Effects of Visual Stimuli on Decision-Making Capacity of People with Dementia for End-of-Life Care

DISSERTATION

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Abstract

The effects of visual aids and medical vignettes on decision-making for end-of-life care of 20 persons with mild and moderate dementia were evaluated. Participants demonstrated Understanding, Making a Choice, Reasoning, and Appreciation of two medical vignettes (Drug Treatment for Dementia, and Feeding Tube Placement for Dysphagia) under two counterbalanced conditions --when presented verbally alone or verbally with visual aids. The visual aids consisted of pictures and text illustrating the two medical vignettes. Transcripts of the experimental sessions were analyzed for quality of the verbal statements made to demonstrate decisional capacity. In addition, twelve speech clinicians blinded to the experimental conditions rated participants’ decisional capabilities using a 7-point Likert scale. Results showed that participants demonstrated significantly better overall decisional capacity in Understanding, Reasoning, and Appreciation when supported by visual aids during the decision-making process. No significant differences between conditions were found for Expressing a Choice, the decisional skill Logical Sequence under Reasoning, and Acknowledgement under Appreciation. Participants generated significantly more Rewordings and Exact Statements, and significantly fewer Statements Not Mentioned, in the visual condition than in the verbal condition. In addition, participants with mild dementia produced more Rewordings, while those with moderate dementia offered more Exact Statements.
Overall, clinicians’ ratings validated participants’ decision making performance on the experimental tasks; clinicians’ ratings reflected greater agreement in the visual condition, than in the verbal condition.
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INTRODUCTION

Decision-making capacity is the key to autonomy (Lord Donaldson, 1992). It is defined as the ability to effectively make decisions, and the capacity to appreciate the choices and consequences of the decision at hand (Grisso & Appelbaum, 1998; Moberg & Rick, 2008). Specifically, “capacity” is operationally defined as the ability – which comes in degrees and can change over time – of an individual to make a task-specific and reasoned choice (Rodin & Mohile, 2008). The scope and practice of making a decision sometimes extends to contexts, such as finance management, independent living, research consent, and voting (Moye & Marson, 2009). The notion of decisional capacity is especially important to end-of-life medical care and treatment contexts.

Because of the advances in medical technology in conjunction with the Patient Self-Determination Act (1990), the right to participate in decisions about one’s own health and well-being has become increasingly accepted in American healthcare (US Presidential Commission, 1982). To obtain authentic end-of-life medical care and treatment preferences from the individuals, patients are presented with an increasing number of choices and are encouraged to be the primary decision maker (Löckenhoff & Carstensen, 2007). While the focus of decision-making is expected to be person-centered (i.e., respecting the patient’s autonomy), health care professionals “have the responsibility to
identify the clinical realities of the individual’s pathophysiology and to integrate them into the decision-making framework” (Mahon & Sorrell, 2008, p. 115). In addition, decision-making capacity is situation specific (Sabat, 2005) and can vary with severity of the illness (Fitten & Waite, 1990). Decision-making outcomes can be further influenced by personal factors such as perspective of future time, emotion, changes in memory, presence of depressive symptomatology, and ethnic and cultural values (Allen, Hilgeman, & Allen, 2011). Failing to identify the person’s decisional capacity as competent can compromise patient autonomy (self-determination) and protection (beneficence), the two core ethical principles in assessing decisional capacity (Berg, Appelbaum, Lidz, & Parker, 2001). Persons with cognition impairing illnesses, such as dementia, are particularly vulnerable to violations of their personal autonomy. Given that dementia also affects an individual’s language skills, people with dementia (PWD) are often reported to have difficulty in communication, which impedes them from conveying their preferences in end-of-life care and treatment (Long, 2009; Peacock, 2008; Volicer, 2001).

**Decision-Making and Dementia**

Dementia is a neurodegenerative syndrome in which the individual experiences cognitive, language, and behavior impairments that are severe enough to interfere with daily living (Alzheimer’s Association, 2014; American Psychiatric Association, 1994). The term cognition is the mental act or process of knowing that involves attention, visuospatial functions, perception, executive function, and memory (Alzheimer’s Association, 2014). Language is a complex system consisting of speech sounds (i.e., phonemes), suprasegmental features (e.g., stress, intonation, length, tone), grammar (i.e.,
syntax), and words (i.e., semantics) to communicate knowledge and information (Fromkin, Rodman, & Hyams, 2003). Language and cognition are closely intertwined (Bourgeois & Hickey, 2009). Deficits in the cognitive domains can lead to subtle changes in language behaviors that affect ability to convey or understand communicative intent, resulting in communication breakdown and challenging behaviors. To recognize the impact of cognitive-communication impairments in dementia on decision-making capacity, there is a need to identify the functional changes in each cognitive domain (attention, visuospatial skills, perception, executive function, and memory) in order to understand their relationship with decision-making capacity.

**Attention**

Attention is the process of focusing on a specific stimulus (selective attention) for a particular length of time (sustained attention), attending to multiple stimuli at the same time (divided attention), or shifting focus from one stimulus to another (shifting sets) (Norman & Shallice, 1986). For example, when an individual is asked a question about their opinion of feeding-tube placement in a noisy environment, he or she needs to filter the conversation from background noise, which includes attending to the words spoken, and to focus on the pronunciation, stress patterns, and intonation (i.e., use of selective attention) long enough to process the auditory information (i.e., use of sustained attention). Attention, therefore, marks the beginning of decision-making process. This cognitive domain is involved throughout the decision-making procedure, of information gathering, predicting immediate and long-term consequences, and evaluating risks and benefits of treatment options.
Disruptions in attention processes are observed across dementia types and can lead to significant decision-making challenges. In the early stage of dementia, PWD may demonstrate preserved sustained attention and good concentration for simple tasks (Assal & Cummings, 2003). However, as task complexity increases, early signs of decline in divided and selective attention emerge (Bourgeois & Hickey, 2009). This is due to multiple and competing demands for attention that exceed attentional capacity (Baddeley, Baddeley, Bucks, & Wilcock, 2001; Foldi, Lobosco, & Schaefer, 2002). As dementia progresses, alertness fluctuation and attentional impairments become increasingly prominent. Determining a medical preference is a complex task given that patients process multiple messages either simultaneously or in sequence, with attention constantly involved throughout the process (Gaddes & Edgell, 1994). With input from multiple sensory stimuli (e.g., information obtained from vision and hearing), PWD become more easily distracted compared to healthy aging people (Vitaliano, Breen, Albert, Russo, & Prinz, 1984). Moreover, in order to remain focused on multiple levels of information with competing demands for attention of different types, PWD have to increase effort to concentrate, which results in fatigue and even frustration when the information is difficult to understand (Baddeley et al., 2001; Bourgeois & Hickey, 2009; Foldi et al., 2002).

Perception and Visuospatial Functions

Perception is the organization, identification, and interpretation of sensory information (i.e., sight, hear, smell, taste, and touch) by the individual (Schacter, 2011). Visuospatial functions allow a person to perceive spatial relationships (Visual Perception and Spatial Cognition Research Group, 2010). Together, these abilities known as
visuospatial perception (Kolb & Whishaw, 1985; Pinel, 1993) enable an individual to process, interpret, and conceptualize visual and spatial relationships, such as recognizing familiar environments and individuals, and integrating current visual information with previously stored knowledge of viewed scenes and objects.

Visuospatial perception plays an important role in decision-making. To express preferences that involve using specific medical equipment (e.g., feeding tube, ventilator, dialysis machine) or a particular medical procedure (e.g., cardiopulmonary resuscitation), the individual first needs to identify and recognize the actual object and/or procedure. This step is necessary to associate the recognized item with potential consequences (e.g., discomfort such as pain; inconvenience such as being bedridden or immobile), based on provided information and/or previous knowledge (e.g., personal experience). People with Alzheimer’s disease (Assal & Cummings, 2003) and Parkinson disease with dementia (Assal & Cumming, 2003; Stern, Richards, Sano, & Mayeux, 1993) have been documented with visual-perceptual impairment. They may fail to identify the salience of visual features or discriminate the visual landmarks of the target from others over time, which would make an incorrect connection between the known and the new knowledge, and generate an invalid preference. However, studies have reported evidence of accurate visuospatial-perceptual functioning in PWD in the later stages when reading and responding to familiar written materials and picture stimuli (Bayles, Tomoeda, Cruz, & Mahendra, 2000; Bourgeois & Mason, 1996; Hoerster, Hickey, & Bourgeois, 2001).
Executive Functions

Executive functions refers to a wide variety of mental abilities that allow a person to account for short and long term consequences of his or her actions and to plan for those results (Madden & Johnson, 2010; Vandenbos, 2007). It also enables the individual to evaluate these actions and make adjustments in their decision-making. Executive functions is an umbrella term for planning, strategizing, shifting mental sets, inhibiting inappropriate or incorrect responses, and using and manipulating new information (Assal & Cummings, 2003; Elliott, 2003), as well as volitional actions and self-monitoring of effective performance (Elliott, 2003; Lezak, 1995; Ylvisaker & Feeney, 1998). Good decision-making capacity requires strong regulation and management of executive skills.

During the process of making a medical decision, the decision maker is constantly filtering and synthesizing information to meaningfully include known and newly learned knowledge (Caron, Griffith, & Arcand, 2005). In addition, decision-making, with medical issues in particular, is a step-by-step sequence of gathering and understanding the given information, organizing the input, taking into account the benefits, risks, and personal choices, and evaluating factual and potential outcomes to draw a conclusion. These complex mental processes require good task flexibility, which is to switch focus rapidly from one task to another. Hence, executive functioning is closely allied with attention (Shiffrin & Schneider, 1977). Impairments in either domain would have a high likelihood of affecting the other and disrupting the process of decision-making.

Across dementia types, executive dysfunction for complex tasks and problem solving skills increase with increasing dementia severity (Bourgeois & Hickey, 2009).
Early deficits in tasks relying on executive and attentional functions become noticeable when simultaneous and rapid integration of multiple types of information is required (Perry & Hodges, 1999), such as managing finances, preparing meals, and shopping. As dementia progresses, PWD experience increasing difficulties in rapid attentional alteration and response inhibition (Perry, Watson, & Hodges, 2000) that interfere with prioritizing actions and organizing skills. Due to these cognitive challenges, PWD have been found to exhibit perseveration and task inflexibility (Van Hoesen & Damasio, 1987). Thus, it is not surprising that, when faced with tasks that require multiple steps of planning, such as making a decision, PWD are found to have difficulty in comprehending disclosed information and demonstrate confusion (Meisel & Kuczewski, 1996). As a consequence PWD experience slower reaction time to respond to stimuli (Baddeley, et al., 2001; Foldi et al., 2002; Tyrrell, Genin, & Myslinski, 2006) particularly under stress (Alzheimer Scotland, 2013).

Memory

Memory problems are typically the first signs and defining feature of cognitive decline of many dementia etiologies (Bourgeois & Hickey, 2009). Memory consists of three main processing components: encoding and registering, which refers to processing and combining information; storing, which refers to creating a record for the encoded information, and; accessing and retrieving, in which the information is recalled for immediate or later use (Baddeley, 1995, 2004). Three types of memory systems are involved in information processing: sensory memory, working memory (or short-term memory), and long-term memory. Sensory memory is the earliest stage of memory and is
the result of processing the environmental stimuli from the senses (vision, hearing, smell, taste, and touch). A person cannot consciously think or choose the type of information to be stored in sensory memory (Winkler & Cowan, 2005). However, sensory memory allows a person to retain the impressions of sensory experiences after the stimulus has ceased (Coltheart, 1980). The “snapshot” of sense-specific stimuli is transferred to working memory (Atkinson & Shiffrin, 1968; Fukuda & Vogel, 2009), where the auditory information is decoded or the visual images are interpreted (Baddeley, 1992) and stored temporarily. If the information or stimulus is important in the moment, then it is processed immediately; if it is useful at a later time, it is processed and stored in long-term memory for later retrieval.

**Sensory Memory**

Although sensory memory is not involved in higher cognitive functions such as memory consolidation (i.e., coding stimuli for later retrieval) or comparing information (Dick, 1974), sensory memory is nevertheless affected in the early stage of dementia because of attentional impairments. This causes PWD to experience problems in processing sensory information from the original stimuli, resulting in transferring insufficient information to working memory that can be extracted for immediate usage (Coltheart, 1980). Hence, when decision-making capacity is evaluated as impaired it may be the result of a failure of sensory information being adequately processed.

**Working Memory**

Working memory processes are particularly vulnerable to the effects of dementia. PWD are documented to have reduced memory span and short-term memory capacity
(Morris, 1986), and performance deficits on short-term memory tasks with divided attention conditions (Morris, 1996). These limitations impair PWD’s ability to encode and temporarily store recent or current information, making it difficult to process and store newly acquired information in long-term memory. Therefore, PWD have been found to exhibit an increased rate of forgetting (Au, Chan, & Chiu, 2003). A typical example is the report from caregivers of PWD that ask the same question repeatedly.

Declines in speed of information processing over the course of degenerative illness also contribute to decreases in working memory capacity. Thus, lengthy and/or complex auditory or written information may require more time to process and comprehend. When making important medical decisions and treatment preferences, patients are not only presented with much complex information by their health care professional, but they may also need to discuss potential decisions with family members. Without appropriate modification of the verbal information to match their literacy level or the provision of additional textual supports people with working memory deficits may fail to process the verbal stimuli, become overwhelmed with processing the information during the discussion, and forget important details. In addition, patients may be viewed as uncooperative because of a failure to initiate comments or questions about the information or the inability to remember what was just said, causing frequent requests for repetition of the new information.

**Long-Term Memory**

Long-term memory is categorized into three processes. *Procedural memory* is the “how to” of information (Schacter & Tulving, 1994), the knowledge of skills to perform
particular types of action even without conscious awareness due to repetition and practice. *Episodic memory* is the knowledge of autobiographical experiences and the capacity to recollect general or specific incidental details from the past (e.g., emotions, personal associations of a particular place or time) that allows the individual to re-experience the event. *Semantic memory*, which in contrast to episodic memory that can be explicitly stated and described, is the knowledge of the world, facts, ideas, and memory of specific words (Baddeley, 1995; Baddeley et al., 2004; Sohlberg & Mateer, 2001). Long-term memory is important in the decision-making process when stored information pertaining to the decision is constantly accessed and retrieved. In a medical scenario, the decision maker not only has to recall factual information about the pros and cons of each treatment alternative from semantic memory, but also has to associate this medical information with personal experiences (e.g., a relative/friend using the same treatment) retrieved from episodic memory.

Long-term memory may be somewhat more resistant to the progression of dementia because knowledge about medical information and treatments may have been stored for years. However, failing to access this stored information becomes noticeable as the symptoms of dementia progress. In the early stages, semantic memory impairments are exhibited by anomia (i.e., word-finding difficulty) (Perry & Hodges, 2000; Lambon Ralph et al., 2001; van der Hurk & Hodges, 1995). As this difficulty becomes more frequent in the middle and late stages of dementia, PWD become less able to express basic wants and needs. Episodic memory is thought to be particularly vulnerable to illness progression. PWD have been reported to demonstrate significant difficulty in
recalling more recent and current events in contrast to better performance in recalling autobiographical events, such as early childhood memories (Sartori, Snitz, Sorcinelli, & Daum 2004). Therefore, PWD may not remember information pertinent to a recent decision without reminders because the new information was not adequately stored in long term memory (Grisso & Appelbaum, 1999).

Language

Individuals with dementia typically have communication difficulties significant enough to impact their ability to participate in activities of daily living (Blackstone, 2009; Wylie et al., 2013). The presence of memory impairment in any form (e.g., recognition, encoding, or retrieval deficits) interferes with language comprehension and expression over the course of dementia. Difficulty retrieving words (i.e., anomia) and using words in conversation are the most common early language deficits across dementia etiologies (Bayles & Kazniak, 1987; Obler, Dronkers, Koss, Delis, & Friedland, 1986). These problems cause the PWD to experience inconsistencies in remembering people’s names, objects, and previously familiar locations. Word-finding problems not only interrupt the train of thought, but also contribute to topic digression and tangential discourse. As the disease progresses, these verbal deficits become more frequent. In addition, the content of discourse is reduced, with more frequent use of circumlocutions, abandoned phrases, repeated phrases, and nonspecific words such as thing that contribute to the perception of “empty speech” (Appell et al., 1982; Bayles, 1982; Bayles & Kazniak, 1987; Ripich & Terrell, 1988). These language behaviors often lead to ineffective communication. For example, tangential speech production causes confusion from the listener’s perspective;
word-finding difficulties may result in reduced production of specific details when explaining pros and cons of treatment options; the use of ambiguous utterances and indefinite terms may prevent an individual from expressing a clear choice. Consequently, even when a choice is made, the outcome may not be viewed as valid by the physician or family members, resulting in increased vulnerability of the PWD’s decision-making capacity.

Auditory comprehension (i.e., the comprehension of spoken language) is also gradually affected by cognitive deficits (Bourgeois & Hickey, 2009). While this skill appears intact for simple, structured, and concrete language, impairments in auditory comprehension are documented in abstract language even in early stages due to deficits in attention or concentration, encoding, or working memory deficits (Code & Lodge, 1987; Kempler, Van Lancker, & Read, 1988). As dementia progresses into the severe stages, comprehension performance declines for one-step commands, multiple-choice and yes–no questions (Bayles & Tomoeda, 1993). However, Bayles (2003) stated that these impairments have very limited effect on linguistic expression; appropriate syntax (Kempler, Curtiss, & Jackson, 1987) and selection and sequencing of phonemes for verbal communication remain intact (Appell et al., 1982). Nonetheless, some subtle declines in sentence length and grammatical complexity have been found in the interview transcripts of people with mild dementia when compared to their normal counterparts (Lyons, Kemper, LaBarge, & Ferraro, 1994).

In summary, making a medical care decision requires a significant amount of effort from multiple cognitive domains. It begins with attending to and concentrating on the
disclosed information. Understanding the information requires processing the input and comparing it to previously stored information retrieved from long-term memory. As more information is provided (e.g., treatment alternatives and relevant risks and benefits), good cognitive flexibility is required for the decision maker to shift from one idea to another while retaining previous information for later retrieval. Simultaneously, the individual needs to recognize the relevance or significance of treatment options, and analyze this information rationally by weighing the risks and benefits as they apply to his/her own circumstances. When communicating a decision, it is essential for the person to focus and stay on the current topic while retrieving specific words needed for the conversation. In addition, inappropriate emotional and verbal responses need to be inhibited so the ideas can be clearly and effectively conveyed.

Pathological changes in cognition are characterized by gradual, but progressive decline in attention, visuospatial-perceptual functions, executive functions, and memory (Perry & Hodges, 1999; Welsh, Butters, Hughes, Mohs, & Heymann, 1992). These cognitive deficits contribute considerably to subtle changes in language behavior. Given that decision making is a complex cognitive process that involves attentional resources, executive functions, and memory (Delazer, Sinz, Zamarian, & Benke, 2007) and that language is crucial for emotional and subjective expression, it has been suggested that increased cognitive and language impairments are associated with decreased involvement in making decisions (Allen et al., 2011; High & Rowles, 1995; Menne & Whitlatch, 2007).
Patient Autonomy in Decision Making

Because of cognitive impairment, Woods (1999) stated that:

There has been the assumption that people with dementia are unable to communicate in a meaningful way, invalidating their participation in decision making about their own situation as well as rendering their lived experience and their perspective as being impossible to research” (p. 36).

Others believe that while PWD may not be able to fully comprehend and express all aspects of complex medical decisions, this does not automatically disqualify that patient as a decision maker, especially if some opinions about the situation are expressed clearly (Meisel & Kuczewski, 1996). A diagnosis of dementia in and of itself does not imply incapacity in consenting to specific medical treatments (Moye, Karel, Gurrera, & Azar, 2005). Decisional capacity cannot be qualified as all-or-none (Karlawish, Casarett, & James, 2002; Sugarman, Cain, Wallace, & Welsh-Bohmer, 2001; Tyrrell et al., 2006).

The Mental Capacity Act 2005 further specified that “the ability to retain information for a short period only will not in itself render the person incapable. As long as the as the person retains information long enough to make a decision then the condition is satisfied” (section 3). The final condition that would indicate an incapability to make a decision is where “the person is unable to communicate the decision by any possible means” (Griffith & Tengnah, 2007, p. 287) while suffering from the prevailing impairment (Leo, 1999). Otherwise, one cannot conclude PWD’s decision making as entirely incapable solely because the ability is questionable. To alleviate the vexing condition of PWD having difficulty understanding relevant information and expressing decisions, as well as
to obtain PWD’s medical care preferences, the availability of advance directives that were completed prior to these communication deficits are a valuable resource (Triplett et al., 2008).

**Advance Directives**

Advance directives, which include medical power of attorney and living wills (Leming & Dickinson, 2011), are legal documents that allow a person to communicate medical and end-of-life care wishes ahead of time in the event that s/he cannot make decisions due to illness or incapacity (Degrazia, 1999). A medical power of attorney, also known as “health care proxy” or “durable power of attorney,” allows an individual to designate someone as a legal proxy to make treatment decisions if the person is temporarily or permanently incapable of making decisions (Braun & Kayashima, 1999; National Cancer Institution, 2013). A living will is a document that indicates what kinds of medical interventions – especially life-sustaining care – an individual does or does not wish to receive (National Cancer Institute, 2013). Common types of care include, but are not limited to, the use of life-sustaining machines (e.g., ventilators, dialysis machines), do-not-resuscitate orders, artificial hydration and nutrition (i.e., tube feeding), and organ and tissue donation (National Cancer Institution, 2013).

Advance directives aim to facilitate joint decision-making (Poppe, Burleigh, & Banerjee, 2013; Widdershoven & Berghmans, 2001) and improve communication of preferences of the patient (Hammes & Rooney, 1998; Molley et al., 2000). Studies in other life-limiting conditions (such as cancer) have demonstrated that advance directives allow people to die in their preferred place of care (Detering, Hancock, Reade, &
reduce costs (Zhang et al., 2009), and reduce hospitalization (Cohen-Mansfield & Lipson, 2008; Volicer, Hurley, & Blasi, 2003). Similar findings were also reported in a literature review of four studies of advance care planning interventions for PWD and cognitive impairment (Robinson et al., 2012). Among the four studies reviewed, Robinson and colleagues reported that two studies documented significantly decreased hospitalization rates (Caplan, Meller, Squires, Chan, & Willett, 2006; Molley et al., 2000), and a third study reported increased use of hospice services (Hanson, Reynolds, Henderson, & Pickard, 2005). Advance directives, therefore, afford patients the opportunity to exercise their right and ensure the “personhood” of the author is not lost (Abbey, 2003), especially for PWD with memory and language deficits.

The use of advance directives remains uncommon in spite of their obvious benefits (Barclay, Leslie, Blackhall, & Tulsky, 2007; Stefanacci, Cavalieri, Flynn, Forman, & Pomerantz, 1994). Several concerns contribute to this phenomenon. Few advance directives provide specific treatment preferences and instructions for a number of illness conditions and potentialities. Teno et al. (1997) analyzed the use of 688 directives collected from 569 patients out of 4804 patients’ medical records from 270 nursing homes in 10 states. Researchers reported that only 90 directives contained specific instructions for medical care; only 36 contained specific instructions about the use of life-sustaining medical treatment. Similarly, in a study about physicians reporting the actual use of advance directives for 70 PWD in a nursing home (Cohen-Mansfield & Lipson, 2008), only some end-of-life treatments were specifically addressed in these documents.
(51 on hospitalization, 11 on intravenous fluids, and 1 on tube feeding). Within the same study, physician reports further disclosed that even when specific instructions were given, they were generally not applicable to the patients’ current situation because PWD’s medical conditions were more complex than the conditions described in the document. In addition to insufficient details, Tripplett et al. (2008) found conflicting end-of-life wishes after reviewing 118 advance directives and other medical requests from 81 nursing home residents with advanced dementia (some residents had more than one directive). For example, pain treatment was one of the most common positive requests (85%) but was stated in only approximately 48% of the advance directives; seventy-nine percent of the residents had DNR orders, and yet only 16% specifically asked for DNR status in their advance directives.

The heightened risk of not involving PWD with increased decisional impairment in decision-making scenarios highlights the idea that advance directives should be attempted in the earlier stages of dementia when a patient still has capacity (Sampson, 2010). It is possible that the earlier one receives a diagnosis that predicts increasing cognitive impairment, the sooner advance directives could be completed. In one retrospective study, however, Lingler and associates (2008) found the rates of formal advance care planning were similar across diagnostic categories (N = 745; 69% of participants who were cognitively intact, 71% with mild cognitive impairment or early Alzheimer’s disease, and 70% with moderate or severe Alzheimer’s disease). In other words, the severity of impairment was unrelated to the rates of advance directives completion. These results were replicated in another retrospective study analyzing advance care plans from
185 participants (Garand, Dew, Lingler, & DeKosky, 2011). In addition, Lingler et al. (2008) concluded that a diagnosis of a cognition-impairing condition had limited impact on document initiation, with only 39% of the sample (127 subjects) having initiated the advance care planning by 5 years of follow-up. This implies the need for education about the importance of advance directives.

Even if advance directives are completed soon after the diagnosis of dementia, the validity of the decisions made at that time remains questionable. Allen et al. (2003) developed a scenario requiring a decision involving the placement of a feeding tube and administered it verbally to 78 nursing home residents with mild and moderate dementia. After the interview, each resident was assessed with 15 open-ended questions delivered in verbal form. The authors found that, while most residents (82%) retained the ability to state a treatment preference, many lacked the capacity to understand the treatment situation and determine the potential consequence of the treatment decision made. It should be noted that open-ended questions may be difficult for PWD to answer because they pose a greater demand on the listener to access stored information than answering yes-no or multiple-choice questions (Bourgeois, 2002). Minimal responses or failure to respond by individuals with dementia may not represent their lack of knowledge, but rather their capability to retrieve words to convey their ideas.

To summarize, albeit advance directives can be used to convey patients’ wishes, the validity concerns about PWD’s responses limit their use in hospital decision-making. Patients have the right of self-determination; it is a fundamental human right and an established principle of ethical medical practice. But, given that “the more serious the
decision, the greater the capacity required” (Lord Donaldson, 1992), additional research is needed to improve procedures for determining PWD’s decisional capacity reliably.

Concepts and Implementation of the Four Legal Standards

According to Wetle (1995), “determining the capacity to make decisions is an inexact science” (p. 67). Nonetheless, four legal standards—or the four functional abilities—that are based on U.S. case law have been identified to obtain information about one’s decision-making capacity (see Table 1): understanding, which is the ability to comprehend diagnostic and treatment-related information, including the risks, benefits, and potential consequences of the proposed treatment; appreciation, which is the ability to relate this information to one’s own situation; reasoning, which is the ability to rationally compare and evaluate treatment alternatives and their likely effects on daily life; and expressing a choice, which is the ability to convey a decision about treatment options (Grisso & Appelbaum, 1998; Roth, Meisel, & Lidz, 1977; Tepper & Elwork,

Table 1. Definitions of Decisional Capacities in Legally Competent Decision Making

<table>
<thead>
<tr>
<th>Capacity</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding</td>
<td>The ability to comprehend diagnostic and treatment-related information and to demonstrate this comprehension.</td>
</tr>
<tr>
<td>Appreciation</td>
<td>The ability to translate and determine the relevance of significance of medical circumstance, treatment information, and potential consequences to his or her own situations.</td>
</tr>
<tr>
<td>Reasoning</td>
<td>The ability to employ logical processes to compare the benefits and risks of treatment options through integrating, analyzing, and manipulating information rationally.</td>
</tr>
<tr>
<td>Express a Choice</td>
<td>The ability to generate a decision or state a preference about treatment.</td>
</tr>
</tbody>
</table>

Note: 1Grisso & Appelbaum, 1999; 2Moye et al., 2004.
1984). Outlined and refined by legal scholars, clinicians, and ethicists, this taxonomy advocates the concept that the legal focus of decision-making capacity should be on the process of reasoning and the ability to carry out the reasoning procedure, not the particular decision that is made (Buchanan & Brock, 1990; Sabat, 2005).

To date, the four legal standards have been widely accepted (Grisso & Appelbaum, 1998; Roth et al., 1977) and applied in numerous decision-making assessments situations. Assessment tools developed for determining decision-making capacity have included some or most of the legal standards, and some tools have been included for use with PWD. The review of decisional capacity instruments (Dunn, Nowrangii, Palmer, Jeste, & Saks, 2006; Grisso, 2002) described the following instruments:

*Brief Informed Consent Test (BICT)*

The Brief Informed Consent Test (Buckles et al., 2003) was designed for a study to evaluate the understanding performance of informed consent for minimal-risk patients with and without mild and moderate dementia. Test items were reviewed by a multidisciplinary ethics committee at a research center on Alzheimer’s disease. A total of 11 true-false questions were developed to address the eight elements of informed consent as stated in the Code of Federal Regulations, Title, 45, Part 46, Protection of Human Subjects (Code of Federal Regulations, 2010): (1) Indication of research involvement, an explanation of research purposes, and requirements of participation; (2) description of reasonably potential risks or discomforts to the participant; (3) description of benefits to the participant; (4) disclosure of treatment alternatives or course of treatment; (5) statement of confidentiality of records identifying the participant will be maintained; (6)
explanation of availability of compensation/any medical treatments to the participant if the research involves more than minimal risks and if injury occurs; (7) contact information for the researcher in the event of patient injury caused by research participation; and (8) a statement to the participant that the participation is voluntary, and refusal to participate will involve no penalty or loss of benefits. There were no reports of time required for administration and “cut-off” scores for the level of performance. A total of 250 PWD (very mild: n = 141; mild = 76; moderate: n = 33) and 165 non-dementia older adults were recruited. Results showed that all participants without dementia, with very mild dementia, and 92% of mild dementia participants correctly answered 8–10 true-false questions. Sixty-seven percent of the participants with moderate dementia reached this level of accuracy. Buckles and colleagues concluded that PWD at the mild stage are capable of understanding informed consent information. However, the authors also proposed that understanding of information does not represent decisional capacity as a whole.

*Capacity to Consent to Treatment Instrument (CCTI)*

The Capacity to Consent to Treatment Instrument (a.k.a. Standardized Consent Capacity Instrument) (Marson, Ingram, Cody, & Harrell, 1995) was developed to assess consent capacity to medical treatment in older healthy controls and persons with mild and moderate Alzheimer’s disease. The CCTI applies the method of vignettes. A vignette is a written description of an imaginary scenario in which the examinee is asked to decide on a proposed treatment or on research participation (Schmand, Gouwenberg, Smit, & Jonker, 1999). There are two hypothetical vignettes in the CCTI: symptoms of neoplasm
(a brain tumor) and cardiac (atherosclerosis heart problem), and two treatment
alternatives with associated risks and benefits are described. Each vignette is presented
verbally and the printed copy is provided to the person to read. The words per vignette
are written at a fifth- to sixth-grade reading level with low syntactic complexity. After
listening to each vignette, the patient is asked 14 questions designed to evaluate consent
capacity using the four legal standards. The process of administering both vignettes lasts
approximately 20 to 25 minutes. Separate quantitative scores are generated for each legal
standard assessed. After summing the scores under each standard, the patient’s decisional
capacity is determined as capable, marginally capable, or incapable. In the original study,
29 participants with Alzheimer’s disease (mild: n = 15; moderate: n = 14) and 15 without
dementia were assessed. The outcomes showed that the Alzheimer group demonstrated
greater compromised performance (i.e., marginal competency or incompetency) than the
group without dementia in understanding (mild and moderate: 100% of the participants),
appreciation (mild: 33%; moderate: > 60%), and reasoning (mild and moderate: > 50%).
Due to the poor performance, especially in understanding, the authors raised concerns
that patients even at the mild stage of dementia may not be competent to consent to
treatment.

Hopemont Capacity Assessment Interview (HCAI)

The Hopemont Capacity Assessment Interview (Edelstein, 1999), which was
initially developed for nursing home residents, measures decisional capacity using a
semi-structured interview format. The assessment contains hypothetical medical (eye
infection and CPR) and financial (purchasing an item, borrowing money from a friend,
and providing financial advice to a friend) scenarios requiring the examinee to make decisions. The interview begins with presenting the examinee with the concepts (e.g., cost, risks, benefits, choice) that are needed during questioning and answering. The scenarios are presented verbally with specific instructions. The performance for each scenario is evaluated by 30 follow-up questions on a rating scale. All items are written at a sixth-grade reading level. The administration time ranges from 30–60 minutes. A 3-point rating system (2 = adequate, 1 = questionable, 0 = inadequate) is utilized to assess the examinee’s capacity for each legal standard. The cutoff scores from Appelbaum and Grisso (1988) are used to determine if the examinee is deemed competent. In a study comparing 88 adults with mild to moderate dementia to 88 matched controls on all four legal standards, the mean of PWD’s performance was found to be worse in understanding and appreciation than the control group. However, no differences were found in expressing a choice and reasoning (Moye, Karel, Azar, & Gurrea, 2004). Edelstein (2000) indicated that the HCAI should be interpreted with caution given that one’s decision-making capacity may not be fully captured through performance on a single domain. In addition, the author stated that standardized scenarios do not necessarily reflect an individual's current medical or financial situation; the familiarity of a scenario may impact one’s decisional ability.

*Hopkins Competency Assessment Test (HCAT)*

The Hopkins Competency Assessment Test (Janofsky, McCarthy, & Folstein, 1992) was used as a screening tool to provide information on patients’ competency in making treatment decisions and to write advance directives. Initially developed for and
administered to neuropsychiatric and medical inpatients, the HCAT can be used by non-clinicians and the average administration time is 10 minutes. Four essays that are written at three reading comprehension levels (6th, 8th, and 13th grade) are verbally presented. The content is related to the nature, value, and effects of informed consent, and the effects of chronic diseases. Each essay is followed by six questions composed at the sixth-grade literacy level, containing four open-ended questions, one true-false, and one sentence-completion questions. For each question, an example of an adequate answer is provided as a reference to the examiner. A score of 1 is given to each correct answer. Receiving a score below 3 indicates incompetence. While the legal standards are not explicitly listed for comparison with participants’ answers, the authors suggest that the capacity in understanding is assessed somewhat given that comprehension is essential to recognize an advance directive and to consent to treatment. In a study recruiting 20 participants with mild to moderate Alzheimer’s disease to complete the HCAT (Bassett, 1999), half of the PWD were judged to be competent (mean = 3.90; SD = 3.84). However, the overall performance was poorer compared to their normal counterparts (mean = 9.25; SD = 1.29). It should be noted that the reading comprehension level selected for individuals was not documented. Hence, it is uncertain whether the results were generated from a specific reading level or a combination of all three.

MacArthur Competence Assessment Tool for Treatment (MacCAT-T)

The MacCAT-T (Grisso & Appelbaum, 1998) is considered to be the most widely used instrument to assess decisional capacity. The test uses a semi-structured interview procedure to assess the 4 decisional capacities of adult patients with various types of
diagnoses, including dementia. The scenario for decision-making is patient-specific. Prior to the interview, the clinician prepares the information that will be disclosed to the patient. The clinician develops a brief description of the patient’s disorder (diagnosis, features of the disorder, course of disorder), the recommended treatment options (range: 2–3), and risks/discomforts and benefits (2 per category). The interview begins with the clinician describing verbally the illness and treatment information. During the interview, it is essential for the clinician to adapt his/her disclosure of information (e.g., word usage, sentence length, pace) to the patient’s status. All of the questions, which are categorized by the four legal standards and are used to elicit patient’s responses, are standardized (i.e., language is not tailored to the examinee’s condition). The time needed for the assessment ranges from 15–25 minutes.

Patient’s responses are documented and rated (2 = meeting full credit, 1 = partial, 0 = none) on the record form in the designated sections. While the MacCAT-T sums up the scores for each section (i.e., legal capacity), it does not yield “cut-off” scores for adequate or inadequate performance as it varies with the demands of the patient’s specific conditions. Hence, the total score is not used. The authors proposed that the absence of a total score addresses the fact that decisional competence is multidimensional and avoids misrepresentation. For example, if a total score were to be used, a patient might obtain high scores on certain domains (e.g., understanding and reasoning) but poor scores in others (e.g., poor performance in appreciation due to denying the disorder applies to oneself). Using MacCAT-T to assess treatment decision-making capacity of PWD, Moye et al. (2004) used a vignette involving treatment of a non-healing toe ulcer with surgery
or amputation. The study showed that PWD at the mild to moderate level were more impaired on understanding (mean = 16.92) and reasoning (mean = 6.67) compared to their normal counterparts (mean = 18.84 and 7.28, respectively). A study conducted in Germany also reported that PWD (n = 31; mean Mini-Mental State Examination = 17.3) performed worse on all four domains than patients with depression (n = 35) or schizophrenia (n = 43) (Vollmann, Bauer, Danker-Hopfe, & Helmchen, 2003). Unlike Moye et al. ’s study, however, the participants were given individual information on their own disorder instead of using a standardized vignette.

**Vignette methods (VM)**

The vignette method was used to evaluate the decisional competence to consent to treatment of geriatric patients with and without dementia (Vellinga, Smit, van Leeuwen, van Tilburg, & Jonker, 2004). There were two vignettes; one described the choice of undergoing an endoscopy for anemia (i.e., low red blood cell count) with unclear cause, and the other to undergo a surgery for colon carcinoma (i.e., colon cancer). The content of these vignettes was developed in collaboration with experienced geriatricians and psychiatrists. Both scenarios and choices were presented verbally either in a hypothetical way or as a reality if the participant did have the diagnosis. During the presentation and the interview, the participants were allowed to read the vignettes. Each vignette was followed by seven questions to evaluate the participant’s legal capacities. The scoring method was similar to the HCAI and MacCAT-T (2 = a satisfactory answer; 1 = somewhat satisfactory answer; 0 = incorrect or no answer). To determine one’s competence, the vignette score was dichotomized into competent/incompetent using a
95% of the control group’s score as criterion (Schmand et al., 1999). The authors concluded that out of 80 patients with mild to moderate dementia, most patients (n = 68) were considered competent for making medical decisions (Vellinga et al., 2004).

As shown in Table 2, a total of six instruments have been used with PWD for assessing medical-related decision-making capacity. The four legal standards were consistently assessed in three instruments (CCTI, HCAI, MacCAT-T). All instrument formats – except BICT – are in structured or semi-structured interview form. All tools are administered by verbal presentation, with CCTI and VM providing additional textual support for the PWD to read during the assessment. Hypothetical vignettes are applied in most instruments except of BICT and MacCAT-T that presented a questionnaire and the actual treatment scenario, respectively. Overall, the studies across the six instruments reported a wide range of reliability. Internal consistency documented in BICT, HCAI, and VM were 0.63, 0.94, and 0.82, respectively. Inter-rater reliability was reported in all instruments except the BICT, ranging from 0.64 to 0.95. It should be noted that while the reliability of HCAT (0.95) and MacCAT-T (0.95) were reported, these results were generated from retirees with and without Alzheimer’s disease, and from medical inpatients without reports of cognitive deficits, respectively.

Among these instruments, validity was reported in the form of correlation with the Mini-Mental State Examination (MMSE; Folstein, Folstein, McHugh, 1975) or reviewed by multidisciplinary health care-related team members. This procedure raises concerns about validity. When assessing functional abilities, the domains evaluated “should have close conceptual relationships with appropriate standards of competence” (Appelbaum &
Table 2. Instruments Used with Persons with Dementia for Assessing Medical-Related Decision-Making Capacity

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Domain(s) Assessed</th>
<th>Express a Choice</th>
<th>Format</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brief Informed Consent Test&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Understanding: Yes</td>
<td>Appreciation: No</td>
<td>Reasoning: No</td>
<td>True/false questions; verbal presentation only.</td>
</tr>
<tr>
<td>Capacity to Consent to Treatment Instrument (a.k.a. Standardized Consent Capacity Instrument)&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Structured interview; verbal and written (text) presentation. Two hypothetical vignettes on neoplasm and cardiac. Each vignette includes symptoms and two treatment options with associated risks and benefits. Decisional capacity is evaluated by 14 questions following administration of each vignette.</td>
</tr>
<tr>
<td>Hopemont Capacity Assessment Interview&lt;sup&gt;4&lt;/sup&gt;</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Semi-structured interview; verbal presentation only. Hypothetical vignettes on making financial (3 scenarios) and medical (eye infection and CPR) decisions. Standardized administration and 20-30 follow-up questions per scenario are on a rating form using a 3-point rating system.</td>
</tr>
<tr>
<td>Hopkins Competency Assessment Test&lt;sup&gt;5&lt;/sup&gt;</td>
<td>--&lt;sup&gt;a&lt;/sup&gt;</td>
<td>No</td>
<td>No</td>
<td>Structured interview; verbal presentation only. Four single-paragraph essays related to informed consent and the nature of chronic diseases written at 3 reading comprehension levels. Each essay has 6 follow-up questions.</td>
</tr>
</tbody>
</table>

Continued
Table 2 continued

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Domain(s) Assessed</th>
<th>Understanding</th>
<th>Appreciation</th>
<th>Reasoning</th>
<th>Express a Choice</th>
<th>Format</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>MacArthur Competence Assessment Tool for Treatment⁶</td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Semi-structured interview; verbal presentation only.</td>
<td>Actual diagnosis and proposed treatment. All disclosed information (include type/nature of disorder, description of probable outcome without treatment), descriptions of treatment alternatives, and risks and benefits are prepared by the examiner. Record form is available to rate responses; total score is not used. A manual is available for general guidance.</td>
</tr>
<tr>
<td>Vignette methods described by Sachs et al.⁷, Schmand et al.⁸, and Vellinga et al.⁹</td>
<td>Yes</td>
<td>Yes⁹</td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td>Structured interview; verbal and written (text) presentation.</td>
<td>Two vignette or actual decision on anaemia and colon carcinoma. Each vignette has 7 follow-up questions.</td>
</tr>
</tbody>
</table>
Table 2 continued

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Administered Population/Research Sample</th>
<th>Validity</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brief Informed Consent Test&lt;sup&gt;1&lt;/sup&gt;</td>
<td>Research sample: non-dementia (n = 165, control group); mild and moderate dementia (n = 250, including Alzheimer’s disease with other disorders. E.g., depression, cerebrovascular disease).</td>
<td>Content adapted from the Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects. Reviewed by multidisciplinary ethics committee.</td>
<td>Internal consistency: Cronbach’s alpha = 0.63 (0.70 with one item removed).</td>
</tr>
<tr>
<td>Capacity to Consent to Treatment Instrument (a.k.a. Standardized Consent Capacity Instrument)&lt;sup&gt;3&lt;/sup&gt;</td>
<td>Mild and moderate dementia, Parkinson’s disease, non-dementia (control group).</td>
<td>Content based on five legal standards of competency. The content of both vignettes were reviewed by a neurologist specializing in dementia.</td>
<td>Inter-rater reliability = 0.83 by three trained raters&lt;sup&gt;4&lt;/sup&gt;. 67%-84% agreement on different legal domains by 5 physicians&lt;sup&gt;12&lt;/sup&gt;.</td>
</tr>
<tr>
<td>Hopemont Capacity Assessment Interview&lt;sup&gt;4&lt;/sup&gt;</td>
<td>Mild and moderate Alzheimer’s disease, non-dementia (control group).</td>
<td>Correlation between the financial section and the Mini-Mental State Examination (MMSE) = 0.66</td>
<td>Inter-rater reliability = 0.93; Internal consistency: Cronbach’s alpha = 0.94</td>
</tr>
<tr>
<td>Hopkins Competency Assessment Test&lt;sup&gt;5&lt;/sup&gt;</td>
<td>Psychotic disorders, retirees (with and without Alzheimer’s disease)&lt;sup&gt;13&lt;/sup&gt;, Alzheimer’s disease, neuropsychiatric and medical inpatients; non-dementia (control subjects).</td>
<td>Correlation with MMSE = 0.75</td>
<td>Interobserver reliability = 95%; Inter-rater reliability (Cohen’s Kappa) = 0.95&lt;sup&gt;13&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

Continued
Table 2 continued

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Administered Population/Research Sample</th>
<th>Validity</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>MacArthur Competence Assessment Tool for Treatment⁶</td>
<td>Schizophrenia, major depressive disorder, dementia/cognitive impairment, psychosis disorders without dementia⁷, medical inpatients (e.g., alcohol-related disorder, cerebrovascular accident, gastrointestinal disorder, musculoskeletal disorder, endocrine disorder)¹⁰</td>
<td>Content based on four legal standards of competency. Correlated with MMSE but not with clinical team’s impression.</td>
<td>Intraclass correlated coefficients = 0.75–0.87¹⁰; Inter-rater reliability (Cohen’s kappa) = 0.76¹¹</td>
</tr>
<tr>
<td>Vignette methods described by Sachs et al.⁷, Schmand et al.⁸, and Vellinga et al.⁹</td>
<td>Research sample: non-dementia (n = 47, control group); non-severe dementia (n = 30)</td>
<td>Content developed by geriatricians and psychiatrists⁷,⁸,⁹. Correlation with MMSE = 0.66⁶</td>
<td>Inter-rater reliability (Cohen’s Kappa) = 0.64 (78% agreement)⁹; Internal consistency: Cronbach’s alpha = 0.82⁸</td>
</tr>
</tbody>
</table>


a Although authors indicated that this domain is not measured, item inspection suggested that this domain is being assessed.
b Although authors indicated that this domain is measured, item inspection raised concerns that this domain is not adequately assessed.
Grisso, 1995, p. 119). Therefore, an instrument such as the MMSE that serves as a screening tool measuring dementia severity is not deemed appropriate for measuring specific, context-dependent abilities to understand disclosed information about a treatment and its alternatives (Glass, 1997; Kim & Caine, 2002; Raymont et al., 2004). As a result, reports of correlations between the decisional capacity instruments and the MMSE scores do not represent strong validation evidence (Dunn et al., 2006). Another validity concern stems from the fact that the four capacity domains are not consistently included for measurement (BICT, HCAT, VM). Supportive psychometric data and generalizability across contexts also remain insufficient across instruments (Dunn et al., 2006). Moye et al. (2004) further reported inconsistent outcomes between MacCAT-T, CCTI, and HCAI when assessing medical decision-making capacity in older adults with and without dementia on all four legal standards. Poorer performance on reasoning in the PWD group was found when compared with their counterparts measured by MacCAT-T and CCTI, but not HCAI. When assessing the concept of appreciation, participants with dementia were reported as not obviously impaired on MacCAT-T and HCAI, but were on CCTI. The authors explained that these discrepancies in capacity tools may be caused by each instrument varying in the method for evaluating and rating the four legal standards.

The fact that not all the instruments are designed to be dementia-specific (e.g., MacCAT-T, HCAT) also carries the potential for generating confusing results when assessing decision-making capacity. This concern also applies to the instruments that were administered only to the dementia population (VM, BICT, HCAI) because there have been few research replications to confirm their psychometric properties. Most
methods for assessment in the current decision-making instruments (including Allen et al.’s (2003) study) use solely verbal delivery and contain very limited additional support, such as written text or pictures. Decision-making for medical issues is a complex skill that requires comprehension, encoding, and retrieval over time, in the face of interference (i.e., remembering information about a first treatment choice while a second treatment option is explained) (Moye et al., 2004). Verbal-only descriptions of the vignettes can cause heavy memory load due to attention and memory-encoding deficits, difficulty in keeping multiple ideas in mind and making inferences, or semantic memory deficits (e.g., failure to recall the meaning of the spoken words). These impairments result in forgetting task instructions or not understanding the abstract ideas of the presented information, which in turn impede patients’ ability to comprehend the given scenario and make rational treatment comparisons.

Among the instruments to assess decisional capacity, hypothetical medical vignettes are the most common format used to measure decision-making capacity. However, these hypothetical conditions may have less personal relevance and familiarity to PWD’s own medical problems. Studies using personalized questions (e.g., decisions about daily living, personalized treatment options) have documented that many individuals with mild to moderate dementia have the capacity to articulate certain preferences and choices for themselves, and to be accurate and reliable in their responses (Fellows, 1998; Mezey, Teresi, Ramsey, Mitty, & Bobrowitz, 2000; Feinberg & Whitlatch, 2001; Moye et al., 2004; Horton-Deutsch, Twigg, & Evans, 2007). In contrast, PWD changed their response frequently and showed less consistent response patterns in tasks that were new and of
little personal relevance, regardless of the risk inherent in the conditions (Delazer et al., 2007; Sinz et al., 2008). PWD’s reactions may be influenced by personally salient experiences (Moye et al., 2004). Therefore, decisional capacity instruments using hypothetical scenarios may engender perplexity in patients and elicit answers that are not clear to examiners.

A closer examination of the content of all instruments (including CCTI) reveals further concern with claiming these instruments as truly disease-specific. The language used for the instructions and the assessment was not always modified specifically for individuals with dementia. PWD’s auditory comprehension may appear intact for simple and structured language (Code & Lodge, 1987; Kempler et al., 1988). But when sentence structure in a vignette is lengthy and complex, and presented in verbal form (e.g., structured or semi-structured interview) without any additional support (e.g., written text), it is challenging for an individual with memory problems to remember because the information requires greater working memory capacity. Even if printed information is provided to improve comprehension, it may be difficult for PWD to keep multiple ideas in mind while trying to focus on the auditory input given by the examiner. These conditions may cause patients to reread the same material, to have difficulty understanding the gist of the information, or to lose interest in reading the material (Bourgeois & Hickey, 2009). Furthermore, failure to store information in short-term memory results in new input becoming less likely to be encoded in long-term memory. PWD may be better at interpreting concrete language (Code & Lodge, 1987; Kempler et al., 1988; Papagno, Lucchelli, Muggia, & Rizzo, 2003) than when the details and ideas in
a vignette are abstract; it may be difficult for the patient to suppress the literal interpretation, which would strongly interfere with understanding the actual meaning of the content (Papagno et al., 2003) and result in making a false judgment. It should also be noted that PWD are often reported to exhibit fatigue and distractibility during assessments (Bourgeois & Hickey, 2009) and this compromises comprehension. Hence, vignettes and/or questions that are designed or delivered inappropriately (e.g., lengthy and complex statements, medical terminology) may require longer time to administer, which can exacerbate these negative behaviors and impede assessment procedure.

In summary, while decision capacity assessment tools have been used with the dementia population, few can claim to be determined as dementia-specific instruments. Content-wise, most vignettes used are of little personal relevance and the language (verbal and written) used is not tailored to the conditions of dementia. Rigorous psychometric properties concerning validity also remain as a concern, given that none of the tools was designed to be dementia-specific. In addition, although (standardized) clinical vignettes seem to provide insight into PWD’s decision capacity, it may be difficult to judge small numbers of vignettes included in an assessment as a reliable criterion for competence (Grisso, 2002).

Due to all of the above-mentioned problems with assessing decision-making capacity in persons with dementia, proxy informants, such as family members, close friends, and medical staff are called upon to confirm PWD’s decisions about end-of-life care when PWD are thought not capable of decision-making. It is common for family members to be involved in proxy decision-making for family members with dementia.
Primary care physicians and/or treatment teams often provide the surrogates with information about the patient’s condition, the possible course of illness, and available treatment options and solicit their opinion about the patient’s probable decisions (Leo, 1999). It is not always clear, however, that the surrogates actually know what the patient might want, as they may not have ever discussed these issues with the patient.

**Surrogates Decision Makers**

In an ideal situation, surrogate decision makers, usually family members, are designated by individuals at the early stage of dementia, a time when they have the capacity to choose surrogate decision makers and express medical wishes (Mezey, Mitty, Bottrell, Ramsey, & Fisher, 2000; Rempusheski & Hurley, 2000). When patients become incapacitated and have not designated a surrogate, most states have statutes to identify a next-of-kin surrogate to make decisions on their behalf (Sabatino, 1999). Therefore, patient-designated and next-of-kin surrogates are expected to know patients’ lifelong values, and to express care receivers’ preferences and goals for medical care when the care receiver’s decisional capacity is compromised. In the United States, surrogate decision making, in the current model of biomedical ethics, is approved under two assumptions. First, patients have produced well-informed and durable treatment preferences for future hypothetical scenarios. Second, patient-designated surrogates are presumed to be able to determine patients’ objectives for care and treatment preferences (Black et al., 2009). In addition, caregivers are reminded to respect and view their care receivers as a whole (e.g. personal history, previous decisions such as advance directive).
to minimize the chance of overriding patients’ wishes, despite the concern that PWD’s
decisions may lack stability over time due to cognitive deterioration and changes in
personality (Horton-Deutsch et al., 2007; Cohen-Mansfield & Lipson, 2008).

Despite these beliefs, studies conducted in countries advocating patient involvement
in decision making have documented relatively inconsistent agreement between the
preferences of competent patients and their chosen surrogate’s beliefs about the patient’s
preferences (Horton-Deutsch et al., 2007; Seckler, Meier, Mulvihill, & Paris, 1991;
Shalowitz, Garrett-Mayer, & Wendler, 2006; Sharp & Payne, 1999; Tyrrell et al., 2006).
Shalowitz and colleagues (2006) completed a systematic literature review based on a
meta-analysis of data from 16 studies. The review involved 151 hypothetical scenarios
and 2595 surrogate-patient pairs, which collectively analyzed 19,526 patient-surrogate
paired responses. Overall results showed that surrogates predicted patients’ treatment
preferences with only 68% accuracy, and showed that the agreement was at the lowest for
scenarios involving stroke or dementia. Results further revealed that neither the
designation of surrogate as the patients’ decision makers nor discussions of patients’
treatment preferences improved surrogates’ accuracy. These disagreements may stem
from personal differences in prioritizing vital needs. In a semi-structured interview of 20
residents with mild to moderate dementia and their family caregivers making health care
decisions, Horton-Deutsch et al. (2007) reported that residents’ focuses were more
holistic by wishing to obtain all possible needs in health care. On the other hand, their
caregivers showed greater consideration to symptoms, psychological and safety needs,
and the chance of survival. These considerable discrepancies in medical choices between
the care receivers and their caregivers further implied potential incongruences in medical knowledge (i.e., unaware of each other’s preferences), agreement (i.e., fail to acknowledge care receiver’s preference), and behavior (i.e., caregiver’s action is inconsistent with the care receiver’s preference) (Feinberg & Whitlatch, 2001).

Patients’ and caregivers’ poor awareness and knowledge of dementia symptoms, progression, and treatment options also exacerbate difficulty in discussing and negotiating around advance medical care issues from the earliest stage of dementia (Johnson, Kuchibhatla, & Tulsky, 2009; Robinson et al., 2005). For example, family members often deny the existence of cognitive and language impairments until the later stage of dementia (Bourgeois, 2002). They also have unrealistic expectations that aggressive interventions are the best possible care for the PWD at the advanced stage (Coppola, Ditto, Danks, & Smuker, 2001; Ditto et al., 2001). Family surrogates’ lack of knowledge also contributes to the feeling of being unprepared for making medical and end-of-life decisions (Livingston, Leavey, Manela, Livingston, & Rait, 2010; Dening, Jones, & Sampson, 2011). In a survey of nursing homes in Canada and the United States, only 48% of proxies felt confident that the patients would want to have a feeding tube. These proxies reported understanding the benefits (83.0%) but not the risks (48.9%) of tube-feeding (Mitchell, Berkowitz, Lawson, & Lipsitz, 2000). To summarize, there are various factors that contribute to surrogate-patient agreement incongruence and that caregivers find making decisions on behalf of the patient difficult. In view of the serious consequences of inappropriate end-of-life decisions, it is thus suggested that family
caregivers and surrogates should not be assumed to be the “gold standard” for determining PWD’s end-of-life preferences (Karel, Moye, Bank, & Azar, 2007).

Health Care Professionals

Physicians were found to be even less accurate than those of patient-designated surrogates when hypothesizing patients’ preferences (Seckler et al., 1991; Uhlmann, Pearlman, & Cain, 1988; Zweibel & Cassell, 1989). For example, Coppola et al. (2001) investigated physicians’ predictions of elderly outpatients’ medical care preferences. Twenty-four physicians from primary care and 17 from emergency and critical care were asked to predict patients’ preferences for four life-sustaining treatments in nine hypothetical illness scenarios. Prior to the evaluation, all physicians were informed about the absence and presence of advance directives for each patient. Results revealed that the accurate prediction for the Alzheimer’s disease scenario for both primary care physicians and hospital-based physicians was only 56% on average, while family surrogates scored 61%. An in-depth analysis further reported that primary care physicians made more under-treatment predictions across all scenarios; hospital-based physicians made errors in both overtreatment and under-treatment, with the former marginally more than the latter. The inaccurate assumptions of health care professionals may stem from the fact that PWD present with a range of severity stages (from mild to severe), and a range of abilities (some preserved, some impaired) depending on the etiology (Riley, 1999). Another possible cause is ineffective communication with the surrogates. Family members were reported to have a low rate (40%) of involvement in medical decisions concerning acute events due to time inconvenience for obtaining their input (e.g., late at
night) (Cohen-Mansfield & Lipson, 2008). In addition, while health professionals are often involved in decision-making conferences with the family caregivers, little is known about how caregivers interact with professionals during the decision-making process and what is required for effective communication (Caron et al., 2005; Goodman et al., 2009). A cross-cultural study of 12 Dutch physicians and 12 U.S. physicians was conducted to investigate the factors that influence treatment decisions of PWD with acute pneumonia (Helton, van der Steen, Daaleman, Gamble, & Ribbe, 2006). Using semi-structured interviews, results showed that physician-perceived care roles (i.e., active role vs. passive role), which affected the amount of contact time with the patient and family, posed a direct influence on the physicians’ knowledge of their patients’ wishes and the way physicians negotiate patient and family preferences regarding care.

To summarize, while surrogates and health care professionals involved in making PWD’s medical decisions should have a common understanding of the patient’s wishes, oftentimes this is not the case. This is reflected in the disagreements between the surrogates, health care professionals, and the patients, as well as their limited knowledge about what factors constitute an effective discussion when making medical care decisions. Sustaining strong decision-making ability is critical to maintain a fine balance between patient safety and a person’s basic human rights. Given that expressions of medical preferences from individuals other than the patients themselves are not always valid, it is crucial to improve patients’ decision-making abilities. The development of specific tools to establish the person’s capacity for decision-making becomes the first step in the process. Clinicians have been using graphic and written aids to improve
conversation and comprehension of language (e.g., Bourgeois 1992, 1993), interactions between the patient and their conversation partners (e.g., Bourgeois, 1992), and quality-of-life decisions (Bourgeois, Dijkstra, & Hickey, 2005). Hence, it is possible that these tools may be helpful to individuals with dementia when making decisions related to medical care preferences.

**External Visual Supports**

External visual supports, such as graphic/written memory aids in the form of sentences, words, phrases, and pictures, have been documented to compensate for the gradual loss of linguistic and cognitive skills in dementia. These materials provide the semantic content that otherwise would be retrieved from long-term memory. Because linguistics skills (i.e., speech sounds, grammar, and discourse production) are relatively preserved in PWD until the later stages of dementia, Dunn and Jeste (2001) have suggested that PWD are able to maximize comprehension and minimize memory demands with the help of appropriate cues and supports. Therefore, external visual assistance may bridge the comprehension deficits of PWD when instructions and/or questions are verbally delivered (Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001).

Research has shown that external visual materials containing photographs and one to two declarative, personally-related statements corresponding to the topic per page can enhance the effectiveness in PWD retrieving long-term memories about personal information (e.g., Bourgeois, 1990, 1992; Chang & Bourgeois, 2012). Improvements in discourse related to the specific and personal topics were documented, including an increase in the participants’ on-topic statements, and a decrease in the amount of negative
verbalizations including ambiguous, perseverative, erroneous, unintelligible, and
tangential utterances when using external aids (e.g., Bourgeois, 1990, 1992, 1993;
Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997; Bourgeois et al., 2001; Bourgeois &
Mason, 1996; Chang & Bourgeois, 2012; Hoerster et al., 2001). Written stimuli used to
augment verbal questions were also found to elicit valid and reliable responses about
quality-of-life topics from individuals with dementia (Bourgeois et al., 2005). In addition,
Egan, Berube, Racine, Leonard, and Rochon (2010) conducted a systematic review of
methods to enhance verbal communication between the PWD and their caregivers. A
total of 13 studies were included for review, 8 of which evaluated the effects of memory
books (a type of graphic/written memory aid), and five of which involved educational-
training or activity-based programs. Results revealed that memory aids were effective in
improving on-topic discourse as well as in enhancing topic maintenance, suggesting that
these interventions address verbal attention and helped individuals focus their thoughts.
The activity-based programs, on the contrary, reported either limited improvement or
even worse performance in conversations between the PWD and their non-dementia
partners.

Supplemental visual support (i.e., picture-text stimuli modified for dementia
condition and used to augment verbal questions) has been shown to be effective for
facilitating conversational interactions between the PWD and their conversation partners
(Andrews-Salvia, Roy, & Cameron, 2003). This is important given that good
communicative interactions are essential for conveying thoughts and improving the
listener’s (e.g., surrogates, family members, physicians, nursing assistants) accuracy in
understanding patients’ decisions. Bourgeois et al. (2003) used communication cards (consisting of pictures and short sentences) to investigate the effects of visual supports on communicative interactions between 125 residents with dementia and 133 nursing assistants. Ratings of PWD’s perceived depression were also examined. Data was gathered from a 4-week baseline, a 2- to 3-week training on communication skills and use of these communication cards, and a 4-week post-training computer observation. Results found that, after the communication training, the quantity and quality of interactions in care interactions and one-to-one conversations improved. Greater agreement between the resident and proxy scores on the Geriatric Depression Scale (Yesavage et al., 1983) was also found after the training.

The results of an extension study (Bourgeois, Camp, & Zeisel, 2010) that evaluated the effects of labeled picture cards on quality-of-life responses added further support to the effects of picture-text aids on PWD’s communicative interactions. Bourgeois et al. (2010) examined the opinions of 90 nursing home residents with dementia on daily quality-of-life topics (e.g., How much do you like the food in the facility?). The residents’ responses were elicited under three conditions: Visual (an enhanced visual/sorting condition), in which the nursing assistants prompted the residents to sort labeled picture cards about specific quality-of-life topics into rating categories (Always, Sometimes, Never); Verbal (an augmented verbal condition), in which the assigned nursing assistants used written cue cards to verbally prompt the PWD to talk about quality-of-life topics, and Control, in which no treatment was provided. The Dementia Quality of Life scale (DQoL; Brod, 1998) was administered pre- and post-treatment.
condition. Residents with moderate dementia in the language-matched dyads were able to provide reliable answers to quality-of-life questions and their nursing aides improved their quality-of-life ratings after using the visual aid materials, while the ratings in the other two groups did not improve. In both language-matched and language-mismatched dyads, residents in the Visual Group were able to discuss more topics than in the other two groups, as well as making significantly fewer requests for clarification of the prompt questions than in the verbal condition. These results supported the contention that supplemental visual materials can improve the quality of the conversational interaction between the PWD and their partners through enhancing PWD’s comprehension of the questions posed by their partners.

To date, the effects of external visual aids on decision-making ability related to decisions about end-of-life medical care by PWD have not been investigated nor have the effects of using visual supports to evaluate PWD performance according to the four legal standards been evaluated. The effectiveness of picture-text stimuli on PWD’s language behavior, including more topic-related utterances and fewer ambiguous utterances, suggests that similarly improved performance on decision-making protocols might be possible with visual supports. Picture- and text-based aids have also been documented to facilitate quality-of-life conversations between the PWD and their conversation partners; PWD became less confused with the topics; there is an increased frequency in interaction, and higher patient-surrogate agreement on quality of life questions. Making a decision requires strong abilities in receptive language (i.e., language comprehension) and expressive language (i.e., spoken language). Given that the combination of picture and
textual materials have been shown to be effective for topics related to non-medical conversations and choices, it is possible that these visual cues might also be helpful to improve PWD’s decisional capacity related to the four legal standards when conversing about medical care and treatment topics.

The purpose of this study was to examine the effects of picture-text visual aids on decision-making capacity of PWD for medical and end-of-life care choices. The study investigated the following questions and hypotheses:

1. Will individuals with mild and moderate dementia demonstrate better decisional capacity for medical scenarios, as measured by the four legal standards, when using visual aids to supplement verbal questioning in comparison to performance elicited by verbal questioning alone?

   It is hypothesized that in comparison to the verbal-only administration, when verbal questioning is augmented by visual aids in medical decision-making scenarios:

   (1) PWD will demonstrate better understanding ability scores,

   (2) PWD will demonstrate better reasoning scores,

   (3) PWD will show better logical consistency scores in determining a treatment decision, and

   (4) PWD will demonstrate better appreciation scores.

   Specifically,

   2. To what extent will visual aids affect the quality of PWD’s appropriate factual statements produced to demonstrate their decision-making abilities?
In addition,

3. To what extent will PWD’s use of visual aids during the decision-making process affect speech clinicians’ perceptions of PWD’ decision-making abilities?
METHOD

A flow chart illustrating the study procedure is provided as shown in Figure 1.

Participant Recruitment

The study was approved by the Institutional Review Board (IRB) at the University of South Florida (USF) and the Ohio State University (OSU). The consent form for social validation was approved by the OSU IRB.

Initial Meeting

The study investigator contacted 15 senior living facilities in Hillsborough County, Florida; initial meetings were conducted with the administrators of 3 facilities where the participants resided. During the meeting, the experimenter explained the purpose and pertinent information of the study, solicited questions and clarified concerns. At this stage, the facility administrators were the only authorized persons to identify potential participants who met the study criteria, and to mail research study invitations and consent forms (see Appendix A) to their surrogates; the experimenter could not access and review residents’ medical record and biographical information, or caregivers’ contact information, until informed consent had been received from the caregivers. Therefore, the experimenter disclosed subjects’ inclusion and exclusion criteria to the facility administrators in order to identify potential participants.
Figure 1. Flow chart of study methods and procedures
To meet the inclusion criteria, participants were required to have a diagnosis of dementia (e.g., Alzheimer’s, dementia not otherwise specified), the absence of other neurologic or psychiatric illness, no prior history of drug or alcohol abuse, age 65 and above, and native speakers of English. Participants with evidence of other neurologic or psychiatric illness and prior history of drug or alcohol abuse were excluded to minimize communication and cognitive deficits caused by non-dementia etiologies. Individuals with dementia younger than age 65 were also excluded given that this type of dementia is defined as early onset Alzheimer’s. In contrast to people diagnosed with Alzheimer’s disease after age 65 who experience stages from mild, moderate, to severe, people with early onset Alzheimer’s (usually develop symptoms in their 40s and 50s) may be at any stage of dementia (Alzheimer’s Association, 2014). Furthermore, the cause of early onset Alzheimer’s appears to be linked with specific genetic defects or attributed to family inheritance (caused by deterministic genes), which affect multiple family generations (Alzheimer’s Association, 2014). Finally, participants were restricted to native English speakers to avoid limited language proficiency as a result of English as their second language.

Profiles Review

After the initial meeting, the administrators provided their letter of authorization to the experimenter. Upon IRB approval, the experimenter delivered the consent forms and cover letters to each facility for the administrators to send to the surrogates of the chosen residents. Once the signed and dated consent form was received from the surrogates, the experimenter reviewed medical and biographical profiles of the potential participants to confirm research qualification using the same selection criteria.
Screening Test Administrations

In addition to reviewing the biographical information and medical records, the experimenter visited the participants and administered the following screening tests to confirm their current cognitive, visual, verbal, and conversational statuses prior to the research study session: The Communication Screening Test (Bourgeois, 1992), the Mini-Mental State Exam (MMSE; Folstein et al., 1975) (see Appendix B), and Subtest VI (Sentence–Picture) of the Reading Comprehension Battery for Aphasia, 2nd ed. (RCBA-2; La Pointe & Horner, 1998). The Communication Screening Test (Bourgeois, 1992) (see Appendix C) was administered to measure the participants’ functional visual status, auditory status, and conversation skills. Participants producing few statements, communicating through simple non-verbal responses only (e.g., smile, nodding), or unintelligible utterances were excluded from the study as the study session required participants to provide verbal explanations. The MMSE was conducted to evaluate participants’ current cognitive status. Participants scoring within the mild and moderate dementia ranges (mild: $25 \geq \text{score} \geq 21$ out of 30; moderate: $20 \geq \text{score} \geq 11$ out of 30) (Mungas, 1991) on the MMSE (Folstein et al., 1975) within two weeks of their participation were recruited for the study. These severity levels were selected due to the fact that previous studies on decision-making assessment tools reported impairment in at least one legal standard in this population regardless of textual assistance (Marson et al., 1995; Vellinga et al., 2004). In addition, the conversational content of people with mild and moderate dementia severity improved with picture/text visual aids in other research studies (Bourgeois et al., 2010). It was thus anticipated that (1) the proposed visual aids would elicit improved responding during decision-related conversations in comparison
with verbal only conversations, and (2) by including participants with moderate
dementia, it would maximize the potential to find differences between visual and verbal
conditions.

In the absence of dementia-specific standardized reading measures, Subtest VI
(Sentence–Picture) of the RCBA-2 (La Pointe & Horner, 1998) was administered to
assess participants’ reading comprehension in sentences. Because this study required
participants to learn information through reading during the process of medical decision-
making, it was important to evaluate and document the participants’ reading performance
prior to the study session. The format of this sentence-picture matching subtest –
containing 3 pictures and 1 short sentence per page – is also similar to the visual aids
developed for this study, which would serve to estimate participants’ performance when
using the study materials.

Residents who met the study inclusion criteria and passed all screening tests
proceeded to the study session. When the residents were determined as not meeting the
criteria, the experimenter thanked them for their time and escorted them to their desired
destination in the facility.

Participants

A total of 26 participants with dementia were originally recruited from a retirement
living residence in Lutz (N = 9), an assisted living facility in Sun City Center (N = 11),
and a memory care center in Tampa (N = 3), Florida. None of the participants in the
memory care met the Communication criteria in the Communication Screening Test and
were excluded from the study. Among the remaining 23 participants, 3 were excluded
before the beginning of the study session due to expressing feelings of physical and
emotional discomfort, long-term hospitalization, or having a diagnosis of a psychiatric illness. Therefore, a total of 20 participants were included for the study.

Screening test results of the 20 participants are presented in Table 3. The overall mean of dementia severity was 20.25 (SD = 3.14), with 11 participants (55%) scored in the mild range (M = 22.55, SD = 1.44) and 9 (45%) in the moderate range (M = 17.44, SD = 2.19). All participants demonstrated functional vision (13 with glasses, 7 without). Eighteen (80%) participants had functional and adequate hearing status (2 with hearing aids, 18 without); two (20%) presented minimal difficulty in hearing status with no hearing appliance available, requiring the study investigator to speak slightly louder when there was background noise in the setting (e.g., staff vacuuming the carpet outside the participant’s bedroom). Eighteen participants were able to have a conversation with elaborated, multiple sentences responses with the experimenter, and 2 responded with single sentences only. Participants’ sentence-picture matching performance on Subtest VI of the RCBA-2 ranged from 7 to 10 out of 10 (M = 9.05, SD = 1.05).

Table 4 presents the demographic characteristics of the recruited participants. Within this population, two were male and 18 were female (mean age = 87.1, range = 76 – 97, SD = 5.68); all were White, with 19 of non-Hispanic and 1 Hispanic ethnicity. Nine participants (45%) obtained a high school degree, 7 a college degree (35%), 3 had some college experiences (15%), and 1 had a doctoral degree (5%). Eighteen of the participants (80%) were diagnosed with dementia not otherwise specified, and 2 (20%) had a diagnosis of Alzheimer’s disease. Three participants were taking prescribed memory medication (Aricept and Namenda) at the time of the study.
Table 3. Participant Screening Test Results

<table>
<thead>
<tr>
<th>Participant</th>
<th>MMSE</th>
<th>Severity</th>
<th>Sentence Comprehension (%)</th>
<th>Functional Vision</th>
<th>Use of Glasses</th>
<th>Functional Hearing</th>
<th>Use of Hearing Aids</th>
<th>Communication</th>
</tr>
</thead>
<tbody>
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<td>1</td>
<td>16</td>
<td>moderate</td>
<td>90</td>
<td>Adequate</td>
<td>Yes</td>
<td>Minimal difficulty</td>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
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<td>90</td>
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<td>Adequate</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>18</td>
<td>moderate</td>
<td>70</td>
<td>Adequate</td>
<td>Yes</td>
<td>Adequate</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
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</tr>
<tr>
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<td>100</td>
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<td>Adequate</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>21</td>
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<td>90</td>
<td>Adequate</td>
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<td>Adequate</td>
<td>No</td>
<td>1</td>
</tr>
<tr>
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<tr>
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<td>Minimal difficulty</td>
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<td>2</td>
</tr>
<tr>
<td>10</td>
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<tr>
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<tr>
<td>13</td>
<td>13</td>
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<td>18</td>
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<tr>
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<td>Adequate</td>
<td>No</td>
<td>Adequate</td>
<td>No</td>
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</tr>
</tbody>
</table>

*M* = 20.25, *SD* = 3.14

3 Communication status: Appropriate, elaborated conversation with multiple sentence responses. 4 Communication status: Single sentences only.
Table 4. Participant Demographic Characteristics

<table>
<thead>
<tr>
<th>Participant (N = 20)</th>
<th>Sex</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Education</th>
<th>Type of Dementia</th>
<th>Memory Medication</th>
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</thead>
<tbody>
<tr>
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<td>F</td>
<td>88</td>
<td>Non-Hispanic</td>
<td>College</td>
<td>NOS(^1)</td>
<td>N</td>
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<td>2</td>
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<td>90</td>
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<td>High School</td>
<td>NOS</td>
<td>N</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>78</td>
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<td>College</td>
<td>NOS</td>
<td>N</td>
</tr>
<tr>
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<td>F</td>
<td>90</td>
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<td>Aricept</td>
</tr>
<tr>
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<td>High School</td>
<td>Alzheimer’s</td>
<td>N</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
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</table>

\(M = 87.1\)

\(SD = 5.68\)

Note: \(^1\) NOS: Not otherwise specified.

Stimuli

The study investigator developed the following experimental stimuli: (1) two medical vignettes (see Appendix D), (2) two sets of decisional aids with pictures and sentences corresponding to each vignette (see Appendix E), (3) a questionnaire (see Appendix F), and (4) a scoring form (see Appendix F).
Medical Vignettes

Several factors were taken into consideration when selecting the medical scenarios. First, the scenarios would be health problems that are common for PWD (Alzheimer’s Society, 2012; Family Caregiver Alliance, 2013; Grant, Rudberg, & Brody, 1998). These decisional scenarios also needed to be sufficiently complex and encompass various concerns (Kemp, Floyd, McCord-Duncan, & Lang, 2008); some medical decisions would involve more impact from emotions (e.g., family bonds) and value (e.g., culture, religion) than others (McCarron & McCallion, 2007). For example, feeding tube placement may be a more difficult decision than taking an oral medicine (Gillick, 2000). Issues of generalizability (Cronbach, Gleser, Nanda, & Rajaratnam, 1972) and content validity (Kapp & Mossman, 1996) were taken into account. It was anticipated that generalizability would increase by selecting scenarios that present different levels of risk (Grisso, 2002). For example, risks that involve physical discomfort may increase participants’ tendency to forego the treatment option, whereas risks without this concern may lead to stronger willingness to consent to the suggested treatment option. Content validity considerations related to whether the medical scenarios selected could universally represent all possible situations were addressed (Edelstein, 2000). For instance, would performance on a medical scenario describing the use of antibiotics for pneumonia generalize to an urgent circumstance (e.g., CPR) or one that requires surgical procedure (e.g., tumor removal)? Based on these considerations, two hypothetical medical decisional scenarios with little similarity in nature were developed to evaluate decision-making capacity: (1) Feeding Tube Placement for Dysphagia: Whether to insert
a feeding tube when one has difficulty swallowing, and (2) Drug Treatment for Dementia: Whether to take dementia medications with unpleasant side-effects (see Appendix D). Each scenario contained three sections: Health problem, treatment option, and risks and benefits of the treatment option. An independent samples t-test determined that the Flesch-Kincaid reading grade levels as used in Microsoft Word 2013 for Feeding Tube Placement for Dysphagia ($M = 6.02, SD = 0.28$) and Drug Treatment for Dementia ($M = 6.20, SD = 0.16$) were not significantly different ($t(6) = 1.09, p = 0.32$).

**Validity**

The content of the vignette on drugs for dementia was retrieved and simplified from the Alzheimer’s Association (2014); the information on feeding tube placement was from the Family Caregiver Alliance – National Center on Caregiving (2013), National Institute on Deafness and Other Communication Disorders (NIDCD, 2014), and Comfort Care: A Guide for Caregivers (2005). Language and content appropriateness of both vignettes were reviewed and discussed with two health care experts. One was an experienced researcher with expertise in aging, dementia, and end of life issues. The other was a speech-language pathologist and a clinical researcher working with PWD for over 30 years. Content appropriateness for the feeding tube vignette was additionally reviewed and discussed with a speech-language pathologist specializing in dysphagia.

All printed materials were constructed based on the (1) guidelines from the National Institute on Aging, and (2) information on health literacy and older adults provided by the U.S. Department of Health & Human Services. To reduce redundancy and to ensure appropriate wording of the questions, the questionnaire was initially tested and then
modified according to the suggestions by two graduate students who were not in the
speech and hearing major and were naïve to the protocol.

Decisional Aids

Decisional aids with content corresponding to the feeding tube placement and the
dementia medication scenarios were developed by the experimenter (see Appendix E). A
set of decisional aids was constructed for each scenario, consisting of simple declarative
sentences and corresponding colored pictures or photos from Google Images (Google
Images, 2014). All printed sentences with corresponding images were mounted on white
letter-size paper and inserted into sheet protectors. Each aid contained 6 pages:

1. Page 1: Health problem, consisting of a heading that indicates the health problem
to be discussed, and short descriptions of the health problem.


3. Page 3: Treatment option, consisting of a heading that indicates the proposed
solution to the health problem, and short descriptions that explain the treatment
process and treatment features.


6. Page 6: Determine a choice, consisting of a question that directs the participant to
make a choice, and two statements on whether to accept or reject the proposed
treatment.

Page numbers corresponding to a particular vignette section were added at the end of the
section heading.
Questionnaire and Record Form

A total of 8 questions (see Appendix F) were developed to evaluate the decision-making capacity comprised of the four legal standards: factual understanding, appreciation of the scenario, reasoning about risks and benefits, and expressing a choice. Each question was modified from MacCAT-T (Grisso & Appelbaum, 1998) and Vellinga et al.’s vignette method (2004), and evaluated a specific decisional skill categorized under one of the four legal standards. These decisional skills and respective definition were:

(1) *Understanding – Health Problem*: The capability in comprehending the presented health problem information.

(2) *Understanding – Treatment Option*: The capability in comprehending the information on the treatment option offered.

(3) *Understanding – Risks and Benefits*: The capability in comprehending the potential risks and benefits accompanied with the suggested treatment.

(4) *Expressing a Choice – Make a Decision*: The capability in selecting a treatment method for the health problem being discussed, including to forego the treatment.

(5a) *Reasoning – Comparison*: The capability in justifying the selected treatment option with statements in comparative form. The statement(s) may or may not demonstrate specific differences (e.g., specific difference: “Treatment X is more likely to work faster (than Y)”; vague: “Treatment X is better (than Y).”)
(5b) **Reasoning – Vignette Consequences**: The capability in justifying the selected treatment option by referring to the risks and/or benefits mentioned in the vignette.

(5c) **Reasoning – Non-Vignette Consequences**: The capability in justifying the selected treatment option by providing reasons other than the ones as stated in the vignette. The justification(s) may be based on the decision maker’s religious beliefs, cultural background, and/or personal experience. Justifications based on a delusional premise or a serious distortion of reality is regarded as a loss of this capability.

(6) **Reasoning – Logical Sequence**. The capability in making a choice that logically follows the justification(s) as stated in (5a), (5b), and/or (5c).

(7) **Appreciation – Acknowledgment**. The capability in expressing an explicit agreement or disagreement with the potential treatment benefits on the decision maker’s current health condition.

(8) **Appreciation – Potential Effects**. The capability in justifying the decision made in (7). Criteria for justifications are the same as in (5a), (5b), and (5c).

Specific page number(s) of the decisional aids corresponding to each decisional skill was added at the end of each decisional skill heading on the record form.

**Setting**

All study sessions were conducted at a table in the facility or in the participant’s own room. Both the experimenter and the participant sat side by side or across the table face-to-face, either on a chair or a wheelchair. Participants were out of range of
computers, televisions, and noisy recreational activities. Visible movements of other passers-by were kept to a minimum. Decisional aids were kept out of sight from the participants during the verbal condition. All sessions were audio-recorded using a digital recorder.

**Experimental Design**

This study was a $2 \times 4$ within subjects design, with one factor being the Condition (visual and verbal), and the other factor being the scores on the four legal standards (*Understanding, Expressing a Choice, Reasoning, and Appreciation*). In the verbal condition the experimenter presented the medical vignette and the questions verbally; decisional aids were not provided to the participants. In the visual condition the experimenter presented the vignette and questions verbally while the decisional aids were provided to the participants throughout the session. Each participant participated in both conditions with their decision-making performance evaluated using the 4 legal standards. Throughout the study, the two conditions and the two medical scenarios (Drug Treatment for Dementia, and Feeding Tube Placement for Dysphagia) were counterbalanced to reduce order effects.

**Dependent Variables**

The dependent variables were categorized into two groups for analysis:

(A) Decision-making capacity: The variables for decision-making capacity were the score of each decisional skill under the 4 legal standards (*Understanding, Expressing a Choice, Reasoning, and Appreciation*) obtained from the Questionnaire and Record Form (see Appendix F). These variables were also the
decisional skills categorized by the four legal standards: (1) Understanding: Health Problem (score: 0 – 5), (2) Understanding: Treatment Option (0 – 3), (3) Understanding: Risks and Benefits (0 – 6), (4) Expressing a Choice: Make a Decision (0 – 1), (5a) Reasoning: Comparison (0 – 2), (5b) Reasoning: Vignette Consequences (0 – 3), (5c) Reasoning: Non-Vignette Consequences (0 – 2) (6) Reasoning: Logical Sequence (0 – 1), (7) Appreciation: Acknowledgment (0 – 1), and (8) Appreciation: Potential Effects (0 – 3). These dependent variables were used to evaluate the effects of visual aids on the participants’ decision-making capacity. Scoring criteria are included in Appendix F.

(B) Participants’ types of vignette statement: This category involved four dependent variables: Rewording, Exact Statement, Statement Not Mentioned, and Distorted Meaning. These variables were used to analyze the quality of statements produced by the participants that demonstrated their decision-making abilities. Definitions of these variables are displayed in Appendix G.

Independent Variables

Six types of experimenter utterances were measured to monitor treatment fidelity: Script Reading, Prompt, Clarification, Inquiry, Filler Utterance, and Other. Definitions of these codes are included in Appendix H.

Procedure

Given that the experimenter is a student at the Ohio State University and a staff member at the University of South Florida, and her advisors are faculty members at one
of the Universities, the current study was reviewed and approved by the IRB of each University.

The screening tests and the study session were completed in one visit that lasted approximately 30 – 45 minutes. Each participant participated in a semi-structured interview with conversation topics on two medical scenarios, “Drug Treatment for Dementia” and “Feeding Tube Placement and Dysphagia”. One scenario was presented in either the verbal condition or the visual condition, and the other scenario in the other condition. Conditions and scenarios were counterbalanced across the participants.

Participants’ decisional capabilities and pertinent decisional skills were examined in the order of Understanding, Expressing a Choice, Reasoning, and Appreciation. Three scripts were implemented when evaluating decisional capacity for Understanding: Health Problem, Treatment Option, and Risks and Benefits (see Appendix D).

*Verbal Condition*

In the verbal condition, the experimenter selected one of the two medical vignettes, started the digital audio-recorder, and introduced the study with:

I would like to know how you would like to handle a specific health problem. I’m going to read a situation to you. Then I will ask you some questions. Please listen carefully so that you can tell me about them later.

The experimenter read the Health Problem section from the vignettes. Then, the experimenter asked the participant the question corresponding to this section (see Appendix F) to determine his or her comprehension of the disclosed information.
Participant’s responses were scored on the Recording form. Criteria for scoring is described in Appendix F.

Each participant was given 1 minute to answer each question. The experimenter started the timer on her iPhone immediately after the question was disclosed. While listening to the participant’s responses, the experimenter sat quietly, maintained eye contact, and responded with head nodding and smiles when deemed appropriate. Affirmations (e.g., “Mm-hmm.” “Okay.”) were provided to demonstrate interest in the participant’s responses, serving as encouragement for the participant to continue. Short statements representing understanding (e.g., “Ah, I see,” “Oh, really?”) were made in response to the participant’s elaborations on the disclosed question. There were no interruptions from the experimenter when the participant produced ambiguous statements irrelevant to the task, or utterances that are unintelligible, perseverative, or clear but tangential. If the participant expressed confusion (e.g., “What are we doing now?” “Why do you want to know this?” “Do I have this problem?”), the experimenter clarified or re-explained the activity and then restated the question. If 10 seconds of time elapsed with no response from the participant after the initial disclosure of the question or after the previous response, the experimenter provided an encouraging prompt or repeated the question (e.g., “Would you share with me what you think about (the question)?” “Anything else?” “It’s ok. Take your time.” “Tell me more.”).

When the time reached 1 minute, the experimenter thanked the participant and verbally presented the next section on Treatment Option, beginning with the prompt, “Now, I’m going to tell you about the solutions to this problem. Please listen carefully so
that you can tell me about them.” Again, the experimenter posed one question immediately after the script information was disclosed, and scored the participant’s responses on the record form. Timing and the experimenter’s types of verbal and behavioral responses were the same as in the previous conversation. The procedure was repeated to evaluate the participant’s comprehension of the information on Risks and Benefits. The prompt to begin this section was, “Now, I’m going to read to you the advantages and disadvantages of this choice. Please listen carefully so that you can tell me about them later.”

The experimenter put away the vignette script after the participant finished responding to all three questions that evaluated the decisional skills under Understanding. Then, the experimenter continued the study procedure by asking the rest of the questions on the record form to examine the other three decisional capacities (Expressing a Choice, Reasoning, and Appreciation) of the participant. The time length per question and the experimenter’s verbal and behavioral responses when evaluating Understanding were replicated. A short break was offered to the participant before introducing the second scenario and proceeding to the other condition.

*Visual Condition*

In the visual condition, time limit and responses from the experimenter were the same as in the verbal condition. The experimenter selected the other medical vignette, started the digital audio-recorder, and began the session with the following statements:

I would like to know how you would like a different health problem to be handled.

Again, I’m going to read a situation to you. Then I will ask you some questions.
Please listen carefully so that you can tell me about them later. Here are some pictures and sentences about the situation [the experimenter presented Page 1 and 2 of the visual aids corresponding to the medical vignette (see Appendix E)] that I’m going to talk about. You may read along as I explain the information. Ready? Okay, here is the situation we are going to talk about now [the experimenter verbally read the Health Problem section].

After reading the script, the experimenter posed the question corresponding to this section to evaluate the participant’s decisional skill with the record form. The prompt, “You may read from these pages to help you answer the question,” was added immediately after the question was posed and the timer began. The experimenter provided the same verbal and behavioral responses as described in the verbal condition while listening or waiting for the participant’s response. Same as in the verbal condition, 1 minute was allowed for the participant to answer the question and to elicit additional responses.

When 1 minute elapsed, the experimenter thanked the participant, asked the individual to return the visual aid, and proceeded to the section on Treatment Option. The experimenter introduced this section with the same statements used in the verbal condition on Treatment Option. Then the experimenter presented the page (i.e., Page 3) that corresponded to this section and explained, “Here are some pictures and sentences about the solution we will be talking about. You may read along while I explain the information.” The remaining study procedure replicated the Health Problem section. The
overall study procedure for Treatment Option was repeated on the Risks and Benefits section, except that Page 4 and 5 of the visual aid were presented instead.

The experimenter put away the vignette script after the participant answered the question for Risks and Benefits. Then, the experimenter continued and posed the rest of the questions on the record form to the participant to examine the other three decisional capacities (*Expressing a Choice*, *Reasoning*, and *Appreciation*). Each time when a question was posed, one to two pages of the visual aid corresponding to the question was provided to the participant to use as a reference to elicit responses.

When the participant finished answering all of the questions, the experimenter thanked the individual for his/her assistance and ended the session with either a casual conversation or escorted the participant to the desired destination in the facility. Scores on the record form were summarized on the Decisional Capacity Scoring Form (see first page of Appendix F).

**Data Summary and Analysis**

The experimenter transcribed and scored all audio recordings. Data from the decisional capacity recording form (Appendix F) and from the scoring form for the types of vignette statement (Appendix G) were summarized onto Excel spreadsheets of Microsoft Excel 2013 to calculate the total score for the overall decisional performance, and for each legal standard, decisional skill, and vignette statement.

All data were analyzed using the SPSS Statistics version 22. To examine participants’ overall decision-making performance (i.e., the total score of all 4 legal standards), the scores for the 4 legal standards were summed for analysis. Given that
there were different numbers of decisional skills for each legal standard, the total score obtained for each legal standard per participant was transformed into a percentage. Then the mean performance on each legal standard was calculated by adding the percentage values of the decisional skills under the same legal standard, and then dividing by the number of decisional skills that were being summed. The mean, standard deviation, critical value, and effect size were also calculated.

Effects of Medical Vignettes and Order Effects

Two omnibus 2 x 4 repeated measures ANOVAs were conducted to examine two types of potential effects on overall decisional performance: 1) effects of 2 medical vignettes (Drug Treatment for Dementia, Feeding Tube Placement for Dysphagia), and 2) presentation order (first, second) of the vignettes and the experimental conditions to which the vignettes were assigned. Sphericity was examined to ensure homogeneity of variance would not be distorted and result in inflated $F$ values (Hinton, Brownlow, & McMurray, 2004). Violations of sphericity were corrected using the criteria proposed by Girden (1992) to produce valid $F$ values. Effect sizes were determined by the partial eta squared ($\eta_p^2$; small: .01, medium: .06, large: .14) (Cohen, 1988).

Two-tailed paired-samples t-tests were conducted to probe for any possible effects of vignettes and presentation order on the legal standards in the two experimental conditions. The Bonferroni correction was applied to the dependent variables given that several dependent tests were being performed simultaneously on a single data set. To perform the adjustment, the critical $p$-value ($\alpha$) of .05 was divided by the number of paired samples. The adjusted outcomes yielded an alpha level of .01 for the legal
standards (4 pairs). Effect sizes were calculated using the Cohen’s \(d\) (small: .20, medium: .50, large: .80) (Cohen, 1992).

**Decisional Performance and Statements**

An omnibus 2 x 4 repeated measures ANOVA was conducted to investigate participants’ performance on overall decision-making (i.e., the total score of all 4 legal standards) and on each legal standard in the visual and verbal conditions. Significant differences on any of the legal standards across the two conditions would justify further exploration of differences between the standards and the individual questions. Sphericity was also examined, and effect sizes were reported by means of the partial eta squared (\(\eta^2_p\)).

Two-tailed paired-samples t-tests were conducted to compare and analyze several performances between the visual and verbal conditions: (1) participants’ decisional performance on (a) the 4 legal standards and (b) decision-making skill scores, especially when a significant difference was found in a particular legal standard, (2) participants’ types of vignette statements, and (3) the changes in experimenter utterances. The critical value of .05 was adjusted using the Bonferroni correction and yielded an alpha level of .01 for the legal standards (4 pairs), .005 for the decisional skill scores (10 pairs), .01 for the vignette statements (4 pairs), and .008 for the experimenter utterances (6 pairs). Cohen’s \(d\) was also applied for effect size calculation.

Due to similar numbers of participants with mild (N = 11) and moderate (N = 9) dementia, and the likelihood that severity might result in different decisional performance and in the amount of verbal behavior, two-tailed independent-samples t-tests were
conducted to explore the potential differences in these areas between the two severity groups in both experimental conditions. With Bonferroni correction, the adjusted alpha level was .003 (16 pairs, with 8 per experimental condition) to investigate the decisional skills under each legal capacity, and 0.006 (8 pairs, with 4 per condition) for the types of vignette statement.

To obtain detailed information on the frequency distributions of statements between the two experimental conditions, the median, the lowest and highest values, and the interquartile range (i.e., IQR, which presents the middle half of the data from the 25th percentile (i.e., first quartile; Q1) to the 75th percentile (i.e., third quartile; Q3)) – of participants’ types of vignette statement and experimenter utterances were reported. Graphical depictions corresponding to these frequency distributions were presented in boxplots to supplement visualization.

Reliability

Inter-rater reliability was conducted in this study as this is an essential means to verify the quality of data produced through subjective observation (Hayes & Krippendorff, 2007; Krippendorff, 2004; Neuendorf, 2002). To do so, the experimenter (1) scored participants’ decisional skills in all of the sessions by listening to the audio recordings, (2) transcribed all audio recordings, and (3) coded all of the utterances in all the sessions by reading the transcripts. A graduate student listened to the audio files and marked on the written transcripts for any disagreements in wording. Percentage of agreement was calculated by dividing the number of words in agreement by the total number of words in agreement plus in disagreement per transcript and multiplying by
100. This procedure yielded an overall agreement score of 99.3 % (range: 98.1% to 100%) and 99.6% (range: 97.9% to 100%) for the visual and verbal conditions, respectively.

A trained undergraduate student majoring in Communication Sciences and Disorders scored 35% of the total transcripts (7 out of 20 total) to determine participants’ decisional performance and the types of vignette statement. Prior to official decisional skill scoring and utterance coding, training sessions were conducted for both tasks. The experimenter explained the scoring criteria and the corresponding record form to the inter-rater observer to ensure familiarity with the content. One transcript was provided to the observer to score responses. The experimenter compared the scoring results with the observer’s, discussed the differences, and calculated the agreement. Then another transcript was scored, compared, and calculated to determine reliability.

Percentage of inter-rater agreement on decisional capacity was calculated by dividing the number of agreements by the total number of decisional skills and multiplying by 100. The inter-rater agreement for the training session on the decisional skills achieved 90% (90% on both trials) for the visual condition, and 100% (100% on both trials) for the verbal condition. This procedure yielded an overall mean agreement of 95% (range: 90 – 100%) for the visual condition and 96.67% (range: 90 – 100%) for the verbal condition.

Kappa statistic (κ) was performed to determine consistency between raters on the types of statements. The standard for the training session was to attain 90% agreement on decisional skills, and κ ≥ 0.70 (95% CI) (Altman, 1991; Landis & Koch, 1977) on the
statement types for a minimum of 2 transcripts each. Cohen’s Kappa results for both training trials and the experimental data indicated nearly perfect agreement, according to Landis and Koch’s (1977) criteria. The inter-rater reliability for training trials was 0.95 (95% CI: [0.85, 1.05], p < .001) in both trials for the visual condition. In the verbal condition, Kappa was 1 (95% CI: [1, 1], p < .001) and 0.90 (95% CI: [0.72, 1.09], p < .001) on the first and second trial respectively. Reliability analyses for the experimental data trials reported Kappa ranging from 0.84 (95% CI: [0.67, 1.01], p < .001) to 1 (95% CI: [1, 1], p < .001) in the visual condition, and from 0.87 (95% CI: [0.62, 1.12], p < .001) to 1 (95% CI: [1, 1], p < .001) in the verbal condition.

Social Validation

Twenty percent of all digital audio recordings (4 out of 20 participants; a total of 8 audio samples, with 4 in the visual condition and 4 in the verbal condition) were randomly selected for appraisal by the naïve judges. These eight audio samples were numbered in randomized order across participants and conditions in mp3 format on a computer. To ensure the naïve judges were blinded to the conditions, the prompt and paraphrase of the prompt, “You may read from these pages to help you answer the question,” were deleted from the original samples. In addition, all audio samples began with the experimenter reading the script on Health Problem (i.e., “Let’s assume that you have…”) and excluded introductions to the study that included instructions specifically for the visual and verbal conditions. The total time length of the audio samples was 67 minutes and 57 seconds (range: 7 minutes and 50 seconds – 8 minutes and 55 seconds).
Twelve naïve judges were recruited to participate in the social validation procedures. The experimenter met with the judges and explained the purpose and the procedure of this research activity; questions were also solicited from the judges. After obtaining their informed consent (see Appendix J), the experimenter provided the scripts of the two medical vignettes to the judges for them to use as references during rating. The rating task began after the judges indicated familiarity with the scripts. Table 5 displays the descriptive characteristics of the judges. All judges (9 female, 3 male) majored in speech-language pathology; 8 were second-year student clinicians, and 4 were doctoral students certified as speech-language pathologists. The judges’ experience with the dementia

<table>
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<th>Judge</th>
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<th>Experience with Dementia Population</th>
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<td>Class on Aging and Gerontology.</td>
</tr>
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<td>2nd year graduate</td>
<td>Family interaction.</td>
</tr>
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</tr>
<tr>
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<td>Family interaction.</td>
</tr>
<tr>
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<td>None.</td>
</tr>
<tr>
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</tr>
<tr>
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<td>Family experience; some clinical experience.</td>
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<tr>
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<td>Doctoral student</td>
<td>Research experience (~1 yr); clinical experience.</td>
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<tr>
<td>12</td>
<td>F</td>
<td>Non-Hispanic</td>
<td>Doctoral student</td>
<td>None.</td>
</tr>
</tbody>
</table>

Note: All non-Hispanic were White. All 2nd year graduate students were student clinicians in speech. All doctoral students were certified speech-language pathologists.
population was diverse, ranging from no experience, classroom experience, interactions with family member with dementia, to different years of clinical experiences and in dementia research.

All judges appraised the participants’ decisional skills in both visual and verbal conditions using a 7-point Likert scale (types of agreements and corresponding rating scores were Strongly Agree = 1, Agree = 2, Somewhat Agree = 3, Undecided = 4, Somewhat Disagree = 5, Disagree = 6, and Strongly Disagree = 7; see Appendix I). The judges listened to each sample through headphones and rated the participant’s decisional performance on a 7-point Likert scale for the dimensions based on the four legal standards. The rating procedure was completed in a single session that lasted approximately 1 hour and 10 minutes. Two-tailed Sign Tests were conducted to compare judges’ evaluations of the participants’ performance in the two conditions. Likert scales fall within the ordinal level of measurement (Blaikie, 2003; Hansen, 2003; Pett, 1997), and yet the results are often required to be treated as continuous or categorical for standard analyses. There have been disagreements over whether to treat ordinal scales as interval scales (Lubke & Muthen, 2004; Glass, Peckham, & Sanders, 1972; Jamieson, 2004), as well as contentions that it is illegitimate to presume the intervals between values (in this study, it is referred to as the quantified intensity of judges’ feeling) to be equi-distance (Cohen, Manion, & Morrison, 2000; Jamieson, 2004). To avoid controversies, judges’ degrees of agreement were treated as a set of ordered categories, and Sign Tests – which are nonparametric methods appropriate for categorical ordinal data – were applied for analyses. Bonferroni correction was applied by dividing the alpha
level of .05 by the number of compared items (i.e., 8 pairs), yielding the new alpha level of .006. To obtain the effect size, the probability of superiority ($PS_{dep}$) was calculated (Grissom & Kim, 2012) and then converted to Cohen’s $d$ using the table available in Grissom’s (1994) study.
RESULTS

Effects of Medical Vignettes

Figure 2 illustrates the mean percentage of participants’ overall decisional performance on the medical vignettes, Drug Treatment for Dementia ($M = 66.3, SD = 17.9$) and Feeding Tube Placement for Dysphagia ($M = 66.0, SD = 20.7$). Analyses of the univariate test from the repeated measures ANOVA revealed that participants’ overall decision-making performance between the two medical vignettes was not significantly different.
different \(F(1, 19) = 0.002, p = .964, \eta^2_p = 0.0001\). The multivariate analysis also showed similar results; there was no main effect for the vignettes (Wilk’s \(\Lambda = 1, F(1, 19) = 0.002, p = .96, \eta^2_p = 0.0001\)).

Sphericity was corrected using the Greenhouse-Geisser correction for the interaction between the two medical vignettes and the four legal standards (Mauchly’s \(W = .051, \chi^2 = 52.8, df = 5, p < .001\)). The univariate analysis indicated the interaction was not significant \(F(1.21, 23) = 0.08, p = .83, \eta^2_p = 0.004\), and the multivariate test reported that the interaction effect was not significant (Wilk’s \(\Lambda = 0.96, F(3, 17) = 0.25, p = .86, \eta^2_p = 0.04\)).

**Analysis of Order Effects**

The mean percentages of participants’ overall decisional performance by the presentation order (first: \(M = 64.9, SD = 19.1\); second: \(M = 67.4, SD = 19.6\)) of the vignettes and the experimental conditions to which the vignettes were assigned are displayed in Figure 3. The univariate test indicated that participants’ overall decision-making performance were not significantly different between the presentation orders \(F(1, 19) = 0.09, p = .763, \eta^2_p = 0.005\). The multivariate analysis also reported no main effect for the order of presentation (Wilk’s \(\Lambda = 1, F(1, 19) = 0.09, p = .76, \eta^2_p = 0.005\)).

Sphericity was corrected using the Greenhouse-Geisser correction for the interaction between the order of presentation and legal standards (Mauchly’s \(W = .04, \chi^2 = 56.6, df = 5, p < .001\)). Both the univariate test \(F(1.19, 22.6) = 0.24, p = .67, \eta^2_p = 0.01\) and the multivariate test revealed no significant interaction effect (Wilk’s \(\Lambda = 0.75, F(3, 17) = 1.86, p = .18, \eta^2_p = 0.25\)).
Figure 3. Mean of Overall Decisional Performance by Order of Presentation

Visual vs. Verbal Overall Decision-Making Performance and Legal Standards

Results of the repeated measures ANOVA were analyzed to investigate participants’ performance on overall decision-making in the 2 experimental conditions. Figure 4 displays the mean performance of the visual ($M = 84.3, SD = 7.39$) and verbal ($M = 49.1, SD = 8.87$) conditions in percentages. The univariate test reported that participants’ overall decision-making performance was significantly different in the two experimental conditions ($F(1, 19) = 364, p < .001$) with a large effect size ($\eta^2_p = .95$). The multivariate test produced similar results, indicating a significant difference between the two conditions (Wilk’s $\Lambda = .05, F(1, 19) = 364, p < .001, \eta^2_p = .95$).

With sphericity corrected using the Greenhouse-Geisser correction (Mauchly’s $W = .27, \chi^2 = 23.5, df = 5, p < .001$), the univariate analysis reported significant differences
among the 4 legal standards \( F(1.67, 31.73) = 81.9, p < .001 \) with a large effect size \( \eta^2_p = .81 \). With sphericity assumed (Mauchly’s W = .71, \( \chi^2 = 6.13, df = 5, p = .29 \)), the interaction between the two experimental conditions and legal standards was also found to be significant \( F(3, 57) = 123.6, p < .001 \) and with a large effect size \( \eta^2_p = .87 \). All observed power was 1.000. The multivariate analyses also found significant differences among the legal standards (Wilk’s \( \Lambda = .02, F(3, 17) = 305, p < .001, \eta^2_p = .98 \)), and there was an interaction between the conditions and the legal standards (Wilk’s \( \Lambda = .03, F(3, 17) = 172, p < .001, \eta^2_p = .97 \) with large effect sizes and maximal power (1.000).

Table 6 displays the mean, standard deviation, \( p \)-values, and effect sizes of participants’ performance on each legal standard in the two experimental conditions. The
mean percentages of these decisional domains for both conditions are illustrated in Figure 5. There was no mean difference between the two conditions \((M = 100, SD = 0)\) in *Expressing a Choice*. A significant difference was found between the visual \((M = 95.5, SD = 7.04)\) and verbal \((M = 14.3, SD = 14.9)\) conditions in *Understanding*, with a large

![Figure 5. Mean of Legal Standards by Experimental Conditions](image)

Table 6. Analysis of Decisional Performance by Experimental Conditions

<table>
<thead>
<tr>
<th>Decisional Performance</th>
<th>Visual</th>
<th></th>
<th>Verbal</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(M(%))</td>
<td>(SD)</td>
<td>(M(%))</td>
<td>(SD)</td>
<td>(p)</td>
<td>(d)</td>
</tr>
<tr>
<td><strong>Legal Standard</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding</td>
<td>95.5</td>
<td>7.04</td>
<td>14.3</td>
<td>14.9</td>
<td>*</td>
<td>5.10</td>
</tr>
<tr>
<td>Expressing a Choice</td>
<td>100</td>
<td>0</td>
<td>100</td>
<td>0</td>
<td>**</td>
<td>**</td>
</tr>
<tr>
<td>Reasoning</td>
<td>63.1</td>
<td>14.6</td>
<td>30.4</td>
<td>9.76</td>
<td>*</td>
<td>2.10</td>
</tr>
<tr>
<td>Appreciation</td>
<td>74.2</td>
<td>21.9</td>
<td>51.7</td>
<td>24.1</td>
<td>*</td>
<td>1.24</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td>84.3</td>
<td>7.39</td>
<td>49.1</td>
<td>8.87</td>
<td>*</td>
<td>4.44</td>
</tr>
</tbody>
</table>

Note: * \(p < .001\), ** Value cannot be computed because the standard error of the difference is 0.
effect, $t(19) = 22.8, p < .001, d = 5.10$. For Reasoning, a significant difference and a large effect was also reported between the visual ($M = 63.1, SD = 14.6$) and verbal ($M = 30.4, SD = 9.76$) conditions, $t(19) = 9.41, p < .001, d = 2.10$. Similarly, Appreciation was found to be significantly different between the visual ($M = 74.2, SD = 21.9$) and verbal ($M = 51.7, SD = 24.1$) conditions with a large effect, $t(19) = 5.54, p < .001, d = 1.24$.

**Analyses of Decisional Skills**

To examine participants’ decisional skills on the medical scenarios in the visual and verbal conditions, data (Table 7) were grouped into 4 categories based on the legal standards for interpretation: Understanding, Express a Choice, Reasoning, and Appreciation. In Understanding, there was a significant difference in the scores between visual ($M = 4.70, SD = 0.47$) and verbal ($M = 0.60, SD = 0.88$) conditions on comprehension in Health Problem with a large effect, $t(19) = 18, p < .001, d = 4.02$. Significant differences were also found in the scores between visual ($M = 2.85, SD = 0.37$) and verbal ($M = 0.70, SD = 0.73$) conditions on comprehension in Treatment Option, $t(19) = 12.9, p < .001, d = 2.87$, and comprehension in Risks and Benefits between visual ($M = 5.85, SD = 0.37$) and verbal ($M = 0.45, SD = 0.69$) condition, $t(19) = 29.4, p < .001, d = 6.58$. There was no mean difference between the two experimental conditions ($M = 1, SD = 0$) in Making a Decision under Expressing a Choice. Data analyses on Reasoning determined that there was a marginal significant difference in the scores for visual ($M = 0.95, SD = 1$) and verbal ($M = 0.10, SD = 0.45$) conditions on Comparison with a medium effect, $t(19) = 3.22, p < .005, d = 0.72$. For Vignette Consequences, there was a significant difference in the scores between the visual ($M =
Table 7. Decision-Making Skill Analysis for Visual and Verbal Conditions

<table>
<thead>
<tr>
<th>Decisional Skill</th>
<th>Visual</th>
<th>Verbal</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td><strong>Understanding</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Problem</td>
<td>4.70</td>
<td>0.47</td>
<td>0.60</td>
<td>0.88</td>
</tr>
<tr>
<td>Treatment Option</td>
<td>2.85</td>
<td>0.37</td>
<td>0.70</td>
<td>0.73</td>
</tr>
<tr>
<td>Risks and Benefits</td>
<td>5.85</td>
<td>0.37</td>
<td>0.45</td>
<td>0.69</td>
</tr>
<tr>
<td><strong>Express a Choice</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make a Decision</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td><strong>Reasoning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison</td>
<td>0.95</td>
<td>1</td>
<td>0.10</td>
<td>0.45</td>
</tr>
<tr>
<td>Vignette Consequences</td>
<td>2.25</td>
<td>1.12</td>
<td>0.20</td>
<td>0.52</td>
</tr>
<tr>
<td>Non-Vignette Consequences</td>
<td>0.60</td>
<td>0.75</td>
<td>0.50</td>
<td>0.51</td>
</tr>
<tr>
<td>Logical Sequence</td>
<td>1</td>
<td>0</td>
<td>0.85</td>
<td>0.37</td>
</tr>
<tr>
<td><strong>Appreciation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acknowledgement</td>
<td>0.95</td>
<td>0.22</td>
<td>0.85</td>
<td>0.37</td>
</tr>
<tr>
<td>Potential Effects</td>
<td>1.60</td>
<td>1.05</td>
<td>0.55</td>
<td>0.61</td>
</tr>
</tbody>
</table>

Note: *p < .001, **Values cannot be computed because the standard error of the difference is 0, ***p < .005

2.25, SD = 1.12) and verbal (M = 0.20, SD = 0.52) conditions with a large effect, $t(19) = 7.70, p < .001, d = 1.72$. There was no significant difference in the scores between the two experimental conditions for Non-Vignette Consequences ($t(19) = 0.57, p = .58$) and Logical Sequence ($t(19) = 1.83, p = .83$). In **Appreciation**, the scores between the visual (M = 1.60, SD = 1.05) and verbal (M = 0.55, SD = 0.61) conditions for Potential Effects was found to be statistically significant with a large effect, $t(19) = 1.71, p < .001, d = 1.39$, but non-significant for Acknowledgement ($t(19) = 1.45, p = .16$).

**Analyses of Decisional Capacity by Severity**

Table 8 presents the mean, standard deviation, and the critical $p$-value in both experimental conditions between the mild (N = 11) and moderate (N = 9) group. In the
Table 8. Analyses of Decision-Making Skills by Conditions and by Severity

<table>
<thead>
<tr>
<th>Decisional Skill</th>
<th>Visual Mild</th>
<th></th>
<th>Visual Mod.</th>
<th></th>
<th>p</th>
<th>Verbal Mild</th>
<th></th>
<th>Verbal Mod.</th>
<th></th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td></td>
</tr>
<tr>
<td>Understanding</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Problem</td>
<td>4.82</td>
<td>0.41</td>
<td>4.56</td>
<td>0.53</td>
<td>0.24*</td>
<td>1</td>
<td>0</td>
<td>0.11</td>
<td>0.33</td>
<td>0.20*</td>
</tr>
<tr>
<td>Treatment Option</td>
<td>2.73</td>
<td>0.47</td>
<td>3</td>
<td>0</td>
<td>0.08*</td>
<td>0.91</td>
<td>0.83</td>
<td>0.44</td>
<td>0.53</td>
<td>0.16</td>
</tr>
<tr>
<td>Risks and Benefits</td>
<td>5.73</td>
<td>0.47</td>
<td>6</td>
<td>0</td>
<td>0.08*</td>
<td>0.82</td>
<td>0.75</td>
<td>0</td>
<td>0</td>
<td>0.005*</td>
</tr>
<tr>
<td>Express a Choice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make a Decision</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>N/A**</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>N/A**</td>
</tr>
<tr>
<td>Reasoning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comparison</td>
<td>1.18</td>
<td>0.98</td>
<td>0.67</td>
<td>1</td>
<td>0.26*</td>
<td>0</td>
<td>0</td>
<td>0.22</td>
<td>0.67</td>
<td>0.35*</td>
</tr>
<tr>
<td>Vignette Consequences</td>
<td>2</td>
<td>1.18</td>
<td>2.56</td>
<td>1.01</td>
<td>0.28</td>
<td>0.27</td>
<td>0.65</td>
<td>0.11</td>
<td>0.33</td>
<td>0.51</td>
</tr>
<tr>
<td>Non-Vignette Consequences</td>
<td>0.64</td>
<td>0.67</td>
<td>0.56</td>
<td>0.88</td>
<td>0.82</td>
<td>0.55</td>
<td>0.52</td>
<td>0.44</td>
<td>0.53</td>
<td>0.67</td>
</tr>
<tr>
<td>Logical Sequence</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>N/A**</td>
<td>0.91</td>
<td>0.30</td>
<td>0.78</td>
<td>0.44</td>
<td>0.44</td>
</tr>
<tr>
<td>Appreciation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acknowledgement</td>
<td>1</td>
<td>0</td>
<td>0.89</td>
<td>0.33</td>
<td>0.35*</td>
<td>1</td>
<td>0</td>
<td>0.67</td>
<td>0.50</td>
<td>0.81*</td>
</tr>
<tr>
<td>Potential Effects</td>
<td>1.91</td>
<td>0.94</td>
<td>1.22</td>
<td>1.09</td>
<td>0.15</td>
<td>0.73</td>
<td>0.65</td>
<td>0.33</td>
<td>0.50</td>
<td>0.15</td>
</tr>
</tbody>
</table>

Note: Mild: N = 11, moderate (Mod.): N = 9.

* Levene’s test indicated unequal variances.

** Values cannot be computed as the standard deviations of both groups are 0.
verbal condition, there were no significant differences in the decision-making performance between the two groups across *Understanding* (Health Problem: \( t(12.6) = 2.77, p = .02 \); Treatment Option: \( t(18) = 1.45, p = .16 \); Risks and Benefits: \( t(10) = 3.61, p = .005 \), *Reasoning* (Comparison: \( t(8) = -1, p = .35 \); Vignette Reasoning: \( t(18) = 0.68, p = .51 \); Non-Vignette Reasoning: \( t(18) = 0.43, p = .67 \); Logical Sequence: \( t(18) = 0.79, p = .44 \)), and *Appreciation* (Acknowledgement: \( t(8) = 2, p = .08 \); Potential Effects: \( t(18) = 1.50, p = .39 \)). Similarly in the visual condition, no significant differences were found between the two groups across *Understanding* (Health Problem: \( t(14.8) = 1.23, p = .24 \); Treatment Option: \( t(10) = -1.94, p = .82 \); Risks and Benefits: \( t(10) = -1.94, p = .82 \), and *Appreciation* (Acknowledgement: \( t(8) = 1, p = .35 \); Potential Effects: \( t(18) = 1.51, p = .15 \)). Differences in decision-making performance in Comparison (\( t(18) = 1.16, p = .26 \)), Vignette Consequences (\( t(18) = -1.11, p = .28 \), and Non-Vignette Consequences (\( t(18) = 0.23, p = .82 \)) under *Reasoning* were also not significant between mild and moderate groups, and there was no mean difference between the two groups for Logical Sequence (\( M = 1, SD = 0 \)). Mean differences between mild and moderate groups were not found in *Express a Choice* (\( M = 1, SD = 0 \)) in either visual or verbal conditions.

**Participants’ Types of Statements**

The second aim of this study was to investigate the differences in the participants’ statements between the two experimental conditions. The mean, standard deviation, \( p \)-values, and effect sizes of all statements in both experimental conditions are reported in Table 9. Data analysis showed that there were more Rewordings in the visual (\( M = 10.5, SD = 4.55 \)) than the verbal (\( M = 4.25, SD = 2.17 \)) condition, \( t(19) = 6.61, p < .001, d = \)
Table 9. Vignette Statement Analysis for Visual and Verbal Conditions

<table>
<thead>
<tr>
<th>Type of Statement</th>
<th>Visual M</th>
<th>Visual SD</th>
<th>Verbal M</th>
<th>Verbal SD</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rewording</td>
<td>10.5</td>
<td>4.55</td>
<td>4.25</td>
<td>2.17</td>
<td>*</td>
<td>1.48</td>
</tr>
<tr>
<td>Exact Statement</td>
<td>10.3</td>
<td>5.46</td>
<td>0.15</td>
<td>0.37</td>
<td>*</td>
<td>1.83</td>
</tr>
<tr>
<td>Statement Not Mentioned</td>
<td>10</td>
<td>2.58</td>
<td>26</td>
<td>2.16</td>
<td>*</td>
<td>4.41</td>
</tr>
<tr>
<td>Distorted Meaning</td>
<td>0.25</td>
<td>0.55</td>
<td>0.65</td>
<td>1.14</td>
<td>0.20</td>
<td>0.30</td>
</tr>
</tbody>
</table>

Note: * p < .001

1.48. Significant differences in the quantity of statements were also found in the visual $(M = 10.3, SD = 5.46)$ and verbal $(M = 0.15, SD = 0.37)$ conditions for Exact Statements, $t(19) = 8.21, p < .001, d = 1.83$, and in the visual $(M = 10, SD = 2.58)$ and verbal $(M = 26, SD = 2.16)$ conditions for Statement Not Mentioned, $t(19) = -19.7, p < .001, d = 4.41$.

The number of statements with Distorted Meaning was not significantly different ($t(19) = -1.32, p = .20$) between the two conditions.

Table 10 displays the median and frequency distribution of particular types of statements (rewording, exact statement, information not mentioned, and distorted statement) in both experimental conditions, with Figure 6 displaying the corresponding visual illustration of the data. For Rewording, the minimal and maximal number of statements, as well as the IQR in the visual condition ($Md(n = 10.5, overall range of values (R): 3 – 21, IQR = 7$) were found to be higher than in the verbal condition ($Md(n = 4, R: 2 – 10, IQR = 2.5$). Similarly for Exact Statement, both minimal and maximal number of statements, and the IQR in the visual condition ($Md(n = 10, R: 2 – 20, IQR = 8.5$) were noticeably greater compared to the verbal condition ($Md(n = 0, R: 0 – 1, IQR = 0$). For Statements Not Mentioned, the minimal and the maximal number of statements
The box-and-whisker plot illustrates the frequency distributions of four types of vignette statement (rewording, exact statement, statement not mentioned, and distorted meaning) in visual and verbal conditions. The box (i.e., interquartile range; IQR) spans data from the 25th percentile (i.e., first quartile; Q1) to the 75th percentile (i.e., third quartile; Q3). The segment inside the box shows the median of the overall data. The light gray portion of the box represents data between Q1 and the median. The dark gray portion of the box represents data between the median and Q3. The solid diamonds indicate the mean frequency (value is indicated by number) of particular types of vignette statement. Outliers are marked by hollow circles.

Figure 6. Analyses of Mean Frequency and Frequency Distributions of Statements by Conditions
Table 10. Frequency Distributions of Vignette Statements in Experimental Conditions

<table>
<thead>
<tr>
<th>Statement Type, Condition</th>
<th>$Mdn$</th>
<th>Q1</th>
<th>Q3</th>
<th>IQR</th>
<th>Tukey boxplot</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>lower fence</td>
</tr>
<tr>
<td><strong>Rewording</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>10.5</td>
<td>7</td>
<td>14</td>
<td>7</td>
<td>-3.5</td>
</tr>
<tr>
<td>Verbal</td>
<td>4</td>
<td>2.75</td>
<td>5.25</td>
<td>2.5</td>
<td>-1</td>
</tr>
<tr>
<td><strong>Exact Statement</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>10</td>
<td>5.75</td>
<td>14.25</td>
<td>8.5</td>
<td>-7</td>
</tr>
<tr>
<td>Verbal</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Statement Not Mentioned</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>9.5</td>
<td>8</td>
<td>11.25</td>
<td>3.25</td>
<td>3.13</td>
</tr>
<tr>
<td>Verbal</td>
<td>26.5</td>
<td>25</td>
<td>27</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td><strong>Distorted Meaning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Verbal</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>-1.5</td>
</tr>
</tbody>
</table>

were prominently fewer in the visual condition ($Mdn = 9.5$, R: 6 – 15, IQR = 3.25) than in the verbal condition ($Mdn = 26.5$, R: 21 – 27, IQR = 2). For utterances with Distorted Meaning, the minimal and the maximal number of statements were also fewer in the visual condition ($Mdn = 0$, R: 0 – 2, IQR = 0) than in the verbal condition ($Mdn = 0$, R: 0 – 4, IQR = 1) with a similar frequency distribution.

**Analyses of Vignette statements by Severity**

Table 11 reports the analytic results (mean, standard deviation, and $p$-values) of the verbal behaviors between the mild and moderate groups. All statements except statements with Distorted Meaning in the visual condition had unequal variances ($F = 9.74$, $p = .006$), and therefore the degrees of freedom were adjusted from 18 to 10.3. No significant differences were found between the two severity groups across Rewording (visual: $t(18) = 3.01$, $p = .008$; verbal: $t(18) = 2.68$, $p = .12$), Exact Statement (visual: $t(18) = 2.49$, $p = .012$; verbal: $t(18) = 1.73$, $p = .09$),
Table 11. Vignette Statement Analysis for Visual and Verbal Conditions by Severity

<table>
<thead>
<tr>
<th>Type of Statement and Condition</th>
<th>Mild (N = 11)</th>
<th>Moderate (N = 9)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td><strong>Rewording</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>12.8</td>
<td>4.167</td>
<td>7.67</td>
</tr>
<tr>
<td>Verbal</td>
<td>5.27</td>
<td>2.328</td>
<td>3</td>
</tr>
<tr>
<td><strong>Exact Statement</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>7.82</td>
<td>4.98</td>
<td>13.2</td>
</tr>
<tr>
<td>Verbal</td>
<td>0.18</td>
<td>0.41</td>
<td>0.11</td>
</tr>
<tr>
<td><strong>Statement Not Mentioned</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>10.3</td>
<td>2.80</td>
<td>9.67</td>
</tr>
<tr>
<td>Verbal</td>
<td>25</td>
<td>1.79</td>
<td>27.1</td>
</tr>
<tr>
<td><strong>Distorted Meaning</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>0.09</td>
<td>0.30</td>
<td>0.44</td>
</tr>
<tr>
<td>Verbal</td>
<td>0.55</td>
<td>1.04</td>
<td>0.78</td>
</tr>
</tbody>
</table>

Note: * Equal variances not assumed ($F = 9.74, p = .006$), degrees of freedom adjusted from 18 to 10.3.

.02; verbal: $t(18) = 0.42, p = .68$), Statement Not Mentioned (visual: $t(18) = 0.51, p = .61$; verbal: $t(18) = 2.44, p = .03$), and Distorted Meaning (visual: $t(10.3) = 1.37, p = .20$; verbal: $t(18) = -0.45, p = .66$).

Table 12 and Figure 7 present the outcomes from probing further into the frequency distributions of vignette statements generated from each severity group. For Rewording in the verbal condition, both mild ($Mdn = 5, R: 2 – 10, IQR = 2.5$) and moderate ($Mdn = 3, R: 2 – 5, IQR = 2$) groups revealed the same minimal number of utterances with a similar IQR; the maximal number of Rewording was greater in the mild group than its counterpart. In the visual condition, the IQR was the same for both groups; however, the values of IQR, and the minimal and maximal number of Rewording in the mild ($Mdn = 14, R: 7 – 21, IQR = 5$) group were greater than the moderate (moderate: $Mdn = 7, R: 3 – 12, IQR = 5$) group. For Exact Statement in the verbal condition, verbal performance
### Table 12. Frequency Distributions of Vignette Statements in Visual and Verbal Conditions by Severity

<table>
<thead>
<tr>
<th>Statement Type, Condition</th>
<th>Visual</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Verbal</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median (Md)</td>
<td>Q1</td>
<td>Q3</td>
<td>IQR</td>
<td>lower fence</td>
<td>upper fence</td>
<td>Median (Md)</td>
<td>Q1</td>
<td>Q3</td>
</tr>
<tr>
<td>Rewording</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>14</td>
<td>9.5</td>
<td>14.5</td>
<td>5</td>
<td>2</td>
<td>22</td>
<td>7</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Verbal</td>
<td>5</td>
<td>3.5</td>
<td>6</td>
<td>2.5</td>
<td>-0.25</td>
<td>9.75</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Exact Statement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>8</td>
<td>3</td>
<td>11</td>
<td>8</td>
<td>-9</td>
<td>23</td>
<td>14</td>
<td>10</td>
<td>16</td>
</tr>
<tr>
<td>Verbal</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Statement Not Mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>10</td>
<td>8</td>
<td>12</td>
<td>4</td>
<td>2</td>
<td>18</td>
<td>9</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Verbal</td>
<td>25</td>
<td>24.5</td>
<td>26</td>
<td>1.5</td>
<td>22.3</td>
<td>28.3</td>
<td>27</td>
<td>27</td>
<td>28</td>
</tr>
<tr>
<td>Distorted Meaning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Verbal</td>
<td>0</td>
<td>0</td>
<td>0.5</td>
<td>1.5</td>
<td>-0.75</td>
<td>1.25</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>
The box-and-whisker plot illustrates the frequency distributions of four types of vignette statement (rewording, exact statement, statement not mentioned, and distorted meaning) between mild and moderate severity in visual and verbal conditions. The box (i.e., interquartile range; IQR) spans data from the 25th percentile (i.e., first quartile; Q1) to the 75th percentile (i.e., third quartile; Q3). The segment inside the box shows the median of the overall data. The light gray portion of the box represents data between Q1 and the median. The dark gray portion of the box represents data between the median and Q3. The solid diamonds indicate the mean frequency (value is indicated by number) of particular types of vignette statement. Outliers are marked by hollow circles.

Figure 7. Analyses of Mean Frequency and Frequency Distributions of Statements by Severity and by Conditions
were reported to be the same in both groups \((Mdn = 0, \text{ R: } 0 – 1, \text{ IQR } = 0)\); in the visual condition, the minimal, maximal, and the IQR values of the moderate \((Mdn = 8, \text{ R: } 2 – 17, \text{ IQR } = 8)\) group were greater than the mild \((Mdn = 14, \text{ R: } 5 – 20, \text{ IQR } = 6)\) group. For Statements Not Mentioned in the verbal condition, the minimal, maximal, and the IQR values of the mild \((Mdn = 25, \text{ R: } 21 – 27, \text{ IQR } = 1.5)\) group were fewer than its counterpart \((Mdn = 27, \text{ R: } 22 – 29, \text{ IQR } = 1)\); in the visual condition, performance were similar (mild: \(Mdn = 10, \text{ R: } 7 – 15, \text{ IQR } = 4\); moderate: \(Mdn = 9, \text{ R: } 6 – 14, \text{ IQR } = 3\)). For statements with Distorted Meaning, similar outcomes were also found in the visual (mild: \(Mdn = 0, \text{ R: } 0 – 1, \text{ IQR } = 0\); moderate: \(Mdn = 0, \text{ R: } 0 – 2, \text{ IQR } = 1\)) and verbal (mild: \(Mdn = 0, \text{ R: } 0 – 3, \text{ IQR } = 0.5\); moderate: \(Mdn = 0, \text{ R: } 0 – 4, \text{ IQR } = 1\)) conditions between the two severity groups.

**Independent Variables**

To examine treatment fidelity, Table 13 presents the mean, standard deviation, paired difference, and \(p\)-values of all experimenter utterances in the visual and verbal conditions. Data analysis showed that there were no significant differences in the number

<table>
<thead>
<tr>
<th>Type of Statement</th>
<th>Visual</th>
<th>Verbal</th>
<th>(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(M)</td>
<td>(SD)</td>
<td>(M)</td>
</tr>
<tr>
<td>Script Reading</td>
<td>3</td>
<td>0</td>
<td>3</td>
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<tr>
<td>Prompt</td>
<td>8.70</td>
<td>0.87</td>
<td>9.20</td>
</tr>
<tr>
<td>Clarification</td>
<td>1.70</td>
<td>1.81</td>
<td>3.15</td>
</tr>
<tr>
<td>Inquiry</td>
<td>4.10</td>
<td>1.77</td>
<td>3.75</td>
</tr>
<tr>
<td>Filler Utterance</td>
<td>22.95</td>
<td>6.48</td>
<td>22.7</td>
</tr>
<tr>
<td>Other</td>
<td>20.05</td>
<td>7.40</td>
<td>24</td>
</tr>
</tbody>
</table>

Note: * Value cannot be computed because the standard error of the difference is 0.
of experimenter utterances for Prompt ($t(19) = -1.39, p = .18$), Clarification ($t(19) = -1.95, p = .07$), Inquiry ($t(19) = 0.67, p = .51$), Filler Utterance ($t(19) = 0.23, p = .82$), and Other types of speech acts ($t(19) = -2.28, p = .03$). No mean differences were found in Script Reading between the two experimental conditions ($M = 3, SD = 0$).

The median and data on frequency distribution of each experimenter utterance type are reported in Table 14. Figure 8 provides a graphical illustration of these data. The range and IQR for Experimenter Prompt were narrow and similar in the visual ($Mdn = 8.5, R: 8 – 11, IQR = 1$) and verbal ($Mdn = 9; R: 8 – 14, IQR = 1$) conditions.

Experimenter Inquiry also displayed similar ranges between the visual ($Mdn = 4, R: 0 –

<table>
<thead>
<tr>
<th>Statement Type, Condition</th>
<th>$Mdn$</th>
<th>Q1</th>
<th>Q3</th>
<th>IQR</th>
<th>Tukey boxplot $\text{lower fence}$</th>
<th>$\text{upper fence}$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Script Reading</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
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<td>3</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Verbal</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>Prompt</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>8.50</td>
<td>8</td>
<td>9</td>
<td>1</td>
<td>6.50</td>
<td>10.5</td>
</tr>
<tr>
<td>Verbal</td>
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<td>8</td>
<td>9</td>
<td>1</td>
<td>6.50</td>
<td>10.5</td>
</tr>
<tr>
<td><strong>Clarification</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>1</td>
<td>0.75</td>
<td>2</td>
<td>1.25</td>
<td>-1.13</td>
<td>3.88</td>
</tr>
<tr>
<td>Verbal</td>
<td>2</td>
<td>0.75</td>
<td>4</td>
<td>3.25</td>
<td>-4.13</td>
<td>8.88</td>
</tr>
<tr>
<td><strong>Inquiry</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>4</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Verbal</td>
<td>3</td>
<td>2</td>
<td>6</td>
<td>4</td>
<td>-4</td>
<td>12</td>
</tr>
<tr>
<td><strong>Filler Utterance</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>23</td>
<td>18.5</td>
<td>28</td>
<td>9.50</td>
<td>4.25</td>
<td>42.3</td>
</tr>
<tr>
<td>Verbal</td>
<td>23.5</td>
<td>18</td>
<td>27.3</td>
<td>9.25</td>
<td>4.13</td>
<td>41.1</td>
</tr>
<tr>
<td><strong>Other</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td>18.5</td>
<td>15</td>
<td>22.8</td>
<td>7.75</td>
<td>3.38</td>
<td>34.4</td>
</tr>
<tr>
<td>Verbal</td>
<td>26</td>
<td>17.5</td>
<td>27.3</td>
<td>9.75</td>
<td>2.88</td>
<td>41.9</td>
</tr>
</tbody>
</table>
Figure 8. Analyses of Mean and Frequency Distributions of Experimenter Utterances by Conditions

The box-and-whisker plot illustrates the frequency distributions of six types of investigator utterances (script reading, prompt, clarification, inquiry, filler utterance, and other) in visual and verbal conditions. The box (i.e., interquartile range; IQR) spans data from the 25th percentile (i.e., first quartile; Q1) to the 75th percentile (i.e., third quartile; Q3). The segment inside the box shows the median of the overall data. The light gray portion of the box represents data between Q1 and the median. The dark gray portion of the box represents data between the median and Q3. The solid diamonds indicate the mean frequency (value is indicated by number) of particular types of investigator utterance. Outliers are marked by hollow circles.
8, IQR = 2) and verbal (Mdn = 3, R: 0 – 9, IQR = 4) conditions, with IQR slightly larger in the latter condition. For Clarification, both the range and IQR were smaller in the visual condition (Mdn = 1, R: 0 – 6, IQR = 1.25) than in the verbal condition (Mdn = 2, R: 0 – 17, IQR = 3.25). The experimenter’s Other speech acts (visual R: 9 – 38; verbal R: 12 – 37) and Filler Utterance (visual R: 10 – 35; verbal R: 2 – 37) in both experimental conditions presented a wide distribution. However, the IQR distribution for Filler Utterance was found to be similar across the two conditions (Visual: Mdn = 23, IQR = 9.5; verbal: Mdn = 23.5, IQR = 9.25), while the Q1 (15) and Q3 (22.75) values for Other speech acts were smaller in the visual condition (Mdn: 18.5, IQR = 7.75) than in the verbal condition (Mdn = 26, IQR = 9.75, Q1 = 17.5, Q3 = 27.25). There was no frequency distribution in Script Reading across the two experimental conditions (visual and verbal: Mdn = 3, R: 3, IQR = 0).

Social Validation

Table 15 summarizes the statistical outcomes of the judges’ ratings for analysis. Data indicated that there was a large effect and a significant difference (p < .001) in rating scores (Strongly Agree = 1, Agree = 2, Somewhat Agree = 3, Undecided = 4, Somewhat Disagree = 5, Disagree = 6, and Strongly Disagree = 7) between verbal and visual conditions in the following aspects: Comprehension of the treatment option being offered (Item 2; visual Mdn = 2, verbal Mdn = 4.5, Z = -6.02, d = 1.50), comprehension of risks and benefits (Item 3; visual Mdn = 1, verbal Mdn = 5, Z = -6.71, d = 2.89), making clear comparisons of the consequences between treatment and no-treatment option (Item 5;
Table 15. Analysis of Judges’ Appraisals on Participants’ Decisional Capacity by Conditions

<table>
<thead>
<tr>
<th>Items</th>
<th>Visual Mdn</th>
<th>Visual Range</th>
<th>Verbal Mdn</th>
<th>Verbal Range</th>
<th>p</th>
<th>d</th>
</tr>
</thead>
<tbody>
<tr>
<td>The participant…</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Provides enough information to demonstrate understanding about the health problem.</td>
<td>1</td>
<td>1 – 4</td>
<td>6</td>
<td>2 – 7</td>
<td>*</td>
<td>**</td>
</tr>
<tr>
<td>2. Provides enough information to demonstrate understanding about the treatment options.</td>
<td>2</td>
<td>1 – 4</td>
<td>4.5</td>
<td>1 – 7</td>
<td>*</td>
<td>1.50</td>
</tr>
<tr>
<td>3. Provides enough information to demonstrate understanding about the potential risks and benefits of the treatment.</td>
<td>1</td>
<td>1 – 4</td>
<td>5</td>
<td>2 – 7</td>
<td>*</td>
<td>2.89</td>
</tr>
<tr>
<td>4. Clearly expresses a specific decision.</td>
<td>1</td>
<td>1 – 3</td>
<td>1</td>
<td>1 – 5</td>
<td>0.42</td>
<td>N/A***</td>
</tr>
<tr>
<td>5. Compares the two treatment options without ambiguous information.</td>
<td>3</td>
<td>1 – 6</td>
<td>5</td>
<td>1 – 7</td>
<td>*</td>
<td>1.50</td>
</tr>
<tr>
<td>6. Provides sufficient reasons for his/her decision.</td>
<td>2</td>
<td>1 – 4</td>
<td>3</td>
<td>1 – 7</td>
<td>*</td>
<td>0.97</td>
</tr>
<tr>
<td>7. Confirms his/her final decision that follows logically from previous reasoning or comparison.</td>
<td>1</td>
<td>1 – 3</td>
<td>1</td>
<td>1 – 6</td>
<td>0.02</td>
<td>N/A***</td>
</tr>
<tr>
<td>8. Supports why the proposed treatment option may or may not benefit his/her current health condition with sufficient reasons that are not based on a delusional premise or a serious distortion of reality.</td>
<td>2</td>
<td>1 – 5</td>
<td>3</td>
<td>1 – 7</td>
<td>0.001</td>
<td>0.88</td>
</tr>
</tbody>
</table>

Note: * p < .001. ** Cohen’s $d$ ($PS_{dep} = 1.00$) cannot be calculated because all judges’ rating scores were higher in the visual condition than in verbal.  
*** Value of Cohen’s d is not available from the table in Grissom’s (1994) study.  
Item 1 to 3 are categorized under Understanding. Item 4 is categorized under Expressing a Choice. Item 5 to 7 are under Reasoning. Item 8 is under Appreciation. The Range indicates judges’ rating scores (i.e., types of agreement among judges), with Strongly Agree = 1, Agree = 2, Somewhat Agree = 3, Undecided = 4, Somewhat Disagree = 5, Disagree = 6, and Strongly Disagree = 7.
visual $Mdn = 3$, verbal $Mdn = 5$, $Z = -6.25$, $d = 1.50$), providing sufficient reasons for the decision being made (Item 6; visual $Mdn = 2$, verbal $Mdn = 3$, $Z = -4.93$, $d = 0.93$), and participants’ appropriate justification for potential treatment values that may/may not benefit their current health condition (Item 8; visual: $Mdn = 2$, verbal: $Mdn = 3$, $Z = -3.34$, $p = .001$, $d = 0.88$). Comprehension of the information on health problem (Item 1; visual $Mdn = 1$, verbal $Mdn = 6$, $Z = -6.25$, $p < .001$) was also found to be statistically significant; Cohen’s $d$ ($PS_{dep} = 1.00$) was not able to be calculated because all judges’ rating scores in the verbal condition were higher than in the visual condition. No significant differences were found on rating participants’ capacity in expressing a choice (Item 4; visual $Mdn$ = verbal $Mdn = 1$, $p = .42$), and logical consistency (Item 7; visual $Mdn = verbal Mdn = 1$, $p = .02$).

Analyses of the type of agreement (Strongly Agree, Agree, Somewhat Agree, Undecided, Somewhat Disagree, Disagree, and Strongly Disagree) per item were conducted to examine the range of judges’ rating. In the visual condition, clinicians’ ratings centered on Strongly Agree and Agree in 4 appraised areas: Comprehension of health problem information (Item 1; Strongly Agree: 65%, Agree: 19%), comprehension of treatment risks and benefits (Item 3; Strongly Agree: 73%, Agree: 17%), capacity in expressing a choice (Item 4; Strongly Agree: 69%, Agree: 13%), and logical consistency (Item 7; Strongly Agree: 77%, Agree: 21%). The types of agreement on comprehension of treatment information (Item 2; Strongly Agree: 46%, Agree: 31%, Somewhat Agree: 15%), reasoning for the treatment choice (Item 6; Strongly Agree: 31%, Agree: 33%, Somewhat Agree: 27%), and justification for potential treatment values that may or may
not benefit current health condition (Item 8; Strongly Agree: 35%, Agree: 31%, Somewhat Agree: 21%), although presented a somewhat wider range of agreement, were nonetheless centralized on Agreed rating. When appraising participants’ ability to compare consequences between treatment alternatives (Item 5), judges’ types of agreement were found to spread mainly from Strongly Agree (19%) to Undecided (10%), with 29% in Agree and 25% in Somewhat Agree.

In contrast to the range of judges’ ratings in the visual condition, the range for the verbal condition was wide and spread across nearly all types of agreement; only expressing a choice (Item 4; Strongly Agree: 58%, Agree: 25%) and logical consistency (Item 7; Strongly Agree: 58%, Agree: 21%) received ratings that exceeded 50% on a particular type of agreement. Results showed that judges’ types of agreement were mainly Strongly Disagree (46%) and Disagree (29%) on comprehension of health problem information (Item 1). For comprehension of treatment risks and benefits (Item 3), ratings ranged between Strongly Disagree (21%), Disagree (25%), and Somewhat Agree (29%). Comparison of treatment alternatives (Item 5) was found to have a similar agreement range as in the visual condition except in the opposite direction (Strongly Disagree: 25%, Disagree: 17%, Somewhat Disagree: 21%, Somewhat Agree: 19%). Similar to expressing a choice (Item 4) and logical consistency (Item 7), judges’ type of agreement centered more on the Agreed rating when evaluating participants’ ability to appreciate potential treatment benefits on his or her current health (Item 8; Strongly Agree: 19%, Agree: 29%, Somewhat Agree: 31%). Judges’ agreement were somewhat split between agreed and disagreed on comprehension of treatment information (Item 2;
Strongly Disagree: 13%, Disagree: 31%, Somewhat Agree: 31%, Agree: 8%) and reasoning (Item 6; Strongly Disagree: 23%, Disagree: 13%, Somewhat Agree: 27%, Agree: 19%).
DISCUSSION

Decision-Making Capacity

The purpose of this study was to examine the effects of visual stimuli on decision-making capacity for end-of-life care of people with mild and moderate dementia. The results showed that the mild and moderate groups demonstrated similar performance in decision-making skills across the four legal capacities per condition, and therefore no significant differences were found between the two severity groups.

Understanding

By examining the overall performance in the visual and verbal conditions for Understanding, the findings revealed that PWD in this study produced significantly more specific aspects of the diagnostic and treatment information with visual aid support, when compared to uttering little or no information with verbal questioning only. Lui and colleagues (2009) suggested that simple verbal repetition of information offered little enhancement of the decision-making capacity of PWD. The substantial contrast in decisional performance between the visual and verbal conditions in understanding the disclosed information of the health problem, treatment option, and risks and benefits in this study underscores the fact that simple verbal disclosure of information alone is not sufficient to provide ample support for PWD’s learning of medical information necessary for later decision making. In contrast, the use of visuals aids enhanced decision-making
performance. It was also observed that the total scores (by summing the sub-scores from Health Problem, Treatment Option, and Risks and Benefits) for participants with mild dementia in the verbal condition for Understanding was low (range: 0 – 6 out of 14). This phenomenon further reflects that even mild dementia can have a considerable impact on decisional capacity when confronted with verbally presented information only.

Expressing a Choice

All PWD in this study conveyed a clear treatment choice in the task of Expressing a Choice, resulting in no mean difference between the two experimental conditions. This outcome is consistent with previous findings in Moye et al.’s (2004, 2005) studies. A qualitative inspection of the conversations revealed that 5 participants made their decision based on “trust in their doctor” either in one or both experimental conditions. One participant emphasized her compliance with the treatment choice would occur only when the treatment option is of doctor’s command (“Only when the doctor says that I have to.”), not recommendation. It was also interesting that 2 participants expressed their belief in the decision made by their caregiver, regardless that they also conveyed a choice of their own.

Reasoning

For the decisional ability to compare the consequences between treatment alternatives (i.e., “Comparison”), visual aids seemed to have a smaller effect on assisting PWD with comparing the risks and benefits of the treatment. This outcome is not surprising because comparison statements are demonstrations of a complex set of cognitive functions; it takes one to successfully retain the input, synthesize the
comprehended pros and cons of the treatment option, decide which consequence(s) outweigh the other, and retrieve appropriate words and relevant linguistic knowledge in order to convey the message.

During the *Reasoning* task, participants produced significantly more and more detailed reasons in the visual condition in support of their choice of treatment option; almost all participants used the factual information listed on the visual aids to justify their decision. This was in contrast with verbal questioning only; nearly none of the participants recalled statements of fact from the vignette, with half of the group expressing personal experiences (e.g., “Crossword puzzle is my ‘cure.’” “I’m already on a lot of things medically.” “I don’t want anything artificial.”) or feelings (e.g., “I want to live.” “It can improve my attitude.”) to support their decision. This suggests that visual aids can serve as useful resources for PWD to retrieve information that they may be less familiar with, as well as providing a more complete overview of the treatment consequences for PWD before making a decision. It was also observed that a few participants met with puzzlement on doubting the doctor’s recommendation (e.g. “I go with the doctor’s recommendation. It’s been my habit through life.”) during the reasoning task. One participant, although providing ample detailed responses in *Understanding* in the visual condition, insisted that “I’d do what the doctor says. I have no thoughts of my own,” and did not provide any additional information from the visual aids. Personal reasons may be salient and important from PWD’s perspective (Moye et al, 2004).

Therefore, in the actual clinical or decisional setting, it is recommended that one should
carefully weigh the significance of personal reasons, and expect a variety of reasons that are or are not specific to the person.

An unexpected finding was that there were no statistical differences between the visual and verbal conditions for Non-Vignette Consequences; one would have expected the visual inputs would trigger PWD’s personal experiences and would have increased supporting statements for their choice of medical care. It might be that the pictures and sentences were not personally relevant or specific. In a previous study, Benigas and Bourgeois (2011) found that generic photographs and words were not as effective as personal photos at helping PWD to access relevant memories related to the material. Another possibility was that the participants might have had very limited personal experience to begin with, as expressed by some participants that the discussed health problem and/or treatment option “never came across my mind.”

Logical Consistency

The outcome for PWD’s logical consistency in making a treatment decision, as determined by the scores under the decisional skill, “Logical Sequence,” showed that there were no statistically significant differences between conditions. It should be pointed out that the evaluation criterion for logical consistency is whether the choice follows logically from the person’s previous reasoning (Grisso & Appelbaum, 1998). In the verbal condition, while 17 PWD (85%) demonstrated stability in the choice that was made, 7 participants’ (41%) final decision was supported by at least one reason that was (1) judged to be too broad and vague (e.g., “I think it would be a big help.” “It would be worthy to me.”) even when pressed for specific information, or (2) based on confusing
hypothetical scenario with reality (e.g., “I don’t have a problem.”) even when clarifications were provided. This reveals the concern that demonstrating adequate logical consistency does not always reflect Understanding diagnostic and treatment information or Reasoning through risks and benefits, which is in line with the conclusion by Moye et al. (2005). In contrast, nearly all PWD stated their final decision in the visual condition was based on factual information from the visual stimuli, suggesting that visual aids may increase credibility for the PWD’s choice.

Appreciation

Most participants in both conditions were able to explicitly agree or disagree that the treatment has the potential to produce some benefit for their current health condition, resulting in non-significant differences between conditions for the decisional skill, “Acknowledgement.” Three participants (15%) with moderate dementia in the verbal condition either constantly digressed to another topic or repeatedly rendered uncertainty on their current health condition (e.g., “I have a health situation?”, “What problem do I have?”) even after clarifications were made. Therefore, they were unable to clearly determine whether the treatment would benefit their current health status. This also generated noticeable increases in the numbers of experimenter’s Prompt and Other speech acts (e.g., “I don’t know. This is why I would like to know [prompt the 8th question]”), with the Prompt shown as outliers in Figure 8. Results for evaluating Potential Effects showed that participants in the visual condition offered significantly more reasonable explanations to support their belief and disbelief in the potential treatment benefits. Further, among these participants, only 2 of them cited every possible
reason on the visual aids. The majority either provided a mix of personal experiences and factual information from the visual aids, or simply a reason or two from one of these two categories. This again, suggests that the participants may usually focus on the reasons (or maybe just one reason) that are the most salient or have the most personal relevance within their perspective. Therefore, it is recommended that one should not automatically conclude PWD’s reasoning capacity as impaired if they fail to cite every possible rational reason for their choice.

Types of Vignette Statement

To conduct an in-depth exploration on the effects of visual aids on PWD’s decision-making capacity, the quality of PWD’s appropriate factual statements elicited by the visual stimuli was examined. The data revealed that when the experimenter interviewed the participants without providing any visual support, there was a significant lack of factual information recalled or cited from the vignette by the participants. In addition, the overall performance of participants with moderate dementia was found to be either similar to or poorer than individuals at the mild stage, despite that these differences were determined as non-significant between the two groups. Participants were also observed to be more confused about the task and produced more tangential utterances. This resulted in the experimenter increasing the number of Clarification, Inquiry, and Other speech acts; Clarification further exhibited outliers (Figure 8) due to frequent topic digression and confusion on personal health condition from two participants with moderate dementia. Some participants were able to offer some Reworded information without visual aids. However, the quantity was low (approximately 2 – 5 utterances) in general.
On occasion, a few participants with mild dementia were observed to use examples – usually in lengthy descriptions – with the intent of explaining one symptom of the disorder.

In contrast, when participants were augmented by visual stimuli during the decision-making process, they produced significantly more succinct reworded vignette statements (e.g., paraphrasing) or read word by word (i.e., Exact Statements) from the visual aids at hand. This resulted in fewer vignette statements that were not being mentioned (i.e., Statement Not Mentioned). There was a wide distribution – even within mild and moderate groups – in the range for Rewording and Exact Statements in the visual condition, suggesting that the effects of visual aids seem to vary across the participants. Further investigation revealed that participants with mild dementia produced more Rewording than those with moderate dementia. However, participants with moderate dementia uttered more direct readings (i.e., Exact Statements) from the visual aids than those at the mild stage. These phenomena suggest that visual aids served as a direct source of information to persons with moderate dementia, whereas for individuals with mild dementia, these tools were used as references to enhance their clarity and language flexibility during expression. It also indicates that the inability to recall of information at a specific time period does not necessarily indicate that the meaning of this information is not encoded and stored in the long-term memory (Sabat, 2005); rather, assistance is needed to activate and facilitate the process of verbal retrieval. Statements that distorted the original meaning of the vignette sentences were few in both experimental conditions and were not significantly different. The cause, however, may be different. The inference
is that participants in the verbal condition encountered greater difficulty in information recall and word retrieval due to memory impairment to begin with. In the visual condition, the participants used the visual aids as references and either cited or read directly from the stimuli. These verbal behaviors prevented the production of inaccurate information and enhanced topic maintenance, resulting in the experimenter producing relatively fewer Clarifications and Other types of statements. Overall, the analysis showed that visual aids were effective in eliciting ample verbal evidence of comprehension from participants with dementia during the decision-making process.

Clinicians’ Perceptions of PWD’s Decisional Skills

By comparing clinicians’ ratings of the visual and verbal conditions, the results showed that participants’ decisional skills in the visual condition were rated as significantly better in comprehending diagnostic symptoms and treatment information (Item 1, 2, and 3), making simultaneous comparison of alternatives (treatment and no treatment) in light of consequences (Item 5), providing reasons for his or her treatment choices related to the assumed medical scenarios (Item 6), and justifying why his or her current health may or may not benefit from the potential value of the treatment (Item 8). By taking agreement distributions into account, clinicians in general judged that participants were able to make the initial decision for the treatment (Item 4), and that the final decision followed logically from previous reasoning (Item 7) with and without visual aid support. Therefore, no significant differences were found in these two appraised areas. In previous scoring analyses of participants’ decision skills in this study, the scores for the visual condition were also reported as significantly higher in the
following areas: Comprehending information about the Health Problem, Treatment Options, and Risks and Benefits; making simultaneous comparisons about the consequences between treatment alternatives (i.e., Comparison); providing sufficient reasons for the treatment decision made for the hypothetical medical scenarios (i.e., Vignette Consequences); and justifying whether potential treatment benefits may or may not apply to the decision-maker’s current health condition (i.e., Potential Effects). In contrast, no significant differences were found in the scores for making a decision (i.e., *Expressing a Choice*) and logical consistency (i.e., Logical Sequence) between the visual and verbal conditions. The overall outcome of judges’ ratings validates previous analyses of participants’ decisional skills in this study, suggesting that from a clinical perspective, PWD’s decision-making abilities can be enhanced by presenting topic-related pictures and statements of fact during the decision-making process.

In the verbal condition, it was somewhat unexpected that the judges’ consensus on participants’ ability to appreciate the value of treatment on his or her health in current reality (Item 8) leaned toward agreed rather than disagreed. However, this may imply the fact that clinicians did not automatically penalize participants for a lack of decisional competence as long as the reason(s) mentioned – whether of factual or personal relevance – was considered salient and deemed appropriate from a clinical perspective. This inference also may explain the bimodal ratings on participants’ good reasoning skill (Item 6), with 40% of ratings in the agreed rating and 37% in disagreed. Clinicians’ split agreement was also reported when appraising participants’ comprehension of the given treatment information (Item 2). This may be attributed to the influence from two audio
samples (50% of all sampled audio recordings for verbal condition) that were from participants exhibiting very mild dementia (MMSE: 24 and 25); their cognitive impairment may not be severe enough to generate noticeable interference with communication as judged by some clinicians, resulting in increasing judges’ wavering when determining the decisional capacity of these participants. This suggests that the effectiveness of visual aids for individuals at the very mild stage of dementia requires further investigation.

Some judges expressed after the evaluation that oral reading does not necessarily reflect comprehension, and therefore had a somewhat challenging time to determine participants’ decisional capacity at times. However, Carrell (1992) pointed out that a text carrying meaning in the eyes of the reader also provides directions for the reader to construct meaning from his or her previously acquired knowledge. By applying these theories in this study, most participants actually demonstrated reading comprehension during the interview such as making direct comments about the visual stimuli (“That sounds terrible!” “Does the doctor manage the liquid food?”) or making personal associations (e.g., “Yes, my biggest memory issue is remembering people’s names.” “I’m not taking these pills because I already have a crazy stomach.”). Another observation that revealed participants’ reading comprehension was during the Reasoning task. In the visual condition, nearly all participants looked at the visual aids and then selected the appropriate information to support his or her decision instead of verbally reading every single treatment risk and benefit. These behaviors supported the purpose of these visual aids, which is to enhance PWD’s decision-making capacity through lessening their
memory load by offering concrete, expository language in familiar words and phrases, and by taking the advantage of PWD’s intact oral reading ability at the mild and moderate stages.

**Study Limitations and Future Research**

The current study contains several methodological limitations. First, the samples of mild and moderate groups were small, and it was therefore difficult to explore the effectiveness of visual aids for individuals with dementia at the very mild and towards the end of moderate stage. It seemed that people with very mild dementia may not need as much assistance from the visual aids, as suggested by clinicians’ split agreement ratings in the verbal condition. Previous studies in assessing comprehension of the content of research consent (Buckles et al., 2003) and medical scenarios as measured by MacCAT-T, CCTI, and HCAI (Moye et al., 2004) also found that many participants with mild dementia performed in the unimpaired range. However, current findings showed that participants with mild dementia received low scores in all decisional skills under the legal capacity *Understanding* when visual support was not available, and that the performance was similar to individuals at the moderate stage. The scoring outcomes also revealed that visual aids can significantly enhance most decisional skills, as well as improving verbal behaviors of persons with dementia overall. Exploring the use of these visual materials with a wide range of severity of dementia with larger samples – and even with individuals with mild cognitive impairment – is warranted to obtain a more precise view of the effects of visual aids and to generate better generalizability.
Another limitation of the study is that the majority of the participants were individuals diagnosed with unspecified dementia. Dementia consists of various subtypes, each with different cognitive symptoms. For example, people with Alzheimer’s disease at early stage experience difficulty with word finding, comprehending and expressing abstract language, and following complex conversations; impairments of dementia with Lewy bodies suffered from more prominent verbal fluency, problem solving, and abstract thinking problems (Galasko, Salmon, Lineweaver, Hansen, & Thal, 1998), and are often found to exhibit visual hallucinations (McKeith et al., 1996). Persons with Vascular dementia display cognitive impairments in judgment and planning, and have prominent neuropsychiatric symptoms particularly depression, anxiety, agitation, and apathy (Aharon-Peretz, Kliot, & Tomer, 2000). The effects of decisional aids on different dementia subtypes, and to what degree the visual aids should be modified for a particular subtype of dementia, are yet to be explored. For example, an individual with dementia with Lewy bodies may encounter greater difficulty in recognizing the items printed on the visual aids due to visual hallucinations, resulting in less effectiveness when using these visual stimuli to indicate his or her medical preferences. Therefore, future research should extend current findings to a larger diversity and number of people with dementia to obtain better insight on the effectiveness of these visual stimuli.

It is also recommended to evaluate the use of visual aids for an individual’s actual medical condition without introducing it as a hypothetical topic. Observation during study sessions revealed that using hypothetical medical scenarios was cognitively challenging for some participants with dementia as they would confuse hypothetical
scenarios with reality. While these behaviors were alleviated through visual aid presentations, discussing topics of their own personal medical situations with reminders of personal relevance might further decrease PWD’s state of confusion. In addition, Pierce (1996) found that emotional issues in general have little impact in hypothetical vignettes. In real clinical settings, however, there is a high possibility of emotional reactions to medical information (e.g., prognosis, treatment consequences on the quality of life) affecting the processing of this information (Pierce, 1996). Furthermore, the nature of different medical scenarios that may or may not pose an immediate threat to an individual’s life (e.g., ventilation, cardinal surgery, shoulder dislocation) also involve various levels of emotional impact and personal values (McCarron & McCallion, 2007), and may further affect interviewees’ desire to consider or discuss the eventualities. There has been little research investigating how visual aids would affect PWD’s emotional reactions when discussing health problems and medical care of personal relevance. Given that the medical scenarios of this study were based on hypothetical conditions, and the study implemented the visual aids on a limited number of medical scenarios – although one (Dysphagia and Feeding Tube Placement) was more life-threatening than the other (Drug Treatment and Dementia), future exploration on this aspect is recommended to ensure practicality of visual materials on PWD’s decision-making capacity in actual health care situations.

Furthermore, the current study only provided one recommended treatment option for the participants to decide whether to accept or forego this option. During study sessions, some participants, especially during the discussion on feeding tube placement, either
requested an alternative treatment option or expressed that feeding tube placement would not be the choice if there were other treatment options available for them to choose from, revealing the intention of balancing the concerns about survival and maintenance of good quality of life. In the meantime, how PWD would process and express the information when two actual treatment alternatives (i.e., excluding the no-treatment option) are presented with visual aids support remain unclear. To begin with, how much information should be disclosed to be considered sufficient for the decision maker to state a choice and justify the decision? Will doubling the amount of information on treatment risks and benefits exacerbate PWD’s confusion and/or increase their anxiety level during the decision-making process even with visual supports? How will these consequences affect the measurement of the decision maker’s comprehension and their willingness to cooperate? Evaluating effectiveness of visual stimuli involving different actual treatment alternatives (i.e., excluding the no-treatment option), therefore, is also warranted.

Determining decision-making capacity of PWD has been a challenging issue for health care professionals (Volicer et al., 2003); low agreement on PWD’s decision-making capacity has been common in health care settings (e.g., Horton-Deutsch et al., 2007; Shalowitz, Garrett-Mayer, & Wendler, 2006; Tyrrell et al., 2006). According to the clinicians’ ratings in this study, however, the judges not only determined that PWD’s decisional skills significantly improved with visual aids support, their types of agreement also centered noticeably on the agreed rating and revealed higher agreement.

Nonetheless, Hayes (2005) argued that when a larger number of observers agree on the outcome they generate from a larger sample, the results can be regarded as reproducible
and trustworthy, and can increase interchangeability with results from other groups of observers. The judges recruited for this study were specifically speech clinicians. In addition, these judges appraised the decision-making capacity of PWD through listening to limited audio recordings, with split agreement reported in the verbal-only condition. More evidence, therefore, is needed to determine whether the use of visual aids in decision-making discussions with PWD can truly increase agreement on PWD’s legal capacities among speech clinicians and other health care professionals.
CONCLUSION

This study, to this investigator’s knowledge, is the first that investigated the effects of picture-textual stimuli on PWD’s decision-making capacity for medical care. On the basis of this study, through both statistical analyses and clinical evaluation, the decision-making capacity of people with mild and moderate dementia can be strengthened in the areas of understanding the disclosed diagnostic and treatment information, evaluating and comparing treatment consequences, and relating the overall disclosed medical information and consequences to their own personal situation with visual aid support. During the decision-making process, these visual stimuli can enhance PWD’s verbal behaviors by serving as references of facts for PWD to read and to cite from. The findings also added evidence to previous research that individuals with dementia of mild and moderate severity can convey a clear treatment choice with logical consistency without any visual support, although this does not always in itself indicate capacity. Finally, visual aids have the potential for clinicians to reach a higher agreement when determining the decision-making capacity of individuals with dementia. To accumulate evidence, it is highly recommended to conduct studies involving larger groups of health care professionals.
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Appendix A: Consent Form for Surrogates
Informed Consent to Participate in Research
Information to Consider Before Taking Part in this Research Study

IRB Study # 17012

You are being asked to decide whether to let your family member take part in a research study or not. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask her to explain any words or information you do not clearly understand. We encourage you to talk with your family member, your family and friends before you decide to let the individual take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

Please tell the study staff if your family member is taking part in another research study.

We are asking you to decide whether or not to let your family member take part in a research study called:

Effects of Visual Stimuli on Decision-Making Capacity on End-of-Life Care of People with Dementia

The person who is in charge of this research study is Wan-Zu Diana Chang, M.A., at the University of South Florida (USF). This person is called the Principal Investigator (PI). The co-investigator and faculty advisor is Michelle Bourgeois, Ph.D., USF. However, other research staff may be involved and can act on behalf of the person in charge.

The research will be conducted at [Redacted].

Purpose of the study

The purpose of this study is to examine the effects of visual aids containing pictures and sentences on decision-making capacity of people with dementia for medical and end-of-life care choices. In this study, “capacity” is operationally defined as the ability of an individual to make a task-specific and reasoned choice. The study investigates the question: Will individuals with mild and moderate dementia demonstrate better decisional capacity for medical scenarios when using visual aids to supplement verbal questioning in comparison to performance elicited by verbal questioning alone? Previous research have shown that graphic and written visual aids in the form of sentences, words,
phrases, and pictures, have been documented to compensate for the gradual loss of linguistic, memory,
and other cognitive skills in dementia. In addition, these materials provide the semantic content that
bridge the comprehension deficits of persons with dementia when instructions and/or questions are
verbally delivered. Therefore, in comparison to the verbal-only administration, it is anticipated that
when your family member is augmented by these visual aids, s/he will demonstrate better ability in:

1. Understanding: Comprehending diagnostic and treatment-related information,
2. Expressing a Choice: Conveying a decision about treatment options,
3. Reasoning: Rationally comparing and evaluating treatment alternatives and their likely effects
   on daily life, and
4. Appreciation: Relating this information to one’s own situation.

This study is being conducted for a dissertation by the student, Wan-Zu Diana Chang. She is a Ph.D.
student from the Ohio State University (OSU) and a staff member at USF. She is being guided in this
research by her advisor, Michelle S. Bourgeois from USF.

Study Procedures

If you decide to let your family member take part in this study, s/he will be asked to answer and
express his/her opinions on a total of 16 questions related to two medical decisions. The study
procedure will be completed in one session that lasts approximately 30 – 45 minutes; short breaks will
be given as needed. The study will be conducted in the facility or in the room that your family member
resides.

After consent is obtained, the investigator will meet with your family member to administer three
measures: (1) *Mini-Mental State Exam*, which determines his/her memory status; (2) Subtest IV:
Sentence – Picture in Reading Comprehension Battery for Aphasia, 2nd ed., which measures his/her
performance in reading comprehension for sentences; (3) *Communication Screening Test*, which
measures his/her functional vision, hearing, and conversation skills. Then, the investigator will ask
your family member to answer and express opinions on a total of 16 questions related to two medical
decisions. During the study procedure, the investigator will introduce one of the medical scenarios first
– sometimes together with the presentation of relevant pictures and sentences, read it, and ask follow-
up questions for your family member to express his/her thoughts. The same procedure will be repeated
for the other medical scenario.

The entire session will be audio-recorded for analysis. An identification number will be assigned
to the audio file. All data collected during the session will be referred to this assigned number. The
data will be stored on a password-protected computer, without direct identifiers. All data will be
destroyed within 6 months after the study results have been compiled and submitted for publication.
The PI and the Study Coordinator are the only persons who have the access to the audio file and the
password-protected computer.

Total Number of Participants

A maximum of 30 individuals will take part in this study.

Alternatives

Your family member does not have to participate in this research study. There are a variety of
alternative resources and services at [redacted] available to participants
who are concerned about their memory.
Benefits
The potential benefits of participating in this research study are that your family member will have a conversation with the investigators about decision-making, and any questions s/he has about the topic of decision-making will be answered by the investigators.

Risks or Discomfort
The potential risks of this research are limited to those associated with embarrassment and discomfort due to memory concerns.

Compensation
Your family member will receive no payment or other compensation for taking part in this study.

Cost
There will be no additional costs to your family member as a result of being in this study.

Authorization to Use and Disclose Protected Health Information
Who will see your health information?
In this research study, we use and share your family member’s health information to the extent authorized (permitted) by you. We know that this information is private. The federal privacy regulations of the Health Insurance Portability & Accountability Act (HIPAA) protect your family member’s identifiable health information. If you authorize us to use his/her information we will protect it as required by the law.

Who will disclose (share), receive, and/or use your information?
To conduct this research, USF and the people and organizations may use or share your family member’s information. They may only use and share your family member’s information:
- With the people and organizations on this list;
- With you or your personal representative; and
- As allowed by law.

In addition to the people and organizations listed below in the Privacy and Confidentiality section of this document, the following groups of people may also be able to see information about your family member and may use the information to conduct the research:
- The medical staff that takes care of your family member and those who are part of this research study;
- Data Safety Monitoring Boards or others who monitor the data and safety of the study.

Who else can use and share this information?
Only the PI and the Study Coordinator may share your family member’s information with each other.
How will my information be used?
By signing this form, you are giving your permission on behalf of your family member to use and/or share his/her health information as described in this document for any and all study/research related purposes. Your authorization to use your family member’s health information will not expire unless you revoke it in writing.

As part of this research, USF may collect, use, and share the following information:

- Your family member’s health information gathered for this research, including diagnosis, and Mini-Mental State Exam score.

You can list any particular information that your family member does not want us to use or share in the space below. If you list nothing here, we can use and share all of the information listed above for this research but for nothing else.

For the Proxy of Research Participant (you) to complete:

☐ I am asking USF and the researchers not to include, use, or share the following health information in this research (if blank, then no information will be excluded):

__________________________________________________________________________________________

Your Rights:
You can refuse to sign this form. If you do not sign this form your family member will not be able to take part in this research study and therefore not be able to receive the research related interventions. However, your family member’s health care outside of this study and benefits will not change.

How Do I Withdraw Permission to Use My Information?
You can revoke this form at any time by sending a letter clearly stating that you wish to withdraw your authorization to use of your family member’s health information in the research. If you revoke your permission:

- Your family member will no longer be a participant in this research study;
- We will stop collecting new information about your family member;
- We will use the information collected prior to the revocation of your authorization. This information may already have been used or shared with other, or we may need it to complete and protect the validity of the research; and
- Staff may need to follow-up with your family member if there is a medical reason to do so.

To revoke this form, please write to:

Principal Investigator: Wan-Zu Diana Chang, M.A.
For IRB Study # 17012
Email: wdchang@usf.edu

IRB Number: Version 1
Date: 2014-10-20

While we are conducting the research study, we cannot let you see or copy the research information we have about your family member. After the research is completed, you have a right to see the information about your family member, as allowed by USF policies.

**Privacy and Confidentiality**

We will keep your family member’s study records private and confidential. Certain people may need to see his/her study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator and all other research staff.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at the records of your family member. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your family member’s rights and safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

We may publish what we learn from this study. If we do, we will not include the name of your family member. We will not publish anything that would let people know who s/he is.

**Voluntary Participation / Withdrawal**

Your family member should only take part in this study with your consent to let him/her volunteer. You should not feel that there is any pressure about your decision whether to let your family member to take part in the study or not. Your family member is free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you and your family member are entitled to receive if s/he stops taking part in this study.

**You can get the answers to your questions, concerns, or complaints**

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, please contact:

**Wan-Zu Diana Chang, M.A. at 626-272-8719**

If you have questions about your family member’s rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.
Consent to Take Part in this Research Study, and Authorization to Collect, Use and Share Your Family Member’s Health Information

It is up to you to decide whether you want your family member to take part in this study. If you decide to let him/her to take part, please sign the form, if the following statements are true.

I freely give my consent for my family member, __________________, to take part in this study and authorize that my family member’s health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing for my family member to take part in research. I have received a copy of this form to take with me.

___________________________  __________________________
Signature of Proxy Consenting the Study  Date

___________________________  __________________________
Printed Name of Proxy Consenting the Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the proxy of the person taking part in the study what he or she can expect from their family member’s participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:

- What the study is about;
- What procedures will be used;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

___________________________  __________________________
Signature of Person Obtaining Informed Consent / Research Authorization  Date

___________________________  __________________________
Printed Name of Person Obtaining Informed Consent / Research Authorization
Appendix B: Mini-Mental State Examination
DECISION-MAKING CAPACITY & VISUAL STIMULI PROJECT: MINI-MENTAL STATE EXAMINATION
Folstein, Folstein, & McHugh, 1975

I. ORIENTATION
Please tell me today's date. Participant's Answer (Score)

1.1 What month is it? ___________ (1)
1.2 What date is it? ___________ (1)
1.3 What year is it? ___________ (1)
1.4 What day of the week is it? ___________ (1)
1.5 Can you also tell me what season it is? ___________ (1)

Score: ___________/ 5

Please tell me (building)...

1.6 What building we are in right now? ___________ (1)
1.7 What floor are we on? ___________ (1)
1.8 What city are we in? ___________ (1)
1.9 What county are we in? ___________ (1)
1.10 What state are we in? ___________ (1)

Score: ___________/ 5

II. REGISTRATION
I'm going to name three objects and I'd like you to repeat them after me.
(Name the three objects, allotting one second to say each time.
Give 1 point for each correct answer on the first trial only. Repeat the objects until the patient can name them all –
maximum of 6 trials. Stop after 6 unsuccessful trials and enter a number 7 for number of trials to indicate failure.)

2.1 Apple ___________ (1)
2.2 Table ___________ (1)
2.3 Penny ___________ (1)

Total trials: ___________
Score: ___________/ 3

I want you to remember these words because I will ask you about them later.

III. ATTENTION AND CALCULATION

[Alternative 1] I'm going to ask you to do some subtraction. Think of the number 7. I want you to subtract 7 from 100. Now, subtract 7 from that number and keep going until I stop you.

3.1 93 ___________ (1)
3.2 86 ___________ (1)
3.3 79 ___________ (1)
3.4 72 ___________ (1)
3.5 65 ___________ (1)

Score: ___________/ 5
[Alternative 2] I want you to spell a word forward and then back backward. The word is ‘WORLD’.

Spell it forward.
(If incorrect, then correct the patient and allow him/her to re-spell it until the word is spelled correctly.)

Spell it backward.

3.6 D
3.7 L
3.8 R
3.9 O
3.10 W

Score: ________ / 5

IV. RECALL

A few minutes ago, I asked you to repeat some words after me. Can you tell me what they were?

4.1 Apple
4.2 Table
4.3 Penny

Score: ________ / 3

V. LANGUAGE

Please name these for me.
(Show the patient a wooden pencil and then a watch, preferably worn on the wrist.)

4.1 Pencil
4.2 Watch

Score: ________ / 2

I’m going to read a sentence and I want you to repeat it after me. Say exactly what I say.

4.3 NO IFS, ANDS OR BUTS.

Score: ________ / 1

I’m going to ask you to do something for me. I’m only going to say it once, so listen carefully.
(Material: paper.)

4.4 Take this paper in your right hand;
4.5 Fold the paper in half with both hands;
4.6 And put the paper on your lap.

Score: ________ / 3

4.7 Read this card and do what the card tells you to do.
(Show the card with “close your eyes” on it. One prompt allowed after initial instructions.)

Score: ________ / 1
4.8 Please write a sentence for me on this blank piece of paper.  
(Do not dictate a sentence or provide a subject; it must be written 
spontaneously. Prompt as often as you like. 
The sentence must contain a subject and verb and be sensible. Correct 
grammar and punctuation not necessary.) 
Score: __________ / 1

4.9 Please copy this design exactly as it is for me. 
(Hold the card with the design on it in front of the patient; do not let 
the patient trace the design. All 10 angles must be present, and 2 
must intersect to score 1 point. 
Tremor and rotation are ignored.)  
Score: __________ / 1

Total score: __________ /30

Patient ID #: ________________  
Date: ________________

Did the patient exhibit any signs of illiteracy, or of physical impairments that would hinder performance on any 
of the items in this test?  
a) No.  
b) Yes.  
   If yes, please specify: __________________________________________

Notes:
_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
_____________________________________________________________
CLOSE YOUR EYES
Appendix C: Communication Screening
Decision-Making Capacity and Visual Stimuli Project: Communication Screening
Adapted from Bourgeois et al., 2001

Subject Demographic Information

Subject Name: ____________________________
Address: __________________________________
Date of Birth: ____________________________
Race: _____________________________________
Gender: _________________________________
Education: ______________________________

Caregiver Demographic Information

Caregiver Name: ____________________________
Address: __________________________________
Phone: _________________________________
Relationship: ____________________________

VISION (from Minimal Data Set 2.0)

0 ADEQUATE
Sees fine detail, including regular print in newspapers/books.
(Ability to see in adequate light and with glasses if used)

1 IMPAIRED
Sees large print, but not regular print in newspapers/books.

2 MODERATELY IMPAIRED
Limited vision; not able to see newspaper headlines, but can identify objects.

3 HIGHLY IMPAIRED
Object identification in question, but eyes appear to follow objects.

4 SEVERELY IMPAIRED
No vision or sees only light, colors, or shapes; eyes do not appear to follow objects.

VISUAL LIMITATION/ DIFFICULTIES

a. Side vision problems – decreased peripheral vision (e.g., leaves food on side of tray, difficulty traveling, bumps into people and objects, misjudges placement of chair when seating self).

b. Experiences any of following: sees halos or rings around lights; sees flashes of light; sees curtain over eyes.

c. NONE OF ABOVE.
VISUAL APPLIANCES

0  No
1  Yes – Glasses / contact lenses / magnifying glass.

HEARING
(With hearing appliance, if used)

0  HEARS ADEQUATELY – normal talk, TV, phone
1  MINIMAL DIFFICULTY – when not in quiet setting
2  MODERATELY IMPAIRED – hears in special situations only; speaker has to adjust tonal quality and speak distinctly.
3  HIGHLY IMPAIRED – object identification in question, but eyes appear to follow objects.
4  SEVERELY IMPAIRED – absence of useful hearing

COMMUNICATION DEVICES/ TECHNIQUES
(Check all that apply during last 7 days)

a. Hearing aid present and used
b. Hearing aid, present and not used regularly.
c. Other receptive communication techniques used (e.g., lip reading).

COMMUNICATION: 5 MINUTE CONVERSATION
Set stopwatch for 5 minutes. Prompt at 3.5 and 2.0 minutes approximately. If necessary, use other general prompts (“tell me more” or “what else can you tell me about your life, family, etc.”).

1. Tell me about your family.
2. Tell me about your life.
3. Tell me about your day.

Rating of Responses

1  Elaborated conversation; multiple sentence responses; appropriate, normal conversation.
2  Single sentences only.
3  Phrases, multiword only.
4  Single word responses, includes yes/no responses.
5  Intelligible verbal responses, or vocalizing only.
6  No verbal or vocal response to interviewer.
Appendix D: Medical Vignettes for Decision-Making
Scenario#1: Feeding Tube Insertion for Dysphagia

Section 1: Health Problem *(Grade level: 5.7)* (p. 1, 2)

Let’s assume that you have swallowing problems. This means that you cannot eat or drink safely by mouth. The food or liquid might go into your lungs instead of entering your stomach. When this happens a lot, you would choke or cough on food or drink, and your lungs might get infected. Because of swallowing problems, you also may not be able to have enough right food and liquid to stay healthy.

Section 2: Treatment Option *(Grade level: 6.3)* (p. 3)

Because you cannot have food and drink safely by mouth, your doctor has suggested you to get a feeding tube. The feeding tube is a small, hollow, and flexible tube that goes into your stomach. Once you have a feeding tube, the liquid food would go directly into the stomach, not through your mouth. To do so, the doctor would make a hole on your stomach for the tube to go in. It doesn’t hurt because the doctor will give you medication.

Section 3: Risks and Benefits *(Grade level: risks = 6.2; benefits = 5.9)* (p. 4, 5)

If you choose to get a feeding tube, the advantages are that you would reduce coughing and choking. You would not starve because you would have liquid food from the feeding tube. The liquid from the feeding tube would also keep you hydrated.

If you choose to get a feeding tube, the disadvantages are that you might have skin irritation around the tube. You cannot enjoy the taste of food because the food doesn’t go through your mouth. Also, you may feel lonely having food by yourself.
Scenario#2: Drug Treatments for Dementia

Section 1: Health Problem *(Grade level: 6.4) (p. 1, 2)*

Let’s assume that you have memory problems. This means that you would become very forgetful. When this happens, you would not be able to remember what happen recently. Later, you might not recognize people, places, and things you used to be familiar with. You would also forget more and more words when you talk to people. You may also get confused and, therefore, you would have trouble with daily activities.

Section 2: Treatment Option *(Grade level: 6.0) (p. 6)*

Because you have memory problems and become confused, your doctor has suggested that you should take some medicine. This medicine is round pills or capsules. You take them with water each day. You start with lower dosage, and the doctor would give you more when it is necessary.

Section 3: Risks and Benefits *(Grade level: risks = 6.2; benefits = 6.2) (p. 4, 5)*

If you choose to take these medicine, the advantage is that your memory and thinking will improve for a few months. This means that you will be able to remember the people and things you love. You will become less confused in daily life. Also, you will be able to remember words and express what you wish to say more clearly.

If you choose to take these medicine, the disadvantage is that you might feel uncomfortable after taking them. It is possible that you would feel dizzy or have a headache. You might vomit and do not feel like eating. Also, you might have an upset stomach and go to the bathroom more often.
Appendix E: Decisional Aids
on Feeding Tube Placement and Drug Treatment for Dementia
If I had swallowing problems.

I cannot have food or drink safely by mouth.

Food or drink might go into my lungs, not my stomach.

If I had swallowing problems, the consequences are:

Coughing or choking.

Having lung infection.

Not having enough nutrition to stay healthy.
If I had swallowing problems, the solution is to get a feeding tube.

The tube is small, hollow, and flexible.

Liquid food goes to my stomach through the tube.

The doctor needs to make a hole on my stomach.

The good things about a feeding tube are:

Less coughing or choking.

Keeping me from starving.

Keeping me hydrated.
The **bad things** about a feeding tube are:

- I might have skin irritation.
- I cannot enjoy the taste of food and drink.
- I might feel lonely during mealtime.

**Do you wish to have a feeding tube?**

- Yes, I want a feeding tube.
- No, I do not want a feeding tube.
If I had memory problems,

I would become forgetful and confused.

I cannot remember what happen recently.

If I had memory problems, the consequences are:

Do not recognize what I used to be familiar with.

Forget words when talking to people.

Have trouble with daily activities.
If I had memory problems, the solution is to take some medicine every day.

The medicine is round pills or capsules.

Take medicine with water.

Start from lower dosage to higher dosage.

The good things about taking medicines are:

Less confused and have a better memory.

Remember the people and things I love.

Express my thoughts more clearly.
The **bad things** about taking medicines are:

I might feel dizzy or have a headache.

I might vomit and do not want to eat.

I might have a sick stomach.

---

Do you wish to take some medicine?

Yes, I want to take some medicine.

No, I do not want to take any medicine.
Appendix F: Questionnaire and Decisional Capacity Record Form
### Decisional Capacity Scoring Form

Adapted from Grisso & Appelbaum (1998)

<table>
<thead>
<tr>
<th>Legal Standards</th>
<th>Scores</th>
<th>Total Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UNDERSTANDING</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1) Health Problem</td>
<td>______</td>
<td>5</td>
</tr>
<tr>
<td>2) Treatment Option</td>
<td>______</td>
<td>3</td>
</tr>
<tr>
<td>3) Risks / Benefits</td>
<td>______</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>______</td>
<td>14</td>
</tr>
<tr>
<td><strong>EXPRESSING A CHOICE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) Make a Decision</td>
<td>______</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>______</td>
<td>1</td>
</tr>
<tr>
<td><strong>REASONING</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5a) Comparison</td>
<td>______</td>
<td>2</td>
</tr>
<tr>
<td>5b) Vignette Consequences</td>
<td>______</td>
<td>3</td>
</tr>
<tr>
<td>5c) Non-Vignette Consequences</td>
<td>______</td>
<td>2</td>
</tr>
<tr>
<td>6) Logical Sequence</td>
<td>______</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>______</td>
<td>8</td>
</tr>
<tr>
<td><strong>APPRECIATION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7) Acknowledgement</td>
<td>______</td>
<td>1</td>
</tr>
<tr>
<td>8) Potential Effects</td>
<td>______</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>______</td>
<td>4</td>
</tr>
</tbody>
</table>
**General Scoring Criteria**

1) All statements must be intelligible and unambiguous in order to receive points.
2) Paraphrase is preferred; verbatim repetition of the original description is not required.
3) Do not score responses that are too broad, vague, or render uncertainty.  
   *E.g., “Treatment X will help me.” “I guess that…” “The treatment seems to…”*

**Key Words, Phrases (can be paraphrased), or Concepts for Scoring Items**

<table>
<thead>
<tr>
<th>Scoring Item</th>
<th>Drug Treatment for Dementia</th>
<th>Feeding Tube Placement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1 Health Problem</td>
<td>Memory problems</td>
<td>Swallowing problems.</td>
</tr>
<tr>
<td>Description</td>
<td>Become forgetful and confused; cannot remember what happened recently.</td>
<td>Food goes to lungs, not to the stomach; cannot have food/drink safely by mouth.</td>
</tr>
<tr>
<td>Consequences</td>
<td>Do not recognize what is known; forget words; have trouble with daily activities.</td>
<td>Coughing, choking, lung infection, not have enough nutrition/cannot stay healthy.</td>
</tr>
<tr>
<td>Q2 Tx Option</td>
<td>Take medicine (everyday).</td>
<td>Get a feeding tube.</td>
</tr>
<tr>
<td>Tx Process</td>
<td>Start with lower dosage; increasing dosage when necessary.</td>
<td>Makes a hole on the stomach/tube goes into the stomach; gives medication/anesthesia.</td>
</tr>
<tr>
<td>Tx Characteristic</td>
<td>Round pills or in capsule form; take medicine with water.</td>
<td>Tube is small, hollow, and flexible; tube goes into the stomach; liquid food goes directly into the stomach; liquid food does not go through mouth.</td>
</tr>
<tr>
<td>Q3 Risks</td>
<td>Feel dizzy, have a headache, vomit (and) may not want to eat, sick stomach.</td>
<td>Skin irritation, cannot enjoy food/drink by mouth, feel lonely (during mealtime).</td>
</tr>
<tr>
<td>Benefits</td>
<td>Less confusion, better memory, remember loved ones, clearer expression.</td>
<td>Less coughing or choking, not feeling hungry/not starving, stay hydrated.</td>
</tr>
<tr>
<td>Q4 Express a Choice</td>
<td>Want medicine; does not want medicine.</td>
<td>Want a feeding tube; does not want a feeding tube.</td>
</tr>
<tr>
<td>Q5 a) Comparison</td>
<td>Statement in comparative form: Option X is/will <strong>(specific difference)</strong> (than Option Y).</td>
<td>Same as Q3.</td>
</tr>
<tr>
<td>b) Vignette Reasons</td>
<td>Same as Q3.</td>
<td></td>
</tr>
</tbody>
</table>
| c) Non-Vignette Reasons | 1. Reasons(s) must be consistent with the participant’s religious beliefs, cultural background, or personal experience OR  
Reason(s) must not be based on a delusional premise or a serious distortion of reality.  
2. If the reason sounds vague (*e.g., I think it would be helpful*), the participant needs to allow the examiner to determine whether the reason represents delusional thinking or serious distortion of reality. |
| Q6 Logical Sequence | Choice logically follows reasons stated in Q5. | |
| Q7 Acknowledgement | Explicit agreement/disagreement with potential tx benefits on current health condition. | |
| Q8 Potential Effects | Same as Q3 and Q5(c). | |
Questionnaire and Record Form

Questions modified from Grisso & Appelbaum (1998) and Vellinga et al. (2004)

1) **UNDERSTANDING: Health Problem** (p. 1, 2)

Q: Now, please tell me about the health problem that I just talked about.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Identify the health problem.</td>
</tr>
<tr>
<td>1</td>
<td>Provide at least 1 specific description of the health problem.</td>
</tr>
</tbody>
</table>

Number of consequences:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>State a minimum of 3 consequences.</td>
</tr>
<tr>
<td>2</td>
<td>State 2 consequences.</td>
</tr>
<tr>
<td>1</td>
<td>State only 1 consequence.</td>
</tr>
</tbody>
</table>

Select ONE only

TOTAL: _____ / 5

2) **UNDERSTANDING: Treatment Option** (p. 3)

Q: Now, please tell me about the solution to the **(problem)** that I just talked about.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Identify the treatment option.</td>
</tr>
<tr>
<td>1</td>
<td>Explain the treatment process.</td>
</tr>
<tr>
<td>1</td>
<td>Describe at least 1 characteristic of the treatment.</td>
</tr>
</tbody>
</table>

TOTAL: _____ / 3

3) **UNDERSTANDING: Risks / Benefits** (p. 4, 5)

Q: Now, please tell me about the advantages and disadvantages of this **(solution)** that I just talked about.

Number of treatment benefits:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>State 3 benefits.</td>
</tr>
<tr>
<td>2</td>
<td>State 2 benefits.</td>
</tr>
<tr>
<td>1</td>
<td>State 1 benefit.</td>
</tr>
</tbody>
</table>

Select ONE only

Number of treatment risks:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>State 3 risks.</td>
</tr>
<tr>
<td>2</td>
<td>State 2 risks.</td>
</tr>
<tr>
<td>1</td>
<td>State 1 risk.</td>
</tr>
</tbody>
</table>

Select ONE only

TOTAL: _____ / 6
4) **EXPRESS A CHOICE** (p. 6)

Q: Now, you have two choices [disclose the treatment options, including no-treatment option]. Which one do you prefer?

| 1 | State a choice. | TOTAL: __________ / 1 |

5) **REASONING** (p. 4, 5)

Q: So you prefer [participant’s choice]. Think about the advantages and disadvantages of the choices. Please tell me why you think this choice is better than the other.

a) **Comparison**

| 2 | Provide at least 1 statement in comparative form and include at least one specific difference. E.g., Treatment X is more likely to work faster (than Y). | Select ONE only |
| 1 | Provide at least 1 statement in comparative form but does not include a specific difference. E.g., Treatment X is better (than Y). | TOTAL: __________ / 2 |

b) **Vignette Consequences**

| 3 | State a minimum of 3 reasons. | Select ONE only |
| 2 | State 2 reasons. | |
| 1 | State 1 reason. | TOTAL: __________ / 3 |

c) **Non-Vignette Consequences**

| 2 | Provide at least 2 reasonable consequences that are not from the vignette. | Select ONE only |
| 1 | Provide 1 reasonable consequence that is not from the vignette. | TOTAL: __________ / 2 |

6) **REASONING: Logical Consistency of Choice** (p. 6)

Q: When we started the conversation, you (did not) wanted [preferred option]. Now you have shared your reasons. Which choice do you still prefer, [restate the two options]?

| 1 | Final decision follows logically from previous reasoning. | TOTAL: __________ / 1 |
7) **APPRECIATION: Acknowledgement** (p. 6)

Q: Do you think it is possible that [treatment option] may be helpful to your health situation right now?

<table>
<thead>
<tr>
<th>1</th>
<th>Participant explicitly agrees / disagrees.</th>
<th>TOTAL: _______ / 1</th>
</tr>
</thead>
</table>
* Circle whether the participant agrees or disagrees.

8) **APPRECIATION: Potential Effects** (p. 4, 5)

Q: What makes you think that this choice would/wouldn’t be helpful to you?

<table>
<thead>
<tr>
<th>Number of reasonable explanations that support the decision:</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

| TOTAL: _______ / 3 |

Number of reasons from the vignette: _________

Number of reasons **not** from the vignette: _________
Appendix G: Criteria for Types of Vignette Statement and Scoring Form
### Definitions and Scoring Criteria for Types of Vignette Statement

Give the following points based on the participant’s type of utterance:

<table>
<thead>
<tr>
<th>Type of Vignette Statement</th>
<th>Score</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rewording (R)</td>
<td>2 points</td>
<td>The participant states the sentence/phrase on the decisional aid with minor changes that do not distort the original meaning. Acceptable forms are changes in: 1) Express person (first, second), OR 2) Singular and plural form, OR 3) Articles (the, a), OR 4) Tense, OR 5) Use of synonym(s) or description(s) on the sentence/phrase being scored.</td>
</tr>
<tr>
<td>Exact Statement (E)</td>
<td>1 point</td>
<td>The participant reads word-by-word or states the exact sentence/phrase as printed on the decisional aid.</td>
</tr>
<tr>
<td>Statement Not Mentioned (N)</td>
<td>0 point</td>
<td>No mentioning of the information (sentence/phrase) on the decisional aid.</td>
</tr>
<tr>
<td>Distorted Meaning (D)</td>
<td>Enter “9”</td>
<td>The participant distorts the original meaning of the original sentence/phrase on the decisional aid. E.g., 1) The feeding tube is small, hollow, and flexible → The feeding tube is small, hollow. 2) Less coughing → No coughing.</td>
</tr>
</tbody>
</table>

### Summary of Score

<table>
<thead>
<tr>
<th>File #:</th>
<th>Condition:</th>
<th>Scenario:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition:</td>
<td>Scenario:</td>
<td>TOTAL</td>
</tr>
<tr>
<td>Scenario:</td>
<td>TOTAL</td>
<td></td>
</tr>
<tr>
<td>2 points</td>
<td>2 points</td>
<td></td>
</tr>
<tr>
<td>1 point</td>
<td>1 point</td>
<td></td>
</tr>
<tr>
<td>0 point</td>
<td>0 point</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>
### Scenario: Drug Treatment for Dementia

**File #:** ___________________________  **Condition:** ___________________________

<table>
<thead>
<tr>
<th>Question</th>
<th>Health Problem</th>
<th>Statements and Phrases</th>
<th>Point(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>Description</td>
<td>I would become forgetful and confused.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I cannot remember what happened recently.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consequences</td>
<td>Do not recognize what I used to be familiar with.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Forget words when talking to people.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Have trouble with daily activities.</td>
<td></td>
</tr>
<tr>
<td>Q2</td>
<td>Tx Option</td>
<td>Take some medicine.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tx Characteristic</td>
<td>The medicine is round pills or capsules.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Take medicine with water.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tx Process</td>
<td>Start from lower dosage to higher dosage.</td>
<td></td>
</tr>
<tr>
<td>Q3</td>
<td>Benefits</td>
<td>Less confused and have a better memory</td>
<td>Memory problem(s)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Remember the people and things I love.</td>
<td>Less confused and have a better memory</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Express my thoughts more clearly.</td>
<td>Remember the people and things I love.</td>
</tr>
<tr>
<td>Q4</td>
<td>Express a Choice</td>
<td>I want to take some medicine / I do not want to take any medicine</td>
<td>I might have a sick stomach.</td>
</tr>
<tr>
<td></td>
<td>Q5</td>
<td>a) Comparison</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Less confused and have a better memory</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Remember the people and things I love.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Q6</td>
<td>b) Vignette Reasons</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Express my thoughts more clearly.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I might feel dizzy or have a headache.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I might vomit and do not want to eat.</td>
<td></td>
</tr>
<tr>
<td>Q7</td>
<td>c) Non-Vignette Reasons</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I might have a sick stomach.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Q8</td>
<td>Logical Sequence</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I want to take some medicine / I do not want to take any medicine</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Potential Effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Express my thoughts more clearly.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I might feel dizzy or have a headache.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I might vomit and do not want to eat.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>I might have a sick stomach.</td>
<td></td>
</tr>
</tbody>
</table>
### Scenario: Dysphagia & Feeding Tube Placement

<table>
<thead>
<tr>
<th>Question</th>
<th>Scoring Item</th>
<th>Point(s)</th>
<th>Question</th>
<th>Scoring Item</th>
<th>Point(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Problem</td>
<td>Swallowing problem(s)</td>
<td></td>
<td>a) Comparison</td>
<td>Less coughing or choking</td>
<td>N/A</td>
</tr>
<tr>
<td>Description</td>
<td>I cannot have food or drink safely by mouth.</td>
<td></td>
<td>b) Vignette Reasons</td>
<td>Keeping me from starving</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Food or drink might go into my lungs.</td>
<td></td>
<td></td>
<td>Keeping me hydrated</td>
<td></td>
</tr>
<tr>
<td>Consequences</td>
<td>Coughing or choking.</td>
<td></td>
<td></td>
<td>I might have skin irritation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Having a lung infection.</td>
<td></td>
<td></td>
<td>I cannot enjoy the taste of food and drink</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not having enough nutrition to stay healthy.</td>
<td></td>
<td></td>
<td>I might feel lonely during mealtimes</td>
<td></td>
</tr>
<tr>
<td>Tx Option</td>
<td>Feeding Tube</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tx Characteristic</td>
<td>The tube is small, hollow, and flexible.</td>
<td></td>
<td>c) Non-Vignette Reasons</td>
<td>I might feel lonely during mealtimes</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Liquid food goes to my stomach through the tube.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tx Process</td>
<td>The doctor needs to make a hole on my stomach.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>Less coughing or choking.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Keeping me from starving.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Keeping me hydrated.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risks</td>
<td>I might have skin irritation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I cannot enjoy the taste of food and drink</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I might feel lonely during mealtimes.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q4</td>
<td>Express a Choice</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I want a feeding tube / I do not want a feeding tube</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I might feel lonely during mealtimes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix H: Types and Definitions of Experimenter Utterances and Record Form
## Types and Definitions of Experimenter Utterances

<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Script reading (SR)</td>
<td>Verbal reading on any of the three scripts (Health Problem, Treatment Option, and Risks and Benefits) from the two medical scenarios.</td>
</tr>
<tr>
<td>Prompt (P)</td>
<td>a) Any of the eight questions from the questionnaire. The <em>initial</em> presentation of “You may read from these pages (to help you answer the question)” stated at the end of the proposed question should be counted as part of the question.</td>
</tr>
<tr>
<td></td>
<td>b) Repetition of the prompt, “You may read from these pages (to help you answer the question).”</td>
</tr>
<tr>
<td>Clarification (C)</td>
<td>Statements that</td>
</tr>
<tr>
<td></td>
<td>a) Clarify the purpose of the current task or re-explain the activity.</td>
</tr>
<tr>
<td></td>
<td>b) Clarify the content of the visual stimuli.</td>
</tr>
<tr>
<td></td>
<td>c) Assist the participant to differentiate the hypothetical scenario from reality (e.g., We are just pretending that you have this problem).</td>
</tr>
<tr>
<td>Inquiry (I)</td>
<td>Instructive comments (e.g., Tell me more.) or requests (e.g., Anything else?) for additional content related to the activity or the prompt.</td>
</tr>
<tr>
<td>Filler utterance (F)</td>
<td>Any speech act that serves to regulate the conversation without providing content, particularly acknowledgments (e.g., mm-hmm, okay, I see, alright).</td>
</tr>
<tr>
<td>Other (O)</td>
<td>Any question or comment that is not one of the specific prompts, clarifications, or inquiries.</td>
</tr>
<tr>
<td>PAR #</td>
<td>Visual</td>
</tr>
<tr>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td></td>
<td>SR</td>
</tr>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td></td>
</tr>
<tr>
<td>18</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>
Appendix I: 7-Point Likert Scale on Decision-Making Capacity of People with Dementia
# 7-Point Likert Scale on Decision-Making Capacity of People with Dementia

**Rater #: ___________________  Audio File #: ___________________**

Based on the audio file you are listening to, please check in the box that indicate how much you agree or disagree with each statement.

<table>
<thead>
<tr>
<th>Statements</th>
<th>Strongly AGREE</th>
<th>Agree</th>
<th>Somewhat Agree</th>
<th>Undecided</th>
<th>Somewhat Disagree</th>
<th>Disagree</th>
<th>Strongly DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>The participant...</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>1. Provides enough information to demonstrate understanding about the health problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2. Provides enough information to demonstrate understanding about the treatment options.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3. Provides enough information to demonstrate understanding about the potential risks and benefits of the treatment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>4. Clearly expresses a specific decision.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>5. Compares the two treatment options without ambiguous information.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6. Provides sufficient reasons for his/her decision.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>7. Confirms his/her final decision that follows logically from previous reasoning or comparison.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8. Supports why the proposed treatment option may or may not benefit his/her current health condition with sufficient reasons that are not based on a delusional premise or a serious distortion of reality.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>
Appendix J: Consent Form for Naïve Judges
The Ohio State University Consent to Participate in Research

Study Title: Effects of Visual Stimuli on Decision-Making Capacity on End-of-Life Care of People with Dementia: Social Validity Study

Researcher: Rebecca McCauley, Ph.D.
           Michelle S. Bourgeois, Ph.D.
           Wan-Zu Diana Chang, M.A.

Sponsor: None.

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose:

The purpose of this study is to examine the decision-making capacity of people with dementia for medical and end-of-life care choices. The study examines the decisional capacity of individuals with mild and moderate dementia under four dimensions:

1. Understanding: Comprehending diagnostic and treatment-related information,
2. Expressing a Choice: Conveying a decision about treatment options,
3. Reasoning: Rationally comparing and evaluating treatment alternatives and their likely effects on daily life, and
4. Appreciation: Relating this information to one's own situation.

Procedures/Tasks:

You will listen to twelve audio-recorded samples on a computer through earphones. These audio files are people with mild and moderate dementia answering questions related to two medical care scenarios. You will rate the decision-making capacity of these individuals using a 7-point Likert-type scale provided by the study investigator.

Duration:

The study procedure will be completed in one session that lasts approximately 1.5 – 2 hours. Short breaks will be given as needed.
You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

**Risks and Benefits:**

**Risks or Discomfort**
The potential risks of this research are limited to those associated with discomfort and confusion when listening to the audio-taped conversations involving memory impaired individuals.

**Benefits**
The potential benefits of participating in this research study are potential enhancements in the social acceptability of the following skills of people with dementia:

1. Decision-making capacity,
2. Improved communication and interaction with the conversation partner,
3. Ensuring patient autonomy as a result of improved decision-making capacity, and
4. Provide health care professionals with insight into the nature of decline of cognitive function in dementia.

**Confidentiality:**
Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

**Incentives:**
You will not be paid for your participation in this study.

**Participant Rights:**
You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at The Ohio State University, your decision will not affect your grades or employment status.
If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study, or you feel you have been harmed as a result of study participation, you may contact:

Michelle S. Bourgeois, Ph.D., CCC-SLP at (813) 294-9778

or

Rebecca McCauley, Ph.D., CCC-SLP at (614) 292-1802

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.
Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

Printed name of subject

Signature of subject

AM/PM

Date and time

Printed name of person authorized to consent for subject (when applicable)

Signature of person authorized to consent for subject (when applicable)

AM/PM

Date and time

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent

Signature of person obtaining consent

AM/PM

Date and time