

CAREGIVERS AND ENVIRONMENTS FOR PEOPLE WITH DEMENTIA

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Caregivers and Environments for People with Dementia

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ABSTRACT

This paper is a report of a study to investigate the perceptions of caregivers regarding the effects of environments on the independence of a family member with dementia living in the home. The majority of persons with dementia are cared for by family members in the home. Caregiving can be stressful and rewarding to the caregiver. This study used a qualitative research design and a phenomenological approach to gather narrative information about caregiving and the home environment. Open-ended interview questions were used to gather information regarding the details of caregiver perceptions. The results of shared caregiving perceptions support previous research suggesting that resistance to change in the home is a barrier to home modifications to promote safety and enhance function. Caregivers need specific training by professionals in home modification in order to enhance functionality in the care recipient before environmental changes create confusion.

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CHAPTER 1. INTRODUCTION

Dementia is not a specific disease. According to the Alzheimer's Association (2014) dementia is an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills that is severe enough to reduce a person's ability to perform everyday activities. The Alzheimer's Association (2014) reports, "Alzheimer's disease accounts for 60% to 80% percent of dementia cases" (p.6).

The National Center for Biotechnology Information (2014) provides examples of impairments in activities of daily living at the mild, moderate and severe stages of dementia. For example, early mild symptoms of dementia include difficulty with tasks that used to come easily, such as balancing a checkbook, learning new routines, losing interest in things previously enjoyed, and personality changes. As dementia advances symptoms worsen leading to moderate impairments such as difficulty preparing meals, choosing proper clothing, recognizing danger and forgetting events in one's own life history. Finally, a person in the most severe stage of dementia can no longer perform basic self-care tasks without the assistance of a caregiver, such as eating, dressing, bathing or recognizing family members (National Center for Biotechnology Information, 2014).

According to the 2014 Alzheimer's Association Facts and Figures report, (Alzheimer's Association, 2014) "...in 2013, the 15.5 million family and other unpaid caregivers of people with Alzheimer's disease and other dementias provided an estimated 17.7 billion hours of unpaid care. This number represents an average of 21.9 hours of care per caregiver per week" (p. 33). This decline in basic self-care abilities requires the assistance of caregivers who are usually immediate family members such as spouses, adult children, or siblings.

Family members are described as informal caregivers and many develop their caregiving skills through trial and error. Although the majority of caregivers want to keep the care recipient with dementia in their own home, there are many environmental and behavioral barriers that prevent the caregiver from meeting this personal goal safely.

Because of the increasing numbers of elderly adults experiencing dementia, it is important to examine how home settings can influence caregivers' experiences as they assist the care recipient with the activities of daily life. Therefore, this study examines the beliefs and attitudes of primary caregivers for persons with dementia who live at home in order to understand their perceptions the effect environment has on their family member's independence.

The purpose for this study is that a home environment that has supportive design features can be created by the caregiver, and these design features allow the person with dementia to perform basic self-care tasks such as dressing, toileting, and engaging in leisure activities with less dependence on their caregivers.

First, a review of the literature identifies caregiver characteristics and home environment designs that influence the functional status of persons with dementia. Second, methodology and interviews conducted with caregivers of people with dementia are used to identify and describe common difficulties of the caregiver in the home environment. Finally, the willingness of caregivers to change the home environment to support the everyday activities of a person with dementia will be discussed.

CHAPTER 2. LITERATURE REVIEW

Caregiving

The number of Americans with Alzheimer's disease and other dementias will grow as the U.S. population age 65 and older continues to increase. The Alzheimer's Association (2014) reported that by 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent, slow or stop the disease. On average, a person with Alzheimer's will spend more years (40 percent of the total number of years with Alzheimer's) in the most severe stage of the disease than in any other stage (Alzheimer's Association, 2014). The Alzheimer's Association 2009 (as cited by Centers for Disease Control and Prevention, 2014) stated that the vast majority (87%) of individuals with Alzheimer's disease, a type of dementia, were cared for at home by family members.

It is for these reasons that numerous studies have been conducted to document the effects of providing care for a person with dementia. Caregivers can experience negative effects related to caring for a person with dementia. For example, Vellone, Pira, Talucci, & Cohen (2008) found that worries about the future and progression of the family member's illness worsened the caregivers' quality of life because many knew that the illness would worsen, but they did not know the speed of this process or what would happen in the future. In addition, Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, (2007) found that family member's behavioral problems had a far greater impact on caregivers' lives than either cognitive or functional impairments, and thus heavily influenced the decision of relatives as to when to place relatives in long-term residential care. For example, caregivers who are adult children often experience a role reversal and begin to make decisions for the parent. More specifically Cicirelli (2000) stated

that adult children reach a point in their life cycle where the norms of filial responsibility come into play and they see themselves as having some responsibility in caring for their aging parents. Filial maturity is a term where the adult child reaches the point in no longer looking at the parents for support but rather the adult children are called upon to provide comfort and support to the parent (Cicirelli, 2000). In the past, the role of caregiver often fell to the female in the home. However, Baker & Robertson (2008) reported that as the demographics of the population change, men are assuming increasingly important roles as caregivers for family members.

Little attention has been given to the positive aspects of caregiving, despite recognition in the literature that some caregivers report improved feelings of well-being as a result of providing care to a loved one (Caswell, Vitaliano, Croyle, Scanlan, Zhang, & Daruwala, 2003). The benefits of being a caregiver for a family member with dementia can create a positive experience. For instance, Donovan and Corcoran (2010) established that female caregivers identified as having positive feelings associated with caregiving used strategies to enhance their roles as caregivers by “simplifying the daily routine and making things as organized and systematic as possible to help them in their caregiving role. Specific approaches to organization ranged from tasks such as table setting or clothes sorting to financial preparation. Although this approach was beneficial to the caregiver, it also helped to reduce the care recipient’s confusion” (p. 592).

Caregiver education and training

Providing care for a person with dementia can be a rewarding and exhausting experience. Kim, Chang, Rose and Kim (2012) found strengthening caregiver’s knowledge of dementia and of strategies to better undertake their caregiving role helps stave off growing distress as the illness progresses and improves caregiving attitude.

The Environmental Skill-Building Program (Corcoran et al., 2002) standardizes the use of caregiver-driven treatment, thereby creating an intervention that is simultaneously reproducible and individualized as applied to three problematic care issues, wandering, catastrophic reactions, and caregiver burden. Using a collaborative process, caregivers in this study used 82% of the strategies introduced to develop successful environmental modifications. Gitlin et al. (2008) replicated the original 2002 Environmental Skill-Building Program with the Tailored Activities Program.

This program, like the Environmental Skill-Building Program was built on the premise that an intervention that tailors activities to the individual strengths and interests of people with dementia is accepted by people with dementia and their caregivers (Gitlin et al., 2008). Its focus was primarily on leisure activities, which have received very little attention for people with dementia living in the community.

The role of healthcare practitioners such as occupational therapy in providing support for older adults striving to remain in their home as they age includes education for the caregiver. Education and training in strategies to reduce falls and maintain independence can be accomplished through engagement in exercise and leisure activities, education about strategies to remain safe and independent, and recommendations for home modifications. Furthermore when used in combination, these interventions are more successful than when physical activity and home modifications are provided individually (Chase, Mann, Wasek, & Arbesman, 2012).

Pighills, Torgerson, Sheldon, Drummond, & Bland (2011) compared the effectiveness of a home modification assessment by an occupational therapist with that of a nonprofessional assessor. Both the occupational therapists and the nonprofessional assessors received training in home modification assessment and then outside agencies provided the home modifications for

the older adults. Pighills et al. (2011) found that older adults in the occupational therapy assessment group had fewer falls than did the old adults in the control group and while no difference was found when comparing falls for the trained assessor and control groups. The outcome of this direct comparison between occupational therapist–led and non-professional–led interventions in high-risk populations indicates that the professional background of the person delivering the intervention influences its effectiveness (Pighills et al., 2011).

Home environment – Aging in place

The meaning of home, as Stafford (2009) notes, “impacts the quality of life of any individual. A home is not just an address or a built structure; it holds meaning and memories” (p. 3). The home provides independence and a frame of reference for life experiences. When family members with dementia must move out of the home and into care facilities it is often disorienting and disturbing, not only for the individual but also for the entire family (Tenenbaum, 2010). “The ability to age in place”, claims Tenenbaum (2010), “can remove the unexpectedness entirely, preventing the likelihood of depression” (p. 10). Finding identity in ones’ home creates a form of consistency for the individual. Even as aging impacts the physical and mental abilities of the body, the home is consistent and the memories and meaning of the home remain the same, for this reason, older adults value their home.

In this study Gill, Williams, Robison, & Tinetti (1999) found that environmental hazards are common in the homes of community-living older persons. They found two or more hazards in the majority of bathrooms with 61.0% of bathrooms lacking grab bars in the tub or shower (Gill et al., 1999). Equally important, Liu and Lapane (2009) found that those individuals having baseline residential modifications, such as bathroom modifications, wide hallways, ramps, or

railings were less likely to experience a decline in physical functioning as they aged compared to individuals who had not installed modifications.

The success of the “The Environmental Skill-Building Program” (Corcoran et al., 2002) and the “Tailoring Activities Program” (Gitlin et al., 2008) support the concept that training caregivers can lead to healthier, safer environments for both the caregiver and the family member with dementia. Indeed, many older Americans enjoy longer and healthier lives due to numerous advancements in the healthcare and healthcare facilities, greater economic security, and the delivery of supportive services (Sharma, 2008). With the availability of such services, older adults have been given the opportunity to choose where to locate throughout retirement.

Gitlin et al. (2013) report the primary challenge of aging in place for individuals with a combination of multiple chronic conditions and functional difficulties in navigating an unsupportive home and community. In addition, managing the mismatch between persons and their environments is an essential feature of the aging process for this group; it can be as time consuming and physically and emotionally stressful as managing medical considerations associated with chronic disease (Gitlin et al., 2013). Unquestionably, fostering aging in place frequently requires assistance from family and friends to help identify, negotiate, arrange, create, and monitor actions, services, and strategies that individuals or families must then independently put into place (Gitlin et al., 2013). Marquardt et al. (2011a) conducted a study that describes home modifications in a community dwelling sample of 82 elderly people with dementia. Marquardt et al. (2011a) found the main barriers to the accessibility of the homes were steps, both inside and outside the house. It was noted that abundant furniture, clutter and lack of handrails presented physical obstacles to moving about as well as possible fall risks.

While home modifications can increase independence for older adults and enhance their opportunities to successfully age in place, Marquardt et al. (2011a) found about one third of all caregivers reported that the care recipient would react with confusion or irritation to alterations made within their home. This confusion seemed to decrease slightly with the progression of dementia, but could be possible and most beneficial to the care recipient if modifications to the home were implemented in agreement with the care recipient (Marquardt et al., 2011a).

Assisting individuals to age in place is a complex process when recommendations are not implemented. The well-being of aging women living in their own homes in France was investigated by Rioux (2005) and even after recommendations for modifications were suggested for their homes, only 21% of the women had remodeled their homes in order to support declining physical abilities. It is unclear why these women choose not to take such preventive actions but Rioux (2005) suggested it could be due to a lack of information, fear of the future, and/or a belief that they were too old to cope with the disruption of remodeling. In addition, Devor, Wang, Renvell, Feigal, & Ramsdell (1994) found the main reason for non-adherence with home modification recommendations was not agreeing that modifications were necessary.

As has been noted, Clemson, Cusick, & Fozzard (1999) found that adherence to recommended home modifications was more likely if older persons perceived that they were able to exert control over their own home environment. Participants who believed it possible to prevent falls by making home modifications were more than twice as likely to make changes as those who did not believe it possible (Cumming et al., 2001).

Van Hoof and Kort (2009) proposed a prototypical dementia residential housing unit. They suggested that the “design of the dementia dwelling can be seen as a non-pharmacologic strategy to support living independently, improve self-care capabilities, and increase well-being

of older adults with dementia” (p. 313). Furthermore Van Hoof and Kort (2009) found older people with dementia may perceive the indoor environment differently from counterparts without dementia, which can go together with certain behavioral symptoms. Therefore it can be expected that people with dementia are not just passive receptors of the indoor environment, but may actually respond to it by displaying positive or negative behaviors (Van Hoof & Kort, 2009).

Marquardt et al. (2011b) found that increased complexity of the interior layout of the residential home was associated with a greater functional dependency in basic activities of daily living, such as eating, dressing and using the bathroom. This means that residents who live in a home that features a high proportion of open spaces, such as circulation areas and interconnected rooms were more dependent on their caregivers than those that lived in homes with enclosed rooms with a clearly legible meaning and function (Marquardt et al., 2011b).

Studies done in facilities for older adults often are searching for the design factors that enhance the hominess of the facility. A study completed by Innes, Kelly, & Dincarslan (2011) of people with dementia living in care homes and their caregivers found that one of the most important design features relates to outside space. Viewing natural landscapes from a window or during a walk have been researched by Velarde, Fry, & Tveit (2007) and related to reduced stress, increasing physical well-being in elderly people, and behavioral changes that improve mood and general well-being.

CHAPTER 3. METHODS

This study used a qualitative research design to gather narrative information about caregiving and the home environment. A phenomenological approach of asking open-ended interview questions was used to gather information regarding the in-depth details of caregiver perception of changing features in the home to increase safety and independence of the person with dementia.

The Institutional Review Board (IRB) approved an application to conduct research involving human participants prior to contact with participants. Potential participants were provided with complete and understandable information about the study, informed of the voluntary nature of their choice, and given sufficient opportunity to consider participation under circumstances that minimize the possibility of coercion or undue influence. Participants were assured confidentiality of their responses and completed an informed consent form prior to the researcher initiating interview questions.

This study used a qualitative method of analysis which leads to revelations regarding caregivers' perceptions of how change affects care recipients' confusion levels and their ability to safely navigate their home environment. The findings of the study resulted in a deeper understanding of how both the caregivers, and their family members, resist environmental changes. Using Creswell's (1998) "data analysis spiral," the data was reviewed in four steps "organization, preliminary interpretations, classification and synthesis" (p. 151). "Organization," the first step of the data analysis spiral, the data was organized in a table to compare the caregiver's responses. For the second step, "preliminary interpretations," the data in the tables from the interview transcripts were repeatedly reviewed by the researcher and an outside

reviewer in order to identify themes and to insure validity. The themes were then categorized per step three, “classification.” These classifications were then “synthesized” into findings.

Sample

In compliance with IRB protocol, a list of care-givers were provided by a social worker in a small community healthcare system as caregivers known to her through use of the healthcare system. The typical sample size for a phenomenological study is 5-25 individuals and who, “...have had direct experience with the phenomenon being studied” (Creswell, 1998, p. 159). This researcher called the caregivers to request an interview regarding caregiving and home environments. Of the seven names provided by the social worker, six agreed to participate in an interview; one caregiver declined to participate. After agreeing to an interview via telephone, arrangements were made for a home visit to conduct the interview for five of the six caregivers. One caregiver, the 55 year old daughter caring for her mother, was interviewed at her place of employment; therefore, the apartment her mother lived in was not seen by the researcher.

Data collection methods

All caregivers were interviewed by the researcher in 30 to 45 minute sessions using a semi-structured face to face interview (Appendix). As prescribed by the IRB protocol, an informed consent was signed by all caregivers prior to the interview. The care recipient was present during the interviews in the homes, but was not included in the interview. All interviews were recorded with the permission of the caregivers. Care was taken by the researcher to assure the respondents that they and their homes would not be identifiable in any subsequent reports. After the interviews, the recordings were transcribed into word documents.

Interview questions emerged from the literature review process. They were organized into five areas including caregiver demographics, time spent in the caregiver role, home

environment, loved ones challenges and leisure and daily living activities. During the interview, further probing questions were generated as the caregivers expounded on their experiences of caregiving and perceptions of how possible changes in the home would affect the care recipient. The questions pertaining to caregiving were designed to gain an understanding of type and quantity of caregiving provided. Additionally, questions addressing the home environment provided the caregiver an opportunity to share the changes in the home that were already made and their feelings about further changes in the home that potentially increase the safety of the family member with dementia. The last question of the interview explored the caregiver's participation in leisure activities with the care recipient. The goal of the interview questions was for caregivers to express their perceptions of how their home environment affects the role of caregiving and the function of the family member with dementia.

Caregiver care-recipient dyad information

The caregiver care-recipient dyads consisted of three husbands being cared for by their wives, two mothers being care for by adult children one son and one daughter and one sister being care for by her younger brother (Table 1). The ages of the care-recipients (CR) ranged from 70 to 88 and the ages of the caregivers (CG) ranged from 58 to 75. The three caregivers who were spouses lived with the care-recipient in their home. The two adult children caregivers lived in their own homes and checked on their parent CG3 checked on his mother at least twice per day and CG1 checked on her mother 3-4 times per week. The sibling caregiver and his sister lived in the family home that was their mothers' home, the brother owned his own home next door but due to the need for 24 hour supervision he stayed in the family home with the care-recipient.

Table 1

Caregiver and Care-recipient Relationship

Caregiver (CG) Identifier	Caregiver (age)	Care-recipient (age)
CG1	daughter (55)	mother (88)
CG2	wife (73)	husband (76)
CG3	son (61)	mother (88)
CG4	wife (75)	husband (72)
CG5	wife (58)	husband (72)
CG6	brother (60)	sister (70)

CHAPTER 4. FINDINGS

Review of the data, including individual interviews and field notes, was conducted to identify themes of the caregiver's perceptions of changing or modifying aspects of the home. The transcribed interview responses were organized into data tables and searched for "meaning units" that reflected various aspects the lived experience of caregiving (Leedy & Ormrod, 2005, p. 145).

Limited independence for a person with dementia

Persons who have dementia gradually lose their abilities to independently perform their activities of daily living such as dressing and bathing. They also lose interest or find it too difficult to participate in leisure activities due to memory deficits (National Center for Biotechnology Information, 2014). Therefore, a family member often begins to assist the person with dementia with these activities.

Loved ones' challenges

Caregivers were asked if their loved ones had challenges such as physical disabilities, sensory deficits or memory impairments. Sensory deficits such as low vision or impaired hearing can increase misperceptions in the environment and physical disabilities can increase the risk of falls. Five of six of the care recipients used walker or cane. Only one did not have an assistive device for walking. Although two of the people did have walkers, they did not always use them. Responses for impaired vision ranged from no deficits, having glasses but refusing to wear them to only being able to see shapes and objects due to complications from diabetes. One man had quit doing the puzzles he enjoyed due to his "eye problems". Two of the care recipients had hearing aids but neither wore them consistently, one spouse joked that her husband had selective hearing. A caregiving spouse (CG2) stated, "He hears fine. But sometimes he can't understand or

comprehend what I want him to do. He'll try hard but he pushes in the wrong direction and it makes it hard to help him".

Not all caregivers were aware of a dementia diagnosis and those who did say their loved one had dementia seemed uncertain of the details of the diagnosis. Even though the care recipients did have memory impairments, two caregivers were sure that their loved one did not have Alzheimer's disease. Two female spouse caregivers CG4 and CG5 stated,

He doesn't have Alzheimer's. But they say he does have dementia. I don't understand the different types of dementia. He started to get bad after he started wearing oxygen after his heart attack; He would wear it most of the time. Now he usually wears it but sometimes he refuses. CG4

Yes, he has dementia; they say it is from his stroke. But he doesn't seem to be getting worse like Alzheimer's. He can actually move his right hand better now than he could a few years ago. CG5

The daughter caregiver CG1 who visited her mother 3-4 times per week was asked "You said she (your mother) has dementia. Is it mild, moderate or severe?"

I don't know how to classify it. She has really bad short term memory, she will repeat herself, like in 5 minutes she might say the same thing 5 times. If I like tell her she has a doctor's appointment on Sunday, by Tuesday she won't remember that or even by the time I leave. I always have to call her to remind her. I'll call her Monday night and again Tuesday morning. Things that are routine that she has done forever, ever and ever, she does pretty good with, like making a pot of coffee, it surprises me that she can remember how to do that when she doesn't remember that she just told me that she got a letter in the mail from the car insurance or something like that. She doesn't have a problem doing the

things she been doing a long, long time. She does things like, you know I don't know what category that puts her in, but like she um, she does things like, she gets up in the morning, and her routine is to cross off the day on the calendar and then take her morning pills. I noticed that sometimes she would cross off 2 days and take her pills ahead to time. So I guess she'd been up for a while, then she dozes off and gets up and takes her meds again, So I bought her a little clock that says the day, the date and the time and I set it by her pill bottles and that seems to be working. I don't know where that would put her, moderate? She's never not remembered who I am or what my name is, or any of the other kids, but sometimes she forgets the great grandkids. But then with a little bit of prodding she will kind of remember them. Only one time I thought she was delusional, thinking things that really didn't happen. I guess it is because I am there so much, that sometimes she puts me in circumstances when I'm not even around. And it's like I wasn't even there, but I try not to argue with her, because if I do, she gets real testy with me. So I just let her be. CG1

Caregiver roles to support the needs of their loved ones

Caregivers were asked open-ended questions regarding the amount and type of assistance they provided to the family member with dementia and if they had outside help with caregiving. When asked about the amount of time spent in the role of caregiver responses five of six of the caregivers, including all the spouse caregivers, reported that they provided daily assistance. Only one caregiver reported less than daily assistance stating she visited her mother 3-4 times per week but she have daily contact by telephone. Daily assistance was further explained as helping the care recipient with dressing, going to the bathroom, and showering or bathing. Caregivers gave examples of the type of care they provide:

All of her shopping, all of her housecleaning, bathing, laundry. I don't have to do meal preparation, she is still using the microwave, and I just get her frozen foods and stuff like that. Her mail, getting her mail in, Bills, I pay her bills, I fix her medicines, prescriptions, pill box, her daily meds, Take her to all her doctor's appointment. CG1

I help him do everything. I help him get dressed. I give him his pills. CG2

I fix her meds, give her something to drink and eat, I take care of the maintenance things, she dresses herself, but she usually just wears flannel gowns. CG3

It depends on what our schedule is, if someone is coming over I help him get dressed because he is so slow. He can do it himself. I help him shower. CG4

I give him his medicine. He can dress himself and walks to the bathroom. I'm always here when he takes a shower but he can heat food up in the microwave. CG5

24 hours daily! I do absolutely everything. Dressing, showering, laundry, cooking, using the phone, using the microwave. CG6

All six of the caregivers report they provide assistance with activities of daily living (ADLs) that include eating, bathing, grooming, dressing and going to the toilet. Instrumental activities of daily living (IADLs) are activities which are more complex and require higher degrees of cognition such as cooking, shopping and managing finances (Table 2).

When asked if outside help was hired to assist with caregiving most interviewees answered no, however two caregivers had daughters available to assist with caregiving. The daughter of CG2 provided bathing assistant to the care-recipient but also provided shopping assistant and transportation for her mother as well. The son caregiver (CG3) hired a home health nurse aide to help his mother shower once a week. Two caregivers mentioned they were able to leave the family member alone for one to two hours but expressed relief that everything was

Table 2

Types of Assistance Provided by Caregivers

ADLs	IADLs
Taking a shower	Laundry
Going to the bathroom	Pay bills
Get dressed	Fix and give medication
Absolutely everything	Shopping
Help him do everything	Housekeeping
	Get her mail
	Get prescriptions
	Take to doctor appointments
	Cooking
	Phone
	Put away dishes
	Clean litter box
	Sweep floor
	Maintenance
	Use of microwave

alright when they get back home after an outing. Arranging to hire caregivers to sit with the family member for a longer period of time creates difficulty. For example, one of the spouse caregivers (CG4) was having a medical procedure and that required using one of her friends as

her driver and then finding another friend to stay with her husband. Following are the caregiver responses when asked; Do you hire anyone to help you provide care?

No. CG1

Oh gosh, no. My daughter just helps; she comes by every day to relieve me. CG2

Once a week to help with her bath. My wife helps by making her supper. CG3

If I go away someplace I hire someone to stay with him. CG4

Our daughter lives in the next block, but she works and has children. CG5

Just recently she got on home health and the nurses visit, other than that, none. CG6

Leisure activities

All caregivers were able to report the type of leisure activities the care recipient enjoys at the time of the interview. Three of the caregivers spoke of the activities that their loved one used to do in the past and two of the caregivers reported a reduction in frequency of activities due to low vision and unsteady gait.

He isn't able to go into his shop anymore and he used to do jigsaw puzzles but his eyes are getting really bad. CG2

He sits at the table. He likes to look at the store ads. Someone said I should have him read to me, but if I ask him what's in the paper he just says "I don't know" CG4

He used to hook the dogs up on the leash outside, but he doesn't do that anymore. He used to be very strong and had broad shoulders. Now I have trouble finding enough meat to give him his insulin shot. CG5

The caregiving brother (CG6) whose sister was able to walk without the aid of a cane or walker expressed his frustration with lack of recognition for the time and effort he spends in his attempt to allow his sister to feel independent and to protect her dignity.

She was a physical education teacher so she loves to walk. She walks every day. She goes down to Main street and then back, she'll do that 4 or 5 times a day. Everyone thinks she walks by herself, but I constantly watch her, sometimes I walk down the alley to keep an eye on her. I put a pot of flowers out by the front walk and she knows that means to walk up that sidewalk. She just has no idea what it takes even though she tells everyone she's fine. CG6

Changes in home environment creates confusion

Marquardt et al. (2011a) found approximately one third of all caregivers in a study involving 303 individuals reported that the care recipient would react with confusion or irritation to changes within the home. This fear of creating confusion in the family member with dementia needs to be taken into consideration when suggesting home modifications to caregivers.

Home environments

The interviews took place in the homes of the caregivers with the exception of CG1; therefore the elderly accessible apartment was not seen by the researcher (Table 3). The home of CG6 had the most obvious hazard of having the bedrooms upstairs; all other homes were one level. CG6 stated, "I'd move the bedroom downstairs. The bedrooms are upstairs, she sleeps in the back bedroom and I sleep on the floor in the doorway so I can tell when is getting up, the steps are steep and she's no good on stairs and I don't feel safe for her on them". The rental home also posed a problem due to the caregiver's hesitation to ask for modifications in the home. She stated, "We rent this place so we can't change a lot of things. The floor is not level but we are used to that by now. We put those cement blocks out front to make the steps easier to get up". CG5

Table 3

Type of Home

Caregiver (CG) Identifier	Type of home
CG1	Elderly accessible apartment
CG2	House bought for retirement
CG3	Mobile home bought with aging in mind
CG4	House built for retirement
CG5	Rental home
CG6	House in the family

When asked about changes that had already been implemented to make the home safer the most often mentioned feature was the use of a chair in the shower and grab bars in the shower and near the toilet. Ramps were present on the homes of CG2 and CG4 which were built for retirement and steps posed a challenge for the care recipients of CG3 and CG5. When asked about building a ramp CG3 stated, “She doesn’t need a ramp, she doesn’t go out by herself and when she does go out, I help her on the steps.” Even with a history of falling in the shower and near the toilet CG2 was resistant to the idea of installing a roll in shower with a level threshold, “Oh we could afford it, but if it gets that bad he won’t be able to be here at home”. The reasons for not making changes in the home are listed in the following table (Table 4).

Table 4

Reasons for Not Making Changes

Caregiver (CG) Identifier	Response to change
CG1	She doesn't like new things
CG2	I don't think we need to make any changes
CG3	She doesn't need a ramp she does go out
CG4	Well, I don't know what I'd change.
CG5	It might not get done.
CG6	No one wants me to change anything.

When asked, “Are there areas of the home that you want to change, that you know needs attention?” Two caregivers responded as follows:

The only thing I would like to do is, that she likes to put those scatter rugs all over the place and they are on top of the carpet. She's real deliberate when she does things and she hasn't tripped and fallen yet, she walks with a cane, she has like chronic bursitis on her hip and she doesn't pick up her foot very high. But she's not going to let me pick up any of those rugs. At all, ever. CG1

Yes, if I had it to do over again I would have made the doorway into the bedroom differently. So it wouldn't make a hard turn like that at the end of the hall. It is hard for the walker and the wheelchair to turn that corner. CG2

Caregivers feel that changing the décor can affect the family members with dementia mood or behaviors but in a negative way only. CG1 stated that she was personally affected by décor but respected her mother's wish to not to change. CG6 also commented on starting to decorate for the Christmas holiday but stopping after moving furniture to make room for the

trees upset his family member. The following table (Table 5) summarizes the responses to the question, “Do you feel that changing the décor can affect your loved ones mood and behaviors?”

Table

Can Changing Décor Affect Mood and Behavior

Caregiver (CG) Identifier	Response
CG1	Good luck (laughs), she’s used to what she has
CG2	No, He’s a farmer, he doesn’t care
CG3	Yes, I do. Change causes confusion
CG4	No. (laughs)
CG5	Yes. If something gets changed, he gets upset
CG6	Yes, it already has. I started to put up the Christmas decorations. She got upset. I stopped

Only one of the caregivers expressed a willingness to change the home environment in an effort to increase the care recipient’s independence with activities that they enjoy. In fact five of six respondents expressed doubt that change would be helpful. One respondent (CG3) required proof that change would increase independence prior to making changes because the change itself would create confusion.

I don’t that there is anything that can make her more independent because of her limited ability to move around, because she can’t stand for a long period of time, and then she has to sit. CG1

Well we have changed many things already. I think the Parkinson's is just advancing. He has memory problems and sometimes can't move. If he can't move himself I won't be able to take care of him. CG2

Show me that it is going to improve her I before I change it...any change we make in her routine causes major confusion. CG3

I don't think that would help. CG4

I'd be open to suggestions but I don't think there is much else to be done. I would be willing to change if it helped him keep his independence, but I don't think anything would increase his independence. I think he's doing all he can do now. CG5

CHAPTER 5. DISCUSSION

As more family members take on caregiving for a loved one in the home, the need will grow for information on how to make the environment safe and conducive to functional independence. Literature from the field of gerontology including environmental modification and family caregiving has suggested that there is a need for education and training for the caregivers in the home. The experiences of caring for persons with dementia in their own homes are typically shaped by factors such as type and amount of assistance required and the environment hazards present. Like the research completed by Gill et al. (1999), comments revealed by caregivers in this study, hazards present in the home such as outside steps, throw rugs, tight spaces and stairs were difficult to manage for persons with dementia. In addition, this study supports the work by Gitlin et al. (2013) that suggests that for an individual with dementia to successfully age in place requires assistance from family caregivers.

Two general themes relevant to the caregiver attitudes emerged from the data: (a) change within the home creates confusion in the care recipient; and (b) there is little that will increase the independence of a person with dementia.

Theme one

The first theme, “Change within the home creates confusion in the care recipient” is demonstrated by the following caregiver responses to the question, “Do you feel that changing the décor can affect your loved ones mood and behaviors?” Only one of the caregivers affirmed that the décor of the home did indeed affect mood in a positive way, for example CG2 reported that she painted the bedroom blue to provide a calming effect for her husband. While this is different than the findings by Marquadt et al. (2011a) that found that a change in the décor would

upset the person with dementia. Some older adults suffering from dementia may not notice or be affected by changes in the environment.

This study, like the findings by Tenenbaum (2010), found that caregivers of persons with dementia were resistant to change for fear of creating confusion in the person with dementia. For example, when CG6 was asked the question regarding if changing the décor affected mood, CG6 said, “Yes, it already has. I started to put up the Christmas decorations and she got upset. She doesn’t like any changes. I usually put a tree in every room but I stopped after I put the tree up in the dining room because she was so upset. I guess it makes her nervous”. Other examples of resistance to change include CG3 who stated, “It causes confusion when you change things around” and “show me that it is going to improve her I before I change it because any change we make causes major confusion”. When asked, “What are your reasons for not making changes?” CG1 responded, “She would throw a fit, she doesn’t like new things. Everything in the place is her stuff and I just work around it. I just don’t feel right by changing her stuff without her approval, she would be mad”.

Providing education for caregivers in the earlier stages of dementia may assist the caregivers by improving attitude and preventing distress (Kim et al., 2012) therefore increasing their loved ones abilities while avoiding confusion.

Theme two

The second theme, “There is little that will increase the independence of a person with dementia” is demonstrated by the following caregiver responses to the question, “What features do you think help your loved one function independently and safely?” For example, the 88 year old mother of caregiver one still lives independently in her own apartment and receives assistance 3-4 times a week. Her caregiver, CG1, stated, “I don’t think that there is anything that

can make her more independent because of her limited ability to move around, because she can't stand for a long period of time, and then she has to sit". In addition, CG5 stated, "I don't think anything would increase his independence. I think he's doing all he can do now". Although caregivers feel this to be true, Liu and Lapane (2009) found that those individuals having minimal residential modification (e.g., railings, bathroom modifications) were less likely to experience a decline in physical functioning as they aged.

Caring for a person with dementia in a home that is familiar may decrease the amount of assistance required from the caregiver. For example, Marquardt et al. (2011b) found a greater dependency on the caregiver when the home had more open spaces and less identifiable purposeful rooms. Therefore, it is possible the homes of the caregivers and family member with dementia were already supportive of greater independence.

The experiences of caregivers caring for persons with dementia in their own homes are typically shaped by factors such as type and amount of assistance required and the environment hazards present. Like the study by Gill et al. (1999) this study found the caregivers did have hazards present in the home such as outside steps that were difficult to manage, throw rugs, tight spaces and stairs within the home. Obviously, any combination of these factors can have an effect on the caregiver's ability to provide a safe environment and adequate supervision for the person with dementia to carry out their activities of daily living. This study supports the findings of previous research stating that suggested home modifications are not always implemented or even found to be helpful or necessary (Clemson et al., 1999; Devor et al., 1994; Rioux, 2005).

The degree of dementia whether it is mild, moderate or severe can increase the demand of caregiving. The National Center for Biotechnology Information (2014) states that as a person with dementia progress through the disease the amount of assistance needed for self-care task

increases the demand on the caregivers. Two of the caregivers, CG2 and CG4, reported that they helped with dressing even though the person with dementia was capable to doing the activity if allowed enough time. CG4 stated, “It depends on what our schedule is, if someone is coming over I help him get dressed because he is so slow. He can do it himself”.

The findings of this study enhance the overall knowledge about caregiver perceptions regarding changes in the home environment. The results of this study support the concepts of aging in place as described by Tenenbaum (2010) in that the caregivers “value their home” (p. 10) with three of the caregivers reporting their homes were built or purchased with aging in place as a goal.

The findings point to the potential value of home modification education and perhaps intervention to assist the caregiver in the early stages of dementia before changes in the environment are likely to create upset in the person with dementia. This study is in agreement with the findings of Marquadt et al. (2011a) that suggest environmental modifications should be made in collaboration with the caregiver and the care-recipient in the early stages of dementia in an effort to reduce confusion. The effectiveness of early interventions to support the caregiver in their role is supported by research completed by Corcoran et al. (2002) and Gitlin et al. (2008).

From this study, it is reasonable to conclude that a supportive home environment can be more readily created if caregivers are educated about effective environmental modifications prior to the middle stage of dementia, when even small changes in routine or environment can result in increased confusion for the person with dementia.

Study limitations

Limitations of this study may include the method of selecting of caregivers to interview. The caregivers were known to the social worker in a healthcare system therefore they were

already receiving services. The language of the interview question regarding increasing the care recipient's independence drew strong negative responses. The question, "What other features do you think help your loved one function independently and safely?" prompted responses such as, "I think he's doing all he can do" and "I don't think there is anything that can make her more independent". Therefore, the use of language that would elicit more thought on the tasks that the person with dementia may be capable of doing if the environment was arranged in a way to increase function or to maintain abilities may have allowed the caregivers to expand on the care recipients potential abilities. An unanswered question is whether it makes a difference if you asked about safety and/or comfort/quality of life versus independence. If someone believes that independence is only going to decline, he/she may not see any point in even minimal disruption caused by changes, but might feel differently if it improved care recipient's or their quality of life or safety.

Future research

Future research should incorporate more in-depth studies of personal experiences in people's homes in an effort to determine ways of increasing the acceptance of home modifications. In particular, researchers can identify the resistance to change and the language used by professionals when addressing functional status of persons with impaired cognition in their homes, therefore increasing the understanding of the perceptions of caregivers.

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APPENDIX. INTERVIEW GUIDE TO OPEN-ENDED QUESTIONS

The questions, used to initiate dialogue between the caregiver and the researcher, are divided into topical areas for ease of presentation. Each of the caregivers was asked most of these questions but not in any particular order.

Caregiver information

- Do you consider yourself a caregiver for your parent or spouse?
- How old are you?
- How old is your parent or spouse?
- How long has this home been in your family?
- How did it happen that you became the caregiver in the family?
- Do you have family members close by?

Time spent in caregiver role

- How much assistance do you provide daily?
- What types of assistance do you provide?
- What type and how often do you hire someone to help you provide care?

Home Environment

- Are there areas of the home that you want to change?
- Have you already made changes to increase the safety in the home?
- What other features do you think help your loved one function independently and safely?
- What are your reasons for not making changes?
- What would make you change a feature right away?
- Do you feel that changing the décor can affect your loved ones mood and behaviors?

Loved ones challenges

- Does your loved one have physical challenges, sensory deficits or memory impairments?

Leisure activities and activities of daily living

- What types of activities does your loved one enjoy doing?
- Do they need assistance or can they do these independently?
- How willing would you be to change the home environment if this increased your loved