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MEMORY MATTERS IN ASSISTED LIVING

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Abstract

Memory loss often signifies loss of independence, which is a growing concern for residents in assisted living (AL). The purpose of this exploratory study was to characterize the memory experiences and concerns of AL residents. Residents (N=6) voluntarily participated in one-hour recorded interviews focusing on memory, guided by eight open-ended questions. Interviews were transcribed and analyzed using qualitative content analysis.

The subjects reported varying degrees of memory loss that they found frightening and frustrating, but also accepted as a natural part of the aging process. Concerns primarily focused on inability to recall staff and resident names and activities, schedules, and appointments.

Understanding the memory experiences and concerns is important for nursing staff that care for AL residents. Memory challenges identified by these residents were used to develop a memory intervention for AL residents. Improving cognitive skills may help AL residents maintain their functional abilities, enabling them to "age in place" in AL.

Introduction

Learning and retaining information is imperative to function successfully and perform activities of daily living (ADLs). The images and impressions that are memories from one's past act as a deterrent or support for future actions. Intact memory elevates one's sense of independence and contributes to improved quality of life. "Forgetfulness is more than a simple loss of information and becomes real through its impact on skills and everyday meaningful know-how (Imhof, Wallhagen, Mahrer-Imhof, & Monsch, 2006, p. 351)."

Individuals living in AL residences are at a pivotal point in their life. Although they need supportive care or supervision they still maintain a certain level of independence. Because of this, AL is the fastest residential care choice of older adults. Many AL residents fear the possible future move to a nursing home (Aud & Rantz, 2005; Williams & Warren, 2008; 2009). They have seen friends and family in similar situations and they value their independence and strive to maintain it for as long as possible. Gathering information about the memory experiences of this population may increase health care providers' understanding of the limitations of those with memory impairment. Increased understanding of AL resident experiences and perceptions of memory loss may lead to nursing interventions that will increase the quality of supportive care they receive in AL.

Literature Review

The causes, effects, and treatments of memory changes in the aging population are topics of increasing interest to researchers in the United States. Memory training research and

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commercial products now target elders based on the premise that “use it or lose it” applies to cognitive as well as physical abilities in aging. Older adults are increasingly concerned about their memory performance due to increased awareness of the risk for and prevalence of Alzheimer’s disease and other dementias. Normal age-associated reductions in short-term working memory and memory processing speed may be confused with signs of an early pathological cognitive disorder. Many older adults fear cognitive decline because it may lead to loss of self-concept or personhood. Memory and other cognitive loss also threaten self-care abilities and independent living, valued universally by older adults (Cutler & Hodgson, 1996; McDougall, 2000, Saczynski & Rebock, 2004).

Research has established a trajectory of decline in performance on a variety of cognitive abilities including memory with aging (Schaie & Zanjani, 2006). By age 60, nearly all individuals demonstrate some measurable decline in cognitive performance. More significant impairments that affect daily functioning are typically present during the 70s. Memory self-efficacy, or the perception of one’s memory abilities, also declines with age and may negatively impact quality of life and participation in social activities that rely on memory. Indeed memory lapses or “senior moments” are frustrating and embarrassing for older adults who hesitate to be labeled as forgetful (Imhof et al., 2006). Memory decline has emotional as well as physical effects and may limit how one functions in his/her daily routines, essential to living independently (Imhof et al., 2006; Willis, Tennstedt, Marsiske, et al., 2006).

Memory training interventions have been shown to significantly increase memory performance and memory self-efficacy (McDougall, 2002). Research evidence supports the effectiveness of memory strategies including mnemonic strategies, visualization, association, attention, and external memory aids as effective for improving memory in older adults (Willis et al, 2006). Saczynski and Rebok (2004) demonstrated that memory decline can be slowed or reversed with the use of memory interventions that focus on modeling and practicing strategies specific to the tasks that require memory. Interventions have been initially successful in improving both the cognitive and emotional aspects of memory performance of older adults, but to this point research has focused on community dwelling elders Limited research has tested cognitive interventions to improve memory and other cognitive functions in older adults who require supportive care in residential long term care settings (McDougall, 2002; Williams, 2008). Older adults living in AL have great potential to benefit from interventions that improve or maintain their memory and may enable them to continue living in AL in supported independence.

Purpose and Problem

The goal of this pilot study was to identify memory issues of AL residents as a basis for developing an AL specific training program to support memory. An additional goal was to identify variables that impact AL residents’ ability to remember. Based on the Health Belief Model (Becker, 1974), questions were designed to address memory loss perceptions of residents, barriers to remembering, resources residents used as memory supports, and actions residents would be willing to try to overcome barriers and improve their memory. Answers to these questions may provide insight into the challenges this population faces and are valuable for developing memory training interventions targeting the specific needs of AL residents.

Methods

Design

A qualitative content analysis of guided interviews focusing on memory experiences was used to discover information about the memory issues encountered by AL residents. Approval to conduct the study was obtained from the University Institutional Review Board. The AL facility provided a letter of agreement indicating their willingness to have the research team conduct the study in the facility. Interviews were conducted to elicit responses from the resident participants. Interviews were guided by questions or prompts and audio recorded.

Subjects

Subjects were recruited from an AL facility that was home to 60 residents in northeastern Kansas. The facility had expressed interest in participating in nursing research to improve care for residents. The research team announced the research opportunity at a resident council meeting and later recruited residents who requested that the staff have the research team contact them to explain the study opportunity.

Four of the six subjects who volunteered were female and two were male. Five identified themselves as Caucasian and one was African American. The participants ranged in age from 77 to 89 (M = 82) years old. The residents had lived in the AL facility for 9 months to four years (M = 1.5 years). One resident had a graduate degree, and one had a high school diploma, the other residents had post-high school education. Residents each had between 4 and 10 medical diagnoses, including chronic medical conditions. The number of prescribed medications ranged from 8 to 14. Half of the subjects reported that they had been diagnosed with a minor form of dementia although dementia was not documented in their AL medical record and their MMSE scores ranged from 25–30. All participants were responsible for decision making regarding their care in AL, were able to summarize the goals, activities, and risks of the study, provide signed informed consent, and respond appropriately to the interview questions. Recruitment of subjects continued until completed interviews demonstrated data saturation.

Setting

The interviews took place in the individual apartments of the residents. This provided a comfortable and private environment for the residents. This setting was chosen in order to aid in the elicitation of sensitive personal information about emotions triggered by memory loss.

Procedures

Eight interview questions were developed based on current research literature about memory loss and aging guided by the Health Belief Model. The questions were reviewed by a qualitative expert consultant (Warren & Williams, 2008). Minor modifications were made to the interview questions (see Table 1). After extensive discussion and modeling of the interview questions and format, the investigators individually conducted the interviews.

The interviews ranged from 8 to 50 minutes. Average interview length was 29 minutes. Each resident consented to be recorded during the interview process. Portable mini-disc recorders were used during each interview. At the end of each interview, the research team member summarized the information given by the resident, as a member check for the data. Interviews continued until the investigators concluded that novel responses to the questions were exhausted (data saturation was achieved). Demographic data were obtained from the AL medical records of each participant.

The recordings were archived in digital audio Wav (Waveform audio format) files in a secure computer. Using the Transcript Builder program version 1.9.1 (Thinking Publications, Greenville, South Carolina), the interviews were transcribed verbatim to allow for further analysis.

Data Analysis

Qualitative content analysis was used to analyze the transcripts using a color-coded system that reflected the interview questions. Prior to analysis, both investigators (authors of this paper) reviewed all the transcripts to become familiar with the data and get an overall impression of the responses. Deductive analysis was then used guided by the health belief model and the interview questions because the goal was to gain specific information about AL resident experiences with memory loss (Elo & Kyngas, 2007; Hsieh & Shannon, 2005). The two investigators agreed on the categories for the analyses and jointly coded a partial transcript. This prompted discussion of the rationale for category assignment, clarification of the categories, and development and revision of written operational definitions.

Several training sessions were held initially. Each guided interview question was assigned a color. Each utterance (sentence) or group of utterances that fit each question category were color-coded (highlighted) according to the corresponding interview question color. We achieved 90% agreement on category assignment on a separately coded transcript. We resolved the coding discrepancies and the first author continued to code the remaining interview transcripts.

To assure trustworthiness of data coding, both authors individually coded one-third of the total transcripts in the sample. Inter-rater agreement on coding was 90% for identifying topic content. Inter rater coding in qualitative research is an established method to demonstrate reliability. However, there is disagreement about the proportion of a sample that should be jointly coded. Some qualitative methodologists do not believe that inter coder reliability is warranted in true qualitative research, where the coder is considered an instrument to subjectively interpret data (Carey, 2009; Elo & Kyngas, 2007; Hsieh & Shannon, 2005).

Once all of the initial color-coding was complete, a compilation of all information pertaining to each category was made. This compilation assisted in finding trends and making conclusions about the data correlating to each research interview question.

Results

Findings are summarized based on the eight interview question categories (see Table 1).

1. Do you feel that your memory is not as good as it used to be?

   All of the residents participating in the study expressed the opinion that their memory was not as good as it used to be. Residents A, E, and F stated that their short-term memory function is lower than it used to be. Residents A and E attribute their loss of memory to medical conditions including visual impairments and stroke. Although residents A, B, D, and E admitted that they experienced some level of memory loss, all emphasized their curent ability to retain their memory. Words and phrases such as “fortunate,” “made good time,” and “long term memory is almost perfect” reflect this optimistic view of memory loss. Residents C and F revealed that their memory loss was a slow process stating that it came on “gradually” and it “sneaks up on you.”

2. Please tell me about the first time you noticed your memory was not as good as it used to be.

3. Describe another situation when you could not remember something.

   None of the six residents could recall the first time that they noticed their memory was not as good as it used to be. All of the residents could describe a separate instance in which their memory failed them. Situations in which the residents' memory failed them included remembering names of neighbors and staff, breakfast items, crossword puzzle clues/answers, multi-step instructions, direct questions, and misplacement of items. Residents A and E reported difficulty with remembering and accomplishing multi-step directions/tasks. During the interview Resident A played an answering machine message that detailed a multi-step process to reach the caller. This process seemed daunting to this particular resident who stated, "now I have to rem …the thing is I have to remember tomorrow and in the mean time I have to find out how to call her. And then I have to go through the process of calling her. So for me those are difficult things."

4. How did this make you feel?

   All of the residents used negative terms to describe their feelings toward memory loss. Common language used included the words, "frustrating," "confusing," "mad," "nervous," "embarrassing," "worry," and "lost." Other negative descriptions include "fear," "scary," "strange," "terrible," "disbelief," "hate," "uncomfortable," and "aggravating." Resident E felt "less than adequate," as a result of memory loss. Resident A stated that not being able to remember and function in certain situations can be "taxing." Resident C recalled an example from a previous shopping experience, "… It's just scary. When you think gosh I don't remember what door I came out of or what store I was at and … it, it uh makes you think about a lot of things." The decreased ability to remember can become dangerous. Recounting an experience which almost resulted in a traffic accident, Resident E felt that it was scary, "because not only are you a danger to others, you're a danger to yourself."

   Although all of the residents held negative views toward memory loss five out of six reported that they tried to maintain a positive attitude about their memory. Resident A clearly states, "I don't let it defeat me." When encountering memory loss Resident C tries to "pass it off" or make "a joke of it." Resident B simply states that "you can't reverse the aging process."

5. What kinds of things do you tend to forget?

6. Are there particular situations that make it harder to remember?

   All six residents reported having trouble remembering names. Resident E stated, "I do have great difficulty remembering peoples' names. I can remember the old, older people that I knew years ago. I can call them almost name all of them but I can't…something happened." The residents felt they had trouble remembering many types of items or situations. These included names (objects, people, places), placement of items, events/appointments, conversations, directions, date/time, tasks (multi-step), addresses, telephone numbers, current events and reading material (newspaper articles and books). Resident C emphasized a particular problem, "I can put things away where I think I know right where they are and they're not there." Many of the individuals interviewed shared common concerns about telephone numbers and addresses. Resident E would carry notes with the address and telephone number of the AL residence when going shopping or to appointments. "I carry two or three of 'em in my pocket so I can always get home," stated Resident E.

The residents attributed their memory impairment to several factors. Resident A thought that a visual impairment made it harder to remember. Resident B and D believed that their hearing impairments hindered their ability to remember. Resident C stated that crowded situations made it harder to remember because resident C, "[didn't] want to miss anything." Resident F stated that loud situations caused distraction that made it harder to remember.

7. Do you use any techniques to help you remember things?

    1. Resident A was the only participant who reported using self-testing techniques. Resident A would name each medication and its purpose before taking it. This resident stated, "I really had a little purpose in it. I was testing my own mind and I'm educating [the other residents] these are valuable things that you take." Resident A also participated in a group crossword puzzle exercise. Resident A expressed that, "its, its good for my mind…I like to do this and I still get my share I think."

    2. Many of the residents shared common techniques to help them remember including written reminders, lists, calendars, routine placement of objects, connection/association and repetition. Resident E used photo albums, journals and other written records to help remember important events and dates. One resident stated, "I have these stickers all over everything. If you were to ask me, 'well, what's your phone number?' I don't know. But I'll have to look it up. 'Where do you stay?' I don't really know but I'll look it up." These stickers were written notes placed on tables, telephones and even carried in this particular resident's pocket. Resident D explained why repetition helped preserve memory, "you have an easier time remembering somebody's name that you, you know, see everyday then you do somebody you haven't seen for a while."

8. If you were able to participate in a memory training class would you do so? Why or why not?

    1. All of the participants expressed an interest in participating in a memory training class. Resident A hoped to get "a little faster response on my part" from a class if it was offered. Resident C stated that there was no particular reason for wanting to participate in a class, but noted potential advantages in being able to, "remember upcoming dates, you know, without having to write out a calendar or something like that." Resident D said that gaining knowledge about techniques "…that would refresh your memory" would be helpful and useful in his/her daily activities. Resident E expressed that there was not a specific thing he/she would like to get out of the class instead the resident, "just hope[s] to remember more."

Discussion

As we age our ability to remember declines. This decline often leaves many older adults troubled by their memory loss. All of the AL resident participants reported memory challenges and concerns. Our findings may not generalize to other older adult populations due to the unique responses of older adults in residential care settings (Warren & Williams, 2009). Although data saturation was achieved, the memory issues presented by our convenience sample also may not be representative of other older adults in AL residency. However, the information provided and consensus between our subjects provides a starting point for designing a memory training intervention for AL populations.

All of the residents expressed difficulty remembering names, dates and appointment times. Telephone numbers, past conversations and addresses were other areas of concern. Although all of the residents suffered from memory loss these participants were able to compensate for their decreased ability to remember. Many residents used calendars, lists and written notes as reminders throughout their day. One resident used self-testing methods to sharpen his/her memory abilities. Others relied on written records, photo albums, special placement of objects and association techniques to strengthen their ability to remember.

The interviews also revealed sensitive details about the emotional toll of memory loss. Words such as “frustrating,” “confusing,” “nervous,” and “embarrassing,” were used when discussing the hardships of memory loss. While all of the residents held negative views of their memory loss five out of the six participants expressed a positive outlook on their experiences with memory loss. Memory loss is a process that all older individuals will experience at some point in their lives. This study identified common themes in the ways in which memory loss is perceived and experienced by members of the AL population.

Implications for Nursing Practice

Nurses strive for excellence in supporting patients in achieving optimal wellness. Understanding the patients’ perspectives regarding health and mental health issues are vital to tailoring interventions resulting in quality care. This study identified important aspects of the memory experiences of AL residents that may inform nursing practice. Nurses may assist residents by being sensitive to and supporting memory abilities. AL nursing staff may be able to provide care that is less reliant on highly functional memory ability and reinforce residents’ previously successful memory strategies. For example, staff should consistently wear name tags and using table place cards in the dining room may reduce memory demands of AL residents. Care can become more personalized as nursing staff and residents share memories. Staff may also learn to increase their knowledge about useful memory techniques that they may suggest to residents during routine care or activities. Knowledgeable care providers can teach residents specific strategies for their individual memory challenges. These techniques, when reinforced in the AL environment and shared with other residents, may increase independence and self esteem. Improved memory self-efficacy may encourage AL resident participation in social and recreational activities such as those where recalling names is considered polite, that will enhance quality of life.

This study was conducted to develop a memory training program tailored for the AL resident population, adding to the few cognitive interventions specifically targeting older adults in AL (McDougall, 2005; Williams, 2008). The findings provided the background to develop a memory training program specifically targeting AL residents. The Memory Exercises in Assisted Living (MEAL) intervention was pilot-tested in a small sample of AL residents. The MEAL pilot study results are reported in a separate article (Williams, in review).

This study established that a priority for AL residents is to learn practical strategies to remember and recall names of other AL residents and staff (a need identified by all subjects in our study). Memory training for AL residents may take place in a formal program or informally during care activities. Teaching a variety of approaches to remember names may be required to meet the needs of diverse residents. Additional AL specific memory topics should include recall of phone numbers, appointments, schedules, locating objects around the apartment, and efficient use of external memory aids (notes and lists). Group classes might feature individual residents explaining their favorite memory strategy to others. Understanding the process of memory encoding and recall may increase and older adult’s perceived control of and confidence in their memory abilities. Negative attitudes,

embarrassment, and fear about memory loss must also be addressed and confidentiality assured for participants. Educating older adults about normal reductions in memory in contrast to pathological cognitive decline may provide reassurance and promote successful adaptation.

All of the residents in this study expressed an interest and were receptive to the idea of possible improvement or maintenance of their current memory performance. Common memory loss experiences will dictate content specifically meaningful and applicable to AL residents. Increasing the awareness of memory experiences of older adults will assist nurses working with older adults in a variety of settings to optimize memory performance and improve quality of care.

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TABLE 1

Interview Questions

1	Do you feel that your memory is not as good as it used to be?
2	Please tell me about the first time you noticed your memory was not as good as it used to be. [use probes to elicit details]
3	Describe another situation when you could not remember something.
4	How did this make you feel? (probes: Embarrasing? Did it make you anxious? Was it frustrating?)
5	What kinds of things do you tend to forget? (ex. Name/face, appointments)
6	Are there particular situations that make it harder to remember? (ex. Crowded, loud situations = hard to concentrate)
7	Do you use any techniques to help you remember things? (ex. Calendar, lists, associating people with jobs or places they live, repeating names)
8	If you were able to participate in a memory training class would you do so? Why and why not? (ex. Time frame of the class is less than one hour…)