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Keeping Memory Alive: Exploring the personal experiences of women in midlife

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Running head: KEEPING MEMORY ALIVE

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Abstract

The purpose of this study was to explore how women in their midlife years use activities of daily living to address possible memory loss by exploring their personal experiences. The review of the literature provides an overview of memory disorders including Alzheimer's disease and other dementias as well as three specific aspects of memory that are affected by these: verbal, spatial, and procedural memory. A questionnaire that targeted women between the ages of 50 and 60 years of age was distributed via social media and e-mail for four weeks. Eighteen women completed the questionnaire. Results of the study suggest that these mid-life women were concerned about memory loss even if they did not have a family history of dementia; that they were physically active but thought more sedate activities such as reading would preserve memory; and that they did not report changing their activities to align with their beliefs about the activities that would preserve memory.

Keeping Memory Alive: Exploring the personal experiences of women in midlife

Everyone has experienced those moments in life where they can't recall an event or a word, and may joke about how old they are getting. It is universally accepted that as a person gets older, their memory gets worse even if it's something as little as forgetting where you last put your keys. According to A Guide to Alzheimer's disease (2012), "almost two-thirds of Americans who have Alzheimer's disease are female. Women who live to age 65 have a one-in-five chance of developing Alzheimer's disease in their remaining lifetime. For men the risk is one in 10" (pg.12).

Television commercials, self-help books, and even cognitive training programs have been written describing memory loss and activities that can improve this. Beyond these publicized helps, there are the personal experiences of individuals who beginning in midlife start new activities or consciously mold old hobbies and interests into memory supportive activities. Examples of these might be word puzzles, reading, and perhaps even needle or hand work. The purpose of this study was to explore the ways that women between the ages of 50 and 60 years use activities within their daily routines in hopes of keeping their memory alive.

As we grow older it becomes more likely that memory loss develops, sometimes even Alzheimer's disease. "Sometimes" is an understatement because it is affecting more and more people every day, especially with the Baby Boomer generation who are entering senior citizen status (Generation Alzheimer's Report, 2011). The need for preventing this fatal disease is of a growing concern. There is no known direct medical prevention or cure. Therefore the steps that are being made to reduce the risk of memory loss focus on activities that stimulate brain function. These range from exercise to diet to mental activities, all of which are based on

research that suggests these are at least not harmful and perhaps helpful (Nagamatsu, Chan, Davis, Beattie, Graf, Voss & Liu-Ambrose, 2013). Little is known, however, about how individuals are shaping and changing familiar activities and routines in order to work on memory in their everyday lives. Based on the supposition that women and men remember differently (Kimura, 1993). This study focuses on women's perceptions of how the activities they engage in preserve their memory.

Review of the Literature

This review of the literature provides a brief background on dementia, including a slightly more in depth overview of Alzheimer's disease (AD), and descriptions of the types of memory that can be important. This is followed by a review of the importance of activities on preserving memory and specific kinds of activities in which women participate.

Dementia and Alzheimer's disease

As people age, the concern of memory loss increases, namely the development of dementia, commonly called Alzheimer's disease. These two pathologies are not one in the same, and it's important to have an understanding of how they differentiate. The following sections provide a brief overview for both, including the stages of decline for Alzheimer's.

Dementia

Dementia is a group of disorders characterized by memory and cognitive impairments. (Shadden, Hagstrom, & Koski, 2008). In other words, dementia is not a disease in itself. Most cases of dementia progress in severity over time, but some causes can be reversible. Some such instances include infections, normal pressure hydrocephalus, and metabolic disturbances (Shadden, Hagstrom, & Koski, 2008). The resulting dementias can include frontal lobe

disturbance that impacts social skills; Pick's disease where an individual picks at their skin; and visual/verbal disorders that can result in facial and object recognition as well as disorders of speaking, reading, writing and spelling (Hodges, 2001).

Alzheimer's disease (AD)

It is important to realize that Alzheimer's Disease (AD) is classified as a distinct form of dementia that requires a differential diagnosis. AD is the most common form of dementia that affects memory, thinking and behavior. According to the Alzheimer's Association, the majority of AD diagnosis is among individuals over 65, but it also affects about 5% of individuals in their middle age, e.g., the 40's-50's. Individuals who have increased trouble remembering newly learned information may be experiencing an early onset symptom of AD (http://www.alz.org). Older memory at first remains intact.

This disease strikes the areas of the brain concerned with learning processes, so it is not surprising many individuals experience difficulties with new learning, for example the name of a son's new wife. As AD progresses through the brain, individuals will experience disorientation, mood swings, behavioral changes, increasing confusion about events, paranoia of family and friends, continuous memory loss, and even difficulty speaking, swallowing and walking (http://www.alz.org).

Reisberg's Seven Stages of AD

Not everyone with AD will progress at same rate or experience the same symptoms. In order to better understand the progression of this disease, Reisberg (1982), the clinical director of the University School of Medicine's Silberstein Aging and Dementia Research Center, developed a framework that outlines seven stages for AD. Below is a table containing a quick reference for

each of the seven stages (see Table 1.), followed by a more thorough explanation summarized from Reisberg's (1982) writings.

Table 1. Reisberg's Seven Stages of AD

Stage	Rate of Decline
1	No Impairment
2	Very Mild Decline
3	Mild Decline
4	Moderate Decline
5	Moderately Severe Decline
6	Severe Decline
7	Very Severe Decline

During the first stage of AD the individual retains normal function and does not experience any symptoms. Stage two shows a very mild decline in the individual who may start to experience memory lapses, or difficulty with familiar words, or objects. During stage three, there is a mild decline and friends and family may begin to notice abnormalities. At this point, individuals may have noticeable problems recalling the right words, remembering names when introduced to new people, greater difficulty completing a task, losing possessions, and increasing trouble with planning or organizing. Moderate decline comes during stage four and is characterized by increased memory lapses of recent events, math difficulties, and greater difficulties in performing everyday tasks. Stage five is a moderately severe decline in memory. At this point individuals will need assistance on everyday tasks, will experience memory loss regarding personal information, where they are, what day it is, and will also need help choosing appropriate clothing. Continuing onto stage six where a severe decline in memory is expected, an individual's memory will continue to deteriorate, personality changes could occur, and extensive help will be needed for daily activities. Individuals during severe decline might wander off or

become lost, and they may have difficulty controlling their bowels, trouble cleaning themselves, and experience changes in sleep patterns. Reisberg (1982) concludes his stages of Alzheimer's with stage seven which is the very severe decline. Around this stage, individuals will lose most control of their movement, cease to respond to their environment, and are not able to carry on a conversation. They have very limited expressive language, and need round-the-clock care.

As can be seen from this brief review of dementia and AD, it is clearly a brain-based disorder that follows a somewhat predictable path of change. The part of the brain affected by the disorder results in a variety of behavioral symptoms that assist with classification of the dementia but provides little insight into the individualized experience of living with dementia.

Forms of Memory

Preservation of function is the most vital current approach to living with dementia. This section will describe key forms of memory cited in the research literature followed by publically available sources for building or preserving each of these.

Verbal Memory

Verbal memory allows individuals to understand, interpret and use words in their spoken and written form (Myers, 2006). The web provides a good deal of information pertaining to improving verbal memory, including ways it can be improved. Memory-improvement-tips.com includes suggestions such as visualizing while reading or listening so two pathways of recall (verbal and non-verbal) can aid in maximum retention. Some ways to visualize include direct visualization, substituting objects such as visualizing running when thinking of "exercise," and word substitution. This substituting of words is ideal for words that aren't easily visualized, for example the actor Brad Pitt's can be visualized with something similar such as the pit of a peach

(Memory-improvement-tips.com). This provides a way for an individual to identify Brad's name with an object that assists in future recall. Another article by Jonathon Mooney (school.familyeducation.com) called "Strategies for Improving Memory" gives a few more ways, which can be summarized as using as many senses possible to ensure maximum retention.

Spatial Memory

Spatial memory is responsible for documenting information about one's environment such as remembering the location of objects, or places (Myers, 2006). A blog called Fitbrains (Lin, 2013) gives quite a few tips for improving spatial memory including maintaining a fixed place where you put things such as your keys, partaking in yoga to reduce stress levels, and exercising on a regular basis.

Procedural Memory

Procedural memory involves performing tasks, skills, and routine actions. Some examples of procedural memory are riding a bike or tying your shoes. This type of memory operates on the unconscious level of the mind and is vital for language, specifically in the areas of grammar and syntax, by allowing individuals to talk without having to think about it (Haywood, 2010). It seems the general consensus throughout internet websites is that the best way to improve procedural memory is to get a healthy amount of sleep.

Research That Supports Lifestyles, Activities, and Memory

Research in the area of dementia as well as the various kinds of memory outlined above have increased over the last decade and provided an evidence base for preventative steps that may preserve memory as individuals' age. These range from exercise to food choices to

personal habits with the key summary point being that individuals can change the aging of their memory processes. The following are examples of this research.

Lifestyle Behaviors

Cadar, Pikhart, Mishra, Stephen, Kuhl, and Richards (2012) conducted a study that focused on the role lifestyle behaviors play in cognitive decline. The participants were in their early to mid-60's, and were examined on the basis of whether or not they smoked, how physically active they were and how healthy their diet was. The results indicated that those with a healthy diet and regular physical activity exhibited a slower cognitive decline over a course of 20 years. Smoking in early midlife was correlated with faster cognitive decline. At the conclusion of the study, it was stated that, "the current findings for dietary choice and physical activity were not always consistent at different ages across midlife, compared to effects of the cumulative scores and change in behavior between the 2 time points" (pg. 6).

A randomized study of 86 women between the ages of 70-80 years with probable mild cognitive decline were observed over 6 months in a study conducted by Nagamatsu, Chan, Davis, Beattie, Graf, Voss, and Liu-Ambrose (2013). The women were divided into three groups that focused on resistance training, aerobic training, and balance and tone (control group). The results indicated that the aerobic training group that met twice a week remembered substantially more at the end of the study than before on the verbal memory test. It also suggests that both types of exercise improved reaction times on both verbal and spatial memory tests compared to the control group. They conclude by stating that spatial memory "…performance appears to be positively associated with physical performance in the aerobic training group after the intervention" (pg. 7).

In perhaps the most benign of study's, Backhaus and Junghann sought to see if daytime naps improved procedural motor memory (2006). They did so by asking 34 participants to take a 45 minute nap in the early afternoon after a normal night's sleep. The results showed that procedural memory was improved for those who were in REM sleep during the nap, and the women actually outperformed men during a declarative memory test which brings up the issue of keeping gender in mind when conducting studies (Backhaus & Junghann, 2006).

Activities of Daily Living

The above studies focused on research that primarily investigated changes in physical aspects of memory change. For example, how diet, exercise and healthy habits result in better memory function. In addition to these kinds of behaviors, there is a commonly accepted but not well researched literature that focuses on everyday activities as ways to enhance memory. This literature builds on the notion that activities encompassed in daily routines are instrumental in exercising memory (Troyer, Murphy, Anderson, Moscovitch, & Craik, 2008) and is supported to some extent by researchers such as Pillai, Hall, Dickson, Buschke, Lipton, and Varghese (2011). Researchers at the Albert Einstein College of Medicine in New York City conducted a study of 488 healthy, middle class, English speaking cohorts between the ages of 75 and 85 years of age. Of those 488 only 101 passed exclusion criteria and were included in the analyses. The participants were interviewed based on reading, writing, crossword puzzling, card or board games, group discussions and playing music, with an emphasis on crossword puzzles. The results from the Buschke Selective Reminding Test (SRT) indicated that those who played crossword puzzles had a delayed onset of dementia by 2.54 years compared to non-puzzlers. However, once decline began the rate was 3.31 SRT points more rapid per year than those who did not puzzle.

They conclude that crossword puzzles slow the onset of dementia. However, the major drawback comes after onset when the rate of decline becomes more rapid (Pillai, Hall, Dickson, Buschke, Lipton, & Varghese, 2011). According to the researchers, the findings support the cognitive reserve hypothesis which states that "cognitively stimulating activities may help delay the emergence of clinical cognitive deficits. But once the cognitive reserve is no longer able to compensate for the increasing pathological brain damage the rate of cognitive decline is more rapid" (pg. 1011). An interesting side note from the study indicated that sometimes the ability to play music and/or games is still present in those with advanced AD. They suggest this is due to the increased cognitive reserve that wasn't used up before onset. The implications from this study on leisurely stimulating activities and delay of cognitive decline provide a good starting point for understanding cognition and aging.

Research by Feeney and Capo (2010) provided additional insight to the role of positive daily routines by specifically addressing women. They state that positive daily routines are important not only for stimulating brain functions, but also to provide a "context for pursuit of meaningful goals" (pg. 3). Meaningful goals motivate the brain to achieve some end, but when cognitive decline begins that motivation deteriorates. So then, women who set goals during their daily routines are engaging in brain motivating activities that could play a role in preserving memory. This approach suggests that the activities of each person are based on individual interests and circumstances. For example, some women enjoy cooking and may following recipes step-by-step versus re-remember the steps from working memory. Other women might prefer puzzles associated with quilting patterns or house-cleaning around the schedule of family members. Feeney and Capo's research provides a glimpse into future possible research in the

uncharted territory of how women might be working to maintain and enhance memory using themselves and their habits associated with everyday life. To date, there is simply not a clear understanding of what such lives and their activities might be.

Summary and Questions of the Study

Preventing dementia, including Alzheimer's disease, is the ultimate goal of medical science. Preserving functional memory and staving off the changes associated with loss of memory is a goal common to many midlife individuals, especially women who have a higher incidence of the disease. As can be seen from the literature reviewed above, a good deal is known about brain changes associated with dementia and the key kinds of memory that are impacted by these changes. It has also been demonstrated that more women than men experience dementia. With regard to preserving function, research has demonstrated that healthy habits, physical exercise, sleep, and good nutrition all contribute to better outcomes and a longer healthy life.

There is an emerging literature on the role of using everyday activities to enhance functional memory; however, there is minimal research specifically on women and their everyday activities that might form the bases for self-planned and regulated memory work within such activities. Gaining information about this is essential for research that goes beyond family lore, the internet, or newspaper advertisements. Therefore, the purpose of this study was to focus on women's perceptions of how the activities they engage in preserve their memory. The specific questions of the study were as follows:

1. To what degree are women concerned about preventing memory loss?

2. What activities are important to women in everyday life?

3. Are women using/changing these activities to preserve their memory?

Methods

Participants

The cohort for the study was sought through the social networking, Facebook and e-mail distributions. The target sample was midlife women between the ages of 50 and 60 years of age.

Materials

The materials consisted of a questionnaire developed from the literature. (see Appendix A) It included ten questions, nine of which were close-set. The first question of the study asked for the participant's age. The next two questions asked about family history/familiarity with memory loss or dementia. This was followed by questions that asked about everyday routines and which of these participants thought might enhance memory. The final question of the study was open ended, which allowed the participants to add any information they thought might be useful for the study.

Procedures

The electronic version of questionnaire, which was the only dissemination used for this study, was created through the Qualtrics survey portal, and then posted through Facebook as well as sent out via email. The questionnaire was posted for four weeks to provide ample time for a reasonably sized sample to respond.

Analysis

A descriptive analysis was conducted after the questionnaire closed. All closed-set items were aligned with specific questions of the study for analysis. Results were narratively described

and then represented by tables and figures. Open ended responses on the questionnaire were qualitatively analyzed by key words and themes.

Results

Demographics

Of the 22 responses collected from the questionnaire, only 18 were completed. The first three questionnaire items asked their age, if they were concerned with future memory loss, whether they had a family history of dementia, and if so who that relative(s) was. Thirteen (72%) of the women were between the ages of 50 and 60 years, which was the targeted age group (see Figure 1.). The remaining five participants ranged in age from 40 to 49. While younger than the study's target population, their responses are included in the data analysis. When asked about family history of dementia or memory loss six (33%) had a history while 12 (67%) had no family history of dementia (see Figure 2).

Figure 1. Percentage of women between 50 and 60 years.

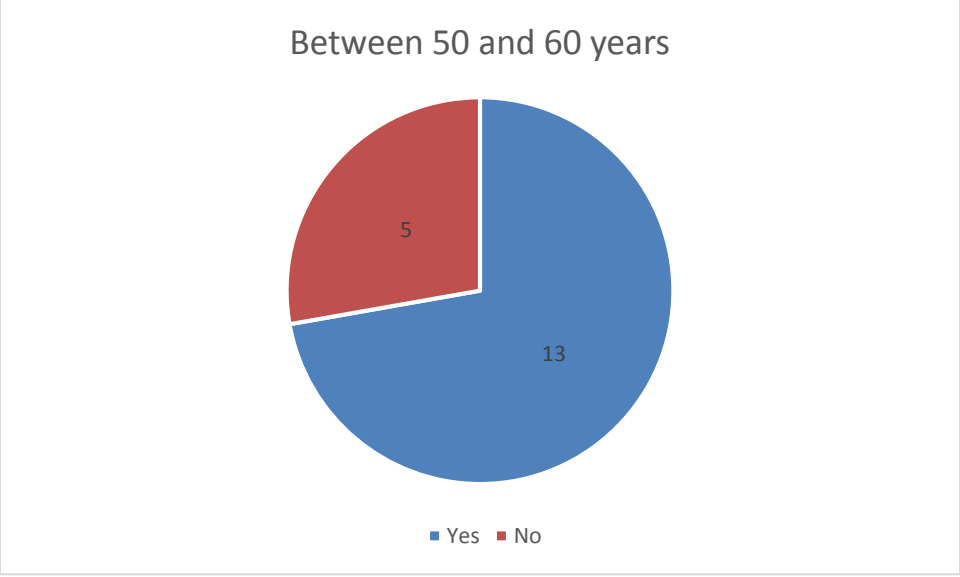
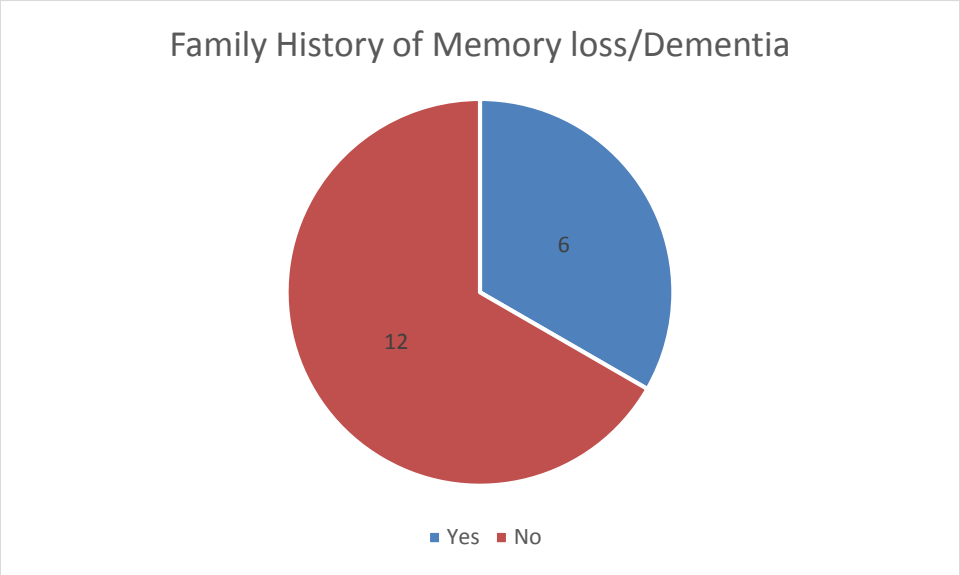


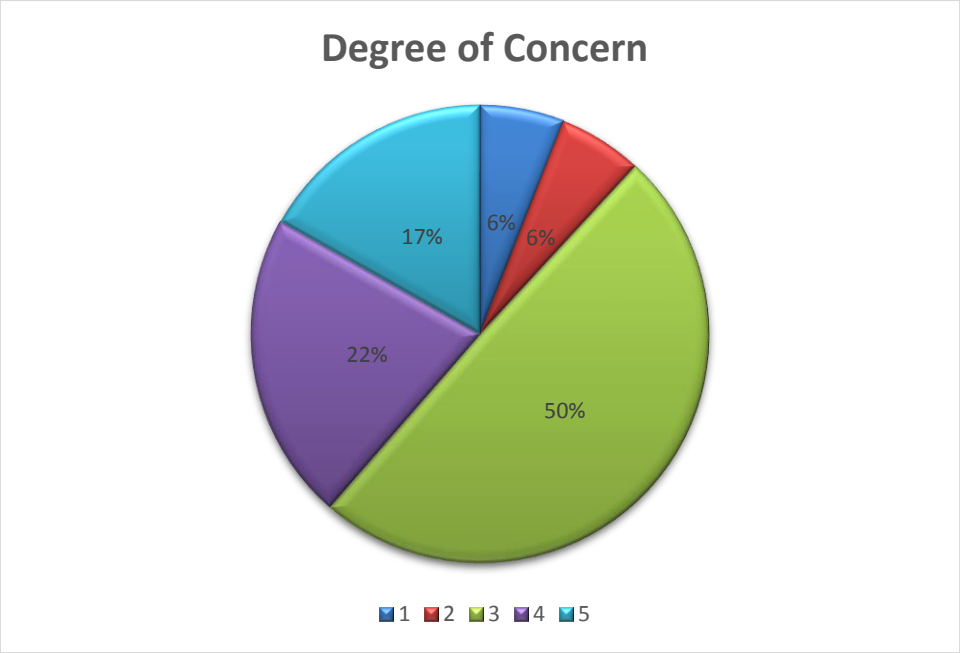
Figure 2. Family history of memory loss/ Dementia



Question One

The first question of the study asked to what degree women are concerned about preventing memory loss. Item five on the questionnaire asked them to rate their degree of concern using a five point Likert scale. Those that selected one were considered to have no concern about memory loss. Those that selected two were considered to have mild concern. Scoring a three or four indicated they were moderately concerned, while a score of five meant they were extremely concerned. The results showed that 50% of participants were moderately concerned about memory loss, denoted by a score of three in the five pt. rating scale (see Figure 3.). The remaining 50% tended to have a higher level of concern with four (22%) answering they were slightly more than moderately concerned (score of four). There were three (17%) who indicated they were extremely concerned (five) with memory loss. The remaining two (12%) indicated that they had lower degrees of concern by scoring a one or two. Put another way, of the 18 participants, 16 scored a three or above with nine women selecting three, four selecting four, and three selecting five.

Figure 3. Degrees of concern



Question Two

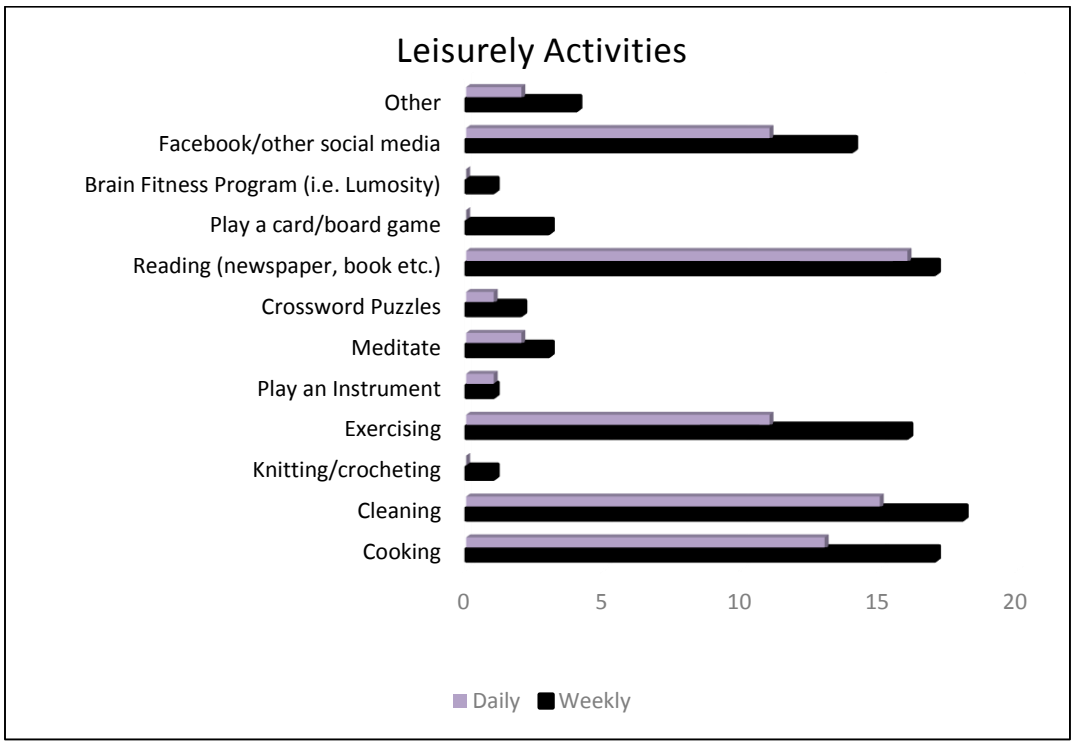
The second question of the study asked which activities were important to women in everyday life. Items six, seven, and eight on the questionnaire were used to answer this by asking them to indicate the activities that are a part of their weekly (one to two times a week) and daily routines as well as those they may have stopped or decreased in frequency. Participants were given the same 13 specific options for all three of these questions. The options included 11 different activities, a “none of the above”, and an "other" option with text entry so they could contribute their own if it wasn't listed. It is also important to note that the activities were chosen based on research and general opinions on the web. These include cooking, cleaning, knitting/crocheting, exercising, playing an instrument, meditating, crossword puzzling, reading (newspaper, book, etc.), playing a card and/or board game, playing a brain fitness program, and Facebook/other social media.

Item six asked participants to indicate the activities they did on a weekly basis. The following provides a breakdown of the results. (see Table 2.). Cleaning had the highest number of responses with all 18 women indicating they do so one to two times a week. Just below that with 17 (94%) responses were cooking and reading, followed by exercising with 16 (89%), and use of social media at 14 (78%). Meditations, playing a card and/or board game, crossword puzzles, playing an instrument, and knitting or crocheting were selected by three or less participants. This was further broken down in the following way. Meditation and playing a card or board game were selected by three women, crossword puzzles by two, and playing an instrument and knitting or crocheting by one. The "other" option was selected by four (22%) women who reported playing word games and “words with friends” on their iPad’s, quilting, and walking/playing their dog.

Item seven asked participants to indicate the activities they do on a daily basis. The following provides a breakdown of the activities women have incorporated into their daily routine (see Table 2.). The results indicated reading (book, magazine, newspaper etc.) was the most reported daily activity chosen by 16 (89%) of subjects. Just below that was cleaning with 15 (83%) responses, followed by cooking with 13 (72%) responses, and exercising, and social media with 11 (61%). Meditation and "other" were selected two times (11%), and playing an instrument and crosswords puzzles one time (6%). The participants that chose an "other" answer specified the leisurely activity that included iPad games and walking her dog. Knitting and crocheting, playing a card or board game, and brain fitness programs were not selected (0%). As can be seen, reading, cooking, cleaning, followed by exercising, and social media were the most frequently reported daily activities by women who participated in this study.

Item eight on the questionnaire asked participants to indicate the activities they used to take part in regularly, but have stopped or decreased in frequency. Eight participants did not respond to this item. Four indicated that there were no activities they have stopped/decreased, and six included painting, reading and scrapbooking, strenuous exercise, running children around, and tennis in the ‘other’ category.

Table 2. Comparison between weekly and daily activities

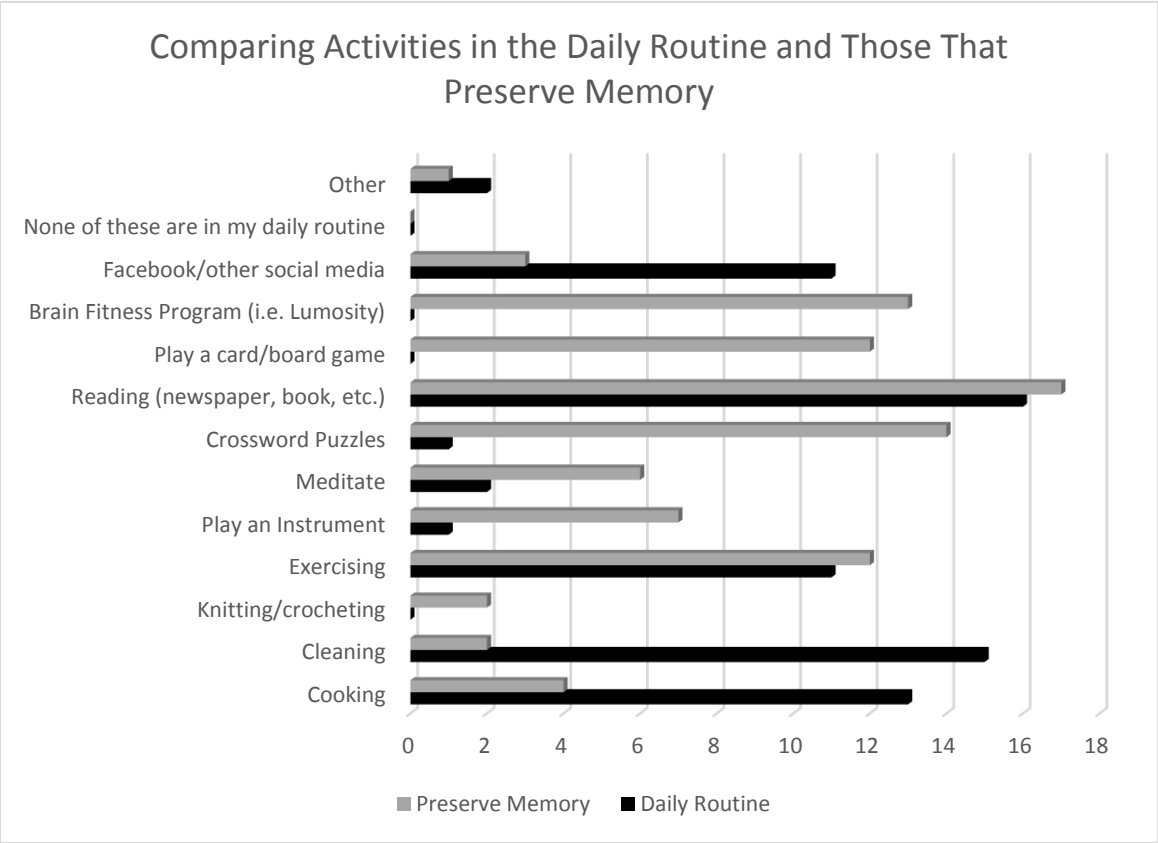


Question Three

The last question of the study asked if women were using/changing activities to preserve their memory. Item nine on the questionnaire was used to answer this by asking them to indicate the activities they believe preserve memory (see Table 3.).The following breaks down the results in order of most to least selected. The highest was reading which was believed by 17 (94%) of the women to have a positive effect on memory. This was followed by crossword puzzles with 14 (78%) responses, brain fitness programs with 13 (72%) responses, and exercise and playing a card and/or board game with 12 (67%) responses. The rest of the activities were selected by less than half of the sample. Playing an instrument was believed to preserve memory by seven (39%) of the women, meditation was by six (33%)

individuals, and cooking by four (22%) respondents. The use of Facebook and other social media was thought to promote memory by only three (17%) of the women. Lastly, few women in this sample, i.e. only two (11%), thought cleaning, knitting and crocheting were activities that could preserve memory. One participant did choose to share that she believed that "speaking more than one language" helps to preserve memory.

Table 3. Comparison between activities in daily routine and those that preserve memory



Qualitative Narrative Responses

The last item on the questionnaire was an open-ended question that allowed participants to describe their personal experiences (if they had any) with memory loss and/or dementia. Of the 18 subjects 10 chose to respond, two of whom indicated they did not have any experiences with memory loss or dementia (See Appendix B for actual responses). Five of the remaining respondents reported that they

have experienced memory loss. Their responses can be summarized that they feel "forgetful" at times. The remaining three women stated they had family members who suffered from cognitive decline or dementia. The first has a mother with dementia, the second had a grandfather and an aunt with dementia, and the last stated her father has shown cognitive decline over the past several years. No details about the experience of living with dementia or seeing someone live with it were described.

These narrative responses did provide insight on why these participants might be concerned about memory loss. Additional analysis revealed that all eight of these women indicated concern on item number three that used a Likert scale to depict concern (see Figure 3 above). Those who had family members with diagnosed dementia scored a five, indicating they were extremely concerned with memory loss. The breast cancer survivor and woman whose father has been experiencing cognitive decline are between moderately and extremely concerned (four). The other four who said they are forgetful and aren't as effected by memory loss scored a three which is still considered moderately concerned.

Discussion

The purpose of this study was to explore how women in their midlife years use activities of daily living to address possible memory loss by exploring their personal experiences. A number of things stood out from the results of the questionnaire 18 women completed. First, it was interesting to see that of the women in this age group who responded to this study most did not have a family member with dementia but still had a significant amount of concern regarding their memory health. Specifically, 16 of the 18 women who participated in this study were moderately to greatly concerned even though there was no family history of the disease. This is a surprising finding in light of the literature that ranges from books to professional websites and news outlets that report studies suggesting AD is genetically linked. Although there is still a good deal of professional speculation about this, the wide dispersal of this possible fact is readily available to the general public. For example, A *Guide to Alzheimer's disease* (2012) states women are more affected by

this disease (two-thirds Americans with Alzheimer's are female). If there is a genetic component in developing dementia, or AD then the women with a family history would be at a higher risk than the others in this study. This study did not predict that most women who participated would have no family history of memory loss or dementia or that those women would still be so concerned with future memory loss.

A second striking results of this study was the difference between the activities that women reported engaging in versus those that they believed would preserve memory. The activities most engaged in by these women on a weekly and daily basis include cooking, cleaning, exercising, reading and using social media. Only reading and exercising were reported by most to be a part of both their daily routines and believed to preserve memory. The other activities they believed affected memory were brain fitness programs, playing a card or board game, crossword puzzles, meditation, and playing and instrument. There is a huge discrepancy between what women believe preserves their memory and what they actually do on a daily basis. This implies that women know what they should be doing, but only a small number actually do.

Additionally, there is some suggestion of generational differences in the results of this study. Specifically, these women who are now in their 50's and 60's did not indicate they make things by sewing, knitting, or crocheting. Rather the respondents in this study indicated they are doing more physical activities (cooking, cleaning, and exercising). Perhaps women in their 70's and 80's, who were not targeted by this study, may use very different activities to preserve memory. These data suggest the possibility of generational shifts in the lifestyles and values of women who are among the first members of the Baby Boomer generation versus their mothers who were part of the Greatest Generation or their daughters who may be Generation X or later (http://www.esds1.pt/site/images/stories/isacosta/secondary_pages/10%C2%BA_block1/Generat

ions%20Chart.pdf). These shifts may be an important expansion of the current research. This would be particularly valuable to clinicians who may be working on memory with a client in their 70's or 80's with daughters or granddaughters are in their 30's or 40's since the concerns and beliefs about how to preserve memory may well be different, presenting a clinical intervention challenge.

The literature review emphasizes the growing prevalence of memory loss among the population, especially among women. Since there is no known cure, the best hope is prevention. The basis of this study was derived from recent scientific research suggesting brain stimulating activities promote memory health (Pillai et.al, 2011). Assuming memory declines with age it would seem that women in their midlife who are part of a generation that has more access to preventative health care would already be thinking about the preservation of their memory functions. As can be seen from this study, they have concerns but those concerns are not matched to action during these mid-life years. This leaves a very open question: what preventative interventions programs should speech-language pathologists be designing and implementing?

Limitations of the Study

The major limitation of this study was the small number of participants. Only 18 women completed the questionnaire with only eight reporting experiences with memory loss or dementia. One reason a limited number may have responded to this study is that women don't want to or may be uncomfortable discussing the subject of losing their memory or dementia. Another limitation of the study is that the questionnaire targeted mid-life women between 50 and 60 years of age. This may have reduced the number of respondents. With regard to the results, additional demographic information would have been useful. For example, asking about educational level of the women and employment history would

have provided an additional way of understanding the results when looking at the different kinds of activities in which they engaged and associated with memory. Lastly, adding questions about their mothers and/or grandmothers would have provided generation detail that would have made this a more interesting study.

Future Directions

A future direction for this study would be to add the demographic and generational items discussed above to the current questionnaire. In addition to using social media for dispersal of the questionnaire, a paper version might also be distributed at community events. Another direction would be to expand the target age group from women between 50 and 60 years of age. Expanding the target age group to 40-80 would reach more women and still provide important information on the leisurely activities of midlife women. A final important future direction would be to explore the development of a preventative intervention program that targets healthy memory functions for mid-life women.

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Appendix A

Leisurely Activities Questionnaire

1. Are you a woman between the ages of 50 and 60 years old?
A. yes
B. no

2. Do you have a family history of dementia, for example Alzheimer's disease?
A. yes
B. No

3. If you answered yes to number 2, indicate the relative(s) that had Dementia and of some form below (select all that apply):
A. mother
B. Father
C. Grandfather(s)
D. Grandmother(s)
E. Aunt(s)
F. Uncle(s)
4. Does future memory loss concern you?
A. yes
B. no

5. To what degree are you concerned with memory loss on a scale of 1-5, 1 being not concerned at all and 5 being extremely so?
A. 1
B. 2
C. 3
D. 4
E. 5

6. Indicate below the activities you do regularly (1-2 times per week):

A. Cooking	F. Meditate	K. Facebook/other social media
B. Cleaning	G. Crossword puzzles	
C. knitting/crocheting	H. Read	
D. exercising	I. Play a card and/or board game	
E. Play instrument	J. Brain fitness programs (i.e. lumosity)	

7. Are any of the activities you indicated above incorporated into your daily routine? If so, please identify which ones:

A. Cooking	F. Meditate	K. Facebook/other social media
B. Cleaning	G. Crossword puzzles	
C. knitting/crocheting	H. Read	
D. exercising	I. Play a card and/or board game	
E. Play instrument	J. Brain fitness programs (i.e. lumosity)	

8. Are there any activities you used to take part in regularly, but have stopped and/or decreased in frequency?

A. Cooking	F. Meditate	K. Facebook/other social media
B. Cleaning	G. Crossword puzzles	
C. knitting/crocheting	H. Read	
D. exercising	I. Play a card and/or board game	
E. Play instrument	J. Brain fitness programs (i.e. lumosity)	

Other:

_____

_____

_____

9. Which activities do you believe preserve memory?

A. Cooking	F. Meditate	K. Facebook/other social media
B. Cleaning	G. Crossword puzzles	
C. knitting/crocheting	H. Read	
D. exercising	I. Play a card and/or board game	
E. Play instrument	J. Brain fitness programs (i.e. lumosity)	

10. Please indicate on the lines below your personal experience, if any, with memory loss and/or Dementia:

Appendix B

Personal Experience Responses

	Personal experiences with dementia and/memory loss: Responses
1	"Am somewhat forgetful. Will walk into a room and wonder why I had gone there. What had I planned to do?"
2	"When my maternal grandfather was in his 80's he suffered from Dementia, and became extremely senile. When one of my paternal aunts was in her 80's, she was diagnosed with Dementia. She never became completely incapacitated, but she had to have constant care by the end of her life at 93."
3	"My father has shown some cognitive declines over the last six or seven years."
4	"Walk into a room and forget what you entered the room for, forgetting what I went to the store for or forgot list."
5	"I have always been a bit forgetful. It seems to get worse as I get older. That's why I do word games on the iPad and occasionally crossword puzzles and board games. I find myself in a room sometimes and forget why I came there. I am easily distracted, probably have some undiagnosed ADD."
6	"At times I feel scattered, should know where something is, maybe I just had it, but what did I do with it? I sometimes have a hard time recalling names of famous people, movies, etc."
7	"As a breast cancer survivor, I went through 29 chemotherapy treatments 2 years ago. I noticed, and my husband confirms that, my memory has decreased after that."
8	"My mother has dementia. She lives in a different state, so I cannot see her often. I do call her every day."

Appendix C

November 25, 2013

MEMORANDUM

TO:	Mary Kate Konz Fran Hagstrom
FROM:	Ro Windwalker IRB Coordinator
RE:	New Protocol Approval
IRB Protocol #:	13-11-284
Protocol Title:	*Keeping Memory Alive: Exploring the Personal Experiences of Women in Midlife*
Review Type:	☒ EXEMPT ☐ EXPEDITED ☐ FULL IRB
Approved Project Period:	Start Date: 11/25/2013 Expiration Date: 11/24/2014

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (http://vpred.uark.edu/210.php). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 200 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 210 Administration Building, 5-2208, or irb@uark.edu.

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