ENVIRONMENTAL MODIFICATION STRATEGIES
USED BY CAREGIVERS

by

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ABSTRACT

Title: Environmental Modification Strategies Used By Caregivers

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Problem Statement. To handle the problems of daily living created by a chronic illness, patients and their family caregivers must develop strategies for "carrying on" in the face of the disease (Strauss et al., 1984). Modifying the home environment is a strategy caregivers are likely to use. Home health nurses provide much of the professional care given to chronically ill older people in the home, and are thus in an ideal position to assist family caregivers with their environmental modification strategies.

Purpose. The purpose of this study was to describe the environmental modification strategies used by family caregivers of chronically ill older people. The specific aims of the study were to:

1. Describe the environmental modification strategies that family caregivers have used in caring for chronically ill older people who are eligible for skilled home health care.
2. Describe the reasons given by family caregivers to explain why an environmental modification was or was not effective in facilitating specific caregiving activities.
3. Describe how and why caregivers changed their environmental strategies over time.

Methods. A qualitative design guided the research. Data were collected from a purposive sample of 24 family caregivers of older people eligible for skilled home health services using intensive interviews and participant observation of the family's caregiving activities.

Analysis strategies recommended by Miles and Huberman (1994) were used to identify patterns in the data.

Findings. The following categories of environmental modification strategies emerged from the data: organizing the home to provide care, supplementing function with devices or environmental cues, structuring the care receiver's day, protecting the care receiver working around environmental limitations, enriching the home and making long-term lifestyle changes. Organizing the home met several needs for the caregiver: the number and burden of tasks were reduced, management of the medical conditions of the care receiver were facilitated, and the needs of other family members for privacy and the freedom to engage in normal activities were met. Supplementing the older person's function with devices or environmental cues freed the caregiver from having to perform the task for the care receiver. Structuring the care receiver's day included establishing routines to create predictability in the caregiver and care receiver's day. Creating fun activities was also essential to reduce stress from boredom and under stimulation. Protecting the Care receiver was critical for ensuring that the care receiver is not harmed by hazards present in the home. Working around environmental limitations, by obtaining special equipment and supplies or by changing how activities were performed, helped the caregiver to reduce environmental demands on the care receiver. Enriching the home environment modification strategies was used by caregivers to improve the quality of the care receiver's daily experience. Making long-term lifestyle changes such as relocating to a new home were particularly resource intensive. Families without a lot of financial reserves, energy, or social support found these strategies impossible to implement. In addition to the seven categories of environmental modifications, caregivers used two strategies in conjunction with and in lieu of modification strategies to rectify a care receiver's mobility to act and function in the environment. The first of these parallel strategies was the caregiver's use of self. With this strategy, the caregiver either did a task for the care receiver without using an environmental modification or assisted the care receiver as he/she used an environmental modification. Getting help included obtaining formal services to either supplement or substitute the assistance that the caregiver provided to the care receiver. There were two strategies that were used when the caregiver decided to not take action to modify the environment. The first strategy was called leave as is. With this approach the caregiver, taking into account the care receiver's view, made a judgment that no modifications were necessary. Caregivers did not take action when thy felt that demands of the environment were not that great or that the caregiver's competence was not that compromised. Learning to live with how things are was an existential coping strategy of altering ones frame of reference or world view of what was and what was not acceptable in the home environment. This strategy helped the caregiver cope with stress created by things the caregiver could not change, such as the inability to maintain the cleanliness of the home because of intense caregiving demands. Caregivers used two primary processes to develop and implement environmental modification strategies: trial and error and serendipitous discovery. Caregivers used three additional process strategies to refine their environmental modifications: individualizing, economizing, and innovating. The decision to continue using a strategy was determined by a complex evaluation of the benefits and disadvantages for both the caregiver and the care receiver. Caregivers varied in their ability to use environmental modification strategies based on a number of conditions that changed over time during the caregiving experience.

Implications. There is a need for better nursing assessment and understanding of the role the caregiver plays in altering the care receiver's environment. Findings indicate that family caregivers use a broad array of strategies to address the care receiver's misfit with their home environment. In addition, the decision to reject or adopt an environmental strategy is influenced by a complex assessment that incorporates a number of factors that have not been understood by home health professionals. In order to assist caregivers, nurses need to be able to assess the many factors that can interfere with the caregiver's ability to make and use environmental strategies. Intervention should be based on a collaborative approach that ensures the caregiver and care receiver's needs and preferences are respected. Further research needs to examine the relationships among concepts identified in this study so that the a model of environmental modification strategy use can be developed.

TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

TABLE

LIST OF FIGURES

FIGURE

CHAPTER 1: INTRODUCTION

The probability of having multiple chronic illnesses increases with age. Women are more likely to suffer from chronic illness than men. Among elders 80 years old and older, 70% of the women and 53% of the men have two or more chronic illnesses commonly reported in population studies. Rates of hearing and visual impairments also grow rapidly with age. Not surprisingly, chronic illness is often accompanied by functional limitations. Functional limitations and the concomitant need for personal assistance with everyday activities, therefore, also increases with age. The percentage of elderly persons requiring assistance with everyday activities increases from 9% among persons age 65-69 to 50% among those over the age of 85 (Hobbs & Damon, 1996). Family caregivers provide 80% of the care needed by chronically ill older people in the home (Abel, 1990), often making it possible for them to remain in the community, a clear preference of older people (Parmelee & Lawton, 1990). The treatment of many chronic illnesses requires the use of numerous and complex care regimens. This care may complicate an already difficult family caregiving situation. Coping with the many key problems of daily living that arise from having a chronic illness and associated functional limitations, patients and their family caregivers must develop strategies for "carrying on" in the face of the disease and its treatment regimens (Strauss et al., 1984). Modifying the home environment is a strategy patients and caregivers are likely to use.

The responsibility of day-to-day management of chronically ill older people falls primarily on themselves and their family caregivers. The center of this care is the home. In the home environment, the physical and mental limitations that accompany chronic illness can create problems with simple daily tasks such as dressing. When older people require complex care regimens as part of their treatment plan, the day-to-day management is made even more complicated. The number and type of side effects produced by care regimens can further increase the difficulty. Making the home environment suitable for chronically ill older people and their care regimens can make family caregiving easier.

Home health nurses provide much of the professional care given to chronically ill older people in the home. When home health nurses meet with family caregivers of chronically ill older people, they discuss problems related to care regimens. Nurses often recommend to family caregivers environmental modification strategies that they believe will make it easier to provide care in the home. For example, the nurse may recommend that a commode be placed at the bedside of a person who has impaired cardiopulmonary function and is too weak to walk to the bathroom. If this person has developed pressure ulcers, the nurse may recommend rearranging the environment to include storage space for dressing supplies, as well as providing a clean area for performing the dressing change. In such situations, nurses suggest interventions to facilitate care regimens, but may not understand the family caregiver's perception of how the recommended environmental modification strategies will bear upon the overall day-to-day management of the illness or the family's regular pattern of life (Hasselkus, 1989).

When family caregivers do not adopt the nurse's recommendations, the nurse may express frustration, the quality of care may suffer, and the older person and family caregiver's needs may go unmet. Such problems can arise from unidirectional communication from professional staff to family caregivers (Hasselkus, 1988; 1989). This unidirectional communication style can happen when nurses do not understand how high the “stakes” are when caregivers consider the trade-offs involved in adopting an environmental modification strategy. When nurses are unaware of family and patient expertise with managing symptoms and disabilities (Harvath et al., 1994), they may inadvertently recommend changes in the environment that are counterproductive (Strauss et al., 1984).

Home health nurses are in an ideal position to assist family caregivers with their environmental modification strategies. Historically, the environment has been a central concern of nursing, and actions taken to modify the environment have been an important focus of nursing care (Nightengale, 1946). However, as a supervisor, I observed that the practice of home health nursing often reflected a limited knowledge base regarding what family caregivers did to modify the caregiving environment. In fact, research indicates that home health nurses impose their recommendations on family caregivers without realizing it (Hasselkus, 1989). Of all the health professionals, home health nurses are the most advantageously placed to help caregivers devise or change environmental modification strategies. If family caregivers play a central role in selecting and tailoring environmental modification strategies, the effectiveness of the modifications may be increased.

The purpose of this study was to examine the environmental modification strategies that family caregivers use, explores the effectiveness of these modifications, and how they changed over time. It is the first study in a program of research aimed at improving the care that home health nurses provide to chronically ill older people and their caregivers. It is hoped that the findings of this study will inform home health nurses about the environmental modification strategies caregivers use to facilitate the tasks of everyday life in the face of illness and care regimens. The specific aims of the study were to:

1. Describe the environmental modification strategies that family caregivers have used in caring for a chronically ill older person eligible for home health care.
2. Describe reasons given by family caregivers to explain why an environmental modification strategy was or was not effective in facilitating specific caregiving activities.
3. Describe how and why caregivers changed their environmental modification strategies over time.

CHAPTER 2: REVIEW OF THE LITERATURE

Literature pertinent to the study includes work focused on the environment and older people, work associated with caregiving activities and negative outcomes, environmental modification strategies to facilitate caregiving activities, and the limited focus of home health nurses on modifying caregiving environments. The impact of environment on older people in various settings is a part of this review because of the generally acknowledged view that the elderly are more susceptible to environmental stress (Kahana, 1982; Lawton, 1982). Literature that examines the work associated with caregiving activities illustrates how environmental circumstances mediate the sometimes negative outcomes of caregiving. A review of the limited research literature that explores how environmental modification strategies can facilitate caregiving activities follows to illustrate the need for this study. The review will conclude with an examination of the current practice of home health nurses in modifying the environment. Environmental modifications have typically been defined by professionals as including such factors as structural changes, special equipment, behavioral changes, and assistive device use (Regnier & Pynoos, 1987). The findings of this study expand upon this definition.

Environment: An Important Area of Care for Older People

Environment is a key variable in the care of chronically ill older people. Considerable theoretical literature addresses the significant role the environment plays in the well-being of older individuals as their range and type of impairments increase with age. Lawton's environmental docility hypothesis states that "the less competent the individual, the greater the impact of environmental factors on that individual" (Lawton, 1986, p. 14). Competence is defined by Lawton (1982) as biological health, sensory-perceptual capacity, motor skills, cognitive capacity, and ego strength. Chronic illness and disability increase with age (Hobbs & Damon, 1996) and adversely affect competence of older people in both institutional and home environments.

Theoretical Definitions of Environment

Person-Environment Fit

Lewin's (1935) life space model argues that behavior is a function of the person and the environment, summarized in the equation $B=f(P,E)$. The life space perspective conceptualized the relationship between the individual and the environment as an open system. The relationship between the individual and the environment is dynamic and reciprocal because the environment might change the person just as the person might change the environment.

Lawton and Nahemow's (1973) model built on Lewin's conceptualization of environment and person in greater detail. They defined the individual in terms of a set of competencies. The demand characteristics of the environment were termed environmental press and included the personal, group, suprapersonal, social, and physical environment. Lawton and Nahemow improved upon Lewin's notion that behavior is a function of the individual and the environment. Their model suggests that there is a specific and liner relationship between an individual's total competencies and the amount of press he or she can stand. The amount of press which the individual can tolerate falls within a range depending upon their aggregate competency. The point where environmental press matches competency is called the adaptation level. Press above this level results in maximum performance level, and press below this level is called the zone of maximum comfort. Beyond these ranges press can have negative impacts. Competent individuals can deal with a greater range of press than people with less competence before they reach the point of negative affect and maladaptive behavior.

Refinements of the Person-Environment Perspective

Kahana's (1982) model extends the work of Lawton and Nahemow (1973) in four important ways. First, the individual is defined as more than just a sum of competencies—needs and preferences drive their behavior. Second, the individual takes an active role in seeking out environments which are congruent with his or her needs and preferences. Third, if there is incongruence between press and needs/preferences, the individual either modifies or leaves the environment. Fourth, if modifying or leaving the environment is not possible, the individual experiences stress and discomfort until his or her needs/preferences are modified.

In addition to the refinements suggested by Kahana (1982), one other environmental theorist has developed a model that can inform or improve the person-environment perspective. Weisman's (1982) model suggests that there needs to be a differentiation between aspects of the environment that can be objectively measured and the environment as experienced. The perspective of person-environment fit, as refined and developed by the above theorists, seems the most useful for examining the literature that deals with the interaction of older persons with their physical setting. A review of clinical and research work focused on the care of older people in institutions (e.g., hospitals, nursing homes, residential care facilities) and private home environments follows.

Institutional Environments

Environment as a Mediator of Older People's Behavior in Institutions

Person-environment fit has been defined by Kahana (1982) as congruence between environmental characteristics and individual needs and preferences. The centrality of the person-environment fit in managing geriatric syndromes in institutional care settings is apparent in the recommendations of the nursing literature related to falls (Hogue, 1992; Hollinger & Patterson, 1992), incontinence (Pearson & Larson, 1992; Smith, Newman, McDowell, & Burgio, 1992; Wyman, 1992), and cognitive impairment (Beck, Heacock, Mercer, & Walton, 1992; Foreman, 1992). Several studies in long-term care settings have explored a wide variety of environmental variables associated with resident behavior and feelings. Type of unit (Swanson, Mass, & Buckwalter, 1993), privacy provided (Ryden, 1985; Ryden, Bossenmaier, & McLachlan, 1991), personal control (Ryden, 1990; 1985), and interaction between staff and residents (Burgener, Jirovec, Murrell, & Barton, 1992) have been examined as potential mediators of resident behavior. Maladaptive behaviors such as aggression, agitation, screaming, and weeping have been linked to manifestations of excess disability created by an over-demanding environment (Kolcaba, 1992). Ryden (1992) and Negley and Manley (1990) have identified environmental stimuli as antecedents of aggression. Conversely, Meddaugh (1990) found that change from a comparatively active life to the inactive environment of a nursing home can result in aggressive behavior. The importance of therapeutic milieu (Taft, Delaney, Seman & Stansell, 1993) and the culture of long-term care institutions (Kayser-Jones, 1992) have also been explored.

Design for Institutions Based on Person-Environment Fit

To better meet the expressed environmental needs of older persons, research questions (Regnier & Pynoos, 1987) were developed to determine how to increase the older person's housing satisfaction, to incorporate the older person's priorities, to address the needs of the disabled and the visually impaired older person, and to develop furniture better suited to the older person's limitations. However, most design initiatives in institutions have focused on meeting the needs of older people with dementia. The emerging trends in design for environments for people with dementia are geared toward the establishment of a more home-like atmosphere to aid the patient in developing a more normalized routine (Cohen & Day, 1994). The environment can be seen as a prosthetic function (Schiff, 1990) that provides cues to memory and behavior while ensuring safety (McCracken & Gilster, 1991). A variety of existing physical designs can be adapted to meet goals for patients (Hyde, 1989). Unfortunately, there are design and cost limitations to this approach. Balancing the competing needs of staff and patients is a design issue that has been identified but not resolved (Cluff, 1990; Coulson, 1993). More importantly, many existing facilities cannot afford to make these changes.

Modifying the Environment to Counter Press in Institutions

The goal of a major environmental modification in an acute care setting is to maximize an elderly patient's rehabilitation while also increasing the participation of family members in the recuperation process (Daly & Rudy, 1993). A 29-bed medical-surgical unit renovation to enhance the functioning of older patients ameliorated functional declines and shortened lengths of stay (Kresevic, Landefeld, Palmer, & Kowal, 1993). In a special care unit where reduced stimulation was emphasized, patient weight loss was curtailed, patient agitation was diminished, restraint use was reduced, and wandering was no longer a concern for staff or other patients (Buckwalter, Maas, Swanson, & Hall, 1993).

Research in institutional environments most pertinent to the focus of this study specifically looked at the use of modifications in the physical environment. A series of nine studies were conducted at the Corinne Dolan Alzheimer Center (Namazi et al., 1991) to test an array of environmental modifications designed to address caregiving issues such as incontinence, disorientation, confusion, food intake, and reinstatement of familiar tasks. Although generalizability of the results is limited due to the small sample size, the individuality of patient problems and the specific environmental context in which the study was conducted, in every case the results were very promising. For example, one study found that unconcealed toilets in residents' bedrooms resulted in an eight-fold increase in toilet use (Namazi & Johnson, 1991). Another study examined whether prominently displaying memorabilia of long-term significance to each resident would serve as orientation clues to help them locate their own bedroom. Results indicated that 4 out of 10 residents were more successful in locating their room (Namazi, Rosner, & Rechlin, 1991). In addition, the use of environmental modifications to address nursing problems has been demonstrated by the work of Beck (1988) and Rader (1991). Dramatic increases in rates of resident dressing and decreased use of restraints were achieved by using a patient-specific environmental modification. A major limitation of this work on institutional environments is its questionable generalizability to the majority of older people who prefer to live in their homes (Lawton, 1986) and resist relocation to institutional settings (Jones & Salvage, 1992).

Home Environments

Environment as a Mediator of Older People's Behavior in the Home

The home environment has been traditionally viewed as a hazard for or barrier to effective functioning for elderly people. The literature on incontinence, falls, cognitive impairment, and functional disability views the home environment as having a negative impact on environmental press. In Pearson and Larson's study (1992), data gathered about the environment of community-dwelling, incontinent elderly women were limited to impediments to reaching the toilet. Wyman, Elswick, Ory, Wilson, and Fantl (1993) identified distance to the toilet as a significant contributor to the severity of incontinence. To prevent falling in old age, Tideiksaar (1989) recommended identifying home fall hazards such as wet floor surfaces, thick carpets, poor environmental lighting, narrow doorways, and door thresholds that are too high. Neelon and Champagne (1992) identified factors in the environment as a cause of confusion development. According to Kolanowski (1992), even slight changes in intensity, spectral power distribution, and temporal patterns of exposure, can interact with visual agnosia in Alzheimer's to make stimuli illegible to the impaired person. Levine and Gitlin (1990) proposed a model of how to make adaptation for older persons with disabilities that views environment in the context of how it impinges on performance.

Designs for Homes Based on Person-Environment Fit

Although the development of design ideas has improved the care provided in some institutions, there has been little crossover in application to the private home sector. As Regnier and Pynoos (1987) identified, redesign or physical remodeling of the home is often not practical. Most families rarely make these kinds of design changes and federal funding for this purpose is generally not available (Parmelee & Lawton, 1990).

Modifying the Environment to Counter Press in Home Settings

Occupational therapy research done on assistive devices—a type of environmental modification—illustrates the importance of assessing the person-environment fit in the context of the in-home caregiving situation. Researchers have found variability in the use of, and satisfaction with, assistive devices according to individual impairment (Mann, Hurren, & Tomita, 1993). As disability progressed and competence declined, devices were not as effective (Mann, Karuza, Hurren, & Tomita, 1992). In addition, recommended devices were frequently not used (Mann, Hurren, Karuza, & Bentley, 1993). Device use appears to be a complex issue that may change over time as patients adapt to their home environment (Gitlin, Levine, & Geiger, 1993). Gitlin and colleagues found that by the end of the first month following discharge from the hospital, 45% of prescribed equipment was seldom or never used in the home. The need to study the family caregiver's perspective is highlighted by perplexing findings in which caregivers and patients can identify the need for additional assistive devices, yet did not obtain them (Mann et al., 1992). The lack of incorporation of the family caregiver's perspective in the institutional and home environment literature may have seriously limited nurses' understanding of the actual range of successful environmental modification strategies for older people in the home.

Environmental Modification Strategies to Facilitate the Work of Caregiving

Describing the hardships of living with chronic illness, Strauss et al. (1984) identified multiple problems of daily living particularly pertinent for family caregivers trying to incorporate care regimen activities into their caregiving situations. Examples included prevention and management of medical crises, dealing with social isolation, adjustments to changes in the trajectory of the disease, and attempts at normalizing lifestyle. Developing basic strategies to manage these key problems was critical. One of the basic strategies the family must devise was the environmental modifications required to facilitate the work associated with caregiving activities.

The idea that chronic conditions have a course that varies and changes over time was conceptualized as the trajectory framework, a model developed by Strauss and Corbin (1992). Empirical evidence for this assertion was provided in a study that examined the 6-year history of functional limitations in a sample of noninstitutionalized elders over the age of 70 (Rudberg, Parzen, Leornard, & Cassel, 1996). The researchers found that elders with either high or low levels of limitation tended to maintain this status; however, those with medium levels of limitation showed a great deal of transitioning to another level of limitation. These dynamic changes in functional level are consistent with findings by Gitlin et al. (1993) that adaptive device use was a complex issue that changed over time. Consequently, to understand how caregivers use modification strategies it is critical that change over time be examined.

Previous Research on Work Associated with Caregiving Activities

The impact of work associated with caregiving activities upon family caregivers has been studied extensively. Studies have varied in the number and types of activities used to define caregiving work burden (Albert, 1991; Baillie, Norbeck, & Barnes, 1988; Bowers, 1987; Cossette & Levesque, 1993; Given, Stommel, Collins, King, & Given, 1990; Haley, Levine, Brown, & Bartolucci, 1987; Horowitz, 1985; McCorkle et al., 1993; Montgomery, Gonyea & Hooyman, 1985; Oberst, Thomas, Gass, & Ward, 1989; Young & Kahana, 1989); how they have defined the intensity of caregiving activity (Albert, 1991; Baillie et al., 1988; Montgomery et al., 1985; Young & Kahana, 1989); and how they have categorized caregiving activities (Albert, 1991; Archbold, 1983). Although these studies have provided important information about the amount and types of caregiving activities, they have provided only limited information about the environment within which the activities are performed.

Studies have also examined caregiving activities designed to manage the older person's illness. Activities measured in this category of caregiving work have included systems to handle emergencies (Smith, Smith, & Toseland, 1991), the monitoring and reporting of symptoms (Oberst et al., 1989), and the provision of health care regimens prescribed by a physician (Horowitz, 1985; Oberst et al., 1989; Stetz, 1989). Because of the uncertainty generated by managing serious medical conditions at home (Cossette &

Levesque, 1993; Oberst et al., 1989; Stetz, 1989) and transitions in these conditions, caregivers need to increase the predictability of the caregiving situation. Environmental modification strategies used to facilitate the provision of care regimen activities may increase the overall predictability of the caregiving situation for the caregiver.

Impact of Caregiver Work on Caregiver Outcomes

Caregiving research has also focused on the impact of caregiving work on caregiver outcomes. Caregiving activities have been associated with higher levels of mental health symptomatology (Cossette & Levesque, 1993; Given et al., 1990; Young & Kahana, 1989), lower levels of physical health (Young & Kahana, 1989; Stetz, 1989), objective burden (Montgomery et al., 1985), strain (Cantor, 1983), and stress (Oberst et al., 1989). As caregiving activities increase, caregivers are forced to change their schedules (McCorkle et al., 1993). The revised schedules may not allow sufficient time for other responsibilities, and frustration may result (Walker, Martin, & Jones, 1992). Strategies suggested as having the potential to reduce the negative impact of work associated with caregiving on caregivers have included environmental modifications such as obtaining equipment and environmental supports (Montgomery et al., 1985) or providing an environment that is modified to accommodate physical limitations (Baillie et al., 1988).

Potential of Environmental Impact on Caregiving

Given, Collins, and Given (1988) present a conceptual framework for understanding the factors that influence stress among families caring for a demented care receiver. The framework identifies the caregiving environment as a factor that influences the quality and course of the caregiving. The authors define the caregiving environment in terms of the social and economic resources available to the caregiving dyad. Three factors are especially salient: the social supports for the caregiver, the community services used, and the financial conditions imposed by caregiving. Research prior to date on these three topics was presented to substantiate the authors' claim that the caregiving environment as defined in the model has a direct effect upon the caregiver's reactions to caregiving. However, the model could be strengthened by utilizing a more comprehensive definition of the environment that would include the physical domain defined by Lawton (1982) as the nonpersonal, nonsocial aspects of the environment. Incorporating this factor into the definition of the caregiving environment provides the clinician using this model with another option for intervention to reduce stress in a given caregiving situation.

Birkel (1987) examined the relationship between the strain in providing home care for demented and physically impaired elders and three social ecological variables: household size and composition, the amount of time and type of tasks involved in caregiving, and the pattern of events of daily living. Two groups of 20 caregiving dyads were included in the study: those in which the care recipient was cognitively impaired but physically well and those in which the care receivers were lucid but physically limited. Lucid physically impaired elders did better in smaller, undermanned households where they were more challenged and experienced reduced competition for scarce resources such as time and space. Demented elders did better in larger households in which there were more social cues and prompts and monitoring was easier. The small nuclear family seemed to be well suited for the demands of caring for a physically impaired elder. However, this same social arrangement appeared to be far less suitable for caregiving for the cognitively impaired. Because of the important differences that Birkel found, a question arises as to whether an optimum environment can be created for the large majority of older people who have both physical and cognitive impairments.

In a study of multigenerational caregiving families, household characteristics were examined in relationship to perceptions of household space, burden, and satisfaction (Pruchno, Dempsey, Carder, & Koropeccky-Cox, 1993). Household characteristics were measured with a series of questions that described: the type of dwelling (e.g., detached, single, attached home or townhouse, apartment); the resources the elder had of their own (e.g., bathroom, bedroom, separate entrance, telephone line, television); the time the elder spends in shared living spaces; and whether physical changes had been made to the home to accommodate the addition of the elder to the household. More rooms were associated with lower levels of burden for all family members and higher levels of satisfaction for daughters. More separate amenities were related to less negative impact on household space perception. Making some sort of conversion of space in the home increased the negative household perception for both the caregiving daughters and their husbands. Although these individual correlational findings are intriguing, a multiple regression analysis using the household characteristics as predictors failed to significantly predict household space perception, burden or satisfaction. Unfortunately, the authors failed to address this in their discussion of the findings and instead focused on the meaning and implied importance of the results. A small sample size may have been responsible for the lack of significance of the findings.

Previous Research on Caregiver's Use of Environmental Modification Strategies

Relatively little research exists regarding environmental modification and its effect on home-based family caregiving. The focus of the limited qualitative research addressing environmental modifications was with dementia caregiving families. Clinical articles directed at teaching home caregivers how to use environmental modification strategies have been written by experts in long-term care who are translating their knowledge of behavior management in the nursing home to the home setting. For example, Pynoos, Cohen, and Lucas (1989) outlined environmental coping strategies that can be used to create home environments that are more safe and supportive for Alzheimer's sufferers and caregivers. In their article identifying management strategies for persons with dementia at home, Hall and colleagues (1995) included interventions to modify the environment. A limitation of this literature is that the knowledge of what works with environmental modification strategies is based on the experience of professionals in institutional settings.

Harvath (1994) examined the specific strategies used by caregivers to manage the behavior problems of cognitively impaired family members at home. A qualitative design was used to gather interview data from 10 female caregivers who were managing behavior problems with low stress as well as from caregivers who were struggling. One of the caregiver interventions identified in this study was managing the environment; it was defined as directing efforts outside the care receiver in order to change the situation in which the care receiver is behaving and included management of the physical and social environment. An additional important finding of this study was that the interpretation of the aberrant behavior affected both the management strategies used and the consequences experienced. There are many nursing implications for this finding for educating caregivers about the cause and control of problem behavior, for identifying problematic contextual situations, for setting realistic measures of success, and for teaching additional ways for caregivers to intervene.

The potential for environmental modifications to make caregiving easier was explored in only two studies (Calkins & Namazi, 1991; Olsen, Ehrenkrantz, & Hutchings, 1993a). The aims of the Calkins and Namazi (1991) study were to identify modifications made by caregivers to homes, to ascertain the effectiveness of each modification, and to evaluate the impact of these changes on the confused person and his or her caregiver. In this study 59 primary caregivers were interviewed over the telephone using a semi-structured interview guide that asked respondents to focus on the difficult behaviors of their care recipients, to report the environmental modifications made, and to rate their effectiveness by choosing one of three options: worked well, worked somewhat, or did not work at all. The findings indicated that home modifications were grouped into four categories: those intended to manage wandering, those designed to manage incontinence, those expected to promote safety and independence, and those intended to manage disruptive activities. Modifications that were rated effective for caregivers included those that made caregiving easier, decreased anxiety, increased safety, and made the home easier to clean. Modifications that were rated effective for care receivers made the environment less distracting, made the patient more independent, averted institutionalization, and increased care receiver safety. Every participant had made at least one modification of the physical environment, which suggested that these caregivers used home modifications as a therapeutic tool in caring for someone with a cognitive impairment.

Calkins and Namazi (1991) acknowledged several limitations of their study including a limited sample size, a lack of differentiation among caregivers according to the stage of dementia of their care recipients, and possible inaccuracies in recording modifications due to total dependence on subject recall to collect data. However, the authors did not address the following deficiencies. First, the sample was not sufficiently diverse from either a gender, race or socioeconomic perspective. Caregiver participants were primarily female (78%), white (96%), high income (53%) with income of $31,000 or more, and were either spouses (44%) or children (51%); as a result, the sample did not represent a broad range of possible caregiving situations. Second, the authors' data collection interview strategy was limited in two ways. The short duration of the interviews (e.g., some were as short as 20 minutes) resulted in a rather limited description of the caregiver's perspective. Second, the interview guide assumed that environmental modifications were only made only in response to behavior problems as opposed to a broader range of caregiving issues or goals. The study could have been improved with a more diverse sample and a data collection strategy that combined broader based interviews with observation.

An environmental modifications study that also used caregiving problems as a focal point of interviewing and data analysis was conducted by Olsen et al. (1993a). The aim of this study was to describe the potential for environmental modifications to make caregiving easier. These researchers interviewed 90 long-term family caregivers of older people with dementia in their homes to elicit their experiences with safety, home modifications, agitated behaviors, and tactics for maintaining the care recipient's strength. Caregivers were asked to talk about the problems they had providing care. They were then asked to rate each modification made and describe why it did or did not work, and to rate the physical dwelling as to whether or not it made caregiving easier. The researchers found that caregivers developed a large number and wide variety of modifications to make caregiving easier and to maintain the functional health of the older person. The authors concluded that the home environment could be an important caregiving variable and source of support. A limitation of this study was its focus on problematic situations rather than the broader concerns of caregivers. As Smith et al. (1991) noted, issues such as enriching the elder's life are just as much a concern for caregivers as is managing problem behaviors. Researchers need to be aware of how they may be truncating the information they receive by the design of their interview or data collection strategies.

The present study expanded upon the work of Olsen et al. (1993a) and Calkins and Namazi (1991) in three important ways. First, the sample was expanded to include older people with physical impairments and chronic illness requiring care regimens. Second, caregiving activities, rather than caregiving problems, was used to prompt the discussion of the environmental modification strategies caregivers used. Third, effectiveness was examined in depth qualitatively and not rated quantitatively. Thus, the study examined a broader range of environmental modification strategies with a more diverse population of older people and their family caregivers.

Home Health Nursing Care: A Limited Focus on the Family's Role in Modifying Caregiving Environments

Caregivers are likely to turn to home health nurses to learn about care regimens and to learn how to meet physical needs (Stewart, Archbold, Harvath, & Nkongho, 1993). Home modifications are usually required if care regimens are to be used successfully in the home (Horn, 1990). In a 1987 Delphi survey of Medicare-certified agencies in the Northwest Region, home care nurses expressed concerns that many homes were not properly equipped for providing care and that households were often confused and disorganized (Pesznecker, Horn, Werner, & Kenyon, 1987). A number of the nine clinical dilemmas identified as most critical included problems that required some degree of home modification such as adapting the home to medication regimens, management of wounds, diabetic care, cancer symptom management, intravenous therapies, and dealing with family caregiving problems (Horn, 1990). The results of the survey guided the development of clinical papers on care problem areas. For example, a paper by Pesznecker, Patsdaughter, Moody, and Albert (1990) reviewed the challenges faced by home care nurses trying to help elderly persons to adapt their medication regimens to the home setting. One of the interventions least frequently used was changing the home environment to compensate for sensory and functional deficits that were making it impossible for elderly clients to adhere to their prescribed regimen. A number of the other clinical papers indicated that nurses rarely thought about assisting the family to make home modifications. In addition, the clinical papers' recommendations for home modifications were directed at the nurse as the agent of implementation, not at family members.

Despite the acknowledged importance of involving patients and family caregivers in the determination of their needs for home care services, evidence suggests that some professionals use observation, rather than communication, to determine needs (Peters, 1991). Because research has shown that family caregivers tend to use formal care in a complementary rather than a substitutive role (Weiner & Hanley, 1992), caregivers and home health nurses can work at cross purposes when there is a lack of communication. There can also be discord between what the family perceives as the home health nurse's role and what the nurse perceives his or her role to be. This is compounded when family caregivers are required to make decisions on behalf of the older person. Such inadequate communication and the perception of some persons who have received home care that home health nurses foster dependence (Magilvy, Brown, & Dydyn, 1988) may explain, in part, why caregivers at times do not adhere to the nurse's recommendations. The intent of this study was to further our understanding of the family caregiver's involvement in decisions regarding home modifications and how these evolve over time.

CHAPTER 3: METHODS

Design

A qualitative descriptive design was chosen for the present study because the research questions involved a little-known phenomenon for which few relevant variables have been identified. In addition, a qualitative descriptive design had the most potential to explore why caregivers' local knowledge and the nursing practice are at odds in the home heath care setting. The unique strengths of this type of research design are its assumption of the value of context and setting, the search for a deeper understanding of the participant's lived experiences of the phenomenon, and the recognition that it is essential to know how participants define their situations (Marshall & Rossman, 1995). The goal for utilizing a descriptive exploratory design was to document the strategies of interest, to discover and identify important conditions affecting these strategies, and to generate ideas for further research. The design strategy (Marshall & Rossman, 1995) was carefully matched with the data collection techniques of intensive interviewing and participant observation (Lofland & Lofland, 1995; Merton, Fiske, & Kendall, 1990; Morse & Field, 1995) to discover the salient behaviors, beliefs, attitudes, and processes occurring in the phenomenon.

It was important to design the research as it evolved. Consequently, building flexibility into the design was crucial (Marshall & Rossman, 1995). The plan for the research included many elements of a traditional approach, but it deliberately contained designated decision points to modify and change the initial plan during data collection. The purpose of these iterations was to increase theoretical saturation of the data via refinements in the sampling strategies, interview guide, and other data collection strategies and analysis methods. Figure 1 is an event-state network (Miles & Huberman, 1994) that illustrates the design iterations of the study according to a time line. Design and procedure changes were made to focus and refine the analysis.

Setting

Whenever possible, data collection took place in the care receiver's home. This setting was selected for this study due to its identification as an environment where all the contextual variables would be operable. The in-home setting was more conducive to providing the researcher with an understanding of the behavior of the caregiver and the care receiver within the framework where they interpret their thoughts, feelings, and actions. The home setting of the care receiver was also chosen because: (a) entry was possible via the investigator's contacts with hospital discharge planners and clinic nurses; (b) it had a high probability of providing a rich mix of the processes, people, and interactions germane to the research questions; (c) the investigator was likely to be able to build trusting relations with participants due to her years of experience as a home health nurse; and (d) data quality and credibility were ensured because of the likelihood the home contained many objects and stimuli pertinent to the research aims (Cookman, 1996; Rubinstein, 1989).

The types of housing observed in the course of the study included mobile homes, apartments, duplexes, condominiums, and private homes. The settings varied in that some were age-segregated, low-income, and/or very expensive. Sixteen (67%) of the care receivers lived with the caregiver. Caregivers who did not live with the care receiver varied

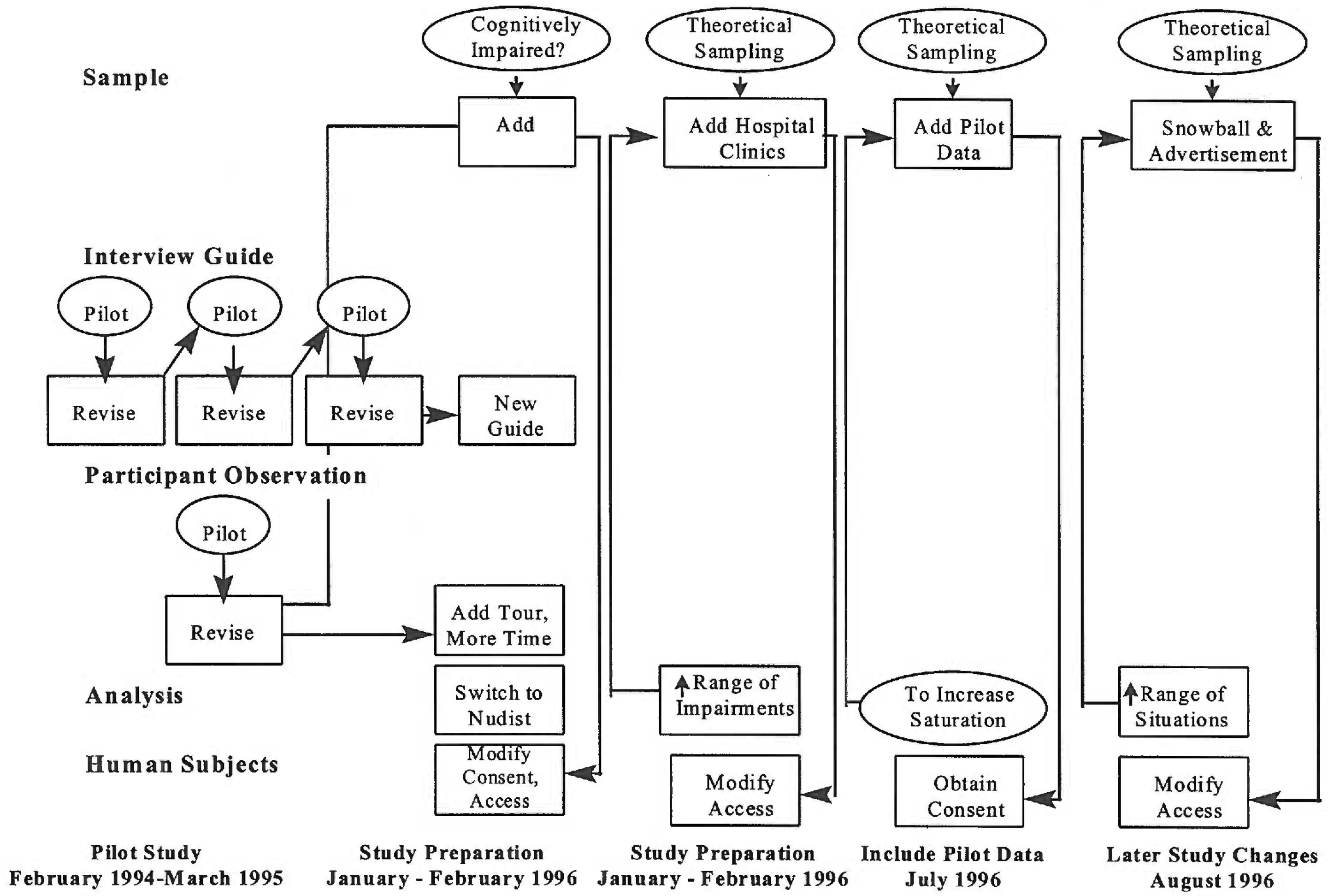

Figure 1.

Iterative design.

in the distance that they lived from the care receiver. Some caregivers lived next door, others lived out of state. Among the child caregivers who lived with the care receivers, all but one had moved the care receiver or parent to live with them in either a house or apartment. Very few of the homes, even in the age-segregated communities, could be considered handicap accessible by the American National Standards Institute and Uniform Federal Accessibility Standards (Mumma, 1987).

Participants

Once the decision was made to focus on environmental modifications in the home setting, waves of subsequent sampling decisions were made. The sampling strategy began as a search for information-rich cases in order to study caregivers who were likely to have made environmental modifications. As the study progressed, it became apparent that the initial sample access procedures and screening criteria needed to be modified. Sampling decisions were always made on the basis of achieving appropriateness and adequacy of the data. Participants were selected according to their ability to inform the research (Morse & Field, 1995). As data analysis progressed, new sources of participant access were identified to meet this ongoing requirement. Sampling adequacy was addressed by ensuring enough data were collected to develop a full and rich description of the phenomenon.

Recruitment

The iterations of the sampling access procedure are described below. Initial participant access and screening procedures are also outlined, and the rationale for changes made to accommodate the need for theoretical sampling are also provided.

Initial Screening Criteria

Initial sampling was guided by the desire to meet family caregivers and older people who, by virtue of their engagement in caregiving activities, were likely to have used environmental modification strategies. The older person had to be: (a) 65 years or older and (b) eligible for skilled home health care (e.g., wound care, diabetic care, IV therapies). Caregiver participants for this study were: (a) the self-identified primary caregiver for the older person referred for skilled home health, (b) at least 18 years of age, and (c) able to speak English.

Initial Participant Access and Screening Procedures

Initial care receiver/caregiver dyad participants (n = 4) were recruited from referrals made to local area home health agencies by a large urban health services university in the Pacific Northwest. The hospital refers older people from a range of ethnic and socioeconomic classes for home health care in the metropolitan area. Sample access and screening procedures were as follows. The investigator reviewed weekly the computer log kept by the discharge planners to identify older persons referred to skilled home care. The investigator reviewed the referral record to determine if the person met the initial screening criteria. When potential participants met the initial screening criteria, a letter from the Associate Hospital Director, a letter from the investigator, a copy of the interview consent form, and the interview guide were sent to the older person's home inviting participation in the study. The letter explained the study and informed them of their right to refuse to participate. The letter indicated that the investigator would like to contact the older person (or guardian) by phone to further explain the study and invite participation.

Persons who did not wish to be contacted were asked to return a postage-paid postcard to the investigator within 2 weeks. For those who did not return the postcard the investigator called the older person, inviting their questions about the study, verifying that there was a family caregiver, and asking their permission to contact the primary caregiver. If the older person was unable to come to the phone, or seemed to be confused during the telephone call, the investigator asked to speak to another adult in the household. The purpose of the phone call was explained to the adult family member. The investigator determined if there was a legal guardian for the older person or a primary caregiver. When there was a primary caregiver, the investigator contacted him or her to invite his or her questions about the study, to determine his or her willingness to participate, and to verify that he or she was 18 years of age or older and spoke English. When the caregiver agreed to participate, an appointment for an interview was set at a place determined by the caregiver.

Refusals to participate were recorded systematically. A relational database was created to track recruitment and participation. A total of 70 charts were reviewed. Of those 19 care receivers who met the inclusion criteria, 12 were ineligible to participate because no family caregiver was available to be interviewed, the care receiver had no current disability, or the family did not wish to participate because the care receiver had died. Among the 7 potentially qualified care receiver participants, 2 family caregivers refused to participate because their own health was very poor. One potential African

American care receiver participant who had agreed to have her caregiver be interviewed went to the hospital on the scheduled date of the interview and died. Thus, 4 caregivers participated from this data source.

Theoretical Sampling

Subsequent purposive sampling was used to achieve maximum variation of the target phenomenon (Sandelowski, 1995) the research questions were intended to address. Throughout the study, maximum variation in the type of impairment of the care receiver, the caregiver-care receiver relationship, and demographic variation found to be germane in quantitative caregiving studies such as gender and race were sought in the sample. To achieve maximum variation, additional sampling access strategies were employed. To increase theoretical saturation of the data, permission was also sought to include pilot work data in the final analysis.

Variation in type of impairment. The care receiver's type of impairment has been found to mediate the relationship between caregiving outcomes and environment (Birkel, 1987). Consequently, maximum variation in the type of impairment of the care receiver was sought in the purposive sampling strategy for this study. Therefore, care receiver/caregiver dyads (n = 8) were recruited via hospital clinics specializing in the care of Alzheimer's and Parkinson's disease patients. Care receivers served by these clinics had cognitive and mixed impairments. Care receivers recruited via the hospital sample were primarily physically impaired.

Sample access and screening procedures from the clinics were similar to the procedure described for hospital discharges with the following exceptions. Instead of the investigator reviewing a log of patients to identify older persons eligible for skilled home care, the nurses in the clinics identified individuals from their caseloads. If potential caregiver/care receiver dyad participants met the screening criteria, the professional staff approached the patient and family caregiver to ask permission to give the investigator their names and phone number for possible participation in the study. The family was given a letter from the investigator describing the study and a postage paid postcard that they could use to decline being contacted. If after 1 week the postcard had not been returned, the investigator called the older person.

A total of 9 care receiver/caregiver dyad referrals were made by the registered nurses in the hospital clinics, all of whom met the inclusion criteria. Among the 9 potentially qualified participants, 1 family caregiver refused to participate because her own health was very poor. A total of 8 participant caregiver/care receiver dyads were recruited from these clinics. Among the care receivers, 6 had mixed disabilities, 1 had a cognitive disability and 1 had a physical disability.

Further saturation of variables emerging in the analysis. To increase saturation of categories emerging from the data analysis, the investigator sought permission from the Institutional Review Board (IRB) to include pilot work data collected to pretest the interview guide in the data analysis. Six caregiver participants had been recruited for the purpose of refining the interview guide in the period from February 1994 to March 1995. In order to gain permission from pilot participants to use the data, a packet was constructed and mailed that included a complete copy of the pilot transcribed interview, a letter explaining the request to use the data for a purpose other than it was originally collected for, and a consent form with a stamped envelope for reply. All of the pilot participants (n = 6) agreed to let their data be used for the dissertation analysis.

Variation in caregiver relationship to care receiver and demographic variables. Previous caregiving research has demonstrated that son and daughter caregivers have different perspectives on caregiving than do husbands and wives (Cantor, 1983;. George & Gwyther, 1986). Differences in outcomes between male and female caregivers have also been documented (Cantor, 1983; Fitting, Rabins, Lucas, & Eastham, 1986; Horowitz, 1985). In general, African American caregivers have experienced less strain despite their objectively more difficult caregiving situations (Mui, 1992). Consequently, further maximum sampling strategies sought to seek variation among participants on these salient demographic variables. Specifically, further recruitment strategies were used to obtain caregiver participants among daughters, females, and from a minority group.

Additional female and minority caregiver participants were recruited via the qualitative participant access technique known as snowball sampling and through a newspaper advertisement. According to Lincoln and Guba (1984), snowball sampling utilizes nominations from participants and others familiar with the study to identify persons who are likely to be knowledgeable informants and who also may be interested in participating.

The newspaper advertisement contained: (a) the name and address of the investigator, (b) the purpose of the research and eligibility criteria, (c) a description of the benefits from participation in the study, and (d) the location of the research and who to contact for further information. The advertisement was displayed in a local weekly paper for 8 weeks. Sample access from these sources were as follows. Individuals who were willing to nominate other potential participants were asked to contact those individuals to see if they could give the investigator their name and telephone numbers to invite participation. When they agreed, the investigator first contacted them by telephone. Potential participants from the advertisement contacted the investigator by telephone. These potential participants did not get a letter from the investigator. Instead, during the telephone contact, the investigator: (a) explained the purpose and the procedures of the study, (b) ascertained the participant's eligibility to participate in the study, and (c) ascertained the participant's willingness to participate in the study. When an eligible participant agreed to participate, the investigator scheduled an appointment for an interview at a time and place determined by the participant. If the eligible participant did not wish to participate, no further contacts were made.

Seven additional caregiver participants were obtained via these methods. One referred husband caregiver refused to participate without providing a reason. This strategy succeeded in adding 4 daughter/female caregiver participants to the study, 1 of whom was an African American. A son caregiver was also recruited via this method for a total of 5 caregiver participants. In addition, one granddaughter caregiver and her husband participated in this study. Although the husband was not recruited as a participant, when the investigator arrived in the home to do the interview, he wanted to participate as well. The husband also signed a family caregiver consent form, and his data was included in the analysis. Thus, of the total sample of 24 primary family caregivers, 4 were obtained from hospital discharges, 8 from Alzheimer's clinic referrals, 6 from pilot participants, 5 from snow ball sampling and 1 from an advertisement.

Description of Participants

Sampling Adequacy

Achieving redundancy in the information learned about the caregiver's use of environmental modification strategies was the criterion used to determine sample size adequacy. A total of 44,186 textual lines of data were collected for the study. The interview component of the study used a sample of 24 family caregiving situations of an older person. During 8 interviews, the care receiver was present and contributed information. Fifteen of these interviews were 2 to 3 hours in length, 6 were 1½ hours in length and 3 were 1 hour long. From this larger sample, a subset of 12 caregivers and their older care receivers participated in the participant observation component of the study. Five of the observation episodes ranged between 2 and 2½ hours in length, 3 were 1½ hours long, and 4 were 1 hour in length. Most of the caregivers and care receivers who participated in the participant observation portion of the study offered a tour of the home (n = 11). One son caregiver spent an hour showing the investigator the special objects he was moving to his mother's new living situation in the trunk of his car. Additionally, five caregivers were observed performing various caregiving tasks for the care receiver. A total of 41 interviews and/or observations were completed.

Demographic Characteristics of the Sample

The sample consisted of 24 caregivers who ranged in age from 33 to 88. Thirteen of these caregivers were under the age of 65 and of these, 10 were in their 40s. Eleven of the caregivers were 65 and older and of these, 9 were between the ages of 65 and 74. However, 2 caregivers were older than 75; the eldest was 88. Age categories above 75 years of age are associated with progressively higher rates of disability than the younger old age group (Hobbs & Damon, 1996). Seventy-one percent (n = 17) of the caregivers were female and 29% were male (n = 7). This percentage profile of gender is consistent with the proportions reported in a national survey of caregivers done by Stone, Cafferta, & Sangl (1987). Twenty-two caregivers were white, 1 was African-American, and 1 was Hispanic. All of the caregivers had at least a high school education. Eight caregivers had high school diplomas, 9 either had some college or a bachelor's degree, and 7 had a master's or doctoral degree. Of the spouse caregivers, 6 were husbands, 4 were wives, and 2 were female live-in partners. Of the child caregivers, 10 were daughters, 1 was a granddaughter, and another was a son. In summary, half of the sample were spouse or spouse-like caregivers and half were children caregivers. Sixteen of the caregivers lived with the care receivers, of these, 12 were spouses, the remaining 4 were daughters. Among the daughters, 3 had brought the care receiver into their home and 1 had moved in with the care receiver. Years of caregiving were relatively evenly divided among fairly new caregivers (1 to 2 years, n = 7), more established caregivers (3 to 4 years, n = 8), and very experienced caregivers (< 4 years, n = 9).

Care receivers ranged in age from 65 to 91. Seven of the care receivers were between 65 and 69 years old, three were 70-74 years old, three were 75-79 years old, four were 80-84 years old, and seven were older than 85. Consequently, 11 or nearly half of the care receivers were in the age categories associated with the highest percentages of persons needing assistance with daily living activities (31% and 50%, respectively) (Hobbs & Damon, 1996). Because of the very frail status of a number of the care receivers, four had actually died prior to the scheduled interview, but the caregivers still wanted to participate and were included in the study. Ten of the care receivers were male (42%) and 14 were female (58%). Twenty-two of the care receivers were white, one was African American, and one was Hispanic. Eleven of the care receivers had a high school education or less, and 13 had a college education or better. The number of care receivers with advanced degrees was substantially less than among the caregivers (n = 2). Consistent with Birkel's (1987) estimates of impairment among the elderly, 50% of the sample (n = 12) had both physical and cognitive impairments. Eight of the care receivers had only physical impairments (33%) and four (17%) had only cognitive impairments. Impairment category decisions were initially made on the basis diagnosis. However, during the analysis of the data it became apparent that diagnosis was not an accurate predictor of level or kind of impairment. As a result, the categorization of care receiver impairment was changed to use of the caregiver's report of observed functional limitations.

Minority representation. Ethnic representation in this study was limited. The study only included one African American daughter and one Hispanic wife. One other African American family agreed to participate, but the care receiver died before the investigator could make the home visit for the interview and the family declined to participate at that point in time. Another Hispanic daughter had agreed to participate, but had to leave the country unexpectedly and did not return in time to be interviewed.

Data Collection Methods

Intensive interviews and participant observation were used to increase the researcher's ability to understand the phenomenon of interest (Lofland & Lofland, 1995). The purpose of participant observation in this study was to observe the physical setting in which caregiving activities took place and the people involved as they performed various caregiving activities (Spradley, 1980). Intensive interviews and participant observation were chosen over other possible approaches to data collection because of the deficits noted in previous studies (Namazi & Calkins, 1991; Olsen et al., 1993a) which relied primarily on interview data.

Intensive Interviews

Intensive interviewing (Lofland & Lofland, 1995) was used to collect detailed information from caregivers. Caregivers were asked to describe the nature and effectiveness of the environmental modification strategies used and how these changed over time. Although care receivers varied in the extent to which they participated in thinking about and incorporating environmental modification strategies, their perspective was not an emphasis of the study. Considerable pilot work was done to ensure that the interview would yield a wide range of applicable data that were of sufficient specificity, depth, and richness of context (Merton et al., 1990) to answer the research questions.

Interview Guide

The interview guide used caregiving activities to help family caregivers describe the environmental modification strategies they had used. The pilot study yielded rich data using caregiving activities as the stimulus for helping caregivers' remember the environmental modification strategies they had made. A paper describing the pilot data appears in Appendix A.

A series of three sets of pilot interviews with 2 caregiver participants per series were conducted with a total of 6 caregivers (four daughters, one wife, and one husband) between February 1994 and March 1995 to develop the interview guide. The steps used in the construction of the guide were similar to those described by Morse and Field (1995). Initially, a semi-structured interview guide was constructed using themes abstracted from the Direct Care Scale of the Family Caregiving Inventory (Archbold & Stewart, 1986, 1994). The scale contains 80 items that address eight categories of caregiving activities: personal care; behavior management; medically related management; protection; health, legal and financial decision-making; little extras; transportation; and housekeeping. The guide was then reviewed by the dissertation committee to ensure questions were open-ended. The guide was pre-tested with 2 daughter caregivers, and the transcripts were reviewed to identify potential areas of confusion. The pilot data were reviewed with Dr. Margaret Imle (personal communication, April 6, 1994) and a qualitative seminar of doctoral students to revise the guide. The revised guide was then tested with 2 spouse caregivers. The interviews were transcribed and the data analyzed to ensure that the information obtained would provide useful answers to the study questions. A problem was identified because it did not seem to the investigator that the interview was capturing the full range of the caregiver's use of environmental modifications because the structure of the guide was still somewhat disorganized.

Consultation with Dr. David Morgan (personal communication, February, 23, 1995) was sought to improve the organization of the guide. Per Dr. Morgan's suggestion, the items of the Direct Care Scale (Archbold & Stewart, 1986, 1994) were written on 3 x 5 cards and those items that were associated with environmental modifications in the pilot data were highlighted. The 80 items were then sorted into the original subscales which address eight categories of caregiving activities. The cards were then sorted again into piles and categorized into thematic areas based on two criteria: (a) a logical possible association with a potential need to use an environmental modification based on the investigator's 12 years of experience as a home health nurse and (b) a demonstrated association of a caregiving activity with an environmental modification based upon pilot interviews. Eight thematic areas in caregiving likely to be associated with environmental modifications emerged from this inductive process: (a) the need to adopt changes in personal care routines, (b) the need to supplement functioning of an impaired care receiver, (c) mobility problems encountered in the home and outside of it, (d) managing behavior changes caused by dementia, (e) assuming medically related tasks and responsibilities, (f) the need to prevent accidents, (g) the need to adopt changes in household functioning routines, and (h) the need to change how the family spends time in the home. The probes were designed to elicit a full description of the specific modifications and goals the caregivers were trying to achieve, the caregiver's perception of the effectiveness of the modifications, and information about the intervening and causal conditions that affected the implementation of modification strategies over time. The general layout of the interview guide was based on a funnel approach to interviewing that starts with a grand tour question, moves initially to thematic areas and then to specific issues as indicated (Morgan, personal communication, February, 23, 1994; Weiss, 1994). The revised interview guide was pilot tested in two different family caregiving situations, one with a physically impaired older person and the other with a cognitively impaired older person. Analysis of the data from these interviews indicated that the organizational problems had been solved. The iterations of the interview guide appear in Appendix A along with a paper describing the pilot study used to develop the guide.

Participant Observation

Participant observation was used with selected caregiver and older person dyads. Participant observation focused on tours of the home with commentary by the caregiver of the features that were especially salient. These tours were recorded by the investigator via detailed field notes. Field notes described the particulars of the physical environment of the home as well as the artifacts families deemed were important to describe. Caregiving activities that were observed included assisting with ambulation, inserting a hearing aid, giving medications, providing food and fluid, taking an older person to the bathroom, filling an oxygen portable canister, and checking on the status of the care receiver. Observations were focused on the physical environment of the home, but details about the caregiver and the older person receiving care within that setting were also included. Field notes were used to document observations about: the physical environment where caregiving took place; the people involved; and the activities being performed, including the physical objects involved, their meanings, and sequencing of all actions (Spradley, 1980). Goals identified by the participant caregiver for any environmental modification strategies were also noted.

Data Collection Procedures

Primary family caregivers to older people eligible for home health care participated in the intensive interview and participant observation components of the study. The older persons to whom they provide care were included in the participant observation component of the study if they also consented. Older people with cognitive impairment were included in the participant observation only if their caregivers gave proxy consent. The investigator asked the caregiver to make the decision regarding participation in the observation portion of the study, keeping in mind what would be the most comfortable for the cognitively impaired older person.

Interviews were scheduled at a place and time convenient to the caregivers that also ensured privacy. All interviews were audiotaped and transcribed verbatim. The investigator always used two recorders to ensure that no data would be lost due to equipment malfunction. The expression of the participant's thoughts was acknowledged with active listening, carefully worded probes, and empathetic responses. The investigator allowed the participant to answer questions as they desired. The participants were regarded as collaborators (Connors, 1988) in this study in recognition of the local knowledge (Harvath et al., 1994) that they bring to the research endeavor. Participant observation took place in the older person's home either at the time the caregiving activity was being performed or during the guided tour. The majority of interviews, and all but one instance of participant observation, took place in the older person's home. The interview guide was referred to during the interview session, but exact wording, probes for more information and the order in which questions were asked, was tailored to each situation (Keith, 1994). The time devoted to each interview was adjusted to the individual participant's availability and fatigue level. Although it was anticipated prior to the start of the study that the time frame would be relatively short (1 to 1½ hours), this was not the case with the spouse caregiving families, who seemed to enjoy the opportunity to speak at length about their homes.

Participant observation was conducted at a time convenient for both the caregiver and care receiver. The spouse caregiving families preferred to participate in this component of the study on the same day that the interview was conducted. For the multigenerational caregiving families, some preferred the same day as the interview (one was conducted in the evening after the caregiver returned from work) and others who did not live with the care receiver suggested a separate visit to the care receiver's home. An unplanned participant observation opportunity arose when a son offered to show the investigator the contents of his car holding his mother's most precious belongings, as he was in the process of moving his mother to an adult foster home. A contact summary sheet was completed following the interview and subsequent observations (Miles & Huberman, 1994).

Data Management Procedures

A coding system was used to track the data. All personally identifying data were removed from transcripts and field notes. The audiotapes of interviews were stored in a locked cabinet once data were transcribed and verified. Names and other identifying information were not connected with the textual data. Data were stored in a locked file in the researcher's home and office and were available only to the investigator and members of the dissertation committee. The coding key that connected participant numbers to the names, addresses, and phone numbers of participants was stored in a separate locked file in the investigator's home. Only the investigator had access to this file.

Interviews were taped and transcribed verbatim and all identifying information was eliminated from the transcripts. Field work notes were transcribed from dictation (Lofland & Lofland, 1995; Morse & Field, 1995) to document participant observations of the environment, people, and activities. Demographic data were collected to describe the sample and were recorded on the interview guide. No participant identifying information was recorded on any of the tapes, notes, or transcripts. All raw project materials, for example write-ups and transcriptions, were stored in a locked file cabinet. The material generated in the analysis was stored in hanging file folders and ordered chronologically and included: coded data; the coding scheme along with its successive iterations; memos; search and retrieval records showing which coded data segments were looked for during the analysis; data displays along with associated text; the step-by-step documentation of what was done to display and write the analytic text; drafts of what was written on the design, methods, and findings; and a chronological log and index of all the above material (Miles & Huberman, 1994).

Human Subjects

The Institutional Review Board (IRB) for the university reviewed and approved the sample recruitment and study protocols. As modifications were made to accommodate the changes needed for theoretical saturation, addendums were filed and approved by the IRB. Risks to participants in this study were minimal. Potential risks to participants included psychological discomfort related to disclosure of aspects of recalling frustrating or difficult caregiving situations. The risk was of low to moderate seriousness and probability. However, the interview topics did uncover sensitive issues or conflicts in the caregiving situation for one daughter caregiver. Psychological discomfort was further minimized during the interview by the investigator's attention to the participant's reactions. The investigator discussed with participants resources for coping with ongoing emotional and psychological stress.

All participants were given the telephone number of the investigator and encouraged to telephone if they had feelings or thoughts after the interview session that they wanted to discuss. Psychological discomfort was also minimized by ensuring that the participants completed the interviews and participant observation in private. Fatigue was a potential risk of low seriousness and low probability. The investigator had experience as a home care nurse and therefore had skill at observing fatigue and discomfort in respondents. Participation in the study did provide indirect benefits through the opportunity for family caregivers to share their innovative environmental modification strategies with the investigator and to gain an appreciation of their own creativity and resourcefulness.

Informed Consent in the Home

Prior to starting the interview the caregivers were asked if they had any questions. The written informed consent (see Appendix B) for the caregiver was reviewed and their signature was obtained. Participants were reminded of their ongoing right to refuse to participate. In order to build trust and rapport (Keith, 1994), time was devoted to explaining why the interview was important and how the participant's contribution fit into the overall study goals. When the caregiver and older person agreed to participant observation of caregiving activities or if they provided a tour of the home, written consent was obtained from the older person or via proxy from the caregiver if the older person was cognitively impaired. The participant's right to withdraw at any time or express discomfort with the observation of the caregiving activity was emphasized.

Procedures for Data Analysis

According to Miles and Huberman (1994), data analysis is broken down into three concurrent flows of activity: data reduction, data display, and conclusion drawing/ verification. Data analysis was begun following each interview and episode of observation. The following discussion is intended to highlight how this iterative process was used to draw final conclusions from the data.

In the initial part of the analysis, coding was done by hand in the margins of the transcripts. The inductive coding technique known as open line-by-line coding described by Strauss and Corbin (1990) and referred to in Miles and Huberman (1994) was used. Colored pens were used to code the modifications used (black ink), statements about effectiveness of the modifications (green ink), and changing conditions bearing on the use of the modifications (orange ink). In addition, larger segments of data were coded with blue ink if they seemed to encompass the description of a more abstract modification strategy. The initial data display for the first four interviews conducted was created on a large roll of butcher block paper using information from these first four cases. This type of display is called a conceptually clustered matrix, and it is used to help the investigator get an immediate grasp on what is going on in the study setting. From this display, a tentative list of codes for the modification strategies were created to facilitate further analysis.

At this point the coded interviews were entered into a qualitative data management program called NU-DIST (Non-numerical, Unstructured Data Indexing, Searching and Theorizing) (Richards & Richards, 1994). Initially, the hierarchical tree coding structure was very difficult to use and did not seem to meet the purpose of inductive coding. Expert guidance was sought from Dr. Margaret Imle (personal communication, July 5, 1996). The consultant suggested putting all codes on one level and categorizing them by assigning numbers to the nodes much like a Dewey decimal system. For example, all the modification strategies had node numbers starting with 500X, all the effectiveness nodes were numbered 600X, and all the changing conditions codes were numbered 800X. Text was kept in an organized data base. The program was also used for recording memos on aspects of the coded data.

Variable data displays were then created for each of the emerging pattern codes. Initially the cell entries were pattern codes juxtaposed with open code labels. Several of these matrices were brought to the dissertation committee meetings which enabled the investigator to verify the conclusions being drawn with experts in family caregiving. Using Nudist search and retrieve functions, variable data displays were also created that juxtaposed data coded as modification strategies along with effectiveness and changing conditions data. This was done to examine the relationships between the emerging pattern codes. At this point an initial attempt was made to map the emerging concepts. The committee gave feedback and direction on these displays. Refinements were then made in the Nudist coding scheme so that the open initial codes were now subsumed beneath the pattern codes.

The command functions in Nudist were then used to create printouts of coded data organized according to the major pattern codes. These printouts were imported into Microsoft Word 7.0 and organized as binders with a table of contents. Over 1400 hundred pages of data were printed out and reviewed by the investigator. From this extensive documentation, meta-matrices or master charts assembling the descriptive data from all of the cases in the analysis were created. Not all of the coded data segments were entered into the meta matrices as the amount of coded data was substantial. Rather, the following decision rules were used for data selection. Data excerpts that were indicative of agreement among three or more respondents, or representative of a certain level of intensity of feeling, or were especially cogent for expressing the significance of a pattern code were entered into the matrix. Detailed feedback was obtained from the dissertation committee on all of these matrices. One of the meta-matrices was presented to a doctoral nursing research seminar. Feedback was used to alter the categorization of some subcodes. To summarize the data further, several causal models were created to examine the role of intervening variables in producing various outcomes. In addition, the effectiveness pattern code was substructed to locate the underlying dimensions of modification strategy outcomes.

Reliability and Validity

Standards for the quality of conclusions described by Miles and Huberman (1994) were used to assess the reliability and validity of the research. The standards contain practical guidelines in the form of questions that can be applied to qualitative work. These standards were chosen to assess the reliability and validity of the study because they follow from the analysis methods used for the study. The standards have parallels to the trustworthiness criteria described by Lincoln and Guba (1984): confirmability, dependability, credibility, and transferability. Each of these will be addressed below.

Objectivity/Confirmability

To demonstrate the objectivity and confirmability of the findings, the studies general methods and procedures were described in detail. The sequence of how data were collected, processed, condensed and transformed, and displayed was presented in a summary of the data analysis. Conclusions were linked with the data displays and verified among the experts in family caregiving on the dissertation committee. Records of the studies methods and procedures were maintained in the following formats. Changes in design and associated thoughts were recorded in detailed minutes taken during each meeting of the dissertation committee and the dissertation chair. In addition, dissertation committee members' thoughts about possible rival conclusions from the data were recorded on the analytical materials presented to them. The investigator usually revised the conclusions to include or account for the alternative interpretations of the data the committee members suggested. Appended to each set of minutes were the analytical displays and write-ups of the methodological questions put before the experts. In addition, a daily journal was kept by the researcher that recorded operational issues and problems throughout the study. Reflections on what might be required to strengthen the study from a methodological perspective were also recorded in this journal. Iterations of the coding scheme and all search operations were saved in dated Nudist database files and stored on Zip (100 Mb) disks to allow later retrieval for reanalysis by others.

Reliability/Dependability/Auditability

Every attempt was made to ensure that the research questions were clear and that the study design was congruent with them. Extensive pilot work was done prior to the initiation of the study to strengthen the interview guide. In addition, pilot work on the observation portion of the study resulted in refinements to these procedures as well. For example, pilot work indicated that a tour of the home helped act as a powerful stimulus for caregivers to think about the researchers questions and link them to their own feelings and responses to the modifications they had made. An observer-as-participant role (Morse & Field, 1995) was maintained in the home settings that the researcher visited. This allowed the investigator the opportunity to spend time observing and interviewing rather than getting involved in the caregiving activities directly. To demonstrate meaningful parallelism across the observation and interview data, the observation data was originally coded into a separate data base in Nudist and then compared with the interview data for discrepancies and contradictory findings. Only after this analytic comparison was accomplished was the observation data integrated into the general study coding scheme.

Definitions were drafted for all of the major pattern codes and then linked with the data displays. Data were collected across a full range of appropriate settings (e.g., various types of housing, different living arrangements), and respondents (e.g., among spouse and child caregivers, care managers and care providers, caregivers of persons with various types of impairments). Coding checks were made on selected portions of the data with the dissertation committee members via the numerous data displays that were brought to the dissertation meetings. One data quality issue arose with one family caregiving husband. In the narrative of the interview, the husband had indicated that his wife had little to no disability prior to her death. The interview data presented a confusing picture of the deceased care recipient's functioning. At times the care receiver was described as moribund, at other times as completely well. Because the care receiver had only recently died, one of the dissertation committee members who was an expert in hospice family caregiving suggested that the spouse's confused recollections were a product of his trying to make sense of what had happened. Otherwise, the investigator felt that the participants' viewed the topic as relatively benign and that they probably felt comfortable rendering a full account of their responses to the phenomenon. In addition, Rodgers and Herzog (1987) found in their study examining the accuracy of factual information obtained from interviewing older adults that older respondents are more accurate than younger respondents. In some cases, although their data were not included in this study, multiple caregiver informants were interviewed and their accounts were convergent with the primary caregiver's observations.

Internal/Validity/Credibility/Authenticity

Every effort was made to provide a thick description of each of the pattern codes that emerged from the data. Thick descriptions were developed for this study that had the following features: (a) the context of the phenomenon was described in detail, (b) the intentions and meanings participants assigned to their actions were enumerated, (c) the conditions that led to the modification's implementation and that effected its' evaluation were made explicit, and (d) the modifications strategies were described in text that could be reviewed by others (Denzin, 1989). These descriptions along with their associated data displays were presented in a research seminar to doctoral students and other faculty to assess the accounts plausibility, comprehensiveness, and internal coherence. Seminar participants were asked to identify rival explanations that could be discussed in the group. Some suggestions were made to change some of the subcode structure, but the basic pattern codes were affirmed as reasonable, given the evidence in the data.

The concepts identified in the data analysis were further verified by an exhaustive review of the literature. The nursing research journals holdings in the university library were searched by hand from the years 1992-1997 for research that might be applicable to the study identified concepts. A similar hand search was conducted in the gerontological nursing and research journals. In addition, a Medline database search with relevant textword terms was conducted for the same time period. All of the findings from this literature review were incorporated into the concept descriptions among the findings.

To verify the accuracy of the conclusions with informants, the causal network display created during the final stages of the data analysis along with a response form modeled on the suggestions presented in Miles and Huberman (1994) was fed back to selected participants. The response form asks the participant reviewer to identify any errors that they see in the causal network, to list any different interpretations, to point out any missing or unimportant elements, and to draw a revised network if they so desire. Feedback from participants was that the investigator's interpretations were consistent with their experiences.

External Validity/Transferability/Fittingness

External validity, or the degree that representations may be compared legitimately across groups, can be compromised in qualitative research by selection, setting, history and construct effects (LeCompte & Goetz, 1982). Selection effects occur when some constructs cannot be compared across groups because they are specific to a single group. This occurs more frequently when the researcher uses designated categories a priori. In this study, all categories were derived from the data. To determine the degree of match between the categories and the reality of the family caregivers, members of the dissertation committee, who are experts in family caregiving, were asked to respond to the applicability of the categories across many family caregiver situations.

Setting effects occur when a construct is a function of an observer-setting interaction and may be treated as equivalent only for groups being observed in a comparable manner. In this study, the home of the care receiver was the preferred setting for doing the interviews because it was assumed that this would provide the most applicable context rich information for other older persons living in the community.

History effects occur when cross group comparisons are invalid due to the unique historical experiences of groups and cultures. It may be that the findings of this study may not apply to minority groups and cultures not included as respondents. Construct effects refers to the extent abstract terms, generalizations, or meanings are shared across times, settings and populations. Peer review by the dissertation committee members served as an audit to ensure that interpretation of phenomenon were examined rather than assumed.

Characteristics of the sample, the setting, and the processes used during the research were fully described to help the individual reader make judgments about the transferability of the findings to other samples. Theoretical sampling was driven by the need to identify families dealing with a variety of care receiver impairments, living arrangements, family relationships, and cultural perspectives. In addition, the literature was reviewed to ascertain the findings congruence with prior related theoretical literature. Findings in other research similar to this study's conclusions were identified.

CHAPTER 4: RESULTS

The discussion of the results is organized according to the study aims. A causal network display was created to facilitate understanding of the emerging concepts from the data in relation to the study aims. According to Miles and Huberman (1994), working toward a variable-oriented display that still retains temporality forces a more inferential level of analysis that pulls the data into a single summarizing form. Thus, the causal network display was used to connect data associated with pattern codes to the specific aims of the study. Figure 2 depicts a causal network display of the most important pattern codes (shown in shaded boxes) related to the study aims that emerged in the data analysis. The arrows indicate how the pattern codes appear to be related.

The central phenomenon of interest in the display is the perceived misfit of the environment with the care receiver's ability to act and function in it. It is important to note that the perception of the caregiver and the care receiver can differ in this regard. The ability of the caregiver and the care receiver to communicate effectively on this issue determines whether or not they have a shared perception of the misfit or a divergent one. The portion of the display that addresses study Aim #1—the environmental modification strategies that family caregivers have used in caring for chronically-ill older people eligible for home health care—is enclosed in the light gray box titled "Using Trial & Error and Serendipitous Discovery." Trial and error and serendipitous discovery, are the iterative processes that caregivers used to implement environmental modifications in this study. The process was iterative, because it was often necessary for the caregiver to try several environmental modification strategies before a satisfactory outcome was achieved. It was

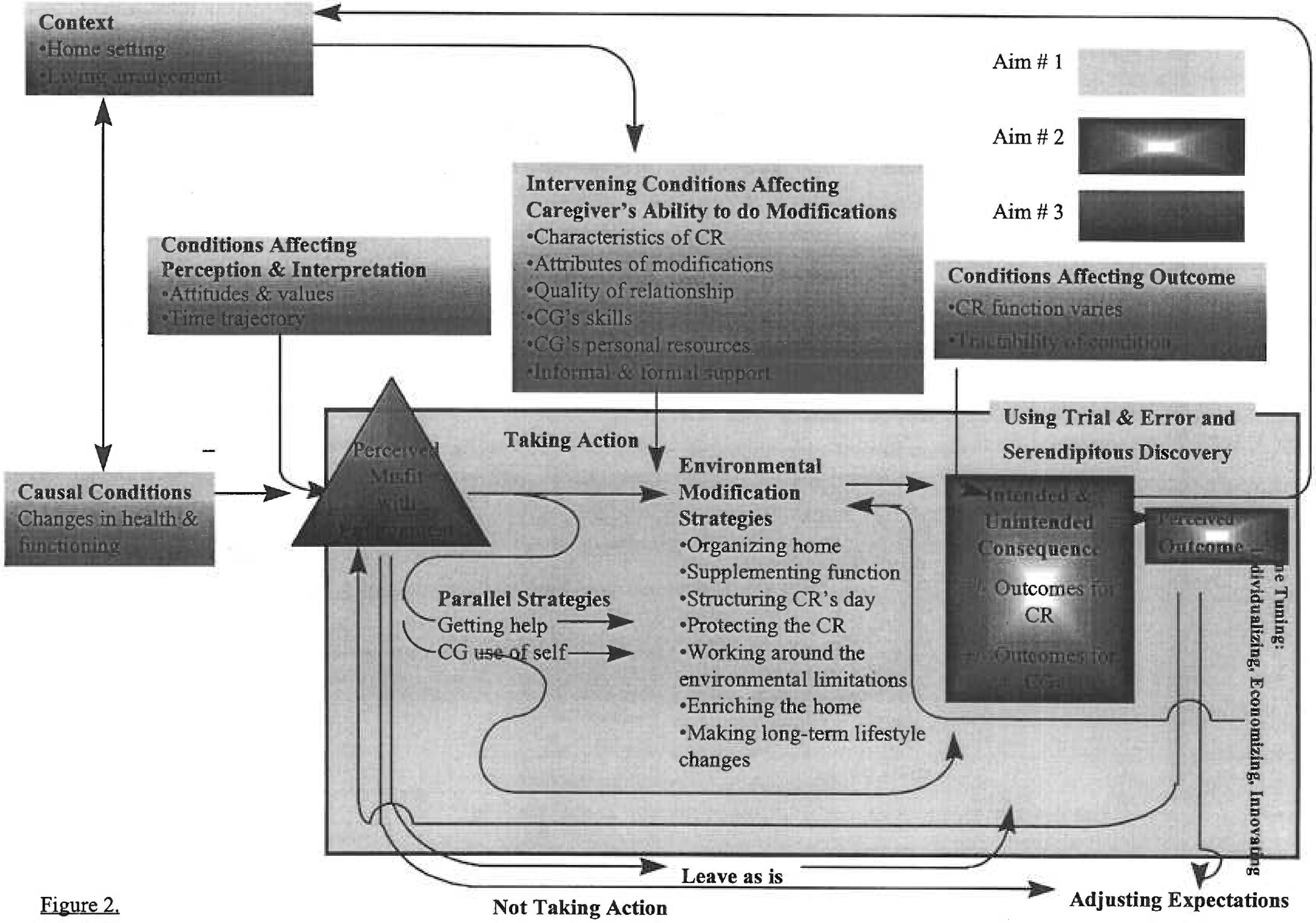

Figure 2.

Causal Network display of the most important codes.

also common for the caregiver to rethink a strategy based upon observing an unintended consequence of some previous outcome. Caregivers either improvised, or refined the environmental modifications strategies they used by innovating, individualizing, or economizing. Within this part of the display, the seven categories of environmental modification strategies used by caregivers are listed. Parallel strategies that can be used either in lieu of making environmental modifications or in combination with these strategies are depicted adjacent to the listed environmental strategies.

Two strategies were employed when no action was taken. These strategies appear outside of the iterative process, but as the arrows indicate, the consequences of these strategies can sometimes initiate new cycles of activity. Leave as is, refers to what happens when caregivers elect not to implement a strategy. If the dyad perceived misfit with the environment to be not of sufficient degree to merit change, there is no reason to take action. In some cases, caregivers adjusted families may adjust to the perceived misfit with the environment by simply changing their expectations about what they could live with and take no action at all to modify the environment. They may also use this type of mental readjustment if the perceived cost of trying to change the environment or maintain a previous level of functioning is too high. Alternatively, families may chose to adjust their expectations if the outcome of some strategy is less than optimal.

There are intended and unintended consequences of taking action and not taking action. The perceived effectiveness of action or no action is based upon a complex assessment of the outcomes for both the caregiver and the care receiver. The portion of the display that addresses study Aim #2—how caregivers evaluate the effectiveness of their environmental modification strategies—is set off by concentric pattern of shading. Caregivers have to assess the outcomes of their actions and nonactions in order for the iterative process to continue. Therefore, making a judgment about the effectiveness of a modification strategy is part of the trial and error process and is included in the iterative loop in the analysis display.

Study Aim #3—how caregivers change their environmental modification strategies over time—was addressed by identifying all the causal and intervening conditions that precipitate, affect, and constrain action and the context in which interaction and action takes place. Analyzing changes in the conditions and context was used to understand how environmental modification strategies were likely to change over time. Notice how in the analytical display, these categories sit outside of the iterative process, but have inputs into various points in the iterative process. The two-way arrow between the context of the home setting and living arrangements, and the causal conditions labeled changes in health and functioning, indicates that both of these inputs interact with one another to produce disability. Notice also that changes made using modification strategies, in turn, may also change the context of the home setting.

In the discussion that follows, categories depicted in the analytical display will be defined in detail. Participants' verbatim quotes will be used to illustrate the description of the categories. In some cases where the meaning of the participant's statement is not clear because insufficient context is provided, additional explanatory information is provided in brackets within the quote. To aid the reader in understanding the context of the individual caregiving situation, salient characteristics of the individual participant are denoted by a coding scheme. The scheme identifies the following characteristics of the participants:

1. The order in the data collection process in which the participant was interviewed (P = Pilot interview; S = Study interview) (e.g., P1, P2 . . . P6; S2 . . . S19).
2. The relationship of the caregiver to the care receiver (e.g., D = daughter, W = wife, H = husband, S = son, O/C = other child-like caregiver [granddaughter], O/S = other spouse-like caregiver [live-in partner]).
3. The impairment type of the care receiver determined from interview data (e.g., PHY = physical impairment, COG = cognitive impairment, MIX = mixed impairment).
4. Whether or not the caregiver lived with the care receiver if lived with (indicated by an asterisk).
5. In cases (n = 5) where the care receiver was interviewed along with the caregiver, or a secondary caregiver was present, the voice of the individual speaker (e.g., CG = caregiver, CR = care receiver, SCG = secondary caregiver).

To illustrate further, the participant coded S15-O/C-PHY*SCG, was the 15th interview in the study, the primary caregiver was not a child or a spouse, but had a child-like relationship with the care receiver (in this case, was a granddaughter), the impairment of the care receiver was physical, the caregiver lived with the care receiver, and the person speaking in the quotation was the secondary caregiver who also participated in the study. In some instances, quotations were arranged in tables to facilitate understanding of a concepts various component parts. In other cases, quotations appear within the body of the discussion to illustrate a point being made in the text.

Aim #1: Describe the Environmental Modification Strategies That Family Caregivers Have Used in Caring for Chronically-Ill Older People Eligible For Home Health Care

Each of the seven major categories of modification strategies is described in detail in this section. Parallel strategies used in conjunction with and in lieu of modification strategies are described as well. A description of how caregivers implemented these strategies follows. Trial and error and the use of serendipitous discovery process, as well as the fine tuning processes of individualizing, economizing and innovating, are illustrated by quotes from participants that show how these process categories are related to what the caregivers actually did. The strategies employed when no action is taken are also included in this section.

Categories of Environmental Modification Strategies

Seven major categories of environmental modification strategies were identified in the study, organizing the home to provide care, supplementing function with devices and environmental cues, structuring the care receiver's day, protecting the care receiver, working around environmental limitations, enriching the home environment, and making long-term lifestyle changes. A definition of each of these categories follows.

Organizing the Home

Organizing the home to provide care is defined as arranging the environment systematically to ensure that the home works in harmony with what the caregiver is trying to achieve. Caregivers achieve this harmony by focusing on a triad of aspects in the environment: the arrangement of objects, the use of space, and the altering of structural aspects of the existing home. Object organization and space utilization are altered or held constant to reduce demand on the care receiver and to increase efficiency for the caregiver. Features of the existing physical environment may be changed to meet these same goals. Organizing the home is similar to the concept developed by Rubinstein (1989) called environmental order. He defined ordering as "an individual's set of ideas about where things go, and it is concerned with tasks such as deciding on room function, furniture placement, and the use of decoration" (p. S47).

Modification strategies for this category and their descriptions follow. Table 1 provides excerpts from the interview text as exemplars of each of the 10 modification strategies included in the category organizing the home: keeping the setup of supplies and objects the same; altering the setup of supplies and objects; arranging setup of an area used for activities of daily living; adapting a medical regimen to the home setting; moving, obtaining or getting rid of furnishings; adapting an activity for a new location; maintaining activities in their proper location; maintaining separate living spaces; changing structure; and minimizing housekeeping.

Keeping the setup of supplies and objects the same. Keeping the setup of supplies and objects the same is defined as rigorously ensuring the exact placement of items in the home is kept constant. Keeping things in the same place and order can be critical for some care receivers' because of their inability to memorize or make sense of a new order. Care receivers' with visual deficits need to keep things in the same location because they rely on this for finding objects. In addition, keeping things in the same place saves energy for the care receivers and the caregivers who do not have to search for items.

Table 1

Data Exemplars for Organizing the Home

Modification Strategy	Definition	Data Exemplar
Keeping the set up of supplies and objects the same	Rigorously ensuring the exact placement of items in the home is kept constant.	She tries to put certain things back in the same place. Like she has her bills in a little box on the desk and she puts her keys in a certain place in her purse (S12-D-MIX). He needs to know where everything is, you know, not to move things or change thing, 'cause he feels mostly by being familiar. So you really have to think twice about . . . (S4-O/S-PHY*).
Altering the set up of supplies and objects	Changing the arrangement of articles, materials, and/or provisions for ease of access or to prevent tampering.	What I did, on the medicine, I realized that, with his hands, he could hardly take a lid off a jar, but occasionally he'd do something that just really shocked me so I put the medicine in Babywipe boxes. He didn't seem interested in Babywipe boxes (S11-W-COG*).
Arranging set-up of an area used for ADLs	Altering the location or placement of objects needed to complete an activity of daily living, so as to make up for functional deficits in the care receiver.	So that's better. The sink could certainly be better. As I said, there's no room around it to set things out to make, you know, those visual cues that would be good (S9-D-MIX). We've arranged her kitchen so everything is within reach. Stuff that she never uses I put all on the top shelf (P1-D-mix).

table continues

Table 1 continued

Modification Strategy	Definition	Data Exemplar
Adapting medical regimen to a home setting	Making changes in both the regulated system of treatment of illness, and the location and set up of the associated materials needed to carry out the therapy in the care receivers' residence.	No. You know, when her oxygen was delivered, we had to figure out a place to put it so that it would be out of sight, but also we tried to figure out the best place to put it where she could get the longest use out of the line (S13-D-PHY). . . .he has a big container with several bottles and most of them he has to take every day, so . . . and pretty much the same time, and then of course, he has . . . takes insulin twice a day, so { Oh, okay. So now do you have to keep that in the refrigerator? } Well, the bottle he's using we don't. We just keep it in the bedroom, but the rest of it we refrigerate (S3-W-PHY*CG).
Moving, obtaining or getting rid of furnishings	Changing in the type or placement of furniture such as chairs, tables, beds, chests, and cabinets.	She had this great big flashlight. She was gonna smash his head in. That was when we said "hey, we gotta do something." It upset him more than it upset her, you know, as far as that goes. He was very upset that we had to break up the bedroom (P6-D-mix*:). So the dining table would have to go or go elsewhere for a wheelchair (S18-D-PHY).
Adapting an activity for a new location	Making a function, a chore or odd job suitable for performance in a new area of the home.	{Where do you feed her?}. just in the bedroom there. You can tell by looking at the carpet I'm not too good at it. I get it cleaned twice a year but it looks horrible, but what the heck you know (S8-H-MIX*).

table continues

Table 1 continued

Modification Strategy	Definition	Data Exemplar
Maintaining activities in their proper location	Striving to preserve normalcy by using rooms in the house in a way that is consistent with past use.	I don't want to be in the bedroom. I won't go into the bedroom and talk after dinner, 'cause I'm afraid that we'll slip easily into hanging out in the bedroom a lot . . . it makes me feel again like an invalid (S4-O/S-PHY*).
Maintain separate living spaces	Increasing the space the care receiver and the caregiver have to their own.	. . . like if we had had one bathroom, that would have made it very difficult, because mom could spend a long, long time in a bathroom (P2-D-PHY*).
Changing structure	Altering the existing home's physical structure. With this modification the caregiver substantially changes some part of the house.	So that was the big project was to raise the floor in the living room so that it was all level (P5-D-PHY). . . . we added that long hand rail, the bench and the shower head . . . . The doors are big enough for a wheelchair, and it wouldn't take too much to put a ramp, you know (S5-H-PHY*).
Minimizing housekeeping	Altering the physical structure of the home, or its' contents to make maintenance easier.	Well, when we came into the place here we wanted to get floor like this which it's easy to keep clean (S10-H-PHY*). . . . she didn't like doing that stuff, and I think that that was one of the reasons she enjoyed living with us is that she didn't have to do any of the housework (S15-O/C-PHY*).

Altering the setup of supplies and objects in the home. Altering the setup of supplies and objects in the home is defined as changing the arrangement of articles, materials, and/or provisions for ease of access or to prevent tampering. Materials usually stored or located elsewhere are relocated for ease of access for either the caregiver or the care receiver. Alternatively, articles or supplies that should not be tampered with may be hidden to prevent a misadventure. For example, something as simple as changing the storage location for the dog food made it possible for one care receiver to continue feeding his dog after he had fallen retrieving the dog food from its previous location. It might also be done to discourage a particular activity on the part of the care receiver, for example discouraging the tampering with medicine bottles or the ingestion of dangerous objects such as marbles or coins. Organizing things around a favorite recliner chair allowed one care receiver to perform most of her daily activities in a comfortable location.

The latter example, altering the setup of supplies and objects in the home for a physically impaired elder, was similar to environmental centralization described by Rubinstein (1989). Rubinstein collected data about the nature and meaning of the linkages between the older individual and the home environment from seven elderly informants using ethnographic interviewing techniques. Environmental centralization, according to Rubinstein, "refers to the way in which the home environment is manipulated over time to accommodate the increasing limitations of the body through the closing off of peripheral areas and the concentration of living spaces in central zones" (p. S51). Centralization addresses physically based decreased competence by making a number of environmental trade-offs to conserve energy for activities deemed necessary for personhood.

Arranging setup of an area used for activities of daily living (ADLs). Arranging setup of a functional area is defined as the altering the location or placement of objects needed to complete an activity of daily living, so as to make up for functional deficits in the care receiver. With this strategy, the caregiver thinks about how an area that is used for some activity of daily living can be rearranged to facilitate the care receiver being able to do certain activities unaided, such as mouth care in the bathroom, dressing in the bedroom, or cooking in the kitchen. This is a special case of altering the setup of supplies and objects in the home that is targeted toward restoring the care receiver's autonomy in functioning by ordering the environment to aid completion of activities of daily living. This strategy is consistent with the environmental strategies to aid dressing for cognitively impaired elders as described by Beck and colleagues (1992). The findings of this study suggested, however, that this strategy was beneficial for physically impaired elders as well.

Adapting medical regimen to home settings. Adapting medical regimen to home settings is defined as making changes in both the regulated system of treatment of illness, and the location and setup of the associated materials needed to carry out the therapy in the care receivers' residence. In this strategy, the caregiver has to help the care receiver adapt a new medical regimen to the home setting. Portions of the regimen may be deleted or amended to suit the new environment. For example, strict aseptic technique for a dressing change may not be possible in many homes, and may not be necessary since the risk of nosocomial infection is nil. The use of space in the home may have to be amended as in the case where a care receiver has to take over one bathroom in the home to store and use their colostomy supplies.

All of the families in this study had to deal with adapting a medication regime to the home setting. Figuring out how to do a medication regime forces the caregiver and care receiver to determine a location to store medications, develop environmental cues to help ensure correct timing and dosage, and make adjustments in the regime so that it is doable from the families perspective. Diabetic regimes introduce problems for families such as storage of injectables and syringes as well as the need to safely dispose of hazardous sharps. Caregivers in this study also had to deal with adapting regimens to the home that they considered dangerous and/or stigmatizing to the patient, such as continuos oxygen delivery. Placement of equipment to maximize functioning while minimizing the disruption of the care receiver's lifestyles was critical.

Moving, obtaining, or getting rid of furnishings. Moving, obtaining, or getting rid of furnishings in the home is defined as any change in the type or placement of furniture such as chairs, tables, beds, chests, and cabinets. This strategy entails managing the type of furnishings used in the home and determining their placement. New furnishings may be obtained that suit the needs of the occupants better. Alternatively, furnishings may be eliminated if they no longer meet a need or are in the way of placing new furnishings that meet the occupants' needs better. Rearranging furnishings can also be a way to solve problems. For example, when the care receiver and their spouse can no longer sleep together because of the functional decline of the care receiver, moving beds into separate bedrooms may be a simple solution.

Adapting an activity for a new location. Adapting an activity for a new location is defined as making a function, a chore, or odd job suitable for performance in a new area or part of the home. For example, a situation was described by one family in which it was no longer possible for the caregiver to garden in her yard. Obtaining potted plants for the care receiver to care for on the patio allowed her to continue her gardening activity in a new location.

Maintaining activities in their appropriate location. Maintaining activities in their appropriate location is defined as striving to preserve normalcy by using rooms in the home in a way that is consistent with past use. When families strive to maintain activities in the appropriate location, its because its important for the caregiver or care receiver to maintain a sort of normalcy of routine. This means that they don't want to use space in the home for other than its original purpose. For example, using the bedroom as a day room would not be desirable because it would be giving into disability.

Maintaining separate living spaces. Maintaining separate living spaces is defined as any action that increases the space the care receiver and the caregiver have to their own, such as a private bedroom, bath, or living room. Actions that also reduce the amount of time that is spent by the caregiver and the care receiver in shared spaces are also included in the definition of this strategy. Caregivers' and care receivers' privacy needs vary. Multigenerational households seem to speak more frequently about taking measures to increase family member privacy. Having space that the care receiver can call their own ensures they can use their part of the home they way that suits them best. For example, when separate living spaces are provided in the caregiving home like a separate living room, the care receiver can go ahead and use a chaise lounge for an alternate bed without making other family members uncomfortable. For many care receivers, having a place of their own where they were free to arrange things as they prefer, was highly valued. Findings from this study are consistent with those by Pruchno et al. (1993) that more rooms in the home were associated with lower levels of burden for all family members and higher levels of satisfaction as a caregiver for daughters.

Changing structure. Changing structure is defined as altering the existing home's physical structure. With this modification the caregiver substantially changes some part of the home. It includes changes as big as kitchen remodeling and as minor as the installation of handrails. These types of changes are usually of a permanent nature and require special skills to implement. Handicap toilets were installed in several homes. Installing a hand rail would also be an example of this type of modification. In one case, the family had remodeled a bathroom and kitchen prior to the care receiver's onset of Alzheimer's, but found afterward that the changes were very useful. Some changes were made that did not fit the usual categories of improved handicap access, but instead were made to facilitate improved quality of life for the care receiver. For example, one family built an especially large closet so the care receiver would be able to store all of her craft items. Another caregiver had a fence installed so that the care receiver could safely enjoy the backyard.

Minimizing housekeeping. Minimizing housekeeping is defined as altering the physical structure of the home, or its contents to make maintenance easier. This can include throwing out clutter. By installing surfaces that are easier to clean, or by moving to another home that is smaller and easier to maintain, caregivers reduced their workload substantially. Reducing the burden of housekeeping gives the caregiver more time and energy to devote to the care receiver. For example, one caregiver downsized her chores considerably by getting rid of possessions that made maintenance difficult.

Supplementing Function with Devices and Environmental Cues

Supplementing function with devices and environmental cues is defined as compensating for a care receiver's deficit with either specially made or created tools and/or altered sensory surroundings. The goal of supplementing function is to make up for a deficiency in the performance of an activity on the part of the care receiver and/or to offset limitations in the care receiver's perceptual capability. Tools can either be prosthetic (e.g., a hearing aid) or assistive in nature (e.g., a reacher). The categories identified include using environmental cues and sensory augmentation, using prosthetic devices, using assistive devices, using assistive clothing, and using the familiar. Table 2 presents representative data exemplars for this category of modifications.

Using environmental cues. Using environmental cues is defined as using signals or hints in the environment to clue the care receiver into what they should do and can include memory or orienting devices like calendars, clocks, and 'to do' lists. Pill dispensers were used by participants for both cognitively and physically impaired care receivers. The use of familiar objects was tried by a number of study participants to orient a confused person, with varying success. A few caregivers used a memory book that they constructed using photographs of family members. In instances where the care receiver was too impaired cognitively, pictures did not facilitate orientation.

Table 2

Data Exemplars for Supplementing Function With Devices and Environmental Cues

Modification Strategies	Definition	Data Exemplars
Using environmental cues	Using signals or hints in the environment to clue the care receiver into what they should do and can include memory or orienting devices like calendars, clocks, and 'to do' lists. Stimuli augmentation is defined as increasing sensory input quality or quantity.	We bought a big calendar to see if we could kind of get things to be remembered, or written down to be remembered. It's probably too big a calendar and so it can't hang on the refrigerator, she lays it on the table sometimes or she sticks it in a chair, but it's not the best (S12-D-MIX). So I think having his own things has overall certainly been a good thing, but has also made it a little bit confusing, 'cause they're his things but they're not in the same place. There have been things about the environment that are confusing simply because parts of the environment are things that have been a part of his life for years and years, and other parts of the environment don't fit (P1-D-MIX).
Using prosthetic devices	Employing an artificial device to replace a missing body part, or a device designed to improve a specific body function, such as hearing aids and glasses.	We have, on the telephone we have a, it increases our voice. It was made so that, you know, when she talks, like talking to you, you probably heard her fairly clearly. Yeah, it's on there, it's a special . . . . (S10-H-PHY*CG). Well I've gotten her a magnifying glass, but she doesn't use it. She recently had laser surgery, which has made her eyes worse instead of better, according to her anyway (S14-D-MIX).

table continues

Table 2 continued

Modification Strategies	Definition	Data Exemplars
Using assistive devices	Using a mechanical contrivance that gives support to the care receiver's functioning.	He has a stamp. We have to . . . we go to the office usually once a week, and he signs checks, you know, for the . . . for different things . . . for the payment of things. And he has to use his rubber stamp. We haven't had any complaints yet. It's his signature on a rubber stamp (P3-W-MIX*). We bought one of those knives and forks with the great big squeezy handles. She tends to kind of save them aside, like I don't know for what special occasion, she doesn't use them (S12-D-MIX). . . . if she goes anywhere like walking in the hall she takes this cart she has which has a seat, a grocery cart with a seat . . . (S18-D-PHY). Because I can't walk that far. If we have to walk very far, then he takes me in the wheelchair . . . takes the wheelchair and gets me into that (S5-H-PHY*).
Using assistive clothing	Providing the care receiver with clothing that is easy to get on and to remove.	And another thing I did was to buy pants with elastic in the back (P1-D-MIX). . . . and then when I was there two years ago I just took all of her blouses that were button front and sewed up, buttoned them and sewed it up so that it would stay closed, put a side vent in the lower part because with the gut motility she's got protruding so she needed more space around the waistband and then so everything is slipped over her head now (S18-D-PHY).

The term using the familiar is defined as trying to hold constant as many elements of the environment as possible to minimize the reorienting a cognitively impaired person must do. Using the familiar as an prosthetic aid to memory has been recommended by professionals in dementia management (Dawson, Wells, & Kline, 1993; Schafer, 1985). This is a strategy that is often recommended to help keep a confused person oriented (Liu, Gauthier & Gauthier, 1991). This strategy received mixed reviews from participants however. For example, familiar furniture in an unfamiliar setting was somewhat confusing to the older person.

Stimuli augmentation is defined as increasing sensory input quality or quantity. Pure sensory augmentation, such as increased light or sound, was also used to make the environment more intelligible. These modifications included things like putting lights on timers, installing task lighting, and obtaining special three-way light bulbs. In one instance, the caregiver used leaving the bathroom light on all the time as a cue to her confused father so that he could find the bathroom in his new apartment. For two of the visually impaired care receivers, caregivers had devised very specialized environmental cues. In one instance, the caregiver had painted large red marks on the dryer so that the care receiver could set the timer independently. In the other instance, the caregiver had placed velcro tabs on a computer keyboard so her father would be able to send email messages.

These findings provide some support to design literature recommendations (Hiatte, 1987). Hiatte has suggested that for many tasks that older people do, lighting levels need to be increased. In particular, task lighting is very effective in increasing the direct lighting to the level needed for performing various activities. The use of contrast that caregivers in this study described has also been used by design experts to communicate important environmental information (Kavanaugh & Tate, 1996).

In summary, providing cues, increasing the stability of setting by using the familiar, and increasing the legibility of the environment were all mentioned by participants in this study as strategies they employed for caring for both physically and cognitively impaired elders. The benefits of these strategies have been identified for victims of Alzheimer's disease previously (Roberts & Algase, 1988). However, the usefulness of these strategies for care receivers with mixed and physical types of impairments has not been described before.

Using prosthetic devices. Using prosthetic devices is defined as employing an artificial device to replace a missing body part, or a device designed to improve a specific body function, such as hearing aids and glasses. Prosthetic devices improve the care receiver's functioning by becoming an extension of that part of the body that is deficient. For example, eye glasses are a prosthetic lens. Some of the prosthetic devices mentioned by the caregivers included magnifying glasses, voice amplification devices, and dentures. Prosthetic devices to aid sensory function are probably underutilized. A study of hearing loss prevalence among nursing home residents demonstrated that medical records failed to identify 48% of residents with moderate to severe hearing losses (Garahan, Waller, Houghton, Tisdale, & Runge, 1992).

Using assistive devices. Using assistive devices is defined as use of a mechanical contrivance or tool that gives support to the care receiver's functioning. For example, a wheelchair might be used by someone who can walk, so that the care receiver and the caregiver don't get too tired. Carts for carrying, ambulation devices, and some of the more unconventional items like rubber stamps for signatures or check writing devices for the blind were described by participants. Walkers and canes were the most frequently mentioned devices used by care receivers. One participant had obtained items like elastic shoelaces and a long-handled shoe horn as a result of her contact with a rehabilitation unit. Assistive devices were also used for leisure activities. For example, one care receiver used a bingo card holder to make playing easier. Findings in this study were similar to reported research findings that older persons "at risk" for needing assistive devices are using a number of devices (Mann, Karuza, Hurren, & Tomita, 1993).

Using assistive clothing. Using assistive clothing is defined as providing the care receiver with clothing that is easy to get on and to remove. Although clothing is not a device per se, designs of dress that are easier for the care receiver to put on or to move in serve a similar purpose to an assistive device in that they improve care receiver functioning with dressing and other activities of daily living. Items of clothing that slip on easily and have a minimum of fastening devices were most often described by participants as the most useful for helping a care receiver dress themselves. Sometimes the clothing aides functioning after it is put on, for example, satin pajamas helped a care receiver with Parkinson's disease be able to move in bed.

Structuring the Care Receiver's Day

Structuring the care receiver's day is defined as managing the patient's daily schedule of activities so that it is neither too unpredictable nor boring. With this strategy the caregiver seeks to keep care receiver in a zone of best adaptation, enough routine to be reassuring, and enough variety to be still stimulating. The care receiver's daily schedule can act like environmental press with too much variation in schedule and too little variation causing negative consequences. This category of environmental modification includes strategies such as establishing routines and inventing care receiver activity. As one husband caregiver said, pattern in daily activities is very helpful to the care receiver:

> You'll find that with people like that you'd better be kinda on a regular basis though when you feed them and put them down. Try to do it the same time every day. Don't interrupt the routine, because they don't understand that and they are kind of, their clock is set pretty well (S8-H-MIX*).

Predictability of routine has been identified by researchers as an important environmental support for cognitively impaired elders (Roberts & Algase, 1988; Schafer, 1985) and can be critical for some caregiving activities. For example, most medical regimens require administration on a regular schedule in order to be effective.

Although routine helps decrease stress for the care receiver, it is also important to provide fun activities as well, to avoid boredom. One husband took his wife to play Keno while he went shopping:

> I take her with me and I can do the grocery shopping and whatever shopping I have to do and I take her into a spot down here, on the other side of Albertson's, and we know the fellow and the gal in there real well and say "will you babysit for a while" and they say "sure, go ahead." And so she has her time and I do the grocery shopping and come back in. She enjoys that part of it, oh, she has a great time. So she does have a little bit of activity (S10-H-PHY*).

Activity can also include diversion at home such as drawing or coloring. Several of the caregivers spoke of taking the care receiver with them on errands just to give them some variety, or as one caregiver said "it breaks up the day."

Protecting the Care Receiver

Protecting the care receiver is defined as preventing accidents of and decline in the care receiver. Protecting the care receiver included eliminating objects or hazards from the environment that were dangerous for a particular care receiver. Caregivers also used their personal knowledge of the care receiver to determine if they should deny access to a part of the care receiver's environment. Supervising and monitoring were the strategies used to ensure that the care receivers' early warning signs of impending deterioration did not go undetected.

Denying access to a part of the environment. Denying access to a part of the environment is defined as caregiver-imposed restrictions on going into parts of the home or neighborhood. Denying access was one way caregivers tried to prevent possible accidents when they could not be present to monitor the situation. As one granddaughter said:

> And from the time she moved in, I did the laundry, because I didn't want her going down the basement stairs. I had this fear of coming home in the afternoon and finding her at the bottom of the steps, and so that was a rule when she moved in. That was about the only rule. You can't tell grandma things. She wouldn't have followed them, kind of like the kids (S15-O/C-PHY*CG).

Denying access was an effective strategy for cognitively impaired elders as well. According to Roberts and Algase (1988), reducing the range in the environment that the cognitively impaired older person has, while increasing access to anything within that range, is one way to make the home setting more supportive.

Sometimes care receivers voluntarily put areas of the home off limits to themselves as one daughter noted: "They have a loft, which every once in awhile daddy goes up. Mother doesn't try those stairs (P5-D-PHY)." Caregivers who used this strategy also did things like taking car keys away from the care receiver, locking doors to prevent wandering, and prohibiting the care receiver from crossing over curbs unattended.

Eliminating hazards. Eliminating hazards is defined as identifying and getting rid of safety hazards. This was a strategy that was used by many of the participants in this study. Generally for physically impaired people, this meant taking something out of the environment that could cause tripping such as throw rugs. The range of items that can be dangerous for cognitively impaired people is greater and harder to identify, as one wife caregiver said:

> But I had to try to keep everything so that he couldn't take it apart and put it in his mouth. I had marbles in a deal and he had a mouth full of marbles one day. But one of the worse things, they came by and gave me a thing for the sink, he managed to get that off, you know to save water, and it had a plastic thing in it about so big and it was round and I spent about an hour trying to get him to take that out of his mouth (S11-W-COG*).

Other potentially dangerous items removed from the environment included knives, cigarettes and matches, and ill-fitting dentures.

Structuring supervising capability. Structuring supervising capability is defined as configuring the use of space, nearby resources, and objects in the home to oversee the activities of the care receiver. For caregivers to structure supervisory capability, they have to learn the extent that the care receiver could be left on their own. They then either accommodated by staying very close by, or by devising other strategies to access the information they needed to keep tabs on the care receiver. One daughter asked a neighbor to check periodically on her mother when she did not answer the phone. Another daughter caregiver was able to use the apartment building manager to keep an eye on her mother. One daughter devised a rule with her mother that she was to keep her portable phone with her at all times so that if she fell, she would be able to call for her assistance. Some care receivers were so impaired that constant 24-hour supervision was necessary. On more than one occasion, child caregivers made emergency visits to care receiver homes to see what was going on when the care receiver did not answer the phone. A number of the spouse caregivers talked about having to keep a very watchful eye on the care receiver.

Monitoring. Monitoring is defined as keeping watch over the care receiver either nearby, or from a distance, without the care receiver's awareness. It is very similar to supervision but is more covert. It is done to keep close watch over; or supervise the care receiver without their knowledge, as illustrated by this comment from a wife caregiver: "I'm getting his pills and . . . and clothing, but I'm also watching him in the mirror" (S2-W-COG*). Another daughter caregiver talked about listening for her mother when she would get up at night to go to the bathroom. One spouse caregiver was able to rig a previously installed alarm system to catch her husband trying to go out of the door to wander. Another daughter set up her parents with E-mail so that she could more easily maintain daily contact.

Working Around Environmental Limitations

Working around environmental limitations is defined as bypassing, avoiding, or ameliorating the shortcomings in the care receiver's home surroundings by adding supplies and equipment, decreasing aversive stimuli, or changing behavior. Working around environmental limitations is a strategy that has a lot of reversibility. For example, obtaining a bath bench is a reversible process, because if the care receiver no longer needs it, or if the caregiver wants to store it temporarily in a closet, it is very easy to remove the bench and pull it out for use again at a later time. If the care receiver's bathing behavior has to be changed to accommodate a limb that can not get wet, taking a sink bath may be easier than architecturally modifying the bathroom. Working around environmental limitations is a strategy that tends to be highly effective and easy to implement. For example, turning off a vacuum cleaner to stop a care receiver's agitation is easy to do and can be very effective. Working around environmental limitations includes strategies such as obtaining special equipment or supplies, making a behavior change to compensate for limitations, reducing aversive stimuli by making the temperature comfortable, simplifying choices in the home for the care receiver, and minimizing or eliminating other types of noxious stimuli. Data exemplars for this category of environmental modifications appear in Table 3.

Table 3

Working Around Environmental Limitations

Modification Strategies	Definition	Data Exemplars
Obtaining special supplies or equipment	Adding materials needed for the purpose of adapting the care receivers' ADL repetoire to work around their limitations in the current home environment.	. . . and so going to the bathroom is a clean up job for me [referring to care receiver]. An I thought I can't stand this when he gets to this point . . . but I found out once I started doing it, it wasn't all that bad. I mean it wasn't "Now you'll need to get me some gloves" and so we just used boxes and boxes of those gloves, so, you know, if someone has Alzheimer's they should certainly be told early on, get those gloves. And the job is still bad, to try to get the briefs off and clean out, but it's a lot better with the gloves (S11-W-COG*). And it was clear that she wasn't taking baths. She said she always said that she could do that and she had like a little stool in the bathtub because she was afraid of falling down (S19-S-MIX).
Making a behavioral change	Changing the how, when, or where of an activity to compensate for environmental limitations that are difficult for either the caregiver or care receiver.	. . . so I said, how are we going to do his hair, and she said, well I find that I get a wet wash rag and I wet it and I put a little shampoo on and then I just keep taking it with the wash rag and he didn't mind that at all (S11-W-COG*). . . . you've talked about falls. She kept herself fairly well, I mean she would clutch anything around that was stable or secure. A chair . . . a back of a chair if it was secure. There was something in her that kind of made her do that (P2-D-PHY*).

table continues

Table 3 continued

Modification Strategies	Definition	Data Exemplars
Avoiding extremes in temperature	Ensuring that the room temperature is neither too hot nor too cold for the care receiver.	As a rule you'll find that people that don't move that much, they are always cold. They want to keep warm that's why I turn the heat up in the winter . . . keep her warm. So I burn a few hundred gallons more a year, doesn't make any difference (S8-H-MIX*).
Simplifying choices	Limiting the number of selections that the care receiver has to make in order to complete a task of daily living.	There were probably 50 shirts, and then I realized immediately that was a big mistake. That he was looking at all those shirts like "how am I ever, ever going to choose one." So I just put most of them away and left him five or six shirts that he wears all the time (P1-D-MIX).
Minimizing or eliminate noxious stimuli	Getting rid of provocative sounds, sights, and situations that were bothersome to the care receiver.	I think he's not hearing but what he is hearing he incorporates it into his real life, like last night there are certain things you don't let them watch, hard programs like ER or any of that because it really causes my dad to become very, very anxious and confused. So what we let them watch, I've been letting them watch a lot of the comedies, TBN, Trinity Broadcasting network is one of their favorites . . . . So there are certain programs that we let them watch. Matlock is one. You know anything that is soft because my dad has the tendency to incorporate the TV into his life (S17-D-COG*A-A).

Obtaining special equipment or supplies. Obtaining special equipment or supplies is defined as adding materials needed for the purpose of adapting the care receivers' ADL repertoire to work around their limitations in the current home environment. Nearly every participant in this study reported using this strategy. This category included a number of bathing and toileting supplies and equipment items such as bath benches, clamp-on grab bars, hand-held showers, raised toilet seats, Depends, and rubber gloves. Most of these items are now readily available in pharmacy sections of large grocery stores. One routine that was often changed radically was food preparation. How and what type of food was prepared was an important component of the care receiver's care, and involved obtaining special equipment, such as a microwave, or other types of special supplies, such as Ensure. A number of the caregivers struggled with difficulties in preparing meals that the care receiver could eat safely and willingly, as one caregiver said ". . . that's the main change, the feeding. The last few weeks my wife has eaten less and less, so but if it weren't for Ensure or the equivalent of it, I wouldn't know how to really feed her" (S7-H-MIX*).

Making a behavioral change. Making a behavioral change is defined as changing the how, when, or where of an activity to compensate for environmental limitations that are difficult for either the caregiver or care receiver. One caregiver did not allow her mother to carry anything upstairs as she felt this activity would put her at risk for falling. For many care receivers, taking a bath in the tub became problematic and they had to switch to taking showers. One caregiver noticed that washing her husband's hair with a wash rag, instead of running water, markedly decreased his combativeness during the procedure. She also devised a strategy of keeping him shoeless while he was in the home to prevent him from going outside to wander.

A couple of the caregivers of cognitively impaired elders had developed elaborate toileting schedules to try to keep the care receiver dry without using Depends. Interestingly, scheduled toiletings with adjustments in the schedule based upon the older person's voiding pattern have also been recommended by nursing experts as a behavioral intervention to treat incontinence (Wyman, 1992). One care receiver switched from eating sitting down to eating while standing up to prevent overeating and gastric distress. Another caregiver shaved her husband in bed so that he would cooperate and not struggle during this process. These diverse behavior changes did not cost any money, they were doable in light of the care receiver's limitations, they did not require permanent changes in the home, and they were easy to implement.

Avoiding extremes in temperature. Avoiding extremes in temperature is defined as ensuring that the room temperature is neither too hot nor too cold for the care receiver. Most of the caregivers did this for the comfort of the care receiver, who often had needs for warmth or cooling that the caregiver did not. Aside from the thermostat in the home, some of the devices used by caregivers to meet this need included fans, gas logs in the fireplace, and electric heaters in the bathroom. Interestingly, professionals have also identified extremes in temperature as having deleterious effects for older people. An excess of heat and/or cold has been identified as a source of environmental stress for cognitively impaired elders (Dawson, Wells, & Kline, 1993). In addition, when acute illness, immobility, and temperature-lowering drugs are imposed on a dysfunctional thermoregulatory system, hypothermia can occur (Worfolk, 1997). Consequently, as caregivers in this study identified, very old people lose more heat than do the young.

Simplifying choices. Simplifying choices is defined as limiting the number of selections that the care receiver has to make in order to complete a task of daily living. This strategy was often associated with dressing for cognitively impaired care receivers. In order to make it easier for care receivers to dress themselves, a number of the caregivers found it necessary to radically reduce the number of clothes that the care receiver was allowed to keep in closets and drawers. Dressing and undressing the care receiver was a struggle for a number of the caregivers.

Minimizing noxious stimuli. Eliminating noxious stimuli is defined as getting rid of provocative sounds, sights, and situations that were bothersome to the care receiver. Sometimes the source of the stimuli in the environment that would trouble a cognitively impaired care receiver was difficult to identify. Some of the most commonly identified irritants included certain programs on television, television and music playing simultaneously, any other kinds of noise and confusion, and crowds or unfamiliar people. The noise of radios and televisions have been identified as an environmental stimuli that increases press for older people with dementia (Dawson et al., 1993).

Eliminating noxious stimuli was a preventative strategy aimed at eliminating periods of agitation in cognitively impaired elders. This approach is consistent with the use of "white noise" to drown out irritating background sound that has been successfully used in nursing homes to decrease verbal agitation among residents (Burgio, Scilley, Hardin, Hsu, & Yancey, 1996). Prior research has found that reducing unnecessary stimulation such as strident colors, unpleasant background noise, and uncontrolled visitor access resulted in dramatic decreases in adverse outcomes for cognitively impaired older people (Cleary, Clamon, Price, & Shullaw, 1988).

Enriching the Home Environment

Enriching the home environment is defined as using objects or sensory stimulation to imbue the care receiver's life with meaning, to provide a connection for the care receiver to the past, and to increase the care receiver's joy of the moment. The caregivers used these strategies to make the care receivers' daily experiences more meaningful and rewarding. One of the most profound ways the caregivers did this was by surrounding the care receiver with meaningful objects and stimuli. The use of pleasing views, nice features in the local neighborhood, and loving pets all contributed to an increased quality of life.

Surrounding the care receiver with meaningful objects and stimuli.

Surrounding the care receiver with meaningful objects and stimuli is defined as filling the care receiver's immediate environment with things that would be important to them, such as memorabilia and familiar sights and sounds. This category contained many diverse modifications, but most served the purpose of preserving a link with the care receiver's past or present identity. Most of the caregivers tried to ensure that the care receiver had retained as many of their special belongings as possible, including favorite pieces of furniture, supplies for craft activities, and special collections of things—like tea cups or glass hummingbirds. As one granddaughter and her husband said:

> I think the most important thing that we did for grandma was to give her space to bring her stuff, because I think her stuff was very important to her. And having her things around her I think was real important (S15-O/C-PHY*CG).
>
> When you go to the nursing homes, those rooms are sterile, and those people lose all their identity. I mean, what makes you part of who you are, is your stuff . . . (S15-O/C-PHY*SCG).

Pictures of family members were identified as being very important and were used by a number of the caregivers to enrich the care receiver's home environment. Seasonal decorations were mentioned by some families as a family ritual that was enjoyed by all. Pets were an important source of joy for care receivers and caregivers alike:

> And you know what? That pet had a link to her husband, my dad, because he was a part of picking it out for the kid, and the dog loved my dad. But after my dad passed away, he did not live with my mother, he lived with us. He came to the new home with us. And when she came to live with us, he [the dog] adopted her (P2-D-PHY*).

The care receiver's favorite music was often played by a number of the caregivers. For example, one caregiver played old recordings of jazz music for her parents' enjoyment.

The attachment of older people to things has been described by Cookman (1996). Possible explanations for object attachment among older people include the use their use as focal points for reminiscence and as a support to the maintenance of self-identity. Pets were also described by Cookman as a positive environmental influence on the lives of older people, with the human-animal bond acting as a possible substitute for the losses of other important people in the elder's life.

Rubinstein (1989) has argued that place attachment is really a more complex phenomenon that he has termed the person-centered process. This process concerns the individual's life course as an object that is manifest in the environment. In this view, "the life course is a sociocultural construct with a diffuse set of collectively acknowledged features individually interpreted and selectively enhanced or diminished by each person" (p. S48). In other words, older individuals construct analogies between their home's present environmental features and events in their lives experienced previously. Hence, significant features of the care receiver's present environment also serve as emotionally valent symbols of their identity.

Carboni (1990) has associated the loss of connectedness with place with the loss of meaningful personal possessions. She interviewed residents in a nursing home as to whether or not in their present circumstances, if they felt homeless. The informants revealed that their connection with the past had been severely threatened and/or completely severed through the loss of familiar places that provided the memories of past experiences. This connection was further damaged when informants had failed to keep their personal possessions.

Using aesthetics. Using aesthetics is defined as using the simple pleasures afforded by the environment to capture the joy of the moment. Providing the care receiver with the opportunity to enjoy pretty Christmas decorations or view the horizon on a carnival ride, were examples of using the environment to enhance well-being. Caregivers often set up opportunities for care receivers to enjoy the beauty of the outdoors. As one care receiver said "if you have an old dumpy house you have to live in it makes you so depressed." To use this strategy, the caregiver did not have to have an expensive home for the care receiver. There were several instances where care receiver enjoyed very simple aspects of the home environment as these daughter caregivers comments illustrate:

> And she loved to sit up in the front room. It's up high enough that she would look out at the sky, and she liked nature and I like nature and she'd look at the sunset and remind me to kind of slow the motor down and sit and talk and spend time together, because you do get busy. You come home and have things . . . and if she was sitting there, you'd sit down and you would see the sunsets or you would see the flowers bloom or that kind of thing (P2-D-PHY*).

> The most fun they have is going outside on the patio. Like I said our apartment patio is right on the main street—a busy, busy street. They go out there and look at the cars and look at people walking up and down. They enjoy that. My dad will sit out there for just oodles of hours, I mean hours. I'm not talking about one or two hours, I'm talking about all day hours and just sit out there and watch the world go by. "Look that blank car is going by so fast" (S17-D-COG*A-A).

The opportunity to observe activity and changes in seasonal landscapes have been identified as great motivators for care receivers to enjoy the outdoor environment (Lovering, 1990). The balcony and living room vistas mentioned in the above examples, were excellent outdoor observation spaces because the care receivers were protected from wind and extremes of temperature, but could still experience the outdoors. Other things that were in the environment that caregivers used to give care receivers pleasure included new clothes, trips to the beach, and day outings.

Making Long-Term Lifestyle Changes

Making long-term lifestyle changes is defined as a substantially and permanently altering the environment in which the care receiver lives, usually by moving to a new residence. Three stages were observed in making a long-term lifestyle change: planning ahead, simplifying, and relocating. In order to plan ahead for possible further changes in care receiver functioning, both the caregiver and the care receiver had to be able to recognize and acknowledge that the care receiver's condition might change. Simplifying was the caregivers' and care receivers' way of preparing for a new life by saying goodbye to their old residence and belongings. Relocating was the culmination of this process and was accomplished by physically moving into the new residence. Making long-term lifestyle changes involved more deliberative planning than any of the other strategies, and required a great deal of energy from the caregiver and care receiver. These strategies were particularly resource dependent. In other words, families without a lot of financial reserves, energy, or social support found these long-term strategies impossible to implement and rejected them as options. Although, the three strategies in this category were typically used together, at times, caregivers or care receivers used planning ahead and simplifying without impending move planned.

Planning ahead. Planning ahead is defined as thinking about possible deterioration in the care receiver's condition that may make the present home environment untenable. To plan ahead the caregiver and care receiver had to be willing to acknowledge that a change in the situation was possible. In addition to further deterioration in the care receiver's functioning, changes could include the death of the caregiver. Planning ahead helped caregivers avoid crisis at a later date. For one caregiver, the care receiver did indeed become so disabled that she was not physically strong enough to care for him and he did have to go to a nursing home for care. Had she moved to the retirement setting discussed in this passage, she would not have had enough resources to purchase proper care:

> Well, we went and looked at this retirement home. Anyway, we went over there one day, and they invited us to stay for the evening meal with them, and we did. And it is lovely, and they have nice apartments, but you know for us it would take . . . for two of you, and we really need a two-bedroom apartment or a large enough one so we could have twin beds, but it would take almost all our social security for the two of us . . . I try to be very protective of what we have in our savings or our time deposit things, because I've been thinking "well maybe he will have to go to a nursing home eventually," and so you know that costs more, too (P3-W-MIX*).

Simplifying. Simplifying is defined as divesting oneself of possessions in anticipation of a move or to make life easier or simpler. Often, care receivers and caregivers were compelled to do this to make a new living situation possible.

> . . . you see, we had all antiques, and shipping it all 4,000 miles we knew it was going to break, no matter how careful they were, and it was a crime, so we gave most of it to friends (S6-H-MIX*).

In some instances, caregivers gave away very valuable possessions to make their move possible. In other cases, materials that had been saved were of dubious value to others, such as old mail and magazines, but were very important for the older person. Care receivers needed help from family members to accomplish their downsizing, as it could be a physically and emotionally demanding process:

> And when they moved to this apartment they knew it was going to be a stretch so mother picked out and measured exactly what was going to fit where and those were the things she had them move and then she walked off and left the rest. And my sister went through everything, you know, the contents of things and sorted them, and then brought sorted boxes to the apartment and put things away. And so everything had a place. It was a little crowded but everything had a place and it fit. Everything had been brought and the rest some estate sale person made a clean-up on and paid them $450 for it, you know, and there were some treasures. But anyway, that's how they coped with downsizing (S18-D-PHY).

The loss of meaningful possessions causes a loss of continuity with one's life history and loss of a sense of self or identity (McCracken, 1987). Some of the caregiver participants identified the stress of giving away possessions as a major impediment to relocating the care receiver.

Relocating. Relocating is defined as moving to a new dwelling to accommodate projected or present functional changes in the care receiver. Moving to a new location was sometimes done to meet the needs of the caregiver, care receiver or both. Usually, this was a good solution when the care receiver's functioning made living in the previous residence untenable.

> Before she had limitations, she could use a shower or a bath, and that was one of the reasons for the move is she could no longer take a bath. So it became imperative that she have a walk-in shower. If she didn't have that, she would not be able to bathe (S14-D-MIX).

In some situations it made the work for the caregiver substantially easier.:

> Yeah, that was the main thing because it would have been very impossible, almost impossible to be able to take care of her, downstairs and upstairs, I would be panting just like the crow up there [referring to a bird outside the window], up and down those stairs (S10-H-PHY*).

Sometimes relocating put the dyad in closer proximity to supports such as children or other services. "No, we were very happy, because of our son. You see that's the main reason we came" (S6-H-MIX*). Relocating required quite a bit of planning and used a lot of resources in terms of money or energy.

Strategies Used in Conjunction with and in Lieu of Modification Strategies

Parallel strategies are defined as actions that do not involve modifying the environment but that are intended to have the same effect as modification strategies (e.g., assist the care receiver with overcoming some obstacle in the environment). These strategies were performed simultaneously or in place of environmental changes. Two strategies used by caregivers in this study in conjunction with and in lieu of modification strategies were: caregiver use of self and getting help. Each of these are described below.

Caregivers Use of Self

The caregivers use of self was often the first parallel strategy employed, especially under conditions where the care receiver and caregiver lived together. This is an option that the caregiver can use in addition to, or rather than, modifying the environment. Caregivers did part of the task for the care receiver, or assisted the care receiver in the use of the environmental modification: "I pick out her clothes, and I help her about 50%. The rest, she can do it on her own, too, but I sort of help her somewhat" (S7-H-MIX*M).

In some situations, the caregiver elected to do a task for the care receiver rather than problem solve a way for the care receiver to do part or all of the task. Sometimes caregivers did not feel they had the time to let the care receiver do the task themselves. A wife caregiver said: "We had to dress him . . . when I was going someplace, I didn't have that much time, so I'd put them [his clothes] on" (S11-W-COG*). Sometimes caregivers felt that letting the care receiver struggle to do the task might have negative consequences for the care receiver that they wish to avoid, such as frustration or an injury. In some instances the care receiver was simply incapable of doing the task even with aids or environmental supports as this husband noted: "I have to do that. She is not able to do any of that" (S8-H-MIX*).

Getting Help

Getting help is defined as obtaining assistance from the array of available community services. The two most frequently used services were a home health aide and a housekeeper. Some of the services caregivers tried to obtain included home maintenance chores, barbering, transportation, home health services such as nursing and social work, volunteers that aide seniors with tasks like shopping, and family day care services. Getting help could also be used in lieu of, or in addition to, making environmental modifications. For example, a personal care aide was employed to give the care receiver a bed bath, thereby making the use of specialized equipment for the bathroom unnecessary. A husband caregiver relayed the following: ". . . a health aide to help her wash down a little bit, which is not always easy, but she was here on Thursday, and she actually managed to give her a shampoo" (S7-H-MIX*M). In another situation, the aide made it possible for the care receiver to use specialized equipment to bathe, because the aide had the strength and know-how to use it. Hiring housekeeping was a strategy that benefitted either the caregiver or the care receiver. Daughters, in particular, found this service useful:

> I'll say for all of us but I know I benefitted probably the most because I would have had to do the activities was . . . she hired a cleaning lady. Or she said, I will pay for a cleaning lady. And so every other week this lady came, and she cleaned the house. And that was a real benefit (P2-D-PHY*).

> She has a housekeeper that comes in once a week and does all the vacuuming, changes the towels and scrubs down the shower, changes her bed and does all of that. She would not be able to do . . . she can't stand for usually more than 5 or 10 minutes at a time. It's painful, so . . . so she wouldn't be able to do any of those things (S14-D-MIX).

For some of the spouse caregivers who had a heavy physical caregiving load, getting help was almost a necessity:

> We just had to make up our minds that we have to have somebody come and do the mowing for us, because neither one of us could do it even though we had a good mower and all, it was no . . . and you know, I don't like to put that pressure on us (P3-W-MIX*).

Major Process Strategies: Trial and Error and Use of Serendipitous Discovery

Caregivers used trial and error and serendipitous discovery to develop and implement modification strategies. Trial and error is defined as a series of actions undertaken to reach a satisfactory outcome by trying out various modifications strategies and their refinements until misfit with the environment is sufficiently reduced or eliminated. Trial and error is characterized by iteration. The more that a modification could be tried out on a limited basis, the better it fit with this preferred way of implementing strategies. Caregivers varied in how deliberative they were in using this process. For some caregivers, the implementation of strategies seemed almost accidental, for others, the process was applied in a very systematic way. Ideas were generated in a number of ways, including brainstorming, seeking advice, and seeing what others in similar situations do. The following quote illustrates the iterative nature of modification strategies. We went there first and they had, yeah they already had something but it wasn't just right and the speakers, they didn't have a speaker like this [referring to voice amplification device]. And so we kept on going back and it was a nice fellow there, he was very gratified to be able to help. And of course the, let's see we've had about two or three of these, but

> we've used about four speakers because over a period of time, there's such a fine wire in there that, when you wrap it around, they do break (S10-H-PHY*CG).

Serendipitous discovery is defined as taking advantage of the caregiver's powers of observation to exploit a here-to-fore unknown positive or overall goal congruent strategy. Usually the strategy was discovered by accident in the course of employing some other strategy that was or was not related to modifying the environment. The caregiver notices that something they tried for some other purpose has an unintended consequence that they find desirable. For example, one caregiver started having dinner in front of the TV set because the care receiver was no longer able to talk. Then the caregiver discovered that when the care receiver was sitting in an easy chair with a TV tray he was not able to get up from the table and get distracted from eating. Thus, a strategy designed to meet a need of the caregiver to have some noise and verbal companionship from the TV, turned into a strategy for getting the care receiver to finish his meal. Ability to use trial and error and serendipitous discovery was dependent upon the observation skills that the caregiver brought to the caregiving situation:

> . . . yeah, yeah. I was looking through the channels and then I couldn't find anything really, you know, worthwhile watching so I don't want to make it worse for him, you know so much garbage, so I noticed that it was on so I left it and then I realized that it was good for him (S16-O/S-MIX*HIS).

Processes Used to Refine Strategies:

Individualizing, Economizing, and Innovating

Three processes known collectively as fine tuning were used to refine the strategies used by the caregivers: individualizing, economizing, and innovating. Using these strategies, caregivers either adapted known strategies to better suit the care receiver and their economic circumstances, or they created new modifications if no suitable alternatives were available to them. An analogy of adapting a new suit of clothes for wear is given to illustrate these processes. If the sleeves of a new suit do not fit, they can be altered to fit the person. Individualizing is like getting alterations. If the style of suit is too expensive, you can either buy a similar used suit or have the suit made with less expensive material. Economizing is like shopping at the resale stores. If none of the suits are appealing, you can wear a dress instead. Innovating is like buying something completely different to suit the same purpose.

Individualizing

Individualizing is defined as either physically altering supplies and devices to better suit the care receiver or, altering the way supplies or devices are used. When caregivers individualized supplies for the care receiver. The supplies were modified to suit the needs of the care receiver better. For example, a wife caregiver purchased a special new pair of incontinence briefs for her husband and knew she would have to alter them to make them work correctly for her spouse:

> It looked awfully big, so I thought, you know, he's just 36, not a 40. And so I thought I better . . . I'm probably gonna have to take them in, wash them, but anyway that's what it looks like (S2-W-COG*).

A daughter caregiver purchased a rug protector so that her father could more easily slide his chair from one location at his desk to another. However, this created problems for him when he would try to stand up, because the chair would roll. She devised an ingenious method of modifying how her father used his rug protector to solve this problem:

> So, I don't quite know what he is using now. We had two suggestions, one suggestion was that he backed up against the desk because it is heavy enough to handle the weight, so the back of the chair would be against the desk and he could push out of the chair that way. And the other alternative was to roll off the mat with at least two of the rollers so that it would stop rolling as he would push off from that (P5-D-PHY).

In both of these examples, being able to adapt materials in the environment to meet the care receiver's unique needs was critical for ensuring that the modifications would work.

Economizing

Economizing is defined as devising methods to make supplies last longer and/or refurbishing recycled equipment or devices obtained from friends and relatives. One of the primary ways that caregivers economized was by using materials in an efficient way to make them go farther. For example, one caregiver said:

> Yeah, and you know what I was thinking. I wanted to find something like this that was soft to put on his Depends, so that when he soiled, you know, and he really didn't wet them that we could save the Depends (S2-W-COG*).

One care receiver reused his diabetic syringes until they could no longer penetrate the skin. Another major expense that some caregivers avoided was buying new durable medical equipment. Two husband caregivers used creative methods to obtain what would otherwise be expensive medical equipment:

> I bought a used wheelchair and cleaned it up . . . it was the U-Haul rental, and they sold them out. If I'd have rent it for three months, I'd have bought it anyway, so I just bought it. And we'll just keep it . . . (S5-H-PHY*).
>
> Well, I made all the furniture here myself years ago, and this one when we lived in our old home I picked up in the trash. And somehow I kept it. It's really . . . it's a hospital side bed, but I use that for breakfast for her. She stays in the bed. And I eat it with her. So that's the only thing we really have that isn't routine (S7-H-MIX*M:).

Both of these items were in very good working order and did not appear to be used, so the functionality of the equipment was not compromised by the use of recycled the materials.

Innovating

Innovating is defined as adapting materials already in the environment for some new purpose, using devices and equipment in some new way, or obtaining materials from outside of the environment and using them for some unusual purpose. There were three primary ways that caregivers used innovation when making environmental modifications. The first way that caregivers used innovation was by using material already in the environment in a new way. In this instance, the caregiver took something already in the environment and adapted it for use as an assistive device or some type of special equipment. It served the same purpose as a medical assistive device or piece of special equipment; however, it had not been made or manufactured for that purpose:

> What she says she does now is she throws it [the laundry] out the door and then picks it up at the bottom because she wants to be able to hang onto the railing with one hand. I gave her a little back pack thing she could stuff it in and put it over her shoulder. I am not sure she is doing anything with it (S12-D-MIX).
>
> In daddy's office we put down the protective sheeting over the rugs, they are called desk protectors, or some such thing. Rug protectors. But he needed something where he could roll, so he can roll from his desk to his computer, with his, behind the desk. So he has an area between about, let's say about 5 feet probably between his desk and his computer, where he doesn't have to push very hard on his chair at all, so he has the mobility of being able to go over and use the adding machine and use his desk and then he pushes himself back and he is there at his computer (P5-D-PHY).

The range and creativity of the inventions described by participants was great. One wife caregiver put on heavy duty household gloves to remove partial dentures from her cognitively impaired husband when he was asleep. Another caregiver placed a camping porta-potty in his van to allow the care receiver to go to the bathroom whenever they were out. Another daughter caregiver had her mother use a serving tray with wheels like a wheeled walker with a tray. She also had her father who had Parkinson's disease use an electric golf cart to make the journey from his home to hers so that he would not have to ambulate up an incline. The granddaughter caregiver had her grandmother use her own phone line within the home as an emergency calling device to summon family that were in a different location within the home. Some very common household items were put to good use by the families. Chairs were often strategically placed so that care receiver could sit to do functions that they would other wise have to do standing up. Household convenience items like portable phones, remote controls, and electric toothbrushes were put to good use by caregivers and care receivers alike. Obtaining a trash barrel with wheels helped one care receiver be able to continue taking the trash out to the curbside. One care receiver used an old fashioned back scratcher as a reaching device.

Another type of innovation strategy was using assistive devices in a new way. In this instance, an assistive device was used for a purpose it was not created for, but for which it did an excellent job. An example reported by one caregiver daughter follows: "She has a bench inside, but what she uses is her cane. She takes her cane into the shower with her, and that's how she holds herself up" (S14-D-MIX).

The last type of innovation strategy was introducing something new. Introducing something new differed from using material in the environment in a new way because in this instance the caregiver had obtained something that was not present in the environment before to meet a need of the care receiver. A number of caregivers obtained magazines or books with large pictures to entertain care receivers who could no longer read. One caregiver found a garden bench with wheels so that her mother could continue to enjoy doing yard work despite her severe respiratory limitations. Some caregivers went to great lengths to set up areas for the care receiver to continue doing their daily activities:

> And then there's one of these lap top things, you know, it's like a solid surface attached to what's like a bean-bag pillow, like a lap desk . . . mother keeps that at her chair side, she eats in the recliner chair, she does everything at the recliner chair and keeps everything on the chair-side table, scissors, tape, pencil, phone. She was keeping everything stacked up on an ottoman next to it and, you know, bills and things she had to attend to, and then when my sister was there they went to Home Base and got one of those closet storage, low, you know, a two-shelf thing, a low unit that's about this tall, and replaced the ottoman, got rid of the ottoman, and so now you've got more space within this unit, and sitting right next to your chair, and this is where you can put your mail here, your things you have to see to there, it's all organized. So, that is something that's being used that wasn't originally intended, that's not what it was intended for (S18-D-PHY).

The findings of this study regarding caregiver innovation were comparable with Steinfeld's (1987) human factors research that looked at adapting housing for older people. Steinfeld found that people readily developed adaptations on their own. Usually adaptations were created by building or modifying conventional equipment or using something in a different way than was originally intended.

Strategies Employed When No Action is Taken

Two strategies were used when the caregiver decided to not take action: leaving as is and adjusting expectations. "Leave as is" was employed when the caregivers and/or the care receivers felt that changes were unwarranted. Caregiving dyads varied in how much they shared the same perception of how the care receiver was managing in the environment. A discrepant view could lead to leaving things as they were because there would be no consensus for action. Alternatively, both the caregiver and the care receiver might agree that the care receivers competence was not compromised enough that action was needed. Adjusting expectations occurred when there was either a perceived problem or after a negative consequence was suffered by the care receiver. In this case, caregivers adapted to the situation by changing their frame of reference rather than by active strategies.

Leaving As Is

Leave as is is defined as considering, but making no attempts to alter or address a perceived misfit with the environment. With this approach, caregivers made a judgment that modifications were not necessary, because they felt the care receiver's competence was not that compromised, or that they could make do without:

> We did have . . . you know, different girls out. I don't know if it was from Home Health or what you know and give us a bunch of suggestions but actually we didn't . . . . Well, I think they would be practical, but he just didn't think he was ready for that stuff yet . . . (S3-W-PHY*).

Sometimes the caregiver made this judgment based on his or her assessment that there was no misfit with the environment as this one daughter said "It's average, it's an average height [the toilet]. So she seems to do okay with that" (S15-O/C-PHY*). One caregiver wife was upset that her cognitively impaired husband came out into the living room in the morning in his shorts, but decided to not do anything about it because no one outside could see him from the window. Therefore, she really did not have to take action to prevent the outcome she was concerned about (e.g., embarrassment in front of neighbors).

Adjusting Expectations

Adjusting expectations is defined as the process through which caregivers learn to live with perceived misfit with the environment or a somewhat undesirable outcome, rather than continuing to struggle to make changes. For example, rather than get upset about either not having time or energy to clean, one caregiver adjusted to the situation by accepting it. Inability to let things go increased caregiver strain in some caregivers. One husband caregiver was especially skilled at being able to adjust his mental attitude:

> . . . then it's not worth it, and I have . . . well, for example, these diaper kind of things, I felt "well, she should have a pair of panties over it," and I eliminated the panties it makes it that much easier, you know, pajamas and the diapers. It comes off easier. So all these things are a little . . . little things that your mind has to come free on the right thing to do (S7-H-MIX*M).

In summary, caregivers take action by using several environmental modification strategies to address the gap between the care receiver's ability to act and function and the demands exerted by environment. These strategies included organizing the home to provide care, supplementing function with devices and environmental cues, structuring the care receiver's day, protecting the care receiver, working around environmental limitations, enriching the home environment, and making long-term lifestyle changes. Caregivers used two additional strategies: getting help and use of self in lieu of or in addition to environmental modification strategies. When caregivers decided not to take action, they either left things as they were and/or adjusted their expectations about how things should be. The problem-solving process caregivers used to implement strategies was termed using trail and error and serendipitous discovery.

Aim #2: Describe the Reasons Given by Family Caregivers to Explain Why an Environmental Modification Was or Was Not Effective in Facilitating Specific Caregiving Activities

Environmental modification strategies used to address the gap between a care receiver's competence and the environment's demand had various outcomes or consequences. These were not always predictable or intended. The failure to take action also had outcomes or consequences. Open coding of the interview data provided the initial clues about how caregivers rated the effectiveness of their environmental modification strategies. Additional information about effectiveness was obtained from participant observation data. Consequences of environmental modification strategies were categorized into positive and negative outcomes for the care receiver and the caregiver. An additional category, called technology adoption was developed to describe the complex process caregivers used to decide whether to retain or reject further use of a strategy. To illustrate each of the categories, outcomes from modification strategies previously described are highlighted to emphasize how their effectiveness was perceived by the care receiver.

Positive Outcomes for the Care Receiver

There were five major categories of positive outcomes from environmental modifications for care receivers. Aesthetic benefits for the care receiver were outcomes that enhance the quality of life either by the giving of pleasure, connection with past identity, increased energy conservation, or increased comfort. Another outcome of a number of the environmental modifications was that care receiver's safety was ensured. Improved functional effectiveness for the care receiver was often described as the main benefit of an environmental modification. Positive affective responses to modifications included increasing feelings of independence and security, while avoiding negative sentiment such as embarrassment, fear, or loneliness. Solving a care receiver's problem such as keeping dry, getting adequate nutrition, decreasing agitation, and receiving medical treatments as prescribed was an additional positive benefit described by a number of caregivers. Each of these categories is described below along with data exemplars.

Aesthetic Benefits for the Care Receiver

Aesthetic benefits were outcomes from modifications that heightened the care receiver's enjoyment of their environment, and thereby increased their well-being. The four outcomes of the aesthetic benefits category were: increased pleasure and well-being, maintained continuity, making life easier, and increased comfort.

Increased pleasure and well-being. Increased pleasure and well-being were attained when the care receivers' were pleased with their surroundings, when their preferences for how they wanted the environment to be set up were satisfied, and when there were elements in the environment that they enjoyed. Environmental modifications that led to the care receiver being pleased with their surroundings usually involved moving to a more pleasant home location:

> What I meant was I knew about . . . we had tried to move here a couple of years before but we couldn't find anything on the golf course. And I wanted the golf course where we had a beautiful view and where I had that to look out on (S10-H-PHY*CR).

Interventions to increase well-being included putting up Christmas decorations, setting up a favorite piece of furniture so that the care receiver could crochet in the sunlight, or displaying objects that the care receiver liked:

> Yeah, those things are positive and she has some pictures that she had bought several years back that she really likes and she keeps them around of her. One of them, she's got strange taste, one of them's Jesus walking on the water with his hands extended and all this stuff and she really likes that. Whatever works . . . (S9-D-MIX).

Customizing the environment to suit the care receiver's preferences was also a critical part of enhancing well-being. As one daughter said "But as far as convenience for her for her own private space, she could have her own room, she had a bathroom that we set up; it became her's. I mean she could have her own things in there. If there were particular soaps or bubble baths or whatever" (P2-D-PHY*). Caregivers seemed particularly attuned to when the care receiver enjoyed some change they had made, as this wife noted "And it just seemed when I bought him nice, young looking, new clothes, it just seemed that he was just pleased and that was so strange, maybe I was imagining it" (S11-W-COG*).

Care receivers really enjoyed some of the structured activities that the caregiver had designed for them. In one instance, a caregiver persuaded her mother to go on a carnival ride with her, over her mother's objections and her mother really enjoyed it:

> . . . and we went on this really cool ride that goes up above the fair . . . first she didn't want to go and she thought it was too scary and she might get sick and then she decided she'd like to do that. And they both [impaired husband and care receiver] had a fantastic time and they loved it, because you were just up above everything and you had no limitations (S12-D-MIX).

In some cases, the caregiver did something as simple as playing catch with her cognitively impaired husband. "And the only thing he had left to do when he got, that he could still do, we found that he liked to play ball, so I had a soft ball about so big, and we'd play catch. He'd just smile and play catch like everything" (S11-W-MIX*).

Maintained continuity. Maintained continuity refers to environmental modifications that support continuity for the care receiver by helping them maintain their link with their past and present identity. These include surrounding the care receiver with meaningful objects such as furniture made by a relative, pictures of family members, or pets they had prior to a spouse's death. Music from the care receiver's era was also used to bring back memories, as this African American caregiver noted: "They like the blues, my mother loves those words" (S17-D-COG*). Maintaining continuity also included helping the care receiver to appear to be living a more normal illness-free life. For example, placing the oxygen concentrator in a position so that it is convenient, but not obvious to guests or the care receiver, is reduces the intrusion of that technology on the care receiver's daily life. Any modifications that prolong the care receiver's ability to stay in a present preferred home setting help maintain continuity for the care receiver. When caregivers need to remove some items from the environment for utility reasons(e.g., to be able to use a wheelchair), the more they can minimize the disruption, the more they facilitate or maintain continuity.

Conserved energy. Conserving energy, and thus making life easier for the care receiver, means that the care receiver is able to avoid activities that would be painful or in some other way unpleasant. For example, having a handicapped toilet prevents the care receiver from having to do painful bending and stooping.

> Right. Handicapped toilets that are higher up. Yeah, and she says it's easier on her knees. She has no cartilage left in her knees so walking is very painful, as is bending. There is a bath seat in the shower that was added probably in the last three years, two years, anyway since she had this problem with her back and can't stand to stand hardly any time at all (S18-D-PHY).

An electric garage door opener made coming into the home that much easier for the care receiver. Maintaining objects in their familiar locations, prevents care receiver distress from the unfamiliar. As one husband caregiver said: "No changes if possible. That's number one. And to make . . . well, I would say no changes if possible. Really, that's because changes are difficult" (S7-H-MIX*M). Moving to a home where the housekeeping is done for the care receiver spares them from performing these tasks.

Increased comfort. One of the primary goals of adapting a medical regime to the home setting was to ensure that the care receiver could comply with the regimen comfortably. This could be difficult when regimens involved technologies that restricted free range of movement or therapies had to be administered that the care receiver did not want:

> Yeah, right handy. I know what I am doing with her. I'll tell you about pill taking too. So we might as well put it in here. That's very difficult with people, she doesn't want to swallow pills. So, either I dilute them with something she is going to drink or I crush them and put them in some pudding or something like that

Keeping the room temperature comfortable for the care receiver could also be difficult, as many care receivers had very different comfort-level needs from the rest of the family (S8-H-MIX*).

Care Receiver's Safety Was Ensured

Another positive consequence of an environmental modification for the care receiver is that his or her safety was ensured. This is defined as no unexpected care receiver injuries or disasters. Avoiding falls was a frequently implied goal of interventions such as denying access to a part of the environment, standing close by, or eliminating hazards for tripping in the home. As this caregiver daughter relayed, some times great pains were taken to prevent accidents:

> Well, at least we didn't kill ourselves, and we didn't kill her. You know, we were so afraid she'd break a hip or break an arm, and she probably couldn't tell us that she was hurting, okay. That was the main thing with us. We were just trying to be careful, 'cause we didn't want her to get hurt, because we didn't know if she would . . . if she'd feel it or not, you know (P6-D-MIX*).

Other injuries that caregiver sought to avoid included burns from fire or hot water, cuts from knives used inappropriately by care receivers, choking from ill fitting dentures or inappropriate foods, accidents from driving, or injury due to getting lost in an unprotected setting. Other unforeseeable calamities were prevented by not leaving the care receiver unsupervised. As the wife of one care receiver with Parkinson's said "I hardly go anywhere myself because I don't like to leave him" (P3-W-MIX*).

Improved Functional Effectiveness

Improved functional effectiveness is defined as how well the environmental modification worked from the care receiver's perspective. Modifications that care receivers could not use were not considered effective. Among the modifications that care receivers could use, there were two very important categories of outcomes identified in this portion of the data: those that deal with gradations of closing the gap between care receiver competence and environmental demand, and those that deal with implications for self-care and autonomy. Four gradations of closing the gap between care receiver competence and demand were identified in the data: care receiver functioning improved, care receiver limitations accommodated, care receiver functional limitations resolved, and care receiver found helpful intermittently. Three categories of implications for self-care and autonomy were also identified: care receiver can do a task independently, makes an activity possible for the care receiver, and the care receiver can read the environment better. Table 4 contains data exemplars that illustrate the eight types of functional effectiveness that emerged in the data. In some instances quotes are from the care receiver, but most are the reported perceived usefulness or effectiveness as noted by the caregiver.

Care receiver can use. The term care receiver can use is a modification the care receiver can physically use, can also remember how to use, and appears to get some benefit from use. Being physically able to use the modification means that the care receiver can use the modification properly. For example, a male care receiver can use the handrails installed to pull himself off of the toilet, or can pull his pants down in time to go to the bathroom because of the elastic in the back. One of the main benefits of adaptive clothing is that the care receiver can get it on and off.

Devices that the care receiver can manipulate in spite of physical or mental limitations provide new options for the care receiver to do activities unaided. For example, several care receivers and caregivers mentioned jar opening devices they had obtained that worked well for the care receiver. One caregiver noted how their family had to purchase an electric recliner because her mother did not have the strength to use a manual one. One daughter noted that her mother was very good at manipulating a flashlight so she could read.

For the cognitively compromised care receivers, being able to remember how to use a modification was essential for ensuring its effectiveness. For example, one caregiver thought that since her husband had used a hand-held shower sprayer before, that he

Table 4

Data Exemplars of Functional Effectiveness

Functional Effectiveness	Definition	Data Exemplars
Care receiver can use	This is a modification the care receiver can physically use, can also remember how to use, and appears to get some benefit from use.	Recliner chairs that are both electric that they've both gotten recently That, and they had to be electric because that was gotten last spring cause my mother didn't have the strength to operate the manual one (S18-D-PHY).
		And I don't know why. I just think now that you've asked the question, I think we were really lucky with that because some other things she wouldn't always remember as well. But she did remember to hold on. It was like something really basic (P2-D-PHY*).
		Yes, we did several things. We . . . he liked magazines and so I ordered all kinds of magazines that had a lot of pictures in them. So we got The Smithsonian, we got The Oregon Coast, we got Pacific Northwest, we got, let's see I got National Geographic, just as many as I could because he didn't really read a book after he got this, but he would look at the magazines, so I got that (S11-W-COG*)

table continues

Table 4 continued

Functional Effectiveness	Definition	Data Exemplars
Care receiver functioning improved	Care receiver competence has been improved by a change in the environment, but the functional problem is not entirely solved.	Well she has . . . she just . . . she's got those three-way bulbs. She turns them up to high when she's working on Care receiveross-stitch or something. And sometimes she'll go into the kitchen and . . . 'cause there's good light in front of the window. And she lays her cross-stitch out there, so she can see better (S13-D-PHY)
Closing gap between demand and competence		
Care receiver physical limitations are accommodated	In this instance the functioning of the care receiver is not improved, it is made irrelevant by a change in the environment that accommodates the lower level of functioning.	So that, you know, it goes up and down and helps him get out of bed by himself. So one of the major things is to get the kind of furniture where he can get some leverage himself and therefore be able to stand on his own, as opposed to needing to be pulled up. So they are in that kind of a bed, and he has the controls and has control then over what position he can sleep in (P5-D-PHY).
Care receiver functional problem solved	In this instance, the functional problem of the care receiver is solved by the changes in the environment.	We bought this house because we couldn't control her in the other house. We had two stories and up and down stairs is a very dangerous thing for her, up and down, you know, she would have a hard time doing it (S10-H-PHY*).
Care receiver found helpful intermittently	In this instance the modification is helpful only under certain intermittent conditions. If the care receiver has a functional set back, it may be impossible for them to use the modification in the short term.	It [memory is really very helpful, I mean, I would say very helpful, it helps. It helps under certain circumstances sometimes (S7-H-MIX*M).

table continues

Table 4 continued

Functional Effectiveness	Definition	Data Exemplars
	Implications for self-care and autonomy	
Care receiver can do task independently	This category assumes that the care receiver can use the modification, and in addition has now become independent with an activity that would have previously required assistance.	. . . and I mean I installed . . . or my husband installed a security bar, little railing things, so that she could have something to push up with her arms, particularly in the beginning with one arm, to get herself up and down off the toilet (P2-D-PHY*)
Makes an activity possible for Care receiver	The care receiver is able to do an activity that would be impossible without the modification, whether someone else was present to help or not.	No, because our camper has a porta potty, and there was a time when she really needed it very often. But now she didn't seem to need it as much anymore. I guess during different times when we've tried the antidepressant and we tried the medicine for Alzheimer's . . . what is it, . . . we tried that. During that she had a lot of diarrhea. That was very difficult. So without it it would have been inconceivable (S7-H-MIX*M).
Care receiver can read environment better	To help the care receiver read the environment better, caregivers often had to increase the sensory input to make up for the decreased functioning that usually accompanies aging.	So then we just left the light on in the bathroom all the time, and somehow looking into the bathroom and identifying it as the bathroom made it . . . you know, very shortly after that he always knew where the bathroom was when he got up, whereas before he would say 'now where's the bathroom around here (P1-D-MIX)

would be able to remember how to use it. Another daughter caregiver noted that her mother would never be able to remember how to use a cane or walker, but that she could remember how to hold on to furniture and walls. The cognitively impaired care receiver's ability to use a modification was a critical factor for the caregiver in terms of evaluating its effectiveness. For example, one care receiver who was no longer able to read would look at magazines that the wife caregiver had obtained for him. Depending upon the nature of the modification and its goal, it may or may not be important the care receiver can use it. However, for modifications directed at aiding the care receiver to do some function that they previously could not do, the care receiver's ability to use it was critical for the modification to be effective.

Care receiver functioning improved. The term care receiver functioning improved refers to improved care receiver competence by a change in the environment although the functional problem is not entirely solved. For example, one care receiver with speech impairment uses an amplifier on her phone to make her voice more audible, but it doesn't return her to the level of functioning she had prior to having Parkinson's disease. Another cognitively impaired care receiver benefits by watching Sesame street and repeating letters and numbers, but it does not return him to his pre-Alzheimer's level of functioning.

Care receiver physical limitations are accommodated. Care receiver physical limitations are accommodated refers to instances when the functioning of the care receiver is not improved, but it is made irrelevant by a change in the environment that accommodates the lower level of functioning. For example, one caregiver noticed that her father kept bumping into one chair or knocking the same plant off the table, so she rearranged the furniture in his apartment to prevent that from happening. Another wife caregiver put her husbands underwear and pajamas in a dresser situated at the end of his bed to facilitate his being able to retrieve his own clothes. One granddaughter caregiver built a walk-in closet with shelves that her grandmother could easily reach. A husband caregiver put his wife's chair up on blocks so that she could rise out of it. Another daughter caregiver noted that her father's lift chair made it irrelevant that her father could not rise out of the chair, because it catapulted him out of his seat.

Improved access was another way caregivers compensated for low level functioning. One daughter caregiver had removed a bathroom vanity so that her father with Parkinson's disease didn't have to move around as many things when he used the bathroom. In all of these instances, the care receiver's functioning did not change, the environment was changed so that the limitations were less or no longer problematic.

<u>Care receiver functional problem solved.</u> Care receiver functional problem solved refers to instances when the functional problem of the care receiver is solved by the changes in the environment. For example, for the care receiver that can no longer negotiate stairs, moving to a home without stairs solves the functional problem. For the care receiver that could no longer cook for herself, moving to a senior apartment complex that provided meals solved the functional problem.

<u>Care receiver found helpful intermittently.</u> The term care receiver found helpful intermittently refers to instances the modification is helpful only under certain intermittent conditions. If the care receiver has a functional set back, it may be impossible for them to use the modification in the short term. One daughter caregiver of a cognitively impaired

father noted that during the time he was confined to a wheelchair, he was unable to use the clock she had placed on the wall to orient himself to the time of day, because he couldn't see it from his wheelchair. If the care receiver has other functional deficits that contribute to the inability to do some task, these will compromise the effectiveness of the modification. As the daughter caregiver of a physically and cognitively impaired mother noted, the special light she had purchased for her to read was only marginally effective, because her mother still had difficulty with understanding the meaning of the text. When the care receiver can't remember to use the modification, it's effectiveness was also compromised. One daughter caregiver noted that unless her mother reminded her father to get his long-handled shoe horn, he would forget to use it and struggle needlessly to get his shoes on. Aides for memory for cognitively impaired care receivers were often helpful only intermittently according to how oriented the care receiver was on a particular day.

Care receiver can do task independently. The category of care receiver can do task independently includes instances when the care receiver can use the modification, and in addition has now become independent with an activity that would have previously required assistance. For example, the care receiver can move about in their apartment, tie shoes, button clothing, get up and off of toilet, or sign documents without assistance.

Makes an activity possible for care receiver. The category of makes an activity possible for care receiver refers to instances when the care receiver is able to do an activity that would be impossible without the modification, whether someone else was present to help or not. For example, one caregiver had painted red marks on the dryer to help the visually impaired care receiver be able to do the laundry. Without this visual cue it would be impossible for him to do the activity. Another daughter caregiver had obtained a rug protector for her father's office to make it possible for him to roll his chair from his adding machine over to his computer. Another care receiver used a gardening cart to make it possible to continue her outdoor activity. Without a raised toilet seat, one care receiver could not use the toilet. Putting a porta potty in their camper made it possible for one caregiver to take his severely impaired wife out with him on errands. One caregiver daughter found that without a pill dispenser, her mother could not manage to take her medication safely. Rearranging the seating arrangements for family holiday dinners made it possible for one cognitively impaired care receiver to eat a meal without becoming distracted, something he could not do without the modification. In all of these instances, the modification was the critical factor in allowing the care receiver to continue some activity that the caregiver valued as being important or essential.

Care receiver can read environment better. The category care receiver can read environment better refers to instances when, to help the care receiver read the environment better, caregivers increased the sensory input to make up for the decreased functioning that usually accompanies aging. For example, lighting was used by one caregiving daughter to help her cognitively impaired father find the bathroom. Another caregiver daughter used lighting to help her physically impaired parents avoid tripping over unseen obstacles. Other caregivers learned to live with blaring television sets so that the care receivers could still enjoy TV despite their limited hearing. Being able to read the environment better is even more critical during the period of time a care receiver is adjusting to moving to a new environment.

In summary, functional effectiveness may be either facilitated by a modification that the care receiver can use, or may be made unnecessary by a modification that accommodates the care receiver's physical limitations. In some instances, the modification is absolutely essential for the care receiver to perform an activity either with help or alone. In other instances, the modification acts as a facilitator of functioning but is not essential for performing that function for the care receiver. Improvement in functioning ranges on a continuum from somewhat improved with assistance to being totally independent. In some cases, the modification is only helpful intermittently

Affective Response to Modification

Affective response to modification refers to instances when the care receiver liked the modification and/or had some other positive feeling associated with the modification such as feeling more secure or more independent. Sometimes when caregivers said the care receiver liked a modification, they meant that the care receiver preferred the modification to other possible alternatives. For example, as one caregiver daughter said, her father liked the bathroom in his new apartment, because he preferred the walk-in shower:

> Yea, in fact when he first moved in there, one of the few things he commented on was the bathroom, that he liked that not having to step into the tub and the fact that it didn't have a slippery bottom, so he liked that (P1-D-MIX).

This same daughter also described how he liked the easy-to-get-on pants with elastic in the back she had obtained for him as an alternative to sweat pants.

One wife caregiver noted that her husband liked wearing Depends as an alternative to going around with wet pants. When contrasting the alternative of using a cane versus holding on to wall surfaces, one caregiver daughter stated that she felt her mother preferred holding onto walls because of the increased security: "I think the walls and the stable surfaces brought her security" (P2-D-PHY*). Some of the participants in the study preferred feeling independent versus having to rely on others for help. Another caregiver who had developed a disability from breaking her hip had this to say about a device she had obtained "I have something to put my socks on. And that's wonderful. It makes you feel independent" (S4-W-MIX*). Sometimes caregivers noted that their care receivers liked something because they found it pleasing or enjoyable. For example, one caregiver noted that his mother seemed to enjoy the memory book he had created for her. Another wife caregiver noted that her husband seemed to enjoy being scrubbed in the tub. She also said that her husband had enjoyed the "making music in the classroom" tapes she had obtained: "another one that he liked that was really good . . . as making music in the classroom with the kids. Now he loves little kids, so and these sing-along with little kids songs, he liked that" (S2-W-COG*).

A positive response to a modification could also include avoiding a negative feeling such as being embarrassed, feeling lonely, or afraid. One caregiver daughter noted that her father finally agreed to wear Depends because he noticed that if he did, he was no longer embarrassed by incontinence episodes. One granddaughter noted that the prime motivation for her grandmother to move in with her family was to avoid loneliness. Another powerful positive outcome of modifications for cognitively impaired care receivers was decreasing fear. As one son observed when he had to move his mother from her apartment to a foster home, an important benefit of moving his mother's own things into her new room was the reassurance they provided:

> I tried to maintain a few items that she feels comfortable so if she goes to a new place, you know, at the foster home all they had there was a bed, single bed in the corner and one of those closets that you bring in. That's all there was so what I did was things like her dresser, she had a cherry hutch that she liked, it wasn't very big. A lamp that she likes, kind of a crystal lamp, and then her paintings and her pictures and there were a couple of chairs. That was the type of things. Of course her television set and the things she was familiar with now and I thought she would be more comfortable with her paintings and pictures up on the wall and what not. So she will feel more comfortable. So if she would have a problem when she would wake she would know where she was and who she was. She would be also be frightened and also at night so I thought by doing that she would be very comfortable (S19-S-MIX).

A Caregiver Problem Solved

An important positive outcome of using various modification strategies was working out a solution to some care receiver dilemma. The problems that were solved by using modification strategies by participants in this study were providing adequate nutrition, managing incontinence, following the medical regimen, and decreasing care receiver agitation.

Modifications that facilitated providing adequate nutrition included obtaining special food preparation devices such as microwaves, obtaining prepared foods such as frozen dinners and Ensure, and changing the timing or method of meal serving. Although these strategies differ in their approach, the universal positive outcome was assuring that the care receiver got adequate nutrition. As one caregiver daughter said "Well anyway, having this microwave allowed me to make . . . always make sure mom's nutrition stayed well" (P2-D-PHY*). Another spouse made this observation "Oh, yes. She is more or less on liquids now. She just eats, drinks Ensure and, oh, I feed her puddings and Gerber's baby food and things like that, otherwise why, it seems adequate she keeps her health very well" (S8-H-MIX*).

Positive outcomes from modifications that facilitate containing incontinence included keeping the care receiver dry, avoiding accidents, and keeping the care receiver clean. Keeping the care receiver dry was an often repeated benefit of using Depends. As one spouse caregiver noted:

> . . . it keeps her dry very well. Well, I think she doesn't mean to do that, but I think when she lays down and relaxes. You know how people do, and then it comes on [urinating]. I don't think she has any problem for that since her mind just, just doesn't tell her that you gotta do this, you know. That's why I can't take her [to the bathroom] (S8-H-MIX*).

As one caregiver wife reported, she meticulously watched her husband's fluid intake so that episodes of incontinence due to infection would be avoided:

> At the adult day care they didn't want so much wetting going on and so I think they kind of held back on it. And so those days I would try to start forcing liquid when he came home because he had more urinary problems if you hold back it, because it gets strong and then you get infection in the urinary tract and then you have wetting because you have this urge to go because of the infection (S11-W-COG*).

Another daughter caregiver noted that wearing the Depends was helping to assure that her mother stay clean:

> . . . see, probably one of the most recent things for her that has been added on, you know she's become incontinent after her last stroke, not all the time, but, you know, just, I think it's more of a, I'm not sure if it's stress incontinence or, but she doesn't seem to use a Depends all the time, or whatever it is. Yeah, she wears those and seems to do okay with that and she's really good about changing it and stuff and, oddly enough, she's a funny person, she was like the kind of mom who always told us: "Make sure you wear clean underwear every day because you never know when you're going to get in an accident" so she was always really good about her hygiene. And she seems, so far, I've noticed she's doing okay with that (S9-D-MIX).

Adapting a medical regimen to the home and the care receiver's routine can be difficult. The positive outcome associated with making modifications that work to solve this problem include being able to successfully follow the medical regimen in the home setting. When caregivers felt that this had been done successfully they made comments about what a good job the care receiver was doing with their treatment:

> Yeah, what she did, she got a big mirror that's one of those magnified mirrors that sits on the . . . you know, it sits on a pedestal on the counter, and it's got a little tray in front. And I think she puts her supplies in that little tray, and then uses the big mirror so she can see her neck and clean that with. And she's got all of her stuff right there, you know, and a chair sitting nearby so that she can sit down if she needs to. And other than that I think, you know, she just makes . . . she is pretty good about keeping that clean and keeping her supplies up on that. You know, she does a good job with that (S13-D-PHY).

Being able to manage the care receiver's medical regimen was critical for the care receiver to remain at home safely.

Decreasing care receiver agitation was the aim of several modification strategies employed by caregivers. Usually when the caregiver felt that they had used an effective strategy, they described it in terms of preventing or stopping episodes of agitation "they're just little things that people come up with that kind of stop these things before they start, because once they get started, they're very hard to deal with" (P1-D-MIX). Sometimes the strategies were effective during periods of agitation as this spouse caregiver noted:

> So I would get him to sit down on the sofa and I would either put my head or my feet on his lap and I might be able to keep him down for a half hour or 40 minutes. By just putting my feet on his lap, or putting my head on his lap, and

> then, you know, he would stay for a while. And then pretty soon he just had to get up (S11-W-COG*).

Other effective modifications prevented an episode of agitation entirely, as one caregiver daughter noted: "So there are certain programs that we let them watch. Matlock is one. You know anything that is soft because my dad has the tendency to incorporate the TV into his life" (S17-D-COG*A-A).

In summary, there are five categories of positive outcomes for the care receiver. Aesthetic benefits for the care receiver are outcomes that enhance the quality of life either via the giving of pleasure, connection with past identity, sustained positive activity, or increased comfort. Another outcome of a number of the environmental modifications was the care receiver's safety was ensured. Improved functional effectiveness for the care receiver was often described as the main benefit of an environmental modification. Positive affective responses to modifications included increasing feelings of independence and security, while avoiding negative sentiment such as embarrassment, fear, or loneliness. Solving a care receiver's problem such as keeping dry, getting adequate nutrition, decreasing agitation, and receiving medical treatments as proscribed was an additional positive benefit described by a number of caregivers.

Negative Outcomes for the Care Receiver

There were two categories of negative results from modification strategies described by caregivers: negative emotional responses and lack of functional effectiveness outcomes. Care receivers had negative emotional responses to modifications that were not to their liking, that were in some way stigmatizing, or that were upsetting to them. Each of these categories are described below along with data exemplars.

Negative Emotional Responses to Modifications

There were three categories of negative emotional responses to modifications, those related to care receiver preferences regarding the modifications, stigmatizing aspects of some modifications, and strong emotional reactions to modifications. When the modification did not suit the care receiver's preferences, it was usually because the care receiver did not like the modification, did not want the modification, or felt they did not need the modification. Care receivers recoiled from stigmatizing modifications that they were too embarrassed to use, that they felt made them appear disabled, or necessitated taking help from the caregiver that they did not want to take. Strong negative reactions to modifications included being terribly upset by the modification, being frightened during the use of the modification, and grieving the way things used to be prior to the modification.

Care receiver preferences. One of the most frequently stated reasons that a modification was rejected by the caregiver was because the care receiver did not like it. Finding a dislike for some adaptive features and/or environmental changes was consistent with results reported in an opinion survey of 201 respondents recruited from a senior citizen's advocacy organization (Steinfeld, 1987). Adaptive clothing that may have worked very well from a functional perspective was frequently rejected because of the preferences of the care receiver. One caregiver daughter noted that the use of sweat pants as an easy-to-get-on item of clothing was an unacceptable solution to her father's difficulty managing regular pants because "Dad would not consider that being dressed, you know" (P1-D-MIX). Another granddaughter caregiver had tried to persuade her grandmother to wear tennis shoes instead of her penny loafers with a heel, but "she didn't like the tennis shoes, and we thought they'd be so much more comfortable . . . [but] she liked shoes that had a heel" (S15-O/C-PHY*CG).

Bath benches were also rejected by care receivers because they didn't like them. In some instances, it was because the care receiver didn't like the idea of getting into the water, as one wife said of her cognitively impaired husband "You couldn't have gotten him to sit down in that water" (S11-W-COG*). In some cases, the care receiver didn't like the bath bench because she couldn't figure out how to use it properly. Sometimes the reason for care receiver's dislike of the bench was not apparent as one husband caregiver noted: "Yeah, I got one here and I tried it but she didn't care too much about [it] . . ." (S8-H-MIX*). Regardless of the reason why the care receiver did not like a modification, the care receiver's preference was usually respected, even when, for example, the modification would have made dressing or bathing easier.

The care receiver may not want a particular modification for a variety of reasons. In the care receiver's view, he/she may feel that they do not need the modification. As one caregiver daughter said "No, she doesn't have a chair or anything yet. I've offered to buy her one but she didn't want it, she said she didn't need it" (S9-D-MIX). More commonly, the care receiver perceived the modification as a threat to his or her pride, dignity, or sense of control. This is what one granddaughter said of her grandmother's refusal to use a cane:

> [Why didn't she like the cane?] I think it was a bother. You know, she . . . I think it was a prideful thing, too (S15-O/C-PHY*CG).

Even when the care receiver was cognitively impaired, the preservation of dignity was still a powerful deterrent to the adoption of some modifications:

> We even tried to get my dad in Depends. It's really strange that my . . . it is so strange that my . . . because he talks. He may be talking out of his head we say "out of his head." He is incontinent and he will not touch them, but there's something there because he won't let us see him undress. He won't wear the Depends. So somewhere in back of his brain there is still something there that lets him know that hey not yet, not yet, not yet. But I don't know what that is and I don't know what part of the brain and you know what is going on. But yeah that's what's going on (S17-D-COG*A-A).

The loss of control by the care receiver was also a factor in the care receiver not wanting a modification, as this caregiver daughter noted: "So, you know, there's still a lot of control and working through the control and what they want" (S18-D-PHY).

Stigmatizing aspects of modifications for care receiver. Stigmatizing aspects of a modification mark the care receiver as abnormal or impaired to others. This differs from the negative consequences experienced by the care receiver that are internal or apparent only to them such as an affront to dignity or a loss of control. Stigma has been defined as "any persistent trait of an individual or group which evokes negative or punitive responses" (Susman, 1994, p. 16). In this instance, the care receiver is marked by the modification as different in the view of society. For example, one caregiver daughter noted that her mother was too embarrassed to use a wheelchair in public: "but it hadn't dawned on me until she said that that she wouldn't use the wheelchair because she didn't want people to think she had to use the wheelchair" (S12-D-MIX). Or as another caregiver daughter noted, the modification may make the care receiver look disabled to others:

> She does not want to use it at a shopping mall and it would clearly be easier for both of them to go shopping if she'd get in the wheelchair. But it puts her down at a level where she doesn't feel in control, and "makes her look disabled." I don't know what she thinks walking with this cart makes her look like, but, you know, she won't do it (S18-D-PHY).

In a study of mobility aids and elderly clients, as nurses described their client's perceptions and responses to mobility aids, a consistent link was made to stigmatization (Rush & Ouellet, 1997). Adult diapers have also been identified as potentially stigmatizing (Fernie & Fernie, 1990).

The care receiver's desire to appear okay to others can include the caregiver. Sometimes, care receivers steadfastly refused badly needed help from caregivers because they did not want to appear to need it:

> No, not yet, but I'm monitoring that and I know there are things you can get to help pull buttons through and stuff like that but she seems to be doing okay. One of the problems that she has when she's using her fine motor skills is she has tremors and so it takes her a long time to tie her shoes, button her shirt. But she does it. And she's really stubborn. I don't bother her too much about it because she'll yell at me and she doesn't think twice about saying "Shut the ___ up" and

> that's what she'll say, too. "Leave me alone, I'll do it myself." She's really stubborn (S9-D-MIX).

Stigmatizing types of objections by the care receiver were very difficult for the caregiver to refute, and would usually cause a care receiver to reject a modification no matter how functionally useful it might have been.

Strong care receiver negative emotional reactions. Strong negative emotional reactions could interfere with the care receiver's acceptance of a modification strategy. Relocating was often very difficult for the care receiver and very unsettling even when the move had many positive benefits. "And just I think for a person in that situation, moving from one physical environment to another is a terribly upsetting thing, and just the passage of time and becoming more familiar with his new environment helped a lot" (P1-D-MIX). Fear generated during the use of a modification strategy, whether rational or not, acted as a powerful deterrent to future use. For example, severely cognitively impaired care receivers were often afraid of water. Even though the devices the caregiver added made bathing safer, they were often rejected due to the fear reaction of the care receiver.

Grieving the way things used to be could interfere with the care receiver's adoption of a modification strategy. As this caregiver daughter stated about her mother, it can be critical to allow the care receiver to work through that grief before the care receiver will be able to accept the proposed modification strategy:

> Now when she thinks of her home state, she thinks it was like when they left it. And by this time people had passed away and people who were around close had ended up in . . . like nursing homes so when I first said, "mom, it's not safe for you

> to be by yourself anymore, and we want you come and live with us," it was, "well, I want to go back home." So, we worked through that. She came. She didn't fight it too much. She came. But I think initially she was a little bit lonesome (P2-D-PHY*).

If the problems were not resolved, the modification would not be permanently adopted, as this daughter caregiver noted about her father's rejection of the use of a magnifying glass: "You know, he can't deal with what's missing from his vision. Instead of just magnifying it and looking around it, he can't deal with [it] . . ." (S18-D-PHY). Strong negative reactions on the part of the care receiver could not be ignored if the modification strategy was to be successful.

Lack of Functional Effectiveness Outcomes

As previously noted, functional effectiveness refers to how well the modification works. When the outcome of the use of a modification strategy is negative from a functional effectiveness perspective, it is often because the care receiver cannot use it at all or will not use it. Sometimes, even though the care receiver can use the modification strategy, the caregiver determines that there are some negative outcomes associated with its use. For example, the caregiver may determine that the use of the modification strategy is too hard on the care receiver. The caregiver may believe that the care receiver benefits more by not using the modification, or the caregiver thinks that the modification is not safe for the care receiver to use. In addition, the care receiver's functioning may not be improved enough for the care receiver. In other words, the modification strategy has not resulted in enough improvement in performance to meet the care receiver's criterion of minimal functioning. Table 5 contains data exemplars that illustrate the categories of lack of functional effectiveness outcomes. All of the observations in the table were reported by the caregivers.

Care receiver cannot use. When care receivers could not use a modification strategy, it was usually because they lacked some critical cognitive or physical skill or capacity. The skill or capacity might only be a small component of what is required from the care receiver in order to use a modification strategy. However, the absence of these functional capacities, whether physical or cognitive, makes it impossible to use the modification at all. For example, one caregiver daughter observed that her mother was unable to use a list as a cognitive aid to memory, because she could no longer write a list due to a fracture of her wrist from a fall. Other physical functional limitations were reported by caregivers as being obstacles to use of modifications. A caregiver daughter noted that her mother was not able to use the magnifying glass she had given her because she could not focus the lens properly. In some instances, care receivers lacked the strength to use a device.

Cognitive limitations that interfered with functional effectiveness included difficulties with learning, sequencing, remembering, recognizing cues, and doing things reflexively. Difficulty with retention makes learning the new skills necessary to use some modifications almost impossible. One care receiver had great difficulty retaining the series of steps required to use her bathroom safety equipment. Care receivers who are unable to sequence very well usually cannot master the use of equipment or machines. For some care receivers, they cannot remember how to use devices that they may have had for some

Table 5

Lack of Functional Effectiveness Outcomes for the Care Receiver

Lack of Functional Effectiveness	Definition	Data Exemplars
Care receiver cannot use	When care receivers could not use a modification strategy, it was usually because they lacked some critical cognitive or physical skill or capacity.	
Care receiver cannot use	**Due to physical limitations**	We tried a walker . . . we had walkers here, but that's really too difficult to handle. It's just not a good option (S7-H-MIX*). He's put a little deal underneath there to open a jar, and I cannot . . . I can't use it, and cannot do it. I don't have strength in my arms anymore. And less since I got this torn up (S5-H-PHY*CR).
Care receiver cannot use	**Due to problems with learning**	Yeah. Now. Yes. When she was in a foster home she used a cane for a while but now she has to be either in wheelchair or walker. The trouble is that she forgets how to use it. You can have maybe therapy there to help the person. Very good, show them how to walk and all this and be careful but then the next day it's like you have to show them again (S19-S-MIX).

table continues

Table 5 continued

Lack of Functional Effectiveness	Definition	Data Exemplars
Care receiver cannot use	**Due to problems with sequencing**	But we both have concerns about anything that's equipment or machines that she's usually not as good at running period. She didn't like the push button phone. She wanted the phone back that just had the . . . well not the rotary, but she didn't like the memory idea or that which we thought was going to help. So she had one of those phones but we took it back out (S12-D-MIX). Yes, well, the microwave she doesn't use. She doesn't have a mind for newfangled things, is what she calls them (S9-D-MIX).
Care receiver cannot use	**Due to problems with remembering**	Her memory is so short she couldn't take her pills. She was on glycine. So I even got one of those weekly things that says Sunday, Monday, Tuesday, Wednesday but since her memory is so short for some reason she would think that she already had taken them (S19-S-MIX).
Care receiver cannot use	**Due to problems with recognizing cues**	{No}, I mean they were loaded with pictures over there too. Say "this, this, this," [to try to get her to remember who she was] but she didn't want to be . . . you know, it was "why are you bothering me?" (P6-D-MIX*).

table continues

Table 5 continued

Lack of Functional Effectiveness	Definition	Data Exemplars
Care receiver cannot use	**Due to problems with doing things reflexively**	We had to practice a little. It's [new specialized walker] a little clumsy for her when she's making a turn. Primarily I think she stops and she worries, "what do I have to do" and then she realizes that she's got to power it by her hands (S10-H-PHY*CG).
Care receiver does not use	Sometimes the caregivers were aware that the care receiver was not using a modification strategy, but they were unclear as to why the care receiver was not doing so.	They don't do very much in the way that they used to. They never over did it like decorating up the apartment for holidays or anything like that, but they still kind of have this belief that they've got to do some things like putting the Christmas lights around the mirror out by the dining room table, and the old paper tree with the light under it that turns around, that's always put out. But there has been less of that. Nowadays there's not a wreath or bow on the door. A lot of those things aren't there. When we try to either send something so they'll do it or make it easier, they'll say they don't get around to doing it. And so it doesn't get done unless we're there to do it (S18-D-PHY).
Care receiver could use but doesn't	Caregivers identified four rationales to explain why a care receiver could have used a modification strategy, but did not.	

table continues

Table 5 continued

Lack of Functional Effectiveness	**Definition**	**Data Exemplars**
Care receiver could use but doesn't	**Due to too hard on care receiver**	We used a walker in fact, when our nurse was here all the way down to the dining room, but it just exhausted her. It just makes no sense to try something that is at best marginal in value for her (S7-H-MIX*).
Care receiver could use but doesn't	**Due to not safe for care receiver**	They're [raised toilet seat] just set about this high and they just set on top and if you're just a little bit off you can tipsee. So there not the safest (S10-H-PHY*CG).
Care receiver could use but doesn't	**Care receiver benefits by not using**	Yeah, I think so, and it [raised toilet seat] didn't seem to help much so, she gets the exercise on pushing up and down (S8-H-MIX*).
Care receiver could use but doesn't	**Care receiver functioning not improved enough for care receiver**	The first thing we did was send him some of those little page size magnifying sheets that you put over a page to read and he says they just don't work, he said he's still got the missing pieces (S18-D-PHY).

table continues

Table 5 continued

Lack of Functional Effectiveness	**Definition**	**Data Exemplars**
	Care receiver functioning not improved enough for care receiver	Okay, now her eyesight . . . she claims to have always been blind in her right eye. I think, what it is, is apparently when she was younger she had an astigmatism and stuff and she . . . the last time I remember her getting glasses was in the 70's and she said the eye doctor said there was nothing more they could do for her eyes. Well, I think she took that as, don't wear glasses anymore and don't go to the eye doctor anymore. I think all he meant was she would, at best, progress to bifocals at some point. And she just really neglected her eyes (S9-D-MIX).

time. In other instances, the care receivers cannot even remember to use the modification strategy at all. Severe visual agnosia in some demented care receivers makes the use of cues or prompts for behavior totally ineffective.

The inability to retain some information on a reflexive level can make the incorporation of some modification strategies into daily routines quite burdensome. For example, one caregiver daughter stated that her mother probably would not be able to use a cane or a walker because she would have to continuously think about how to use it. Although the care receiver cited in the previous example was not diagnosed with a cognitive impairment, these findings were similar to reports from a study by Dick et al. (1996) that acquisition and long-term retention of gross motor skills are compromised among person's with Alzheimer's. In their study, they found that only Alzheimer's patients receiving constant practice of a gross motor skill showed no forgetting across post-tests. Patients receiving varied practice, which would be similar to the methods commonly employed to teach skills such as using a walker, had difficulty accessing and/or developing motor schemas.

Tideiksaar (1989) has identified that improper device use may actually cause or contribute to falling. Recommendations for assessing the older person's ability to use a device include ensuring that the device has been measured properly, that the device is not defective in some way, that the device can be used in the space limited areas of the home, and that the patient has the necessary strength to operate the safety features of the device such as the locks on wheelchairs. Assessment of mild cognitive limitations such as forgetfulness, and problems with sequencing that impede or interfere with device use, are not adequately addressed in Tideiksaar's professional recommendations.

Care receiver does not use. Sometimes the caregivers were aware that the care receiver was not using a modification strategy, but they were unclear as to why the care receiver was not doing so. For whatever reason, the care receiver's motivation to use the modification appeared to be lacking. One husband caregiver described the cane his wife had, in addition to her very specialized walker, as kind of a toy to her. Another caregiver daughter said that her mother set the specialized utensils she bought her aside, as if keeping them for a special occasion.

Sometimes caregivers were not sure if the care receiver used the modification strategies they developed for them or not. Another caregiver daughter said that she thought her mother sometimes did not use the modification strategies she developed for her because her mother was rationalizing to herself that she did not need them. One son expressed great frustration at his cognitively impaired mother's not using the prepared meals he set up for her. Caregivers often appeared to be frustrated when they could not discern why the care receiver was not motivated to use the modification strategies devised for them.

Care receiver could use but doesn't. Caregivers identified four rationales to explain why a care receiver could have used a modification strategy, but did not. Sometimes the caregiver determined that the modification was too hard on the care receiver. Examples given by caregivers that illustrated this outcome included noting that the care receiver became too exhausted or too frightened while using the strategy. In some cases, the care receiver benefitted by not using the modification. In other cases, the caregiver felt that the modification was potentially unsafe to use. One of the most interesting observations by the caregivers was that a modification could sometimes be rejected by the care receiver because it did not improve the care receiver's level of functioning up to the criterion level that the care receiver deemed it should to make it worthwhile to use. In each of these cases, even though the care receiver could physically use the modification strategy and it may in turn do for the care receiver what it was intended to do, it still may be rejected as unsatisfactory for one of the above reasons.

Positive Outcomes for the Caregiver

There were five major categories of positive outcomes from environmental modification strategies for the caregiver. Aesthetic benefits for the caregiver are outcomes that improve the caregiver's quality of life. These benefits included the changes made in the care receivers living arrangements that secondarily benefitted the caregiver by assuring them that the care receiver had the best possible situation. Positive affective benefits related directly to the modification strategies included having the caregiver's preferences satisfied or accommodated and having caregiver task unpleasantness decreased. Another outcome of a number of the environmental modification strategies was that monitoring of the care receiver was made easier. One of the positive outcomes of relocating the care receiver to home closer to services and relatives was increased social support for the caregiver. Improved functional effectiveness in performing caregiver work was the most frequently described positive outcome of environmental modification strategies. Each of these categories are described and data exemplars are provided.

Aesthetic Benefits for the Caregiver

As noted previously for the care receiver, aesthetic benefits heighten the caregiver's enjoyment of the caregiver situation and thereby increase well-being. In some instances, a change originally made for the care receiver unexpectedly benefits the caregiver. As one wife caregiver observed: "the cat probably has helped me, because he's so much fun, you know. And he really shows a lot of affection, something my husband doesn't do anymore . . ." (S2-W-COG*). Sometimes, caregivers set up the environment specifically to support some time away from caregiving for rest and relaxation: "I do all the flower work outside. I work inside and outside a lot. I enjoy it. It gives me a little out there. I can't play golf anymore because I can't leave her for two hours at a time" (S10-H-PHY*CG).

One of the ways caregivers increased their own quality of life was by ensuring that the care receiver's surroundings were pleasant:

> But very soon she became Grandma to the neighborhood. There were little, a lot of little kids in the neighborhood, and they'd know it was Grandma. So if she'd be outside or they would see her in the front window, or the neighbors would wave. So she shortly got integrated. But that was her way of staying in touch with that little local community there was being in that front window and knowing who was coming and who was going . . . and when the mail came . . . and kind of watching for the kids . . . and we had a puppy who would always be at her side. He kind of sensed and adopted her. And so she had the companionship of that puppy, and she could see up there. So it wasn't like she just had a view of one house. She had a

> view of the whole cul-de-sac. And I think it was her sense of that room . . . and it was light . . . and it does have a nice view early in the morning and late in the evening. And because that's been where I'd find her . . . she'd be watching for me to come home, and I'd come up and I'd find her there . . . and we'd sit down and we'd visit. So, it's kind of a combination of all those things. I think was, it's a pleasant room, and she enjoyed being there and that kind of thing (P2-D-PHY*).

By ensuring that the care receiver was pleased with the environment in which caregiving takes place, a great deal of the negative emotional burden associated with caregiving was often avoided. Caregivers often spoke with pride about the living situations they had created to make the care receivers remaining years pleasant: ". . . an ideal place to bring him to live. I hate to say 'to bring him to die,' but actually that's . . . well, to spend the last years of his life would be here in a very pleasant home" (S2-W-COG*).

Affective Benefits

There were two primary affective benefits of environmental modifications for caregivers, having their preferences satisfied or accommodated and having their task unpleasantness decreased. When the caregiver's preferences are satisfied or at least accommodated, his/or choices are allowed for in the strategy that is selected. Task unpleasantness is decreased whenever the distasteful aspect of some caregiving activity is ameliorated.

Caregivers' preferences satisfied or accommodated. Modification strategies that satisfy the caregivers' preferences allow caregivers to meet their own needs in addition to meeting the needs of the care receiver. For example, having adequate space in the home allowed both the caregiver and care receiver to set up their respective private areas according to their own tastes and preferences. In one family, having sufficient bathrooms allowed the caregiver daughter to set aside one bathroom exclusively for her mother's use, which allowed the caregiver to maintain her own bathroom in the way she preferred. One wife caregiver really appreciated having her own bedroom where she could stay up late at night and read without compromising her husband's sleep.

In other instances, a move may have been made to accommodate the care receiver's functional limitations, but the caregiver found that there were other features of the new home that met their needs better. For example one wife caregiver said she loved the new kitchen in her new home, and one husband caregiver really liked the landscaping in their new retirement home. There were also aspects of some equipment and supplies that suited the caregivers' preferences better than others. For example, one wife said that she thought that she was going to prefer incontinence briefs with hidden pads over the Depends her husband had been using.

Caregiver task unpleasantness decreased. Modifications that made difficult or unpleasant tasks easier to perform were especially valued by caregivers. Usually the tasks caregivers found difficult to perform were related to incontinence cleaning or other types of hygiene care. One wife caregiver made this important discovery:

> Of course I had a little grandson who was born after he got Alzheimer's, and so I was quite well aware of baby wipes so we had baby wipes and the caregiver said "Now you'll need to get me some gloves" and so we just used boxes and boxes of those gloves, so, you know, if someone has Alzheimer's they should certainly be

> told early on, get those gloves. And the job is still bad, to try to get the briefs off and clean out, but it's a lot better with the gloves (S11-W-COG*).

Other spouse caregivers described other ways to manage the unpalatable task of cleaning up from a bowel accident. One wife purchased a special supply of wash clothes to perform this disagreeable task. Others relied on the use of Depends and baby wipes. Regardless of the strategy used, it was evaluated as effective by the caregiver only if it removed some of the offensiveness of the task from the procedure. Another common undesirable effect from bathing activities was getting water all over the bathroom and the caregiver. Modifications that prevented this from happening were viewed very positively:

> Oh, yeah, well, I suppose that the shower thing would probably be the sprayer, something like that to take care of them when they are, because it was rather difficult to get under the shower. And after I got her in there then I was getting all wet too, so, I rigged her that and I can control that (S8-H-MIX*).

In addition, anything that made a cognitively impaired care receiver more cooperative with the bathing procedure was viewed as a great benefit. Prior to learning how to wash her husband's hair without putting him under running water, this wife caregiver said the following:

> And sometimes I would just come behind and just physically force him to lean over the sink. And it would just be my strength against his strength to force him to lean enough so I wouldn't get water too far and wide (S11-W-COG*).

After this wife caregiver learned how to wash her husband's hair by using a wash cloth, she lamented the fact that she could have used this much easier alternative from the beginning.

Monitoring Made Easier

A positive outcome of some of the modification strategies was making monitoring of the care receiver easier. There were two categories of this type of benefit. One applied to those caregivers who lived with the care receiver. The other applied to those caregivers who did not live with the care receiver and had to do their monitoring long distance.

Monitoring while living with care receiver. The most commonly identified benefit of the monitoring strategies used by caregivers living with the care receiver, was being able to keep an eye on their status, without being intrusive. One caregiver daughter noted that just by listening she was able to determine if her mother was having difficulty ambulating to the bathroom: "Because I was aware when she was up. And different times in the night, she'd get up to go to the bathroom, because I'd listen. No? Okay, she's back in bed, there was no falls" (P2-D-PHY*). This was because she had carefully planned the placement of her mother's bedroom to be close to her own. Another caregiver wife was able to do other caregiving activities while she watched her husband in the mirror. In other words, the modification she made had made it possible for her to monitor her husband and still do other activities simultaneously: "I'm getting his pills and . . . and clothing, but I'm also watching him in the mirror" (S2-W-COG*).

A benefit of some of the strategies in terms of monitoring the care receiver was that the caregiver was able to easily listen for aberrant or dangerous behavior easily and to prevent dangerous wandering without having to have the care receiver in sight at all times. As this wife caregiver said:

> Now I already had that, but this was the thing that it did, if somebody needs to know information, I had that, put that security system on, so if I was sleeping soundly and he got up, that would go off. And I would know he was up. And it only did that one time. He was very ill one time and I didn't want to catch what he had, he seemed to have the flu, and so I slept in the other bedroom and he got up and of course the alarm went off and so that way I knew he was up and needed some help. But that security system was good. And then, also, it's fixed up on both doors so every time I would be in the kitchen, cooking, and I'd hear the bell, that noise, and then I could go. But that was something we just happened to have that worked well. But if we hadn't had it, I don't know how I would have known it would have been a good thing to put in but it was worth its weight in gold, to have those doors with the bell on (S11-W-COG*).

Dangerous activities on the part of the care receiver were also prevented when the caregiver denied access to a part of the environment deemed unsafe for the care receiver and in situations where 24-hour continuous supervision was set up. As this wife caregiver said:

> He knows that when I say sit, he sits. I say lets go, then we go. But if I allow him, I feel if I allow him to just walk all around the first thing he does is come and turn off the stove or turn on the water (S16-O/S-MIX*HIS).

Another positive benefit of an ingenious modification strategy was the caregiver's ability to be in a remote part of the home, yet be available to the care receiver on a moments notice: "And by us having our own phone [line], if she needed us in the night and couldn't get out of bed, she had her phone [with a separate line] right there where she could have called us" (S15-O/C-PHY*CG). Being able to monitor the care receiver with a minimum of effort was a very positive outcome for the caregiver of several with the modification strategies.

Caregiver can monitor care receiver from a distance. There were two outcomes of modification strategies that caregivers who did not live with the care receiver found helpful. The first was the caregiver being assured that the care receiver could get help if and when they needed it. For example, this was the benefit of the care receiver having a set of call lights in her apartment.

> And all the rooms, except for the living room, I believe, have call lights, emergency call lights. So, it's kind of neat. I feel better having her in a place like that because right now she's pretty well out of it (S9-D-MIX).

Some caregivers were able to achieve this same positive benefit by using innovations such as portable phones:

> . . . she has a phone, a portable phone that she's supposed to carry with her whether she goes to the bathroom or to the bed or wherever, or even into the shower, not in the shower, but put it on the thing. That's the rules, so that if something happens, she can use the phone and call (S14-D-MIX).

Another positive benefit of some of the modification strategies was that the caregiver could be assured that there was someone readily handy to physically check on the care receiver either routinely or in an emergency. For example, the Meals on Wheels delivery people were often mentioned by the caregiver as a resource for routinely monitoring the condition of the care receiver: ". . . are angels and they look out for her and they help her. And they are probably her daily contact. The Meals on Wheels people are her daily contact" (S12-D-MIX). Other caregivers had the benefit of being able to gain assistance for emergency check ups on the care receiver from neighbors:

> There is one other adjustment that we've made that has come in very handy for me, and that is that the neighbors that live across the street, I have their phone number. And he can see in her house window if she has her curtains open. And there's been a few times that she's left the phone off the hook by accident or forgot to hang up the cordless. And I call and call and call, and it scares the living daylights out of me. I think, "oh my gosh, she's laying there and can't get help."
>
> And so I've called her neighbor, and he checks on her for me (S13-D-PHY).

Some of the caregivers used the phone and Email to check on the care receiver routinely. The disadvantage of that system was that the caregiver would often have to physically check on the care receiver if something was going awry, but overall, this worked better than no system at all.

Informal and Formal Social Support Facilitated

A benefit of relocating the care receiver was increased social support for the caregiving work. Sometimes this was because the caregiver could get help from organized services more easily, as this son caregiver noted:

> No I think, I think when you have the nurse, will know the situation, the visual situation. I looked at the notebooks of some of the other patients and how they have, the file there they have a list of symptoms to look for if you're diabetic, they look for the different symptoms so she will know that, she'll be monitoring the blood sugar and the other vital signs. So she should know ahead of time whether something is coming and then we will be able to get the right medicine or get her into the doctor. Now this fellow said that what he did he would go with her himself to the doctor's office. You would go ahead and use the county taxi wheelchair, wheelchair taxi. He says he goes along. He's concerned because they just dump the people off at the doctor's office and he'll stay with her (S19-S-MIX).

Another positive outcome of relocating the care receiver for the caregiver was being able to get help from adult children or other family members. As this husband caregiver noted: "And it wasn't . . . it . . . we loved it here, because our son was here. But it was an adjustment, you know, especially if you didn't have all your friends here" (S6-H-MIX*). In both of these instances, it is important to note that the location of the care receiver home can make a big difference in terms of how much support is available to the caregiver. Obtaining additional supports for caregiving was often a goal of relocation in addition to placing the care receiver in a physical environment that was easier to manage.

Positive Functional Effectiveness Outcomes for the Caregiver

There are two major categories of positive outcomes that are associated with increased functional effectiveness for the caregiver. The first major category represents outcomes that are associated with the use of the parallel strategy of getting help. The outcomes associated with getting help for the caregiver and functional effectiveness include permitting the caregiver to do other activities, discovering that hired help does a task better, and being relieved of a task the caregiver cannot do. The outcome associated with the caregiver's use of self primarily included saving time for the caregiver.

The second major category represents outcomes that are associated with the environmental modification strategies described in Aim #1. These outcomes included decreasing the caregiving workload associated with particular caregiver activities, decreasing the caregiving workload associated with other household maintenance chores, and making a specific caregiver activity easier to perform by changing the way it is performed. Each of these categories are described and data exemplars are provided in Table 6.

Getting help: Caregiver can do other activities. In this instance, the parallel strategy of getting help has allowed the caregiver the flexibility to do other activities rather than the caregiving or household maintenance task the hired help provides. For example, one caregiver daughter stated that the housekeeper her mother hired for her allowed her to spend more free time with the family on fun activities. Another spouse caregiver was contemplating the use of respite care for his wife in anticipation of not being able to take her with him on errands in the future.

Table 6

Positive Functional Effectiveness Outcomes for the Caregiver

Functional Effectiveness	Definition	Data Exemplars
Getting help: Caregiver can do other activities	In this instance, the parallel strategy of getting help has allowed the caregiver the flexibility to do other activities rather than the caregiving or household maintenance task the hired help provides	You know, you can go for a walk, or do things, even with mom that you would have had to take your time and your energy to be cleaning the house. So that was wonderful for us (P2-D-PHY*).
Getting help: Caregiver finds hired help does task better	In this instance, the caregiver finds that the positive benefit of obtaining hired help is that the help actually does a task better than the caregiver could possibly do. Some times this is because the hired help possesses skills or training that the caregiver does not, such as a barber or hairdresser. In other cases the caregiver finds that the hired help has greater strength or flexibility than the care receiver and therefore can do a better job than the care receiver. Or it may be that the caregiver simply does not have time to do an adequate job and thus the hired help is able to do it better.	Yeah, I have a lady come in and do that. Whenever she needs it she cuts her hair a little bit. I do rinse it off you know. No, no. I tried once put curls in it, it looked terrible. I am not going through this no more. (Laughter) Poor soul she puts up with me, you know, not to imagine. Terrible (S8-H-MIX*).
Getting help: Caregiver relieved of task they can't do	In this case, the caregiver is relieved of a task that they cannot do. There were several reasons why a caregiver might not be able to do a caregiver task at all. In some cases, the caregiver simply did not have the strength to the activity. Occasionally, the caregiver did not have the necessary skill to perform the task needed.	So then when this lady left [first paid caregiver], she quit, she said, "We've got to have a caregiver with a car,"so the new caregiver had a car and he would take him in the car and we'd pay him mileage (S11-W-COG*).

table continues

Table 6 continued

Functional Effectiveness	Definition	Data Exemplars
Caregiver use of self: Saves time for care receiver	When the caregiver elects to do a task for the care receiver, the primary benefit for the caregiver is that the task is done more quickly. The outcome of this efficiency for the caregiver is saved time. In most of the examples cited by caregivers of when they employed this strategy is was with helping the care receiver dressing. Functional impairment really slows the dressing process.	I didn't, when I was going someplace I didn't have that much time so I'd put them on. But we had no problem with the dressing (S11-W-COG*).
Caregiver work load decreased	In this case, the benefit reported by the caregiver for the modification strategy was a reduction in work load.	Now, with the walker, she can get around pretty well without have to be right on her all the time. {So that's been a help, then?} It has, a tremendous help (S10-H-PHY*CG).
Other task work load decreased	In this instance, the other burdens associated with household maintenance tasks were decreased.	And we took out the carpeting and put in wood and some of that is that it is easier to clean wood if there is any kind of problem with urination (P5-D-PHY). And I do have, when we went to the doctors I do have some slip on shirts and so on, and some slacks I put on her their like pajamas they're easy to wash and they don't have to ironed or anything (8-H-MIX*).

table continues

Table 6 continued

Functional Effectiveness	Definition	Data Exemplars
Caregiver task easier	There were several instances where caregivers had devised ingenious alternative methods or approaches to performing some necessary caregiving task. The main benefit from an innovative modification strategy was making the task easier to perform for the caregiver.	No, not the tub. Well, she can get in but she can't get out. And it's hard for me to get her out alone and so consequently we take showers (S10-H-PHY*CG). Yeah, yeah I had to adjust to you know on the every day basis of how we start our day. The routine is that way he, well I have to shave him before hand in bed because if I do it when he's already up he doesn't let me, you know as easy as when he is laying in the bed (S16-O/S-MIX*HIS).

Getting help: Caregiver finds hired help does task better. In this instance, the caregiver finds that the positive benefit of obtaining hired help is that the help actually does a task better than the caregiver could possibly do. Some times this is because the hired help possesses skills or training that the caregiver does not, such as a barber or hairdresser. In other cases the caregiver finds that the hired help has greater strength or flexibility than the care receiver and therefore can do a better job than the care receiver. Or it may be that the caregiver simply does not have time to do an adequate job and thus the hired help is able to do it better.

Getting help: Caregiver relieved of task they can't do. In this case, the caregiver is relieved of a task that they cannot do. There were several reasons why a caregiver might not be able to do a caregiver task at all. In some cases, the caregiver simply did not have the strength to the activity. For example, one wife caregiver had to hire someone to mow her lawn because she could not handle the mower they had purchased. Occasionally, the caregiver did not have the necessary skill to perform the task needed, such as the wife who did not know how to drive and therefore could not transport her husband to his appointments.

On a number of occasions, the caregiver had conflicting demands upon their time and had to be elsewhere when the task needed to be done. Conflicting demands included those from a job and those from the obligations to other family members. Even though the other demands or the caregiver might not conflict directly with when a task needed to be done, some times the caregiver just did not have the time to do the task for the care receiver. Sometimes the caregiver could not perform a task for the caregiver because they lived too far away to make that a violable alternative. In all of these examples, the consistent benefit of hiring help was that the caregiver was relieved of doing a task they could not possibly do for the care receiver, but yet was essential for the care receiver's health and well-being.

Caregiver use of self: Saves time for caregiver. When the caregiver elects to do a task for the care receiver, the primary benefit for the caregiver is that the task is done more quickly. The outcome of this efficiency for the caregiver is saved time. In most of the examples cited by caregivers of when they employed this strategy is was with helping the care receiver dressing. Functional impairment really slows the dressing process.

Caregiver workload decreased. In this case, the benefit reported by the caregiver for the modification strategy was a reduction in workload. As one husband caregiver noted, once his wife with Parkinson's disease obtained her new walker, his physical burden was reduced because he no longer needed to be physically present when she ambulated. A number of caregivers remarked that obtaining a microwave had dramatically decreased the amount of effort they needed to put into food preparation for the care receiver. Creative organization of the home made it easier for caregivers to keep potentially dangerous items like medications out of reach of the care receiver. It also prevented them from having to spend many hours searching for needed supplies or items because the care receiver hid them.

Other task workload decreased. In this instance, the other burdens associated with household maintenance tasks were decreased. One wife caregiver noted that by moving to a much smaller home, she had minimized housekeeping. In a number of cases, caregivers reported that the changing of the floor covering greatly reduced cleaning onus. Another caregiver husband stated that buying only no-iron clothing had reduced his chore time. Modifications that simplified maintenance such as moving to a home with a very small yard, were identified as decreasing caregiver workload. Even small changes such as obtaining a portable phone, decreased the amount of energy the caregiver had to expend to manage the care receiver's care.

Caregiver task easier. There were several instances where caregivers had devised ingenious alternative methods or approaches to performing some necessary caregiving task. The main benefit from an innovative modification strategy was making the task easier to perform for the caregiver. For example, one wife caregiver noted that shaving her cognitively impaired husband in bed increased his cooperation with the procedure enough so that she was able to do the task with a minimum of struggle. One husband caregiver reported that without being able to use their home's new shower stall, he would not be able to bathe his wife with Parkinson's disease because she was impossible to get out of a tub once wet. The wife of a cognitively impaired husband said that without the hand held shower sprayer installed in her remodeled bathroom, she could not have bathed her husband without being hit. A couple of the caregivers were able to more easily work with their cognitively impaired care receivers' fear of water by reducing the amount of shower spray the care receiver would have to tolerate when having his or her hair washed (wash hair in sink) or when getting a bath (by using a bucket as the source of water rather than the shower sprayer). Another caregiver daughter found that by insisting that her mother get a wash and wear hair cut they were able to eliminate weekly trips to the beauty shop for which the daughter could no longer spare the time. In all of these cases, the caregivers changed how they did an activity to make the performance of that activity easier to manage.

In summary, there are two major categories of positive outcomes that were associated with increased functional effectiveness for the caregiver. One category is associated with the parallel strategies of getting help and the caregiver's use of self. The other category of outcomes are those associated directly with the caregiver's use of modification strategies. Outcomes for the caregiver for both categories included being able to do other activities, getting the task done better, being relieved of a task the caregiver could do, saving time for the caregiver, decreasing the caregiver workload from caregiving and other responsibilities, and making the caregiving tasks easier to do.

Negative Outcomes for the Caregiver

There were two categories of negative outcomes for the caregiver associated with reported modification strategies, increasing the caregiver workload and care receiver functioning not being improved enough for the caregiver. There were several modification strategies that created more work for the caregiver. Despite this negative outcome from the caregiver's perspective, caregivers often continued to use the strategy because it benefitted the care receiver. The outcome that was most likely to lead to the caregiver not using a modification was disappointment in the improvement in care receiver functioning. If the caregiver felt that the care receiver's functioning was not improved enough to meet a minimum criteria of functioning, they did not support further use of the modification.

Care Receiver Workload Increased

There were numerous instances where caregivers continued to use a modification strategy even though it increased their workload. A number of the caregivers went to great lengths to keep up a toileting regimen so that the care receiver could remain continent. As this caregiver daughter reported, the work that this involved could be quite substantial:

> Don't let him get excited. We always try to take him for a ride you know to get him out of the house and we have to cover our seats and we have to stop every ½ hour and try to force him to go use the bathroom (S17-D-COG*A-A).

Notwithstanding this burden, caregivers often kept up these difficult regimes to respect the care receiver's preference to not wear adult diapers.

Another strategy that was difficult for the caregiver was continuously monitoring the environment for potentially hazardous materials. Caregivers did this in lieu of restricting the care receiver's movement in the home. As one wife said: "you know, you just couldn't have anything around, you had to treat it like a, probably an 18-month-old baby, the way you kept things around" (S11-W-COG*). Again in this instance, the benefit for the care receiver outweighed the disadvantages from the caregiver's perspective. Another strategy that the caregivers used that was often difficult for them was taking the care receiver on outings with them while they did errands. They did this for the benefit that the care receiver obtained from getting a chance to get out of the home. But a lot of times, this was really difficult for the caregiver:

> As far as going, now they like going grocery shopping even though they are confused but it takes forever, it is so hard to take them grocery shopping because

> either my dad has to go to the bathroom or he wets on himself so we have to leave so you know you know the time to take them and when not to take them (S17-D-COG*A-A).

Although clearly it would be easier for the caregiver to leave her parents at home, she continues to provide them with outings because they like it.

In some instances, the choice between a positive benefit for the care receiver and negative outcome for the caregiver was less clear. For example, it was not always clear to the caregiver if the benefit the care receiver would receive from the use of some modification was going to be worth the hassle for the caregiver. As one wife caregiver observed, she thought her husband would like to use a bath bench and a hand held shower device rather than shower. However as she stated "I keep thinking if I get one of those little stool-like things, that we're going to have water all over the bathroom" (S2-W-COG*). Only in instances where the caregiver could determine that the benefit of the modification was marginal for the care receiver did the caregivers feel comfortable abandoning a modification strategy that increased their workload. As this husband caregiver observed about day care for his wife: "And it was my judgment that leaving her would bring more distress and would be . . . it would be stressful for me because I had to get her ready and to go, get back, take-her up and back" (S7-H-MIX*).

In conclusion, just because a modification strategy resulted in an increased workload for the caregiver, it did not necessarily follow that the caregiver would abandon the strategy. Only in instances where the caregiver could not perceive a clear benefit for the care receiver did an increase in workload cause the caregiver to drop the use of a modification.

Overall Caregiver Evaluation of Effectiveness

Caregivers used a complex evaluation process to determine whether they should adopt or reject a given environmental modification strategy. Figure 3 illustrates graphically how caregivers examined outcomes for themselves and the care receiver in order to make a decision about retaining a given strategy. Outcomes that resulted in positive benefits for the caregiver or care receiver were adopted. A number of illustrations of this phenomenon were present in the data. Likewise, strategies that resulted in negative outcomes for the caregiver and care receiver were rejected. In situations where the outcomes for the caregiver and care receiver were mixed, the decision to adopt or reject a modification was less clear. In general, caregivers that participated in this study tended to weight the care receivers' benefits more than their own. Consequently, modification strategies that had negative outcomes for care receivers were usually rejected, even though they may have had positive benefits for the caregiver. In addition, caregivers often adopted strategies that has some negative outcomes for them if the care receiver benefitted from them. Examples of mutually beneficial or synergistic outcomes are described below to illustrate the evaluation process.

Mutually Beneficial or Synergistic Outcomes

There were two mutually beneficial categories of outcomes. The first are those in which the care receiver and the caregiver's needs were balanced. In this instance, the caregiver and care receiver have needs that would be opposite or not complementary but

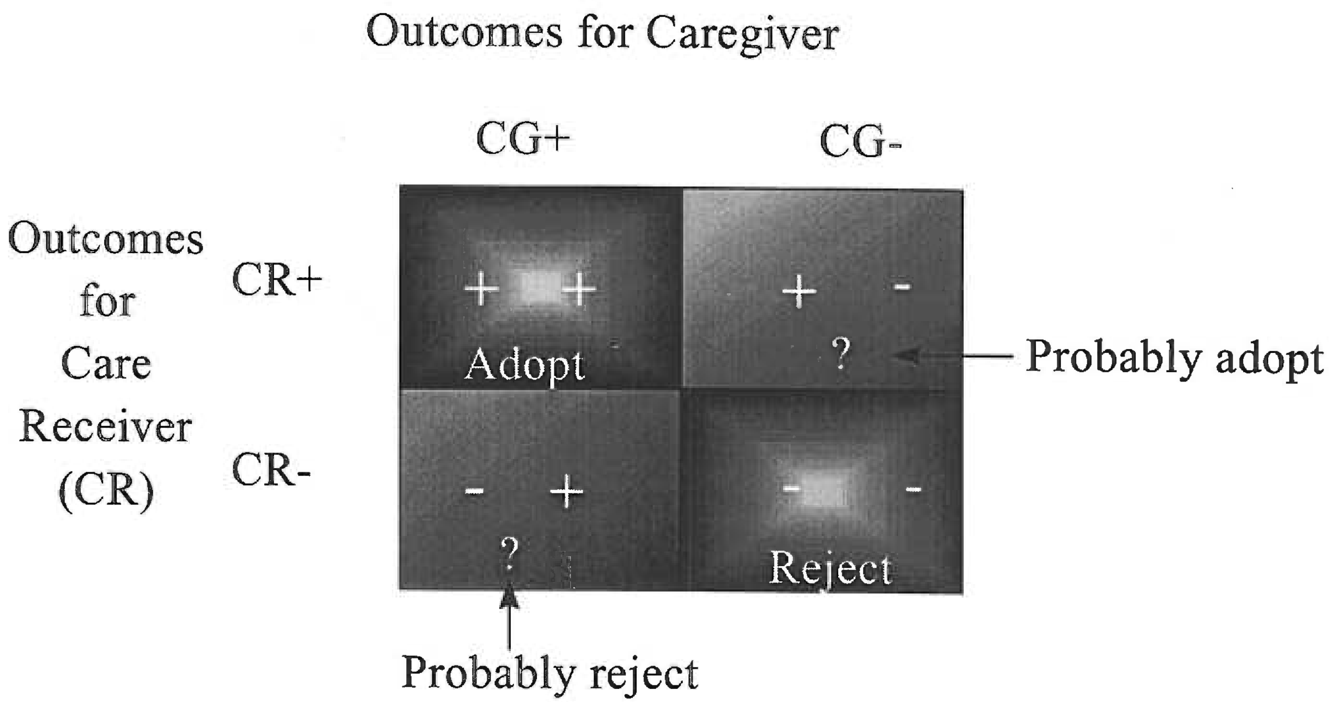

Figure 3.
Effectiveness of modification strategies.

the modification strategy was flexible enough to allow both parties to have their needs met. In the second category, the beneficial outcome of a modification strategy was enjoyed by both the caregiver and the care receiver. In some instances, the beneficial effect of the modification was extended to the whole family.

Care Receiver and Caregiver Needs are Balanced

Needs are balanced when competing or opposing preferences of the caregiver and care receiver are accommodated. For example, there were some instances where the modification strategies described by the caregivers seemed to perfectly balance the opposing needs of the caregiver and care receiver. For example, one husband strongly preferred taking showers to baths, but his wife was no longer able to stand to take a shower and she preferred baths. The husband outfitted the bathroom with equipment for her that could be removed when he wanted to use the shower. In that way, they were both able to have their own preferences accommodated even though they were at odds with one another. In another instance, the caregiver liked to watch TV and listen to the radio. However, his wife would become distressed when these devices were on because she could not understand the stimuli. The husband acquired a set of headphones so that he could enjoy his programs and still be at his wife's side.

Care Receiver and Caregiver Benefitted

In this instance, the caregiver also used and enjoyed the environmental modification. For example, one caregiver stated that the grab bars he had installed for his wife were a great help to him also because of his severe arthritis. Although the spouse of one daughter caregiver had purchased a microwave to make meal preparation easier for the care receiver, the daughter discovered that the microwave was a real benefit to her as well. Another wife caregiver reported that the fans she had obtained to control the room temperature made both her and husband more comfortable in the summer time. The specialty beds one husband caregiver had obtained to help his wife sleep at night turned out to be good for his bad back as well. Another husband caregiver got rid of some of the furnishings in his home because neither he nor his wife could rise out of the couch any longer. A beneficial effect for the caregiver from a modification was like an unexpected bonus.

In the households that were multigenerational, some times the entire family benefitted from a modification. For example, one family had installed a mini kitchen in their downstairs family room. The main benefit for the care receiver was that she no longer had to make risky trips up and down stairs carrying dishes and cold drinks. However, the family found this downstairs kitchen to be convenient as well. This same family reported that they all seemed to benefit when the house cleaner was hired. Another family found that maintaining a separate phone line for their live-in grandmother:

> . . . was a convenience thing for everybody, because then every, then her friends still had her phone number. We didn't answer her phone unless she wanted us to answer her phone. And by us having our own phone, if she needed us in the night and couldn't get out of bed, she had her phone right there where she could have called us (S15-O/C-PHY*).

In all of these instances, the added benefit to the caregiver and the rest of the family from a modification was a very desirable outcome.

Aim #3: Describe How and Why Caregivers Changed Their Environmental Modification Strategies Over Time.

To answer the question of how modification strategies change over time, Strauss and Corbin's (1992) notion of changing conditions was used to bring time and movement into the analysis. According to Strauss and Corbin: ". . . a change in conditions of sufficient degree . . . brings about a corresponding change in action/interaction strategies, which are carried out to maintain, obtain, or achieve some desired end in relation to the phenomenon under study" (p. 149). Coding for conditions shows how the modification strategies move and respond to changes in conditions that inevitably occur with the passage of time. The time that elapses between each change in conditions and corresponding change in the modification strategies which make up one part of a sequence or series, may be a moment, a week, or longer. Change can occur in the set of conditions that leads to or causes the phenomenon under investigation. Change can occur as a result of the intervening conditions that influence action interaction. Consequences of previous modification strategies can feedback to cause new conditions or alter interaction among the actors.

Changes in behavior have to be understood in a specific context. Context denotes the particular set of conditions within which the modification strategies are taken. Context includes the immediately relevant aspects of the situation such as where the person is physically, and who else is involved; as well as the aspects of the social setting. In order to understand the meaning of events of individual behavior, it is critical to attend to the context in which it occurs.

Conditions and context that affected the modification strategies caregivers used were coded in detail in the analysis. Conditions were then mapped out according to the procedures described by Strauss and Corbin (1992) and Miles and Huberman (1994). A data display was created. A data display, according to Miles and Huberman, is a visual format that presents information systematically. The systematic display helped to discover relationships, develop explanations, see patterns, and summarize the data. To address Aim #3, the conditions and context categories associated with environmental modification strategies are described in detail.

Conditions and Context Categories for Environmental Modifications

Context and causal and intervening condition categories are outlined in Figure 1 (p. 26). Context and causal and intervening conditions are defined prior to discussing specific findings from the study.

Context is defined as the circumstances in which caregiving occurs. It includes both the physical aspects of the setting as well as the relevant aspects of the social system of the care receiver and caregiver. The physical aspects of the home setting includes the type, size, layout, and location of the home in which caregiving takes place, as well as the positive and negative physical features of the home. The level of maintenance of the home as well as the kind and nature of possessions provide cues about how well the care receiver is managing currently and how they lived historically. The socially relevant aspects of the situation includes who lives in the home with the care receiver, who lives nearby and far away, and what supports exist in that home setting.

Causal conditions according to Strauss and Corbin (1992) are events, incidents, or happenings that lead to the occurrence or development of a phenomenon. In this study, the phenomenon of interest was the misfit of the environment with the care receiver. In reality, a single causal condition rarely produces a phenomenon. The properties of the events, incidents, or happenings that are antecedent to the phenomenon combine together with the characteristics of the care receiver to create the misfit with the environment.

Intervening conditions are factors that facilitate or constrain the use of modification strategies within a specific context. There were three categories of intervening conditions that were identified in this study: (a) those that affected the perception and interpretation of the misfit of the environment for the older person, (b) those that affected the implementation of the modification strategies, and (c) those that affected the effectiveness or outcome of the modification strategies.

Context

Context is important because it is the general frame of reference that directly influences current decision making about specific environmental modification strategies. In order to gain a more general understanding of how caregivers implement these strategies, the settings in which caregiving occurred and the immediately relevant aspects of the living situation of the care receiver were observed. The most pertinent aspects of the various aspects of the home settings and living arrangements of the care receivers are described below. Table 7 presents data exemplars of the home setting categories.

Table 7

Home Setting Context Data Exemplars

Home Setting	Definition	Data Exemplars
Type of housing	Care receiver participants' housing varied according to the kind of dwelling, the degree of age segregation, the degree of say or control that residents had over the physical structure, and the levels or stories in the home.	We haven't had to do that. See these homes are built for old people and a lot of them are chronically ill anyway. So a lot of the bars were in like the bathroom (S10-H-PHY*). The home health lady, nurses were arguing to have a grab bar put in and something on the edge of the tub. Like we put one like that in this tub for my husband and we finally, the landlord took awhile, we had to have her permission because it's a rental and finally she, they just came and installed those things from home health, and agency they hired. And we crossed our fingers and no I'm not going to get mad and it's fine (S12-D-MIX). You see in mobile homes, we're different than anybody else now. I mean everything is [smaller] I bought this and it's for a normal bathtub I just got a piece of wood and cut it off and put it in there Anybody could do that . . . even a woman could do that! (P4-H-COG*CG).

table continues

Table 7 continued

Home Setting	Definition	Data Exemplars
Adequacy of size of home	Adequacy of the size of the home is defined as a subjective evaluation on the part of the caregiver or care receiver as to how well the amount of space in the home meets the needs of all family members. Home size needs of the caregiver and the care receiver may not be the same, indicating that while one may benefit the other must sacrifice in order to make the situation work.	And its small enough that I . . . so [if small is one] thing that you're interested in, that I minimized housekeeping (S2-W-COG*). You know, the furniture in the apartment is so crowded that a wheelchair cannot go through some of the spaces as they've got it arranged (S18-D-PHY). So the new house, it was more spaced, and she didn't like having to walk so far from the refrigerator to the stove to the table (S15-O/C-PHY*F). And then we didn't realize, of course, that we think . . . and most people think bigger is better. Well in grandma's case, smaller was better (S15-O/C-PHY*M).

table continues

Table 7 continued

Home Setting	Definition	Data Exemplars
Layout of the home	This category refers to how well the plan of the house works from both the care receiver and caregiver's perspective. The more the home layout accommodates a wider range of behaviors on the part of the care receiver, the less stress there will be for the caregiver.	He has taken to coming out in the morning in just what he wore to bed. And he'll stand in the window which annoys the heck out of me, but there's the railing there, so they can't really tell that he's in his shorts (S2-W-COG*). So we . . . you know, we had . . . we . . . in this house, we had extra space so that, you know, everybody had their space, but if grandma was doing things, the people she did stuff with was either us in the family or if she was doing something with her little ol' ladies, most of the time, she'd do it during the day while we were at work. And . . . 'cause that's when the older people are out and about is during the day. Most of her friends didn't want to be out at night. so, yeah, it worked well, because she had a big enough place to do her entertaining, and you know, plenty of space for all those people to park, and they were all gone before we'd come home most of the time (S15-O/C-PHY*F).

table continues

Table 7 continued

Home Setting	Definition	Data Exemplars
Location of home	The proximity of the home to supports such as family and services.	Sometimes his traveling and all, and we lived in a cul-de-sac where we still live, and we have a lot of neighbors and we are a group of people that know one another and have lived there, most of us that time since our houses were built, raised our kids. It was a very supportive environment (P2-D-PHY*). So, she does have a neighbor who keeps a pretty good eye on her . . . . But she is a little bit out in left field, too. I mean, you know, she walks to the store, she's very spry and chipper for a woman her age. But she's a little strange, just some strange stuff she comes out with so I kind of, you know, I know that she keeps an eye on my mom but at the same time I know that I still have to check on her. And there are other neighbors in the building that kind of, they all kind of watch out for her (S9-D-MIX).
Positive physical aspects of the home	This category included positive contextual features that increased safety, facilitated mobility, or made ADLs easier.	So, the bathrooms do have some safety rails and stuff already installed in the bathtub and stuff like that and there are no stairs in the place; it's all elevators and flat, you know, hallways, and flat into the apartment so it's pretty easy access for her (S9-D-MIX).

table continues

Table 7 continued

Home Setting	Definition	Data Exemplars
Negative physical aspects of the home	This category included negative contextual features of the home that constrain care receiver mobility and ADL performance after the care receiver's functional status declined.	So anyway . . . but that's a nightmarish house for anybody that has, I think, any kind of hesitation. You would never know when a seizure might come. There are steps . . . there's even steps up to the front to come in the door and then those four steps once you get inside. Then there's all the stairway going downstairs. So in that essence, it was a lot of stairs. It probably wasn't ideal for caregiving, and it surely wouldn't be if your back ever goes out or anything like that, because you've always got steps to negotiate (P2-D-PHY*). Oh, yeah, no, that was a problem, because it was high. The bathtub. And that . . . when we first moved here, there wasn't a problem. But it started . . . see, her spinal arthritis, that's what was the cause (S6-H-MIX*).

table continues

Table 7 continued

Home Setting	Definition	Data Exemplars
Maintenance of home	This category included the amount of and difficulty of tasks required to keep up home's structure and appearance.	[field notes] and so had an opportunity to look around the yard and the exterior of the house. The house gave the appearance to me of a place that had once been very well cared for, but that had fallen into some disrepair. The yard in particular, was really overgrown and it was apparent that the trees and the shrubs hadn't had attention for probably about four or five years. I could see that the gutters of the house were jammed with tree-type of debris and the exterior of the house had insect webs, etc., on it, suggesting that no outside maintenance had been done for quite some time, although the paint job on the house indicated to me that this had been a home that had been very well cared for (S11-W-COG*).
Cues to personhood	Cues to personhood are items of information about the care receiver and the caregiver that can be learned through careful observation of the artifacts in the home environment combined with questioning of the residents as to the meaning and history of these artifacts.	Oh it is . . . 'cause we knew . . . you see, we had all antiques, and shipping it all 4,000 miles we knew it was going to break, no matter how careful they were, and it was a crime, so we gave most of it to friends (S6-H-MIX*). She used to do a lot of artwork (S7-H-MIX*). nothings changed, you know, except we grew old with the furniture, so that's exactly the way it goes (P4-H-COG*).

table continues

Table 7 continued

Home Setting	Definition	Data Exemplars
Supports in home	Supports in home refers to home maintenance services provided.	Oh yeah, 55 and older, and it's run by Good Samaritan Homes and Hospital. There is an associated nursing home. There's a cafeteria for people who want it but their apartment is fully a sufficient apartment, people can live there totally and never go to the cafeteria. There is no, other than cleaning service once a month, there's no services provided in the apartment itself. No nursing, no assistance, no anything except cleaning once a month as part of the rent, maintenance rent (S18-D-PHY).
Security in home	Security systems were electronic or physical barriers to unauthorized person entry in the home.	Yeah. But the good part about it was we had unlisted telephone number for her and then she was in apartment that had real good security so you don't have people knocking at the doors trying to sell her stuff or vitamins (S19-S-MIX).

Home Setting

The home setting is defined as the physical structure where most of the care receiver's day-to-day activities take place and where they fulfill their various roles. Physical dimensions of this setting that emerged as important in terms of the focus of this study included the home type, size, layout, location, accessibility features, and ease of maintenance. Social dimensions of the home setting that impacted upon the central phenomenon in this study included cues to person-hood such as artifacts in the home, supports available such as housecleaning, security in place, and living arrangements of the caregiver and care receiver. Findings of this study are congruent with Strauss and Corbin's (1992) assertion that the setting of care is an important factor in managing a chronic illness trajectory.

Type of housing. There were four main types of dwellings that care receiver participants in this study lived in: assisted living senior complexes, apartments, houses, and trailers. The home settings varied on a couple of important dimensions that affected or impacted the likelihood or need for environmental modifications. The degree of age-segregation refers to how much the home setting type dictates the amount of daily contact with individuals of various age groups. Individuals who lived in age-segregated communities often benefitted by learning about possible environmental modification strategies from other residents or by having structural modifications already in place. Individuals that live in multigenerational family settings benefit by having other physically stronger family members available to do the work they are no longer able to do.

Home setting types also vary in the amount or degree of say or control that residents have over the physical structure of the home. Planned or structured communities often limit what residents can do to private homes, and assisted living complexes frequently constrain resident input or autonomy. Rental homes and apartments require landlord or owner permission to make permanent changes. Dwellings also varied in the number of levels that had to be negotiated on a daily basis. Levels varied from one to two, to multiple high rises. The apparent cost of the housing also varied, although higher cost was not necessarily associated with a greater likelihood of more positive physical aspects.

Adequacy of size of home. Adequacy of size of home is defined as a subjective evaluation on the part of the caregiver or care receiver as to how well the amount of space in the home meets the needs of all family members. A number of the spouse caregivers expressed a preference for a smaller home, suggesting that a smaller space requires less maintenance. However, too small a space can result in the caregiver not having enough room to store supplies in a manner that facilitates the most effective functioning. When the furniture arrangement is too tight, rearranging options are limited and are discouraged. As study participants indicated, the home size needs of the caregiver and the care receiver may not be the same, indicating that while one may benefit the other must sacrifice in order to make the situation work. This is another contextual variable that the caregiver must assess when trying to maximize the organization of the home.

Layout of the home. This category refers to how well the plan of the home works from both the care receiver and caregiver's perspective. The more the home layout accommodates a wider range of behaviors on the part of the care receiver, the less stress there will be for the caregiver. For example, if the care receiver has certain behaviors that are disturbing to the care receiver, such as going about inappropriately dressed or falling down without warning, the more the home layout makes their behavior not problematic, the better.

In almost all caregiving situations, the caregiver was doing some type of monitoring, and the physical layout of the home could either really facilitate or interfere with this function. For example, in the home situation where the caregiver could not clean unless the care receiver was nearby (because she had to assure he would not wander away), having areas in the home that the care receiver could not access was problematic for the caregiver . The more that the care receiver's preferences can be met in the home setting, the more the care receiver will enjoy the setting and the more the caregiver can feel good about the care receiver's quality of life. A critical component in a multigenerational household is how well the home is set up to provide maximal usage of private and shared space.

To summarize, layout refers to how the particular arrangement or setup of the home meets a number of needs related to maximizing freedom for the care receiver's behavior, maximizing caregiver opportunities for monitoring the care receiver in the least stressful manner, maximizing satisfying care receiver preferences for daily life, and ensuring that the use of private and shared space is satisfactory for all family members. The layout of the home can be changed by remodeling, rearranging furnishings, or by the reassignment of certain activities to other locations. When the caregiver uses the organizing the home strategy, home layout is one of the factors they must address. Caregivers may vary in how well they are able to assess how home layout may be impacting on the stress of the caregiving situation.

Location of home. The location of the home is defined as the proximity of the home to supportive neighbors, family members, and salient resources. It could make a big difference as to the kinds of supports readily available for the care receivers. Neighbors with whom one has something in common are a great help. Anything that distances a care receiver from their surroundings, such as a remote location or an unsafe area, makes getting support more difficult. Caregiver that lives a long distance from the care receiver encounter special difficulties while modifications especially troublesome. A number of the daughter caregivers noticed that they could use neighborhood supports to shore up their monitoring function.

Positive physical aspects of the home. These are the positive contextual features of the home environment that were present before the care receiver's functional status changed. In many instances, people had moved to more supportive physical environments because of changes in the care receiver. Features that increased safety, facilitated mobility, or made ADLs easier were described by participants. For example, intercoms in the various rooms of the apartments in the senior assisted living complex were a common safety feature. Features that enhanced mobility were having everything all on one level, having a slopped entrance, and some other type of handicapped access. Handicap showers with grab bars made bathing easier for a number of care receivers. Home environments that had helpful physical features made it easier for the caregiver to adapt the care receiver's home to caregiving. Unfortunately, these features are not commonly used in most housing environments built for general use in the United States.

Negative physical aspects of the home. These are the negative contextual features of the home that constrain care receiver mobility and ADL performance after the care receiver's functional status declined. Impediments to the care receiver mobility included uneven floor levels, multiple stairs, or narrow doorway access. The home entrance was often problematic for many of the care receivers in this study, especially in those instances where the entrance had many stairs. Stairs inside the home could be difficult as well, especially when their design was particularly hazardous. Other undesirable features included inconvenient location of garages, communal dining rooms, or in general anything that increased the amount of ambulation that the care receiver had to do to make it from one room in the home to another.

Impediments to use of the bathroom were the other major category of problematic features in home settings. Negative attributes could include the presence of dangerous obstructions, such as hazardous sliding glass doors, or the absence of a necessary safety features, such as grab bars. In most of the care receiver homes that were observed, bathrooms were problematic. There were other negative features that were observed in some of the homes that could be described as detractions to the quality of the environment. For example, the lack of central air conditioning was very hard on frail older care receivers that had little ability to leave their environment.

Maintenance of home. Home maintenance is defined as the amount and difficulty of tasks required to keep up the home's structure and appearance and includes the periodic repetitive needs such as housecleaning and yard work, and the more long-term types of maintenance such as painting and minor repairs. Homes will vary in how difficult they are to maintain, as well the caregiver and care receiver's ability to perform the tasks necessary to maintain the home. In undermanned home situations, where the caregiving workload was high, maintenance suffers. The ability to maintain the home can also be a resource dependent activity. Caregivers that lack the personal time or energy to maintain the home can pay for these services if needed. A number of the children caregivers who had other demands on their time, employed housekeeping services to help the care receiver.

Cues to person-hood. Cues to person-hood are items of information about the care receiver and the caregiver that can be learned through careful observation of the artifacts in the home environment combined with questioning of the residents as to the meaning and history of these artifacts. For example, a dining room filled with ornate silver services in a modest home suggests that the residents may have lived in a more grand manner historically. Artwork hanging in the home may suggest a taste for this kind of accouterment. When the residents are questioned about the meaning of these objects, insights can be obtained into their past lifestyle.

Supports in home. A number of the more supportive living situations (senior assisted living apartments) provided meals and cleaning for the residents. Some also had medication aides. However, it seems that this minimal level of support is often not enough to really help people age in place, leaving the caregivers with many problems to solve from an environmental standpoint. For example, even though intercoms were provided through out one assisted living apartment complex, a man fell in the shower and was left helpless for more than two days because he was not able to reach the intercom and no one was designated to check on him or the other residents on a regular basis.

Security in place. Some of the home settings had electronic security systems in place. These ranged from an intercom to buzz in admittance, various burglar alarms, and different types of gated communities. Having good security systems in place takes some of the burden off of son and daughter caregivers who worry about the safety of the care receiver who may be vulnerable to exploitation by strangers.

In summary, the most pertinent aspects of the home setting were the physical features of the dwelling, such as type, size, layout, and accessibility; and the supports that are readily available, such as nearby relative, service, and security systems. The context of the home setting has a direct bearing on the care receiver's ability to manage in the home following changes in their functional status. In addition to home setting, the living arrangements of the caregiver and the care receiver are an important aspect of the home situation context

Living Arrangements

This refers to whether or not the caregiver lives with the care receiver. Among the participants in this setting who lived with the care receiver, all were either spouses or daughters. For the daughter caregivers who lived with their care receivers, all but one had moved the care receiver into their existing home. The one exception to the co-residence pattern of a married woman taking in a disabled parent was a divorced daughter who moved into her mother's home to provide care. This is consistent with Brody, Litvin, Hoffman, and Kleban's (1995) finding that divorced or separated women were more likely to move into the parent's home to provide care than married women. Among the caregivers who did not live with the care receiver, some lived as close as next door and while others lived across the country, as far away as the eastern seaboard. The proximity of the caregiver made a difference in how readily available the caregiver was to make environmental modifications. For those caregivers that lived far away, making modifications required more planning and generated more frustration than for those who lived nearby.

Causal Conditions

The view of causality adopted for this study is based upon the writings of Miles and Huberman (1994). First, causality brings in the question of time as part of an explanation. Prior events are assumed to have a more or less clear connection with later events. Among the participants in this study, care receiver medical diagnoses such as

Parkinson's disease, preceded or were thought of as causal by the caregiver for the functional declines that the care receiver was experiencing. Even though later effects can produce new effects, events still unfold over time and must be understood that way when thinking of particular cases.

Second, causality is local, the immediate causal chain of events is always bounded in a particular setting and at a particular time. In this study, participants with similar functional limitations experienced different levels of misfit with their home environments due to variations in their living situations.

Third, determination of causality can be made via a number of possible criteria, rather than being strictly rule-bound. In addition to the classic criteria of temporal precedence (A before B), constant conjunction (when A, always B), and contiguity of influence (a plausible mechanism links A and B), other epidemiological criteria can be used as well. For example, Hill's (1965) criteria are equally helpful when examining the data. His criteria include: strength of association (much more B with A than with other possible causes), biological gradient (if more A, than more B), coherence (the A-B relationship fits with what else we know about A and B), and analogy (A and B resemble the well-established pattern noted in C and D) are equally helpful when examining the data. In this study, the concept of coherence was useful in examining causality associated with the inability to make sense of information in the environment of care receivers with Alzheimer's. Because Alzheimer's produces a phenomenon known as visual agnosia, it follows that the cues in the environment others use to do such tasks as finding the bathroom, are no longer useful for care receivers with Alzheimer's disease. Consequently, they are not able to find the bathroom on their own and this creates a misfit of the environment for them in terms of meeting their own needs.

Fourth, causality is always complex, causes are always multiple and conjectural. Consequently, causes combine and affect each other as well as the supposed effects and are deeply influenced by the local context. For example, in this study, health declines are often associated with functional limitations that then cause a misfit with the environment. The health status changes and their associated functional declines in turn affect how well a particular environmental modification strategy works for a particular care receiver in a specific home setting.

Finally, assessing causality is of necessity, a retrospective process. Data are gathered and analyzed after the fact to understand how some event has occurred in a particular case. From this data, an account is organized that attempts to make sense of the events in such a way that their part in the whole story becomes clear. In this study, a number of the caregivers were very methodical about reporting the exact sequence of events that led up to the care receiver's inability to negotiate and operate in their environment unaided. These narratives formed the basis of the descriptions of the causal conditions for this study.

Care Receiver Health Declines

A health decline is a situation where there is either a diminishment of the soundness of the body or mind or the development of a disease or abnormality. Health declines can precipitate the need for caregiving, or add to the complexity of an existing caregiving situation. Health declines can range from either long- or short-term duration, or abrupt or slow onset. Two scenarios were observed in association with health declines: functional declines prompted the care receiver and caregiver to seek an explanation for changes that then leads to a medical diagnosis, or a medical diagnosis provides the framework for explaining subsequent functional declines. As two spouse caregivers noted:

> And I knew something was wrong. I forget just when the doctor actually told us he had Parkinson's, but we were told that's what they thought it was. So I don't just remember when that was, but he has had problems (P3-W-MIX*).

> Oh, yeah, no, that was a problem, because it was high. The bathtub. And that . . . when we first moved here, there wasn't a problem. But it started . . . see, her spinal arthritis, that's what was the cause (S6-H-MIX*).

Not all health declines lead to functional limitations. So health declines are not necessarily sufficient to cause a misfit with the environment. As this one daughter caregiver said:

> So last year they put in a pacemaker and she had another stroke. And her strokes have all been mild ones. Like the first one, nobody ever noticed anything, none of us, not even her. And the second one put her in the hospital here. I stopped over to visit her one time and her speech was really slurred and I looked at her and I said "Let me look at you" and she goes "notice the way I'm talking?" and I said "yes, I noticed" and I'm looking at her and I looked at her face and I said "You had a stroke, I'm going to take you to the hospital now." So I took her over here and sure enough they put her in and they did C.T.s and stuff and she did have a

> stroke and they told me she had an old stroke. And we're like "what?" So, so far old strokes. And then this last stroke was after her pacemaker (S9-D-MIX).

With the first stroke, the care receiver did not experience any difficulties coping with the environment, but with subsequent vascular insults, the care receiver had problems with using her kitchen, bathroom, and operating electronic devices like her microwave and her tape player. So it is the overall amount of functional decline associated with a health decline and/or its salience in the given home situation that produces the misfit with the environment.

Care Receiver Functioning Declines

Functional declines are produced by a variety of decrements in physical abilities and mental activity. Impairment leads to situations where the care receiver begins to have difficulty performing some of their former activities. The impact of these changes varies. Some losses of function are easily accommodated by giving up the activity. Hobbies such as photography can be abandoned and doing home maintenance tasks can go by the wayside without compromising quality of life too much. Other losses of function, such as driving, are far more troublesome when lost. The three most consistently mentioned changes in functioning included the care receiver kept falling down, the care receiver became more forgetful and demented, and/or the care receiver became incontinent. These changes tend to have more of an impact on how the care receiver interfaces with their environment because they create multiple problems. Falls are particularly problematic in that they carry a high risk of causing other injuries that will compromise the care receiver' functional status further:

> Yeah, it was almost a year ago, October. And we got through November and December but January she fell and in February or March she fell again. That's when she fell so hard that she cracked a couple of ribs (S10-H-PHY*).

Becoming more forgetful or demented can create other physical problems which compromise health status in addition to the problems associated with inability to manage ADLs:

> She basically had gotten to where she didn't cook at all anymore and was eating things like cookies and other you know obviously things that don't require preparation but are not very good for a person with diabetes which was her situation (S19-S-MIX).

Incontinence frequently produces an element of unpredictability in the caregiving situation for the caregiver that makes it hard to plan daily routines: "And on bowel movements we had to guess when he might have them, so I had quite a few little clean ups to do in that line" (S11-W-COG*). Another very serious consequence of a decline in functioning occurs when the care receiver loses the ability to do ADLs independently in their home situation: "Yes, although again he used to shower by himself, and then when he had this kind of decline, he just stopped doing it, and then you'd notice after a few days that he wasn't showering" (P1-D-MIX). This type of misfit with the environment usually acts as a strong impetus for the caregiver and/or the care receiver to try to rectify the misfit of the environment.

Care Receiver Health and Functioning Improves

Improvement in the care receiver's health or functioning can avert a misfit with the environment or ameliorate its effects. When caregivers reported health improvements in the care receiver, they were usually due to a positive response to medication or therapy. In some instances, improvement was so great, that the misfit with the environment was resolved:

> And I, she has a chair that she used when she first got home from the hospital, but I think she's better now and doesn't need to use that. But she put the chair . . . you know, those bathroom shower chairs inside so she could sit down and rest (S13-D-PHY).
>
> I'm so much better than I was before I got operated on, why . . . the day before, every time I moved I hurt. And [now then] I can . . . once I get up and get going, why I'm . . . pretty good now (S3-W-PHY*CR).

In other cases, the improved health status of the care receiver permitted use of an environmental modification strategy that could not be used before, such as a wall clock for time orientation:

> But when he was confined to a wheelchair, he couldn't see the clock without getting out . . . you know, having someone turn him around to see it. And so he didn't use it as much. Now when he's getting up and walking around, he notices the clock, or he'll see it. And once he started doing that, now he'll look for it. He knows where to find it (P1-D-MIX).

Improvements in functioning sometimes occurred spontaneously but were usually the result of deliberate medical intervention directed at addressing the care receiver's competence.

In summary, the central causal condition of a misfit with the environment was a decline in the care receiver's functional ability. In some of the caregiving scenarios, the caregiver's observation of changes in functional status prompted the uncovering of the underlying medical diagnosis. In other situations, the medical diagnosis preceded the development of functional declines. Health changes did not always necessarily cause a problem with a misfit with the environment, nor were functional declines always associated with a pathological health condition. Despite the complexity of the causal nexus, whenever a misfit of the environment occurred, it was always associated with some kind of functional change in the care receiver. Not all functional changes necessarily cause a misfit with the environment however. Figure 4 depicts the interrelationship of the threshold of functional decline with the context of the home situation in creating a misfit with the environment. The figure illustrates how two care receivers with identical functional limitations may or may not experience problems with negotiating their home environments.

Intervening Conditions

Intervening conditions are mitigating circumstances that promote or restrain the environmental modification strategies used within a specific home setting. The three categories of intervening conditions identified in this study and their subcategories will be defined and described using data exemplars.

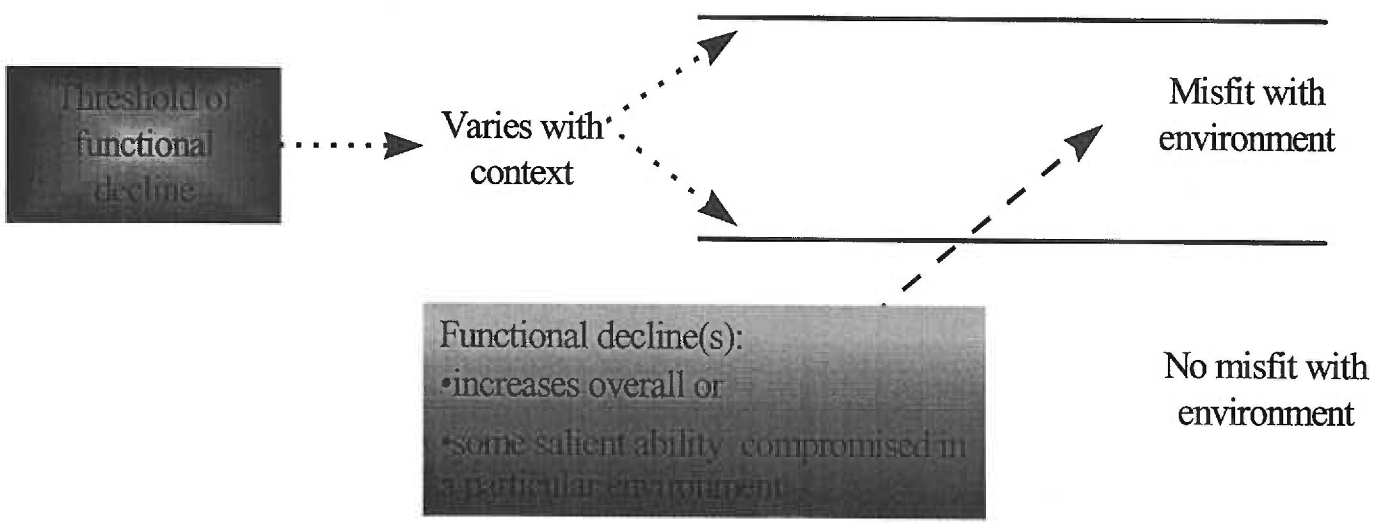

Figure 4.

Home setting and functional limitations.

Conditions that Affect the Perception and Interpretation of Misfit

There were two categories of conditions that influenced how caregivers and care receivers viewed the care receiver's changes in functioning relative to their environment: values and attitudes regarding functional limitations and the time trajectory of onset and duration. Values and attitudes of both the caregiver and the care receiver influence their perception and interpretation of the misfit of the care receiver's competence with the environment. Their perception and interpretation of the situation can either facilitate the exploration of environmental modification strategies or interfere with their implementation. In addition to values and attitudes regarding disability, the time trajectory of an illness or disability course can greatly influence how the misfit with the environment is perceived by both the care receiver and the caregiver. Variations in these trajectories influence whether or not the changes in the care receiver's condition are viewed as being discordant with the environment or not.

Positive attitudes and/or flexible approaches to caregiving. Positive attitudes and flexible approaches to caregiving were identified by participants in this study as important mediators of how the caregiver responded to the care receivers environmental dilemma. In the interview data bits, caregivers describe reasons why living with someone who required environmental adaptations was not problematic for them. Being able to maintain a positive mind set, to laugh at one's situation, and to adjust one's expectations in the face of unchangeable circumstances facilitates a more productive response to modifying the home for the caregiver. As one wife said:

> And I went to a support group, and I was horrified when I heard "he has to do this," and "he has to do that." And I said "why are you fighting it?" If it was your kid, you wouldn't be doing that (S2-W-COG*).

Flexibility in terms of the response to caregiving was described by statements from participants such as "why fight it" or "whatever works."Being able to tolerate the care receiver's need for accommodation is a part of this flexibility

> Like the bathroom that she was in, and I told you I put those handlebars? Well, every once in a while she'd sit down, and they would lift up. They're just aluminum railing, and so one time, I don't know if she maybe had a seizure or whatever, but I know that the next time I looked or was cleaning the bathroom, here was a little chip, and she had pulled . . . so I don't know if she fell against them or what, but there's a little chip in that top part that goes on the toilet tank. And I could go out and replace that, but at this point in time it doesn't bother me (P2-D-PHY*).

It's not clear how much of the above are personality traits of the caregiver or are learned responses to the frustrations of the caregiving situation. However they are developed, these positive attitudes and flexible responses facilitate exploration of strategies to make the care receiver's situation easier.

Attitudes and values of the caregiver and care receiver that interfere with the implementation of strategies. Acceptance of the care receiver's condition by either the care receiver or the caregiver is a factor in how much either the care receiver or the caregiver is willing to explore environmental modifications. Being unable to accept the limitations can interfere with or delay dealing with the environmental misfit: "He accepts [care receiver]

. . . we're very different personalities. He, whatever comes up . . . 'I'm getting old, that's it.' I get like angry, like . . . 'it shouldn't be happening to me'" (S4-O/S-PHY*).

To a certain degree, the willingness to use assistive devices or special equipment can be diminished if it is viewed as "giving in to disability."One husband caregiver was very emphatic about not allowing this to happen. To illustrate his point, he talked about a head injury he had experienced in his youth. He said that he had recovered far beyond the level his physicians thought possible because he had refused to give in to his situation. When his wife became cognitively impaired, he insisted that she try to cope as he had, by not acknowledging that her functioning had changed: "No, no, I mean she wasn't . . . I wouldn't say she was 110%. She was 99.44%. We were all I'm only 82%" (S6-H-MIX*). As a result of this approach, this family made no modifications in the home to accommodate the wife's changed functioning: "There was no modifications. No, we didn't. Everything was the same" (S6-H-MIX*).

The care receiver's attitudes and values about independence and autonomy can interfere with the caregiver's efforts to introduce the topic of making environmental modifications. Caregivers have stated that it is difficult to introduce environmental modifications that would either be threatening to the care receiver's autonomy or would compel the care receiver to be more independent than they might like. For example, this daughter caregiver found that her mother always changed the subject whenever she or her sister tried to talk about her possible future need to use a wheelchair:

> And, well, both my sister and I have been trying to break her and daddy into the fact that she may eventually need a wheelchair to get around and, you know, the

> furniture in the apartment is so crowded that a wheelchair cannot go through some of the spaces as they've got it arranged, so my sister's been trying to break them into that and so far when my mother doesn't want to hear anything, the wall goes up, and the ears close, and then the next time you say it to her it's like, oh well, that's interesting but we don't need to talk about that now (S18-D-PHY).

Another daughter indicated that her father's preferences about not being independent could limit his willingness to try some environmental modifications:

> But I think you have to make people . . . help people to make those decisions for themselves about how much help they need rather than assuming that they need a whole lot of help, because sure enough they will in no time at all if you make that assumption for them. You know, you can really . . . especially, I mean I think he's the type of person who isn't going to work real hard to stay independent if it looks like somebody is just gonna wait on him hand and foot. He'd probably think that was fine (P1-D-MIX).

In contrast to this daughter's experience, one son talked about how his mother's pride in being independent greatly interfered with his efforts to put more environmental supports in her home:

> Yeah. And she was a very proud woman and would not allow Meals on Wheels. I could have got them. They had them there. She wouldn't allow that. I was trying to get a service to come in and make lunch for her but she just wouldn't do that. She always kept talking "I can do this and that" and wouldn't to it (S19-S-MIX).

Another value that many of the older caregivers and care receivers shared was described by several participants as a "depression era mentality." This value often prevented families from trying something new. These older care receivers and caregivers had a great reluctance to throw anything away, feeling that one should economize by reusing materials whenever possible. In this instance, it was difficult for them to part with materials that had become dysfunctional in their environment, such as an overabundance of furniture or clothing. These superfluous materials made organizing the home to accommodate care receiver changes more difficult, as this daughter noted:

> So the dining table would have to go or go elsewhere for a wheelchair. It took quite a while before she was willing to get rid of a second twin bed in order to get a computer or in order to do anything and she never had more than one person stay in that second bedroom. She usually sleeps in there and he sleeps in the main bedroom but when there's company, the company sleeps in the second bedroom, and she never needed more than one bed but there were always two twin beds because they had a square table that you fit between beds up to an L-shape but then with the computer came a computer desk and they had to get rid of the twin bed to do that, which was kind of difficult for her, so there's things that, you know, they both, their depression era mentality of don't throw away anything, not even plastic bags and twist ties, everything is saved and reused and reused (S18-D-PHY).

Time trajectory of changes in care receiver. Caregivers identified four dimensions of the time trajectory of changes in the care receiver that affected the perception and interpretation of the misfit with the environment. The first dimension involved the stage of life the caregiver or the care receiver were at when the limitations occurred. For older caregivers and care receivers who had disengaged from a number of their previous activities already, a loss in the care receivers functional ability was not that important, as these two caregivers pointed out:

> No, I worked all of my life, and when I retired, I retired, so that's about it. I get out and work on cars a little bit. (S3-W-PHY*CR).
>
> Well when you are 80 you don't have too much hobbies actually (S8-H-MIX*CG).

Younger caregivers who were still very much engaged in things like the work world, or going to school, had a lot more difficulty:

> Just did it. Well like I'm going to school during the day and I only had two classes. I was working a full-time job. I was I really was. I worked for three months and for some reason, the Lord knows, I was just dying I was so tired. I was just too tired and I was only getting four hours of sleep, I was going to bed about 12 and I was getting up at 4:30 because I didn't have transportation (S17-D-COG*A-A).

Consequently, the biographical impact (Strauss & Corbin, 1992) of the management of the care receiver's illness and functional limitations varied according to where the caregiver and the care receiver were in their life course.

The second dimension of time trajectory that affected perception and interpretation of the misfit with the environment was the speed of onset of the functional disability. With abrupt changes in health, the caregiver and the care receiver have little time to adjust to their new condition:

> See, you know, it's so sad that you can be . . . one day everything is fine, and then the next day, your whole world is upside down, and nobody can explain to you what the hell happened to you, you know (P6-D-MIX*).

Gradual changes in the care receiver's condition made the adjustments the family has to make seem less perceptible, as this husband caregiver noted "I'm not saying it was 100%. It did start about very slowly, very slowly as of like December of '95" (S6-H-MIX*).

The third dimension of time trajectory that affected perception and interpretation of the misfit with the environment was the stage of the care receiver's disease. In some instances, as the care receiver's disease progressed, environmental management for the caregiver became easier as this wife observed: "The very beginning. He used to take off. He would disappear in the morning to the night. We never knew where he was" (S16-O/S-MIX*HIS). In other cases, the workload of the caregiver became heavier as the care receiver's disease progressed. This was especially true for the care receivers with Parkinson's disease. The finding that stage of illness can shape or influence caregiver management strategies is corroborated by Strauss and Corbin's (1992) work. Stage of illness is very similar to the concept of trajectory phasing. Trajectory phasing is defined as the many changes in status that can occur in a chronic condition. Consequently, caregiver management strategies may periodically have to be changed thorough out an illness course to accommodate either upward and downward progression.

The fourth and final dimension of time trajectory that affected perception and interpretation of the misfit with the environment was the duration of the disability. Where the duration of misfit was going to be short, care receivers and caregivers did not explore long-term environmental solutions. As one wife caregiver explained, the reason her husband did not obtain the bathroom safety equipment the home health staff recommended was because his need for accommodation was of relatively short duration: "Yeah, or the walker there that he could . . . he did come home with a walker so . . . and he didn't have to use that very long though" (S3-W-PHY*).

Conditions That Affect the Implementation of Modification Strategies

The study identified a constellation of factors that directly impact upon the caregiver's ability to make or use environmental modifications. Characteristics of the care receiver and the attributes of the modification directly affect the caregiver's ability to use modification strategies. In addition, these two factors often indirectly affect one another. For example, the height of the caregiver may determine the appropriateness of a particular type of raised toilet seat. So often one cannot be considered without taking into account the attributes of the other. The quality of the relationship between the caregiver and the care receiver also impacts the caregiver's ability to perform modifications. When the caregiver and the care receiver cannot communicate easily, the caregiver has more difficulty in devising the type of environmental solutions that the care receiver will like and use. The caregiver's assessment skills in assessing the care receiver's functioning and their surrounding environment directly bears on the amount and quality of the caregiver's information available for putting environmental modifications in place. In addition, the caregiver's preparation for managing the various manifestations of disease and disability of the care receiver affects how well or easily the caregiver will be able to devise environmental modifications.

The personal resources of the caregiver directly affects the caregiver's ability to adopt environmental solutions. For example, such resources as their amount of physical and emotional energy, their prior caregiving experience, the ease of getting to and from the care receiver's home, their personal health and the level of other obligations that they have outside the home as well as the resources they have to install modifications once selected all have a bearing on what is possible for the caregiver to achieve. Informal and formal supports refers to the help received both by people whose job it is (Archbold & Stewart, 1986) to help in this kind of situation as well as family members and friends. These types of supports affect the caregiver's ability to obtain ideas and materials from the community to implement modification strategies. Each of these categories will be described and data exemplars will be given to illustrate the definitions.

Characteristics of the Care Receiver

The physical and social characteristics of the care receiver was identified by a number of caregivers as being a critical consideration when exploring possible environmental modifications. Physical characteristics affect the implementation of strategies because failure to address them may cause the strategy to not fit the dimensions of the care receiver. For example, for some care receiver's a raised or elevated toilet seat was a godsend:

> Oh another . . . we got one of those kind of risers for the toilet so he doesn't have to sit so far down, and as I said he's so tall that . . . I mean I think . . . you know, and this hasn't been just since he's been old, but probably for his whole life, it seemed like he was lowering himself practically down to the ground to sit on the

> toilet, because he's a very tall man. And especially now, it's just not an easy thing for him to do. So he has one of those plastic things that sits on top of the toilet, and that's been good, because he feels less frightened about sitting (P1-D-MIX).

In other instances, the same type of modification for a much shorter care receiver would be totally inappropriate: [In response to the question: Did you ever think about like a riser or something to make the toilet height higher?] Grandma was only 4'9" {Laughing} (S15-O/C-PHY*F).

The care receiver's strength and coordination was also a factor in the use of most assistive devices.

> It's a very difficult thing. I mean you have to have strength and coordination, so we tried it before we got the wheelchair. They have two wheelchairs here, but they're really for emergency use, so it wasn't . . . I felt we needed our own, which we finally did get. We used a walker in fact, when our nurse was here all the way down to the dining room, but it just exhausted her. It just makes no sense to try something that is at best marginal in value for her (S7-H-MIX*).

For the confused or combative patient, or the bedridden patient, how difficult the person is to handle because of the size and strength of the care receiver relative to the caregiver can make a big difference.

> [Did he resist your efforts to undress him?] Oh yes. Strongly. And he was, fortunately he had rheumatoid arthritis, a very bad case of it. He retired at age 59 because he could no longer work, it was so bad in his hands, and so therefore,

> even though I'm slight, I could still handle him who was 175, 180 pounds, because his hands would hurt too bad (S11-W-COG*).

Consequently, size and mobility of the care receiver were a frequent impediment to the use of some strategies. This finding helps to shed light on the cause of burden generated by toileting regimens designed to keep the care receiver continent. As some researchers have stated (Flaherty, Miller, & Coe, 1992), burden in maintaining continence could be argued to be caused in part by the difficulty in getting the care receiver to the bathroom. Other aspects of the care receiver's physical dimensions were also a factor that made some equipment or adaptive clothing unusable for particular care receivers. For example, one care receiver with terrible edema was limited to very few styles of slippers because of the swelling in her feet. Findings were consistent with Steinfeld's (1987) observations that differences in impairment and personal characteristics can result in different levels of functional ability, different even though both may suffer from the same impairment.

The social characteristics of the care receiver included aspects of personality such as self-sufficiency, being cautious, and positive mood. Care receivers who were more self-sufficient, want to do more for themselves. Consequently, caregivers looked for ways to make it possible for the care receiver to perform their own care:

> I oh, I think I changed them like in the evenings [dressings for shingles], but she'd change them during the day. But she didn't . . . she was very self sufficient. The only reason she lived at our house, was because she didn't like coming home to an empty house (S15-O/C-PHY*F).

In instances where the care receiver was cautious, they could be relied upon to take good care of themselves. This meant that the caregiver had to put in fewer environmental monitoring supports:

> But she was careful, too. She was . . . if she didn't feel well, she would take two aspirin and she would go, and she would lay in her bed all day, and she wouldn't go anywhere (S15-O/C-PHY*CG).

Cognitively-impaired care receivers who had maintained their social skills, were able to have more latitude in the environments that they could function in, for example:

> And now this is something that many people have a great deal of problems with. No, he was a gentleman all the way and we could still take him to a restaurant (S11-W-COG*).

As a result, the caregiver did not have to be as proscriptive about how much they limited the range of the care receiver's areas that they could be free to go into. Care receiver's that were more flexible and positive, were in turn more willing to accept a change in how they ordinarily did things as this caregiver daughter noted:

> Right. And she allows herself to lay down and take a nap if she needs to and/or if she wants to sleep in and not get out of her pajamas 'til noon, she has let herself do that. Whereas before that was just totally uncalled for . . . (S13-D-PHY).

Being able to accept changes in their condition, made it easier for the care receiver to accept the modifications that needed to be made in the home.

Attributes of the Modification

Attributes of modifications are defined as those qualities of the environmental change that facilitate or impede adoption. The attributes of modifications most salient for participants in this study were cost, availability, ease of use, and ease of installation. The cost of the modification was affected by whether or not caregivers could obtain reimbursement for their expenses from Medicare or insurance. Some items, like wheelchairs were very expensive without reimbursement as this husband noted: "Regulations . . . in fact, well Medicaid may still not approve it, and they wanted $60 a month for the rental of the wheelchair. It's ridiculous, you know" (S7-H-MIX*M). Other potentially very beneficial modifications were completely out of reach for caregivers due to their expense:

> But my dad loves to walk and he is a wanderer so we have to really watch him really carefully. We had thought about getting . . . putting safety measures in their house to keep him you know within a certain parameter It's so expensive. Oh my God, we can't afford that (S17-D-COG*A-A).

Modifications also vary in how easy they are to obtain. In some instances, caregivers used materials at hand in the home to make a modification. In other cases, caregivers had to do substantial searching in specialty stores that were difficult to locate and find. Under conditions where the caregiver had limited time available for shopping, modifications that were not available in the local pharmacy or department stores were very hard to obtain:

> . . . couple of times he had fallen down. I once looked for another chair or you know something to help him there, but I could never find or was expensive or what ever and then he stopped doing that so I didn't pursue it (S16-O/S-MIX*HIS).

Ease of installation was another important limiting or facilitating factor. In situations where installation of the modification requires special skills, special tools, or requires physical strength, the caregiver may not be able to do the installation themselves. In these cases, the caregiver was dependent upon other family members or outside hired help to install the modification. This help may not be readily available:

> want to get a hand-held shower. I haven't. I'm sort of dawdling, 'cause the guy who does the work for me is a teacher, and my son is a teacher, and I'm sort of waiting until school is out. And get a hand-held shower (S2-W-COG*).

Ease of use is defined by how much effort the modification requires for the care receiver to physically manipulate. There were several instances where caregivers described difficulty using the modification. Sometimes this appeared to be due to the fact that the caregiver may have needed training to use the modification, but received none:

> . . . she had like a little stool in the bathtub because she was afraid of falling down. I remember once I even I talked her into taking a bath and it took quite a bit of talking and then I had a hard time pulling her out of the water and I guess she got a little scared so she didn't want to do that again even though I was there. So no she wasn't taking her baths properly (S19-S-MIX).

In summary, the attributes of modifications were important conditions that in combination with other conditions, influenced the caregiver's ability to implement various modification strategies.

Quality of Relationship

The quality of the relationship between the caregiver and the care receiver is determined by their history of affective dealings with one another, the impact of the care receiver's functional declines on that association, their present closeness in terms of the amount of time they spend together and how enjoyable or unpleasant that time is, and any burdensome feelings the caregiver may harbor about the care receiver's current state of affairs. These factors that help to define the quality of the relationship can, in turn, affect the ability of the caregiver and the care receiver to communicate effectively around the disability or decline issues for the care receiver.

Historical quality of the relationship. A number of the caregivers stated that they felt the good quality of their relationship prior to the care receiver's decline had a protective effect in the current caregiving situation. As this wife caregiver noted: "and that's why I think that my husband and I do so well, because we have had a good marriage" (S2-W-COG*). A good relationship made it easier for the caregiver to make environmental accommodations for the care receiver, because they did not resent the demands the care receiver's condition placed upon them. For example, one husband caregiver was compelled to spend almost every minute of the day with his cognitively impaired wife, because she would become fearful when he left her alone:

> I would say one of the things, observation, it's my feeling that my wife's reactions are probably not typical of Alzheimer's, they are reactions to memory loss, but we have a close relationship, and she feels my complete support, and therefore, a lot of things wouldn't manifest themselves in her. The only problem we really have is she is very fearful of me not being with her. I cannot leave her, and so I am a 24%, 24-hour-a-day caregiver which I don't mind. It's I have nothing else to do since I'm retired. But very seldom do I feel a little bit discouraged, but it's very seldom (S7-H-MIX*).

In other situations, where the history of the relationship between the caregiver and the care receiver was difficult, the caregiver had a much harder time planning for or executing effective modification strategies because they felt like the care receiver may have resented their identification of problems that need to be addressed:

> Since, over the last 25 years, most holidays she will not come over because she's too upset herself. And usually it's a real, feels to me like a real setup. I know it's coming but I always think it will be better. Half the time it is and sometimes it isn't, so it's not in any way predictable. I would say she has some kind of clinical depression. So far her doctor hasn't looked at that or addressed it and genetically I have, and my sister has, and it's pretty likely that it came from either her or my dad. But she doesn't talk. She doesn't give us the same talk when she goes into the doctor's office. It's how good she is and how well she's doing. So then again you sound like some kind of an ogre because you're saying well what about this time

> when you wouldn't come out, and what about this, you wouldn't do this. So I would say that's an unaddressed problem (S12-D-MIX).

Conflict in the relationship between the parties jointly managing an illness trajectory has been identified as a condition that impedes effective illness management (Strauss & Corbin, 1992). Parent-adult child historical relationship quality in the present study seemed to be more likely to be problematic. This finding is consistent with empirical evidence that supports the hypothesis that parental divorce and memories of family problems adversely affect the quality of parent-child relationships later in life (Webster & Herzog, 1995).

<u>Changes in the relationship due to changes in the care receiver.</u> Among some of the participants in this study, the changes in the care receiver precipitated a change in the quality of the relationship between the care receiver and caregiver that in turn either positively or negatively impacted the caregiver's ability to work effectively with the care receiver. For some of the caregivers, their relationship with the care receiver improved dramatically after the functional declines changed the care receiver's behavior:

> The other day he said, "I love you." He looked at me just so tender and if you were to know him before, he was always so rough and so strong and just set in his ways you know so now it is the other side of that man (S16-O/S-MIX*HIS).

> Yeah. And, just a little background on that, this is nothing really new, violence is nothing new for my mother. My mother was an extremely abusive parent, extremely abusive. I have PTSD from years of physical abuse with her and stuff. She almost killed me any number of times from when I was just little on up. So violence is nothing new for her. In fact, quite the opposite. I think she's mellowed

> out a lot and one of the blessings about her short-term memory lapse is she forgets to get mad. So actually it's kind of a blessing in disguise. She might get mad and then two minutes later she's forgotten all about it. It's kind of a blessing in disguise, actually (S9-D-MIX).

For other participants, however, the changes in behavior in the care receiver had a very negative impact on the quality of the relationship:

> No, no. I don't think she really . . . you know, where she was always very, very clean and everything, but after the stroke, it was . . . it was entirely different. She didn't care what she looked like. You know, she never looked in the mirror, you know, to say "god, is this me or . . . or what's going on?" Like I said, the brain . . . the first stroke I guess wasn't as bad as the second one, you know. Of course, she got hit when she fell down, and she hurt herself, and you know, but when I flew in that day, she knew me. And the next day when she had the other stroke, she didn't know me anymore (P6-D-MIX*).

Not all caregivers and care receivers experienced changes in their relationship due to the declines in the care receiver. It was interesting to note however, that the impact of declines in the care receiver could change either a positive relationship to a negative one, or a negative relationship into a more positive one. This demonstrates how situation dependent the impact of a functional decline in the care receiver is.

Quality of time spent together. This refers to how enjoyable or unpleasant the time that the care receiver and the caregiver spend together is. In some of the families, caregivers found care receivers very interesting and they enjoyed spending time with them.

"Oh, just . . . just . . . I could sit and listen to her all day" (S15-O/C-PHY*SCG). In other families, prolonged contact with the care receiver caused a great deal of unpleasantness:

> But she got all the way to the ER and they called me up and I went to get her and brought her home, brought her to here and then we tried to work out, I can't even remember now what would happen. I think she stayed here for 2 or 3 days. It always seems like a great idea that she'll stay with us and that lasted about 3 days and then one or the other of us is close to killing each other (S12-D-MIX).

Under conditions where the caregiver found spending time with the care receiver difficult, the caregiver usually spent less time with the care receiver which in turn made it more difficult to implement modification strategies and monitor their effectiveness.

Under conditions where the caregiver and care receiver were inseparable, it was often easier for the caregiver to do an activity for the care receiver than to devise a modification strategy, as this caregiver noted "because we always worked together . . ." (S6-H-MIX*).

Burdensome feelings for caregiver. Not being able to directly supervise the care receiver at all times of the day often created burdensome feelings of worry and guilt for the caregivers in this study. As one daughter noted when reflecting about her mother's present living situation, that she often experienced pangs of guilt about not having her mother live with her where she could be more closely supervised. Even in situations where the caregiver and the care receiver lived together, the caregiving situation often created feelings in the caregiver that were difficult to live with:

> But I remember that I would go away in the morning, and as you drive away you're thinking about your mom and you're thinking about the day; and then you get to

> your office and you get busy. And I remember every night as I'd start home, as I'd get closer and closer and closer, I'd wonder, 'What will I find? Where will she be? Will she still be on her feet? Will she be okay?' And that was just part of going home. I mean, you just, you knew that. But that's just something and you know, the more you do that, you realize that the vast majority of time she was fine. I mean, depending . . . I mean within the parameters of the disease process. She was obviously losing ground . . . (P2-D-PHY*).

Feelings of worry or concern that not enough was being done for the care receiver to keep them safe were in conflict with trying to ensure that the care receiver remained autonomous and was not over protected by environmental restrictions that were unnecessary.

Communication around disability issues. Of all the aspects of the quality of the relationship of the caregiver and the care receiver, their ability to communicate around the issues raised by the care receiver's health or functional decline was the most central one affecting the caregiver's self-reported ability to effectively implement environmental modification strategies. Some caregivers reflected on how they felt very comfortable talking with their care receiver about the problems their misfit with the environment created:

> I think some of this is maybe related to the fact we'd worked together before. I mean we'd been in communication. When they came to [our state], they had helped us. We asked them to, but they had moved, and they had been part of our baby-sitting system, because it enriched the kid's life knowing his grandparents and

> building memories of them. It also helped them, because I paid them, and that was nice for them. So there had been that ability to sit down and to talk and reflect and negotiate (P2-D-PHY*).

Other caregivers described with great frustration their difficulty in eliciting two-communication with the care receiver about how well a modification is working:

> Well the nurses put it on the calendar. Do this now and do this at noon and do that. Umm, they got her bottles that were easier to open with one hand. I mean I recognize that some of the things that we tell her she can't do. But she doesn't always say that (S12-D-MIX).

Other caregivers reflected on how they perceived the care receiver's needs differently than the care receiver either did or was willing to say that they did:

> And she has severe neuropathy and, in my opinion, has never been very good about her diet though she thinks she is. I don't think she's monitored her glucose very often though she says she does (S18-D-PHY).

Having trouble communicating around a potentially sensitive issue makes it that much harder for the caregiver to problem-solve. Caregivers noted that when they did not feel that the care receiver was communicating openly with them about their needs and preferences, they often had difficulty getting the care receiver to accept or use the modifications they made or suggested.

Caregiver's Skills

The caregiver's skills are defined as the ability or expertise of the caregiver to assess and manage the care receiver's misfit with the environment. There are three domains that caregivers must be able to accurately assess if they are to be successful in managing the care receiver's misfit with the environment. The first domain is assessment of the care receiver's functional status. Caregivers need to be able to correctly identify and describe the functional limitations of the care receiver. In addition, they must be able to recognize changes in that status. The second domain of assessment is the cognitive and affective responses of the care receiver to changes in functional status. Caregivers that report success with managing care receiver misfit with the environment are able to unerringly discern the care receiver's thinking, feelings, and wishes. The third domain of assessment is the environment that the care receiver is acting in. A number of the caregivers were able to very accurately describe how components or aspects of the physical environment impacted the functioning of the care receiver. The ability to manage the care receiver's problems was also an important skill element that caregivers identified in the interviews. Among the participants in this study, caregivers reported varying levels of preparedness for dealing with the care receiver's condition.

Caregiver can assess care receiver function. This caregiver skill is defined as the ability to correctly identify and describe the functional limitations of the care receiver, and to recognize changes in that status. Caregivers in this study were able to describe in exacting detail the nature of the care receiver's specific functional limitations and their effect on the care receiver's performance of activities. Table 8 presents a number of data

Table 8

Caregiver Skills

Caregiver Skills	Definition	Data Exemplars
Caregiver can assess care receiver function	This caregiver skill is defined as the ability to correctly identify and describe the functional limitations of the care receiver, and to recognize changes in that status.	. . . if it's all right there, then I think he just . . . he can kind of do the process, but he might forget even that he needed a towel or something (P1-D-MIX). You see, their . . . with Parkinson's, their hands don't work very good, and they have trouble doing things with their hands (P3-W-MIX*). . . . her problem is that she drinks too fast and a lot of times she gets too much and she starts coughing (S10-H-PHY*). . . . we both have concerns about anything that's equipment or machines that she's usually not as good at running period She didn't like the push button phone (S12-D-MIX). . . . she'll get dizzy if she moves too quickly, you know, so she tries to . . . you know, she just moves slow deliberately (S13-D-PHY). She isn't good at focus . . . you know how with a magnifying glass, it takes a little skill to do this . . . to focus it (S14-D-MIX). I needed to be there to supervise and I would give him everything but then I noticed that he didn't know what to do with it (S16-O/S-MIX*HIS).

table continues

Table 8 continued

Caregiver Skills	Definition	Data Exemplars
		We began to see my mom waste away you know and my dad losing all this weight and that was because she wasn't cooking, she didn't know how to cook anymore actually (S17-D-COG*A-A).
		In the other eye he has a lot of spots that are missing. He can't read anything but headlines any more. Everything else is, you know, just too much missing (S18-D-PHY).
		She has a kind of palsy, a Parkinsonian sort of shake and a tremulousness in one of her hands, I think it's more the, I guess it's more in the right hand. It's not all Parkinson's cause it never quite goes away even during intentional movements but her writing has gotten tremulous but she can still write and pay bills (S18-D-PHY).
		. . . in any procedure, if there's six steps to the procedure, I . . . you never know which one they're going to lose, but they're going to lose one (S2-W-COG*).
		. . . on it's . . . he needs a lot of contrast. If things are contrasted, he can see them better. Making things larger does not help [him], at all (S4-O/S-PHY*).
		When she doesn't know where her feet are at, like we do, I guess. And when she'd walk, instead of going down this way to the next step, she doesn't clear her heel (S5-H-PHY*).

table continues

Table 8 continued

Caregiver Skills	Definition	Data Exemplars
		She has sort of a fear of water actually. She does not take showers or a bath, and the bathtub is such that it would be impossible for her to get in and out of it (S7-H-MIX*). Oh, she can drink, she can hold a cup if she's not jerky, if she is jerky I don't let her do it because she just spills it over the area, and there's our carpet again {Laughter} (S8-H-MIX*).
		Yeah, mobility's okay. Her main problem is the mental faculties going (S9-D-MIX). . . . he stopped talking but there was two things he could still do . . . but when I would come home at night he would take a magazine and read to me out of it, or a newspaper. And then he did that for a little while, and then his little grandson was born in 92 and when he was about 12 months, in 93 into 94, he could read the children's books to the little boy, but he couldn't talk, he couldn't answer a question, he never offered to talk. But he read and then suddenly he couldn't read anymore and then another year, he had great faith and was always very active in his church, you could say, would you say grace, and he could pray when he couldn't talk, and thank God for the food in very simple language. And then suddenly he couldn't do that and he could not be bothered to have anybody pray once he got the food so we stopped praying. It was just one more thing to do (S11-W-COG*).

table continues

Table 8 continued

Caregiver Skills	Definition	Data Exemplars
Caregiver can assess affective and cognitive responses of care receiver	This caregiver skill is defined as the caregiver ability to able to discern the care receiver's thinking, feelings, and wishes around the changes in functional status. Being able to discern what the care receiver is thinking helps the caregiver interpret and respond to how the care receiver is reacting to a particular proposed environmental modification strategy. Being able to predict the care receiver's preferences or wishes also helped the caregiver tailor modification strategies to meet the care receiver's needs.	I think when he was looking at that roast beef on his plate at my house, you could almost tell what was going through his mind. He was thinking "I either have to ask for help with this, or I have to try to do it on my own. And if I try to do it on my own, I might make a mess of it and spill the whole thing on the floor. But I really don't want to ask for help" (P1-D-MIX). I think the walls and the stable surfaces brought her security (P2-D-PHY*). . . . see that's the thing. He doesn't say, I'm hurting you know, I have a headache, I have a throat ache, or you know or I am hungry, I am cold, you, you know he doesn't say that but it is you just you get to know him so well you know it is just reactions that he gets and then if I say are you cold honey? Yes (S16-O/S-MIX*HIS). And we always slept together. And at night he got in bed and you could just see how safe he felt and he'd put his arm around me and he'd sleep that way all night long. And I think that closeness made that difference at night. So I think people with Alzheimer's probably need to realize that they need to do a lot of hugging and letting them know that you care. When he'd start wandering, sometimes I'd just stop him and give him a hug and see if that would just calm him down (S11-W-COG*).

table continues

Table 8 continued

Caregiver Skills	Definition	Data Exemplars
Caregiver preparation for managing care receiver's problems	Many caregivers were unprepared to manage the care receiver's chronic illnesses and or cognitive impairment. In instances where the caregivers relied upon the formal medical system to educate them to the challenges that faced them in the care of the care receiver, they were sometimes disappointed.	But like I said, we weren't well prepared. There was . . . hey, you know, well the doctor figured my sister is a nurse, and everybody else my brother's in this racket, so they'll all know what to do. Well, hell we didn't know what to do (P6-D-MIX*). Well I think a couple of things. One is you have to recognize the symptoms and whatever disease or you know problem it is and you have to keep that in your mind, particularly if the person has a couple of different problems. It's like this blood sugar thing. I just didn't have that on top of my mind that that was, you know, but I didn't realize that I had to keep after it. I felt the caregiver would know enough. She was going home with her. Apparently they thought that she was going to die and didn't recognize there was a diabetic situation (S19-S-MIX)._ I know the biggest thing that made me feel better was that I was there when the oxygen was delivered, and I listened to the whole spiel on how to run it, what the dangers are, how to fill the stroller. I learned all about it, so that . . . when I talk to my mom, I can say, "well, did you do blah, blah, blah?" . . . I would know certain things to ask her so that in case she did forget . . . just kind of checking in, making sure that she's fully understood, because she didn't understand, 'cause she was still . . . extremely weak. And so I think it's important to have somebody there at the beginning to hear all the different things and to . . . see how . . . how she gets around. Like her cord gets twisted a lot . . . like if you twist a phone cord a whole bunch of times, it spirals together. And so things like that . . . we would make sure that her cord was straight, because if it pulled . . . it hurt her (S13-D-PHY).

Table 8 continued

Caregiver Skills	Definition	Data Exemplars
		No, we would never, could never do it behind their back because mother, first of all, there would never be any forgiveness of that, and she has always been in control, and even to do it now we'd have to do it at her pace when she's ready and if she doesn't want to deal with it, you know, like the clothes closet on her side has things that have been there 20 years, but she's not ready to deal with that yet, and no, we're not going to do it while you're here, and that's the end of that (S18-D-PHY).
Caregiver can assess environment	This caregiver skill is defined as the ability to correctly identify and describe how the environment impacts the care receiver. It includes the ability to identify the triggers to aberrant or undesirable behavior in cognitively impaired care receivers.	That cataract so there is only one light in the living room and the living room is not at all that big. It's just apartment size you know. so there is only one lamp and then the dining room is right next to the living room and it has a low chandelier so there is plenty of light but it is not that glaring light and when the sun is out it is horrible for my mother. So we have bought her some you know pop on shades uh huh so when she goes outside we have her hat so she can shade her eyes even further (S17-D-COG*A-A). It used to be when I got on the phone That's when he would go over and talk on the mirror (P2-D-PHY*).

table continues

Table 8 continued

Caregiver Skills	Definition	Data Exemplars
Caregiver preparation for managing care receiver's problems	Many caregivers were unprepared to manage the care receiver's chronic illnesses and or cognitive impairment. In instances where the caregivers relied upon the formal medical system to educate them to the challenges that faced them in the care of the care receiver, they were sometimes disappointed.	But like I said, we weren't well prepared. There was . . . hey, you know, well the doctor figured my sister is a nurse, and everybody else my brother's in this racket, so they'll all know what to do. Well, hell we didn't know what to do (P6-D-MIX*). Well I think a couple of things. One is you have to recognize the symptoms and whatever disease or you know problem it is and you have to keep that in your mind, particularly if the person has a couple of different problems. It's like this blood sugar thing. I just didn't have that on top of my mind that that was, you know, but I didn't realize that I had to keep after it. I felt the caregiver would know enough. She was going home with her. Apparently they thought that she was going to die and didn't recognize there was a diabetic situation (S19-S-MIX)._ I know the biggest thing that made me feel better was that I was there when the oxygen was delivered, and I listened to the whole spiel on how to run it, what the dangers are, how to fill the stroller. I learned all about it, so that . . . when I talk to my mom, I can say, "well, did you do blah, blah, blah?" . . . I would know certain things to ask her so that in case she did forget . . . just kind of checking in, making sure that she's fully understood, because she didn't understand, 'cause she was still . . . extremely weak. And so I think it's important to have somebody there at the beginning to hear all the different things and to . . . see how . . . how she gets around. Like her cord gets twisted a lot . . . like if you twist a phone cord a whole bunch of times, it spirals together. And so things like that . . . we would make sure that her cord was straight, because if it pulled . . . it hurt her (S13-D-PHY).

Can assess care receiver environment. This caregiver skill is defined as the ability to correctly identify and describe how the environment impacts the care receiver. It includes the ability to identify the triggers to aberrant or undesirable behavior in cognitively impaired care receivers. Examples of the caregiver's ability to accurately assess environment and it's impact on the care receiver appear in Table 8.

Caregiver's preparation for managing the care receiver's problems. Many caregivers were unprepared to manage the care receiver's chronic illnesses and/or cognitive impairment. In instances where the caregivers relied upon the formal medical system to educate them to the challenges that faced them in the care of the care receiver, they were sometimes disappointed. In the one situation where the caregiver was able to obtain the medical information she needed to assist her care receiver in managing her oxygen, that caregiver was able to greatly enhance her ability to intervene for the care receiver to make her adjustment to her new medical limitations less troublesome. The data in Table 8 illustrates this situation as well as others where the caregiver was not able to obtain this very important information.

Caregiver's Personal Resources

The caregiver's personal resources are individual assets and means that can be drawn upon in difficult situations. They include the caregiver's emotional and physical energy level, the time they have available to work on environmental solutions, the financial resources they can devote to purchase modifications, and the resources they have to have the modifications installed. The emotional and physical energy level of the caregiver is determined in part by the health of the caregiver as well as for some, their ability to draw upon spiritual resources. The time the caregiver has available to make modifications is determined by two factors, the other family obligations that make demands upon the caregiver and the ease of getting to and from the care receiver's home. Financial resources available to make modifications are dependent upon the state of financial affairs of the care receiver, the possibilities of obtaining government or other outside agency assistance, and the caregiver's finances and their willingness to spend them on the care receiver. In situations where modifications need to be installed, installation resources are determined by knowing who to contact for installation or having the skills to install the modification oneself. These findings support Strauss & Corbin's (1992) view that caregiver resources such as time, money, and social support influence their management processes. The findings are also consistent with research that indicates caregiver depression and burden are associated with inadequate finance, family support, health, and time availability (Given et al., 1992). Each of these categories will be described and illustrated with data from participants.

Physical and emotional energy level. The physical energy level of the caregiver is mostly determined by the caregiver's health status. A number of the spouse caregivers were performing onerous caregiving duties in spite of having compromised health themselves. The wife caregiver of a Parkinson's patient described how here own health problems placed additional burden on her when she was trying to meet her husband's needs:

> He wakens in the night. He doesn't sleep real good, and he wants to eat. Now I'm a . . . I have a problem running to the bathroom myself . . . just urinating, 'cause

> when I had this original surgery, they had . . . I had a ruptured bladder, because of a tumor that I had . . . a fibroid tumor . . . a large . . . they said it was like a 6-month pregnancy. So I don't know anything about it, if that's large or not, but anyway, it caused a rupture to my bladder, and I don't have as big a bladder, and I always blame that, that maybe that's why I run to the bathroom. But something . . . something is different in that department. And I do get up at night about every hour and a half and run to the bathroom (P3-W-MIX*).

Some of the husband caregivers also had physical functional limitations that made their caregiving duties difficult. As these husbands noted:

> Yeah, this past weekend I was in pretty tough shape. In fact I thought I'd have to go to the emergency (S10-H-PHY*).

> Oh, yeah. She used to get in and out of the tub. Actually, I use it pretty well too. Having arthritis sometimes it gets, I haven't got it in my knees or my hips but just in my ankles and it's kinda . . . {chuckle} (S8-H-MIX*).

If the caregiver's emotional energy was depleted, it made it very hard to be resourceful or creative in developing environmental solutions. In the following quotations, a wife and daughter caregiver describe how the demands of work and the caregiving situation can limit the energy the caregiver has available for being creative:

> It's very difficult to care for an Alzheimer's patient. And so I'd come home at night, sometimes, pretty tired. Until March of 95 I had a very high powered job and then I moved to a different job and it turned out to be very busy and so I

> would want to sit down and he would go through the house, through drawers and closets, and he wouldn't sit down and it was very frustrating (S11-W-COG*).
>
> But at that time I didn't understand all of that either. I can see it now. I'm a lot older. It could happen to me. But in those times you're so agitated with what's going on, you don't come up with any answers. Then when you have time to look at it, you say "well, yeah, I understand now" (P6-D-MIX*).

A small subset of the caregivers used spiritual resources to try to shore up their emotional energy. This was particularly true of the minority caregivers in the sample:

> No, he would come back. No, he would say "I got lost." We would say "where were you?" "Well I found myself in [a suburb on the other side of the city]." He had gone all the way [across town] and then I would say what time was that because I remember I had such a heaviness in my heart and I pray. I said "Lord wherever he is, show him the way" and he say that in that time he found a way and that was about the time I was praying. I cried (S16-O/S-MIX*HIS).

Inner resilience among minority caregivers has been identified by other researchers as a potential explanation of better caregiving outcomes among African Americans in spite of their objectively more difficult caregiving situations (Young & Kahana, 1995). In another study, African American caregivers perceived higher levels of rewards than Caucasians and the relationship between race and perceived rewards was mediated by religion and prayer (Picot, Debanne, Namazi, & Wykle, 1997). God was perceived as the most helpful source of help followed by the family in a sample of 83 African American female caregivers who provided care to an elderly demented relative (Picot, 1995). Some of the other participants in this study identified prayer as a source of strength under difficult circumstances as well:

> I feel I've been lucky even with all the work, all the flying out here, I still feel that things could have been a lot worse in terms of trying to find the services. I feel still I was very lucky. I would recommend prayer. Seriously, that's about all, and you can't worry too much because it's like, you can't really know about what the combat situation is until you get out there. There are all sorts of things going on that you hear about, you know, because you're let alone and short memory, mind is mixed up, they tell you all kinds of things, you don't know what to believe. The caregivers tell you things you don't know what to believe, you know, and you really can't tell until you actually get out there and tell what the situation is (S19-S-MIX).

Using prayer as a method of coping is consistent with Kaye and Robinson's (1994) study in which prayer was an important coping method used by 94% of the caregivers in a sample of 17 dementia caregivers. The findings in this study support that spirituality is a source of strength for some caregivers.

The caregiver's energy level was only one component of a configuration of resources that caregivers had to draw upon when making or using environmental modifications. For the spouse caregivers, energy level was often compromised because of health problems. Very difficult to manage care receivers depleted the emotional energy of some of the caregivers. The use of spiritual resources had a protective effect for a subset of the caregivers who tended to use this as a source of renewal.

Time available. The amount of time that the caregiver has available to work on environmental modifications is another factor that affects the caregiver's ability to implement, refine, and use environmental modifications for the care receiver. The amount of time that the caregiver has available is dependent upon their other family obligations and the ease of getting to and from the care receiver's home.

Other family obligations that affected the amount of time caregivers had available included assuming the duties of the care receiver and/or caring for other relatives. In a number of instances, caregivers assumed some if not all of the family duties of the care receiver.

> I didn't allow her to [cook] do in the last few months, only because I didn't want her, in case her back was bad, she could have burnt herself by just moving, but she wanted to, you know (S6-H-MIX*).

This left a number of the caregivers with very little time for exploring other helpful options or seeking other ideas about how to manage the care.

> I don't know how other Alzheimer patients are because I did not have time or did not want to join a help group so I don't know, but I'm sure it's a problem (S11-W-COG*).

Besides assuming the family duties carried on by the care receiver, a number of the caregivers were caring for other relatives. In some instances, the caregiver was caring for another care receiver in a separate home apart from the older person. One of the caregiver daughters had to care for a severely disabled husband in addition to being the only caregiver for her mother:

> She also knows the demands that my husband brings. She's gotten less attention in the last few years, 'cos sometimes my husband would take her out . . . . Well now, not only does he do not do that, but I need time to help him and she's not getting the same amount of time (S12-D-MIX).

Some of the caregivers were caring for multiple care receivers who lived together. These were usually parents who both had impairments. In some cases, the care receiver's impairments allowed the couple to supplement one another's functioning as this daughter noted:

> Oh, yeah, that's the only way that they can survive, him preparing the meals, getting her chair into the bathroom so she can take care of herself, getting her clothes out where she can get them. He pulls her stuff out or he puts it up to hang up where she can get it. And, she can dress herself once everything's accessible to her but if he doesn't put the chair there, doesn't get the stuff out for her, doesn't fix the meals, she could I suppose get into the kitchen and get one or two things but it would probably exhaust her and she might not be able to continue to do it or all day to do it. He cannot see well enough to pay a bill, read a bill. He could dial the phone because of knowing where the buttons are but he can't take care of any of that part. She does the taxes, the bills, all of the paperwork. The bank work, if he goes to the bank she's written the check, or if she writes the check and gives it to him to sign, she has to put her finger down and say this is where you sign, and you know, it's not even on the line because he can't be sure where he's signing (S18-D-PHY).

Unfortunately, in other instances, the combination of two individuals in the same household with similar functional impairments made managing care far more difficult:

> Sometimes at night he will refuse to take off his shoes and his clothes, and put on his pajamas. But my mom is greater cusser you know, even because she does not understand because of her mental capacity that he doesn't understand anything but she just cusses him out and her term is put those pajamas off. So he has always in total confusion about what he is supposed to do because she throws him all off so it is a real battle getting him dressed (S17-D-COG*A-A).

Other caregiving obligations tended to limit the amount of time that caregivers had available for addressing the care receiver's problems. This in turn limited their ability to devote many hours to devising environmental solutions.

The ease of getting to and from the care receiver's home varied from no difficulty at all (caregivers who lived with the care receiver) to a great deal of difficulty (caregivers who lived in another part of the country). The ease of getting to and from the care receiver's home was an issue for all the caregivers who did not live with the care receiver. In a couple of instances, the caregiver lived so far away from the care receiver's home that out-of-state travel was necessary to make environmental changes.

> [field notes] so every time his mother needs something he has to fly here you know do a cross continental flight to come here. Of course he has a full time job so usually what that means is that he leaves on a Friday tries to gets here Friday afternoon, Friday evening desperately tries to take care of things for her, and then usually tries to depart like on Monday afternoon or evening (S19-S-MIX).

Managing care from a distance makes it very difficult for the caregiver to intervene or suggest changes. Prior research found that living arrangements had a major impact on the time allocation of the caregiver's day. Caregivers that lived separately spent more time in daily travel, more time working, and less time helping the care receiver than caregivers who lived with the impaired person (Moss, Lawton, Kleban, & Duhamel, 1993).

Financial resources. Financial resources are defined as discretionary income available for spending on environmental modifications. The financial resources available to the caregivers to spend on modifications varied among the families interviewed. Two trends were noted among the participants interviewed, one where finances limited options and the other where they increased options for the caregiver. Most of the families were constrained by their financial resources even in situations where their income could be considered more than adequate. One wife talked about how she had explored moving with her severely disabled husband to a retirement home where she could get help with his care. Although she really liked the facility, she ruled out moving as an option because of the cost. A daughter caregiver noted how much easier it was to bathe her mother in a specially modified bathroom in the nursing home. She stated it would not have been an option, however, to make similar bathroom modifications in her mother's home so that she could remain in that setting.

Some of the caregivers did have substantial resources available to them. In these instances, the families spent very large sums of money to meet the environmental needs of the care receiver in innovative ways. One daughter purchased a golf cart for her father with Parkinson's disease so that he would be able to get around in his neighborhood easily without appearing to be disabled. "They bought a little golf cart. Some of these things, you know, wouldn't be available to other people because they wouldn't have the resources" (P5-D-PHY). Another spouse caregiver was able to afford $3,000 dollars a month to hire certified nursing assistants so that she could continue to work and keep her demented husband at home. However, these families seemed to be more the exception than the rule.

Due to the high cost of living with chronic diseases, many families were left scrambling trying to pay for all of their expenses in addition to their needs for environmental modifications. One care receiver talked about how critical it was to get Medicare to pay for her walker: "My medication is so high. My medication is about $200 a week. And then everything costs. So the doctor said I'll see if I can get Medicare to pay part of it [let's do it]" (S10-H-PHY*). These type of constraints were made even more difficult if the caregiver did not have an adequate financial income: "When I retired, we thought between the two of us, we were getting $500 a month. We thought that was good. That was before the big wages started . . . " (P4-H-COG*CG). Limited income was also a factor that made it more difficult for families to keep the care receiver's home in good repair. As this husband noted, home maintenance can be very expensive: "I put plastic on the screens, because they want $5,000 for storm window" (S5-H-PHY*). In summary, caregivers in this study financial resources were limited by inadequate income, other medical expenses, and costly home maintenance.

<u>Installation resources.</u> Installation resources are defined as having the means to find, buy, and set up an environmental modification. Not all types of environmental modification strategies are dependent upon the caregiver having these types of resources.

However, in order to install some modifications, the caregiver must first be able to find the modification, have the money to pay for it, and know who to contact to install it and/or be able to install it themselves. One wife caregiver reported that she did not put grab bars in the bathroom because she was unable to muster the installation resources:

> One of the things that I got and didn't get put up because I didn't know who to find to do it, I got some bath some holds to put in the bathroom, in the bathtub. Grab bars. And I didn't know who to call, you know, to get them put in so they wouldn't mess the tile up. So we didn't get those, but you should have grab bars (S11-W-COG*).

Most of the caregivers in this study had limited installation resources.

In summary, inadequate personal resources make it hard for caregivers to give effective care or to problem solve difficulties. The findings of the present study were similar to reported research findings on caregiving effectiveness for technologically dependent adults residing at home (Smith, 1994). Smith found that caregivers whose incomes were inadequate and/or whose personal health or emotional energy was low, had difficulty providing implementing caregiving strategies effectively. These similarities in findings between the present and Smith's study suggest that differences among caregivers in terms of personal resources may impact the caregivers ability to make environmental modifications.

Formal and Informal Supports

Formal supports are those supports to the caregiving situation where the parties who provide that support get paid for their actions, or involve volunteer networks that are organized by groups that have coordinators that arrange services. Community resources such as Meals On Wheels or aging services are examples of these kinds of services. Also included in the definition of formal supports are hired aides who may be obtained through either community resource networks or via the health care system. The health care system itself constitutes another source of formal supports and includes physicians, nurses, hospitals, durable medical equipment companies, and home health agencies. Formal supports also include support groups that may be run by organizations such as Alzheimer's Association or through senior service centers. Caregiver's success in utilizing these services varied considerably. As Archbold (1983) noted in her study of caregiving daughters, personal services were not only difficult to locate but costly.

Informal supports are those supports that are provided because of kin affiliation or out of friendship. They are not paid services. Caregivers also vary on the amount of assistance they receive from informal networks. Most of the caregivers in the study reported very little help with direct care from other family members. However, the African-American participant in this study reported that she had a tremendous amount of family support from a very large family:

> We can't do that. We have a huge family. Now surprisingly, now on the 26th and 27th, us four girls are going to go off for a weekend together because we don't get to do that often and we are going to go [out of town] to see our cousin and spend a weekend and our niece, two nieces are coming over to spend the weekend with my parents so all four of us can go up (S17-D-COG*A-A).

Other supports include those supports caregivers receive from formal social organizations that are not created or intended to meet their needs as caregivers. Employers and police were mentioned by participants as groups they had contact with that were and were not supportive. Table 9 contains data exemplars illustrating the various types of supports caregivers used.

The study's findings regarding the impact of social support as a resource for effective strategy implementation, complement quantitative survey findings that suggest that lack of adequate support has negative outcomes for caregiver well-being. In a study that examined the influence of family resources on well-being of caregiving families, Fink (1995) found that resource variables such as support, strains, and socioeconomic status accounted for 65% of the variance in family well-being. Unfortunately, most of these surveys were designed to answer questions about group differences in satisfaction with support according to gender and relationship (Cossette, Levesque, & Laurin, 1995; Hibbard, Neufeld, & Harrison, 1996). Therefore, the potential value of support in aiding caregiver problem solving can only be inferred from these studies. However, in the future, examining the availability of tangible and informational support as defined by Cossette et al. (1995) may better inform researchers about the dynamics of caregiver implementation of environmental modification strategies.

Conditions that Affect the Outcome of Modification Strategies

There were two conditions that affected the outcome of the modification strategies employed, both were functions of the care receiver's condition. A number of the care receivers had chronic health conditions that created variability in functioning on a day

Table 9

Data Exemplars of Formal and Informal Supports

Formal and Informal Supports	Definition	Data Exemplars
Formal supports	Formal supports are those supports to the caregiving situation where the parties who provide that support get paid for their actions, or involve volunteer networks that are organized by groups that have coordinators that arrange services.	I only called Alzheimer's Association once, about the teeth, and they didn't seem to know as much as I did. I think maybe you can call them when you get tremendously frustrated. Like if you've spent an hour getting someone to bed and you feel like you're going to crack into a million pieces, I think you can call there but I don't know, I never did. And I realize I should have maybe thought (S11-W-COG*). . . . but I wasn't too sure how to handle it, I . . . the first thing I did was talk to Aging Services, and they gave me a lot of information. And that kind of stuff is what I relied on. I mean it was very valuable. 'Cause I didn't know about . . . first, I didn't know why it was difficult for her to get in the bathtub. I didn't realize that all I needed to do was put a bar up. I mean I wasn't conscious of that. I didn't realize that was the problem. After talking to Aging Services, you know, they told me of different things that were available. And that was something that they mentioned. The toilet seat was another thing that they had mentioned. And not being exposed to that ever before, I didn't have a clue, so . . . That was . . . yeah, very important, and knowing where to go. They referred me to other places for other information about the elderly, you know, Medicare/Medicaid stuff, VA, resources (S14-D-MIX).

table continues

Table 9 continues

Formal and Informal Supports	Definition	Data Exemplars
		Not only that a lot of these social service people, they work a 4-day week and it's really a pain to get help on Fridays. You just forget about Fridays. Because usually what happens is there will be maybe four or five people in the office. On Friday there's one person unless it is a real rush thing. So Fridays, I don't know if they're out on Fridays or what the deal is, but they must but I've learned that Fridays are shot. So you can't get anything done on the weekend at all, and it usually takes four or five hours to get a hold of them. I call from back East, I just hate here. This place is horrible when you're calling long distance. You call them long distance and you have to go through a hurdle. You've got to do the front receptionist and then a second receptionist and then you get the tape recorder on the phone and so what I would do is in a half an hour I would try again another long distance call to try to get through. Right now, like last month I got letter where they were going to cut off her social security or Medicaid rather because of some indication that she had a source of funding. I got the nice letter and that was a Friday so the lady was off and finally I got to the manager and after about six calls the manager told me it was a mistake. They had somebody else's account (S19-S-MIX).

table continues

Table 9 continues

Formal and Informal Supports	Definition	Data Exemplars
		I put some lotion on her, kinda dry and what not and the house nurse was kind of perturbed about it because, see what was it, must have been her left ankle was real swelled or something, but her doctor said "Well, I don't worry about it, if both of them were swelled, then I would worry." That's what he told me so I said okay. But the home nurse said "Keep her foot propped up", and have you ever tried to keep anyone's foot propped up? (S8-H-MIX*).
		She had a visiting nurse coming in to assess her after her stroke and stuff, but she's real slick, she's real slick and she was able to answer questions appropriately because she was real paranoid. And she somehow knew not to say certain things in front of strangers. Really funny. And I think, in that sense, initial assessments and stuff, with visiting nurses, if it could be done more than once a week, I think that would be a big help. Just to catch the person in different moods, maybe different times of the day . . . and I think that that would be a big help because she was able to pull the wool over the nurses' eyes (S9-D-MIX).

table continues

Table 9 continues

Formal and Informal Supports	Definition	Data Exemplars
		I put some lotion on her, kinda dry and what not and the house nurse was kind of perturbed about it because, see what was it, must have been her left ankle was real swelled or something, but her doctor said "Well, I don't worry about it, if both of them were swelled, then I would worry." That's what he told me so I said okay. But the home nurse said "Keep her foot propped up", and have you ever tried to keep anyone's foot propped up? (S8-H-MIX*).
		She had a visiting nurse coming in to assess her after her stroke and stuff, but she's real slick, she's real slick and she was able to answer questions appropriately because she was real paranoid. And she somehow knew not to say certain things in front of strangers. Really funny. And I think, in that sense, initial assessments and stuff, with visiting nurses, if it could be done more than once a week, I think that would be a big help. Just to catch the person in different moods, maybe different times of the day . . . and I think that that would be a big help because she was able to pull the wool over the nurses' eyes (S9-D-MIX).

table continues

Table 9 continues

Formal and Informal Supports	Definition	Data Exemplars
		Alzheimer's clinic. And during that process, we found a very strange thing happening. See I'm . . . I was always involved in her medication since she's been sick, because I know that the only way we can get somewhere while . . . the reason we switched from the regular internal . . . internist, she had . . . she was . . . became slightly incontinent, so I thought maybe it is a infection. So I took . . . I took the urine specimen to the doctor. It's right near here. And it was clear, but the nurse gave me the message: 'What do you expect at her age?' and so on so on so on." And I . . . somehow it didn't sit right with me (S7-H-MIX*).
		. . . he was a nice-looking man, and he was nice when we'd go in there, but he kind of shuffled you through so fast. And we tried to get information from the nurse, or I'd want to talk to him. She told me one day, she says "Doctor just doesn't talk to patients on the phone." And it kind of irked me (P3-W-MIX*).
		We tried the Alzheimer's support group, which is . . . well, you get some information, but basically it's meaningless for what I need, because I need support for me, not for her or anything else, and that's not . . . it's just not adequate for any sustaining kind of support which I guess that's all they can do. I don't know (S7-H-MIX*).

table continues

Table 9 continues

Formal and Informal Supports	Definition	Data Exemplars
Informal supports	Informal supports are those supports that are provided because of kin affiliation or out of friendship. They are not paid services.	. . . other arrangements for her. I watch her very, very closely. In fact, I'm the only one in the family who really does. I'm pretty much alone in this. I always have my brothers and their wives saying "Oh, we'll help out, oh, we'll help out" but they never do (S9-D-MIX). It was an effort, I'll tell you. It was an effort. She, my daughter-in-law is a great help to me. She had a calming effect on her. Real calming effect on her. She would get mad at me, but she wouldn't be mad at her, my daughter-in-law could get her to do things. I couldn't (S8-H-MIX*).
Other supports	Other supports include those supports caregivers receive from formal social organizations that are not created or intended to meet their needs as caregivers.	If the caregiver doesn't have something on the outside, I used my job as my fun. I very seldom had any social life outside that job because I had to pay, you know you can't get somebody to come and watch an Alzheimer's patient for $5 an hour like you can a child. It's $15 an hour. So I didn't have any of that. But I had a job which I liked, I enjoyed it (S11-W-COG*).

to day basis. For example, it was quite common for some of the cognitively impaired care receivers to vary on a regular basis in what they could do. As one wife caregiver described it, their functioning was like a light bulb flickering on and off. This variability in functioning is a consistent pattern of unpredictable functioning. The net effect of this variability is that it causes the environmental modification strategies to be effective only intermittently and in an unpredictable manner. As these spouse caregivers noted:

> It is really very helpful, I mean, I would say very helpful, it helps. It helps under certain circumstances sometimes (S7-H-MIX*).

> We got her, sometimes I can get her in the shower and sometimes I can't so we have another bathroom there (S8-H-MIX*).

The positive benefits of a modification strategy were diminished when they were not used consistently:

> Well, that's another thing that I bought when he came out here was a big clock with big, clear, black numerals on a white background "easy-to-read." His eyesight is not real great, and so I bought a clock that we didn't have before that he can read easily. And sometimes he really relates to the time of day and can look at the clock and tell it . . . other . . . it depends on how with it he is. Other times it just doesn't mean a lot to him (P1-D-MIX).

Therefore, as a rule, care receiver variability in functioning acted as a constraining factor in the caregiver's willingness to use a modification or to be satisfied with its results.

Another condition that tended to affect the outcome effectiveness of modification strategies employed was the tractability of the care receiver's condition. In situations where the care receiver had symptoms from their disease that were not easily ameliorated, caregivers were less successful in employing modification strategies to their satisfaction. Severe behavior problems that either put the care receiver or the caregiver at risk were particularly troublesome. Behaviors that put the care receiver at risk were wandering away and becoming lost for an extended period of time and episodes of paranoia that made the caregivers fear for the care receiver's safety.

> And . . . but nobody told us how bad the mind was until that episode with dad, and then when she got out of the house and my sister came home and she wasn't here, she could have got killed. She was down the corner at another . . . the lady recognized her and took her in. She didn't know where she was (P6-D-MIX*).

Behaviors that put the caregivers at risk physically included aggressive violence during bathing and threatening behavior with knives or other dangerous implements:

> And within the year, then, of his getting it, probably six or eight months, he was no longer able to bathe. And this became increasingly difficult because he didn't like the water and this was the only time he ever became aggressive. He would try to hit me; that was the only time (S11-W-COG*).

> Well back in the apartment she got pretty angry a few times like taking the pills. I think once my sister was there for some reason, my sister I guess didn't realize what was happening and would correct her a lot. And one time my sister said that she shook a knife at her (S19-S-MIX).

Some of the care receiver's behavior put caregivers at risk emotionally because of the unsettling nature of the symptoms the care receivers were exhibiting. These included such distressing behaviors as looking for dead relatives, not recognizing or appreciating who family members were, and screaming and cursing at the caregiver.

> No memory whatsoever but dog gone it he can remember his brother and his mother. It has been a real trial because he can't remember that they are both dead and that he went to the funeral both times in his home town but he says his brother is right here. Just had dinner with him. Just talked to him. Just saw him (S17-D-COG*A-A).

Physical symptoms of disease that were difficult to resolve were also very troubling for caregivers. For example, uncontrollable nausea and vomiting, pain, or unremitting edema were identified by caregivers as being particularly disturbing when they remained partially or wholly unresolved.

> What we do when she gets up in the morning we give her coffee and water. No medicine, no toast, no nothing so her stomach can . . . what it does . . . but anyway has to get all that stuff out and the doctor says because of the cancer she is throwing up all that stuff, all that junk, I don't know what you call it. So sometimes she has to throw up stuff and sometimes she won't. It just depends how congested and all that stuff has accumulated overnight. She doesn't have any cigarettes. She has coffee and water. No toast, dry piece of toast, no cigarettes, no food until at least a half hour to 45 minutes (S17-D-COG*A-A).

Tractability of the care receiver's condition was a factor in limiting the effectiveness of some of the caregiver's efforts at using environmental modification strategies. The findings of this study provide some support to the literature that suggests severity of illness is associated with a higher toll on the well-being of dementia caregivers in particular (Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Lieberman & Fisher, 1995). Some care receiver problems were very difficult to treat, hence modifications that might have worked in one setting, would not always be effective in every setting.

In summary, the conditions and context categories associated with environmental modification strategies were described in detail to bring time and movement into the analysis. Coding for conditions showed how the environmental modification strategies moved and responded to changes in conditions that inevitably occurred with the passage of time. For example, causal conditions such as a decrease in the care receiver's competence often combined with certain salient features in the environment to create new environmental challenges for the caregiver. Intervening conditions that affect the perception and interpretation of the misfit of the environment for the care receiver, such as a shift in the trajectory of a chronic illness, might also prompt a caregiver to make changes in their strategies. Intervening conditions that affected the outcome of the modification strategies, such as a change in the tractability of the care receiver's condition, could also trigger changes in strategies. For example, for some of the caregivers of cognitively impaired care receivers, the care receivers actually got easier to manage as they progressively lost more functional ability. Several intervening conditions that affected the caregivers' ability to implement modification strategies were identified in the analysis for Aim #3. These intervening conditions included attributes of the care receiver, attributes of the modification, quality of the caregiver-care receiver relationship, caregivers' skills, personal resources of the caregiver, and the informal and formal supports available.

Identification of these conditions may make it possible to develop nursing interventions designed to optimize the care receivers' environment. The identification of salient features of context in the home situations suggests a need for better assessment of environmental demand in the home setting.

CHAPTER 5: DISCUSSION

Discussion of Results

Strengths

This study contributes to the literature in several ways. Its main contribution is a more detailed description of the environmental modification strategies caregivers use, along with an improved understanding of how caregivers evaluate the effectiveness of the strategies. Conditions amenable to nursing intervention that directly impact the caregiver's ability to implement these strategies were also identified. The findings of this study inform the medical and health care literature that has labeled the lack of taking action as noncompliance, so that lack of action is more correctly interpreted as reasoned decision-making shaped by the perceptions and values of the caregiving family.

Thick Description

The main strength of this study is its thick description. Previous research had been lacking in detail, reporting the caregivers' actions independent of their intentions and circumstances. In this study, a thick description of environmental modification strategies used by caregivers was achieved based on 41 interviews and/or observations. The goal of this description was to present more than a superficial commentary on the modifications caregivers made. Consequently, details of the affects, relationships, contexts, and backgrounds of the strategies used were presented along with the participants interpretations of their feelings and the meaning of the situation.

To achieve this end, several methodological strategies were employed. Theoretical sampling resulted in a diverse sample of various types of caregiving situations. Decisions were made on analytic grounds about what data to collect and where to find them. Consequently, caregivers were interviewed who cared for care receivers with a variety of impairments, not just cognitive impairment. When the data being collected indicated that spouses might differ from child caregivers in their approach to making modifications, sampling recruitment strategies were changed to accommodate obtaining data from sons and daughters. Because living arrangements seemed to influence the use of modification strategies, participants were sought that varied in their proximity to the care receivers' homes. Pilot data, used to refine the interview guide, were incorporated into the analysis after it became apparent that these data would add to the saturation of the emerging categories. Participants were also sought later in the analysis that had incorporated more medical technology into their home situation. As a result, the description provided makes transferability judgments possible on the part of potential appliers.

Data Adequacy

Another strength of this study was the adequacy of the data obtained. Considerable effort was put into development of the interview guide. The interview guide was refined using a number of pilot interviews and by obtaining expert consultation with noted experts in qualitative research. The goal of the interview refinement work was to develop a mechanism for collecting data that prompted participants to talk about their strategies, without over specifying the substance or perspective of this talk. Planned prompts were designed to give participants an opportunity to consider or discuss aspects of the strategies they employed that did not readily come to mind because they were part of tacit or background knowledge. A major focus of the iterative work in the development of the interview guide was to ensure that data collection methods provided an exhaustive description of each participant's use of strategies. In addition, observations were used simultaneously and sequentially to examine the same phenomena. Extended visits combining informal interviewing and observations facilitated persistent observation. The amount of data obtained in this analysis was substantial. Saturation of the modification strategies was obtained so that variation was both accounted for and explained. Negative case analysis was achieved by accounting for all known data, without exceptions. Findings were confirmed with a subset of two participants in the study and via peer debriefing with advisors and research seminar members. Analysis techniques permitted examination of data that yielded insights difficult to achieve across cases with other methods. The goal of these methodological measures was to ensure that the strategies used by caregivers were accurately described and identified. Evidence for the credibility of this analysis rests on the consistency of the descriptions of specific strategies which are detailed across the different accounts.

Limitations

There are clearly limitations to the study and to evaluation of the results. The study could have been improved if better methods had been used to categorize care receiver impairments as seen from the caregiver's perspective. Initially, impairments were categorized on the basis of medical diagnoses. This method proved to not be useful as the data provided early on by caregivers indicated that diagnosis was a poor predictor of functional limitations and need for environmental interventions. The method finally adopted to categorize impairments of care receivers was to use caregivers' reports of care receiver functional limitations as the basis of classification.

Although minorities were included in the sample in the proportion that they are represented in this geographic area, their perspectives, and different cultural approaches may not have been adequately sampled theoretically. Including ethnic minorities as individual participants in a small qualitative sample runs the risk of treating the data obtained as an aberration of the dominant culture, rather than being interpreted in its own cultural context. An adequate and appropriate minority sample may in fact require doubling or tripling the size of the study in order to achiever saturation of that group's perspective (Morse, 1995).

Because of the importance of having adequate financial resources to use some environmental modification strategies that emerged in the study, more demographic information regarding income and income adequacy should have been collected. According to Sandelowski (1986), the "elite bias" is a particular problem in qualitative research because subjects who act as informants in studies are frequently the most articulate, accessible, or high-status members of their group. Because the sample consisted of participants who were varied in their educational backgrounds, it may be safe to assume that the participants were from a variety of socioeconomic strata. However, an elite bias may have occurred if the strategies of poorer families were not adequately sampled.

Given that one of the aims of the study sought to discover how caregivers changed their modification strategies over time, a serious limitation of this study was not using a sampling strategy that would examine illness trajectory in conjunction with the building of the caregivers' repertoire of strategies as they gained experience. Instead, participants' were asked to recall the processes they used throughout their caregiving experiences. Retrospective reports that are related to present difficulties must be interpreted cautiously. The reports are subjects to errors of memory. Prior research suggests that individuals will alter accounts of the past to create a coherent picture of the present (Cohler, 1982). Although this may be viewed as a limitation especially in terms of collecting accurate details of what happened when, it may also be seen as a strength in that participants stories are "the most internally consistent interpretation of presently understood past" (Cohler, p. 207). Therefore narrative interview data shared by participants represents their present construction of events concerning the environmental modification strategies they have developed over their careers as caregivers.

Summary of Major Findings Relation to Other Literature

This study examined the environmental modification strategies used by caregivers of care receivers with a wide range of different types of impairments. Some of the findings of this study corroborate the results of earlier studies that have examined the strategies used by caregivers of the cognitively impaired. Because environmental strategies that work well in caring for elders with one type of disability may be ineffective or stress-producing with another (Birkel, 1987), this study also examined the strategies used by caregivers of care receivers with physical and mixed disabilities. Findings of this study will be compared and contrasted with the previous work done with cognitively impaired care receivers. The new information that emerged in this study regarding the use of strategies among caregivers of mixed and physically-impaired care receivers will then be highlighted.

Modification Strategies: Corroboration of Previous Findings

The findings of the present study regarding the use of the environment as a caregiving strategy, support the views presented by Harvath (1994) that changing the situation in which the cognitively impaired care receiver is behaving is an effective caregiver intervention for problematic behaviors. Tempering the environment to adjust environmental press for cognitively impaired care receivers was accomplished by caregivers in this study by using the strategies structuring the care receiver's day, simplifying choices, and eliminating noxious stimuli. Structuring the care receiver's day is similar to the environmental coping strategy Pynoos et al., (1989) termed providing appropriate environmental and sensory stimulation. This strategy strives to achieve a balance between too much or too little stimulation.

In addition to establishing routines to introduce predictability, the clinical and research literature has recommended that caregivers provide care receivers with activities to avoid boredom (Harvath, 1994; Olsen, Ehrenkrantz & Hutchings, 1993b; Zgola, 1990). Another approach to tempering press in the environment recommended by clinicians (Pynoos et al., 1989; Zgola) that was utilized by caregivers in this study was simplifying the environment. Removing potential irritants in the environment by identifying and eliminating noxious stimuli is supported by the professional and caregiver cognitive impairment management literature (Beck, Heacock, Rapp, & Shue, 1993; Olsen et al.; Zgola) as well. The findings of the present study confirm that these are strategies primarily used with cognitively impaired care receivers, although structuring activity was a strategy that was also employed with physically-impaired care receivers.

Prior research and recommendations in the literature on the subject of caregiving modifications has identified several strategies similar to the strategies identified in this study aimed at protecting a vulnerable cognitively impaired care receiver. The strategies identified in this study that were similar to prior research included: denying access to a part of the environment (Calkins & Namazi, 1991; Pynoos et al., 1989), eliminating hazards (Calkins & Namazi, 1991; Harvath, 1994; Olsen et al. 1993b; Pynoos et al., 1989; Zgola, 1990), and structuring supervisory and monitoring capability (Olsen et al., 1993b; Zgola, 1990). Findings in this study differed from prior research in that all of the above strategies were also employed for care receivers with mixed and physical impairments.

Other findings in this study regarding strategies that were used with care receivers with cognitive impairments included providing cues and using the familiar to improve environmental legibility. Providing cues has been identified by several researchers and clinician experts as an important aid to supplement cognitively impaired care receiver function (Beck et al., 1993; Calkins & Namazi, 1991; Harvath, 1994; Namazi et al., 1991; Olsen et al., 1993b). Using the familiar, likewise, has been employed as an orienting device by clinical experts in nursing homes (Beck et al., 1993; Pynoos et al., 1989; Zgola, 1990). Findings in this study differ from the opinion literature in that these strategies were often only intermittently effective from the caregiver's perspective, depending on what kind of day the care receiver was having. In addition, the use of environmental cues was found to be helpful for the visually impaired but cognitively intact care receivers in this study.

The findings regarding making long-term lifestyle changes were similar to research findings by Olsen et al. (1993b) that some caregivers solve their environment problems by moving to a new dwelling. The results of this study expand this knowledge by describing the processes that caregivers use to prepare for such a move and by identifying the substantial economic and support resources necessary to make these kinds of changes. In addition, findings from this study indicate that care receivers with severe physical functional limitations may benefit more from this type of strategy than cognitively impaired elders who do not tolerate a change of venue as well.

Categories of home modifications that emerged in this study were compared to the five categories described by Regnier and Pynoos (1987). Structural changes and obtaining special equipment were made by the caregivers in this study as well as by caregivers in Calkins and Namazi's (1991) study and the study by Olsen et al. (1993b). Numerous behavioral changes to accommodate some limitation in the environment were made by caregiver participants in this study and the study by Olsen et al. Many instances of assistive device use were also described by caregivers with all types of impairments in this study. However, the material adjustments category of modifications described by Regnier and Pynoos did not seem to coincide clearly with only one modification subcategory. Rather, material adjustments seemed to include several aspects of the general strategy of organizing the home for caregiving. Consequently, findings of the present study expand and modify previous research and hypothetical notions regarding the caregiving strategies that caregivers employ to modify the home setting.

Further verification of this study's findings was supported by research that investigated caregivers' care planning strategies. Several of the environmental modification strategies described by participants in this study, were similar to the caregiver planning strategies identified by 168 adult offspring caregivers who were asked to describe their lay caregiving decisions (England, 1996). England found that caregivers focused on creating day-to-day structure (e.g., by structuring the care receiver's day), protecting the care receiver (e.g., by using surveillance to monitor, providing direct supervision), manipulating the environment (e.g., by changing structure), and encouraging enriching experiences (e.g., with leisure activities).

Findings Not Previously Identified in Environmental Modifications Research

This study discovered several important themes not discussed or identified in previous environmental modification studies. Trial and error was the preferred problem-solving method that participants in this study used to devise, implement, and revise environmental modification strategies. Although trial and error has been identified as a process used by family caregivers by other researchers, its centrality in modifying the environment is something new that emerged in this study. The use of personal assistance in conjunction with and in lieu of making environmental modifications was further explained by the data from this study. Findings in this study also shed light on the phenomenon noted when caregivers do not follow professionals' recommendations. New information regarding caregiving concepts previously described, such as protection and enrichment was also obtained. Data analysis of caregivers' evaluation of the effectiveness of their strategies provided new insights regarding the criteria used in adopting or rejecting a strategy. Finally, new information was obtained regarding the context and conditions that constrain or facilitate caregiver action.

Use of Trial and Error

Trial and error has been identified as both a process and as a source of information in the literature. The term trial and error was identified by Archbold (1983) as a process used by daughter caregivers to derive solutions to the problems of administering care. Archbold interviewed 30 parent-caring women to identify and describe the strategies used by caregivers to manage problems of the care receiver. In this study, caregivers were categorized as either care providers or care managers. Care providers perform the services the care receivers need themselves, care managers obtain these services for the care receiver from others. Both care providers and care managers used the trial and error strategy to devise solutions to care management problems. The findings among these daughter caregivers are consistent with the findings of this study that demonstrate that trial and error is a central process used to make environmental modifications by a variety of family caregivers in a wide range of settings.

Trial and error has also been identified as an important strategy to adjust and refine caregiving strategies by Nkongho and Archbold (1996). Their study focused on caregiving in African American families. Seventeen caregivers were interviewed regarding their experiences with caregiving activities. Caregivers reported that caregiving was difficult at first, but became easier as the caregivers worked out a system. Trial and error was described as the iterative process used when caregivers were not satisfied with the outcomes of their strategies.

Trial and error has also been identified as an important source of information used by caregivers (Stewart et al., 1993). In a study of role acquisition in family caregivers of older people recently discharged from the hospital, participants reported that trial and error was a frequently used and helpful source of information to learn about meeting the physical and emotional needs of the care receiver, and to reduce the stress of caregiving. Although participants more frequently identified professionals as sources of information, the mean ratings of their helpfulness in dealing with the emotional needs of care receivers and reducing the stress of caregiving were rated far lower than the helpfulness attributed to use of trial and error.

Trial and error has also been identified as an important source of information used by individuals with chronic illness. Michael (1996), in a phenomenological study of integrating chronic illness into one's life, found that much of what participants learned about managing their disease came through trial and error. This suggests that trial and error as a source of information offers special benefits to caregivers struggling to adapt the home to caregiving and that professionals may want to understand this process better.

Findings of the present work expand and modify these notions about trial and error and add some empirical support to their documented usefulness for caregivers. Trial and error has been expanded in this study to include the act of using serendipitous discovery. In addition, the processes that refine this overall strategy were identified and include individualizing for the care receiver, economizing to save precious monetary resources, and innovating to develop new solutions when other options seem inadequate. Rather than being viewed as a tangential process for obtaining information and solving problems, trial and error among participants in this study was the central process used to make environmental modifications.

Parallel Strategies

Findings in this study regarding the parallel strategies of getting help and caregiver use of self, were similar to other reported research findings that assistance from others is often used in conjunction with making environmental modifications. Using data from the National Survey of Self-Care and Aging (NSSCA), use of three types of self-care strategies for coping with functional limitations were examined: use of equipment and/or devices, changes in behavior, and modifications in one's environment (Norburn et al., 1995). The survey's definition of use of equipment and/or devices, and changes in behavior were similar to environmental modification strategy categories identified in this study: supplementing with devices and environmental cues; and making a behavior change. Modification of one's environment, as defined by the survey, to incorporated elements of this study's definitions of organizing the home and making long-term lifestyle changes. Functional changes were grouped into three categories, termed basic ADLs (e.g., eating, dressing, bathing, maintenance of continence), mobility ADLs (e.g., getting to toilet, transferring, getting outside, walking), and instrumental ADLs (e.g., using phone, managing money, preparing meals, doing housework, shopping). The researchers found that receiving assistance from others (e.g., getting help), supplements rather than supplants the use of equipment, changes in behavior, and modifications of the environment strategies.

Further confirmation of the trade-offs caregivers make between providing personal assistance and using environmental modifications has been supported by analyses of the National Long Term Care Survey (Manton, Corder, & Stallard, 1993a, 1993b). Changes in the use of equipment and other housing modifications such as assistive devices, prosthetic devices, special supplies and clothing, and in the use of personal assistance from either the caregiver or a paid aide were examined. The researchers found that dependence on equipment, by itself or in combination with personal assistance increased. Moreover, at higher levels of impairment, neither personal assistance only, nor use of equipment only, appear sufficient to support individuals in the community. This is consistent with the findings in this study that in many cases, equipment is necessary to supplement active personal assistance.

The findings of this study also support the theoretical view presented by Schumacher (1996) that caregiving dyads shift between patterns of the caregiver doing activities for the care receiver and the care receiver attempting to do an activity independently with the aid of a device or by changing how an activity is done. Caregiver use of self was identified in this study as an option that caregivers frequently used either in place of, or along with, environmental modification strategies. Among the participants in Schumacher's study, caregivers shifted back and forth between doing activities for the care receiver, and letting the care receiver take a more autonomous role. Consequently, caregivers expand their role at times and supplement what the care receiver would do if he or she were able, while at other times the caregiving role contracts as the care receiver's abilities expand. Caregivers in the present study reported that they often shifted from doing something for the care receiver, to letting them do an activity for themselves depending upon the conditions at the time.

Strategies When No Action Is Taken

The strategies "leave as is" and "adjusting expectations" have previously been labeled as noncompliance. New insights from the data emerged as to why caregivers may take these approaches. First, perceptions of the caregiver and the care receiver regarding the degree of misfit with the environmental incongruence may not agree with the professionals' perception. Second, values and needs may conflict with a possible strategy that the professional wants the caregiver to adopt. Third, the caregiver may lack the resources or skills to implement a strategy, so they adjust their expectations instead.

Protecting Not Just For Cognitively Impaired

Protecting the care receiver, a concept that emerged in this study, was similar to three categories of caregiving described by Bowers (1987): preventive caregiving, supervisory caregiving, and protective caregiving. Preventive caregiving was defined by Bowers as caregiving activities carried out for the purpose of preventing illness, injury, complications, and physical and mental deterioration. Supervisory caregiving activities included checking up, making sure, setting up, and checking out. Protective caregiving was defined as activities designed to protect care receivers from threats to their self-image. The purpose of protecting the care receiver as it emerged in this study, was to ensure that injury from accidents and/or declines in health did not occur without making it appear as though the care receiver was being patronized by the caregiver. Most of the caregivers in this study devised elaborate mechanisms to monitor the care receiver in an unobtrusive manner. Just as in Bower's research, caregivers expended a great deal of time and energy engaged in these surreptitious surveillance activities, rather than create a more restrictive monitoring situation that would be demoralizing to the care receiver. In contrast to Bower's work however, these activities were not limited to caregivers of the cognitively impaired. Caregivers of physically impaired care receivers engaged in these activities as well.

Enriching The Home Environment

Unlike previous studies that examined caregiving environmental modification strategies by focusing on caregiving problems, this study examined a wider range of caregiving activities. As a result, a new category of environmental modification strategy that has not been previously described emerged. Findings from this study indicate that caregivers, beside using the environment to solve problems, also use the home environment as a source of creating pleasure and meaning. Enrichment processes in family caregiving have been defined as "the process of endowing caregiving with meaning or pleasure for both the caregiver and the care recipient" (Cartwright, Archbold, Stewart, & Limandri, 1994, p. 32). In this study, enriching the home environment was defined as using objects or sensory stimulation to imbue the care receiver's life with meaning, to provide a connection for the care receiver to the past, and to increase the care receiver's joy of the moment. Although Cartwright et al.'s description of enrichment focused primarily on caregiving activities as the source of the enrichment in the care receiver's life, this study found that enrichment could additionally be accomplished by the placement and/or introduction of objects and personally meaningful stimuli. The outcomes for the care receiver in this study, as in Cartwright et al.'s research, indicated that enrichment plays a powerful role in maintaining the identity of the person in the face of multiple losses and personal set backs. Similarly, enriching the home environment provides opportunities for creative expression by caregivers that assist them in finding rewards of meaning from the caregiving experience (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991).

How Caregivers Evaluate Effectiveness

Previous research on adaptive device use was consistent with the findings in this study that found that care receivers had a variety of reasons for rejecting some modifications. In a pilot study that examined use of equipment from the perspective of older adults (Gitlin et al., 1993), major reasons for nonuse of assistive devices from the care receivers' perspectives included perception of no need for the device, the equipment was too "cumbersome" to use, the device was not needed because the task it is suppose to facilitate is performed by others, and equipment or device does not work for the purpose it is intended. Adoption or rejection of a device appeared to be the norm among participants in both studies rather than infrequent use or partial adoption. Consequently, the presence of one negative factor from the care receiver's perspective, if it was important enough, could cause a modification to not be used, even if it had some positive benefits. The researchers concluded that failure to address the needs and values of the caregiver and care receiver could be responsible for the high rate of adaptive device rejection noted in other research.

Findings from this study indicate that caregivers' likelihood of environmental modification strategy adoption may be predicted by the characteristics of innovation adoption described in the literature. Five characteristics of innovations have been associated with a higher likelihood of adoption of an innovation: relative advantage, complexity, compatibility, trial ability, and observability (Crane, 1989). Relative advantage refers to how much better the innovation is perceived to be over existing practices. Often times, caregivers and care receivers made a decision that a possible modification was not necessary. Some of this may have been attributable to not seeing a relative advantage.

Complexity is how difficult the innovation is to learn. Findings from this study indicate care receivers had a number of difficulties learning how to use certain devices or methods that could be attributed to problems with sequencing, remembering, adopting new gross motor patterns, and learning in general. These difficulties were not limited to the care receivers who suffered from cognitive impairment. In this study, participants often reported rejecting a modification the care receiver could not learn how to use.

Compatibility is the perceived consistency with the adopters attitudes and values. It was evident from data in this study, that care receivers' and caregivers' values influenced both their perception of their environment and their willingness to make some changes. For example, care receivers raised during the depression era, according to some of the caregivers, had great difficulty throwing things away because of their values regarding frugality. As a consequence, efforts to simplify the environment by eliminating possessions were resisted.

Trial ability refers to how easy it is to try the innovation on a small scale. Several participants in this study reported that the ability to try out a change before it was made permanent was a critical factor that greatly increased a care receiver's willingness to use something new. Hence, reversibility of a modification was a big plus for its adoption. This may help to explain Regnier and Pynoos' (1987) observation that changing behavior was the primary home modification adopted by impaired older people faced with a challenge in their environment.

Observability is the extent to which the benefits of the innovation can be observed by adopters. Findings of this study indicate that the modifications must generally meet some criterion level of positive benefit for the care receiver if they were to be adopted. For example, a hearing aid that does not improve the care receiver's ability to follow conversation, will probably not be used. Examination of these characteristics from both the caregiver and the care receiver's perspective may help to predict which strategies are more likely to be adopted or rejected.

How Context Interacts With Causal Conditions

The most salient causal condition for creating a misfit with the environment in this study was the development of a context specific functional limitation. Findings of this study confirm previous research (Song & Lee, 1996) that indicates diagnosis is not a good predictor of the amount of nursing care an impaired care receiver will require. In Song and Lee's study, functional capacity which was defined as the behavioral outcome resulting from the interaction of personal competence with the environment, was far more useful in determining the assistance needs of a group of vision impaired care receivers. In addition, a path analysis of the data from the vision impaired subjects indicated that the perception of the environment had a powerful mediating effect between the environment and behavior. The researcher's discovery about the importance of perception is consistent with this studies findings that it is the perceived misfit with the environment that prompts caregivers to take action.

Diagnosis was also a poor indicator of need for environmental modifications because it did not reflect the dynamic nature of most chronic illness trajectories. Rudberg et al. (1996) examined the probability of functional level changes in a population of community-dwelling elders. The researchers found that among elders with medium levels of limitation, a great deal of transitioning to another level of functional status was highly probable. Elders with either high or low levels of functioning were more likely to not have changed at subsequent measurement points. The dynamic nature of functional limitation status changes suggest that use of diagnosis as an index for need for services may be an unreliable predictor of service consumption.

The dimensions of the causal conditions that emerged from this study can be viewed from the perspective of the disablement process as described by Verbrugge and Jette (1994). The disablement process "describes how chronic and acute conditions affect functioning in specific body systems, fundamental physical and mental actions, and activities of daily living, and describes the personal and environmental factors that speed or slow disablement" (Verbrugge & Jette, 1994, p. 1). This approach emphasizes the importance of viewing disability as a gap between personal capability and environmental demand. The pathway to disablement is through pathology, impairments, and functional limitations which may or may not culminate in disability. Pathology refers to biochemical and physiological abnormalities that are medically labeled as disease, injury, or congenital conditions. Impairment is defined as dysfunctions and significant structural abnormalities in specific body systems. Functional limitations are restrictions in performing fundamental physical and mental actions used in daily life. Disability is only experienced if one has difficulty doing activities in a domain of life due to a health or physical problem. Any activity domain may be affected, not just ADL or IADLs. Hence, disability refers to the expression of a functional limitation in a specific context.

The disability process can be viewed from a person-environment perspective. In this view, disability can be reduced or eliminated by reducing the demands of a task. When disability is viewed as a gap between capability and demand, environmental modification strategies are the equivalent of what Verbrugge and Jette's (1994) have termed intra- and extra-individual factors that affect demand. The findings of this study add empirical support to the tenets of this model of disability. Hence, the person-centered approach to functional limitations which ignores the effect of the environment on function appears limited in light of these findings. The need for equal attention to person and physical environment to understand performance problems is highlighted by this study's findings.

Have To Assess Home As Well As Functional Limitations

Some noted falls experts have tried to address the person-centered approach to assessing functional limitations. Tideiksaar (1989) maintains that an environmental assessment should take place with an observed functional assessment. Suggested functions the older person should perform during this assessment include ambulating throughout the home's different rooms and over its various floor coverings; sitting down and rising from chairs, toilets, and beds; getting in and out of the bathtub and/or shower; and reaching up or bending down to retrieve various items from kitchens and closets. The environmental assessment tool designed to be used with this functional assessment focuses on identifying extrinsic fall hazards such as inadequately lighted stairways.

Once the functional and environmental assessments are completed, Tideiksaar (1989) recommends modifying only the hazards that present the greatest risk to the older person in that particular home, rather than taking an undirected approach. There are three limitations to this approach. First, the professional must use separate assessment procedures to evaluate an interactive process: the older person's functioning within the home setting. Second, the emphasis in the environmental assessment is on identifying hazards, supports or aids to ambulation are not included. Third, the older person's perspective on the environment and their functioning is not included in the assessment.

Separate assessments of environment and functional status have failed to reliably predict persons who may benefit from falls intervention. A fall's prevention intervention program that included home inspection of safety hazards using a standard hazards protocol failed to have a significant effect on decreasing the probability of suffering a fracture from a fall or being hospitalized as a result of a fall (Hornbrook et al., 1994). The researchers concluded that the intervention was not of sufficient intensity or duration to have a marked effect. Findings of this study help to shed some light on the lack of impact of the environmental portion of the falls prevention intervention, which may have lacked specificity due to inadequate assessment of the interaction of the older person's functional disabilities with the home setting's physical features.

Conditions That Influence the Use of Environmental Modification Strategies

There were a number of conditions that influenced the use of environmental modification strategies. These conditions included those that affected the caregiver's perception of the misfit with the environment and those that affected their ability to do environmental modifications.

Perception of misfit. Findings from this study indicate that it is the perceived misfit of the environment that predisposes the caregiver to take action. The study complements a quantitative survey's findings that suggested that the client's denial for the need for modifications is the primary reason given for "noncompliance." A telephone survey of 124 frail geriatric patients (Devor, Wang, Renvall, Feigal, & Ramsdell, 1994) examined the self-report of compliance with social and safety recommendations in an outpatient comprehensive assessment program. The social and safety recommendations surveyed included changing the living situation, implementing home safety measures, utilizing outside support services, and attending adult day care. Reasons for noncompliance were categorized as: did not understand the recommendation, understood but disagreed, and agreed but did not implement. Half of all the geriatric assessment clinic recommendations were not implemented. Most noncompliance was due to disagreement with the recommendation, either because the clients denied the need for the recommendation (61%) or because the problem had been resolved (25%).

Conditions identified in this study that affect the perception of the care receiver's functional status misfit with the environment were also similar to variables identified in the program of research conducted by Schulz and Williamson (1993). According to their disability impact model of the impact of disability, care receiver and caregiver response is mediated by the speed of illness onset, the visibility of the care receiver's condition, and the elapsed time since diagnosis. The findings of the present study support the view that illness trajectory affects the caregiver and care receiver's perception and interpretation of the misfit with the environment. For example, if the care receiver's disability is viewed as short-term, the caregiver and care receiver may be more likely to not perceive a need to substantially change the environment.

Ability to do modifications. Findings from this study indicated that the caregivers ability to implement environmental modification strategies was influenced by several intervening conditions. Prior research has identified the caregiver's access to resources and social support as salient factors that affect the caregiver's well-being as well as their ability to make environmental modifications. In their discussion of psychosocial aspects of physical frailty, Schulz and Williamson (1993), identified conditioning variables that affect perceived stress among caregivers and care receivers from physical frailty. The findings of the present study regarding intervening conditions that affect the caregiver's ability to use environmental modification strategies support the view presented by Schulz and Williamson that economic resources, social support, and relationship quality alter the impact of care receiver disability.

In addition, findings from this study demonstrated that the attributes of the modification influence their likelihood of adoption have been corroborated in other research. Those who failed to implement social and safety in the study by Devor et al. (1994), reported a lack of resources as the most common reason. Attributes of the recommendations were also associated with the likelihood of adoption. Compliance was greatest with those recommendations that were easy to implement. The researchers also speculated that the cost of the modifications, the lack of resources to install the modification, and sentimental attachments to possessions deemed hazardous were all factors in the disagreement with the recommendation. The highest rate of noncompliance was with the recommendation to move to another living situation, which the researchers thought was due to clients lacking the resources to make such a change.

Findings in this study regarding the impact of conditions on a caregiver's ability to make home modifications were confirmed by an analysis of population data from the Survey of Housing Adjustments supplemented by data from the Annual Housing Survey (Reschovsky & Newman, 1990). The analysis examined the ability of older frail households to make adaptations for independent living via making room use alterations, adding special features to the dwelling such as ramps or grab bars, by making residential moves within the last 12 months, and by obtaining help with personal assistance or household operation activities like cleaning. The researchers found that those lacking financial resources and informal support are less likely to be able to make housing adaptations.

The results of this study point to the need for nurses to assess intervening factors that facilitate or constrain caregiver taking action to modify the environment. Prior research supports conclusions drawn from this study that access to resources and social supports are critical. The findings of the present work expand this list of factors to include assessment of certain salient caregiver's skills, caregiver and care receiver communication, and the interaction of the attributes of the modification with the care receiver's functional status.

Theoretical Implications

The findings of the present work expand and modify previous theoretical notions and add some empirical support to most of the assumptions within the refined person-environment fit perspective described by Kahana (1982). To illustrate how the findings fit with pre-existing theory, the taxonomies of the environment that have been described by Barris (1982) and Lawton (1982) will be reviewed and their frameworks will be compared to a caregiving environment definition used in previous quantitative research (Given et al., 1990). Person environment interaction will then be defined in relation to the findings of this study and what has previously been understood by theorists such as Lawton, Kahana (1982), and Weisman (1982). Finally, the concept of a threshold of environmental mismatch will be addressed via review of Hall's (1994) model of progressively lowered stress threshold and this study's findings regarding a threshold of functional decline.

Person-Environment Fit and Caregiving

Definition of Environmental Taxonomies

Two taxonomies of the environment have previously been described in the literature. The first taxonomy was proposed by Lawton (1982) and classified environments according to the physical, personal, suprapersonal, and social environment. The physical environment was defined as the nonpersonal, nonsocial aspects of the environment such as objects, or things with tangible dimensions. The personal environment was defined as the significant others constituting the major one-to-one social relationships of an individual. The family caregiver would be an example of someone Lawton would consider to be in the personal environment. The suprapersonal environment was defined as the characteristics of all the people in close physical proximity to an individual. This would include the demographic features of the individual's surrounding neighborhood. The social environment was defined as the norms, values, and institutions operating in the individual's subgroup, society, or culture.

The other taxonomy was described by Barris (1982) as an extension of the Human Occupation Model. In Barris' model, the environment is conceived of as four hierarchically organized, concentric layers: objects, tasks, social groups, and culture. These four domains of environment influence physical and social interactions and shape the quality of performance. Objects were defined as tangible, stable, and visible things used by individuals. Tasks were defined as a set of activities that share some common purpose recognized by the task performer. Social groups and organizations were defined as the individuals who form collective opportunities for interaction. Culture was defined as the way in which a group shares a collective way of living and carrying out activities.

Taxonomies and Previous Operational Definitions of Caregiving Environment

The hierarchical categories defined by Barris (1982) will be used as a common frame of reference to describe how the taxonomies fit with operationalized definitions of the caregiving environment and with the findings of this study. Given et al. (1990) defined the characteristics of caregiving environment in terms of the types of activities performed for the care receiver, the hours of care provided each day, the amount of involvement in ADLs and IADLs, and the amount of support received from family members and others. Using the taxonomy of object, task, social group, and culture, Given et al. defined the caregiving environment as an interaction between the task and social layer of Barris' hierarchy, or as the personal environment in Lawton's (1982) taxonomy.

Consequently, the object layer or the physical aspects of the environment were not included in Given et al.'s (1990) caregiving environment definition. The social environment or the culture with its attendant norms and values are also not included in the Given et al. caregiving environment definition. The data from this study suggest, however, that both of these aspects or categories of the environment, impact the use of environmental modification strategies. The context of the home setting interacts with the functional status of the care receiver to create care receiver- and home-specific disability. The norms and values of both the care receiver and the caregiver influence the perception of misfit with the environment that preceded any described deliberative action. Hence, all the layers described in the Barris model are important for understanding the conditions and context of the caregiving environment. Person-environment interaction will now be described using the findings of this study and the work of previous theorists.

Caregiving and Person-Environment Interaction

A secure and nurturing environment according to Lawton (1990), may be self or other created. Consistent with Lawton's ecological model of aging, data from participants in this study suggest that care receiver ADL and IADL performance in a given home setting is a function of the competence of the dyad working together and their perceived environmental press in the specific situation. The results of this study point to the need to assess dyadic competence in terms of managing the environment. Even among the caregivers of the cognitively impaired care receivers, data emerged in this study that indicated the caregiver's ability to anticipate or guess the care receiver's preferences made a difference in how effectively strategies were used. Caregivers among the cognitively-intact care receivers acknowledged the critical importance of communication and cooperation in order to successfully identify and implement modifications.

It is evident from the data in this study that the perception of press is more important in terms of explaining caregiver and care receiver behavior than the objective environment. This is consistent with Weisman's (1982) view that understanding the environment-as-experienced is necessary to understand the complex reciprocal relationships between the environment and the individual. In this view, the objective environment is only important as an antecedent to the perceived environment.

The findings of the study also illustrate that needs and preferences of the caregiver and the care receiver were important driving forces for behavior (Kahana, 1982). Needs and preferences in this study played an important part in the caregivers and care receivers perception of misfit with the environment. For example, for the care receiver who said "when I retired, I retired" (S3-W-PHY*CR), it is not a problem for him to spend the entire day sitting in a comfortable chair in the living room. Another care receiver with different preferences and needs would define that same situation differently.

Findings from this study also support Kahana's view that if leaving the environment is not possible, modifying needs and preferences is a very effective way to reduce stress and discomfort. Participants in this study did this by adjusting their expectations. This is a form of coping best described as existential. In other words, the person makes a conscious decision to transcend their current perceived inescapable circumstances by choosing to define the situation differently.

Figure 5 represents a revised press competence model that suggests that behavior is a function of the competence of the dyad working together to resolve environmental misfit and their agreed upon perceived environmental press of the situation. As in Lawton's model, behavior is characterized as falling in the range of adaptive and nonadaptive and affective response is evaluated as positive or negative. The range of adaptive behaviors increase as dyadic competence increase. Conversely, as dyadic competence declines, so does the range of adaptive behavior.

Hall's Progressive Stress Threshold

Findings from this study support the view presented by Hall (1994) that suggested a stress threshold exists beyond which cognitively impaired care receivers exhibit behaviors that are labeled by their caregivers as dysfunctional. In addition, the dimensions that emerged from the data regarding a critical threshold included implications for cognitively-intact care receivers. Functional declines that involved an overall decrease, or a decrement in some salient ability in a given environment were often a stimulus for caregiver action to modify the environment.

Clinical Implications

The use of the person-environment perspective has been used in other settings as an organizing framework to provide care. Topf (1994) has argued that a goal of nursing care is enhancement of person-environment compatibility. Person-environment compatibility is defined as a fit between the needs and goals of occupants and the supports

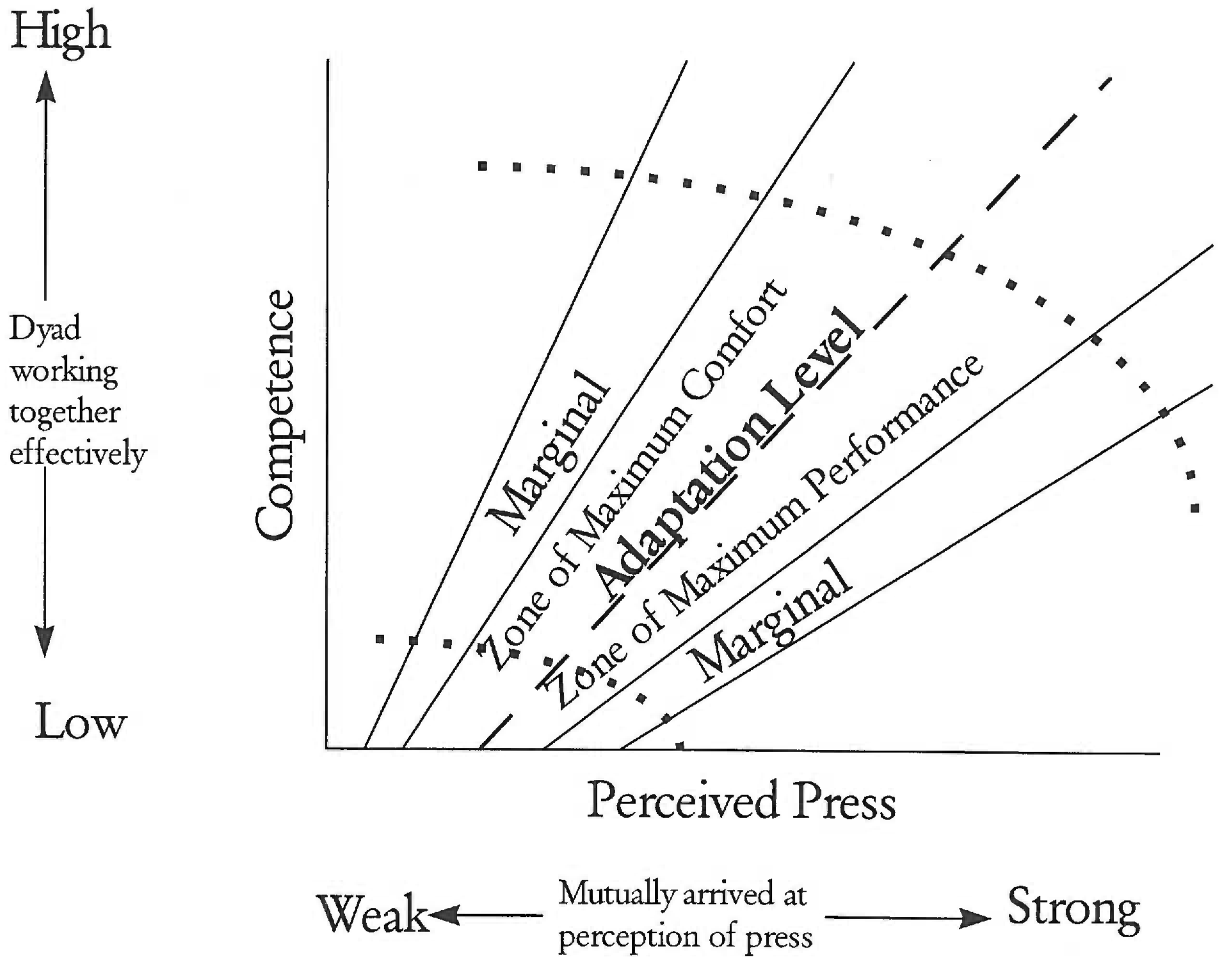

Figure 5.

Revised press competence model.

in the environment as well as an absence of barriers that prevent occupants from helping themselves. A compatible environment is restorative, permits occupants to exercise control, and accommodates individual differences such as restricted capacities and/or sensitivity to ambient stressors. Topf's definition of person-environment compatibility is based upon her experience working in a hospital setting, but the tenets can apply in other settings as well. In Dawson et al., (1993) recommendations on enhancing the abilities of persons with Alzheimer's in nursing homes, manipulation of the environment for prosthetic purposes is identified as an ability compensating nursing action for older people with dementia. Application of this study's findings to providing person-environment compatibility interventions in a home health setting will be provided.

Points For Nursing Interventions

Explore Attitudes And Values Regarding Misfit Prior To Goal Setting

Findings from this study provide support to the literature that advocates forming collaborative working relationships with caregivers. A collaborative relationship, according to Hasselkus (1988), depends on understanding the family's perspective of the caregiving situation. Developing respect for the knowledge that caregivers bring to the caregiving situation was advocated by Harvath et al. (1994) in an article describing methods for establishing effective partnerships with family caregivers. Local knowledge was defined as the unique information that the caregiver has that is essential to the care of the care receiver. Failure to assess the caregiver's local knowledge and to appreciate their perspective on the caregiving situation will preclude developing a collaborative relationship.

Prior research on developing therapeutic relationships with family caregivers found that professionals often assume a directive approach when they are instructing (Clark, Corcoran, & Gitlin, 1995). In this study, instruction by the occupational therapist tended to evoke a submissive type of involvement in which the caregiver followed orders or directions. According to the researchers, directing interactions indicated that the professionals were working on their own goals and following their plans, rather than working on client-centered goals. The findings of Clark et al.'s (1995) study agree with the clinical advice literature in nursing that a basic component of collaboration is acknowledging the caregiver as an expert or lay practitioner in caring for the care receiver.

Viewing the caregiver as a lay practitioner suggests a sharing of responsibility within the relationship. In a collaborative model, it is essential that the nurse and the caregiver and care receiver develop a shared understanding of what the environmental problems are and a common set of goals to address those issues. To accomplish this shared understanding, the nurse must be willing to adopt a more open-ended, less directive interview style.

Caregiver's Skills (Teach, Enhance)

Findings of this study that indicate that caregivers devote considerable mental and physical energy toward assessing the functioning of the care receiver were corroborated by Davis and Grant's (1994) research describing the home care management strategies of family caregivers of stroke survivors. Practicing vigilance was defined as family caregivers functioning as diagnostitians in their efforts to monitor and evaluate the stroke survivor's condition over time. Practicing vigilance also included caregiver's monitoring the stroke survivor's environment. The researchers concluded that given that family caregivers spend considerable time in assessing and evaluating the ill family member's symptoms as well as functioning, more attention should be placed on helping caregivers refine these skills. The findings of the present study lend support to this conclusion.

In a review of education and support programs for caregivers, Clark and Rakowski (1983) identified a need for programs focused on skills development. The results of this study point to the need to develop caregiver's skills as part of person-environment competence interventions. The skills that were helpful for caregivers in this study included care receiver functional status and environmental assessment skills, use of trial and error problem solving, and the care receiver impairment specific environmental management strategies. Previous research and clinical advice literature on caregiver skill development will be reviewed to illustrate how this might be accomplished.

Corcoran and Gitlin (1992) described an occupational therapy intervention designed for family caregivers of persons with dementia that focused on building caregiving skills to identify and implement environmental modification strategies. The intervention combined a collaborative approach with a competence-environmental press framework, that was designed to identify problems, plan and implement treatment. Each caregiving situation is recognized as unique, therefore the professional is cautioned to thoroughly assess the use of supports in the home, the caregiver's problem-solving skills, rewards of caregiving for that particular caregiver, and the caregiver's preparedness for dealing with the problems of the care receiver. Consequently, treatment is shaped by the unique needs, goals, preferences and resources of the caregiver.

An intervention that was planned for the families of visually impaired older adults used an innovative method for teaching family members about the functional changes that their care receivers were enduring. An exercise was created using goggles that simulated vision impairment conditions. Participants were asked to perform activities that help family members understand what it is like to cope with impaired sight. In addition, participants are shown a video that then acts as a stimulus to talk about the feelings generated by the vision loss among family members. A lecture on services for the visually impaired follows the other sessions. Participants have rated this program as highly effective in helping them to understand the functional limitations of the older person with impaired sight and as a mechanism to improve communication among family members and as well as obtain ideas of where to get additional services (Kleinschmidt, 1996).

Another caregiver education intervention targeted for caregivers of the cognitively impaired has been developed by Gerdner, Hall, and Buckwalter (1996). The intervention is based on the progressively lowered stress threshold (PLST) model. The goal of the intervention taught to caregivers is to modify environmental demands to promote adaptive behavior. The first module of instruction addresses understanding behavior in Alzheimer's. The second module addresses assessing environmental stimuli. Suggested interventions that participants in this study used successfully include removing misleading stimuli such as certain television programs, eliminating unnecessary noise such as a background radio, and avoiding crowds. Structuring the care receiver's day and supplementing the environment with cues were also included among the teaching program's recommendations.

The use of systematic observation as a means of identifying possible environmental stressors has been advocated by Nelson (1995) based on her success in using this strategy in a study of disruptive behavior in the nursing home setting. She documented 185 disruptive incidents and the environmental factors present during the onset and escalation of the behaviors to examine the elements that might be perceived as stressors by cognitively impaired persons. Nelson felt that this method could be used in other settings in which environmental restructuring is desired.

A documentation process for identifying problem behavior in cognitively impaired elders has been developed and described by Rader and Harvath (1991). The method was developed for use in a nursing home setting, but could be transferred or used in other environments to train family caregivers. A behavior monitoring chart is created that allows the caregiver to develop a data base that identifies the care receivers pattern of behavior as well as track the effect of interventions. Better problem identification could help caregivers fine tune their environmental modification interventions to improve their satisfaction with results.

Specific environmental modification strategies directed at helping family caregivers promote care receiver independence in dressing have been successfully used in the home setting (Beck et al., 1991). These findings suggest that efforts directed at building caregiver skills show much promise for improving home management strategies.

In summary, prior research and the results of this study indicated that the development of the caregiver's assessment skills was probably the most critical factor that either impeded or facilitated the caregiver's ability to effectively use the environment to support home caregiving goals. This would be an instance where the nurse would be sharing her cosmopolitan knowledge with the caregiver to build these skills. The home visit would provide an excellent opportunity to do this kind of teaching.

Caregivers Personal Resources (Supplement)

The caregivers personal resources include their physical and emotional energy level, the time and money they have available to devote to developing environmental solutions, and the means to find, buy and set up an environmental modification. The nurse can identify areas that may require supplementation by obtaining this information from the caregiver. For example, if the caregiver is too physically drained from providing care, obtaining a home health aide or housekeeper may help. This may free the caregiver's time so that they are now able to shop around for modifications that they would otherwise not be able to obtain. Consequently, supplementation of resources in one area, may have multiple beneficial effects.

Informal and Formal Supports (Enhance Connection With Resources)

Informal and formal supports were defined in this study as assistance provided to the caregiver either by family or friends, or by people whose job it is. Other researchers have explored ways to help caregivers expand their networks or develop innovative new resources for support such as the internet (Brennan, 1991). For the home health nurse, there are two very simple, inexpensive approaches that can be taken to help caregivers take better advantage of the support that they have that already exists. Teaching the caregiver how to delegate tasks to other family members has worked very well in the past for some families where others are available, but rarely provide tangible assistance. In this instance, the caregiver is taught how to comfortably tap into the help that others may be willing to give, but do not know how to offer. For example, the caregiver might ask a friend or relative to go to the store or the post office for them. This type of help decreases the caregiver's overall workload, without usually making others feel over taxed or put upon.

The nurse can also help the caregiver obtain community resources that they may be eligible for, but unaware of. This is especially true for resources such as the Cancer society, or Lion's club that are private and not government funded. In addition, the nurse may be able to access data base sources of information that contain environmental adaptation devices. Researching funding sources for selected modifications could also be an important part of the nurse's teaching.

Facilitate Improved Communication Around Disability Issues

Phillips et al. (1995) have suggested that focusing interventions on how caregivers interact with care receivers could yield improved outcomes in terms of quality of care. As noted by Fink (1995), family confidence in problem solving and the ability to work together are important factors in maintaining well-being. Family meetings in the home may be helpful when the nurse is trying to assist the family with strategies. The possibility of improving communication between even cognitively -impaired care receivers and caregivers has been demonstrated by a caregiving intervention developed and described by Quayhagen and Quayhagen (1996). The intervention focused on the use of cognitive stimulation to enhance communication and conversation skills. Activities included shared conversational exchange in family issues. Although success was not immediate, after the fourth month of the intervention, participants reported dramatic improvement in life quality. Participants in the study remarked: "It doesn't matter whether she really improves or not. It is what the program has already done for our family. We are now communicating with her where before we just let her go" (p. 132). The results of the present study pointed to the futility of caregivers trying to make changes in the care receiver's environment without adequate communication.

Work With Process Caregivers Use to Make Modifications

To understand the process that caregivers use when they make modifications, it is helpful to understand certain background features of the use of trial and error. Trial and error is based on a need to experiment with several different strategies. The best solution may not immediately present itself to the caregiver. Nursing staff need to resist the urge to present their ideas as the best and only solution. While using this process, caregivers need to be encouraged to use their intuition and exploit their serendipitous discoveries that only their local knowledge makes possible. Caregivers should be encouraged to use refinements that adapt the strategies they use to their unique situations.

Evaluate effectiveness from both caregiver and care receiver perspective. The response to a given modification is more than just does it work. It is important to look at the affective response to the modification as well. Were the caregivers and the care receivers minimum criterion met? Did the modification make life easier, or has it somehow complicated things. Viewing modifications from an innovation perspective will assist nurses in modifying suggestions they may make so that they are more likely to be adopted.

Future Research Recommendation

Results from this study indicate the need for further research in three areas. The first research priority should be to develop improved measures of functional limitations that incorporate a context specific focus. The second area of needed research is to examine the relationships of intervening conditions to environmental modification strategy outcomes. The third area for future research would be the development and testing of nursing interventions to optimize the care receiver's environment.

Measurement of Environment Specific Functional Limitations

Human factors task analysis may hold promise as a technique that could be used by researchers to more accurately measure functional status in a given home environment. Researchers have found using human factors analysis that many ADL and IADL tasks have common components (Czaja, Weber, & Nair, 1993). Human factors analysis breaks tasks into subtasks and then identifies each action (e.g., lift), posture (e.g., bend), grip (e.g., precision), product (e.g., food item) and location (e.g., kitchen shelves) used in the tasks. Demands of the environment were then examined to further specify the performance requirements of a task. For example, the height and depth of the shelves were tracked, and the force needed to open an oven.

With this approach, the care receiver's limitations are more accurately identified for the specific environmental context that he or she is trying to negotiate. For example, rather than noting that the care receiver is not independent in bathing, this approach to measurement would list the care receiver's inability to lower themselves down as the physical limitation. This limitation would only become a disability in a home where a bathtub is the only option for bathing. This approach to measurement of limitations has so far only been used with individuals with physical impairment. However, the approach could be used with cognitive impairment as well. In addition, certain salient aspects of the caregivers functioning as they physically assist the care receiver could be measured as well. The potential benefit of this approach would be develop a measure of functional status that incorporates task demand as part of the assessment.

Relationship of Intervening Conditions to Environmental Modification Strategy Outcomes

A study proposal has been developed that would use an existing data set from the Caregiver Relief Study to examine the relationships of identified intervening conditions on the probability of making environmental modifications. The study uses data collected with the Family Caregiving Inventory (Archbold & Stewart, 1986, 1994) to determine via statistical analysis, the family characteristics that are associated with making observable environmental modifications in the older person's home. Logistic regression will be used to answer the research question. Understanding which intervening conditions are most salient for predicting who may find it easier to make environmental modifications should improve the understanding developed from the present study about the factors that facilitate or impede modification use.

Developing and Testing Nursing Interventions to Optimize the Environment

Further pilot work may be needed to develop and test nursing interventions suggested by the results of this study. Specifically, the area that seemed to hold the most promise for future development, were interventions designed to build the caregiver's functional status and environmental assessment skills.

Conclusion

In summary, this study has extended the work of Olsen et al. (1993a) and Calkins and Namazi (1991) by developing a more detailed description of the environmental modifications that caregivers used. The description of the strategies used has been extended to include those used by the caregivers of care receivers with physical and mixed impairments. In addition, a better understanding of the decision process caregivers use when evaluating their strategies has also been developed. Conditions amenable to nursing interventions that constrain or facilitate a caregiver's ability to use these strategies have been identified. Implications for practice included developing collaborative partnerships with caregivers to facilitate caregiver skill building.

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APPENDIX A

INTERVIEW GUIDES

PILOT STUDY

RESEARCH STUDY

ENVIRONMENTAL MODIFICATIONS AND FAMILY CAREGIVERS:
A PILOT STUDY TO DEVELOP AN INTERVIEW GUIDE

PILOT INTERVIEW GUIDE
OREGON HEALTH SCIENCES UNIVERSITY

Title: Caregiving Environmental Modification Strategies

Definition: Environmental Modifications are structural changes, special equipment, assistive devices, material adjustments, and behavioral changes (Pynoos, Cohen, Davis & Bernhardt, 1987).

Obtain Informed Consent: Review study goals, confidentiality, how information will be used, treatment of data and tapes, etc. using consent forms.

Interview Guide

1. Can you tell me about __________:

    a. How old is he/she?
    b. Why does he/she need help?

2. In general how well set up is (care receiver) home for taking care of him/her?:

    a. How easy is it for _______to get around?
    b. How is the space set up?
    c. How well does the physical setup of the home serve ________ needs?
    d. What is the bathroom like?

I will be asking you about a series of caregiving activities. If you do a certain activity, feel free to tell me a little about it, then I will ask you some further questions. I may take a few notes.

1. Do you do _____________? (Caregiving activity)

2. If yes, and no elaboration provided, then ask:

Tell me how you assist your family member with his or her activity.

Or: Describe to me how you assist your family member with his or her activity so that if you weren't here and I had to do it I would know what to do.

    a. Have you tried any changes to make it easier to do that?
    b. Have you changed how you do things in order to do this?

Do you use anything to help you do this? any special equipment?

d. Any special devices?
e. Have you changed the surroundings in some way?

3. Why do you think the changes worked?

What were the benefits for (care receiver)?

4. Were there any disadvantages to the changes made?

5. Is ________still working? If not, why not?

6. Overall, how would you rate the effectiveness of the changes you made on a scale of one to ten?

Demographic Information:

1. Study Number______________

Caregiver:

2. Relationship to older chronically ill person____________

3. Years/Months involved as a caregiver______________

4. Age_____________

5. Gender___________

6. Ethnic/Racial group________________

7. Education____________

Care Receiver:

8. Age_______

9. Gender_____________

10. Diagnosis____________

11. Education____________

CONTACT SUMMARY FORM

Contact Type:
Interview____________ Contact Date ____________
Phone ____________ Today's Date ____________
Observation List
(with whom)

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1. What were the main issues or themes about environmental modification strategies that struck me in this contact?

2. What information did I get about:
   a. environmental modification strategies?
   b. their effectiveness?
   c. how they change over time?

3. What was salient, interesting, illuminating or important in this contact?

4. What new or remaining questions do I have if I make another contact?

STUDY INTERVIEW GUIDE
OREGON HEALTH SCIENCES UNIVERSITY

Title: Caregiving Environmental Modification Strategies

Definition: Environmental Modifications are structural changes, special equipment, assistive devices, material adjustments, and behavioral changes (Pynoos, Cohen, Davis and Bernhardt, 1985).

Obtain Informed Consent: Review study goals, confidentiality, how information will be used, treatment of data and tapes, etc. using consent forms.

Interview Guide:
I want to talk to you about changes you have made in your home because you've been caring for _________. Close your eyes and visualize your home before you started caregiving. Is there a change that has been especially important in relation to your care for __________? The kinds of changes I have in mind are those related to daily routines such as bathing or dressing and other functions, changes in getting around in the house and getting outside the house, changes you have made to accommodate taking on the medically related tasks and responsibilities that you have had to assume, and protecting the other person from harm, and/or changes in how you manage the house and spend time in it.

Can you remember any changes in daily routines such as
- eating,
- grooming changes such as teeth care, hair care, nail care?
- bathing and dressing, using a chair or stool, mats?
- getting adequate rest?
- using the bathroom or cleaning up if there's and accident?

2. Do you now do anything or use any helps for an activity that has now become difficult for _________ to do, for example
    - tasks such as cutting with a knife, buttoning shirts, or opening jars?
    - writing letters or checks, signing their name or reading things ___________ would have read for self?
    - ways to compensate for poor eyesight? for example magnifying devices, extra lights?
    - ways to make it easier for him or her to hear?
    - ways to make sure he or she gets the right amount of food and liquids?
    - ways to help with activities such as using the phone, writing, reading? such as a book holder, reachers or other long-handled tools?
3. What about changes in __________ getting around the house? getting outside the house?
    - do you assist your family member with walking around the house?
    - do you have to lift or transfer them?

- is slowness in moving a problem? for them? for you?
- do you have to help them on stairs?
- what about getting around outside?
- going to the doctor?
- going other places? for example out to eat, errands, post office, bank, dry cleaners/laundry, visits, church, clothes shopping?

4. What about any changes you have made to help manage the behavior caused by a loss of memory, ability to concentrate or be independent?
    - such as remembering where he or she is; hiding things; asking repetitive questions? or wandering?
    - have you made changes to help manage his or her depression, sadness or crying?
    - have you made changes to help manage episodes of swearing, or yelling?
    - what about hitting or agitation?
    - have you made changes to help manage hallucinations or paranoia?
    - do you have to handle episodes of undressing occurring in the wrong place or time? sexual behavior in the wrong time and place?
5. Do you have to help with ________ medical treatment needs such as
    - managing medications or treatments?
    - do you have to keep others informed about health problems?
    - managing medical conditions and/or problems such as skin conditions or breathing problems;
    - helping to control symptoms like nausea or pain? diarrhea or constipation? fatigue? swelling?
    - do you have to handle medical emergencies?
6. Have you changed your home to accommodate?
    - keeping one eye on him or her? checking on him or her constantly?
    - preventing falls?
    - do you have to prevent him or her from poisoning themselves? Burning themselves or spilling hot food?
    - or having driving misadventures?
7. Have you had to change how you manage the housework and meal preparation in relation to having to be with or watch____________?
8. What about how you spend time at home
    for example, have you made changes in your leisure activities?
    - spending time together?
    - enjoying life in general?
    - what changes in the house have allowed him or her to continue being involved in activities? to find meaning in life or meet spiritual needs?
    - have you changed the surroundings in some way?
9. What are the most important changes in the home caregivers could make to help the older person?
10. What are the most important changes in the home caregivers could make to help themselves?

11. What advice do you have for other caregivers? For nursing students? For visiting nurses?

Generic Probes to be used with each modification discussed:

> Have you made any changes in the home to make it easier to do that?
> Do you use anything to help you do this? any special equipment or devices?
> If you had an unlimited amount of money, what changes would you make?
> What were the benefits of the changes? what were the disadvantages?
> What was the goal you were trying to achieve?
> How do you feel about the changes you have made? How does the older person feel about these changes?

Demographic Information:

1. Study Number______________

Caregiver:

2. Relationship to older chronically ill person____________
3. Years/Months involved as a caregiver______________
4. Age_____________
5. Gender___________
6. Ethnic/Racial group________________
7. Education____________

Care Receiver:

8. Age_______
9. Gender_____________
10. Diagnosis____________
11. Education____________
12. Race/Ethnicity_____________
13. Care provided:

Running Head: ENVIRONMENTAL MODIFICATIONS PILOT STUDY

Environmental Modifications and Family Caregivers: A Pilot Study to Develop an Interview Guide

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Environmental Modifications and Family Caregivers:

A Pilot Study to Develop an Interview Guide

Of the 10.6 million older people who need assistance with activities of daily living and instrumental activities of daily living, 84% or 8.9 million live in the community (NAHC, 1992). Family caregivers provide 80% of the care needed by chronically ill older people in the home (Abel, 1990), often making it possible for them to remain in the community, a clear preference of older people (Aging in America, 1991). To handle the many key problems of daily living that arise from having a chronic illness, patients and their family caregivers must develop strategies for "carrying on" in the face of the disease (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suzek, Wiener, 1984). Modifying the home environment is a strategy caregivers are likely to use. Environmental modifications from the professional's perspective, have typically been defined as including such factors as structural changes, special equipment, behavioral changes and assistive device use (Regnier & Pynoos, 1985).

However, little is known about the environmental modifications family caregivers make. This is evident in a review of literature that reveals only two studies of caregivers' perceptions of the effectiveness of their home modifications (Calkins, & Namazi, 1991; Olsen, Ehrenkrantz, & Hutchings, 1993). Caregivers of cognitively impaired elders were asked to talk about the problems they had providing care. The researchers, who were from an architectural and environmental psychology background, found that caregivers developed a large number and wide variety of physical environmental modifications to address problems and to maintain the functional health of the cognitively impaired older person. The authors concluded that the home environment can be an important caregiving variable and source of support.

A limitation of the work of Olsen et al. (1993) and Calkins and Namazi (1991) was their focus on problematic situations, rather than the broader concerns of caregivers. As Smith, Smith, and Toseland (1991) noted, issues such as enriching the elder's life are just as much a concern for caregivers as are managing problem behaviors. The focus on problems truncates the possible range of reported environmental modifications caregivers make by excluding changes such as those made to enrich the caregiving situation, to protect the elders self esteem ,and/or to promote higher level physical and cognitive functioning. A more comprehensive approach would be to use a variety of different kinds of work, tasks and concerns facing family caregivers to guide the interview.

The pilot study reported here was designed to refine the interview guide of a larger study that expands upon the work of Olsen et al. (1993) and Calkins and Namazi (1991) in two important ways. First, the sample will be expanded to include older people with physical impairments and chronic illness requiring care regimens. Second, caregiving activities, rather than caregiving problems will be used to prompt the discussion of the environmental modification strategies caregivers have used. The initial interview strategy planned to use the discussion of caregiving activities from the Direct Care Scale (Archbold & Stewart, 1986, 1994) to stimulate caregivers to think and talk about the environmental modifications they have made. The Direct Care Scale (Archbold & Stewart, 1986, 1994) was designed to capture the full domain of the work of caregiving. The scale contains subscales like 'little extras' and 'protection' as well as 'behavior management' and 'personal care' and is thus very comprehensive. The purpose of the larger study is to describe the environmental modification strategies that family caregivers use in caring for a chronically ill older person, explore the effectiveness of these modifications, and to describe how and why caregivers changed their environmental modification strategies over time. The focus of this pilot research was to obtain preliminary data on the effectiveness of the interview data collection strategy and to revise the procedure as needed.

Method

Data for the pilot study were gathered by intensive interviewing (Lofland & Lofland, 1995) with family caregivers of cognitively or physically impaired older persons. The goal of intensive interviewing is to obtain rich, detailed information from the respondent that can be used in qualitative analysis. The purpose of this data collection strategy is to discover the respondent's experience of a particular topic. In contrast to the "structured interview" (such as opinion polling) which tries to determine the frequency of preconceived topics, the intensive interview "seeks to find out what kinds of things exist in the first place" (Lofland & Lofland, 1995).

Originally, orderly emergence of the sampling events (in this case the sampling events were the environmental modification strategies rather than individual cases) was to be accomplished through the serial selection of caregiving activities as the focus for the interviews. Each successive participant was to be asked, in order, about a different portion of the caregiving activities from the Direct Care Scale (Archbold & Stewart, 1986; 1994). This strategy was piloted with the first two participants in the pilot study, and modified for the third and fourth participant interviews. The problems encountered using this strategy will be described in the interview procedures section of this report. Based upon the analysis of data in these four pilot interviews, an alternative interview strategy will be proposed for the larger study. A new interview guide based on this strategy will also be presented.

Sample

The pilot study participants were recruited from among professional colleagues of the investigator's research mentor and members of the church to which the investigator had been a long-time member. Initial contact was made with the professional colleagues via direct phone call by the investigator. Two respondents were contacted and both agreed to participate. This procedure produced two respondents, all of whom were used in the pilot study. The church member, a long-time acquaintance and friend of the investigator, was contacted by phone to ask for help with this pilot project. This person qualified for the pilot study and agreed to participate. One more participant came as a result of contact with a local senior health service. All respondents were interviewed at a time and place that was convenient for them. Two of the interviews took place in the home of the care receiver.

Research Participants

Of the four volunteers, all four met participation criteria. They were all self-identified primary family caregivers of older people who, by virtue of their caregiving activities, were likely to have used environmental modification strategies. The respondents included two adult daughters and two elderly spouse caregivers, one husband and one wife. The age range of the adult daughter caregivers was mid-to-late forties, the age range of the spouse caregivers was mid-seventies to mid-eighties. The caregiver's level of education ranged from PhD (the two adult daughter caregivers), to some college (the wife caregiver), to high school education (husband caregiver). All the participants were white. One couple lived on an extremely low income in a small mobile home. The other couple enjoyed a far higher income and lived in a newly built high-income seniors' housing development in a single family one story, two bedroom home. One of the daughter caregivers had brought her mother to live with her in a large two story suburban home. The other daughter caregiver did not live with her father who was instead residing in an expensive individual apartment in a senior supported independent living facility. All of the caregiver participants were married.

The care recipients were all 65 years old or older and white. Two participants had physical impairments. The husband care receiver had Parkinson's disease which limited his speech, movement and ability to perform fine tasks. The wife care receiver was newly diagnosed with Alzheimer's disease and suffered from mild to moderate cognitive impairment. The widowed father of the one of the daughter caregivers had a dementia caused by an adult onset hydrocephalus. The widowed mother of the other daughter caregiver was diagnosed with a slow growing malignant brain tumor that severely limited her balance and safety in walking. The two male care receivers had some college education and the female care receivers were high school graduates.

Interview Procedures

The two interviews with the caregiving daughters were completed in locations outside of where the care receivers lived. The spouse interviews took place in the care receiver's home. The data-gathering segment of the interview began with explanations of the nature and purpose of the pilot project, a description of the interview procedure, and an assurance that the confidentiality of all volunteered information would be maintained. The participants were assured that they could end the interview at any time. With the participants consent, all interviews were recorded on audiotapes. The investigator assumed a peripheral member role and did not assume a role in the family (Adler & Adler, 1987).

For the first interview, the interview guide was followed closely using some of the selected caregiving activities in the Direct Care Scale (Archbold & Stewart, 1986, 1994) for that portion of the interview. Despite the very high educational level of the first respondent, the structure of the interview questions was very confusing. It was also distracting for the participant to answer relatively short response questions about one caregiving activity when clearly her inclination was to talk at length about a number of related activities and/or modifications as a category. However, it was clear even in this early part of the interview that the caregiving activities were an excellent stimulus for eliciting discussion of the tacit knowledge caregivers possess about environmental modifications. During the first interview, after attempts to follow the guide as written seemed to be impeding the flow of the interview, an unstructured approach was adopted. As successive caregiving activities were brought up by the respondent, questions that explored the new content were raised. The second interview proceeded in the same pattern.

Prior to the third and fourth interviews, an expert in qualitative research (M. Imle, personal communication, April 6, 1994) reviewed the interview guide and identified another critical concern. The guide would not ensure that every caregiver would be interviewed about every environmental modification they might have made, because the caregivers were not necessarily asked to identify all of the caregiving activities they performed. In the second iteration of the interview guide, a question was added to try to address this critical deficit: "What does he/she need help with? Do you help with this?" In the subsequent two interviews in which this guide was used, this question stimulated lengthy in-depth discussion of multiple caregiving activities and associated modifications. However, these interviews were also unstructured in format because the caregivers did not in their discourse explore single activities and their associated modifications one at a time. All four of the interviews required two to two and a half hours to complete. The course and content of all four interviews was very different.

Data Analysis

Only the portion of the data analysis for the pilot that relates to the further development of the interview guide is reported here. The tapes were transcribed verbatim and entered into Ethnograph 4.0 (Seidel, 1994). The data were analyzed and processed in a manner recommended by Miles and Huberman (1994). Data reduction, data display, and conclusion drawing/verification occur concurrently in data analysis according to Miles and Huberman (1994). Final analysis identifies any patterns or themes that emerge from the data reduction process. The data reduction process was facilitated in this pilot study analysis by the creation of a number of displays. The goal of this process for this pilot analysis was to identify salient issues that could help the investigator refine the here-to-fore unstructured interview format into a semi-structured guide that was more consistently comprehensive. Inferences, conclusions and a proposed set of understandings about how the caregiving activities were associated with patterns of care were proposed from analysis of the data displays and from a sorting of the 80 items of the Direct Care Scale (Archbold & Stewart, 1986, 1994) written on 3 x 5 cards into thematic areas.

Coding for the pilot study interview guide analysis was based on the caregiving activities and reported environmental modifications. A provisional start list of codes was developed from the caregiving activities in the Direct Care Scale (Archbold & Stewart, 1986, 1994). Eighty codes were created for the caregiving activities. For example, a question such as do you have to handle his or her hallucinations was coded A44HALLUCI (A=activity, 44=#item on the DCS, and HALLUCI=label for caregiving activity). If the caregiver spontaneously mentioned that they assisted their care receiver with an activity, the item that most closely approximated that activity from the DCS was used to code that segment of data. In addition, each caregiving code when applied to the text in the Ethnograph, was asterisked if the caregiver mentioned the activity spontaneously in their discourse, or marked with a cross if it had been raised by the investigator via a question. If a caregiving activity was associated with a reported environmental modification, it was marked with an additional asterisk or cross.

A set of tables was created in Microsoft Excel 5.0 to create the graphical displays. These data displays were created to answer a series of questions. First, how many caregiving activities are mentioned spontaneously by the respondent without formally being questioned. The investigator hypothesized that if caregivers were speaking spontaneously about their caregiving activities, than it was more natural for caregivers to talk about the activities in groups rather than as separate elements. Because this data was difficult to interpret when all cases were represented in the display, this same data was plotted for each individual caregiver. Both graphical representations recorded all discussion of caregiving activities and included activities that were not associated with modifications.

During the interviews, most of the activities were mentioned by the caregiver as part of their spontaneous discourse on a given topic or thematic area. A question about one activity would lead to a discussion of several other activities. Interrupting the caregiver to focus on only one activity at a time seemed counterproductive. The pilot interview data indicate that addressing the caregiving activities in groups using the elements from the DCS as probes would be a more useful interview strategy than focusing on unrelated items one at a time.

The second question addressed using graphical displays was which caregiving activities were associated with modification strategies and how many times were these activities discussed during the course of the interview per each caregiver. A graphical display was created of the number of times particular caregiving activities associated with environmental modifications were discussed by case. To some extent, each caregiving situation was unique. Caregivers placed greater emphasis upon different caregiving activities and their associated modifications in their discussions. For example, dressing adaptations were discussed at length by caregiver one. Caregiver two focused a lot of her discussion on preventing falls. To some extent, there was commonality across caregiving situations. Approximately half of the caregiving activities discussed by caregivers were associated with multiple environmental modifications by different caregivers. For example, caregivers one, three, and four had made changes in their homes to facilitate bathing.

Data from the cognitively impaired cases and the physically impaired cases were combined to contrast and examine these two different family caregiving situations. The graphical displays indicated that even though the functional limitations of physically and cognitively impaired older persons were quite different, many of the same caregiving activities prompt caregivers to make environmental modifications. The data display argued for giving all participants the opportunity to discuss the full range of caregiving activities they engaged in to elicit a thick description of the environmental modifications they have made. To determine if some caregiving activities were not likely to require environmental modifications by either group of caregivers, the data was plotted across all 80 caregiving activities from the Direct Care Scale (Archbold & Stewart, 1986, 1994). The data indicated that some caregiving activities are more likely to be associated with environmental modifications than others. In particular, caregiving activities associated with Instrumental Activities of Daily Living (IADLs) seem less likely to prompt environmental modifications.

A third question addressed was how might the caregiving activities more likely to be associated with environmental modifications be regrouped into categories that would act as a meaningful stimulus for the eliciting of tacit knowledge. To answer the third question, a card sorting process was used. The items of the Direct Care Scale (Archbold & Stewart, 1986, 1994) were written on 3 x 5 cards and those items that were associated with environmental modifications were highlighted in yellow. The 80 items were then sorted into the scales original subscales which address eight categories of caregiving activities: personal care; behavior management; medically related management; protection; health, legal and financial decision-making; little extras; transportation; and housekeeping. The cards were then sorted again into piles and categorized into thematic areas using two criteria: 1) a logical possible association with a potential need to use an environmental modification based on the investigator's 12 years of experience as a home health nurse, and 2) a demonstrated association of a caregiving activity with an environmental modification based upon the pilot interviews. Based on the qualitative assessment of the data, the investigator made inferences about which caregiving activities could be clustered into thematic caregiving topics that could be used to elicit the most fruitful reporting of environmental modifications.

Limitations

Due to the small number of respondents and inability to use systematic sampling of the caregiving activities in these unstructured interviews, generalizability of these findings may be a basic limitation of these findings. However, to counteract this limitation, the investigator did conduct lengthy interviews that constitute some small measure of prolonged engagement in the field (Lincoln & Guba, 1985). In addition, an expert in qualitative data collection (Morgan, personal communication, February 1, 1995) reviewed the procedure used and described in the data analysis section to identify weaknesses in the analysis and to suggest strategies to stimulate inductive thinking e.g., the use of the 3 x 5 cards. Another limitation of the pilot analysis was that the sample was one of convenience. Although an attempt was made to interview caregivers of both physically and cognitively impaired older people, a true theoretical sampling procedure was not used. In addition, member checking with participants was not used to provide caregivers the opportunity to comment on the hypothesized thematic areas of caregiving associated with environmental modifications (Lincoln & Guba, 1984).

Findings

The narrative that follows describes the thematic areas of caregiving activities likely to be associated with environmental modifications developed from the data analysis.

Changes in Personal Care Routines.

Respondents described many changes in personal care routines that were prompted by functional decline in the older person. Personal care routines that were likely to change included bathing and dressing, toileting, getting adequate rest, and eating. For the cognitively impaired persons, this could be due to the inability to perform routines independently that they were physically able to do, but lacked sufficient where-with-all to do without prompting or cues. For the physically impaired older persons, performance of an activity was not possible due to some limitation in range of motion or lack of mobility. Environmental modifications were used to compensate for these deficits by supporting the lost function as these examples with bathing demonstrate:

> There was a time I was concerned about him taking showers, and I put a stool in there for a while, but he . . . after he had that one fall, I think he was nervous to take showers for a bit. but now he's gotten so he manages, and stands up for his shower. There is a little bench on each side of the shower.

> . . . although again he used to shower by himself, and then when he had this kind of decline, he just stopped doing it, and then you'd notice after a few days that he wasn't showering. and I asked the staff to help shower him, and then when Dorothy came after he had been in this decline for a week or so, she just started showering him everyday. And she still does, and that's another thing that I'm asking her not to do . . . <u>just kind of giving what he needs for his shower and telling him it's time for his shower.</u>

Trying to promote or maintain independent dressing resulted in the use of multiple environmental modifications:

> There were probably 50 shirts, and then I realized immediately that was a big mistake. That he was looking at all those shirts like 'how am I ever, ever going to choose one.' So I just put most of them away and left him five or six shirts that he wears all the time.

> . . . he can sit right there on the bed and open . . . there's doors on the top of his chest of drawers that open out, and then drawers pull out. And he can reach all his . . . his pajamas, his underwear. And then there's a bedside table that has the deep drawer that he has all his socks in.

To assist with toileting, caregivers used many common structural modifications:

> We installed a security bar, little railing things, so that she could have something to push up with her arms, particularly in the beginning with one arm, to get herself up and down . . .

Getting adequate rest often necessitated changes in sleeping arrangements:

> And that's something that changed, too. We always shared the bed together, you know, bedroom together. But when he . . . he did so much wiggling, and I didn't know what was wrong with him. But I couldn't get a good night sleep, and he didn't have a good one with me, 'cause I bothered him, you know. And so I started sleeping in the other bed, and when we were still at the condo, I was doing that. And he sleeps much better now . . .

Eating was promoted by this change of furniture:

> . . . he kept bumping his feet into this table, and it confused him. He couldn't figure out what he was bumping into and why it was there. So we bought a table that he could get his legs under to eat but then put it away when it wasn't needed.

Because the older persons limitations tended to cause problems across a number of personal care routines, it seemed logical to group these into one thematic area of caregiving, using some of the caregiving activities of the Direct Care Scale (Archbold & Stewart, 1986, 1994) as probes to elicit more description.

Supplementing Function.

The category supplementing function is similar to changes in personal care routines in that in both cases, the caregiver promotes use of an environmental modification to supplement a waning capability of the care receiver. It differs from changes in personal care routines in that it tends to be associated more with instrumental activities of daily living that are adversely impacted by sensory or fine motor deficits. For example, this category would include compensating for poor eyesight, hearing, communicating, or poor motor control or self feeding skills.

> But that's one thing that changed is that was about the time that a microwave came into our house. And it really helped, because she . . . we could have something that you could fix and that you could have some leftovers or something. And if it was something that you knew she enjoyed, why you could make sure that you kept up her nutrition . . .

> And anyway, he . . . it was a gradual thing, but he has gone downhill as far as being able to do his movements, you know . . . he can't sign his name very good. He has a stamp. We have to . . . we go to the office usually once a week, and he signs checks, you know, for the . . . for different things. And he has to use his rubber stamp. We haven't had any complaints yet. It's his signature on a rubber stamp.

Mobility Problems Encountered.

Although relatively few items from the Direct Care Scale (Archbold & Stewart, 1986, 1994) address mobility problems, this was a common and difficult deficit for the caregivers to deal with for both the cognitively and physically impaired older persons. Concerns about potential falls were a source of worry for many of the caregivers.

> Whenever he does much walking, he takes his cane. And then when we try to go out and walk on the sidewalks . . . we haven't done that for a bit . . . but I should get him out there to do that, 'cause they . . . that seems to be the thing the doctor always says: 'keep him moving'

> We've moved furniture around. Actually the place where he is living right now was designed to make it maximally, environmentally appropriate for people with movement disabilities and so forth. For example, it's considered a two-room apartment with a living room and a bedroom, but there's not really a wall between those two rooms. There's a partial wall and then a wide area where you could move a wheelchair and so forth.

Therefore, asking about changes in getting around the house seems especially important and may elicit many descriptions of various environmental modifications.

Behavior Management.

Behavior management was usually a concern of caregivers of the cognitively impaired. A wide range of behavior problems such as forgetfulness, agitation, wandering, aggressive behavior, and confusion can be addressed by environmental modifications. Some of the strategies one caregiver employed included:

> . . . just a little thing, but at first we would always have the light off in the bathroom unless he was using it, and he could never find the bathroom. He would forget. So then we just left the light on in the bathroom all the time, and somehow looking into the bathroom made it . . . you know, very shortly after that he always knew where the bathroom was . . .

> One of the things I should mention is that and this is related to his illness, too he gets very upset and agitated and sometimes verbally aggressive when he gets upset about a little thing, like bumping into the legs of the table can kind of set him off. So it's very important to kind of minimize or eliminate obnoxious stimuli, if you want to call it that, or just things that are a bother that you can't quite figure out. So bumping into something every time he went to the bathroom would not just be bumping into it, but it could set off this whole kind of chain of events . . .

Because of the sensitivity of cognitively impaired people to environmental stimuli, asking caregivers how they manage the behavior changes associated with dementia is likely to stimulate a lot of discussion about environmental modifications.

Medically Related Tasks

None of the caregivers interviewed were dealing with managing complex medical regimens for their care receivers, so few of these kinds of tasks were talked about in the interviews. However, this is likely to be an important area of questioning for the sample in the larger study. Tentatively, medically related tasks from the Direct Care Scale (Archbold & Stewart, 1986, 1994) were divided into the broad categories of managing medications and treatments and helping to control symptoms. The former seems more likely to be associated with environmental modifications if for no other reason that often complex equipment will have to be integrated into the household and accommodations may have to be made as a result of this. Among this group of caregivers, giving medications was a common task that often was facilitated by dispensing aids such as medisets:

> . . . we have a long thingy for his pills, you know . . . that has seven little spots for his pills, and I leave that set right on the counter, 'cause he has to take these before meals . . .

Preventing Accidents

Preventing accidents, particularly falls, was a big concern of the caregivers interviewed regardless of the type of impairment of the care receiver. This category included items like protecting the care receiver from poisoning, driving misadventures and monitoring for safety in general. This category differs from the mobility category in that it includes broad safety concerns in addition to the prevention of falls, and the focus is far more on prevention and constant vigilance than the assisting with mobility problems would imply. An example of an environmental modification (moving location of older person's bedroom) in response to the need to assume supervisory tasks follows:

> So, indeed, mom was upstairs, and I could hear her. In the early days of caregiving or the early days of having her in the house, I heard her up just like you hear you

> newborn, breathing change, or the noises that little newborn makes or that kind of thing . . .

Changes in the Management of Household Functioning

Environmental changes made to keep the household functioning could include time saving devices like microwave ovens or hiring outside help with chores to make life easier for the caregiver.

> . . . But I know I benefitted probably the most because I would have had to do the activities was . . . she hired a cleaning lady. Or she said, I will pay for a cleaning lady. And so every other week this lady came, and she cleaned the house. And that was a real benefit.

Although not discussed by this group of caregivers, strategies such as removal of clutter, or changing floor surfaces say from a carpet to linoleum, could facilitate positive changes in the household management by decreasing the workload of the caregiver. Surprisingly, the caregivers who received paid outside help with household work said this was a tremendous benefit, even greater than that received from help from personal assistance aids such as a bath aid. It may be that people prefer to deliver personal care themselves, and therefore the housekeeping assistance does more to relieve their role strain than the direct care services. To investigate this phenomenon in further interviews, management of household work was treated as a separate interviewing category.

Spending Time in the House

This category incorporates those caregiving activities that add pleasure or meaning to the caregiving situation such as taking part in leisure activities, keeping the older person involved in activities, spending time together, or having discussions about what is important in life.

> . . . a seasonal thing. But it was a very important part of the environment around Christmas time, and it still is because we still do it. We have a lady who comes and paints at Christmas time our great big front window. So she would start out and she would outline it and when she first started doing it for us, it would be with soap . . . . Then she fills it in with all the different colors. And then when she's done, she takes her black paint and goes back over the outline. So what happened is , my mother always thought that picture was drawn for her. And she loved it.

This category of caregiving activities seems likely to elicit a lot of information about how environmental modifications may be used to enrich the caregiving situation.

The Revised Interview Guide

In conclusion, the respondents helped the investigator examine the utility of the use of caregiving activities as a stimulus for caregivers to talk about the environmental modifications they had made. Carving activities have been clustered into eight new thematic areas which have been translated into interview questions with appropriate probes. The eight thematic areas included: changes in personal care routines, supplementing function, mobility problems encountered, behavior management, medically related tasks, changes in the management of household functioning, and spending time in the house.

Discussion

Data from this study supports the theoretical importance of the consideration of environment as an important variable in family caregiving. Person-environment interaction theories have already been used successfully in long-term care settings to obtain desired outcomes. Radar (1991) used a case study to illustrate the use of Lawton's (1986) environmental docility hypothesis and Hall's (1994) model of progressively lowered stress threshold to decrease the use of restraints in a nursing home setting. In this clinical paper, the author makes the point that residents lack the capacity to adapt to the nursing home environment and staff must therefore take the initiative to modify the environment to meet the resident's needs. In the article, staff are advised to think creatively to solve problems using the above mentioned theories rather than use restraints. Radar points out that demented residents become anxious when their environment provides too many stresses and there is no opportunity to relax or avoid stimuli. Caregivers in this pilot study also noted this same phenomenon and adjusted their interventions accordingly.

Given, Collins and Given (1988) present a conceptual framework for understanding the factors influencing stress among families caring for a demented care receiver. The framework identifies the caregiving environment as a factor that influences the quality and the course of the caregiving environment. The authors define the caregiving environment in terms of the social and economic resources available to the caregiving dyad. Three factors are especially salient, the social supports for the caregiver, the community services used and the financial conditions imposed by caregiving. Research prior to the publication date on these three topics was presented to substantiate the author's claim that the caregiving environment as defined in the model, has a direct effect upon the caregiver's reactions to caregiving. Comments made during the pilot interviews support the author's conclusions that the caregiving environment has this direct effect upon reactions to caregiving. However, the findings suggest that the model could be strengthened by utilizing a more comprehensive definition of the environment that would include the physical domain defined by Lawton (1986) as the nonpersonal, nonsocial aspects of the environment. Incorporating the home environment into the definition of the caregiving environment provides the clinician using this model with another option for intervention to reduce stress in a given caregiving situation.

The specific strategies used by caregivers to manage the behavior problems of their cognitively impaired family members was the focus of the Harvath (1994) study. A qualitative design was used to gather interview data from caregivers who were managing behavior problems with low stress as well as from caregivers who were struggling. An important finding of this study was that management of the environment was one of the specific caregiver strategies identified. In the preliminary pilot data, the caregivers of the cognitively impaired have described a number of environmental modifications they have made to change behaviors in a nonconfrontive way. One very interesting strategy employed by a number of caregivers in this pilot study was the elimination of noxious stimuli such as street lamp glare at night. This is very consistent with Harvath's (1994) description of caregivers directing efforts at changing the surrounding circumstances in which the care receiver is behaving.

Birkel (1987) examined the relationship between the strain in providing home care for demented and physically impaired elders and three social ecological variables; household size and composition, the amount of time and type of tasks involved in caregiving, and the pattern of events of daily living. Two groups of 20 caregiving dyads were included in the study, those where the care recipient was cognitively impaired but physically well and those who were lucid but physically limited. Lucid physically impaired elders did better in smaller undermanned households where they were more challenged and there was reduced competition for scarce resources such as time and space. Demented elders do better in larger households where there are more social cues and prompts and the monitoring is easier. The small nuclear family seems to be well suited for the demands of caring for a physically impaired elder. Data collected from the spouse caregiver of the older person with Parkinson's disease would support this conclusion. However, this same social arrangement appears to be far less suitable for caregiving for the cognitively impaired. The pilot data suggest a possible explanation for this dichotomy. The caregivers of the demented care receivers reported being in a state of constant vigilance to protect their elder from possible hazards. This would probably be easier in a larger household where there are more people around to share in this responsibility. The primary implication of this finding for nursing is the identification of and the targeting of more resources for the undermanned household at risk for more strain in dementia family caregiving.

Pruchno, Dempsey, Carder and Koropeccky-Cox (1993) examined household characteristics in relationship to perceptions of household space, burden, and satisfaction. Household characteristics were measured with a series of questions that described the type of dwelling e.g., detached, single, attached home or townhouse, apartment or other; the resources that the elder had to their own e.g., bathroom, bedroom, separate entrance, telephone line television etc.; the time the elder spends in shared living spaces and whether physical changes had been made to the home to accommodate the addition of the elder to the household. More rooms were associated with lower levels of burden for all family members and higher levels of satisfaction for daughters. More separate amenities were related to less negative impact on household space perception. Making some sort of conversion of space in the house increased the negative household perception for both the caregiving daughters and their husbands. Data from the pilot study also seems to support the need to examine how family members spend time in the house in order to assess these space perceptions.

The aim of the Olsen et al., (1993) study was to describe the potential for environmental modifications to make caregiving easier. These researchers interviewed 90 long-term family caregivers of older people with dementia to elicit their experiences with safety, home modifications, agitated behaviors, and tactics for maintaining the care recipient's strength. Caregivers used environmental modifications to promote safety, to keep the elder involved in activities, and to support function. These findings are consistent with the findings in the pilot study where environmental modifications were associated with prevention of accidents, use of leisure time, and changing personal care routines.

Findings also are consistent with those obtained by Calkins and Namazi (1991). The aims of the their study were to identify modifications made by caregivers to homes, to ascertaining the effectiveness of each modification, and to evaluate the impact of these changes on the confused person and their caregiver. In this study 59 primary caregivers were interviewed over the telephone using a semi-structured interview guide that asked respondents to focus on the difficult behaviors of their care recipients, to report the environmental modifications made, and to rate their effectiveness by choosing one of three options, worked well, worked somewhat, did not work at all. The findings indicated that home modifications were grouped into four categories: those intended to manage wandering, incontinence, to promote safety and independence and those intended to manage disruptive activities. Modifications that were rated effective for caregivers included those that made caregiving easier, decreased anxiety, increased safety, and made the home easier to clean. Modifications that were rated effective for care receivers made the environment less distracting, made the patient more independent, averted institutionalization and increased care receiver safety. Every participant had made at least one modification of the physical environment suggesting that these caregivers used home modifications as a therapeutic tool in caring for someone with cognitive impairment.

In summary, eight thematic caregiving activities likely to be associated with environmental modifications emerged from this process: changes in personal care routines, supplementing function, mobility problems encountered, behavior management, medically related tasks, preventing accidents, and changes in management of household functioning. Data indicated that environmental modifications were associated with all eight categories of caregiving tasks. The results of this pilot study suggest that an interview guide based on these eight thematic categories will elicit the rich detailed information that will be needed for a qualitative analysis.

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APPENDIX B

INFORMED CONSENT

Pilot Study, Oregon Health Sciences University
Participants Consent To Use Data

Research, Oregon Health Sciences University
Family Caregiver Consent Form
Older Person Consent Form

IRB# 3595-2
Approved (August 15, 1996)

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: FAMILY CAREGIVER

ENVIRONMENTAL MODIFICATION STRATEGIES USED BY CAREGIVERS

PRINCIPAL INVESTIGATOR:	Deborah C. Messecar, R.N., Ph(C) Doctoral Student School of Nursing, Oregon Health Sciences University (503) 494-3573
	Jane M. Kirschling, R.N., D.N.SC. School of Nursing, Oregon Health Sciences University (503) 494-1425
	Patricia G. Archbold, R.N., D.N.SC., F.A.A.N. School of Nursing, Oregon Health Sciences University (503) 494-3840
CONSENT FORM:	To be used with family caregivers who are involved in performing caregiving activities.

Study Purpose and Background

Deborah C. Messecar, R.N., M.S. under the direction of Patricia G. Archbold, R.N., D.N.SC., F.A.A.N. and Jane M. Kirschling, R.N., D.N.SC. is doing a research study about family caregivers. The purpose of this study is to learn about the environmental modification strategies caregivers use when caring for a chronically ill older person. Environmental modifications may include structural changes you have made to your home, special equipment or assistive devices you use, or ways you have changed how you do things or arranged the furniture or space in your home. I would like to use the transcript of your interview conducted as part of a class project that describes the changes you made in your family member's home for caregiving. The duration of your participation in this study will only include the time needed to review the interview transcript to determine if is okay to use for this new purpose.

Procedures

A complete transcript of the previously conducted interview will be provided for your review. After reading the transcript, if you agree to allow your interview data to be a part of this study, your consent will be obtained in writing at this time. You may consent to allowing use of the entire transcript, or only a portion of the transcript by striking through those areas you do not wish to be included in the current study.

Risks and Discomforts

Some part of the previously conducted interview may touch on experiences that may be upsetting to you. You are free to delete from the transcript any topics that may be uncomfortable for you. You may choose to not allow use of the interview at all. Some people become uncomfortable and nervous when they read statements about themselves, their family members, and/or their thoughts and their feelings. If you would like counseling to discuss the problems or feelings raised during reading the interview, the investigator will help you arrange this.

In the event that elder abuse is discovered, the investigator is required to report it to the State of Oregon Senior and Disabled Services Division.

Benefits

Participating in this study may not provide benefits for you. However, reviewing your transcript may allow you to appreciate your accomplishments as a caregiver. Your interview data may contribute new information that nurses may be able to share with other families in similar situations.

Confidentiality

Personal identifying information has been deleted from the written notes and the questionnaire. The information you share will be kept confidential. Only the investigator and the faculty dissertation advisors will have access to your responses. Any publications, including the dissertation report, will take necessary precautions to protect your identity. These include deletion of personally identifying information, and the opportunity for you to review materials in the report that directly describe your situation.

Costs

You will be contributing your time as a result of agreeing to review your interview transcript. There will be no reimbursement or compensation to you as a result of participating.

Liability

The Oregon Health Sciences University, as a public institution is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please contact the Medical Services Director at (503) 494-8014.

Your Rights as a Participant

Participation in this research project is completely voluntary and you may refuse to allow use of your interview transcript for this study at any time.

If you have any questions about this research, or your rights as a research participant, you should first contact Deborah Messecar at (503) 494-3573. If you have further questions, you may contact the OHSU Institutional Review Board at (503) 494-7887.

Your signature below indicates that you have read the foregoing and agree to allow use of your interview data in this study. You will receive a copy of this consent form.

____

Participant's signature Date

IRB#3595
February 20, 1996

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: OLDER PERSON

ENVIRONMENTAL MODIFICATION STRATEGIES USED BY CAREGIVERS

PRINCIPAL INVESTIGATOR:	Deborah C. Messecar, R.N., M.S., Doctoral Student School of Nursing Oregon Health Sciences University (503) 297-3587
	Jane M. Kirschling, R.N., D.N.SC. School of Nursing, Oregon Health Sciences University (503) 494-1425
	Pat G. Archbold, R.N., D.N.SC., F.A.A.N. School of Nursing, Oregon Health Sciences University (503) 494-3840
CONSENT FORM:	To be used with older persons who are involved in an ongoing caregiving situation.

Study Purpose and Background

Deborah C. Messecar, R.N., M.S. under the direction of Patricia G. Archbold, R.N., D.N.SC., F.A.A.N. and Jane M. Kirschling, R.N., D.N.SC. is doing a research study about family caregivers. The purpose of this study is to learn about the environmental modification strategies caregivers use when caring for a chronically ill older person. Environmental modifications may include structural changes you have made to your home, special equipment or assistive devices you use, or ways you have changed how you do things or arranged the furniture or space in your home. I will be interviewing caregivers to obtain descriptions of the changes they made in the older person's home for caregiving. I will be asking the caregivers to describe how the changes they made worked, and how they changed their strategies over time.

Procedures

I may ask to observe some caregiving activities in your home. If you agree to the visit, the time for the visit will be determined by both you and your caregiver. This visit will last approximately one and a half hours to two and a half hours. The purpose of the visit will be to observe a particular caregiving activity in which you use an environmental modification strategy. During the visit, I will be taking notes and will audiotape our conversation.

Risks and Discomforts

On the visit, you may find that having someone present while you are receiving care makes you uncomfortable. If this happens you are free to ask for privacy during any part of this visit.

If you find that the visit makes you very uncomfortable, you may choose to withdraw from the study during that visit.

In the event that elder abuse is discovered, the investigator is required to report it to the State of Oregon Senior and Disabled Services Division.

Benefits

Participating in this study may not provide direct benefits for you. However, your participation may contribute new information that nurses may be able to share with other families in similar situations.

Confidentiality

Our conversation during the observation of the caregiving activity will be tape recorded and written notes will be kept. The tapes will be transcribed, with all personal identifying information deleted in the transcription process. The audio tapes will be destroyed after the study is complete. Personal identifying information will be deleted from the written notes and the questionnaire. The information you share will be kept confidential. Only the investigator and the faculty dissertation advisors will have access to your responses. Neither your name nor your identity will be used for publicity or publication purposes.

Costs

You will be contributing your time as a result of agreeing to participate in the observation visit. There will be no reimbursement or compensation to you as a result of participating.

Liability

The Oregon Health Sciences University, as a public institution is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please contact the Medical Services Director at (503) 494-8014.

Your Rights as a Participant

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care you receive at the Oregon Health Sciences University.

___ I have read what is written above and agree to be in this study.

___ I have had read to me what is written above and agree to be in the study.

If you have any questions about this research, or your rights as a research participant, you should first contact Deborah Messecar at (503) 297-3587. If you have further questions, you may contact the OHSU Institutional Review Board at (503) 494-7887.

Your signature below indicates that you have read the foregoing and agree to participate in this study. You will receive a copy of this consent form.

Participant's signature Date

Witness' signature Date

Family member/guardian signature Date

IRB#3595
February 20, 1996

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: FAMILY CAREGIVER

ENVIRONMENTAL MODIFICATION STRATEGIES USED BY CAREGIVERS

PRINCIPAL INVESTIGATOR:	Deborah C. Messecar, R.N., M.S., Doctoral Student School of Nursing, Oregon Health Sciences University (503) 297-3587
	Jane M. Kirschling, R.N., D.N.SC. School of Nursing, Oregon Health Sciences University (503) 494-1425
	Pat G. Archbold, R.N., D.N.SC., F.A.A.N. School of Nursing, Oregon Health Sciences University (503) 494-3840
CONSENT FORM:	To be used with family caregivers who are involved in performing caregiving activities.

Study Purpose and Background

Deborah C. Messecar, R.N., M.S. under the direction of Patricia G. Archbold, R.N., D.N.SC., F.A.A.N. and Jane M. Kirschling, R.N., D.N.SC. is doing a research study about family caregivers. The purpose of this study is to learn about the environmental modification strategies caregivers use when caring for a chronically ill older person. Environmental modifications may include structural changes you have made to your home, special equipment or assistive devices you use, or ways you have changed how you do things or arranged the furniture or space in your home. I will be interviewing caregivers to obtain descriptions of the changes they made in the older person's home for caregiving. I will be asking the caregivers to describe how the changes they made worked, and how they changed their strategies over time. The duration of participation will not exceed one month.

Procedures

If you agree to participate in this study, you will be interviewed at a time and place that is agreed upon by yourself and the investigator. If agreed to by you and the older person you provide care to, the investigator may visit the home in which you provide care to conduct this interview. The interview will need to be conducted in private. The interview will be taped and will last approximately one to one and a half hours. I will ask you questions about the types of help you give to the older person. If you provide a certain type of help, I will ask you additional questions about changes in the home you may have made to do that activity. I will ask you to supply some additional information about yourself including your age, how much education you have had, your relationship to the older person to whom you provide care, and the number of months you have been engaged in caregiving. I may contact you by telephone after the interview to clarify information.

I may ask to return to observe some caregiving activities in the home of the older person you provide care to at a later time. If you agree to the second visit, the time for the visit will be determined by both you and the older person. This visit will last approximately one a half hours to two and a half hours. The purpose of the second visit will be to observe a particular caregiving activity in which you use an environmental modification strategy.

Risks and Discomforts

Some part of the interview may touch on experiences that may be upsetting to you. You are free to decline to discuss any topics that may be uncomfortable for you. You may choose to stop the interview at any time. Some people become uncomfortable and nervous when they answer questions about themselves, their thoughts and their feelings. If you become upset during the interview, the interviewer will stay with you until you are no longer upset. If you would like counseling to discuss the problems or feelings raised during the interview, the investigator will help you arrange this.

If a second visit is made, you may find that having someone present while you are providing care makes you uncomfortable. If this happens you are free to ask for privacy during any part of this visit.

In the event that elder abuse is discovered, the investigator is required to report it to the State of Oregon Senior and Disabled Services Division.

Benefits

Participating in this study may not provide benefits for you. However, talking about your experiences may allow you to appreciate your accomplishments as a caregiver. Your participation may contribute new information that nurses may be able to share with other families in similar situations.

Confidentiality

The interviews will be tape recorded and written notes will be kept. The tapes will be transcribed, with all personal identifying information deleted in the transcription process. The audio tapes will be destroyed after the study is complete. Personal identifying information will be deleted from the written notes and the questionnaire. The information you share will be kept confidential. Only the investigator and the faculty dissertation advisors will have access to your responses. Any publications, including the dissertation report, will take necessary precautions to protect your identity. These include deletion of personally identifying information, and the opportunity for you to review materials in the report that directly describe your situation.

Costs

You will be contributing your time as a result of agreeing to participate in interviews. There will be no reimbursement or compensation to you as a result of participating.

Liability

The Oregon Health Sciences University, as a public institution is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please contact the Medical Services Director at (503) 494-8014.

Your Rights as a Participant

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw form this study at any time without affecting the care you receive at the Oregon Health Sciences University.

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If you have any questions about this research, or your rights as a research participant, you should first contact Deborah Messecar at (503) 297-3587. If you have further questions, you may contact the OHSU Institutional Review Board at (503) 494-7887.

Your signature below indicates that you have read the foregoing and agree to participate in this study. You will receive a copy of this consent form.

____

Participant's signature Date

____

Witness' signature Date