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The Importance of Cultural Competency in Alzheimer's Disease Care Giving

Submitted by Jacquelyn M. Lotter
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MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW
students at St. Catherine University/University of St. Thomas School of
Social Work in St. Paul, Minnesota and is conducted within a nine-month
time frame to demonstrate facility with basic social research methods.
Students must independently conceptualize a research problem, formulate
a research design that is approved by a research committee and the
university Institutional Review Board, implement the project, and publicly
present their findings. This project is neither a Master's thesis nor a
dissertation.

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Abstract

While the importance of cultural sensitivity has been actively researched in healthcare settings, there is little research about the importance of culture as it relates to people with Alzheimer's disease. As the most common cause of dementia, there are currently over 5 million Americans over the age of 65 who are believed to have AD and is it expected to increase to over 15 million by 2050. Previous social work research has revealed two major themes in the study of caregiving and Alzheimer's disease: 1) importance of a familiar environment and 2) management of aggressive responses, both of which factors into a persons' quality of life. This research was designed to discover in what ways is cultural competence important to providing care for and improving the quality of life of a person with Alzheimer's disease?   Seven professionals working in a nursing home's Alzheimer's unit participated in the qualitative study. The study included offsite interviews where participants completed a self-reflection questionnaire and recorded interviews which were then transcribed for the research. Several themes emerged from the study. Six out of seven professionals interviewed believe that cultural competence was important to providing care and the quality of life demonstrated through communication barriers, dependence on family, diet, trust, Resident advocacy, inter-staff relations and sense of community. The results of this study suggest that the cultural sensitivity of care providers plays a direct role in maintaining the quality of life for those living with Alzheimer's disease. Additionally, a lack of cultural sensitivity can lead to frustrated Residents, exclusion, aversion to standard care and poor nutrition. More research is needed to understand to what extent culture influences aggressive responses and overall quality of life.

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Introduction

The purpose of this study is to examine the importance of culture in providing care to populations diagnosed with Alzheimer's disease (AD). Today, the United States' geriatric population faces increasing cultural diversity (U.S. Census Bureau, 2010), as well as increasing diagnoses of AD (Alzheimer's Association, 2011). Both of these characteristics place a demand on our healthcare system to understand and meet the complex needs of this changing population.

Research has indicated that overall, minority populations receive inferior healthcare due to a variety of barriers. For example, research found that white patients with terminal cancer are more likely to have their end-of-life wishes honored than Black patients, despite communicating their wishes to a doctor (Mack, et al., 2010). Additionally, it was reported that almost half of all colorectal and cervical cancers and a third of breast cancers are diagnosed at late stages, with disproportionate percentages for ethnic minorities (U.S. Department of Health & Human Services, Centers for Disease Control and Prevention, 2010). Barriers to accessing and receiving care include lack of insurance, lack of a primary physician, lack of income, legal issues (immigration), structural barriers (such as transportation), language barriers and lack of health literacy (AHRQ, 2003). This research highlights the need to improve how well we serve culturally diverse populations.

Our continuously diversifying population magnifies this issue. According to the 2010 U.S. Census, the 71.6 million people over the age of 65 were made up of 80% Whites and 20% of combined minority groups (Black, Hispanic, Asian and Non-Hispanic White). The U.S. Census Bureau (2010) defines White people as having origins from Europe, the Middle East or North Africa. Nationally, the percentage of all white Americans has declined every decade since the 1940's. For example, 89.8% of all Americans were white in 1940, 87.5% in 1970, 75.1% in

2000 and 72.4% in 2010. Over the next few decades, projections indicate a continued percentage shift resulting in a further decline of the white majority and an increase in the minority populations (U.S. Census Bureau, 2010).

The second aspect of the stated problem relates to our aging population. The United States faces an increasing demand for geriatric healthcare services. Geriatrics refers to people who are aging or elderly.   According to the medical dictionary, elderly is defined as "quite old; past middle age" (Collins English Dictionary, 2011). There are two compounding factors creating our elderly population growth: 1) the impact of extended life expectancy, and 2) baby boomers moving into their later phases of life. For example, the average life expectancy of Americans has increased from 69.8 in 1960 to 78.7 in 2009 (World Bank, 2011). Americans are living longer which increases their likelihood of having health concerns. In addition to living longer lives, the U.S. geriatric population is experiencing unprecedented growth due to the baby boomer population reaching age 65. In 2000, there were 35 million people over the age of 65 and 63.9 million in 2010 (U.S. Census, 2010). According to the Center for Disease Control (2004), by 2030, more than one-fifth of Americans (70 million people) will be over age 65 and as a person ages, they will require more healthcare services.

As the population over 65 expands, so does the number of persons diagnosed with Alzheimer's disease (AD) (American Alzheimer's Association, 2011). As the most common cause of dementia, there are currently over 5 million Americans over the age of 65 who are believed to have AD. This number is expected to increase to over 15 million by 2050. Reports indicate that as our nation's life expectancy increases, so does our risk of getting AD, especially after age 60 (American Health Assistance Foundation, 2011).

Alzheimer's disease is a degeneration of the brain resulting in a reduction in cognition, memory loss, aggressive responses, personality alterations, language difficulties and ultimately death due to decreased brain functioning (American Health Assistance Foundation, 2011). In most people, the symptoms appear after age sixty (U.S. Department of Health & Human Services, National Institutes of Health, National Institute on Aging, 2011). As the disease progresses, people need assistance with daily living skills like bathing, eating and toileting (2011). Treatment is also complicated by common responses such as agitation, repetition, hallucinations, sundowning (late-day confusion), pushing, wandering, yelling and other responses (Alzheimer's Association, 2011). Additionally, the complexity of Alzheimer's treatment is further magnified by the patient's word finding difficulties and memory impairment (2011). The cost of this disease is significant, depleting physical, emotional and financial reserves tied to it. Our national healthcare costs related to AD are expected to grow from $183 billion in 2011 to $1.1 trillion in 2050 (2011).

Simply stated, our nation is in the midst of changing demands on our healthcare system. First, the U.S. population continues to diversify magnifying access to care issues already experienced by ethnic minorities. Secondly, as life expectancy increases and the baby boomers enter their later years, the number of people at risk of developing AD also increases. Given the implications of cognitive decline in this extremely vulnerable population, it is essential to understand how introducing more cultural variance into the population impacts care requirements. Social workers play a critical role in promoting social justice for minorities, brokering geriatric services and maintaining the dignity and worth of elderly populations. As stated in the National Association of Social Worker's (NASW) Code of Ethics (2011), social workers are charged with preserving the values of social justice for vulnerable populations,

human dignity and social diversity by means of striving for cultural competence. Given that those suffering from AD are one of our most vulnerable populations, a further look into how cultural competency impacts their care is warranted.

Review of Literature

Much research has been conducted to understand the complexities of our healthcare system and how it best meets the demand of the public. A review of literature was conducted to understand the two focuses described in the introduction: 1) the impact of culture on health providers' ability to deliver quality care and 2) the care practice for treating persons diagnosed with AD. Provider cultural competency surfaced as the major theme in the literature on culture as it relates to healthcare. The Alzheimer's care research presented themes focusing on the impact of familiarity and response management.

Cultural Competency in Healthcare

The magnitude of the healthcare issues facing our culturally diversified nation has fostered a great deal of research. The underlying theme of most studies is the concept that we need to understand the uniqueness of our varying cultures to develop quality services that ultimately meet our needs. First, it is necessary to understand how culture is defined.

Culture is defined as "the integrated system of socially acquired values, beliefs, and rules of conduct which delimit the range of accepted behaviors in any given society." (The Columbia Encyclopedia, 2008). Culture is further defined to include language, thoughts, communications, actions, and customs (Blackwell, 2005). To deliver quality services transculturally requires the pursuit of cultural competence.

The notion of competence in culture is a never-ending task of self-exploration and continued pursuit of understanding of others. Cultural competency is defined as "an ability to

interact effectively with people of different cultures" (Martin & Vaughn, 2007, para 8) and requires an awareness of one's own cultural perspective, attitudes about cultural differences, knowledge of other cultures and the ability to effectively interact across cultures (2007). Considering the diversity of our nation, it is important for healthcare providers to become culturally competent in order to provide effective care across a variety of cultures (Jovanovic, 2008).

One of the leading researchers defining cultural competency in healthcare is J.R. Betancourt. Betancourt influenced the development of a practical framework that clinicians can use to provide quality care to culturally diverse populations (Betancourt, 2006). Culturally competent healthcare systems are able to "provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients' social, cultural and linguistic needs" (Betancourt, Green & Carrillo, 2002). To deliver cultural competency within a healthcare system, a focus of organizational, structural and clinical interventions are required (Betancourt, Green, Carrillo & Ananeh-Firempong , 2003). Administration must acknowledge and incorporate culture into operation by including recognition of the importance of culture, cross-cultural relations, expansive cultural knowledge and service adaption to meet the varying cultural needs of their client populations (2003).

There is now a sizeable focus of cultural competency in the field of healthcare. The theory of social exclusion and minority healthcare is the premise of such research (Jovanovic, 2008; Boyd-Seale, 2008; Quist & Law, 2006). With an emphasis on the theory of social exclusion, one study conducted by Debra Boyd-Seale (2008) sought to understand the relationship between a provider's cultural competence and the extent of culturally diverse activities in a nursing home. This research indicated that although activity directors perceived

themselves as culturally competent, representations of cultural diversity in their activity plans were not consistent (Boyd-Seal, 2008). This suggests that provider's perceptions of cultural competence alone are not enough to mitigate social exclusion.

Similarly, a Netherlands study (Sloots, Dekker, Bartels, Geertzen, & Dekker, 2011) researched the impact of culturally adaptive programming on non-native patients (minorities) seeking treatment for chronic pain. The study indicated that there was a statistically significant relationship between a program's level of cultural adaptation and the number of non-native patients seeking treatment from their center. This study suggests that cultural competency in programming has a positive effect on the delivery of treatment to minorities. The results of these studies are supported by additional research suggesting that in order to achieve cultural competence; healthcare programs must factor culture into both their practice and administration (Quist & Law, 2006).

While these studies are both founded in cultural competency, they diverge in their variables. For example, the Boyd-Seal (2008) study of nursing home program directors was based in Cook County, Illinois researching program director's perceptions of their competence and comparing it to their program calendars. Another study's sample was taken from a small group of pain clinics in the Netherlands (Sloots, et al., 2011). Another example of variance is the dependent variable. One evaluates cultural competency through the outcomes of event planning while the other measures its results by the impact of cultural competency on the minority group's visitation counts.   There is more to learn about the impact of cultural competency on the nursing home population. Research suggests that there is a lack of cultural competency in nursing homes and that culturally competent programming has a positive effect on treatment, however the

question of how cultural competency impacts people with Alzheimer's disease is left
unanswered.

Treatment of Alzheimer's Disease

Overall, there is little literature focusing on how the provider interacts with a person with
AD. Previous social work research has revealed two major themes in the study of caregiving and
Alzheimer's disease: 1) importance of a familiar environment and 2) management of aggressive
responses, both of which factors into a persons' quality of life. Because the advanced stages of
AD prevent people from clearly speaking for themselves, care providers generally use quality of
life (QOL) assessments to determine the course of care. Quality of life assessments are critical
to evaluating the effectiveness of healthcare interventions (Kutner, Ory, Baker, Schechtman,
Hornbrook & Mulrow, 1992). Characteristics measured by QOL assessments generally include
social interaction, awareness of self, feelings and mood, enjoyment of activities, and response to
surroundings (John Hopkins Medicine, 2011). Quality of life assessments also take into account
aggressive responses as a sign of impaired QOL. It is essential that care providers measure a
person's quality of life and create an environment where a person reaches their fullest potential.

Familiar environment. Research suggests that psycho-social wellbeing is influenced by
the familiarity of one's environment and that familiarity also plays a direct role in sustaining
QOL characteristics. One study reported the benefits of maximizing familiarity in the patient's
living environment (Son, Therrien & Whall, 2002). Bringing a resident's familiar items into the
nursing home likely invokes memories of their former home which has a perceived
"psychological, social and cultural" meaning to the resident (Son, Therrien & Whall, 2002).
Such responses would ideally translate into the QOL characteristics of self- awareness, positive
mood, enjoyment and response to their surroundings. Another study indicated that positive QOL

indicators can be elicited through familiar music and activities (Moore, Gilbert, Jacelon & Ready, 2010). This research indicated that people were more likely to be self-sufficient in the dining room and experience improved dietary intake when listening to familiar music. Again, these results may improve the QOL characteristics of self-awareness and responses to their environments. Collectively, these studies emphasize the value of embedding familiarity as a key tenet in QOL care planning.

Aggressive response management. A second major theme in Alzheimer's disease research is aggressive response management. As previously stated, pushing, wandering and yelling are common characteristics of people with AD (Alzheimer's Association, 2011). Response management impacts the QOL for the individual as well as others. Research indicates that aggressive responses are a result of some type of provocation (Stanford, Houston, Mathias, Villemarette-Pittman, Helfritz, & Conklin, 2003). Social workers must seek understanding around what provokes agitation in people with AD.

Just as a person's environment may improve their wellbeing, research also indicates that it may have a negative impact. One study reported a cause and effect relationship between unfamiliar objects and aggressive behavior (Son, Therrien, & Whall, 2002 and Moore, et al. 2010). Another study by Whall, et al. (2008), revealed a negative correlation between a patient's level of familiarity with their care provider and aggressive responses during care routines. This study also provided insight into how the negative behavior of a care giver (tone of voice, facial expressions, posturing, etc.) is associated with inducing aggressive responses in AD (2008). Additionally, Todd (2002) recognized the negative correlation between agitation and how effective a care provider communicates. This means that when a care provider's level of communication effectiveness decreases, the patient's agitation level increases.

Research also focused on a predictor of aggressive responses outside of environmental stimuli. Sleep deprivation has been identified as a predictor of aggressive behavior (Whall, Colling, Kolanowski, Kim, Hong, DeCicco, Ronis, Richards, Algase, & Beck, 2008). Interventions, like exercise, are used to improve a person's ability to sleep and in turn, minimize other responses like aggression and wandering (Logsdon & Teri, 2010). Sleep deprivation provokes irritability, restlessness and other responses. Such research is important because it helps care providers learn techniques to minimize a person's aggressive responses and improve their QOL.

While the Alzheimer's disease studies in the literature review suggest the importance of familiarity in sustaining QOL, they did not all factor culture as a variable. For example, the study conducted by Whall et al. (2008) explored negative care provider messaging which provoked AD aggressive responses; however the study did not account for culture. According to Toale & McCroskey (2009), communication responses vary between ethnic backgrounds. What constitutes as a negative facial expression or tone of voice in one culture may be different in another culture. Additionally, what provokes such expressions and tones varies between cultures (2009). Similarly, the study reporting the benefits of playing familiar music during meal time (Moore, Gilbert, Jacelon & Ready, 2010), failed to factor culture into the equation. The study referenced familiar music but did not specify how it was familiar. It is necessary to understand how cultural meaning and interpretation factor into the outcome of these studies.

Research Question

Previous research designed to understand the value of cultural competency in healthcare suggests that cultural competence is an important element in delivering effective care. Such research indicates that cultural competency improves care for minorities. Alzheimer's disease

research has also demonstrated an emphasis on quality of life care planning with a focus on managing aggressive responses and maximizing familiarity. Although much remains to be learned about the disease, managing responses and delivering care grounded in familiarity tend to have more favorable outcomes with patients. Considering the knowledge about the complexities of culture and the potential barriers to providing transcultural care in addition to the psycho-social impairments of AD, additional research should be conducted to understand the importance of cultural competency in care treatment for AD. Based on this analysis the proposed research question is: In what ways is care provider cultural competence important to the quality of life of a person with Alzheimer's disease?

Conceptual Frameworks

Ecological Systems Theory

Ecological *s*ystems theory, developed by Urie Bronfenbrenner in 1979 (Kazdin, 2000) is a significant device used to support the study of development as influenced by a person's environment. Bronfenbrenner's theory defines five environmental systems, two of which emphasize systems inherent in the study of cultural competency in care providers, macrosystem and microsystem.

Macrosystems. First, Brofenbrenner's macrosystem (2000) refers to the culture in which a person lives helping to shape a person's values, heritage and identity. Recognition of one's own culture and the prospective culture of another is the foundation of cultural competency. Care providers are responsible for respecting and protecting their patients' values which can be especially ambiguous given the Alzheimer population who cannot advocate for themselves. As previously stated, research demonstrates that awareness of culture is critical

because it emphasizes intrinsic differences between people; some of which can be barriers to providing quality care if gone unrecognized (Goode, Dunne & Bronheim, 2006).

Microsystems. A second system defined by Brofenbrenner (2000) is known as the microsystem. The microsystem reflects the influence that a person's biology has on their behavior (2000). As previously mentioned, one of the central focuses of providing care for those diagnosed with Alzheimer's disease is response management. Research indicates that AD commonly stimulates aggressive responses in its victims (Whall et al., 2008), and the application of microsystem theory supports this correlation. The disease is believed to cause hallucinations, wandering, pushing, and yelling. It is important for care providers to recognize and manage the biological effects of AD as it shapes their patients' responses. For example, if a patient is wandering the hallway and looking for a deceased husband, the person most likely forgot about her husband's death. An understanding of the biological impact of the disease helps care providers deliver appropriate interventions.

Social Constructionism Theory

Social constructionism represents the concept of how a person's interpretation of reality is influenced by their social interactions (Dickins, 2004). The theory suggests that we develop through social exchanges founded language, customs, culture and history (2004). Theorist Kenneth Gergen (1999) challenged traditional cognitive theory that suggests that development relies on individual minds, rather it is founded in human relationships. This theory may help to explain how the interactions between care providers and the Alzheimer's population are grounded in culture and language. Understanding that both the care provider and care recipient are products of their personal histories, cultural influences and language; the question of how important is cultural sensitivity to providing care to people diagnosed with Alzheimer's disease

becomes more critical. Given the cognitive regression of the patients and our ever diversifying population, language and interplay between provider and recipient is increasingly complex.

Methods

Research Design

The research was based in a qualitative design. The design was qualitative in nature and consisted of semi-structured interviews.

Sample

A purposive convenience sample was used to access the targeted population. Eligible participants were required to be a professional care provider working with people diagnosed with Alzheimer's disease living in an AD care unit. Care professionals with medical and non-medical backgrounds were encouraged to participate. The Executive Director of a nursing home located in a northern suburb of Minneapolis, Minnesota granted permission for the staff to participate in the research.

To prevent the feeling of coercion, anonymity was maintained by separating the notification of the opportunity from the identification of interested candidates. The nursing home's Executive Director hosted staff meetings where the researcher presented the research opportunity to the staff. The information provided to the staff was printed on a piece of paper and included the intent of the research, researcher's name and telephone number, dates and times of interviews, interview location and the offering of a monetary incentive to each interviewee upon completion of the interview. Interested candidates were asked to contact the researcher outside of the staff meeting. In total, 90 professionals were targeted for participation in the research with the objective of conducting 10 interviews.

Protection of Human Subjects

This research study was approved by the University of St. Thomas' Institutional Review Board prior to data collection. Copies of the questions and the consent form (see Appendix A) were provided at the beginning of each interview. Respondents were notified that their participation was voluntary and that they could decline responses to any questions. Respondents were also informed that they could stop the interview if they felt uncomfortable and still receive the monetary incentive.

Participants were informed that the interview was recorded and transcribed for use in a clinical research project and presentation. The participants were assured that their responses would remain completely confidential as well as their participation in the research. Respondents were told that results of the research may be shared with the nursing home's Executive Director, however all information would be de-identified.   All identifying material was kept in a locked computer at the researcher's home office. The participants were also informed that by June 1, 2012 all record of identifying material and audio tapes would be deleted. Initially Respondents were offered $10 per interview. Low response rates influenced an increased offering of $25 for participating in the survey and interview.

Data Collection Instrument and Process

Process. Participants contacted the researcher to demonstrate interest and schedule an interview appointment. Each participant agreed to meet for their individual sessions in a meeting room at a nearby government center. Sessions lasted 45 minutes on average. Participants were notified that if they did not show up for their session it would not be rescheduled unless initiated and requested by the participant. The session consisted of a self-assessment and an in-person interview.

Self-assessment. The self-assessment survey used was the "Cultural Competence Checklist Personal Reflection" created by the American Speech-Language-Hearing Association (2010). The tool was designed to heighten awareness of how care providers view their clients who have different cultures and languages. The survey consisted of questions related to personal perceptions about culture paired with a 5-point likert-type scale with answers ranging from strongly agree to strongly disagree. The survey questions that explicitly did not relate to nursing home care for people with Alzheimer's disease were removed. The questions focused on general cultural questions, the impact of culture on life activities and how cultural norms influence communication (see Appendix C). The survey was conducted at the beginning of the interview to promote self-awareness and foster concepts and ideas about the respondents' own cultural competency.

Qualitative interview. The qualitative portion consisted of a semi-standardized interview structure. The survey questions were open-ended with the purpose of understanding healthcare professionals' opinions on the importance of cultural competence in their practice of managing the quality of life for people diagnosed with Alzheimer's disease (see Appendix B).

Data Analysis Plan

Data analysis of the interview transcripts consisted of grounded theory methods. Based on the themes within the literature review, a general coding list was created and applied to each transcript. The coding list expanded based on words and ideas that emerged from the individual transcripts. The transcripts were reviewed several times to elicit general themes, enhance reliability and ultimately elevate them into abstract themes (Berg, 2009). Abstract themes that had a minimum of three in-text examples were reported as themes within the research.

Findings

The research project was conducted to gain better understanding of the question: in what ways is care provider cultural competence important to the quality of life of a person with Alzheimer's disease? To determine the importance of provider cultural competence the research question was broken into three sub-questions 1) In what ways does culture impact QOL? 2) In what ways does culture impact sense of familiarity? and 3) In what ways does culture impact aggressive responses in persons with Alzheimer's disease?

Sample

Seven individuals agreed to participate in the study by completing the 45 minute interview. Interviews were conducted on seven different days between January 25th and February 8th. Of the seven participants, two were male and five were female. Four of the seven held a nursing role and three held non-medical roles. Five participants identified as White and two as Black / African American.

A variety of themes reflecting the research question were present in the data. These themes were elevated into three abstract themes: 1) Culture and a Resident's sense of familiarity, 2) Culture and a Resident's aggressive responses and 3) Culture and a Resident's QOL.

Culture and Residents' Sense of Familiarity

The responses revealed four subthemes related to culture and the Resident's sense of familiarity: 1) familiar diet, 2) verbal communication, 3) body language, and 4) delivery of care.

Familiar diet. Culture was recognized as important to Residents' diets as it related to nutrition and consumption. Many respondents suggested the importance of familiar foods and that Residents prefer foods that they recognize. For example, one respondent referenced the benefit of family helping bridge a cultural dietary gap by stating *"They are from India and the*

families also support with food or signs for us to use." Another participant recognized the family's importance in providing familiar foods when saying *"currently, we have some residents that really like certain kinds of food. Their families are pretty good at supporting that."* One respondent noted the nutritional impact of familiar foods:

> *We see where his diet is not adequate, we have to add vitamins and a protein drink as a nutritional supplement because he's not getting enough American foods that we serve...We serve him 2 entrees and we'll serve both of them and he'll turn his nose up to it and he'll go to his room and bring out a package of Raman noodles.*

Several of the interviews revealed that diets based in the Resident's culture seemed to improve consumption.

Verbal communication. Culture was recognized as important in verbal communication between the providers and the Residents. The interviews revealed that communication was complicated by unfamiliar accents and when Residents spoke foreign languages. Two participants noted that communication was complicated by a care provider when they had accents or spoke English as a second language. One respondent noted that: *"I speak with accent and I'll speak to a resident whose memory is not good, they cannot hear you very well."* Additionally this respondent said, *"when I was new, I was worried about (Residents understanding) my accent."* Another participant stated that *"even with languages they know, they have a hard time understanding. If they have English that isn't "perfect", Alzheimer's has a hard time understanding, even the simplest things."*

When responding to a question about the impact of the language barrier, a respondent not only noted the difficulty in communication, but also reflected on the quality of life. *"It's significant. Um, I think that after the staff person gets used to the Resident and the Resident*

gets used to the staff person, you kind of get used to them. You develop a routine of cares and things, but I think that it does reflect in their quality of life." These responses indicate a concern that unfamiliar accents or dialects of the care provider can impact the understanding of a Resident. In addition to accents, Residents who do not speak English seem to have a particularly difficult time communicating. It was noted by respondents that when they did not speak the same language as their Residents, alternative methods were employed. One participant stated:

> *We had the family make some signs for us because he was going into other people's rooms, signs that say "stop" or "do not enter" that type of thing. We've done that before. It's challenging for us because none of the staff speak Chinese.*

Alzheimer's disease further complicates language differences as the mind atrophies. Persons who learned English later in life are at risk of reverting to their original language as their disease progresses. Within a discussion about a Resident reverting to a former language, one respondent said:

> *If you have somebody that only understands or recognizes little bits and pieces or if you're having a conversation where they can probably pick out one word that somebody's telling them…and if they can't understand anything, that has to be totally foreign. Like us listening to Chinese (you don't speak Chinese, right)? If you can't even pick out one word that would have to make you think you were crazy.*

Another respondent mentioned a Resident who reverted to a formerly spoken language and stated *"He used to be an interpreter for culture and trade in China. He moved here 12 years ago and has since contracted Alzheimer's. He speaks a lot of Chinese to us and I don't understand anything except for Mu How."* Respondents noted that it was difficult when a Resident was

reverting to a formerly spoken language, making dialogue in English seem unfamiliar and perhaps significantly limiting the Resident's understanding.

      Body language. Respondents had mixed responses when discussing the impact culture had on body language. It was said to be common practice for care givers to assume a neutral, non-threatening approach with their patients and that such posturing is designed to minimize aggressive responses. When asked about the impact of culture on body language, respondents had mixed opinions. One respondent noted, *"gestures are universal regardless of the culture or one belief system."* Another participant believed that their non-verbal communication was influenced by their culture. This respondent stated, *"I think in our culture, of the nonverbal communication of touch and love and eye contact is enhancing to Alzheimer's patients because that's the bottom line communication that they can really understand at this point of their life."* Other respondents felt that culture should be factored into the universal approach strategies for AD. For example, one person stated *"Like I've worked with the Indian [Native American] culture and the eye contact thing. They don't look at you in the eyes so in order to respect their culture it's really difficult because I tend to look people in the eye, you know."* And another respondent stated, *"You need to approach them from the front – eye level. Make eye contact. Except some cultures don't like you to make eye contact so you have to be careful of that, so you have to work through those things."* The responses provided by the sample population were diverging: some folks believe there is a universal body language while others recognized that there could be cultural differences in body language.

      Delivery of care. Many respondents felt that familiarity was a key part of delivering care. There were differences in opinions about whether or not culture was required to achieve familiar routines. Most respondents believed that the development of a routine trumped the

impact of unfamiliar cultures. For example, one respondent stated *"Um, I think that after the staff person gets used to the resident and the resident gets used to the staff person, you kind of get used to them. You develop a routine of cares and things."* Another person reflected *"You have to create a system to make you get used to these people."* On the contrary, one respondent discussed how common culture enabled them to get Residents to respond more than staff of a different culture. This person stated *"I think that I can probably get people to do a lot more than other people can do...and oh yes, I usually can."* Familiarity plays a role in delivering care, however the extent culture plays into routines is undetermined. Opinions diverged about whether a common culture assists in delivering care. It appeared as though providers from the same culture believe it does make a difference where those from a different culture did not.

Culture and Aggressive Responses

The interviews provided one theme reflecting the impact of culture on a Resident's aggressive responses: verbal communication.

Verbal communication. The research revealed an association between culture, verbal communication and Resident agitation or aggressive responses. When a provider communicates with a Resident, the provider needs to be seen as non-threatening and easy to understand. One participant reflected on the impact of their communication style:

> *I am a very outspoken person and often times I make a lot of movement when I talk. You can see as I talk to you. Something I personally work very hard over time to control, and I cannot help it. These are weaknesses that I work on myself in terms of serving as a barrier for other people.   Sometimes I think I realize that my tone of voice, I have to be very mindful of that.*

When asked if communication barriers impact aggressive responses, a respondent replied *"Yes, because they're trying to communicate and they can't get anybody to understand what they want."* Overall, respondents indicated that culture adds another layer of complexity for verbal communications and impacts responses. At least one respondent indicated that they believed that cultural differences can lead to agitation and possible aggressive behaviors due to the Residents' inability to communicate with their care givers. However, the majority of respondents did not seem to make a connection between verbal communications, culture and Resident agitation.

Culture and Quality of Life

Throughout the interviews, six themes were generated which recognized the impact of culture to quality of life: diet as an expression of culture, language barriers and exclusion, relationship quality with caregivers, sensitive delivery of care, care providers' culture and Resident cultural preservation.

Diet as an expression of culture. Diet was frequently referenced as a way to celebrate Resident culture at the nursing home. One person stated, "…*[I] recognize that their diet is different, [and that]… my bringing in Chinese food tomorrow in recognition for Chinese new year is a good thing."* Additionally, another participant stated *"well, you know sometimes we have special days for those residents that are from a different country…For instance, if [the Resident is] from India. And a family member was with her who told us about India. And then we served some Indian food."* Similarly, another respondent noted *"right now we have a gentleman from Lebanon, so his diet…his family brings in different ethnic foods at times."* The research revealed that care providers used diet and ethnic foods as a means for enhancing the Residents' quality of life.

Language barriers and exclusion. Resident quality of life was reported to be negatively impacted by language barriers. At least one person felt that activities and social events were limited for Residents speaking languages other than English. This respondent believed providers focused less on the Residents with whom they had a communication barrier. For example, the respondent stated *"with our activities, they're [providers are] more in-tuned to the Residents that are easier to take care of."* Additionally, the respondent felt that volume or variation of activities did not improve inclusion rates for language impaired Residents. The respondent stated *"There are a lot of therapies and activities, but I think they're more in tuned to the easier people."* The research revealed that language barriers can limit or exclude Residents from activities and impact their quality of life.

Relationship quality with caregivers. Six of the seven participants revealed relationship development and trust as a major theme in providing quality care. The ability for a care provider to build trust with a Resident is directly related to their ability to deliver care. The participants varied, however in how they interpret culture's role in relationship development. Two participants indicated that culture was not a factor in building trust. One participant responded *"when a person has AD, no matter what culture they are, it's mostly in the approach. If you can get them to buy into you and be comfortable around you, then the care is easy no matter what."* The other suggested that short term memory loss nullifies the impact of cultural differences because *"they have such short attention span, they don't remember what you said five minutes ago."* Both of these participants felt that culture was not a significant factor in building trust.

Conversely, four respondents suggest that culture plays a significant role in a provider's ability to build Resident relationships. On a scale from 1 to 10 with 10 representing the most

difficulty, one respondent felt that their challenge in bonding with people from a different culture ranked an eight. This person stated *"it's very much hard to connect [with those from other cultures]"*. Another participant recognized culture as a key factor in building trust by stating the following:

> *We had a resident who did not want to take a bath and did not want to do anything [due to dementia]… The question is: how do we get her to take bath? How do we get her to get involved? We realized that taking communion was a big thing for her. You know, taking her to chapel, telling her we had to go to chapel, and so this was the issue and trusting relationships was another issue. She didn't trust anyone. She didn't want to take bath. So how do you get her to trust you? This is something she grew up doing all of her life. One of the staff takes her to church and she started developing a relationship with that staff. And that translated her to taking a bath. And that translated into her having friends.*

Another participant believed that racial differences effected trust. This respondent stated: *"There are a lot of white elderly residents that they start out not comfortable working with the aids of a different culture."* Some shared their opinions on how knowledge of a Resident's background and culture helped to accelerate relationship development. One person said *"normally when I take care of a Resident, you already know who the Resident is because the care plan tells you everything about this person."* Another participant said:

> *We put a big sheet of paper up that says "get to know me" and we write down all of those things that they like. If they dislike something, let's say the eye contact thing, if they don't like eye contact (people from Africa sometimes don't like eye contact), if it's something like that we would write that in there.*

The general response of those interviewed recognized that knowing information about a Resident was an asset in building a relationship and delivering quality cares; however opinions on the implications of culture were somewhat varied.

        Sensitive delivery of care. Throughout the interviews, respondents repeatedly referenced their need to think like the Residents. In essence, the limits AD places on a Resident's ability to communicate, requires the care providers to continuously get inside the Resident's mind. Coupling communication issues with intense confusion, understanding a Resident's needs and situation is significant to providing care and limiting aggressive responses. An example of this approach is illustrated through this respondent's comments: "I go there in the morning and I start their day, putting their minds into my mind. I say 'ok, you know this person could have gone to the bathroom.'" One participant discussed the importance of knowing a person's history in delivering care as illustrated in this reflection:

> *One thing I found in dementia is that several WWII vets were kind of difficult to work with. One family member said that the one guy was always kind of in charge. In the war, he was a leader in his platoon. She thought that perhaps he couldn't understand he was back in his time. With that fella, I had to say to him, "you know, I need you to help me. You see these other people in here? Well, we're all in this together and they're going to watch you and if you watch me they're gonna get through this".*

The respondent noted a positive response from the Resident when elements of their history were brought into the context. Another discussion emphasized the importance of knowing religion in delivering care. The respondent shared an intervention strategy based in religion as follows:

> *I had one lady said that she didn't think it was proper for women to exercise. I had to think about that because I didn't really know how to respond at the moment. The next*

time I invited her to exercise I said "does it say in the Bible that we should take good

care of our health?" and she said "yes" and I said so, does the Lord want us to do the

best we can with the body he's provided? And that's how I got her to come.

Other respondents shared a similar opinion in that knowing a person's cultural background assisted in providing care. One respondent stated:

Some residents like to pocket their food, if you look at the generational differences, you'll

see that during the time of the Great Depression, people kept their food and if you

understand their history, you'll understand that it's not that they want to keep their food,

it's their mind is saying to keep it.

In addition to improving care, respondents felt that knowing a Resident's cultural background helped to limit or prevent aggressive responses. For example, one respondent applied knowledge of racial tensions in care planning. This respondent stated: *"sometimes I have to be very sensitive of putting an African black resident next to a very elderly female (white) resident who I know for a fact argues with her black caretakers."* These respondents believe that in order to most effectively deliver care and improve quality of life, they have to think like the Resident and that culture plays a key role.

Care providers' culture. There was one theme related to culture which had less to do with cultural sensitivity toward the Residents than it had to do with the care providers themselves. The culture of the care providers was referenced by three of the respondents as being a central factor in their ability to deliver care. One participant stated:

Every culture is a little bit different in how you approach them. And actually, not only

just Resident to care taker, but care taker to care taker, you've seen instances of us

working together cultural clashes because we didn't understand each other.

Another respondent reinforced this message by saying, *"You know the moment you have nurses and nursing assistants not talking to one another because of their belief system, who suffers? The Resident who is in the middle of that."* Additionally, there are cultural differences between staff and their interpretations of the role of the nursing homes in our society. One participant shared this opinion: *"Their [staff from another country of origin] elderly were never in what I would call an 'institution', they kept them at home. They don't understand how you send your grandma to a 'home'. I think a lot of times you hear 'how could they send their grandma's to assisted living?'"* These opinions indicate that a care provider's culture can influence how they provide care and their ability to manage the Residents' quality of life.

Cultural preservation. At the end of each interview the participants were asked whether or not they felt preserving culture was important in maintaining a person's quality of life if their memory was atrophying. Six of the seven participants responded that maintaining a person's culture was an essential part of maintaining their quality of life. For example, one person stated, *"It is important because they belong to society."* Another respondent similarly stated *"Because that's their right as a human being. Have their religion and their faiths out there, I think that's important because it's very important for every human being regardless if they have AD or not."* One of the seven interviewed felt that the mind atrophy made cultural preservation less significant. This person stated:

> *No. I don't. I think as the mind atrophies there is less that they …I don't know, let me*
> *think. I don't want to say it's not important (as far as diversity), as far as cares go, I*
> *don't see it. They're still an individual, we want to respect their dignity and their cultural*
> *beliefs. But does the Resident display it? I don't think so. I think a lot of it is lost.*

The majority of the respondents believed that culture was a significant part of managing Resident quality of life. While the one dissenting voice believed that the person's dignity and cultural beliefs should be respected, they did not think these persons displayed their distinct culture.

Discussion

The purpose of this research was to discover the how a care provider's cultural competence impacts the quality of life of a person with Alzheimer's disease. The research examined how culture impacts the areas of environmental familiarity and aggressive response management which are both established focuses for managing quality of life. The topics of diet, verbal communication, body language, delivery of care, relationships, care provider culture and cultural preservation were presented as themes most common to culture and quality of life. Professional care provider perceptions were explored to better understand how to best care for this population.

Diet (Familiar and Expression of Culture)

All of the respondents recognized how culture factored into care as it relates to Resident diet. Expressing culture through diet was seen as valuable based on Resident familiarity with food, nutrition, and a means to improve their quality of life through ethnic celebrations. Similar to the research of Moore, Gilbert, Jacelon and Ready (2010), where dietary intake was improved by using familiar music, this study indicates that intake improves when the food itself is familiar. In addition to diet intake or nutrition, care providers reported that diet is a vehicle for introducing culture into community events and enhancing quality of life. Given the existing research and the results of this study, it is important for care providers to understand what kinds of foods are familiar to a Resident.

Verbal Communication

Verbal communication was a significant theme in this research. Only two respondents indicated that cultural differences between the Resident and the care provider make communication more complex than AD alone. Care providers had difficulty understanding Residents with unfamiliar accents or who did not speak English well. This communication barrier sometimes resulted in problematic situations. Likewise, unfamiliar accents of the care providers were reported to be confusing to Residents. These results were consistent with Todd (2002), who found a negative correlation between agitation and how effectively care providers communicate. If the Resident is unable to understand the care provider due to an unfamiliar accent, frustration or agitation could occur. The respondents of this study did not comment on to what extent accents were posing problems. Also, the opinion that accents pose a communication barrier was not universally reported by the sample.

The participants' commonly reported that caring for non-English speaking Residents was more difficult. The study found varied intervention strategies to mitigate the impact of language differences. Strategies including reliance on family, other staff members and pictures to diffuse the problem. For example, signs were posted in the nursing home written in the Resident's language to help provide direction. Additionally, staff who spoke Resident languages were relied upon to write messages for the Residents to be passed along by non-native speaking staff at later times. Also, it was suggested that those Residents speaking another language inevitably had limited involvement in community activities. This is consistent with findings from the U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ), (2003). AHRQ (2003) reported barriers to care were caused by language barriers,

among other things. If a care provider and the Resident do not speak a common language, there would be an impact to a Resident's inclusion and quality of life.

Body Language

Body language was another common theme presented in the context of culture and AD care providing. Some respondents believed that body language was not universal and that culture should be considered by AD care professionals. Other respondents believed that body language is universal, especially the methods taught as standard AD approaches. One respondent said that eye contact was a good way to make the Resident feel loved and another said that eye contact with Native American Residents was to be avoided. It is important to understand if facial expressions and posturing are universal or if there is room for interpretation on intent. Social construction theory suggests that people are influenced by their social exchanges. This would imply that respondents from the dominant culture may not see the importance of cultural nuances because they have not experienced social interaction barriers to the same extent as those in the minority.

Respondents did not discuss the relationship between body language and aggressive responses as indicated by previous research. Research conducted by Whall, et al. (2008) reported that the negative behavior of a care giver (tone of voice, facial expressions, posturing, etc.) is associated with inducing aggressive responses in AD (2008); however there was no available literature on the effects of different cultural communication styles in instigating aggressive behavior.

Sensitive Delivery of Care

The effect of culture on the sensitive delivery of care was a strong theme throughout the study. The research results indicated that in order to most effectively limit aggressive responses

and improve quality of life, care providers had to think like the Resident. Most respondents

indicated that cultural competency was essential to effectively interpret thoughts and actions for

Residents; however one participant did not feel that culture was relevant in providing sensitive

care.   Most respondents also recognized the benefits of understanding cultural elements like a

person's religion or history to provide more effective care. Additionally, we may infer that as

the quality of the care provider's technique improves, the Resident would be more relaxed, less

agitated and sustain improved quality of life. The more a care provider knows about a person's

background, the more they can bring familiar and meaningful context to a given situation and

improve their interaction. This is consistent with cultural competence literature suggesting that

cultural adaptive programming improves access to care (Sloots, et al., 2011). It is important to

recognize that cultural competence appears to be central to many healthcare interactions and that

social workers should advocate for cultural competency in any healthcare interaction, even with

persons with Alzheimer's.

Relationship Quality with Caregivers

The study revealed that culture was important to the care provider's relational

development with the Resident. These responses were consistent with the literature as it related

to limiting aggressive responses and improved quality of life based on the nature of the

relationship with the care provider.   According to Whall, et al. (2008), familiarity with a care

provider limited the chance for aggressive responses; however they did not factor culture into the

study. Additionally, this study recognized tone as a factor in provoking aggressive responses.

This study requires a care provider to both be familiar to the Resident as well as be perceived in

a positive light. As noted in by the respondents in this study, it is important for care providers to

build trust with their Residents. Some respondents felt that their culture limited them from

creating bonds or building trust with Residents. One respondent felt that culture did not factor into a care provider's ability to create relationships with the Residents. If culture were a factor in how well a provider developed a relationship with a Resident, it may be that providers should be paired with Residents based on their backgrounds to maximize their ability to sustain quality of life. It may also be that the respondents interpret culture and its impacts differently as supported by the theory of social construction.

Care Providers' Culture

The study revealed care providers' culture as a theme. The literature did not focus on interpersonal dynamics of the care providers, however, several of the participants did. The respondents suggested that cultural competency should not only be afforded for the Residents, but be demonstrated between staff members. One respondent observed that when care providers were unable to function successfully due to culture clashes, the Resident's quality of life was put at risk. It is possible that cultural clashes between staff could also manifest in negative energy that translates through the providers into Resident aggressive responses. It would be important to maintain cultural harmony across all of the relationships.

Cultural Preservation

When asked the question of whether or not the participant believed that culture was an important factor in persons with AD's life, the majority responded yes. Many examples were provided in the study that indicated culture was a means of connecting with a Resident. Much information was provided suggesting that knowledge of a Resident's background was a useful tool in engaging them in daily care routines. Additionally, several respondents suggested that knowledge of cultural differences between the care provider and the Resident were required for effective communication. It is then logical to conclude that the more a Resident loses their

ability to communicate and the more confused they become as the disease progresses, the more

critical it is to retain knowledge about their culture. As a Resident loses the ability to both

produce communication and understand the communication of others, any cultural cue (such as

hand gestures, raised eyebrows to denote a question, etc.) could make a difference in receiving

communication. This is in line with cultural competence literature (Sloots, et al., 2011). It is

important for medical professionals to provide culturally sensitive programming by maintaining

and understanding of the Resident's culture and how culture factors into the Resident's sense of

familiarity, agitation and overall quality of life.

Implications for Social Work Practice

The results of the study suggest that culture plays an important role in understanding a

Resident's needs and managing their quality of life which in turn suggests the importance of

cultural competence of care providers. Given the increasing and ever diversifying AD

population as well as a diversifying care provider demographic, it is essential that social workers

advocate for culturally competent care. Nursing administration should be aware of how cultural

differences factor into a provider's ability to deliver care and implement related training and

intervention strategies to reduce the cultural gap. Given the extent of research conducted to

provide best practice guidelines for posturing and approaching people with AD, it would make

sense to expand the guidelines to include culturally competent factors such as diet.

Additional research would be beneficial in understanding to what extent culture factors

into familiarity, aggressive responses and quality of life. With respect to familiarity, social

workers must understand to what extent diet is impacted by culture and how to maximize

Resident nutrition. Additionally, a further understanding how verbal and non-verbal

communications are thwarted by cultural differences between care providers and Residents is

warranted. Also, there is more to learn about how care provider and Resident cultural

differences impacts the providers' ability to take care of the Resident. It is important to

understand if cultural differences can be overcome by consistence and routine.

Research is also needed to further understand how culture impacts a Residents' agitation

levels and aggressive responses. While existing literature suggests that aggressive responses are

influenced by familiar environments and relationships (Son, Therrien, & Whall, 2002 and

Moore, et al., 2010), verbal communication was the only theme revealed related to aggressive

responses. Empirical evidence is lacking as to whether or not communication barriers driven by

cultural differences influence aggressive responses in Residents. Providers could use such

empirical evidence to improve the quality of life of the Resident and reduce the impact agitated

Residents have on the provider and other members of the living community.

Finally, research is needed to assess how culture manifests in a care providers' ability to

sustain a Residents' quality of life. Research could be done to learn more about ways to improve

inclusion for non-English speaking Residents such as the impact of using culturally diverse

cuisine during group activities. Additionally, it is important to better understand how cultural

differences influence a care providers' ability to think like the Resident.   There is also more to

understand about what factors into a care provider's ability to bond and build trust with

Residents from a different culture. Not only is it critical to understand the impacts that bonding

has on the Resident's quality of life, it would also be beneficial to learn understand how bonding

levels impacts a care provider's motivation or performance and how awareness of culture

impacts care. It is also important to understand the extent that cultural clash between care

providers impacts Resident care. Lastly, research is needed to empirically demonstrate whether

or not culture is relevant for a person who is losing their cognition. Social workers need to better understand if memory loss translates into culture loss.

Quantitative research measuring things like the impact that unfamiliar accents and language barriers had on aggressive responses would be beneficial to bringing more attention to this population. Although this study benefited from context validity and rich data, quantitative research is necessary to understand to what extent culture impacts Residents' sense of familiarity, aggressive responses and quality of life. Also, quantitative research is needed to further generalize the findings. The use of a standardized instrument measuring providers' cultural competence would enrich the results and provide opportunities to make inferences based on competence. This purposive sample was limited by its lack of wide generalizability because of the narrow population the sample was drawn from (Berg, 2009). Additional research should include a larger sample.

In conclusion, the study of culture and Alzheimer's disease is becoming increasingly imperative. Given the expanding geriatric population and our country's diversified population, it is increasingly important to understand the impacts of culture on people diagnosed with Alzheimer's disease. The results of this study suggest that the cultural sensitivity of care providers plays a direct role in maintaining the quality of life for those living with Alzheimer's disease. Additionally, a lack of cultural sensitivity can lead to frustrated Residents, exclusion, aversion to standard care and poor nutrition. Social workers must continue to apply empirically based interventions to maintain the dignity and quality of life for the at-risk population suffering from Alzheimer's disease.

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Appendices

Appendix A

CONSENT FORM
UNIVERSITY OF ST. THOMAS
GRSW682 RESEARCH PROJECT

The importance of cultural sensitivity in care providing for people diagnosed with Alzheimer's disease.

I am conducting a study about the impact culture has on treatment for those diagnosed with Alzheimer's Disease. I invite you to participate in this research. You were selected as a possible participant because of your professional experience with nursing home residents and Alzheimer's disease. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Jacquelyn Lotter, a graduate student at the School of Social Work, College of St. Catherine/University of St. Thomas and supervised by Dr. Jessica Toft.

Background Information:
The purpose of this study is to understand how care professionals manage a person's cultural identity after being diagnosed with Alzheimer's disease and placed in a nursing home. The aspects of culture in focus for this study are race, traditions, religion, gender roles and family systems.

Procedures:
If you agree to be in this study, I will ask you to do the following things: Sign the consent form and participate in a 15 minute online survey followed by a 45 minute recorded oral interview. During the interview, I will be taking field notes that will be included in the research project. The interview will be transcribed and presented to a fellow GRSW 682 classmate to be coded into data categories. Data from the survey and interview will then be delivered to the University via an oral report and a written research report.

Risks and Benefits of Being in the Study:
The study has no risks.

The benefit of the study is the pursued understanding of how culture impacts the quality of care provided to people with Alzheimer's disease.

Confidentiality:
The records of this study will be kept confidential. Research records will be kept in a locked file in my office. I will also keep the electronic copy of the transcript in a password protected file on my computer. A research partner and my Research committee will have access to the transcripts but will not know who you are. I will delete any identifying information from the transcript. Findings from the study will be presented in my research paper and in a research presentation. Findings will also be made available to the Executive Director of the nursing home excluding any identifiable information. All distinguishing

information will be omitted from the report to protect your anonymity. The audiotape and transcript will be destroyed by June 1, 2012.

Voluntary Nature of the Study:
Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used.

Contacts and Questions
My name is Jacque Lotter. You may ask any questions you have now. If you have questions later, you may contact me at xxx-xxx-xxxx or Dr. Jessica Toft at xxx-xxx-xxxx. You may also contact the University of St. Thomas Institutional Review Board at xxx-xxx-xxxx with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:
I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audiotaped.

_____   _____
Signature of Study Participant   **Date**

_____
Print Name of Study Participant

_____   _____
Signature of Researcher   **Date**

Appendix B

Interview Questions

Research Question: In what ways is cultural competence important to improving the quality of life for people diagnosed with Alzheimer's disease?

Background: The purpose of this study is to identify how culture plays a role in care providing and shaping interventions. As a professional care provider, it is important to understand how your experience shapes your opinion on how culture impacts the care you provide for this population. The term "Resident" used in this interview refers to the person living at the nursing home who is diagnosed with Alzheimer's disease. The term "care provider" refers to you and the staff at the nursing home who work directly with the Residents. The term "family" refers to a member of the Resident's primary support system who may or may not be legally bound to the Resident.

Interview Questions:

1. What are some of your initial responses/reflections regarding the "Cultural Competence Checklist"?

2. What is your role at the nursing home?

3. Describe the ways you work to improve a Resident's quality of life.

4. Describe responses or emotions displayed by the Residents that you try to prevent (disruption to the community, physical aggression, self-harm, sleeplessness, rage, etc.) and your intervention strategies.

5. Describe some of the distinguishing cultural characteristics of the Residents at your nursing home (race, religion, language, diet, country of origin).

6. Can you give some examples of how you factor in the culture of the resident when you work with them?

7. Do you think your culture affects how you work with residents? Can you give an example?

8. What are your feelings about the practice of cultural sensitivity with respect to providing care?

     a. Does it improve quality of life? If so, how?

     b. Does it impair quality of life? If so, how?

9. Research suggests that Resident behaviors are tied to their sense of familiarity. Considering those Residents who have a different background than you, on a scale from 1 to 10 (one being not at all, 10 being very much), how much do your differences impact your ability to connect or bond with the Resident?

1   2   3   4   5   6   7   8   9   10

Can you explain your answer?

10. How do you take into account culture when you consider a Resident's socializing and enjoyment of activities?

11. Can you think of ways your culture effects your verbal and non-verbal communications and how you interact with the Residents?

12. Consider the residents and their cultural background at your facility. Is there anything in the physical surroundings or schedule for the day that you think either positively or negatively affects them?]

13. Persons with Alzheimer's Disease have many major challenges to face with their declining condition. In the big picture, do you think culture is all that important in their care? Can you explain?\

Appendix C

*Cultural Competence checklist: Personal Reflection

This tool was developed to heighten your awareness of how you view clients/patients from culturally and linguistically diverse (CLD) populations. *This assessment is a modification from the original. American Speech-Language-Hearing Association (2010). Cultural Competence Checklist: Personal reflection. Available:
www.asha.org/uploadedFiles/practice/multicultural/personalreflections.pdf.

Questions:			
1.	What is your race? (select one or more):	**"X"**	
			White
			Black / African American
			American Indian, Alaska Native
			Asian
			Native Hawaiian or Other Pacific Islander
			Other (please list)

To what extent do you agree with:		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
2.	I consider a resident's culture when working with them;"	1	2	3	4	5
3.	I do not impose my beliefs and value systems on my clients, their family members, or their friends.	1	2	3	4	5
4.	I believe that it is acceptable to use a language other than English in the U.S.	1	2	3	4	5
5.	I am driven to respond to others' insensitive comments or behaviors.	1	2	3	4	5
6.	I do not participate in insensitive comments or behaviors.	1	2	3	4	5
7.	I accept non-traditional families (i.e. divorced, same gender couples, etc.)	1	2	3	4	5
8.	I understand the difference between a communication disability and a communication difference.	1	2	3	4	5
9.	I understand that views of the aging process may influence the clients'/families' decisions to seek intervention.	1	2	3	4	5
10.	I understand that there are several American English dialects. I recognize that all English speakers use a dialect of English.	1	2	3	4	5

To what extent do you agree with the following: Culture impacts life activities, such as:		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
11.	Education	1	2	3	4	5
12.	Family roles	1	2	3	4	5
13.	Religion/faith-based practices	1	2	3	4	5
14.	Gender roles	1	2	3	4	5
15.	Alternative medicine	1	2	3	4	5

16.	Customs or superstitions	1	2	3	4	5
17.	Employment	1	2	3	4	5
18.	Perception of time	1	2	3	4	5
19.	Views of wellness	1	2	3	4	5
20.	Views of disabilities	1	2	3	4	5
21.	The value of Western medical treatment	1	2	3	4	5

To what extent do you agree with the following: Clients' cultural norms may influence communication , including:	**Strongly Disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
22. Eye contact	1	2	3	4	5
23. Interpersonal space	1	2	3	4	5
24. Use of gestures	1	2	3	4	5
25. Comfort with silence	1	2	3	4	5
26. Turn-taking	1	2	3	4	5
27. Topics of conversation	1	2	3	4	5
28. Asking and responding to questions	1	2	3	4	5
29. Greetings	1	2	3	4	5
30. Interruptions	1	2	3	4	5
31. Use of humor	1	2	3	4	5
32. Decision-making roles	1	2	3	4	5