Using Memory Books to Enhance Sense of Self
A Senior Honors Thesis

Presented in Partial Fulfillment of the Requirements for graduation with research distinction in Speech and Hearing Science in the undergraduate colleges of The Ohio State University

by

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The Ohio State University
December 2009

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Acknowledgements

I would like to take this opportunity to thank my advisor, Michelle Bourgeois, for her encouragement and support during this new and exciting adventure into the world of research. Everyday I am more inspired by her to be a strong and successful clinician in this field and to truly make a difference. It has been an honor to work with her.

Special thanks to Eric Healy and John Brooke for their assistance in the completion of my defense. I would like to extend additional thanks to Cassie Wilhelm for her help during the reliability procedures.

Most importantly, I would like to thank my parents for their constant support and unconditional love. I am truly thankful for their understanding and encouragement regarding this research. My Mother is the inspiration to my life and my Father is my hero who I admire more than anyone.
Abstract

The purpose of this study was to explore the preservation of self-identity in a person with early onset dementia using a memory book. Symptoms of dementia are visible by outsiders because of behavior changes. These changes in the person with dementia cause doubt in sense of self and self-identity. The memory book created was to study the effect of visual cues in the form of sentences and pictures about the person’s personal accomplishments. A single participant with moderate dementia was made a memory book about self-identity and conversational sessions were analyzed with and without the memory book. Conversations between the participant and a single researcher lasted five minutes each for a total of eight sessions. The results revealed that in the presence of a memory book as an intervention tool, positive statements about self-identity increased along with the person’s ability to communicate their thoughts effectively. Negative statements and ambiguous statements decreased in the presence of the memory book. In addition, the participant demonstrated the ability to maintain quality conversations with few errors. Due to these promising results, this study should be replicated with more subjects with dementia and a wider range of dementia severity in the future.
Introduction

Dementia is a progressive, irreversible and degenerative neurological disease that affects aspects of cognition including memory, language and communication, thinking and social skills. Different etiologies of dementia are Alzheimer’s disease, Vascular Dementia, Frontotemporal Dementia, Parkinson’s Disease, Huntington’s Disease, and Pick’s Disease. Symptoms may reveal themselves in many more disorders and diseases (Bourgeois & Hickey, 2009). The primary symptom of these diseases is memory loss. Other cognitive functions, however, such as reasoning ability and the ability to function during everyday activities become increasingly difficult if not impossible over time. In early stages, the person can easily compensate and cover up these symptoms. As the disease progresses it becomes increasingly difficult to hide or mask these symptoms. This may cause the person to experience increased stress, confusion, and embarrassment (Gruetzner, 1988). Although there are no medical cures for dementia, professionals have worked to improve the person’s life using a variety of behavioral interventions and approaches (Bourgeois & Hickey, 2009).

Persons with dementia who experience change in cognition, language and memory also have doubts about their identity. They may make negative statements about themselves that undermine their self-esteem and their Quality of Life (QoL). QoL can be determined by a person’s view about their social life, financial situation, work status and independent identity (Brod, Stewart, Sands & Walton, 1999). QoL involves social, physical, familial and psychological areas of self. When one or all of these issues are impacted by dementia, a person’s QoL can suffer (Pearce, Clare, & Pistrang, 2002).
Symptoms may vary person to person. These symptoms may include: disorientation, hostility, delusions, anxiety, personality alterations and uncooperativeness. The inability to recall incidents and events combined with these indicators of dementia, especially when they become more prevalent and severe, can cause a person to experience a loss of self and self-identity. The person with dementia may feel uncomfortable with their abilities and also fear that others notice these changes. Once the person with dementia experiences loss of self, people in their environment may also notice these changes and possibly treat the person differently or in a negative way (Sabat, 2001). Not only does this feeling of inadequacy effect the person with dementia but also family and friends who witness this regression. People with dementia are often misunderstood. Therefore, caregivers and family members do not interact with the person as they did before the visible symptoms. This inability to interact creates problems with communication and identity (Cohen-Mansfield, Parpura-Gill, & Golander, 2006).

Cohen-Mansfield and colleagues addressed these issues of social role and identity in persons with dementia (2006). Their studies indicated that there is a difference between social identity and personal identity. People who have dementia may have difficulty sustaining their sense of self when their social skills are fading and disappearing. Trying to cope with the loss of sense of self tends to frustrate and depress many individuals who have dementia. The researchers have investigated four different aspects of identity: professional, family role, leisure activities and personal attributes. Their studies have concluded that the family role is the most important one to sustain even if all other aspects have changed.
Learning how to preserve the self during disease progression was an important issue explored by Pearce, Clare and Pistrang (2002). Ideally when a person experiences a change to their environment or situation, they rely on their instincts and previous experiences to compensate and adapt to the change. However, a person with dementia may have these abilities weakened due to their disease. When they have lost their ability to do this, confusion, uncertainty and disorientation set in. Intervening in the early stages of dementia is ideal according to Pearce and colleagues (2002). People with dementia tend to lose their sense of self at a more rapid rate due to the way others treat them. Because they are now viewed as dependent on others, their ability to function on their own and be themselves is undermined. Many people with dementia display behaviors of frustration, depression and isolation because they are ashamed of their cognitive abilities.

To address the problems associated with dementia symptoms, professionals in the field have conducted research to help the individuals with dementia and their caregivers cope. Dijkstra, Bourgeois, Youmans and Hancock (2006) explored the idea of advice-giving and teacher roles for a person with dementia as a way to maintain self-identity. They asked persons with dementia to teach another person a task such as a recipe, using step by step visual cues. They found that persons with dementia had the ability to teach the task, confirming their social role. It also proved that the persons with dementia were able to fill the role of an advice-giving confidant. Having these social roles intact could improve their QoL and may allow these individuals to communicate more effectively. Dijkstra and colleagues (2006) mentioned that people with dementia are often stereotyped as reliant on others, powerless, feeble and inept due to their dementia symptoms. Many people who live with dementia formerly gave guidance to others until
their symptoms started to become visible and obvious. Once this occurred, caregivers, family members and friends changed the way they communicated with the individual such as not confiding in them or their ability to address a situation. This may have created a decrease in communication skills creating even more problems. They believe that this perception provoked feelings of self-doubt and incompetence in the person with dementia.

Another study explored maintaining identity through creating artwork (Rusted, Sheppard & Waller, 2006). The people with dementia were asked to paint a self portrait. This brought back creativity and exploration through the mind of the person with dementia. Specifically the researchers were interested in the conversations that would be provoked through this artwork. Data was taken by conversing with the person with dementia with and without the portrait to determine if the artwork assisted the person to converse in a positive way. The conversations would not only include the person with dementia but their caregiver as well. The discussions of the completed artwork demonstrated a higher number of positive affirmations about the self.

One approach to helping people with dementia with memory, cognition and language problems is to use memory books. Recent studies have documented the effectiveness of a memory book designed to provide information that the person has trouble remembering (Bourgeois, 1990). Memory books were first created to stimulate dialogue between persons with dementia and their caregivers (Bourgeois, 1992). Because the people with dementia had trouble recalling names and places, the memory book provided visual cues in the form of pictures and written text to help them with these issues. Memory books vary in size and detail. Small memory wallets fit in pockets and
are easily read on the go. These are usually lighter in weight and contain fewer pages. Others are the size of photo albums called memory books. These usually contain information on more topics and are longer in length. Each contains information about the person with dementia (Bourgeois, 2007). Memory books were found to help increase factual autobiographical statements and to decrease negative conversational utterances, such as ambiguous and error statements (Bourgeois, 1990, 1992, 1994). Because most of these memory book studies addressed personally relevant information about the person with dementia, it is possible that these books could impact self-identity statements. To date, however, researchers have not evaluated the potential of memory books to deal with the preservation of identity specifically.

The purpose of this research was to explore the preservation of self identity in a person with early onset dementia using a memory book including pages about the person’s self identity. It was hypothesized that a memory book filled with visual and written cues about the person’s personal accomplishments would increase positive statements about self and reduce negative statements. The use of the memory book as a tool has the potential to enhance the ability to communicate effectively. Along with improvement in communication, thoughts and comments about sense of sense were hypothesized to increase as well.

Methods

Participant

This was a single participant case study. The subject was a 59 year old Caucasian woman. She was a homemaker who raised nine children. She lives at home with her 60 year old husband who provides her with 24 hour care. Her husband provided consent for
her to participate in this study. See Appendix A for the Consent Form. One adult child continues to live at home to help with her care as well. The participant completed two years of undergraduate college level classes. She was diagnosed with early onset dementia by a neurologist in May of 2006. Family members stated that she consistently makes negative comments about herself, such as suggesting that she is unable to complete tasks and that she is incompetent. She scored 10 out of 30 on the *Mini Mental State Exam* (Folstein, Folstein & McHugh, 1975) categorizing her with a moderate case of dementia. She then scored 22 out of 24 on the *Bourgeois Oral Reading Test* (Bourgeois, 1992) indicating that the Memory book text should be a font size of approximately 36 pt.

**Setting**

All sessions were conducted in a quiet room at the participant’s home during the day or early in the evening. Researcher and participant sat next to each other either at the dining room table or in the bedroom of the participant with no television, radio or other family members present.

**Procedures**

This study consisted of four baseline sessions at least 24 hours apart in which the participant was engaged in conversation for five minutes per session. Five minutes was chosen in order to be consistent with previous research by Bourgeois (1990, 1992). The researcher prompted the conversations with questions pertaining to the participant’s accomplishments, fears and worries. Table 1 lists the question prompts used in both the baseline and treatment sessions. The sessions began with the experimenter stating, “Today I’d like us to talk about your life. Is that ok?” followed by one of the prompt
questions. The experimenter acknowledged some of the participant’s statements with neutral comments, such as “sure” or “ok”. When the five minutes had lapsed, the experimenter ended the session by stating, “ok, thank you”.

There were 4 treatment sessions conducted after the memory book was completed. During these sessions, the experimenter stated, “I made this book to help you talk about your life,” followed by one of the prompt questions.

**Table 1: Conversation prompts**

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are you proud of in your life?</td>
</tr>
<tr>
<td>Can you tell me about your fears or worries?</td>
</tr>
<tr>
<td>What do you hope for or wish for your life?</td>
</tr>
<tr>
<td>What makes you special?</td>
</tr>
<tr>
<td>What would you change about your life?</td>
</tr>
</tbody>
</table>

**Materials**

The experimenter compiled a memory book of the subject’s accomplishments since high school with the help of her husband. Some accomplishments included: student council president, honor roll and her marriage lasting 38 years. The memory book consisted of sixteen pages with a sentence on each page along with at least one picture of the subject or a picture representing the idea on the page. Appendix B lists the sentence stimuli. The memory book was a one inch binder with plastic sleeves holding each page. The treatment sessions consisted of four five minute interviews with the memory book. Each session was recorded with a Sony ICD-B600 digital voice recorder.
The experimenter monitored the time on the recorder to indicate when five minutes had passed.

**Dependent Variables**

The recording of each session was transcribed and numbered by utterance. Each transcript was then coded using the codes listed in Table 2 and then the ten categories were summed and entered into an Excel spreadsheet. Descriptive statistics and t-tests were calculated using SPSS.17.

**Table 2: Dependent Variable Codes**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>M</td>
<td><strong>Memory Aid Statement:</strong> must be the printed statements read from the memory book; must be intelligible and unambiguous; exact wording.</td>
</tr>
<tr>
<td></td>
<td><strong>Content Novel Statement Related:</strong> must be an intelligible and unambiguous statement of a fact contributing to content related to stimuli:</td>
</tr>
<tr>
<td>C+</td>
<td><strong>+ positive statement:</strong> a statement made of a positive nature about herself or her life; during treatment sessions statements included recognition or statement about a person, place or event in the memory book</td>
</tr>
<tr>
<td>C-</td>
<td><strong>-negative statement:</strong> a statement made of a negative nature about herself or her life</td>
</tr>
<tr>
<td>NU</td>
<td><strong>Novel Statement Unrelated:</strong> must be an intelligible and unambiguous of a fact; not related to stimuli present but stimuli in the environment; comments may pertain to something that she sees around the room, etc.</td>
</tr>
<tr>
<td>R</td>
<td><strong>Repetitive utterance:</strong> any intelligible utterance that is a repetition of a previously stated utterance</td>
</tr>
<tr>
<td>O</td>
<td><strong>Other Speech Acts:</strong> including intelligible and ambiguous statements such as “ok”, “oh”, “yes”, “sure”, “I don’t know;” also included answers to a direct question that do not contain content</td>
</tr>
<tr>
<td>A</td>
<td><strong>Ambiguous Statements:</strong> not related to subject material; mispronunciations of words or any paraphasias; fragments and incomplete thoughts</td>
</tr>
<tr>
<td>E</td>
<td><strong>Error:</strong> any statement containing content that is false; this includes naming a person in the picture by the wrong name, etc.</td>
</tr>
<tr>
<td>PP</td>
<td><strong>Partner Prompts:</strong> the beginning script for each trial; phrases such as “tell me about that”, “how does that make you feel”, “what else could you say about that?” “Do you want me to help you?”, etc.; any questions that relate to the subject matter</td>
</tr>
<tr>
<td>PO</td>
<td><strong>Partner Other:</strong> any speech act that serves to regulate the conversation without providing content, particularly acknowledgements and reassurances; included statements from others in the environment including, “yes”, “ok”, “sure”, questions may be considered in this category such as “are you ok”, etc.</td>
</tr>
</tbody>
</table>
Reliability
A second experimenter was trained to code transcripts. Twenty-five percent of the transcripts (two of eight) were re-coded for reliability, yielding an overall percent agreement of 83%, ranging from 82% to 84%.

Results
The descriptive statistical analysis of the data is shown in Tables 3 and 4. The analysis includes the mean and standard deviations of all dependent variables. The dependent variables reflect two conditions, pre-memory book or baseline sessions and post-memory book or treatment sessions. Table 3 displays the participant data and Table 4 the partner data.

Table 3: Descriptive Analysis of Dependent Variables for Participant
Pre-Memory Book – Baseline Sessions

<table>
<thead>
<tr>
<th></th>
<th>MB</th>
<th>C+</th>
<th>C-</th>
<th>NU</th>
<th>R</th>
<th>O</th>
<th>A</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>0</td>
<td>7.0</td>
<td>4.75</td>
<td>1.0</td>
<td>1.5</td>
<td>7.25</td>
<td>9.5</td>
<td>0</td>
</tr>
<tr>
<td>Std Dev</td>
<td>0</td>
<td>1.63</td>
<td>1.25</td>
<td>1.41</td>
<td>2.38</td>
<td>2.98</td>
<td>3.5</td>
<td>0</td>
</tr>
</tbody>
</table>

Post-Memory Book – Treatment Sessions

<table>
<thead>
<tr>
<th></th>
<th>MB</th>
<th>C+</th>
<th>C-</th>
<th>NU</th>
<th>R</th>
<th>O</th>
<th>A</th>
<th>E</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>5</td>
<td>22.25</td>
<td>.75</td>
<td>0</td>
<td>1.25</td>
<td>9.25</td>
<td>3.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Std Dev</td>
<td>2.94</td>
<td>5.90</td>
<td>.95</td>
<td>0</td>
<td>1.25</td>
<td>5.31</td>
<td>1.41</td>
<td>.81</td>
</tr>
</tbody>
</table>

Table 4: Descriptive Analysis of Dependent Variables for Partner
Pre-Memory Book – Baseline Sessions

<table>
<thead>
<tr>
<th></th>
<th>PP</th>
<th>PO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>12.0</td>
<td>1.63</td>
</tr>
<tr>
<td>Std Dev</td>
<td>5.75</td>
<td>2.75</td>
</tr>
</tbody>
</table>

Post-Memory Book – Treatment Sessions

<table>
<thead>
<tr>
<th></th>
<th>PP</th>
<th>PO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>5.0</td>
<td>2.16</td>
</tr>
<tr>
<td>Std Dev</td>
<td>6.75</td>
<td>1.8</td>
</tr>
</tbody>
</table>

The data were grouped for interpretation into three categories. The first set of data was described as desired or positive conversational responses; the second was
categorized as undesired or negative conversational responses and the third set was partner utterances.

To answer the question of the effect of the memory book on self-identity statements, the desired and positive conversational utterances, including the Memory book and Content Positive dependent variables were analyzed. Figure 1 illustrates the pre- and post-treatment positive and desired conversational utterances. The mean and standard deviation of Memory Book utterances during baseline sessions was 0, because no memory book was present during those sessions. During treatment sessions the Memory Book statements had a mean of 5.0 and a standard deviation of 2.94. A paired samples t-test of the baseline and treatment sessions revealed a statistically significant difference between means [t(1,3)=-3.397; p=.043]. In baseline, Content Positives had a mean of 7.0 and standard deviation of 1.63; and during treatment Content Positives had a mean of 22.25 and standard deviation of 5.9. A paired samples t-test revealed a significant difference between these means [t(1,3)=-4.453; p=.021].

**Figure 1: Positive and Desired Conversational Utterances**
Figure 2 illustrates undesired and negative conversational responses consisting of Content Negative, Novel Unrelated, Repetitive, Error, Ambiguous, and Other utterance categories. During baseline sessions, Content Negative had a mean of 4.75 and a standard deviation of 1.25; during treatment Content Negative had a mean of .75 and a standard deviation of .95. The t-test comparing these means revealed a significant difference $[t(1,3)=3.703; p=.034]$. In baseline Novel Unrelated had a mean of 1.0 and a standard deviation of 1.41; during treatment there were 0 statements in this category. In baseline sessions, Repetitive had a mean of 1.5 and a standard deviation of 2.38; treatment sessions had a mean of 1.25 and standard deviation of 1.25. The means for this variable were not significantly different. The Ambiguous statements during baseline had a mean of 9.5 and a standard deviation of 3.5; treatment had a mean of 3.0 and a standard deviation of 1.41. The t-test revealed that the means for Ambiguous pairings were significantly different $[t(1,3)=4.914; p=.016]$. During baseline, Error had a mean and standard deviation of 0 because the memory book was not present. During treatment it had a mean of 1.0 and a standard deviation of .81. The means for this variable were not significantly different. For baseline, the Other category had a mean of 7.25 and a standard deviation of 2.98; treatment sessions had a mean of 9.25 and standard deviation of 5.31. The means for this variable were not significantly different.
As shown in Figure 3, the Partner utterances were analyzed. The variables included Partner Prompts and Partner Other. During the baseline sessions Partner Prompts had a mean of 12.0 and a standard deviation of 1.63; treatment sessions had a mean of 5.0 and standard deviation of 2.16. Paired t-tests revealed significant differences between the means \([t(1,3)=5.715; p=.011]\). During baseline, Partner Other had a mean of 5.75 and a standard deviation of 2.75; treatment sessions had a mean of 6.75 and standard deviation of 1.89. The means for this variable were not significantly different.
Discussion

The purpose of this study was to explore if a memory book focused on personal achievements would increase positive statements about self. It was hypothesized that positive statements would increase and the ability to communicate effectively with fewer errors would occur. This study revealed that, during treatment sessions with a memory book, positive and desired utterances increased dramatically. The Content Positive dependent variable nearly tripled from a mean of 7.0 without the book to a mean a 22.25 with the book. The memory book allowed the participant to read the sentence on the page (M Memory Book) and to expand on what was written in a positive way (C+ Content positive). These results are similar to those of Bourgeois (1990, 1992) that showed factual statements increased when using an autobiographical memory book.

The analysis also revealed significant reductions of Content Negative and Ambiguous utterances in the memory book condition. These results are also similar to those of Bourgeois (1990, 1992), which demonstrated decreased frequency of ambiguous utterances in the treatment condition. There were no significant differences in Novel
Unrelated, Repetitive, and Error utterances as a function of the memory book. This finding is different than the findings of Bourgeois (1990, 1992) but may be related to the fact that in this study there were very few instances of those utterance types in either condition. The variable Other was also not significantly different from baseline to treatment despite the fact that there were many Other utterances in both conditions. Similar to Bourgeois (1990, 1992), this variable labeled as Other caused some debate as to whether it belonged to negative/undesired variables or positive/desired variables. It was decided that it did not belong to either category but was thought of as neutral because it reflected utterances used to keep the conversation progressing.

The analysis of Partner Prompts and Partner Others confirmed that the researcher followed the protocol as designed for the baseline and treatment sessions. The mean number of Partner Prompts decreased significantly in the memory book condition possibly due to the fact that the participant required fewer prompts to communicate effectively. For example, many of the prompts made by the researcher were in response to the participant’s content positive and novel statements. During the second treatment session the participant stated the name of a friend in a picture without any verbal or written cues, “That’s Kelly.” A follow-up prompt by the researcher was made asking for more information about the friend, “What can you tell me about Kelly?” The participant responded with several content positive utterances such as, “She was a friend and a very sweet girl.” Partner Other utterances were not significantly different between the conditions, similar to the findings for the participant Other category. These utterances are viewed as neutral conversation facilitators.
In addition, there were anecdotal observations made to support the use of this type of memory book for enhancing self-identity utterances. The participant was observed by the researcher to smile and laugh often when looking through the memory book. At first she was apprehensive about the book, possibly worried that it would highlight her inadequacies. However, after giving her time to look through each page she appeared to be relieved and surprised about the contents and used the book to remember much more than was written there. The spouse enjoyed the book as well. He was eager to find out how much she remembered and was extremely pleased with her reaction to it. The participant sat with one of her adult daughters and adult sons at different times and looked through the memory book. She was observed talking about the individuals in the book and they conversed about her memories of the people and incidents that occurred. This suggests the possibility of this type of memory book changing interactions between people with dementia and their family members.

Study Limitations and Future Research

The main limitation of this study was that it was a pilot study of one individual’s use of a memory book to address self-identity issues. The positive findings of this study suggest that future research should attempt to replicate the effects of self-identity memory books with similar participants with dementia. It would also be important to investigate these effects with participants with a wider variety of dementia severity. In order to make this study more powerful, an A-B-A-B experimental design could be employed in which four more baseline sessions without the memory book (A) could be conducted after the treatment sessions to explore if the participant’s utterances return to baseline levels.
Reinstating the memory book condition (B) could be conducted to observe if the participant responds to the book as in the first B condition. In addition, there is potential for this type of intervention to affect other family members, their opinions about the disease and its impact on the patient, their feelings about the person and their ability to communicate. The memory book helped the participant in this study to communicate more effectively. Therefore, it helped her, and others, to see that she is still the person that she always was, in spite of the disease. Other variables, such as mood of the participant and self esteem, should be explored as possible factors to document improvements related to memory book use. Also, since dementia affects the patient as well as their family members, a future study could explore how the family members could move from denial to acceptance in the five stages of family adjustment or grief (Gruetzner, 1988).
References


Appendices

A. Consent Form

B. Memory Book Sentence Stimuli
Appendix A
The Ohio State University Consent to Participate in Research

Study Title: The Effects of Print and Picture Stimuli on Conversation in Dementia
Researcher: Michelle S. Bourgeois, PhD
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 research is to determine the effects of print stimuli and/or picture stimuli on the conversational content of persons with dementia.

Procedures/Tasks:
Twenty subjects (male and female; 65-85 years) with dementia will be identified at various locations (e.g., Laurel Nursing Homes) by staff at those facilities or by family members. Proxy consent for participation in the study will be solicited from a family member or legal representative and the person with dementia will be asked to assent to the study. After consent and assent are obtained, the investigators will meet with the individual to administer two measures: 1) the Mini Mental Status Examination (Folstein, Folstein, & McHugh, 1978) and 2) the Bourgeois Oral Reading Screen (Bourgeois, 1994); family members will be asked to complete the Memory Book Information Short Form (Bourgeois, 1994) and to provide pictures for 12 of the statements. The investigators will then create memory aids (books or posters) for each participant. Participants will be asked to have 5-min conversations using their memory aid. The initial screening protocol should take no longer than 60 minutes to administer. At any time if the participant expresses fatigue or disinterest in the procedures, the session will be discontinued. Each participant will be visited on up to seven separate occasions (1 screening and 6 conversational sessions). All sessions will be audio-taped for analysis.

Duration:
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:**

The purpose of this study is to determine which type of stimuli is better for supporting conversation of the participants about their life, living conditions, family members, and other personal topics, many of which could be sensitive or embarrassing. Therefore, some participants could consider the questions posed in the protocol as an invasion of their privacy. If a participant expresses, either verbally or nonverbally, that they are confused, suspicious, reluctant, or unwilling to engage in conversation with the researcher, the session will be terminated immediately. It is the experience of the PI that these expressions of discomfort are rare and easily resolved by terminating the session. The researcher will notify the staff or family member immediately after terminating a session, in order that the appropriate support measures are implemented to resolve any negative ramifications of the session.

The direct benefit to participants is that they will receive individualized attention, including opportunities to converse with the investigator, and that may be pleasurable for them. The benefit to others includes providing 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 Ohio State, 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 you may contact:
Michelle S. Bourgeois, Ph.D., CCC-SLP, (614) 292-1742.

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.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact: Michelle Bourgeois, PhD., (614) 292-1742.
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.

<table>
<thead>
<tr>
<th>Printed name of subject</th>
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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.

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**Appendix B**

Memory Book Sentence Stimuli

1. My name is Mary Trela. I was born February 26, 1950.
2. I live in Lakewood, Ohio with my husband, Jim. We have been married for 38 years!
3. My faith in God and Jesus Christ has made me who I am today.
4. I had a lot of friends growing up.
5. I really enjoyed school.
6. I was on the honor roll in high school and graduated with honors!
7. I was student council president in high school.
8. After high school I went to Cleveland State University in Cleveland, Ohio to become a teacher.
9. During college I met my husband, Jim. It was true love!
10. Jim and I were married on December 12, 1970.
11. My first child, Katie, was born on June 24, 1971.
12. Jim and I had 8 more children!
13. I volunteered a lot when my kids were growing up.
14. My Mom, Anne Marie, lived with us for many years and I took care of her.
15. I also cared for my mother-in-law, Marie, and my two great aunts, Fran and Bernie.
16. I’ve been a teacher my whole life!