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INVISIBLE INTERACTIONS: COMMUNICATION GUIDELINES FOR
CAREGIVERS FACING DEMENTIA-INDUCED SUBJECTIVE REALITIES

by

Christian Pollema

A Thesis Submitted in Partial Fulfillment
Of the Requirements for the
University Honors Program

Department of Communication Studies
The University of South Dakota
May 2019

The members of the Honors Thesis Committee appointed
to examine the thesis of Christian Pollema
find it satisfactory and recommend that it be accepted.

Dr. Jill Tyler
Chair of Communication Studies
Associate Professor of Communication Studies
Director of the Committee

Dr. Gerald Yutrzenka
Associate Professor of Biomedical Sciences
Associate Dean for Diversity and Inclusion

Dr. Kathy Magorian
Assistant Professor of Nursing
(Briar Cliff University)

ABSTRACT

INVISIBLE INTERACTIONS: COMMUNICATION GUIDELINES FOR CAREGIVERS FACING DEMENTIA-INDUCED SUBJECTIVE REALITIES

Christian Pollema

Director: Jill Tyler, Ph.D.

Dementia is a complex disease comprised of multiple stages, causing it to present differently from person to person. While many people characterize people with dementia as forgetful, this symptom is often coupled with one or more of the following: decreased competency in communication and language formation, impaired judgment or reasoning, a hard time focusing attention, and impaired visual and auditory perception. In light of these symptoms, it is not uncommon for an individual with dementia to experience mild hallucinations or subjective realities. While research with dementia patients has been conducted to observe how communication competencies are affected, as well as what communicative strategies may be utilized while completing activities of daily living, communication tactics utilized specifically when caring for patients experiencing some form of subjective reality has not yet been explicitly investigated. This is an important topic, as approaches to hallucination and delusion can significantly impact a patient's perception of, and engagement with, their surroundings and caregivers. This study aims (a) to shed light on what types of communicative strategies those caring for individuals with dementia use to bridge the gaps between their residents' environments and their skewed perception of them, and (b) to establish guidelines that caregivers may implement in their everyday practice.

KEYWORDS: Dementia, Communication, Caregiving, Hallucination, Psychosis,
Behavioral Psychological Symptoms of Dementia (BPSD), Mindful Communication

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PREFACE

I would like to preface my Honors Thesis by giving special thanks to the woman it is dedicated to: Emma Shuck. I first met Emma at the age of sixteen while visiting my grandmother at her nursing home. Over the course of the next year, I came to learn that Emma had no family living in the area and, consequently, no regular visitors. Despite spending the majority of her time alone, Emma was one of the most cheerful and genuinely kind people I have ever encountered. After my grandmother's passing in 2014, I continued my weekly visits to the nursing home to spend more time with Emma. During these visits I learned of her caring, selfless nature, serving as a school nurse for over forty years. Emma always prided herself on being ahead of her time, traveling solo as a young woman during the 1940s and seeing past racial prejudice. She especially loved to tell the story of when she rallied her fellow staff members to prepare a Christmas dinner to a less-privileged, African-American family that could not afford to buy one of their own. These were just a few of the anecdotes that I heard on a weekly basis; due to her dementia, Emma rarely remembered that she had already told me the stories of her life too many times to count. Strangely, though, I never got tired of hearing them.

After Emma passed away in 2016, I felt called to register for a CNA course, allowing me to continue spending time with the elderly. It was during my time working in a dementia-care unit that I first encountered the subjective realities that inspired this study's primary research question. I remember my first experience with a dementia-induced subjective reality very clearly: I went to escort a resident from her bedroom to lunch when I noticed that she was crying. I asked what was wrong and she said, "I can't. I just can't stand to look at her in a box!" When I asked who, she said, "My mother." I

came to the realization that this woman seemed to be reliving her mother's funeral and I, being a brand-new CNA, had absolutely no idea what I was supposed to do. I asked if she would like to go to the funeral reception and eat some food, suggesting that this may make her feel better. She agreed, and upon arrival at lunch table her anguish was resolved. Mine, however, was not. I was left nervous that my response was the wrong one; had I just confused this woman's sense of reality by lying to her? What would her response have been if I had told her that her mother had passed many years ago? Which was the *right* way? Which way was the more compassionate,? And did it make a difference?

If it would not have been for this experience, I do not believe that I would have taken interest in this specific topic or pursued such an in-depth project. And if it were not for Emma, I do not believe that I would have ever felt called to geriatric care. It has been over three years since her passing, yet I think of her frequently. Not only did my time spent with her foster a special place in my heart for the elderly, but her love of helping others influenced my own passion for service as well. Emma was an inspiring woman and I will never be able to thank her enough for all that she taught me during our time spent together. I hope that dedicating this project in her name it is at least a start.

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First and foremost, I wish to thank my family and friends for their advice, love, and support throughout my academic career.

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To Kathy Magorian: you and your nursing expertise served a vital role in virtually every stage of this project, having listened to my thoughts in its infancy and providing feedback on my final drafts. I cannot thank you enough for your patience or the direction and reassurance that you provided me throughout the course of this study. Additionally, your humble excellence and unparalleled compassion have inspired in me a revitalized outlook on medical practice that I hope to carry with me into my future career as a healthcare provider.

Although she is not listed as a committee member, the organization and writing of this project would not come even close to what it is without the enthusiastic help or grammatical savvy of Heather Love. I cannot begin to express my gratitude for your help on this thesis, determined instruction in English, or your never-failing belief in my academic pursuits. I wish you and your family the absolute best on your new beginning in Toronto.

I would additionally like to thank Gerald Yutrzenka for serving as a member of my thesis committee on top of his very busy schedule, as well as acting as my pre-

medical advisor throughout my undergraduate career at USD. Thanks to your patience and wisdom, I have always seemed to find my way. Furthermore, I would like to thank both Leah Seurer and Kelly McKay-Semmler for your thoughts, advice, and time. Though our meetings were limited, their discussions in addition to your courses' materials were extremely beneficial in the early stages of this project.

Finally, I would like to extend my utmost thanks to all of the caregivers who volunteered their time and knowledge by participating in this study. Your stories, experiences, and insights have allowed this project to flourish and it was an absolute honor and privilege to get to know each and every one you.

For Emma

I. INTRODUCTION

“I had this moment where I Googled the rules of caregiving for someone with Alzheimer’s. And I thought-- I wondered, for some reason, if they were even out there, if there was some.”

In this quotation, Karen Stobbe discusses her experiences caring for her mother, Virginia, who suffers from Alzheimer’s disease. This moment of wondering whether there is a “right way” to interact with people with dementia (PWD), which Stobbe describes in the 2014 podcast “Magic Words,” is all too familiar for many caregivers. Dementia is commonly associated with memory loss, but the term actually refers to a much wider array of highly-variable symptoms, which can make tending to those affected by it a highly dynamic process that appears different from person to person.

In many ways, this individuality of symptoms makes caring for PWD devoid of a distinct set of rules; there are, however, general trends and guidelines. The field of dementia care used to emphasize the principle of “keeping your loved ones with you, mentally speaking” (Joffe-Walt, 2014). Care providers may achieve this mode of care by frequently reminding people with dementia of who they are, showing them pictures of their friends and family, and hanging orientation boards to remind them of the present time, date, or weather. However, there has been a recent shift in focus: dementia care today is much more concentrated on validating PWD’s feelings and accepting that they may no longer see the world through the same lens as unaffected individuals (Elkins, 2011; Feil, 1982; Söderlund, Cronqvist, Norberg, Ternstedt, & Hansebo, 2016).

This shift toward effective, meaningful communication has been accompanied by frustration for many caregivers. Communication is a multifaceted process dependent on a collaborative exchange of information. However, as the disease progresses, PWD's capacity to communicate is often affected by their ability both to deliver messages and to comprehend them. Caregivers often struggle getting through to their patients, and frequently have trouble understanding what they are trying to say as well. It is crucial that a connection is found with PWD despite the various barriers that may prevent these relationships. As Elkins (2011) puts it, "once an effective communication bridge has been achieved, the individual is much more likely to remain calm and anxiety-free, and dialogue with healthcare professionals is significantly improved" (p. 17). Consistent with many other factors of dementia, these so-called communication bridges are incredibly variable and will look different in each individual.

Karen says that her breakthrough in caring for her mother occurred when she heard the phrase "step into their world," an idea that evoked parallels from her experience as an improvisation actor. She explains that to care for PWD, one must be able to constantly be "letting go of the old scene and trying to be ready for what's next" (Joffe-Walt, 2014). When her mother says something, whether it is coherent or confusing, Karen will often respond with the phrase "Yes, and?" She explains that her mother will often know how she is feeling but not necessarily why she's feeling that way. By using dialogue as a means to investigate, not only is Karen able to better understand how Virginia comprehends her surroundings, but she is also able to maintain a communicative relationship with her mother.

While this method of communication works for Karen, her husband, Mondy, takes it one step further. If Virginia says something that may not make complete sense, Mondy pretends that it is perfectly clear. For example, if his mother-in-law says that there are monkeys swinging from the trees outside of the window, Mondy not only “watches” the monkeys but he might even suggest that they *catch* one. He commits to her subjective realities unconditionally and interacts within her frame of understanding, even if it is disjunctive from the “real world.” This mode of communication is highly unpredictable, yet Mondy argues that Virginia is at her happiest when they are engaging in such discourse. These types of interactions with PWD add another layer to the complexity to dementia care: what does it really mean to “step [or, perhaps, in Mondy’s case, to *dive*] into their world?”

Karen’s “Yes, and?” strategy lines up with communication methods supported by several research studies while Mondy’s tactics are not substantially justified by any literature (Downs & Collins, 2015; Elkins, 2011; Söderlund et al., 2016). Although their tactics are similar in nature, the difference in the *degree* to which Karen and Mondy commit themselves to Virginia’s point of view (as well as the contrast of her responses) is intriguing. Her positive reactions to Mondy’s creative improvisations raise the question of whether other caregivers are utilizing similar methods. If so, are they effective? What are the “rules” for caregiving for a person with dementia when their contextual understanding of the world no longer mirrors your own? Is there a definite answer? The published literature surrounding dementia care has yet to tackle these important questions, although it does explore similar topics. The findings of this thesis will be prefaced by a literature review focused on the core themes currently guiding those caring

for PWD. The study itself aims to answer the question of how we can best establish effective communication bridges with those who are unable to perceive their surroundings the same way we do. Through interviews with both family and certified care providers, I hope to uncover and express the modes of communication caregivers commonly employ when interacting with PWD, more specifically, when they seem to be experiencing the world through a subjective lens or reality.

As a result of the current aging population, the number of cases of dementia globally is steadily increasing making this type of work more crucial than ever before. It is estimated by Meyer, Hariari, & Shellack (2016) that an individual's risk of developing Alzheimer's disease or vascular dementia, the two leading causes of dementia, doubles approximately every 5 years after reaching age sixty-five. This statistic positions dementia as the leading cause of both morbidity and mortality in elderly populations worldwide. With nearly 47.5 million affected, dementia has been deemed "one of the major health challenges of current times and a global public health priority" (Meyer, Harirari, & Schellack, 2016, p. 48). Taking this information into account, it is essential to take steps toward providing this growing population of PWD the right to a life of quality and meaning. It is my hope that this study is accessible and of value to those caring for PWD, and that its findings may contribute to an ever-growing body of literature working to assure these individuals the quality of life they deserve.

II. LITERATURE REVIEW

Defining Dementia

Before trying to understand how to best care for a person with dementia, it is essential to first know the various components of this complex diagnosis. First and foremost, dementia is not a specific disease, but rather an overarching term used to characterize a decline in cerebral activity drastic enough that it impedes upon affected individuals' everyday lives (Alzheimer's Association, 2017). There are various forms of dementia and, consequently, a wide array of associated symptoms. However, to be classified as a person with dementia, individuals must present with significant impairment of two of the following core cognitive functions: communication and language, the capacity to pay attention or focus, memory, judgement and reasoning, or the ability to interpret visual information (Alzheimer's Association, 2017). Deficits in cognition are commonly mistaken for a simple, natural result of the aging process. The structure of the brain does change with age, this is true. However, minor senescent changes are not the same as the more serious deficiencies that present with dementia. In many cases, though, the brain's dynamism can complicate the differentiation between age-related and disease-specific cognitive declines. Despite this fact, symptoms of dementia are generally associated with more specific diagnoses such as Alzheimer's disease, vascular dementia, or dementia with Lewy bodies. The following section will examine the most common classifications and causes of dementia.

Types of dementia.

Alzheimer's disease (AD) is the most common cause of mental deterioration in elderly populations, accounting for approximately sixty to eighty percent of all cases

(Meyer et al., 2016). AD is a degenerative disease in which neural connections and pathways are lost as a result of cell death in the cerebral cortex, a large portion of the brain that contributes to vital capacities such as memory, attentiveness, reason, language, and consciousness. The deterioration of this brain tissue is caused by beta-amyloid protein fragments that aggregate to create insoluble plaques between neurons. These plaques block the synapses between brain cells, compromising their ability to communicate with one another and ultimately resulting in cell death. Another cause of neuronal degradation in AD is the formation of neurofibrillary tangles of tau protein. In a normal neuron, this protein acts as a transport system for materials up and down the cell, similar to a railroad track. In AD, these proteins no longer function properly and instead intertwine with one another leading to a disruption of the cell's ability to move materials, eventually causing the neuron to die (Meyer et al., 2016; National Institute on Aging, 2010).

The location and degree of neuronal degradation in Alzheimer's patients is extremely variable, and, as a result, affected individuals may exhibit a multitude of symptoms. While memory loss is by far the indicator most commonly associated with this disease, those with AD may also exhibit sensory abnormalities, language deficits, difficulty reasoning, or behavioral changes; as cell death increases, more symptoms may develop or existing ones might worsen (Meyer et al., 2016). For this reason, the progression of Alzheimer's has been divided into three primary stages: early stage (mild), middle stage (moderate), and late stage (severe), according to Meyer and colleagues (2016). Early stage AD is typically characterized by the inability to perform routine tasks, minor changes in personality, and slight confusion or memory loss (i.e. misplacing

objects or forgetting names and recent events). Symptoms of middle stage AD may include needing help with activities of daily living (ADL), increased anxiety, agitation, paranoia, difficulty recognizing loved ones, or severe impairment of short-term memory. Those in the later stages of Alzheimer's exhibit decreased communication abilities, the inability to identify familiar faces, and are completely dependent upon caregivers. AD presents itself differently from person to person. Affected individuals may present a combination of symptoms from several stages, making treatment and care for those living with this condition highly variable and complex.

Following AD, vascular dementia is the second most commonly diagnosed type of dementia (Denning & Sandilyan, 2015). This form can be caused by a number of arterial diseases or episodes (i.e. strokes) that deplete the brain's blood supply. This reduced blood flow decreases neuronal function and eventually leads to cell death. Vascular dementia may present itself in a number of ways, and symptoms are dependent on the location and severity of blood deprivation in the brain. In addition to the previously discussed markers of Alzheimer's, vascular dementia patients also commonly exhibit depression, apathy, and a more pronounced, comprehensive slowing of basic cognitive processes. Following a major stroke, such indicators may appear suddenly and progress overtime (Denning & Sandilyan, 2015). However, other instances, such as a series of smaller strokes, may cause a slower development of symptoms.. Subcortical vascular dementia (small-vessel disease) consists of the narrowing of cerebral blood vessels, and may present a similar, gradual loss of cognitive ability due to continuous white matter damage (Alzheimer's Society, 2017).

Lewy body dementia is the third most prevalent type of dementia, accounting for nearly ten percent of all diagnosed cases (Denning & Sandilyan, 2015). This condition is very closely related to Parkinson's disease (PD), as both conditions involve the formation of Lewy bodies. These small aggregations of alpha-synuclein protein interfere with neuronal communication resulting in cell death. They are very similar to beta-amyloid plaques in AD, distinguishable only by the protein responsible for their formation. In PD, these protein clusters occur in the brain stem and the substantia nigra, areas responsible for the coordination of uninterrupted muscle movement (Green, 2015). As a result, those affected exhibit violent tremors, shuffling when walking, and reduced facial expression (Green, 2015). In Lewy body dementia, alpha-synuclein aggregates are not only present in the substantia nigra, but also throughout the cerebral cortex, causing an array of additional symptoms including memory loss, visuospatial disorientation, severe cognitive decline, and hallucinations (Denning & Sandilyan, 2015). Often times, Lewy body dementia is misdiagnosed as either AD or PD early on, because it is so closely related to the two. Generally, it is not until the symptoms of AD are accompanied by those of PD, or vice versa, that Lewy body dementia is properly identified.

While Alzheimer's, vascular dementia, and dementia with Lewy bodies are most common, they are not the only diagnoses that contribute to the 47.5 million individuals affected by dementia worldwide. There are a number of other types, including frontotemporal dementia and dementias formed as a side-effect of other conditions, such as Huntington's disease, multiple sclerosis, or HIV (Denning & Sandilyan, 2015). Additionally, diagnoses are not always restricted to a singular origin; the term mixed dementia refers to patients whose dementia has more than one cause. This is more

common over the age of eighty, with a combination of AD and vascular dementia being most typical (Denning & Sandilyan, 2015). Noting the wide array of physiological causes for neuronal degradation is essential in understanding the various ways that dementia may present as cognitive symptoms. Whether it be due to AD, vascular dementia, or dementia with Lewy bodies, the bottom line is that any of these physiological abnormalities may cause PWD to lose their capacity to effectively process information. In recognizing the root causes of these cognitive insufficiencies, the behavior of people with dementia can be better understood. The various effects that these changes in brain structure may have on PWD's outward behaviors is outlined in more detail in the following section, as they are pertinent to the questions proposed by this study.

Behavioral and psychological symptoms of dementia (BPSD).

The above section demonstrates numerous ways that neuronal degradation may impair one's cognitive abilities, but dementia can significantly impact an individual's behavior as well. The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) diagnostic criteria characterizes dementia's ability to impact one's social competencies: "[PWD experience] a significant decline in social and occupational functioning due to memory impairment with one or more of the following associated disturbances: aphasia, apraxia, agnosia, or dysexecutive disorder" (Reilly, Rodriguez, Lamy, & Neils-Strunjas, 2010, p. 439). These symptoms all take their toll on PWD's behavioral and communicative capacities, making it difficult for caregivers to effectively interact with them.

While various diagnosis-specific symptoms have been outlined, core traits contributing to "alterations of the perception, thought, humour or behavior" of these

patients may be observed across dementia-types (Milano, Saturnino, & Capasso, 2013, p. 32). These characteristics are defined as behavioral and psychological symptoms of dementia (BPSD). BPSD are highly variable and fluctuate between individual PWD. They are separated into four overarching clusters: 1) apathy, 2) depression, 3) agitation or aggression, and 4) psychosis. Due to substantial overlap in the presentation of these behaviors among specific dementia-types, these clusters are not reliable diagnostic tools. They are, however, useful in determining targets for drug therapy, and are often utilized by care providers when determining treatment plans (Milano et al., 2013).

Apathetic individuals experience a lack of enthusiasm and overall disinterest. These symptoms are closely related to depression, but these clusters remain separate because the depression also encompasses mood swings, feelings of hopelessness, low self-esteem, guilt, and profound sadness (Milano et al., 2013). Consistent with other markers of dementia, manifestations of depression are widely variable. Depression is also a risk-factor for dementia; these symptoms are more frequent in individuals who have experienced depressive states previously and are most commonly observed in early stage dementia (Milano et al., 2013). The behaviors of agitation and aggression are grouped into one cluster, although they present themselves quite differently. Agitation symptomology includes repetitive acts, wandering, and interrupted sleep patterns. Aggression may be demonstrated physically or verbally; aggressive PWD often exhibit threats, violent resistance, or destruction of property (Milano et al., 2013).

The fourth and final cluster of behavioral and psychological symptoms of dementia is psychosis, which consists of misidentifications, delusions, and hallucinations, and is the primary focus of the present study. The prevalence of these symptoms is

widely variable, appearing in anywhere from twenty percent to fifty percent of patients (Milano et al., 2013). One study focused specifically on hallucinations in AD found an even larger variance: “[hallucinations] may be observed in Alzheimer’s disease with a prevalence ranging from 4% to 73% of patients” (Haj, Jardri, Laroï, & Antoine, 2016, p. 1). As these subjective states are a core focus of this study, the following section examines the presentation of psychosis in PWD in further detail.

Psychosis: Subjective Realities and Hallucinations

In his 2012 book *Hallucinations*, famed physician-author, Oliver Sacks, contemplates the complexity of "discern[ing] where the boundary lies between hallucination, misperception, and illusion" (p. xi). What often makes the psychosis cluster of behavioral psychological symptoms of dementia (BPSD) so difficult to deal with amongst people with dementia (PWD) and their caregivers is the lack of consensual validation between the altered perception and the “real world.” In this section, the various behaviors associated with the psychosis cluster of BPSD and their causes will be outlined, and the implications of subjective realities among PWD will be explored.

Misidentifications and delusions.

Misidentifications and delusions are the first subset of the psychosis cluster, and can be characterized by any of the following types of behavior: a belief that there are strangers living in the home, misinterpreting sequences of events, confusing identities of others or one’s self, and accusations of theft (Milano et al., 2013). Fuji, Butler, and Sasaki (2014) describe PWD “often have disturbance in orientation and may have difficulty recognizing people,” (p. 204). To minimize these behaviors, the authors state it is more favorable for caregivers to respond empathetically than to confront their

misconception. The following example provides a more concrete way of understanding this approach.

Suppose a caregiver is falsely accused of stealing money by a resident with dementia. Knowing that this is untrue, she/he may respond defensively and try and correct any perceived gaps in the resident's understanding. In this scenario, it is unlikely that the resident will comprehend her/his shortcoming; it is more probable that she/he will perceive that she/he is being challenged, an emotion which often elicits a negative or defensive response in PWD. Situations such as these are difficult to understand because the PWD's misguided perceptions could be stemming from a multitude of causes. Many times, these behaviors are not the result of a single interaction, but are rather a singular release of delayed feelings compiled into one emotionally-charged response (Fujii et al., 2014). By responding sympathetically and catering to the resident's emotions, more often than not the caregiver's response will be favored and the resident will exhibit less BPSD (Fujii et al., 2014). Caregivers may do so by saying something along the lines of, "Oh no, that's terrible," emptying her pockets, and initiating a search for the missing money.

Fujii and colleagues (2014) state that while neuronal death has a strong effect on patients' neocortical function, their limbic systems remain relatively intact and symptoms consistent with the psychosis cluster are often caused by emotional distress. Through their analysis of Neuropsychiatric Inventory (NPI) data and depression rating scales, the researchers found that while cognitive aptitudes decline, the emotional abilities of PWD remain relatively intact. Fujii and his team argue that emotions belong at the center of care as they are the "fundamental being of the patient and the source of ultimate quality

of life” (Fujii et al., 2014, p. 206). But is there further evidence supporting PWD’s emotional capacities go uncompromised as their disease progresses?

The limbic system, which Fujii and colleagues (2014) state remains intact in PWD, is a complex network of the brain, comprised of the hippocampus, amygdala, fornix, cingulate gyrus, septal nuclei, and mammillary bodies. Together, the components of this assemblage are recognized as the neuroanatomical structures responsible for memory, emotion, and learning (Fujii et al., 2014, 204; Hooper & Vogel, 1976). Perhaps the most vital organs to these functions are the hippocampus and the amygdala. Upon postmortem pathological assessments, a study conducted in 1976 found that the hippocampi of all brains examined were markedly affected by Alzheimer’s disease: “neuronal loss was usually prominent and rarely, if ever, were the remaining neurons normal” (Hooper & Vogel, 1976, p. 7). This structure is responsible for the transmission of short-term memories to long-term storage in the cerebral cortex. Its function was discovered when a team of surgeons removed a patient’s entire hippocampus to treat an unmanageable case of epilepsy. Upon waking up, the patient was able to remember his entire life prior to his operation but was unable to maintain any new memories, illustrating that the hippocampus is absolutely essential for laying down new memories in the brain” (Ramachandran & Blakeslee, 1998).

With hippocampal degradation being among the first of effects of Alzheimer’s disease (AD), these findings are consistent with the disease’s distinctive short-term memory loss and inability to learn new information (Simons, 2014). Meanwhile, pathologies of the brain tissues affected by AD revealed neuronal death in the amygdala to be drastically sectioned off from unaffected regions. Typically, large numbers of

neuronal plaques are juxtaposed by regions of brain tissue free of any indication of protein aggregates or cell death (Hooper & Vogel, 1976). The amygdala is recognized as the integrative center for emotional behavior and attention (Gallagher & Chiba, 1996). Although this structure did show degradation in Simons' study, according to the Alzheimer's Society (2017) the amygdala is often affected much later than the hippocampus. This could explain PWD's ability to comprehend emotional aspects of an event, even though they may not recall the factual content surrounding it (Simons, 2014). This information indicates that while Fujii and colleagues were accurate in stating the emotional capabilities amongst PWD are preserved, the limbic systems of those living with dementia do not go entirely unaffected. Rather, it is the degree to which components of the limbic system are affected that conserves an individual's ability to recall and recognize the emotional elements of a given situation.

Hallucinations and their causes.

Another example of psychosis associated with dementia is the occurrence of hallucinations, which are defined as "perceptual experiences that occur in the absence of any corresponding external stimuli" (Haj et al., 2016, p. 1). This is perhaps the most obvious form of PWD's misunderstandings of their surroundings. As mentioned previously, hallucinations are most typical in Lewy body dementia due to plaque deposits in the cerebral cortex. However, these manifestations may be present in other forms of dementia as well. Pathologically, this symptom can be attributed to protein aggregations and neuronal degradation in the hippocampus, sensory cortices, and the prefrontal cortex (Haj et al., 2016).

Additional physiological causes may attribute to hallucinations in PWD, but they are more closely associated with patients' advanced age than they are with their dementia. One example of this type of hallucination source is Charles Bonnet syndrome (CBS), a rare condition associated with partial or complete blindness (Sacks, 2012). Patients with CBS present with intricate visual hallucinations in accordance with ocular deterioration, and nearly always are aware that their perceptions are a result of their condition (Nair, Nair, Shah, & Ghandi, 2015). Though these patients recognize their hallucinations are not real, the hallucinations present themselves as vividly as if they were. This phenomena is described in a 1998 study conducted by ffytche and colleagues in which patients with CBS underwent a functional MRI scan while actively hallucinating. For those who reported their visions to be in color, activity was observed in the V4 region of the fusiform gyrus (a color-processing center in the brain), whereas stimulus in those who reported their hallucinations to be in black and white was found to be outside this area (ffytche et al., 1998). These MRI findings indicate that although the subject's eyes are no longer able intake information visually, their brain is able to produce and process information as if it were actually there. As previously mentioned, most individuals with CBS are aware that their realities are subjective, but if present in PWD this may not be the case: "if there is an ongoing dementia ... there may be less and less ability to recognize hallucinations as such -- which, in turn, may lead to frightening delusions and psychoses" (Sacks, 2012, p. 28).

While dementia with Lewy bodies and Charles Bonnet syndrome can both be attributed to physiological degradation, not all sources of hallucinations can be so easily pinpointed. Many people tend to associate symptoms of psychosis with mental illness or

insanity (e.g. schizophrenia, delusional disorder, etc.), while the surprising reality is that nearly twenty-eight percent of the general population admit to having a psychotic-like experience at some point in their lifetime (Daniel & Mason, 2015). Hallucinations and similar occurrences may be caused by a multitude of experiences that are common among the elderly, including loneliness and bereavement.

Because loneliness is defined as “discrepancies between one’s own expectations and one’s actual relationships,” individuals may still feel alone even if they are surrounded by other people (Jansson et al., 2017). Psychiatrist Frieda Fromm-Reichmann spent a large portion of her career studying loneliness and its various implications on the human psyche. She notes that nonconstructive loneliness has the power to emotionally paralyze those who suffer from it, and even produce psychotic states (Fromm-Reichmann, 1959). This information is worrisome, as loneliness is more common than ever in elderly populations. In a recent study examining seclusion, 26% of nursing home residents reported feeling lonely sometimes, and 9% reported feelings of isolation often or always (Jansson et al., 2017). These elevated levels of solitude may be attributed to the loss of a spouse, shrinking social networks, separation from one’s children or family, or the loss of one’s home or long-term community as elderly people frequently move into long-term care facilities (Singh & Srivastava, 2014). The prevalence of loneliness amongst elderly populations may stem from a multitude of factors, and some hallucinations could be attributed to this psychological phenomena as opposed to more physiological explanations.

On the same note, interactions with stimuli that are not in physical existence may occur more frequently with the loss of a spouse or other close relationship. In a 1996

study, 80% of respondents reported perceiving their deceased loved one's presence after their death (Weiner, Aikin, Gibbons, & Hirschfeld). These stimuli have even been reported to be experienced through all five senses (Hayes & Leudar, 2016). For the purposes of psychological medicine, these occurrences have been classified as hallucinations, yet many who experience them choose to view them as apparitions or instances of continued presence (Sacks, 2012; Hayes & Leudar, 2016). This class of hallucinations differs from others in the sense that they are often regarded as meaningful experiences, contributing to the quality of one's healing process. However, if one interacts with their bereaved 'ghost' for too long, the continued relationship could lead to clinical depression, a lost sense of reality, or pathological grief (Hayes & Leudar, 2016). Given their tendency to fall into psychotic states, PWD suffering from bereavement hallucinations may be at a higher risk of losing touch with the "real world."

An intriguing component of hallucinations caused by Charles Bonnet syndrome, loneliness, and bereavement is that they all seem to be serving some sort of compensatory mechanism. In CBS, visual hallucinations replace degraded or lost eyesight while in loneliness and bereavement, variable sensations may be manifested in the presence of perceived isolation (Sacks, 2012; Hayes & Leudar, 2016). This phenomenon is not restricted to these instances, either: "Whether darkness [or] solitude ... the deprivation of normal visual input can stimulate the inner eye instead, producing dreams, vivid imaginations, or hallucinations" (Sacks, 2012, p. 34). These vivid experiences are commonly referred to as "the prisoner's cinema," in reference to inmates in solitary confinement, but they have also been observed amongst sailors, polar explorers, long-distance truckers, and pilots (Sacks, 2012, p. 34). Hallucinations as a result of sensory

deprivation are significant in regards to PWD in light of their physical and psychological condition. As the prevalence and severity of dementia increases with age, so does the degradation and loss of other capacities such as sight, hearing, and sometimes even speech. Additionally, with shrinking social networks and separation from those closest to them, many elderly individuals report feelings of social isolation or loneliness. In response to these losses, PWD may experience hallucinations to replace stimuli that they are no longer able to engage with, whether sensory perceptions or social interactions.

The previous sections provided a wide overview of the various components contributing to the global health challenge dementia poses today. Between the varying causes of this diagnosis (AD, vascular dementia, etc.), individual stages of severity, varying ranges of symptoms, the four clusters of BPSD, and, more specifically, the multitude of possible explanations for hallucinations and subjective realities, the inherent irregularity of dementia cannot be ignored. Each case is unique. These idiosyncrasies are a large component of what makes establishing best-practices for caring for individuals with this neurodegenerative condition so challenging. As context for the methods and findings of the current study, the following section reviews a range of literature discussing communicative strategies for interacting with PWD, highlighting the various ways in which caregivers are currently navigating the communicative and perceptual deficits of their patients.

Caregiving Literature Today

The previous sections outline the various explanations for alterations in behavior commonly observed in people with dementia (PWD). These descriptions of neurological degradation's effects are based on objective pathological findings and correlative

scientific observations substantiated by numerous clinical cases. While caregiving literature, too, is supported by reproducible outcomes, it is much more loosely based on scientific objectivity. Articles regarding communicative aspects of dementia care profess the importance of tending to PWD's psychological and emotional needs. These facets of human existence are widely recognized as subjective, making the research surrounding them far more qualitative than quantitative.

As outlined in previous sections, difficulty communicating is a common symptom of dementia and is determined by the type, severity, and comorbidities of the disease. Changes in PWD's communicative capacities often result in social exclusion and social isolation, which may eventually lead to a weakened sense of identity, depersonalization, unmet needs, objectification, and an overall poorer quality of life (Downs & Collins, 2015). Alongside reduced communication skills, anxiety and depression often emerge which, in turn, have a negative effect on communication confidence (Allan & Killick, 2008). However, communication is a collaborative act, and a caregiver's difficulty is, to some effect, due to their own inadequacy as communicators as well. The Commission for Social Care Inspection (2008) commented on the insufficiency of communication between PWD and staff in nursing homes, stating that the current state of typical nurse-patient relationships is being significantly influenced by *each* party's ability to communicate, not just the demented (as cited in Downs & Collins, 2015). The literature presented in this section provides a basis of the general trends surrounding the communication strategies for caregivers in dementia care today, highlighting the concepts of validation therapy, communication bridges, and person-centered communication.

The innovative notion of validation therapy was brought onto the dementia care scene by Naomi Feil with her publication of *Validation: The Feil Method* (1982). It has been both celebrated and criticized for its radical suggestions that the subjective realities of PWD are a product of the “resolution stage” of developmental psychology, rather than a consequence of the accumulation of neuronal plaques in the brain (Atwood, 2005). According to Feil, PWD exhibiting BPSD are working through unresolved internal dialogues, suggesting that the seemingly erratic behaviors of people with advanced dementia are caused by historical and deeply personal conflicts. Feil directs caregivers away from typical interventional methods, such as reorientation or distraction, challenging them to face these behaviors head-on. By validating the emotional responses presented by PWD with contemplative understanding of their feelings of guilt, fear, or panic, caregivers may be able to help them work through these internal struggles and, in turn, decrease the presentation of BPSD (Atwood, 2005).

Feil’s notion of the resolution stage of Alzheimer’s disease (AD) has received some pushback for its lack of empirical, scientific evidence. Many critics question Feil’s methods, as her writing contains many case-specific examples and informal explanations. One critic questions Feil’s principles in stating “she believes that use of Validation can prevent someone with Alzheimer’s from slipping into vegetation. Science does not necessarily support this. There is continued buildup of plaques and tangles and ongoing loss of brain cell function” (Atwood, 2005, p. 182). Yet, validation therapy has continued to grow in popularity and use. Those utilizing Feil’s methods far and wide profess their efficacy, prompting the publication of the *Validation Training Program* in 1999, making validation therapy accessible to a broader audience. Despite its lack of formal objective

evidence, Feil's work is still admired today for its simplicity, effectiveness, and humane virtue.

Similar to Feil's approach, other alternate explanations for the behavior of patients with advanced dementia have been offered. Passmore, Ho, and Gallagher (2011) suggest that BPSD can be explained by some other discomfort, whether directly related to their dementia or not. They propose that behaviors observed in PWD could be a response to underlying physical pain or psychological irritation resulting from their senescent physiological decline. As dementia often decreases communicative capacity, these PWD may be unable to voice their discomfort resulting in BPSD. Despite their patient's inability to properly convey their desires in the end-stages of their disease, these researchers do not feel that this means they are any less entitled the right to a quality of life, comfort, or dignity. For this reason, they argue that PWD should be provided palliative care options, which aim to deliver patients a sense of agency and mental well-being during their declining physical health (Passmore et al., 2011).

Passmore and colleagues (2011) additionally recognize the complex web of factors that play into the bioethical decision-making of caring for a person with dementia. They outline just a few, including medical indications (risk analysis of antipsychotic use, beneficence vs. non-maleficence, etc.), patient and family preference, contextual factors such as resources and caregiver stress, and overall quality of life. All factors must be considered in providing PWD dignified lives of comfort and meaning in their final days, and the research team assesses them with equal weight in their publication (Passmore et al., 2011). The consensus they reach states that in order to adequately provide PWD lives

worth living in their final days, efforts must be taken on an individual basis; they refer to this notion as person-centered care.

Accompanying person-centered care, the term “personhood” has been increasingly present in the vocabulary of dementia care. The concept of “personhood” is focused on both the boundaries and interactions that exist systematically between both humans and their surroundings. In other words, a human being is not inherently a “person” without some degree of interaction with the relational aspects of societal life (Passmore et al., 2011). Kitwood (1997) describes personhood as a status that is ascribed to one person by a social group and implies recognition or respect. In the context of AD or dementia, Buron (2008) defines three specific levels of personhood: biologic, individual, and sociologic. The biologic level implies a position of basic awareness or sentience, while individual personhood considers the intricate characteristics of one’s personal life, including history, values, spirituality, personality, and self-image. Finally, the sociologic level of personhood is characterized by how the person as an individual is seen and treated by society.

There is evidence that when PWD are tended to with an alertness, attention, and respect for their varying levels of personhood, they exhibit a heightened awareness, fewer BPSD, and a greater overall sense of well-being (Swedish Council on Technology Assessment in Health Care, 2008). Addressing one’s personhood can be achieved by taking the necessary measures to decrease anxiety, foster self-esteem, and minimize perceptions that they are bothering others with their presence (Sabat, Fath, Moghaddam, & Harré, 1999). Achieving these goals can play a significant role in assuring PWD a sense of dignity. However, doing so can often prove to be a difficult task; promoting

one's personhood is largely communication based, and it is understood that communicating with PWD can be a challenging process due to the very nature of the disease (Elkins, 2012).

Elkins (2011) recognizes the varying components of dementia that may account for gaps in communication with those affected, but proposes several techniques that can help to “develop interaction and enhance a feeling of wellbeing [to] improve care and increase practice efficiency” (p. 16). Elkins encourages caregivers to serve as a link that connects the gaps in information with their patients. She proposes this may be achieved by attempting to continuously search for behavioral clues as to what may generate positive reactions, negative reactions, or BPSD. The use of direct or close-ended questions are largely discouraged as they put strain on the working memory and can raise patients' level of stress (Elkins, 2011). Additionally, Elkins promotes the use of information sheets. She describes these resources as info-graphical documentation developed to help caregivers use associations from their patients' past to better grasp what they are trying to achieve in the present. Elkins (2011) states “through using intact positive memories from the past, [PWD] can be gently steered to a position in which they understand and accept the context in which treatment is being provided” (p. 18).

Elkins (2011) further discusses the importance of recognizing that communication bridges can always be found by taking the time to listen to PWD. She regards PWD as ‘experts,’ and states that they, and they alone, can provide you with the information needed to effectively form communication bridges and deliver appropriate care. Repetition of single words or phrases should be regarded as significant communicative attempts instead of annoyances or wastes of time. The patient should never be blamed by

a caregiver for complicating care delivery as it could damage their already fragile self-esteem (Elkins, 2012). Above all else, Elkins (2011) professes the message that “taking a few minutes to provide quiet assurance, imparting the feeling that all is well, is a good investment of time” (p.19), as it encourages breakthroughs in communication and helps to retain individual PWD’s sense of identity and self-worth.

More recent caregiving literature stresses the communicative aspects of care as well. Authors Downs and Collins stress that the terms ‘cognitively impaired’ and ‘communicatively impaired’ are not directly interchangeable; many PWD retain the ability to communicate to some extent, whether verbally, non-verbally, or both (Downs and Collins, 2015). For this very reason, the authors argue that communication must be regarded as an individualized, person-centered pursuit that takes into account the subject’s abilities and needs. Their article provides concrete communication strategies for conversing with a person with AD, as well as some more specific person-centered tactics.

Downs and Collins offer that when communicating with a person with dementia, it is essential that their attention is gained prior to beginning a conversation. They recommend that you ensure you are on the same physical plane so that eye-contact is natural and easily maintained; reducing background noise and other distractions can aid in maintaining PWD’s attention in conversation as well. They encourage caregivers to speak clearly and listen actively, allowing ample time for responses so that misunderstandings or gaps in communication are not overlooked. Visual cues are promoted as well; the authors comment that offering visual choices can often be helpful (i.e. providing two plates of food instead of a written menu) in decision making, and liberally using gestures and pictures may help propel conversations. These details may

seem minute, but in caregivers' hectic lives they may often be overlooked for that very reason. Taking the time to slow oneself down in communication can often make a significant difference in PWD's responses, and influence the overall course of their communicative behavior.

Downs and Collins offer additional communication strategies which are better tailored to person-centered communication and tending to individual patient's specific strengths. They state that in attempting to effectively converse with a person with dementia, it is essential to know them *wholly*; the authors stress the importance of acknowledging their personality and life history. In doing so, caregivers are better equipped to recognize what their patients value, what makes a conversation meaningful, and how to develop a more impactful, longer-lasting relationship with their patients overtime. They recommend developing a life-story book or memory album, similar to Elkins information sheets, to help form shared reverence and respect through communication between caregivers and PWD.

Downs and Collins go on to stress the utmost importance of recognizing the fact that every person with dementia is going to have different abilities. Adapting how you communicate to their strengths is essential in facilitating meaningful social interactions. Every person, whether they have dementia or not, has something they are able to bring to a conversation. By recognizing and respecting the inherent knowledge and experience of others, we are naturally inclined to value them more. Applying this approach in caregiving may aid in combating the discounting of those afflicted with dementia as "empty shells," help to nurture meaningful relationships, and better PWD's overall qualities of life.

In summary, communication is a collaborative process requiring equal effort from *both* participating parties. In this section, various sources were analyzed to stress the importance of effort on the caregiver's part to treat each conversation as an informative opportunity. The cited authors suggest that PWD's BPSD are not merely a result of the neuronal blockages in their brain, but rather meaningful sources of communicative data waiting to be interpreted. These articles provide useful tools including Feil's validation method, Elkins tips toward creating communication bridges, and Downs' suggestions toward achieving more meaningful relationships through person-centered care. However, none of the discussed communication methods *explicitly* express what is to be done when a person with dementia is hallucinating or experiencing a subjective reality. How can caregivers effectively communicate with a person with dementia when that person's contextual understanding of the world no longer mirrors their own? The following qualitative paper attempts to answer this question.

III. METHODS & DEMOGRAPHICS:

Setting and Participants

Participants were caregivers with experience working with people with dementia (PWD) in their daily lives, either currently or previously. Participants were required to have a minimum of one year's experience in order to participate in this study. Insights from both family caregivers and long-term facility healthcare workers, including employees of three separate residential nursing homes, were gathered. All facilities included specialized dementia care services. To recruit respondents, the Directors of Nursing of several care facilities were contacted and asked if their establishment would be interested in participating in the study. Snow-ball sampling was then used within each selected nursing home; each interviewee asked one of their co-workers if they would be interested in participating as well. All respondents received a comprehensive description of the study (see Appendix A) and they offered voluntary consent to full use of their responses.

A total of fourteen interviews were conducted: eleven in-person interviews and three via telephone. Participants lived in the following states and provinces: Iowa, North Carolina, and British Columbia. Three respondents were from Residential Home 1, six from Residential Home 2, and three from Residential Home 3. The recruited participants included three Directors of Nursing, one medication manager, two certified medication assistants (CMAs), two certified nursing assistants (CNAs), one licensed practical nurse (LPN), one dietary assistant, one activity director, and three family caregivers. The majority of participants were female (13/14). All respondents confirmed that they currently administer (or have previously administered) care in some capacity on a daily

basis, and therefore are referred to, collectively, as ‘caregivers’ or ‘providers’ in the text of the study. Providers had an average of 15.68 years of experience (range: 2-36 years), with eight providers having over eight years of experience caring for PWD. Figure 1 outlines each individual caregiver’s gender, experience, position, and location. Respondents are listed in the order they were interviewed.

Figure 1: Respondent Demographics

	Preferred Gender	Years’ Experience	Professional Title	Location
R1	F	36	LPN & Director of Nursing	Home 1
R2	F	2	Medication Manager	Home 2
R3	F	30	RN & Assistant Director of Nursing	Home 2
R4	F	21	CNA/CMA	Home 2
R5	F	5.5	CMA	Home 2
R6	F	3	CNA	Home 2
R7	F	22	RN & Director of Nursing	Home 2
R8	F	8	Activities Director	Home 1
R9	F	21	Family Caregiver	NA
R10	F	32	CNA	Home 3
R11	F	6	LPN	Home 3
R12	M	18	Family Caregiver	NA
R13	F	10	Dietary Assistant	Home 3
R14	F	5	Family Caregiver	NA

Procedures

An interview protocol was developed with the aim of gaining a broad representation of what communication methods caregivers frequently employ when

working with PWD and why. Questions were constructed to address their daily communication habits when interacting with PWD and how communication efforts are changed when interacting with subjective realities. The interview guide was initially piloted with a Director of Nursing with thirty-six years of experience working in a residential nursing home to clarify the questions' wording and fine-tune the flow of their presentation. Changes made following the pilot interview were very minor and, thus, these responses were included in the final data set. The final interview guide (see Appendix B) included questions regarding: caregivers' communication with PWD on a daily basis, difficulties when interacting with PWD, responses to dementia-induced hallucinations or subjective realities, education prior to experience on this matter, and what strategies they feel work best when interacting with dementia-induced hallucinations of subjective realities. Interviews were semi-structured and ranged from 10-60 minutes in length (mean 25 minutes). Interviews were audio-recorded in a comfortable, private setting at the participants' place of work or over the telephone. They were later anonymized and transcribed by the researcher. Recruitment ended when a perceived saturation of thematic data had been met.

Data Analysis

I was the primary coder for this project, and became familiar with the data by listening to all interviews a second time during transcription, and re-reading them multiple times during their analysis. Initial coding was broad and included numerous themes that were later organized into four overarching categories. Classification of the final themes was determined by myself and reviewed by my advising committee. The process of refining potential themes was extensive and well-documented, including

numerous discussions of data-topics and clarification of thematic categories and purposes. Guidance from my advising committee led to the conclusion of the most suitable themes in accordance with the initial research question and the primary literature reviewed. Key-words and phrases were included in the coding process and to generate a more objective division of the data.

Ethical guidelines were followed and approval of the study was gained through The University of South Dakota's Institutional Review Board on May 23 of 2017 (See Appendix A). This project was funded by a grant approved through USD's Council for Undergraduate Research and Creative Scholarship as well as an Undergraduate Research Excellence Award.

IV. RESULTS:

From the participant's responses, four overarching themes were derived: 1) engaging with subjective realities, 2) caregivers' perceived lack of preparation, 3) behavioral psychological symptoms of dementia (BPSD) as a mode of communication, and 4) maintaining an attitude of patience and respect. A majority of caregivers (10/14) reported having similar interactions and communication strategies regardless of their professional title or years of experience. Although no explicit definition of the term was provided, *all* respondents seemed to assume communication to imply both linguistic choice and gestural actions, given their responses considered both verbal and nonverbal dimensions of communication.

Theme One: Engaging with Subjective Realities

Ten of fourteen of respondents (71.43%) disclosed that they frequently engage with PWD's hallucinations or subjective understandings of their surroundings. Three of fourteen reported redirecting patients to the present moment and one of fourteen denied having experience with dementia-induced subjective realities at all. Several respondents referred to the residents' or family members' personal viewpoints as "their world," and described that they, as caregivers, are cautious not to influence their shifted perceptions.

I would say getting into their world is the best for, you know, alternative [reality] situations. Because I've seen where people argue the fact with them and all it does is recreate [bad memories]. You know, if they're talking about their dead spouse then it's, "Oh my God! They died?" I mean, it's like they died again! You know? For the second time, or the third time, or however many times you told them that. So, it can cause more behaviors when you try to *not* go into their world (R7).

You can't [change] reality with somebody who goes that far back. You can't reorient, that will just make them more confused and angry. So, you have to go into their world, which is different than somebody who is [has] no dementia, no

hallucinations. So, you kind of go [and] you play it per person. Every person is different. Every communication is different (R3).

Caregivers expressed that by engaging with realities, they are able to protect PWD's fragile understanding of their surroundings. All fourteen respondents stated that as an "absolute rule" you are never to argue with a person with dementia. Doing so, according to the caregivers, nearly almost results in BPSD or combative behaviors. Instead, the respondents shared that they acknowledge the individual's subjective understanding of the world and communicate within PWD's framework of reality. In doing so, they are able to maintain more affirmative relationships with those they care for, providing them with a sense of comfort and ease. One of the most commonly reported delusions in PWD was women looking for their long-deceased husbands. Caregivers reported frequently responding that he was somewhere else and would be returning later. This response diffuses the anxiety at that given moment, and respondents reported that PWD will likely not remember the conversation later.

With those, like with Donna and her husband I'll say, "No, Donna." 'Cause you can't just come out and say, "He's dead." No, try and find out things from them that they liked to do before they passed away. I'll say, "No he's on the golf course." And then she'll go, "Well, I gotta go find him." And I'll look at her: "So, you're gonna be one of *those* wives, huh? Back off and let him have some private time!" [*Laughs*] It works. "Yeah, I don't wanna be one of those wives," [she'll say] ... You're not lying to 'em, but you're giving 'em something to understand (R6).

There were a few caregivers who reported having interacted with true hallucinations. For example, R6 stated that every night she takes the hands of two invisible children and guides them out of the room before the resident will go to sleep. R11 provided that there used to be a resident who "swore there were families [in her

food]. There were little babies and people and as she was eating she'd say, like, 'I can't eat that! I can't eat that! I'll kill the family!'" However, the majority of subjective realities discussed reflected deep ties to the PWD's personal lives and past identities. These subjective realities often included recurring themes, such as wondering where a deceased loved one was, reliving a particular life-event, or believing they were somewhere they had been in the past. In other words, PWD's subjective realities are often *memory-based*, which is ironic considering a primary symptom associated with dementia is memory loss. It is important to recognize that while neuronal degradation strongly affects short-term memory centers of the brain, such as the hippocampus, long-term memories established in the pre-frontal cortex often remain relatively intact (Fujii et al., 2014).

While many residents were said to be concerned with their home lives, respondents expressed that some PWD's skewed realities revolved around their prior occupations. R1 told a story involving a resident who worked as a rancher his entire life. One day, she entered his room to find him swinging his bed remote around his head like a lasso. When she asked what he was doing, he responded that he was trying to "rope a calf." She described that he was repeatedly hitting himself in the head with the remote but still refused to stop swinging it, so she engaged with his reality at the present moment: "Why do you want to do that to that calf? What's wrong with where he's at?" He subsequently stopped harming himself with the remote. R3 also expressed the importance of engaging with subjective realities, stating she tries to work within her residents' frame of understanding as much as she possibly can because it "makes them feel like they're back in their world." R12 shared a similar sentiment: "I adjust [my communication] by

basically stepping into the environment that she understands and try to go along with and not conflict it so that she feels that she is correct in her understanding of things.”

R3 went on to discuss a former-surgeon who consistently tried to leave the facility saying “I have to see patients. I have to leave.” She said that they would try to tell him that the patients were alright, but since he had no proof, it was difficult to convince him otherwise. The solution? She, too, reported engaging with his reality:

There’s a desk outside this gentleman’s room that has information – medical information. The names are whited out, but it’s a chart. It’s a stethoscope. It is everything for – he was a surgeon and he feels the need to help people. It just kind of reels him in and keeps him; we’re giving him space and time. His old routine. But, yet, we’re not saying he can’t do it. So, yeah, I mean, we do [try to set up PWD’s environments in accordance with ‘their world’] (R3).

What is important to recognize is that, for these caregivers, engaging with PWD’s subjective realities is not necessarily about avoiding conflict or making their own lives easier; it is about providing the necessary reassurance that we all desire in knowing that we are not alone or mistaken in our interpretation of our environment.

But I do believe that their reality ... I suppose you could say alternate, it’s very different. I’ve never really thought of it that way except that it’s *theirs*. Their reality is part of their past, but it’s part of the present. So, I’m not sure how much of an alternate reality it is, [rather] that it is a blended reality. That it’s their reality to them at that moment. And I think the biggest thing that you have to do is realize that they really believe, for whatever reason, that [it] is happening right then. They really believe they went to school with the guy who is checking you out at Home Depot ... you have to go with wherever they are. And hopefully when I have a mistaken reality of someone and think that they’re a guy I went to

elementary school with, they'll forgive me for having an alternate reality for that moment even though I don't have dementia. [*Laughs*] (R9).¹

From their various experiences, the caregivers expressed a nuanced understanding of how PWD seem to navigate the world around them. While the respondents did articulate how caregivers should respond to PWD's altered senses of reality, they also recognized the importance of understanding the significance of their perceptions. They posited that these realities serve as the means by which PWD come to understand their environment and should be given proper attention, rather than being written off as a byproduct of their dementia. Although delusion and hallucination fall under the 'psychosis' cluster of BPSD, the terms 'psychotic' or 'crazy' were never used to describe residents' behaviors. Their altered senses of reality, rather, were appreciated by the respondents as "delicate" and "normal" (R3; R9).

Theme Two: Caregivers' Perceived Lack of Preparation

Twelve of fourteen respondents (85.71%) said they were not prepared for these situations (meaning dementia-induced subjective realities) when they first encountered them. The same percentage answered no when asked whether or not this topic was ever covered in their formal training. Eleven of fourteen caregivers (78.57%) professed the importance of experiential learning in dementia care, even though the interview did not explicitly ask that question. This notion seems to suggest that training cannot adequately

¹ In response to the question: Do you have experience with your family member experiencing dementia-induced hallucinations or alternative realities? The term 'alternative' was used in questioning initially, until it was deemed to have negative connotations. 'Subjective' was later installed to the interview protocol instead. The term hallucination was questioned by those who had not experienced this class of BPSD, but supported by those who had. 'Hallucination' was kept in the interview protocol to ensure these types of perceptions were discussed by those who could identify them.

prepare caregivers to respond to dementia-induced realities prior to gaining some experience interacting with them. In response to the question “did you feel well-prepared for these situations (being subjective realities) when you first encountered them?”, respondents’ answers included:

Not at first, no. It was something that basically once I got in the field I more or less learned. Throughout it, I think when I was in schooling, they don’t really fully prepare you for it (R2).

After years of experience; I think that’s the only thing that prepares you for it. You can be college, you can be textbook. [But] you have to actually work the floor – work in the unit. Years of experience is the only thing I can say that’s helped me (R3).

It was all very new and I had not a clue about anything ... Now that I’ve had the experience, and I’ve dealt with it, yeah, I’m prepared and I understand and I’m more educated, per say, on what to do and how to do things. So, it makes it a little bit easier. But I would say from my experience is where I got most of my education or, you know, learning experiences. Because people can say one thing, but what you do with one resident you’re not necessarily gonna do with the next one (R4).

That is something that I don’t care about how much schooling, how much book training you have. Until you’re face-to-face with it – I don’t care. You can sit there and read all these case studies. This happened this way, this happened this way. Well, until it happens in real life in front of you, you can’t be prepared ... I’ve seen these twenty-year-old gals come in here with no training, nothing. And they encounter some of the behaviors back here and they’re scared to death. And I don’t blame ‘em. I try to train ‘em, you know, don’t ever put yourself in a harmful situation ‘cause we’ve got a couple of ‘em that will strike out at ya. So, no. It’s gotta be life experience; it’s not book (R5).

R5 is not the only respondent who mentioned CNAs being scared of working with PWD. R4 recalled that when she first began working she “was not prepared at all” and went on to say “there [were] actually of a few of them here that [she] was terrified of.” She stated that there was a resident at her facility that will curse, hit, or bite caregivers to get her way. R8 discussed similar behaviors, stating that she was assaulted by a patient in her first week of providing home health care. She said that, at that time, “[she] knew

nothing about Alzheimer's and dementia." She shared that she refused the particular patient a candy bar and he got out of his wheel-chair, swung at her, and they both fell onto the table as he continued to punch her. R8 was hospitalized with a broken jaw, four cracked ribs, and a fractured femur. Yet, she was adamant that behaviors such as these are not to be blamed on the patient, arguing that it is the caregiver's responsibility to know how to appropriately respond to BPSD to prevent such adverse reactions.

R8's experience points to the importance of caregivers having a basic knowledge of how to communicate with PWD prior to working with them in order to protect themselves from the dangers posed by potential misunderstandings. Other respondents emphasized the importance of understanding dementia as a disease before trying to care for people with it as well. They expressed that it is otherwise hard not take these behaviors personally.

I think education is the key to getting people to understand that there's different [behaviors]. Like family members – if they're not educated they don't know how to speak to their own family. They don't understand that, okay, they might not remember who you are today, but then tomorrow when you come they may remember who you are. It's just the disease itself (R4).

I think it is [misunderstood] because it is just such an unknown thing. People don't understand what the experience is. They can't really conceive not having their short-term memory. So, it's more of a fear of the unknown than it is an accurate assessment of the issue (R12).

I really think the entire nation needs to be more educated about dementia. You know, we were just talking about the other day. Seventy years ago, I'm sure there were numerous people with dementia but it wasn't recognized. And somebody goes, "That's just because they called 'em senile!" (R6)

Theme Three: BPSD as a Mode of Communication

Though less commonly discussed, a particularly fascinating theme introduced by some caregivers was the recognition of PWD's behaviors as a form of communication

rather than a byproduct of their disease. Amongst the various caregivers interviewed, and across varying facilities, there seemed to be an acute understanding that PWD, while they may not always be able to verbally express it themselves, have a lot to say. For example, R8 expressed her frustration with the notion of staff at her facility labeling PWD's emotional responses as 'behaviors': "I hate – I don't like it when caregivers are like 'he's having a behavior today.' No, he's not. He's scared. He's confused. He doesn't understand." Other caregivers expressed that they felt it was their duty to unpack PWD's communicative cues and piece together their messages:

You're still communicating, and I think one of the biggest parts of that communication that might change is that you really need to see things from [PWD's] point of view. You need to really put yourself in their shoes to understand how they're trying to communicate to you. So, one of those things that happens that I believe is that you become a better listener. You really have to work on how you listen and look at the information you're given in a brand new way ... because sometimes their words and their actions may not match and you've gotta be there to figure that out (R9).

R9 went on to outline a hypothetical situation in which a caregiver may be able to improve their care by contemplating what the connections between what a person with dementia may be saying versus what they actually mean. She proposed a resident living in a nursing home complaining that they could not sleep at night because they are "hearing voices." Often times, per R9, caregiving staff will "fluff these statements up" by saying that "it is just the disease." R9 argues that you cannot do this to PWD. She says:

They might really be hearing voices at night because there's people outside their window having a smoke break. Or they might be right outside their door not thinking that they're lying there awake. And we do that all the time and say it's just the disease when they're really trying to tell us something. And I think that we need to think of it that way because I think we do that as "normal" human beings. We fill in the blanks as we go along trying to figure things out and we are kind of a paranoid people. Like, we think we lost our keys when we're the ones

who put them down in the bathroom instead of the entry way. You know? And when you get Alzheimer's or dementia it doesn't change that, it might just increase it a little (R9).

This perspective was echoed by other caregivers. R11 expressed a situation at her care facility in which a 104 year-old woman with Alzheimer's frequently sat by the window during the day. Every so often, she would begin screaming "NOOOOO! TAKE ME! TAKE ME!" R11 remarked that she, along with the rest of the staff, thought that she was hallucinating and didn't know what to do. They would move her away from the window and she would stop screaming. Eventually a new staff member in the unit suggested that she was not hallucinating, but was rather yelling at the people she saw leisurely walking outside of the window. This connection was not made for several months. However, after it was, staff began walking her outside daily and she exhibited significant mood improvements.

R11's story demonstrates how difficult it can be to make these types of connections between PWD's communicative actions and their meanings. Other caregivers expressed how challenging this may be to accomplish too, and the extreme importance of collaborative care in nursing home settings. There was an overall awareness that the behaviors of PWD can often times be an absolute mystery. By having other staff members to work with, forming these types of communicative bridges can be achieved by means of analyzing a situation through a broader lens than just that of one person.

I don't know, it's kind of a hit and miss. You just keep trying and trying and approach it different ways until you find something that works. And there may be times that you're a complete failure at it. And then you just look at another coworker and I always say "Hey, tap in for me 'cause I'm not getting anywhere."

And you're not. You're not gonna redirect every resident every time. You know, some interact with you and so you just try the best you can. And if you can't do it then you ask another coworker to do it (R6).

You don't ever walk into this knowing it all. I'm saying I don't care how old you get, the new ones coming in or whoever can teach the older ones something they learned in the newer classes. I say don't ever shun the new ones coming in, because they may know something that we never thought of. And they're always coming up with more stuff (R10).

Sometimes it just takes new people. And that's why we rotate people, because when you get staff that works in memory care units all the time sometimes you get accustomed to the people. So, it's like, "Okay, that's typical. I don't have to address that." But then if somebody is new or someone comes in and they're like, "Well, what's that?" And you're like "Oh, I didn't even notice that!" (R11).

Ultimately, respondents shared that some of the largest barriers to overcome in learning to care for those with dementia are 1) trying to figure out the various ways in which individuals understand their surroundings, and 2) how to adjust their own communication tactics as caregivers to achieve a shared appreciation for the context of both parties' realities. R12 summarizes this notion in detail in the following quotation:

I see her understanding the world in different terms. Because there's the whole 'hallucinations' and 'alternate reality' [terminology], and it kind of has a this sort of "off-the-rails" connotation that I don't experience. It's not as if she thinks she's outside when she's inside, or she perceives that everyone around her as a different set of people. It's just that since she doesn't have any short-term memory, the only thing that comes along to fill that void is long-term memory. And I suppose you call that an alternate reality, but it seems to be mudding the water.

The way I see it is that she seems to be using different labels for the things that she actually perceives around her. I mean, anything that I say is around us or near us or with us she would agree to. You know? Like, if we're sitting in the living room she'd say that we were sitting in the room. Only, she might say that this is the house that she grew up in, because that's the only label she has available for "house that she feels good in."

... When you're going through the world and suddenly you have a brain lesion that causes you to then label everything you see as either circle, square, rectangle, or triangles, or a basic shape, no one would say that you are hallucinating. They would say that you have lost the capacity to label things other than circles,

squares, etc. They wouldn't say that you are seeing these things all the time, they'd say you've lost the terms for it, and it's the same thing with Alzheimer's.

... So, yeah. It's just addressing things from the terms that the person with Alzheimer's has set them up to be and present them with the energy you would like to see reflected back. It's a light touch. And there has to be a sense of humor about it as well. You have to be okay with making mistakes and being dumb. You know, feeling like you're dumb but if you can be okay with that – the problems come with people who are not okay with making mistakes and are rigid about it. Then they get angry and they don't understand why the person they're taking care of is angry.

R12's approach gives a simplified way of viewing the reasons why those with dementia and Alzheimer's disease seem to experience the world differently than those without these neurodegenerative conditions. According to him, it is actually not that they are experiencing their surroundings differently, but rather their condition has stripped them of the capacity to properly label their environment. In his interview, he summarized subjective realities in a way that exudes patience for the difficulties that PWD often undergo when trying to express themselves. This leads into the fourth and final theme drawn from the collected data: maintaining an attitude of patience and respect whilst caring for PWD.

Theme Four: Maintaining an Attitude of Patience and Respect

From the interviews conducted, all of the respondents expressed the importance of maintaining an attitude of patience and respect for PWD while caring for them, and many of the study participants emphasized this concept multiple times over the course of their interview. What makes this theme especially poignant is that nowhere in the interview protocol was there an explicit question targeting this facet of caregiving. The notion of maintaining an attitude of patience and respect is not just necessary, but, rather, it is a piece that is so central to caregiving that it transcends training, years of experience, and

all of the other characteristics that differentiated the respondents in this study. All of the participants felt that this aspect of their day-to-day work was such a vital component that they all brought it forward to some effect without being overtly asked to do so.

You have to take a step back, take a deep breath. Sometimes it's frustrating and overwhelming, but in general I think it is just like you said. Communication is the main thing, even amongst the staff and the residents, with the clients, and then it's just being a human being basically. You gotta be caring, you gotta show you care (R3).

I love it. I would prefer to work in dementia care than anywhere else. And I feel like you can be a great asset if you learn the people and, you know, take care of them properly. Because sometimes people don't understand how to take care of them and they don't take the time to learn them and they don't have the patience. And you really have to have a lot of patience to work with Alzheimer's and dementia (R4).

You have to have a lot of patience. You can't let the little nit-picky stuff get to you 'cause you'll be out of here in less than a week if you do. You just gotta let it flow. This is their home; they basically are in charge of you. You're just here to make sure that they don't get hurt (R5).

You gotta rely on your coworkers to have your back. And I guess a lot of patience, a lot of trust in your coworkers, a heck of a lot of love in your heart, and a sense of humor always helps (R6).

I think that the biggest adjustment that you have to make is you stop and really listen and not multitask and to only focus on what that person is saying to really respect how hard it is to sometimes find the correct words or just the word you are trying to find in your mind when you're living with dementia. And respect that so that you slow yourself down and you really listen to what the person is trying to tell you (R9).

They need the low-key voice ... maybe offer a hand. You know, just a little bit of kindness. Respect. That's what they need, they need respect (R10).

It forces you to slow down and let go of things. And that can really be healthy. It's really healthy for anyone to have a moment where they are trying to accomplish something and they don't necessarily need to create anything they just have to be there with another person and stop and take a little vacation for a little bit because you're just open to the other person and you're making sure that they're alright (R12).

V. DISCUSSION AND CONCLUSION

Discussion

Of the fourteen participants in this study, ten (71.42%) reported that they frequently engage with the hallucinations or subjective realities expressed by people with dementia (PWD). Examples of these realities included individuals mistakenly believing that their long-deceased spouses were still alive, that they were sitting in their childhood home, or that they had to report to work despite being retired for a number of years. While ‘true hallucinations’ were described (e.g. seeing people and places that appeared to be unfamiliar to the patient), the majority of realities discussed were in some way related to the PWD’s earlier lives. This is not surprising, considering that research suggests hallucinations and delusions often present in conjunction with emotional experiences, such as loneliness or bereavement (Fromm-Reichmann, 1959; Hayes & Leudar, 2016; Jansson et al., 2017; Sacks, 2012). This may serve as a method of compensating for the loss of these relationships and the fulfillment they offered. Hallucinations have also been frequently observed in lonely and bereaved individuals *without* neurological deficits (Sack, 2012). It is unsurprising, then, that they commonly present amongst those with dementia, who are often going through the emotional trauma of losing spouses or close friends, being separated from their families, and relocating into nursing homes *alongside* coping with the of loss core neurological competencies such as their memory and communicative ability.

The respondents in this study seemed to grasp how difficult it can be for PWD to find their words and accurately express themselves. The caregivers’ answers reflected a deep appreciation for the emotional lives of those they cared for, echoing Fujii and colleagues’ (2014) view that emotions belong at the center of care as they are

fundamental to quality of life. With this in mind, it is not surprising that such a large percentage of respondents reported frequently engaging with subjective realities. By communicating within PWD's understandings of their surroundings, caregivers are able to confirm the perceptions of people with dementia in much the same way their perceptions would have been communicatively confirmed before the onset of disease. In this way, caregivers help their patients feel as though some sense of their personhood is maintained. Passmore, Ho, and Gallagher (2011) argue that a human being is not inherently a person without some degree of interaction with the relational aspects of societal life. How is a person with dementia supposed to interact with these relational aspects if they are unable to understand them as they actually exist in the present? By communicating with PWD within their own understandings of the world, caregivers are simultaneously providing their patients the dignity that has been, to some degree, stripped away from them by their disease, as they have often lost the ability to adequately identify and evaluate their surroundings and circumstances. As outlined by the Swedish Council on Technology Assessment in Health Care (2008), there is evidence that when caregivers focus on individual PWD's personhood, the PWD subsequently exhibit heightened awareness, fewer BPSD, and an overall greater sense of well-being. Whether they realize it or not, caregivers efforts to "step into their patient's world" do far more than just preventing potential BPSD; these efforts provide those they are caring for with a greater sense of stability and ultimate quality of life.

While a few examples of true hallucinations were shared, the majority of subjective realities discussed in interviews encompassed some sense of the patients' past lives, further suggesting the importance of knowing PWD on a personalized and more

intimate basis. By recognizing the idiosyncrasies of each individual, such as personal history, values, spirituality, personality, and self-image, caregivers may improve the accuracy with which they are able to interact within PWD's altered understandings of their environments. Within the interviews, this was exhibited by caregivers communicating with widowed patients. Numerous respondents expressed that if a resident was in search of their long-deceased spouse, they told them that they were out rather than that they were dead. This spares these PWD the emotional trauma of re-discovering their life partners had passed away and the confusion of why they could not remember it happening. Caregivers most frequently chose to prioritize the emotional needs of their patients over their own understanding of what is true. They recognize that it often does more good to operate within a PWD's framework than to try to force these individuals back into what they, being unaffected by dementia, appreciate as the "real world." By "stepping into *their* world," caregivers are effectively able to 1) decrease the frequency of BPSD, 2) improve the overall emotional state of those they care for, 3) and encourage the maintenance of a communicative relationship, as PWD are more inclined to engage in conversation when they feel they are being heard.

This concept resembles the philosophy of Naomi Feil (1982). Feil directs caregivers away from typical interventional methods such as reorientation or distraction, but rather challenges them to face these behaviors head-on. By validating the emotional responses presented by the PWD with contemplative understanding of their feelings of guilt, fear, or panic, caregivers may be able to help them work through their internal struggles and, in turn, decrease the presentation of their BPSD (Atwood, 2005). In other words, when caregivers choose to set aside their own assumptions of reality and attempt

to understand and appreciate the environment as their patient's do, they may be surprised at the results. This does not mean caregivers are to *abandon* their own perceptions, but rather suggests that they recognize PWD's subjective realities as legitimate communicative efforts and, thus, treat them with appropriate care. For example, R3 discussed a former surgeon who was constantly trying to leave the facility to attend to patients. His caregivers recognized this drive to leave was not an effort to run away, but rather this individual running toward his familiar, lifelong desire to help others. They subsequently modeled his environment to reflect a doctor's office to fulfill his yearning to treat patients as he had done for the majority of his life. Shortly after this modification, his attempts to escape ceased and the caregivers were able to get to know him in a whole new way. The resident was transformed from an escape-artist who needed to be monitored (placing additional stress on nursing staff) into an experienced, caring, and noteworthy individual. By providing residents the space to reveal parts of their past, caregivers may be amazed at the depth and breadth of awareness and knowledge that these individuals still possess. By choosing to listen, caregivers assure PWD a sense of dignity, despite them having a diagnosis that strips them of nearly everything else.

These examples point to the idea that PWD's behavior should not necessarily be accepted at face value, but should rather be appreciated by caregivers as a mode of communication – a legitimate attempt by PWD to share meaning. This notion may be observed in the hypothetical example of a person with dementia complaining of hearing “voices” at night provided by R9. She proposed caregivers would likely perceive this to be an auditory hallucination, when in reality these voices could just as easily belong to chatty nurses smoking just outside of the resident's window. This simple example is

suggestive of a much larger array of potential circumstances. It is known that dementia has the ability to limit individuals' communicative abilities, but this does not mean that it strips those affected of their innate need to interact with others. BPSD should be understood as a form of communication, even when including subjective realities and hallucinations, because these behaviors may be the attempts of PWD to express notions they can no longer find the words for. Given that research suggests altered perceptions are a compensatory mechanism employed by our stimulation-deprived brains, the very existence of subjective realities suggests that PWD who experience them are lacking fulfillment in some aspect of their life. As PWD may no longer have the communicative capacity to articulate what they need, or the cognitive capacity to determine what it is they desire, it becomes the caregiver's mission to investigate the origins of such behaviors. As Elkins (2011) puts it, it is the care provider's responsibility to serve as a link that connects the gaps in information with their patients.

In order to effectively form such connections, it is essential for providers to listen attentively and apply a mindful approach towards those they are caring for. To maintain a mindful approach, it is essential that caregivers refrain from being quick to judge or label the information they receive from PWD. Harvard psychologist Ellen Langer (1989) writes that there are three necessary components to becoming more mindful in one's approach to communication: creation of new categories, openness to new information, and maintaining an awareness of more than one perspective. By recategorizing BPSD as valuable communicative artifacts, opening themselves to the wealth of information their patients' behavior holds, and by trying to view the world from the PWD's perspective, caregivers are better equipped to interpret their patients' behaviors as modes of

communication. In other words, by maintaining a mindful approach to communicating with PWD, caregivers become more effective at tending to their emotional needs, which literature has established to be fundamental to a patient's ultimate quality of life (Fujii et al., 2014).

The practice of mindful communication with PWD may prove difficult as the disease can severely diminish the coherence of their communication. This points to the importance of collaboration within healthcare settings. R11 discussed this notion in her story of the resident who screamed at the window daily until a new employee suggested that she may have just wanted to go outside. This story may serve as a cautionary tale, attesting to the ease with which one may fall into a routine, accepting things as they appear to be based on their *own* experience. Maintaining a mindful approach when caring for PWD may improve this short-sightedness, but there will always be details that can be missed or taken for granted. There will always be gaps in communication when interacting with people whose cognitive capacities have declined. In such cases, respondents argued that it is essential to recruit a fresh pair of eyes. Maintaining a sense of presence and humility may help to realize when this is necessary. This notion was recognized by several respondents who expressed that collaboration within their work is essential. R10, a CNA with over thirty years of experience, commented on this idea: "You don't ever walk into this knowing it all. I'm saying I don't care how old you get, the new ones coming in, or whoever, can teach the older ones something they learned in the newer classes."

In addition to the importance of collaboration, R10 points to the significance that education can have in preparing certified nursing assistants (CNAs) to be effective

communicators when caring for PWD. However, 85.71% of respondents expressed that they did not feel prepared to interact with PWD experiencing subjective realities, suggesting that this facet of dementia care is not being addressed in nursing assistants' training regimens. While 78.57% of respondents discussed the importance of "on-the-job" or experiential learning in terms of dementia care, the fact of the matter is that *not* knowing how to interact with subjective realities can be dangerous. R8 shared that she was hospitalized after being attacked by a resident for refusing to give him a candy bar, and other respondents reiterated the violent tendencies of distressed PWD. By not teaching caregivers-in-training the proper guidelines for communicating with PWD, educators are both doing a disservice to patients and potentially putting unsuspecting caregivers in harm's way. Given these statistics and stories, it is apparent that communicating with PWD is a sector of CNA-education that requires greater development. It is important for incoming caregivers to recognize that communication is a collaborative process; that mindful listening *and* respectful responses are critical in the delivery of quality care. As stated by the Commission for Social Care Inspection (2008), the current state of typical nurse-patient relationships is significantly influenced by *each* party's ability to communicate, not just those with dementia (as cited Downs & Collins, 2015). Stressing the effect that communication skills can have on relationships with patients should be regarded as an essential component of education not just to protect caregivers from potentially combative residents, but also because encouraging this type of mindfulness ultimately improves their patients' quality of life.

The fourth and final theme that emerged from this study was the shared principle amongst caregivers of maintaining an attitude of patience and respect in their work. There

was a communal acknowledgement that dementia care demands caregivers to be patient. They must be patient with the sometimes difficult process of getting to know those they care for; tolerant of the inevitable frustrations that are bound to come along with this practice. They are to be patient in establishing communication bridges, and patient in gaining their patient's trust. Caregivers are not to rush this process, because by doing so they would be failing to fulfill their second requirement: remaining respectful towards PWD. Maintaining respect for each individual and the precious dignity of their independence is essential in making people with dementia feel as though they are valued members of a community. For caregivers, respecting the fact that they are caring for an autonomous human being is essential in this process.

Patience and respect are both essential components in terms of becoming the type of communicator who is able to meet PWD where they are in terms of engaging with subjective realities. To do this, caregivers must set aside their own perceptual assumptions. They must orient their understanding of the world to another's set of rules. This is an experience that is foreign to many, and can be a difficult philosophy of care to adopt for some. However, by maintaining an attitude of patience and respect toward the process of stepping into PWD's worlds, caregivers ultimately increase the likelihood of 1) maintaining communicative relationships with those they care for and 2) improving their overall quality of life. By practicing mindfulness and actively engaging with those they care for within their individual subjective realities, care providers may effectively reposition power from themselves as more able-bodied individuals to PWD as human beings with a voices worthy of respect.

Conclusion

This study set out to answer the following question: What are the “rules” for caring for a person with dementia when their contextual understanding of the world no longer mirrors your own? The majority of respondents expressed the value of actively engaging with PWD’s subjective realities. However, there was also an acute understanding amongst many of the caregivers that while “stepping into their world” serves as a helpful piece of advice, this approach should not be deemed a “rule.” R12 succinctly summarized this notion when he stated the following:

Strategies can sometimes seem to be an absolute thing. Like, this is what you should always do and achieve. Veer from that and you are wrong, or if somebody else is veering from that then they are wrong. Science has a bias towards true or false, *but life does not*. These are living situations, and these are guidelines. If it’s a guideline that means that you do it so long as it's helpful. When it’s not helpful you change.

When attending to something as dynamic as human emotion, absolute “rules” cannot be applied. One can only hope to be pointed in the right direction by guidelines. This is true whether patients have neurological deficits or not. It is important for caregivers to remember that the term “dementia” is a blanket term for an array of symptoms, not the individual personalities of the people who possess them.

Caregivers may be successful in developing communication bridges only if they commit to embracing these irregularities and mindfully addressing patients as people rather than as a collection of symptoms. By accepting PWD’s realities, orienting to the terms by which their patients understand the world, and actively engaging with these perceptions, caregivers relinquish their power. They lend a portion of their dignity to those they care for, those whose own sense of self is incrementally claimed by their

disease. They communicate to PWD that their perceptions, while potentially out of touch with the present, possess inherent worth as potential avenues for connection. By approaching BPSD individually and mindfully, caregivers can ultimately transform what are traditionally viewed as negative-emotional experiences into potentials for communication breakthroughs. And by actively working toward affirmative, communicative relationships with PWD, caregivers may effectively decrease the frequency of their patients' BPSD, improve their emotional state, and, more importantly, their overall quality of life.

APPENDICES

APPENDIX A: IRB-Approved Informed Consent Statement

UNIVERSITY OF SOUTH DAKOTA
Institutional Review Board
Informed Consent Statement

IRB Approval effective from: 5/23/2017
IRB Approval not valid after: 5/22/2018
USD IRB

Title of Project: Investigating Communication Strategies Utilized by Care Providers When Interacting with Dementia Patients Experiencing Alternate Realities

Principle Investigator: Kathy Magorian, EdD
209 Julian Hall, Vermillion, SD 57069
(605) 658-5809 kathy.magorian@usd.edu

Other Investigators: Christian Pollema

Purpose of the Study: The purpose of this research study is to investigate communication strategies utilized by care givers when interacting with dementia patients experiencing alternate realities or hallucinations.

Procedures to be followed: You are invited to participate in a recorded ~20 minute interview, in which we will ask you about your personal experiences with patients experiencing alternate reality situations and how you responded. The interview will take place in a location of your choosing, such as a conference room at your place of work, a coffee shop, or a library. We are inviting you to be in this study because you are either a caregiver who primarily works in a memory care unit or has had previous experience with dementia patients. Questions asked may include: Do you find that you change your communication methods when interacting with dementia patients? Could you tell me about encounters you have had caring for patients' dementia-related hallucinations or alternate realities? Do you believe that there are strategies that work best in situations such as these?

Risks:

There are no risks in participating in this research beyond those experienced in everyday life.

Benefits:

You may not benefit personally from participating in this research project however after participating in this study you may be more sensitive to how patients respond to specific communication strategies, and have a better understanding of what methods are more effective in interactions with these patients.

Duration:

It will take about 20 minutes to complete the questions.

Statement of Confidentiality:

The interview group does not ask for any information that would identify who the responses belong to. If this research is published, no information that would identify you will be included since your name is in no way linked to your responses.

Right to Ask Questions:

The researchers conducting this study are Christian Pollema and Kathy Magorian. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Kathy Magorian at (605) 658-5609 during the day.

If you have questions regarding your rights as a research subject, you may contact The University of South Dakota- Office of Human Subjects Protection at (605) 677-6184. You may also call this number with problems, complaints, or concerns about the research. Please call this number if you cannot reach research staff, or you wish to talk with someone who is an informed individual who is independent of the research team.

Compensation: You will not receive compensation for your participation.

Voluntary Participation: You do not have to participate in this research. You can stop your participation at any time. You may refuse to participate or choose to discontinue participation at any time without losing any benefits to which you are otherwise entitled.

You do not have to answer any questions you do not want to answer.

For this study you must be 18 years of age older to consent to participate in this research study.

Participation in the interview process implies that you have read the information in this form and consent to participate in the research.

Please keep this form for your records or future reference.

APPENDIX B: Interview Protocol

Thesis Research Interview Protocol:

Respondent #

Working Title:

Years Experience in Dementia Care:

Preferred Gender:

- 1) Communication is a large part of your everyday career ... could you tell me more about how you use it on a day-to-day basis?
- 2) Do you find yourself changing communication methods when interacting with dementia patients?
- 3) Do you have experience with patients experiencing dementia-induced hallucinations or subjective realities?
 - a. Can you remember how you first responded?
 - b. How do you respond now?
 - i. What strategies do you tend to use?
- 4) Did you feel well-prepared for these situations (being subjective realities) when you first encountered them?
 - a. Do you feel that these types of situations were addressed anywhere in your training or education?
- 5) Do you believe that there are strategies that work best for these situations (being dementia-induced subjective realities)?

- 6) After this conversation that you can think of that pertains to this topic that we may not have discussed?
 - a. Additional past experiences that you would like to share?
 - b. Advice for other professionals in the field?
 - c. Etc.?
- 7) Finally, what is your favorite part about being a caregiver?

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