, extra time was allotted for development of an action plan for costs and time. To create an adequate number of activities for each color, continuous research was necessary to determine what type of activities would be appropriate. Several websites provided information regarding appropriate activities (Alzheimer’s Association, 2017; Vargo, 2017). Activities were also based from the speech therapist wants and desires from her own previous research.

Few modifications were made to the nurse in-service due to receiving positive feedback through post survey. Rather than only hosting the in-service for staff members on Cherished Members, the information was provided to the long-term care team members as well. Staff members were acknowledged for receiving additional training regarding dementia after completing the in-service. Although there were minimal post surveys completed, results indicated staff members were accepting and grateful for the information provided and also provided feedback indicating the information will be helpful in their career. Every staff member who attended reported learning something new during the in-service that he/she feels comfortable using in their career, feeling more comfortable with the three stages of dementia, can better communicate with individuals with dementia, and feel better about distinguishing behavior. Each individual also reported the scenarios being helpful.

The family care packet was utilized to address the concerns of the residents’ family members and to educate them about Cumberland Trace Memory Care. Several components went into this packet; therefore, modifications were required. Initially, the surveys were to be reviewed and completed via phone call but quickly changed due to site supervisor strongly feeling family members would not give honest feedback. The creation of the care packet was delayed due to a delay in the needs assessment survey. With this delay, the student decided to continue creating the packet but to add in family members information and suggestions after completing the rough draft. The timeline was continuously pushed back due to inconsistency and delay of feedback throughout the process. Due to the packet being reviewed by both the supervisor and unit manager, it took increased time but was necessary in order to implement the completed packet to the standards of both individuals.

Sustainability

The student continuously reviewed and brainstormed how to encourage the staff members of Cumberland Trace to continue utilizing the nursing in-service information, activity boxes, and family care packet following the completion of the experience. The student created a binder including the following items: research articles from the in-service, the Power Point from the in-service, and quick tips/hints for effective communication strategies for each stage that will be available to the staff members on *Cherished Memories.* Research has proven that individuals retain and learn more through scenarios and videos therefore the student provided the video links within the binder (Kolanowski, Van Haitsma, Penrod, Hill, & Yevchak, 2015). These specific videos addressed bathroom or shower scenarios, depression, or anger scenarios are here to be quick reference. The student discussed with the unit manager and supervisor about the possibility of utilizing the information from the in-service for new employee training at Cumberland Trace. The unit manager agreed to utilize the resource binder for new employee training. To ensure the activity boxes are continuously used post upon completion of this DCE, the student provided step by step instructions printed on a notecard outside the box rather than demonstrating and teaching the activity staff member currently in *Cherished Memories.* By leaving step by step instructions, the activity will be readily available for nurses, family members, staff members to easily pick up an activity box and know exactly how to present the activity to the individual without the need to be trained. Lastly, to create sustainability with the family care packets, the student discussed with the unit manager about creating a distribution process during initial care plan meetings. The student strongly believes the unit manager will stick to distributing these packets because he is one of the main individuals who influenced the creation of these packets. The site mentor strongly believes that the family care packets will be carried over to other CarDon sites in order to facilitate knowledge about Memory Care units (J. Saldana. Personal communication, Jan 2018). After speaking to Jonathan, he agreed to distribute the packet during initial family care plans or as he sees fit.

Society Needs

This experience solidified the need for education and training on Alzheimer's Disease be offered to staff members working with this population. Not only for this facility and memory care units, but all staff members who directly work with older adults. Workers should be educated and trained on proper techniques for caring with individuals with dementia. As research has already proved, nursing staff and physicians have repeatedly reported facing challenges when caring for individuals, specifically when communicating and addressing behaviors (Dewing, 2010). In order to begin facilitating this type of care and creating person centered practice, staff members must be aware of residents' past history including family history and behavior triggering information (Kolanowski, Van Haitsma, Penrod, Hill, Yevchak, 2015). With residents' past history, staff members will be able to resonate and connect with residents in order to establish a trustworthy relationship. Research has also stated that by providing educational in-services, aides felt more confident and comfortable communicating with individuals with AD therefore decreasing negative emotions (Sprangers, Dijkstra, & Romijn-Luijten, 2015). This experience skimmed the surface of advocacy for this population but it's a start to beginning the process. This experience directly advocated for individuals with AD by educating their caregivers and daily caretakers on the disease, effective communication strategies, how to handle challenging behaviors, and resources to assist in the caregivers own health and wellbeing. Although this experience focused on beginning the advocacy and educating process at Cumberland Trace, it is with great hope that the knowledge will be spread through other memory care units owned by CarDon. By providing education and training to the staff members of Cumberland Trace about AD and how to properly care for these individuals, *Cherished Memories* will hopefully be better equipped with educated and knowledgeable staff members. With educated and knowledgeable staff members, better care will be given to the residents. By creating a family care packet, the residents' family members at Cumberland Trace will be more knowledgeable on AD therefore decreasing the lack of public awareness. By educating more individuals, especially loved ones who are directly impacted by AD, the hope is that these individuals will then turn to society to spread their own knowledge and education in order to create a chain of events leading to an awareness of disease.

Leadership

Several aspects of this experience allowed the student to utilize leadership skills. The key leadership components included communication, responsibility, and self-motivation. Throughout this experience, effective communication was an essential part of initiating the needs assessment and implementing the in-services for staff members. Obstacles were handled each time through professional and open communication with the unit manager and supervisor. Miscommunication and misconstrued focus of the DCE resulted in several weeks passing by before the in-service was finally schedule. Through self-advocacy and open communication, the issues were resolved. Since this experience is new to both the university and the facility, being able to professionally advocate and describe this DCE experience is a large part of creating a successful experience. Responsibility and self-motivation determined the success of this experience because of the experience being solely based on how well established goals were, as well as how responsible the student was at completing tasks on time. Both of the supervisors had busy schedules; therefore, meeting time was limited and often included minimal detail. The student discovered that with several questions and verbalizing needs and desires, the feedback given was more beneficial. With each obstacle came increased responsibility to keep on task and balance time management with each task.

Discussion

Overall Learning

Cumberland Trace is one of the skilled nursing facilities that host an in-house memory care unit. This DCE focused on bridging the gap between individuals with AD, healthcare professionals, and family members through advocacy and providing educational trainings and knowledge to all parties. Positive outcomes were noted regarding the advancement of the memory care unit and the educational documents provided to healthcare professionals and families. Staff members of *Cherished Memories* voiced positive feedback through post survey and positive feedback from supervisors regarding family care packet therefore indicated a successful experience. This experience created a snapshot of the importance for healthcare professionals and families to be properly educated on AD. Overall, this experience accomplished what the OT student had in mind.

This experience required a variety of skills to effectively complete the desired outcome. Communication is key to accomplishing a large goal. A variety of different communication styles were necessary in effectively achieving each goal. The student had to effectively communicate with staff members, supervisors, residents, residents' family members, and other personal when completing each goal. Communication skills are how a solid foundation for a relationship was built between the supervisor and the student. All communication via email, face-to-face, and non-verbal gestures was professional and respectful of the other profession. When communicating, demonstrating clear and concise needs and desires was imperative to creating the desired outcome. Through collaboration and effective communication, goals were established and successfully accomplished. The outcomes would not have been accomplished without successful communication between all individuals.

Limitations

When reviewing the goal attainment scale to address the status of each goal, limitations were highlighted. Only receiving 50% (n=5) of surveys back from *Cherished Memories* staff members was the main limitation during this experience due to surveys designed to provide the student with the needs of the unit. The lack of responses could be contributed to by the limited number of staff members per shift therefore increasing responsibilities and caseload for each staff member to pass along the word. The limited response may have interrupted the course of action by not effectively describing the needs of the unit. Another limitation noted was the limited number of post-surveys received following the in-service on *Cherished Memories* therefore inhibiting feedback. The minimal number of attendees could influence limited response. Due to timeline shift for family care packet, there was not enough time post completion to verify satisfaction with potential residents' family members.

Further Advancement

As indicated throughout this paper, there is a need for advocacy with individuals with AD in order to bridge the gap between healthcare professionals, family members, and these individuals. With the diagnosis expected to exponentially grow in the upcoming years, that places a large focus on the need for knowledgeable practitioners and family members. This experience attempted to begin the advocacy process at Cumberland Trace in order to emphasize the importance of training and education for healthcare professionals and family members. The need for further advancement for properly educating/training individuals is essential in preparing for the future. By excluding this population and refusing to acknowledge the decrease in amount of adequately educated individuals to treat and care for individuals with AD, as healthcare facilities, it will be doing injustice to the family members who trust the healthcare provider to properly care for their loved one. Failure to continue education on AD will only create disheartening and ill-equipped facilities to care for this population. It is imperative to continue educating current and future nurses about the disease process, effective communication, appropriate activities, structured routines, mealtimes, and simply how to treat them like a person rather than for the unfortunate disease with no cure. In order to treat the individual, we need to see him/her for themselves rather than the disease (Ericson-Lidman, Franklin Larsson and Norberg, 2013) and with nurses continuously reporting feeling incompetent when communicating and treating residents with AD (Wang, Hsieh, & Wang, 2013; Ahmad, 2014; Kolanowski, Van Haitsma, Penrod, & Yevchak, 2015) it becomes a constant battle to maintain this perspective. Therefore, facilities bear a great responsibility to provide educational trainings to staff members in order for them to effectively begin treating the individual. It all will begin with acknowledging the lack of awareness and understanding of the disease.

With the growth of Alzheimer's disease only expected to continue growing, it is essential our healthcare professionals are well equipped with the proper knowledge to provide quality care. The purpose of this experience was to explore the gap between healthcare professionals, families, and residents with Alzheimer's disease in order to establish meaningful connection and provide quality care. To fulfill this purpose, concerns of both healthcare professionals and family members of *Cherished Memories* were identified then answered with educational trainings and documents. Educational in-services were provided to staff members in order to adequately equip them with necessary knowledge to effectively care for individuals with AD. A family care packet was developed for potential new residents' family members in order to educate on the stages of the disease as well as the details about memory care. Positive feedback was given from both staff members and supervisors regarding educational in-services and family care packet. Information retrieved for in-services will be provided to new employees and the packet will continue to be distributed to potential new residents' family members. This exploratory experience will assist in bridging the gap in order to begin advocating for individuals with AD and create a holistic approach to care.

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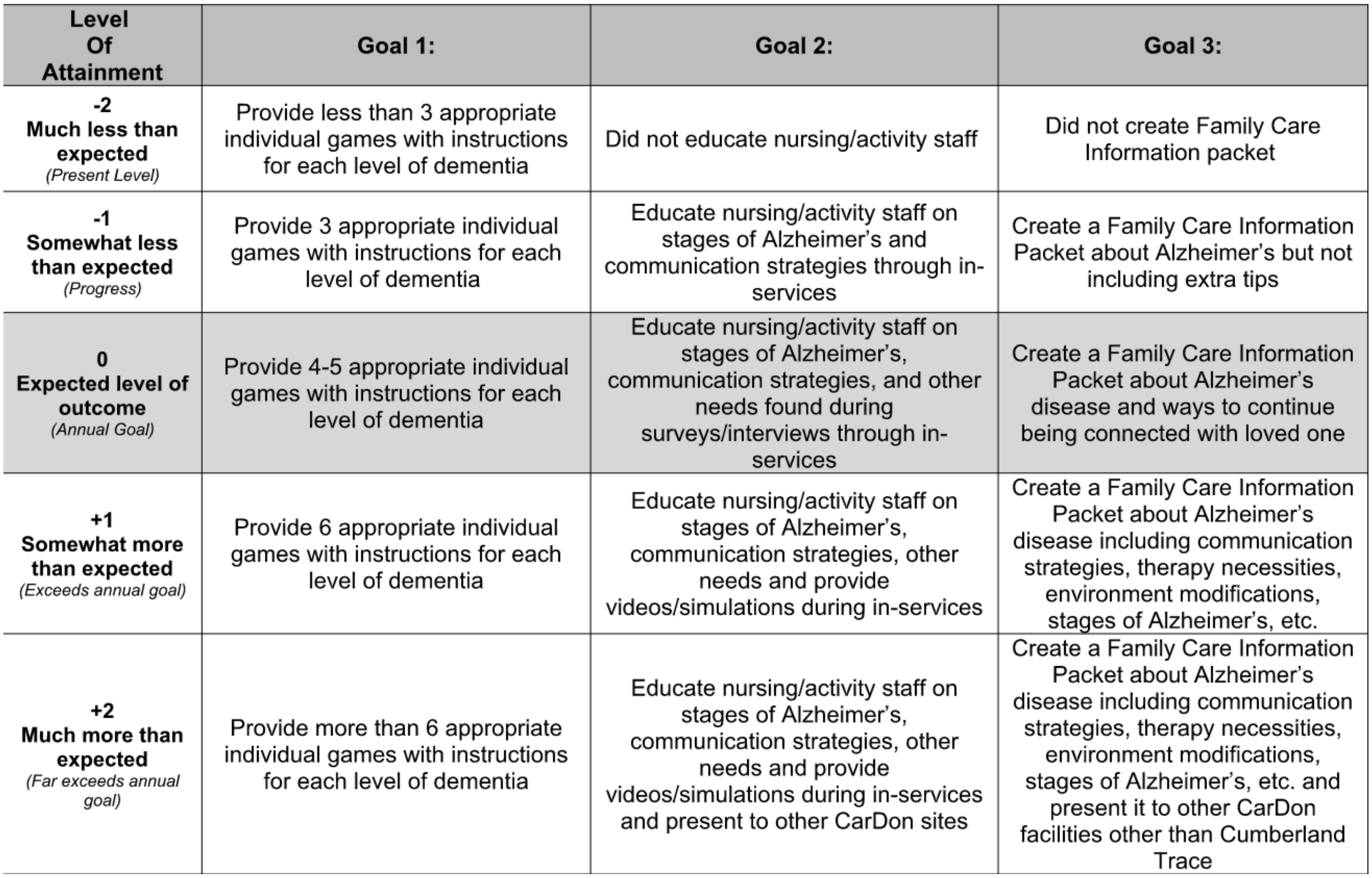
Appendix A

Table 1

Student's Goal Attainment Scale



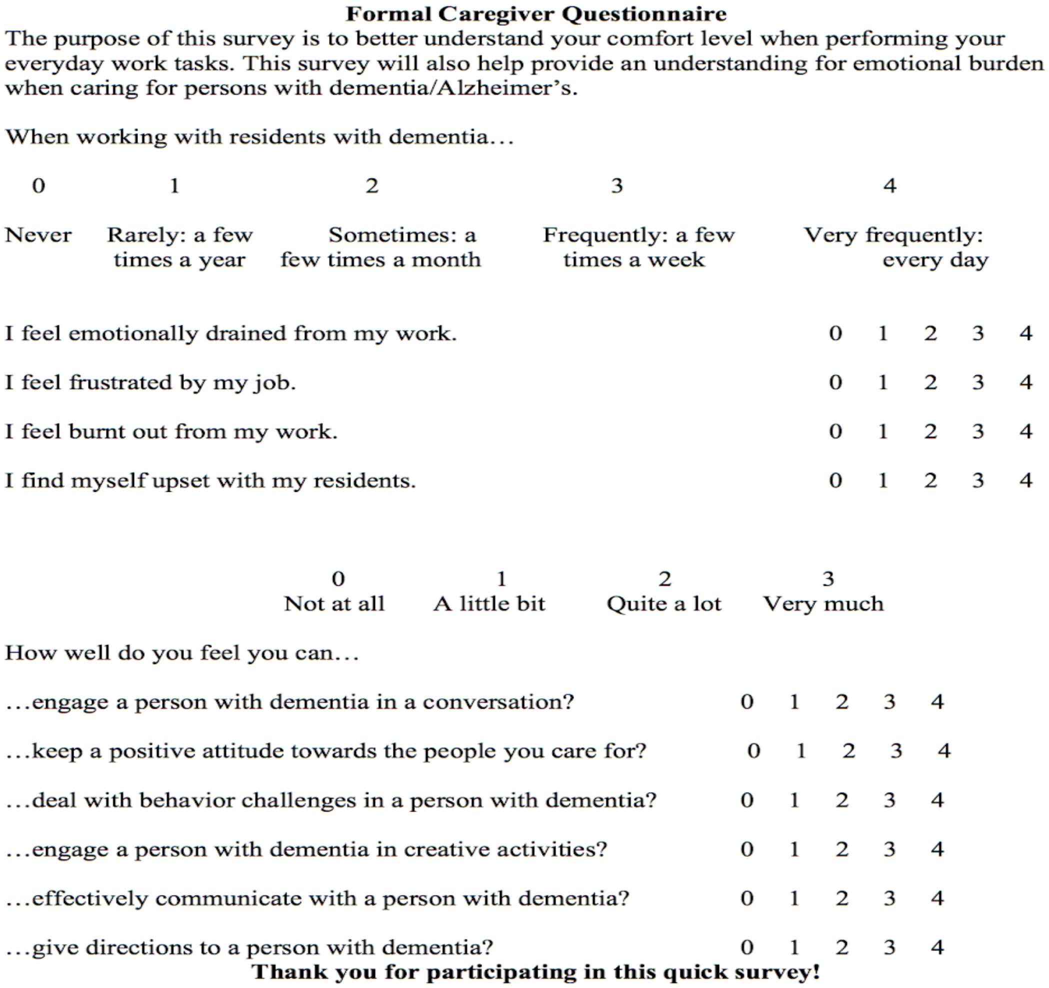
Level Of Attainment	**Goal 1:**	**Goal 2:**	**Goal 3:**
-2 **Much less than expected** *(Present Level)*	Provide less than 3 appropriate individual games with instructions for each level of dementia	Did not educate nursing/activity staff	Did not create Family Care Information packet
-1 **Somewhat less than expected** *(Progress)*	Provide 3 appropriate individual games with instructions for each level of dementia	Educate nursing/activity staff on stages of Alzheimer's and communication strategies through in-services	Create a Family Care Information Packet about Alzheimer's but not including extra tips
0 **Expected level of outcome** *(Annual Goal)*	Provide 4-5 appropriate individual games with instructions for each level of dementia	Educate nursing/activity staff on stages of Alzheimer's, communication strategies, and other needs found during surveys/interviews through in-services	Create a Family Care Information Packet about Alzheimer's disease and ways to continue being connected with loved one
+1 **Somewhat more than expected** *(Exceeds annual goal)*	Provide 6 appropriate individual games with instructions for each level of dementia	Educate nursing/activity staff on stages of Alzheimer's, communication strategies, other needs and provide videos/simulations during in-services	Create a Family Care Information Packet about Alzheimer's disease including communication strategies, therapy necessities, environment modifications, stages of Alzheimer's, etc.
+2 **Much more than expected** *(Far exceeds annual goal)*	Provide more than 6 appropriate individual games with instructions for each level of dementia	Educate nursing/activity staff on stages of Alzheimer's, communication strategies, other needs and provide videos/simulations during in-services and present to other CarDon sites	Create a Family Care Information Packet about Alzheimer's disease including communication strategies, therapy necessities, environment modifications, stages of Alzheimer's, etc. and present it to other CarDon facilities other than Cumberland Trace

Note. This Goal Attainment Scale (GAS) was utilized to address each component throughout this experience. The scale is effective in determining if each established goal has been met as expected, less than expected, or more than expected. It allowed the student and supervisors to determine the progress of the experience as well as make adjustments as necessary.

Appendix B

Table 2

Sample Survey Questions for Staff Members



Formal Caregiver Questionnaire

The purpose of this survey is to better understand your comfort level when performing your everyday work tasks. This survey will also help provide an understanding for emotional burden when caring for persons with dementia/Alzheimer's.

When working with residents with dementia…

0	1	2	3	4
Never	Rarely: a few times a year	Sometimes: a few times a month	Frequently: a few times a week	Very frequently: every day

I feel emotionally drained from my work.	0	1	2	3	4
I feel frustrated by my job.	0	1	2	3	4
I feel burnt out from my work.	0	1	2	3	4
I find myself upset with my residents.	0	1	2	3	4

0	1	2	3
Not at all	A little bit	Quite a lot	Very much

How well do you feel you can…

…engage a person with dementia in a conversation?	0	1	2	3	4
…keep a positive attitude towards the people you care for?	0	1	2	3	4
…deal with behavior challenges in a person with dementia?	0	1	2	3	4
…engage a person with dementia in creative activities?	0	1	2	3	4
…effectively communicate with a person with dementia?	0	1	2	3	4
…give directions to a person with dementia?	0	1	2	3	4

Thank you for participating in this quick survey!

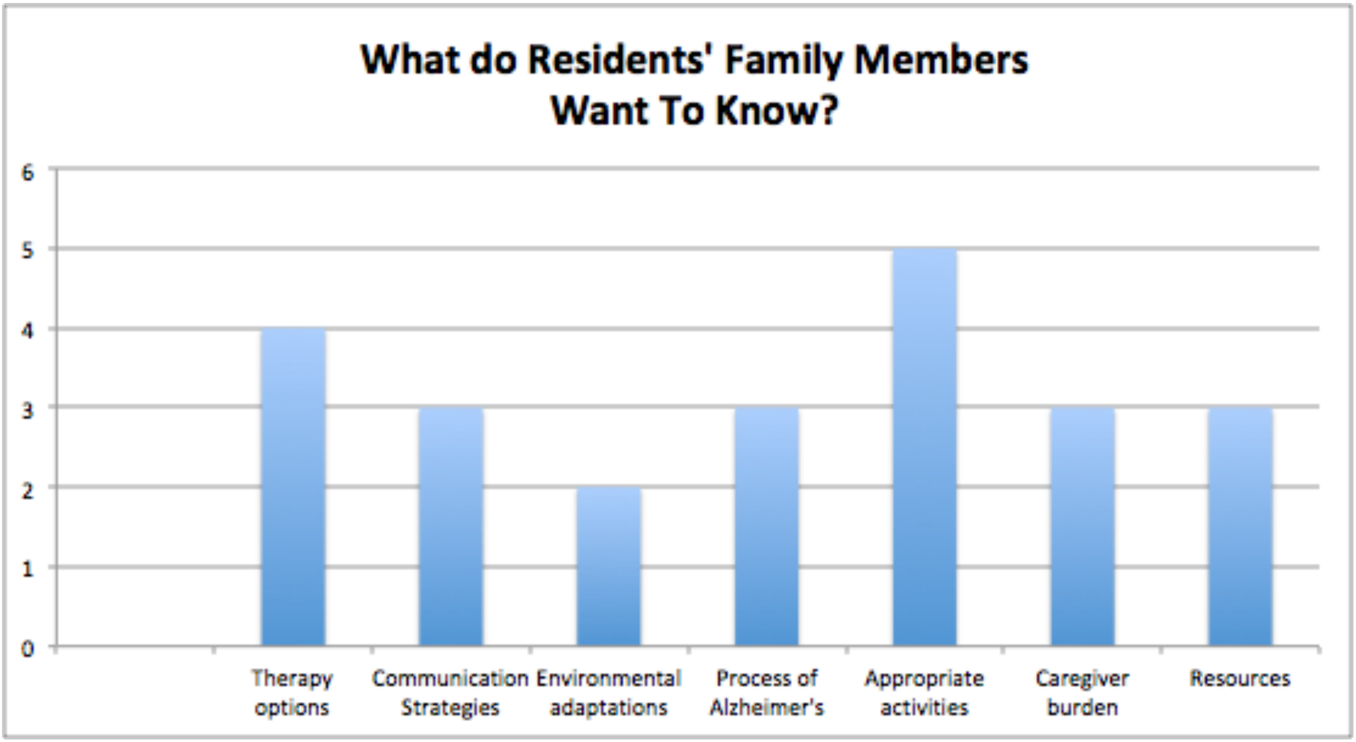
Note. These survey questions were utilized to determine the level of burnout experienced by staff members on *Cherished Memories.* These survey questions were loosely adapted from the Maslach Burnout Inventory (Maslach, Jackson, & Leiter, 1996) and the Sense of Competence in Dementia Care Staff (Schepers, Orrell, Shanahan, Spector, 2012).
]

Figure 1. Experiences of nurses caring for individuals with alzheimer's disease. This figure illustrates an observation of two nurses feeling frustrated and agitated when caring for individuals with dementia.

Appendix D

Table 3

What do Residents' Family Members Want to Know?

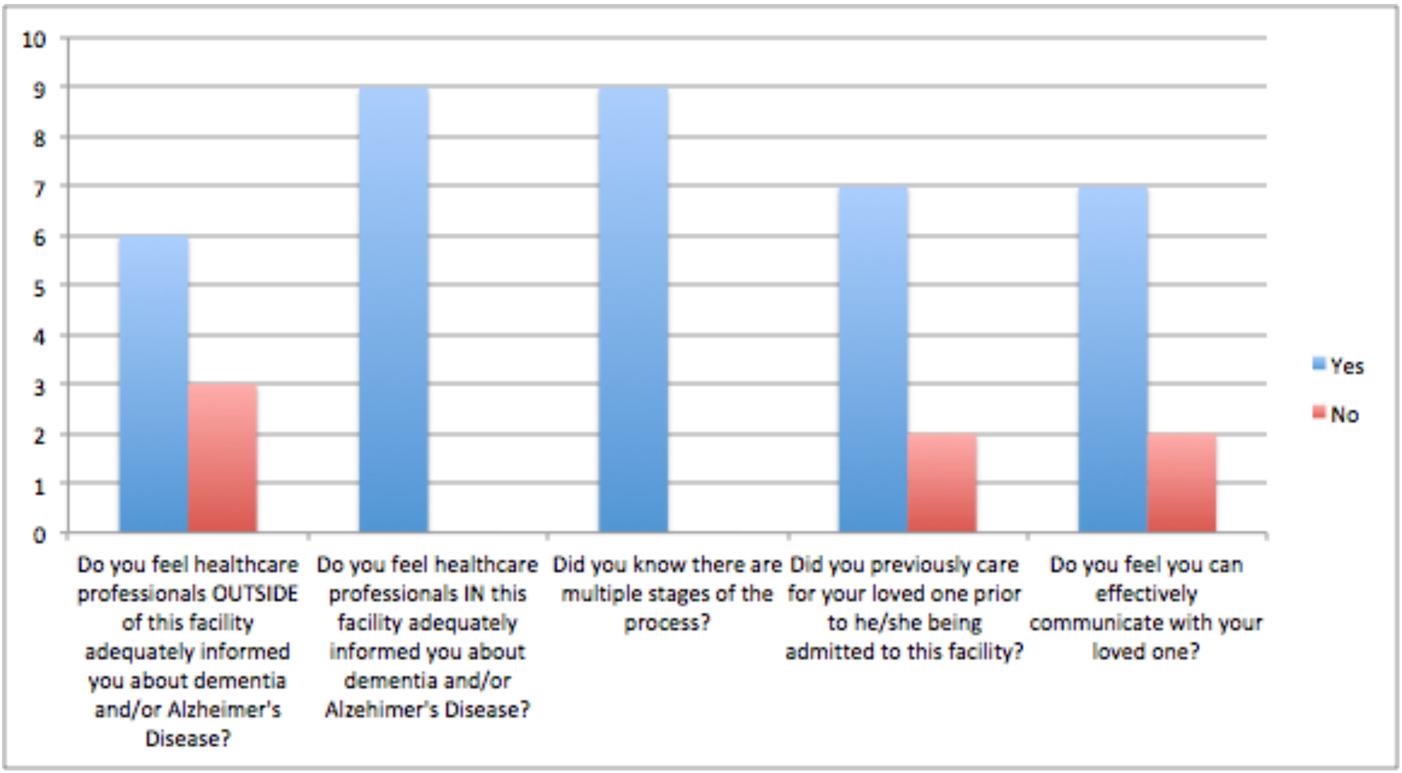


Note. This graph depicts the results based upon the responses received from the residents' family members surveys. As indicated above, several topics are of interest for family members. Due to the high response in each of categories except environmental adaptations, he family care packet will encompass each of these categories.

Appendix E

Table 4

Residents' Family Members Knowledge of Alzheimer's Disease

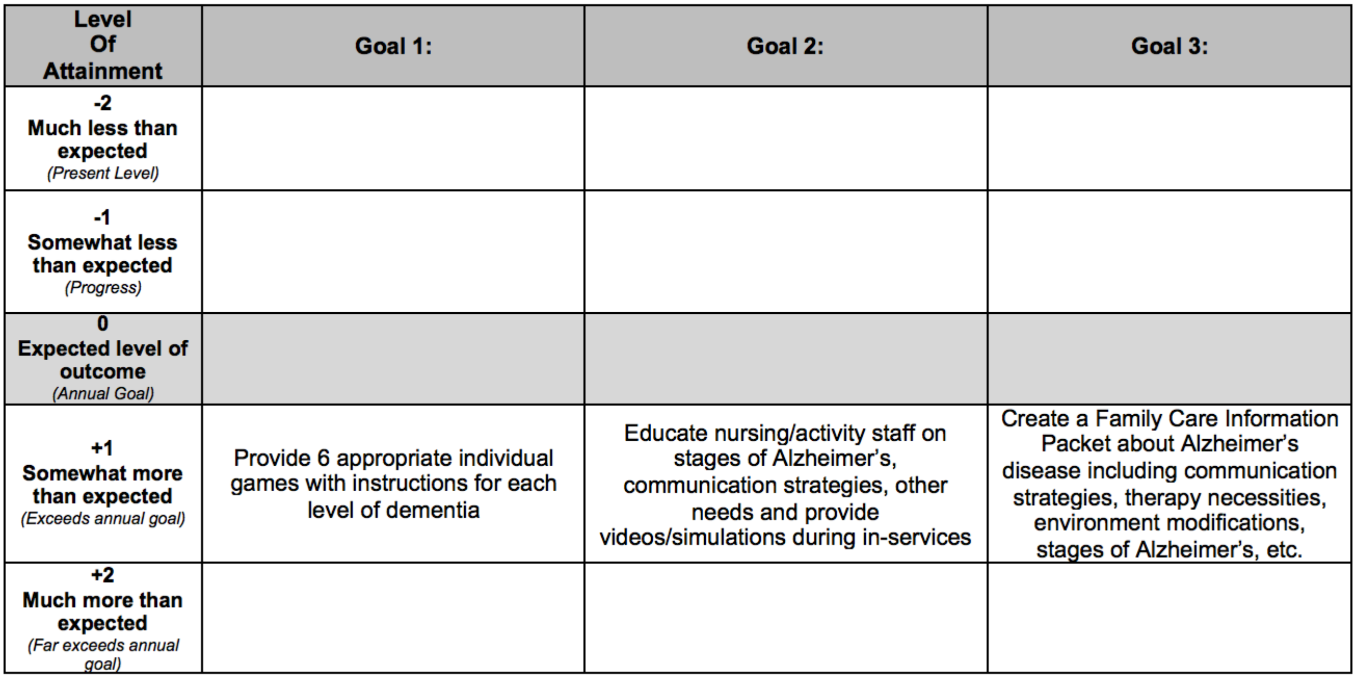


Note. The graph above depicts the results from the yes/no questions asked about loved ones knowledge of Alzheimer's and how well they were educated by healthcare professionals. As shown above, Cumberland Trace effectively educates their residents' family members but education falls short outside of the facility.

Appendix F

Table 5

Goal Attainment Scale Results



Level Of Attainment	**Goal 1:**	**Goal 2:**	**Goal 3:**
-2 **Much less than expected** *(Present Level)*			
-1 **Somewhat less than expected** *(Progress)*			
0 **Expected level of outcome** *(Annual Goal)*			
+1 **Somewhat more than expected** *(Exceeds annual goal)*	Provide 6 appropriate individual games with instructions for each level of dementia	Educate nursing/activity staff on stages of Alzheimer's, communication strategies, other needs and provide videos/simulations during in-services	Create a Family Care Information Packet about Alzheimer's disease including communication strategies, therapy necessities, environment modifications, stages of Alzheimer's, etc.
+2 **Much more than expected** *(Far exceeds annual goal)*			

Note. This Goal Attainment Scale (GAS) depicts the final outcome results. This image indicates all goals were achieved above expectations.