

**STAYING PUT:  
Adapting the Places  
Instead of the People**

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CHAPTER  
6

**The Importance of a  
Consumer Perspective in Home  
Adaptation of Alzheimer's  
Households**

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As many as four million people in the United States have Alzheimer's disease or a related disorder [1], and the National Institute of Aging expects this number to increase to fourteen million by the year 2050 [2]. From the onset of symptoms, the lifespan of a person with Alzheimer's can extend to over twenty years. Thus, while the number of elders with physical disabilities continues to grow, along with related home adaptation needs, a second group of home adaptation users, older persons with cognitive disabilities, is mushrooming alongside them.

Lawton reported that the great majority of people with Alzheimer's disease reside in the community with their spouses or adult children. He observed:

Almost all published material on designing for the person with Alzheimer's disease assumes that the appropriate environment is the nursing home. . . . Our thinking about environment as a therapeutic agent must take into account [the] diverse residences for older people with some element of dementia. The redesign of these dwelling units may well become a community-based service that will enable demented individuals to remain at home [3, p. 344].

If this large noninstitutionalized population of elders with cognitive impairments is to be appropriately served, then home adaptation programs must respond to their needs. In particular, the perspectives, wants, and needs of family caregivers are central, since the purpose of home adaptation in these cases is to allow

the caregivers to gain control of their situation. In keeping with this approach, the next section uses the authors' research findings and the experiences of others in the field to address the following questions:

- How is home adaptation for the cognitively impaired different from other home adaptation?
- What information is currently available about home adaptation for the cognitively impaired and what additional information is needed?
- What are the most common adaptation recommendations currently being made for this population?
- For the purposes of providers, researchers, and policymakers, what kind of framework or system is suitable for this field?

The third section focuses more narrowly on the authors' findings with respect to:

- the issues involved in (and barriers to) the use of adaptations for this user group.
- how adaptations and recommendations can be made more useful for those with dementia and their caregivers.

## BACKGROUND

### Some Preliminary Answers to These Questions

*How is home adaptation for the cognitively impaired different from other home adaptation?*

Home adaptation for those with cognitive impairments is different from other types of home adaptation in several respects. First, providers must demonstrate awareness of and sensitivity to cognitive as well as physical impairments and the recommendations offered must function prosthetically for both. Second, the caregiver is as much the "user" of the adaptation as the impaired person, and is the decision maker in terms of assessing the usefulness of the adaptation and its likelihood of implementation. Third, while most adaptations for those with physical frailties are targeted to existing problems, many adaptations recommended for individuals with Alzheimer's are designed to prevent potential problems.

*What information is currently available about home adaptation for the cognitively impaired and what additional information is needed?*

Many community support programs for Alzheimer's caregivers do, in fact, provide information and recommendations regarding home adaptation or brief

home adaptation "audits," and several guides list possible adaptations as well as a few articles and reports of preliminary research in the field. Most available literature takes the form of descriptions of adaptations that families may find helpful.

The first systematic documentation regarding home adaptation for dementia was undertaken as part of a multi-faceted project under the leadership of Jon Pynoos at the Andrus Gerontology Center. In-house interviews were conducted with twenty-five families enrolled in a home adaptation program, all of whom received recommendations, funding, and other assistance for implementing adaptations. The project produced several articles and a practical report for families and professionals entitled *The Caring Home Booklet: Environmental Coping Strategies for Alzheimer's Caregivers* [4]. This booklet addresses the role of the environment in supporting the needs of those with Alzheimer's disease and caregivers in the home. It covers behavior problems and management strategies; caregiver reluctance to change the environment; help available for making changes; need for alternative settings; and strategies for environmental management of such issues as behavior problems, memory loss, wandering, incontinence and difficulty with toileting, personal hygiene, hallucinations, aggressive behavior, eating, boredom, destructive or dangerous behavior, and safety. Appendices list mail-order retailers of adaptive products and supplies, activity resources, clues for reducing behavior problems, and a caregiver-oriented bibliography.

Another valuable guide for families and professionals, *Home Modifications: Responding to Dementia* [5], was released by the Research Center of the Corinne Dolan Alzheimer's Center. The researchers surveyed by telephone fifty-nine families who were caring for someone with dementia regarding their use of and satisfaction with home adaptations. In the foreword the authors stated:

When we began this project, we had no way of knowing what our results would indicate. By the time the study was concluded, we had learned that families devise a great number of ingenious solutions to the many difficult problems that arise when caring for a loved one with dementia. Every one of the respondents we interviewed made at least one environmental modification. Of these, 78% indicated that the modifications made the caregiver's life easier, while 68% said that the modifications helped the confused person. This positive response to environmental modifications seems to indicate that more information should be available to caregivers.

A more recent guide, *Homes that Help: Advice from Caregivers for Creating a Supportive Home* [6], is based on interviews with ninety veteran caregivers who had cared for loved ones in all types of home settings. A wide range of behavioral and physical adaptation recommendations are described under three main goals:

First, the home should be calming and reassuring. Second, it should be safe and supportive. Third, [it] should provide activities that engage your loved one, sustain his or her remaining strengths, and encourage independence [6, p. 5].

Although the materials described are a good beginning, both providers and family caregivers require more information on useful adaptations.

*What are the most common adaptation recommendations currently being made for this population?*

The authors of this chapter, in their preliminary work with three provider agencies, generated a list of the ninety-nine most commonly recommended adaptations for this population (see next section). The list can provide a useful checklist for providers and caregivers considering possible adaptations. Another list of most-often-made adaptations is available in Calkins [5]. The problem with lists such as these is that they give providers and others working in the field little guidance as to which adaptations are appropriate for particular users and circumstances. Thus, a systematic understanding of the issues is crucial. Both the caregiver's perspective and outcomes regarding the functioning of the cognitively impaired person must be considered.

*For the purposes of providers, researchers, and policymakers, what kind of framework or system is suitable for this field?*

At the Spring 1992 Alzheimer's Association conference, Calkins reported on a systematic framework for discussing home adaptation in this area [7]. As in all environment-behavior (E-B) studies, this framework addresses the physical environment, human behavior in the environment, and the interactions between the two. First, Calkins defines six types of adaptations:

- Structural changes to the home (moving walls, doorways)
- Adaptation modifications (changing existing features of home such as railing or locks)
- Special equipment (such as grab bars)
- Assistive devices (which Calkins points out can be difficult for those with dementia to learn to use)
- Material adjustments (moving furniture to create a wandering path, keeping poisons locked away)
- Behavioral modifications (changes in how activities are carried out such as giving someone a sponge bath)

Calkins then classifies the reasons for (or purposes of) adaptations. The list includes safety-related adaptations, changes made to assist people with age-related physical disabilities, modifications to support independence in recreational and daily living activities, modifications that address orientation and confusion, and adaptations that simplify caregiver tasks or reduce caregiver confusion or frustration.

Hiatt briefly discusses the environment side of the equation, and suggests that adaptations may be an effective way to help meet behavioral goals for cognitively impaired individuals [8]. For examples, adaptations may help to:

- Support attention span
- Support social interchange, sensitivity to personal spaces
- Maximize remaining vision
- Motivate by aroma
- Support hearing
- Encourage motion
- Cue memory

Little work has been done to date to link our understanding of behavior and behavioral goals to our knowledge regarding the adaptations available to assist cognitively impaired individuals. It is likely that family caregivers have considerable insight into this relationship, which focused interviewing techniques may elicit. These relationships could then be further tested.

## RESEARCH FINDINGS

### Issues and Barriers to the Use of Adaptations for this User Group

#### *The Role of Caregiver*

Calkins [7] and others [9, 10] have noted that the few studies that have been done focus more on the physical adaptation and less on the behavior, needs, and subjective experiences of the impaired person or caregiver. The authors of this chapter concur: Researchers to date have neglected to emphasize the transactional aspects of home adaptation, placing their focus on either the person and the disability or on the environment. To the extent that adaptations are recommended, the emphasis has usually been either on assessing physical characteristics of the caregiving household (such as clutter, unsecured exits, stairs, and cooking hazards) or on patient characteristics (including wandering, sleep cycle disturbances, and difficulties with activities of daily living). Little attention has been paid to the third step in good E-B practice: understanding the relationship of the environment to the behavior.

In this case the "behavior" to be considered includes that of the caregivers. Key to implementation but often ignored is the congruence of adaptation recommendations with the strengths, values, and preferences of the caregiver who must implement and live with them. In a situation that allows caregivers few tangible successes, home adaptation may be an area in which concrete steps lead to concrete positive results, as well as a greater feeling of control. More information is needed on how families utilize professional advice with respect to home adaptation.

Family support as an integral component in the care of people with Alzheimer's disease has been well documented [11-13]—indeed, focusing on family caregivers has become an important branch of inquiry within Alzheimer's research (see, e.g., [14-16]). Caregivers across the United States may avail themselves of support groups and educational workshops that provide them with information and coping strategies with respect to erratic behavior and social losses, as well as learning techniques to compensate for the declining competencies of the person for whom they are caring. In many locations, caregivers also receive information and recommendations regarding home adaptation both for behavior management and to improve the safety of the home environment for the person with Alzheimer's disease. This type of information is critical. Hall notes that in the early stages of the disease the client can be taught to structure his or her own schedule and environment to maintain comfort and function; however, "as the disease progresses . . . tighter control is required to maintain normative behavior. . . . In the ambulatory demented phase . . . the caregiver must assume responsibility for monitoring and structuring of the client's environment" [17, p. 37].

Studies by Handler [18] and Pynoos and Ohta [19] suggest that home adaptation is indeed an important factor in managing the person with Alzheimer's disease in the community. Both studies tested the hypothesis that home adaptation will improve patient behaviors and reduce caregiver burden. While the researchers concluded, based on their limited samples, that home adaptation as an intervention may be effective, they also acknowledged that caregivers do not always comply with provider recommendations. Pynoos and Ohta noted that caregivers are often reluctant to change the environment:

In many instances the caregiver did not make adjustments to the home which the researchers believed would minimize danger/promote functioning of the patient, such as providing alert signals on doors or safety guards on electric outlets [19, p. 2].

Reluctance on the part of the caregiver may come from the negative image of a stigmatized environment, cost of making change, difficulty in identifying resources or uncertainty over whether the modification will be effective. Yet many of the preventative measures that are recommended are non-therapeutic in nature, low cost, and relatively simple to make [19, p. 5].

### *The Decision-Making Process for Caregivers*

The authors' recent study of Alzheimer's caregivers' implementation of home adaptation recommendations builds on the model created by Ohta and Ohta [20]. Described in Chapter 5 of this book, the model hypothesizes that four factors are important to older consumers when they decide whether to implement home adaptation recommendations: 1) the likelihood that the target problem will occur without the adaptation, 2) the severity of the target problem, 3) the potential effectiveness of the adaptation, and 4) the cost of the adaptation. The model used for this research differed from the Ohta model in two respects. First, the decision-making process of caregivers, rather than that of the impaired elders themselves, was examined in this study. Second, the adaptations addressed were intended for those with cognitive impairments, rather than with physical frailty.

The primary objective of this project was to assess the relationship between home adaptation recommendations made by geriatric nurse practitioners to Alzheimer's caregivers and the level of implementation achieved. More specifically, the aims of the study were to:

- Determine the degree to which professionals' perceptions of barriers to implementation, the caregiver's perceptions of the recommended adaptation, and patient characteristics affect the perceived likelihood of following through with the recommendations
- Determine the degree to which the type of target problem addressed through the recommended adaptation affects the perceived likelihood of following through with the recommendation.

### *The Difference between Caregivers' and Users' Perceptions*

The first phase of the study documented professionals' perceptions of barriers to the implementation of adaptation recommendations. These perceptions "consensus scores" would later be tested as predictor variables of the caregivers' level of implementation of recommendations. Health care professionals from the Harvard Geriatric Education Center, in addition to professional staff and support group leaders from the Alzheimer's Association of Eastern Massachusetts, were surveyed in Spring 1990 regarding ninety-nine home adaptation recommendations. These adaptations were compiled by a review of environmental assessment forms used by three Boston-area community agencies that provide in-home assessment and counseling for Alzheimer's caregivers.

The professionals were asked whether they perceived any of four barriers to a recommendation: whether the recommendation cost too much, required outside help, required a change in caregiver behavior, or required a change in household appearance. Table 1 illustrates the range of adaptation recommendations reviewed and provides summary scores [21].

Table 1. Professionals' Perceptions of Barriers to Home Adaptation Recommendations to Family Caregivers of Persons with Alzheimer's (Percent) (n = 18)

Recommendation	Financial Output	Needs Outside Help	Requires Change in Caregiver Behavior	Requires Change in Household Appearance	Overall
1. Add additional bathroom	100.0	88.9	27.8	72.2	72.2
2. Fence in yard	94.4	88.9	16.7	72.2	68.1
3. Build ramp	88.9	72.2	22.2	72.2	63.9
4. Install stair/elevator chair	83.3	72.2	22.2	77.8	63.9
5. Fence in swimming pool	94.4	77.8	16.7	50.0	59.7
6. Install additional locks on exit doors	72.2	83.3	38.9	38.9	58.3
7. Install movement monitor	94.4	66.7	50.0	11.1	55.6
8. Install handrails in hallway	72.2	72.2	11.1	66.7	55.6
9. Install safety locks on windows	77.8	77.8	16.7	33.3	51.4
10. Install alarm system	100.0	77.8	11.1	11.1	50.0
11. Install grab bars in bathroom	66.7	61.1	11.1	55.6	48.6
12. Render automatic locks on storm/screen doors inoperable	61.1	83.3	38.9	11.1	48.6
13. Install gate on stairway	61.1	55.6	22.2	50.0	47.2
14. Install locks on closet doors	55.6	61.1	38.9	27.8	45.8
15. Install locks on doors to cellar and attic	55.6	66.7	33.3	27.8	45.8
16. Install door buzzer	72.2	77.8	22.2	5.6	44.4
17. Improve poor lighting conditions in stairs, hallways, and bathrooms	72.2	61.1	11.1	33.3	44.4
18. Remedy overloaded electrical sockets	61.1	77.8	16.7	16.7	43.1
19. Install refrigerator lock	55.6	66.7	38.9	11.1	43.1
20. Use hospital bed	66.7	38.9	16.7	44.4	41.7
21. Repair frayed electrical wires	55.6	77.8	11.1	16.7	40.3
22. Install lock on yard fence	61.1	66.7	22.2	11.1	40.3
23. Add non-skid strips to stairs	44.4	33.3	5.6	77.8	40.3
24. Install radiator covers	72.2	38.9	5.6	44.4	40.3
25. Insulate hot water pipes	66.7	66.7	5.6	16.7	38.9
26. Install childproof kitchen cabinet locks	55.6	50.0	33.3	16.7	38.9
27. Repair step carpeting	61.1	55.6	11.1	27.8	38.9
28. Tape or paint stair edges	33.3	38.9	16.7	61.1	37.5
29. Install smoke detectors and insure proper placement	50.0	61.1	11.1	27.8	37.5

Table 1. (Cont'd.)

Recommendation	Financial Output	Needs Outside Help	Requires Change in Behavior	Requires Change in Household Appearance	Overall
30. Use hand held shower	50.0	33.3	44.4	11.1	34.7
31. Install bed rails	55.6	44.4	11.1	22.2	33.3
32. Provide clocks in multiple rooms	50.0	5.6	33.3	38.9	31.9
33. Use shower chair or tub seat	61.1	16.7	33.3	11.1	30.6
34. Use reflector tape on floor or walls to guide patients	33.3	22.2	5.6	61.1	30.6
35. Use wheelchair	55.6	27.8	16.7	22.2	30.1
36. Remove auxiliary heating sources	33.3	33.3	38.9	16.7	30.1
37. Store household kitchen appliances under lock and key	22.2	11.1	72.2	11.1	29.2
38. Protect upholstered furniture	22.2	5.6	33.3	66.7	29.2
39. Have commode available	38.9	16.7	16.7	38.9	27.8
40. Create and utilize signs for identification cues	22.2	0	38.9	50.0	27.8
41. Store sharp kitchen tools in locked cabinets	16.7	11.1	72.2	11.1	27.8
42. Store razor blades in locked cabinets	16.7	11.1	72.2	11.1	27.8
43. Change to electric razor	50.0	0	55.6	0	26.4
44. Eliminate shiny, glaring surfaces	33.3	22.2	22.2	27.8	26.4
45. Store medications in locked cabinet	22.2	11.1	66.7	0	25.0
46. Simplify clothing	61.1	0	38.9	0	25.0
47. Immobilize stove, remove dials	5.6	16.7	55.6	22.0	25.0
48. Use vinyl tablecloth	11.1	0	38.9	44.4	23.6
49. Use automatic dial telephone	50.0	0	33.3	11.1	23.6
50. Remove clutter	0	11.1	50.0	33.3	23.6
51. Remove area rugs	0	0	33.3	61.1	23.6
52. Put decals on glass doors	16.7	5.6	22.2	44.4	22.2
53. Store household cleansers and insecticides in locked cabinet	16.7	11.1	61.1	0	22.2
54. Store matches and lighters in locked cabinets	16.7	11.1	61.1	0	22.2

Table 1. (Cont'd.)

Recommendation	Financial Output	Needs Outside Help	Requires Change in		Overall
			Caregiver Behavior	Household Appearance	
55. Rearrange furniture to protect from radiators	5.6	16.7	16.7	44.4	20.8
56. Lower hot water temperature to <120°	27.8	38.9	16.7	0	20.8
57. Use walker	44.4	16.7	16.7	5.6	20.8
58. Install outlet covers	38.9	5.6	16.7	22.2	20.8
59. Store valuable items in locked or inaccessible area	27.8	11.1	50.0	5.6	20.8
60. Store tools under lock and key	11.1	5.6	66.7	0	20.8
61. Regularly replace batteries of smoke detectors	16.7	22.2	38.9	5.6	20.8
62. Remove low furniture, i.e., coffee tables and stools	0	11.1	27.8	38.9	19.4
63. Store firearms under lock and key	11.1	5.6	61.1	0	19.4
64. Post pictures as cues	5.6	5.6	33.3	33.3	19.4
65. Have easy access to fire extinguisher	27.8	16.7	33.3	0	19.4
66. Clear path in center of room	0	0	50.0	27.8	19.4
67. Use sturdy chairs that do not tip	38.9	0	16.7	16.7	18.1
68. Post calendar, cross off days and record appointments and activities	5.6	0	61.1	5.6	18.1
69. Use straw and finger foods	5.6	5.6	55.6	5.6	18.1
70. Limit smoking area to non-carpeted area with non-upholstered chair	0	0	61.1	11.1	18.1
71. Tape electrical cords across walkways	11.1	11.1	16.7	33.3	18.1
72. Remove or pad sharp corners on furniture	16.7	0	11.1	44.4	18.1
73. Post lists of AD family member's and caregiver's responsibilities	0	0	55.6	11.1	16.7
74. Check trash before discarding	0	0	66.7	0	16.7
75. Remove firearms	5.6	0	61.1	0	16.7
76. Post daily schedule	5.6	0	50.0	5.6	15.3
77. Double tape area rugs	16.7	22.2	16.7	5.6	15.3

Table 1. (Cont'd.)

Recommendation	Financial Output	Needs Outside Help	Requires Change in		Overall
			Caregiver Behavior	Household Appearance	
78. Remove fake fruit/look-alike decorations	0	0	22.2	38.9	15.3
79. Keep patient's belongings in one place	0	0	38.9	16.7	13.9
80. Limit rummage areas	0	0	50.0	5.6	13.9
81. Use cane	33.3	11.1	11.1	0	13.9
82. Use sturdy plastic plates	16.7	0	33.3	5.6	13.9
83. Remove car keys from easy access	0	0	55.6	0	13.9
84. Have AD family member wear ID bracelet	33.3	11.1	11.1	0	13.9
85. Remove small magnets from refrigerator	0	0	27.8	22.2	12.5
86. Have copies of a current photo of AD family member	22.2	11.1	16.7	0	12.5
87. Use selfcare devices, i.e., curved hairbrush handles and utensils	33.3	0	16.7	0	12.5
88. Use non-skid tub mat	22.2	0	22.2	5.6	12.5
89. Use nightlights in hallways and bathrooms	11.1	0	22.2	16.7	12.5
90. Remove electrical cords across walkways	0	5.6	16.7	22.2	11.1
91. Notify police and offer photo	0	11.1	33.3	0	11.1
92. Notify neighbors	0	11.1	33.3	0	11.1
93. Remove small ingestible objects from environment	0	0	22.2	22.2	11.1
94. Hide an extra set of keys outside the house	5.6	0	33.3	0	9.7
95. Post emergency numbers near telephone	0	0	33.3	5.6	9.7
96. Provide large deep ashtray for smoker	5.6	0	33.3	0	9.7
97. Use non-skid bathroom mats	22.2	0	16.7	0	9.7
98. Keep furniture arrangement consistent	0	0	33.3	0	8.3
99. Place ID info in AD family member's wallet and clothing pockets with note about being forgetful	5.6	0	22.2	0	6.9

A "simple" recommendation like "removing an area rug" may not be simple at all, as 61 percent of the professionals noted that a barrier existed due to the change required in the household appearance. Further, storing medications in a locked cabinet may require a change in the caregiver's behavior, and 68 percent of the professionals surveyed thought that this might be a barrier to implementation. Caution should be exercised in interpreting these data in that the perceived strength of the barrier was not asked.

#### *Matching Adaptations to Caregiver Perceptions and Needs*

The second phase of the study addressed the match between adaptation recommendations and caregiver perceptions. Data were collected in the Boston metropolitan area during Spring 1991. Four geriatric nurse practitioners representing three community agencies conducted assessments in thirty-one Alzheimer's households. The care recipients ranged in age from fifty-seven to ninety while their caregivers ranged in age from thirty-three to eighty-four. Over half (55%) of the caregivers were spouses and over a third (39%) were adult children. The duration of the illness reported by the caregivers averaged 4.33 years and ranged from one to ten years. The nurses' assessment included the Zarit Burden Interview [22], an ADL checklist, and a home environment assessment designed by the authors. Like Calkins, the researchers categorized adaptations by purpose. Nurses were asked to identify the "target problem" the adaptation was intended to address. These areas related to:

- Cognitive and behavioral impairments
- ADL impairments
- Caregiver ease
- Safety

Table 2 lists the recommendations by the target problems addressed, as noted by the geriatric nurse practitioners. An adaptation recommended to address one target problem for one care recipient may have been recommended to address other target problems for other care recipients. For example, installing additional locks on exit doors was recommended to address cognitive and behavioral impairments as well as safety and caregiver ease.

An average of twenty-five and a median of thirty-one recommendations were made, with one family caregiver receiving fifty-three recommendations. This is considerably higher than the fifteen to twenty recommendations per caregiver which the research team had anticipated. One caregiver expressed the feelings of many when, explaining why she had not made all the adaptations recommended, she said, "It was just too much for me to deal with."

Table 3 depicts the adaptations that were most frequently recommended.

Table 2. Recommended Adaptations by Target Problem

	Cognitive or Behavioral Impairment	Safety	Caregiver Ease	Impairment in ADLs
1. Create and utilize signs for identification cues	X	X	X	X
2. Install additional locks on exit doors	X	X	X	
3. Simplify clothing			X	X
4. Install childproof cabinet locks		X	X	
5. Immobilize stove—remove dials	X	X		
6. Double tape or remove area rugs	X	X		
7. Post emergency numbers near telephone	X	X		
8. Use hand-held shower			X	
9. Have patient wear ID bracelet	X			
10. Install hand rails		X		
11. Install grab bars in bathroom		X		
12. Store medications in locked cabinet		X		
13. Add non-skid strips to stairs	X	X		

Three of the top five recommendations dealt with concerns about potential wandering and two related to the potential for poisonous ingestion. Adaptations that promoted care recipient independence were less frequently recommended.

Table 4 provides the specific categories addressed within each target problem and the percent of recommendations made regarding each. Almost half (45%) of the recommendations addressed problems related to cognitive or behavioral impairments, while 31 percent of the recommendations addressed safety concerns, 20 percent addressed caregiver ease, and only 3 percent addressed impairments in activities of daily living. In fact, fewer than 1 percent of the recommendations made were specifically targeted to promote independence for the care recipient.

A social worker called the thirty-one family caregivers approximately one month after the nurse's visit to assess the caregiver's initial response to the home adaptation recommendations. At the time of the telephone interviews, 68 percent of the care recipients were still at home with no plans to move, 26 percent were awaiting nursing home placement, and 6 percent were already institutionalized. The caregivers were asked a series of ten questions about each recommendation made. These questions were designed to obtain the caregiver's perception of the

Table 3. Most Frequently Recommended Adaptations

1. Have copies of current photo available
2. Have patient wear ID bracelet
3. Store household cleaners and insecticides in locked closet
4. Install childproof cabinet locks
5. Install additional locks on exit doors
6. Post emergency numbers near telephone
7. Store medications in locked cabinet
8. Remove clutter
9. Notify police and offer photo
10. Double tape area rugs
11. Simplify clothing
12. Immobilize stove/Remove dials
13. Remove area rugs
14. Remove low furniture
15. Create and utilize signs for identification cues
16. Place ID information in patient's wallet
17. Notify neighbors
18. Install grab bars in bathroom
19. Use non-skid bathroom mats
20. Use night lights in bathroom
21. Use straws and finger foods
22. Keep furniture arrangement consistent

care recipient's susceptibility to and severity of the target problem; perceived barriers (expense, requirements for outside help, requirements for change in the caregiver behavior, and requirements for change in the household appearance); perceived effectiveness of the recommendation; and the likelihood of following through on the recommendation.

Table 5 illustrates that while caregivers perceived certain target problems as very serious, they did not perceive their family members as susceptible. For over half (53%) of the recommendations made, the caregivers perceived that the target problems were "very" serious; however, they only considered their family member "very" susceptible to the target problems addressed by 27 percent of the recommendations. The variability of behaviors over the course of the disease may make it difficult for caregivers to assess their family member's personal degree of susceptibility.

Caregivers did not perceive major costs associated with a majority of the recommendations made. In fact, for over 70 percent of the recommendations, the caregivers did not rate the adaptation as having a perceived "cost" (requiring

Table 4. Target Problems Addressed by Adaptation Recommendations (Percent) ( $n = 501$ )<sup>a</sup>

Cognitive and behavioral impairments	45.4
Falling	22.4
Wandering	15.4
Reality orientation	4.0
Visual perception	1.8
Wayfinding	1.0
Hiding	0.6
Memory and coordination	0.2
Safety	30.9
Prevention of poisonous ingestion or choking	12.0
Fire prevention	10.0
Rapid response to crises	7.2
Prevention of injury due to sharp objects	1.8
Caregiver ease	19.8
Minimize rummaging	10.8
Increase caregiver coping strategies	4.4
Increase awareness of Alzheimer's disease	3.8
Prevent breakage of valuable items	0.8
Impairments in activities of daily living	3.4
Decrease incontinence	1.8
Decrease in fine motor coordination	0.8
Promote independence	0.6
Decrease fear and resistance in bathing	0.2

<sup>a</sup>Tables 4 and 5 reprinted from *Technology and Disability*, 24, N. M. Silverstein, J. Hyde, and R. Ohta, "Home Adaptation for Alzheimer's Households," pp. 58-68, 1993, with kind permission from Elsevier Science Ireland Ltd., Bay 15K, Shannon Industrial Estate, Co. Clare, Ireland.

outside help; change needed in caregiver behavior, change required in household appearance, or the inconvenience or unsightliness of the adaptation). Professionals have traditionally approached issues of implementation by assessing the associated costs. The level of implementation for the caregivers in this sample was affected by factors other than perceived costs.

Such a factor was the perceived effectiveness of the adaptation. Caregivers perceived that the adaptation was likely to be effective for just over half (55%) of the recommendations. Moreover, they reported that they were likely to implement the recommendation. Further, the "cost" of the adaptation in terms of difficulty

Table 5. Caregiver Perception of Target Problem and Recommended Adaptation at Time of Telephone Follow-Up

	Very	Somewhat	Not at All
Susceptibility to target problem (n = 616)	27.3	34.4	38.3
Seriousness of target problem (n = 616)	53.4	24.0	22.6
Expense of adaptation (n = 613)	7.8	21.7	70.5
Level of outside help required (n = 616)	9.1	16.9	74.0
Change required in caregiver behavior (n = 614)	6.2	22.1	71.7
Inconvenience of adaptation (n = 613)	10.3	20.7	69.0
Change required in household appearance (n = 613)	8.2	21.5	70.3
Unsignificalness of adaptation (n = 614)	4.4	11.2	84.4
Perceived effectiveness of adaptation (n = 611)	54.8	24.1	21.1
Likelihood of implementing adaptation (n = 640)	53.3	15.8	30.9

of installation, financial output, required changes in caregiver behavior, and unsightliness or institutional appearance when combined with the "perceived effectiveness" was correlated to the likelihood of implementation ( $r = .32$ ,  $p < .001$ ). Fifty-two percent of the recommendations were implemented by the time of the social worker's in-home visit.

The average number of recommendations implemented per household was thirteen. Table 6 depicts the adaptations that were most frequently recommended by the nurse practitioners and the percent of implementation by the caregivers. Of the adaptations that were most often recommended, only nine were implemented at a rate of 50 percent or greater:

- Post emergency numbers near telephone
- Keep care recipient's belongings together
- Lower hot water temperature to <120 degrees

- Double tape or remove area rugs
- Use night lights in bathrooms and hallways
- Remove low furniture
- Use sturdy chairs
- Use non-skid bathroom mats
- Regularly replace smoke detector batteries

Table 6. Adaptations Most Frequently Recommended by Nurses and Implemented by Caregivers (n = 31)

	Recom- mendation (%)	Imple- mentation (%)
1. Have patient wear ID bracelet	80.7	16.0
2. Store household cleaners and insecticides in locked cabinets	74.2	21.7
3. Have copies of current photo available	71.0	36.4
4. Post emergency numbers near telephone	64.5	100.0
5. Store medications in a locked cabinet	61.3	5.3
6. Simplify clothing	61.3	47.4
7. Remove clutter	58.1	38.9
8. Create and utilize signs for identification cues	58.1	11.1
9. Double tape or remove area rugs	54.8	88.2
10. Notify police and offer photo	51.6	18.8
11. Notify neighbors	51.6	43.8
12. Use non-skid bathroom mats	51.6	56.3
13. Immobilize stove/remove dials	48.4	26.7
14. Remove low furniture	48.4	60.0
15. Use night lights in bathroom and hallway	48.4	86.7
16. Install grab bars in bathroom	45.2	21.4
17. Keep furniture arrangement consistent	42.0	46.2
18. Limit rummage areas	42.0	23.1
19. Install additional locks on exit doors	42.0	15.4
20. Use straws and finger foods	35.5	45.5
21. Maintain clear pathways	35.5	45.5
22. Use sturdy chairs	35.5	63.6
23. Pad sharp corners	35.5	18.2
24. Use hand-held shower	35.5	36.4
25. Keep patient's belongings together	35.5	100.0
26. Lower hot water temperature <120°	32.3	100.0
27. Use tub seat	32.3	20.0
28. Remove small ingestible objects	32.3	30.0
29. Regularly replace smoke detector batteries	32.3	50.0
30. Keep sharp utensils in a locked cabinet	29.0	33.3
31. Use contrasting dishes	25.8	0
32. Keep valuables in a locked cabinet	25.8	25.0

The major reasons offered for not following through on recommended adaptations were that the care recipient was currently or would soon be institutionalized (49%) or that the caregiver did not agree that the adaptation was necessary (44%). The study also investigated whether at times caregivers partially implement adaptation recommendations; it seems that caregivers either followed through "completely" on implementing the recommendations or "not at all." This was true across all of the target problem areas.

### **How Adaptations and Recommendations Can be Made More Useful for People with Dementia and their Caregivers**

While this analysis is based on a small sample, it does provide some interesting observations. First, caregivers may be receiving home adaptation recommendations too late in the disease process. For almost a third of this sample, institutionalization was expected in the near future and caregivers may have been reluctant to make short-term adaptations. Thus, timing may be a strong factor in implementation. Caregivers, however, tend to be crisis-oriented and may not access the service network earlier on. If agencies can encourage the use of supportive services earlier in the disease process, the challenge for providers will be to offer the recommendations in stages. That is, caregivers may be able to address current problems but be overwhelmed by recommendations that are designed to prevent problems in the distant future.

Further, caregivers are not likely to follow through with a recommendation unless they are convinced of its effectiveness, and their feedback in this regard is crucial. It was apparent during the telephone interviews that many caregivers did not understand why certain recommendations were made or did not think them necessary. One caregiver reported that she did not implement the recommendation to put visual cues or signs around the house because her husband is visually impaired. In other cases the caregiver understood the purpose of the adaptation but developed an alternative method, often a change in caregiving behavior, to accomplish the same purpose. For example, instead of removing the dials from the stove, the caregiver installed a switch to turn off the electricity when not in use. The rationality of these responses is clear only when the caregiver's point of view is clear.

More time may be needed to educate the caregiver about the importance of the recommendation as it relates to the disease process. Home adaptation assessments made over time may prove to be more effective than one-time visits. Moreover, the manner in which recommendations are made may also influence caregiver compliance. Caregivers need a chance to explore their feelings about the disease and may be hesitant to give up coping patterns that work, even for better solutions. Thus, one caregiver did not get a cane for his wife, stating "I am her cane." Ruth Gordon, RN, MS, of the Community Alzheimer's Specialist Program in Watertown, Massachusetts states that, "Unless the nurse educates the caregiver

about the disease process and establishes trust, adaptation recommendations are not likely to be followed."

Following is a summary of the study's findings relevant to the unique characteristics of Alzheimer's home adaptation:

- Many caregivers do not seek help until late in the disease process. A home adaptation "audit" may be a good early service for agencies attempting to attract families earlier in the course of the disease.
- Recommendations are more likely to be implemented if practitioners elicit and consider caregiver concerns, experiences, and priorities when deciding which adaptations to recommend.
- Professionals' understanding of barriers to implementation of recommendations may be different from the caregiver's own assessment.
- Barriers such as financial cost or need for outside help when taken alone may not be significant deterrents to implementation if caregivers believe in the potential efficacy of the adaptation; however, the cumulative effect of "cost" factors does mitigate against the implementation of the adaptation.
- Agencies may be giving caregivers too many recommendations. Recommendations may need to be staged, addressing current problems now and listing recommendations to be implemented later.
- For those recommendations that are not in direct response to caregiver requests, practitioners may need to provide ongoing counseling and support. In this way they will be able to assist caregivers in understanding and accepting the progressive nature of the disease and to recommend adaptations more relevant to the care recipients' current or near-future problems.

## **CONCLUSIONS**

### **The Need for Further Research**

As discussed, home adaptation services for those with cognitive impairment may differ from those for adaptations that deal with purely physical impairments. The authors' research suggests, for example, that differences exist in caregivers' responses to adaptation recommendations and the need to educate caregivers about the progressive course of the disease and how some adaptations may work. The efficacy of particular interventions as they support cognitive functioning, enhance safety, and reduce caregiver burden remains to be fully documented. In addition, a better understanding is needed of the environment-behavior relationship of adaptations for the cognitively impaired as a basis for such research.

### Recommendations for Future Practice

Across the United States, agencies increasingly offer in-home assessments that include home adaptation recommendations to families caring for someone with Alzheimer's disease or a related disorder. Practice implications for this type of analysis include the need for preparing assessment workers such as nurse practitioners, social workers, or other health care or housing professionals as to the caregiver's perspective when making recommendations. The next step would be to develop appropriate interventions to increase the likelihood of implementation. If providers are to include adaptation as an integral part of their services, it is important that they understand the caregiver's perspective as well as the factors that influence caregiver decision-making.

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