



## Aging in Place with Dementia: A Single Case Study

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### Abstract

This single case study report explored what home modifications a caregiver considers for a spouse with dementia and the decision making process for implementing home modifications. The method for gathering case study data was an in home interview and administration of the Home Environmental Assessment Protocol- revised. Qualitative coding was used for data analysis. Results indicated that home modifications were both physical and temporal. The decision making process was influenced more by adverse events than by professional recommendations.

**Keywords:** Aging in Place; Caregivers; Dementia; Home Modifications

### Introduction

The purpose of this case study was to explore what home modifications caregivers consider for spouses diagnosed with dementia so that they can safely age in place. The aim of this case study was to identify what home modifications caregivers of spouses diagnosed with dementia make to promote safe aging in place. A secondary aim was to explore how and why a decision is made concerning home modifications. The central question was: What changes to the home do caregivers of spouses with dementia make to promote safe aging in place?

Reports estimate that 5.4 million people in the United States age 65 years or older have Alzheimer's dementia. It is projected that this number will triple by 2050, to 13.8 million (Alzheimer's Association) [1]. As the incidence of dementia and specifically Alzheimer's Disease (AD) increases, many older adults report they want to age in place. Aging in place is defined by the Center for Disease control as "the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level."

Research has shown home modifications can increase independence, safety, and self-esteem while reducing health care costs (Sanford, Pynoos, Tejral, & Browne, 2002) [2].

In a study on caregiver burden Kim et al. (2011) identified that it may be beneficial to both the person with dementia and the caregiver to have nursing interventions and community services so

that the functional abilities of individuals with dementia might be improved [3]. In a recent study on home modifications for people with dementia, when recommendations were made - which were followed- they were recommended by physical and occupational therapists (Marquardt, et al. 2011) [4].

A study of 82 elderly persons with dementia (Marquardt, et al. 2011) found the main barriers to accessibility were both inside and outside steps [4]. The majority of participants had made physical modifications. Participants were skeptical about the usefulness of modifications to support cognitive deficits so these were not made very often. Finances were the most frequent reason given for not making physical changes. The assessment in this study consisted of an observation of the home, including a diagram, and an eight -item questionnaire done by an architect experienced in environmental design for dementia. Marquardt (2011) reported it took approximately 20 minutes to administer both [4].

A qualitative study consisting of 42 in-depth interviews with person ages 25-87 explored the experience of the home modification process in Australia (Aplin, Desleigh, Gustafsson, 2013) [5]. Four dimensions were found to affect home modification decisions. The first dimension identified was the personal dimension, which consisted of appearance, safety, and privacy. Second was the societal dimension, this included governmental standards as half of the persons in the study lived in government housing which paid for the modifications. The other half of the participants lived in private homes and was funded for up to 50% of the modification costs. The third dimension identified was the physical dimension, which included lifts and grab bars as well as modifications that involved finding studs or load bearing walls. The fourth

dimension identified by Aplin, Desleigh and Gustafsson (2013) was the temporal dimension [5]. Items in this dimension included consideration of deteriorating health due to medical condition and planning for a child's growth needs. The authors concluded that the implication of this study for occupational therapy practice is the consideration of a collaborative approach to decision making in home modifications (Aplin, Desleigh, Gustafsson, 2013) [5,6].

The literature in the previous paragraphs shows progress in home environmental research. A forum paper proposes several reasons related to societal trends for conducting research on the home environment (Gitlin, 2003) [7]. First among these is the desire of elderly persons and caregivers to age in place. A second consideration is the sense of the home environments' contribution to well-being. Third, the home is increasingly becoming the setting for long term care. Research in the home can present many challenges. The home is a dynamic, individualized, and unpredictable place. Gitlin identifies that research in the home environment can be time consuming and costly. Furthermore, Gitlin stresses that research in home environments has lacked theoretical direction and has been mostly descriptive. The above literature further illustrates this is a continuing trend. Gitlin proposes the need to study the home environment from a theoretical framework and with the use of psychometrically sound instruments. One additional direction identified for research is to develop an understanding of the person-environment relationships (Gitlin, 2003) in the home environment [7,8].

## Investigator's Perspective

As a home health care therapist I observed many older persons, especially those with dementia, and their caregivers, struggling to maintain their independence enough to remain in their homes. I saw how changes in the physical home environment could promote this. Simple additions of things like grab bars or lift chairs, removal of things like clutter and throw rugs, and rearrangement of items like phones, pictures, and lighting all seemed to make a difference. Sometimes the recommendations are followed; sometimes they are not. Therapists need clearer direction on what recommendations are best to suggest, and some rationale as to why some are followed through and others are not. This study will help to answer these questions and build the evidence to help care professionals in the clinical reasoning process of recommending home modifications for persons with dementia.

## Materials and Methods

The qualitative tradition used for this study was a single case study. Case studies develop an in-depth analysis of what home modifications are made to promote aging in place for persons with dementia and their caregiver spouses. Case studies obtain data from multiple sources, in this case an interview and observation in the participant's home.

## Selection of Participant

Participation was voluntary and verbal consent was gained for this course project. Confidentiality was maintained at all times and pseudonyms are used in this paper. This initial study was n=1. The caregiver, Phil, is 87 and his wife, Jane, is 85. They have been married for 63 years and have lived in their current home for 43 years. Phil has a PhD and is a retired professor. Jane has a master degree in music. Phil reports he had a stroke several years ago and is fully recovered. Along with dementia Jane has A-fib, a pacemaker, and a heart catheter (Table 1). This case is considered to be a combination of intensity rich and convenience sampling.

Demographic characteristic	Caregiver	Care recipient
Gender	Male	Female
Age	87	85
Education	doctorate	master's degree
Diagnosis	CVA	Dementia
Comorbidities		A-fib Pacemaker Heart catheter

**Table 1:** Demographic characteristics of participants

## Data Collection Procedures

**Interview:** The interview took place in the front sunroom of Phil and Jane's home. They sat together on the sofa. Phil, a retired professor started the interview with "let me give you some background information about us first." This interview lasted approximately 40 minutes and was conducted using the questions listed in Appendix A. The interview was audiotaped and field notes were taken throughout the interview.

**Observation.** Participant observation was a guided tour of the home lead by Phil, the caregiver. Jane walked along and was eager to share information about their home as I observed the home. The Home Environmental Assessment Protocol -Revised (HEAP-R) evaluation form (Struckmeyer, 2016) served as a general guide for the observation. The HEAP- R is a two-page home assessment specific to persons with dementia and their caregivers. It has good concurrent validity with the longer Home Environmental Assessment Protocol and good clinical utility (Struckmeyer, 2016) [9].

## Data Analysis

Data analysis started with coding. After the transcript was completed and checked for accuracy, each line was assigned a number. This updated transcript was saved as a new file name to keep the integrity of the transcript intact. A coding partner

verified the accuracy of the transcript. Each line of the transcript was coded using track changes. Thoughts and notes about the data were recorded by hand as ideas about themes and categories emerged. Initial categories were routines, awareness based on background, being active, physical modifications and putting off making modifications. Other categories discovered were (a) other types of modifications and (b) support system as well as c) changes after an accident/illness/event. After the transcript was coded with track changes it was cut it apart and sorted into themes. A table was created and compared with student peer results. Final themes were derived after comparing the two and consulting to reach agreement.

### Trustworthiness Techniques

Curtin & Fossey (2007) identify six characteristics of trustworthiness: thick description, triangulation strategies, member-checking, and collaboration between the researcher and the researched, transferability, and reflexivity [10]. Thick description started with accurate transcription of the interview. The interview was audio taped and transcribed. An independent reviewer listened to the audio tape and compared it to the transcript to ensure accuracy. During the observation, field notes were taken, and a diagram of the home was drawn.

Triangulation was obtained by the combination of interview, observation, field notes and diagram. Peer checking further increased the rigor of this study (Table 2).

Peer list of themes	Primary researcher list of themes
Motivation/Lack of Motivation	No changes/Incidents that result in change
Interests	Active Life Style
Health Needs	Modifications-physical
Roles	Other comment (I would add this category)
Planning	Not addressed
Environment	Modifications
Physical	Modifications-physical
Temporal	Other comment- routines (would add this)
Strength	
Physical strength	Active Life style
Inner strength	Awareness
Financial strength	Other comment
Adaptation	Modifications-physical

Values	Support systems (also similar to roles)
Awareness	Awareness
Education	Awareness
Self-awareness	Awareness
Denial/Acceptance	Awareness

**Table 2:** Comparison of coding results for peer checking.

Member checking was not done with this study as the participant had agreed to one visit. Good collaboration was obtained as the participant is a former professor and was interested participating in this study. This study has limited transferability due to the individual sample size. Reflexivity was obtained through the field notes and comments written during the interview and observation. The transcript and notes were reviewed several times making additional notes.

### Results

Five themes developed from this case study. First environmental modifications were both physical and temporal. Some examples of the physical modifications identified are the picking up of throw rugs, the use of night lights, and the widening of stairs. Temporal changes included adhering to a daily routine and having a routine for entering and exiting the home as well as verbal and touch cues. A second theme that emerged was the lack of incentive on Phil's part to implement recommended or identified changes to the home. When asked about this Phil replied "It's just procrastination," and "We'll make the changes when we have to." Another theme that emerged was the importance of maintaining an active lifestyle to keep up physical and inner strength. Phil expressed that being active kept them independent at home. A fourth theme was the importance of their current and previous roles. In regards to the caregiving role, Phil stated, "I just do it." He related that he has made home safety changes recommended by Jane's physical therapist but not those made by his daughter (a nurse) or son (a physician), although they were good suggestions. The last theme that emerged was that of awareness. Phil stated his background in biological sciences helps him to understand the aging and dementia process. He also obtained resources on Alzheimer's Disease from family and physicians. During the observation several books on Alzheimer's were observed on the coffee table. Appendix B, themes and categories, further illustrates the results of this study.

Not all the physical modifications were identified in interview. Additional physical environmental modifications were identified during the HEAP-R evaluation form home walk through. One was the removal of the bathroom door so it wouldn't block

the shower entrance when open. A second was that the steps to carport had been widened to prevent a fall. During the observation a few safety hazards were identified that were not identified during the interview. They were throw rugs, shoes on floor that could be tripped over, and a loose board that Jane held onto when going up the stairs. Other types of modifications were observed such as verbal cues, touch cues and routines.

## Discussion

Identification of what home modifications caregivers of spouses diagnosed with dementia make to promote safe aging in place was achieved for this case study. Examples were the widening the steps, improved lighting and the removal items such as rugs and the bathroom door. Other examples were temporal such as adhering to routines and continuing engagement in previously enjoyable activities. The secondary aim was to explore how and why a decision is made concerning home modifications. Decisions to make home modifications were not initially followed when made by family members or health care professionals. Often decisions were not made until after an adverse event such a fall on a throw rug then resulted in removal of all the rugs.

The use of the HEAP-R to provide structure to the home walk through helped identify information not obtained through the interview. Phil and Jane had made modifications that were not mentioned in the interview such as the removal of bathroom door that swung open in front of the shower stall. Safety issues that were not identified in the interview were: Jane holding onto a board resting along the wall next to the door as she walked up the garage steps, several thresholds of approximately 1 inch between three different rooms, and cleaning supplies in the food pantry. Two issues conflicted with the interview comments, loose throw rugs and clutter (four pairs of shoes) on floor.

## Significance

Home assessment should include both an interview and an in-person home assessment. Use of a standardized assessment can provide valuable information missed in a home interview or unstructured home walk through. Recommendations for home modifications made by health care professionals were not implemented until after an adverse event.

## Future Projects

Further research is needed to verify findings across case examples and identify methods for achieving follow through with recommendations made by health care professionals.

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## Appendix A

### The Interview Questions

Central question: What changes to the home do caregivers of spouses with dementia make to promote safe aging in place?

Sub questions and probes:

1. What changes to your home have you made in regards to safety?
  - a. (examples if needed) things like adding a deadbolt lock?
  - b. Locking up poisonous cleaning supplies?
  - c. Added lighting?
  - d. Putting away anything?
2. What physical modifications (ramps, rails)?
  - a. Bathroom?
  - b. Outside?
  - c. Have you done any remodeling to your home to make life easier?
3. How did you decide what changes to make?



- a. May have artifacts, like a web page or handout
- b. Books, persons?
4. How do you think being the husband vs the wife caregiver makes a difference?
5. What things you haven't done but were recommended, why?
6. What special equipment do you still need that you don't have?
7. What plans do you have for making any changes to your home?

## Appendix B

### Themes and Categories

- ☐ **Environmental Modifications**
- ☐ Physical- picking up throw rugs, lighting, removal of door, widening steps
- ☐ Temporal- routines, verbal cues, touch cues
- ☐ **No changes/lack of motivation**
- ☐ Putting it off/procrastination
- ☐ Satisfied with way things are
- ☐ Will make changes when we have to
- ☐ **Active lifestyle**
- ☐ As part of remaining at home: importance of being active and keeping a workout in their daily routine
- ☐ Going for walks, hold hands for safety
- ☐ Keeping up strength (physical & inner)
- ☐ **Roles**
- ☐ Previous role as professor /biologist
- ☐ Parent role- recommendations from adult children
- ☐ In patient role (PT) made some recommended changes
- ☐ Importance of spouse/caregiving role "I just do it"
- ☐ **Awareness**
- ☐ Of caregiving situation/safety through education on Alzheimer's
- ☐ Related to work back ground
- ☐ **Other related comments**
- ☐ We can afford to make modifications/get what we need
- ☐ Future plans include assisted living