

ALZHEIMER'S PATIENTS AND THEIR CARE-GIVERS: A REVIEW OF LITERATURE WITH HOUSING IMPLICATIONS

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Abstract

This study examines the current state of knowledge of Alzheimer's disease and the implications for housing concerns of patients and care-givers. The incidence of Alzheimer's disease is becoming more prevalent with increases in the elderly population, exacerbating environmental problems already faced by the elderly. A model of environmental complexity is used to contrast the levels of need for Alzheimer's patients with the physically impaired and the cognitively and physically intact elderly. Housing policy implications are also suggested.

Introduction

The optimal environment for the elderly has been defined as that which will promote independence of activity, provide challenges to the individual, and maximize safety and physical comfort (Fozard, 1981). The individual variation, symptoms, and expressions of Alzheimer's disease (AD), however, make it difficult to provide appropriate environmental settings (Pynoos & Stacey, 1986). With custodial and medical orientations, overmedicating, and isolation of patients leading to excess disability in institutions, it may be preferable for AD patients to remain in a home environment as much and as long as possible.

This paper defines the problems that AD patients and their care-givers experience with the physical environment and contrasts their needs with those of the elderly population in general. A model of environmental complexity is proposed to serve as a basis for defining environmental needs throughout the lifespan.

Alzheimer's Disease

Dementia has been defined as a decline in intellectual function, accompanied by global cognitive impairment while being in clear consciousness, i.e., awake and alert (U.S. Congress, Office of Technology Assessment, 1987). Global cognitive impairment refers to memory loss and at least one of the following: impairment of abstract thinking; impairment of judgment; impairment of other complex capabilities such as language use, ability to perform complex physical tasks, ability to recognize objects or people, or to construct objects; or personality change.

Dementia can be caused by more than 70 conditions which are classified into 11 groups. Of the degenerative group, AD is the most prevalent, accounting for 66 percent of all cases (U.S. Congress, Office of Technology Assessment, 1987). The causes of degenerative dementias are not known, and their progression cannot be arrested. Other degenerative diseases are often lumped together as "Related Disorders." In addition to AD, many other types of dementias are known, as well as disorders that are similar to dementia, such as psychiatric, nutritional, and metabolic disorders, and some drug-induced disorders.

Alzheimer's disease has been characterized as a neurodegenerative disease whose incidence and prevalence is approaching epidemic proportions (Altman, 1987). One major reason is that people are living longer, and the elderly population is significantly more

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likely to contract the disease. In the United States, the population aged 65 or older is predicted to rise from 27 million in 1984 to 73 million in 2030 (Zedlewski, Barnes, Burt, McBride & Meyer, 1989). By 2050, 20 percent of Americans are estimated to be at least 65 years old (Subcommittee on Human Services, 1988). This population growth is alarming in light of the results of a recently published medical study of persons over the age of 65 which indicated that over 10 percent of the subjects had probable AD; of those over the age of 85, almost half had probable AD (Evans et al., 1989). A probable diagnosis of AD can be made from observations, neurological and physical examinations, EEGs and CAT scans, and certain psychosocial evaluations (Mace & Rabins, 1981). A definite diagnosis can only be made by postmortem examination of brain tissue.

Persons suffering from dementing illnesses decline at different rates and exhibit a variety of symptoms. Cognitive/neurological symptoms include memory impairment, aphasia (language impairment), apraxia (inability to carry out purposeful motor acts or movement), agnosia (perception disorder), impaired ability to learn new material, and disorientation. Activities of daily living (ADLs), such as dressing or bathing, and instrumental activities of daily living (IADLs), such as answering the telephone or shopping, are gradually lost (U.S. Congress, Office of Technology Assessment, 1987).

Behavioral or psychological symptoms of AD may include catastrophic reactions (exaggerated anger), depression, apathy, wandering, suspicion/paranoia, disruptions in sleep cycle, perseveration (repetitious activity), social inappropriateness, impairment of judgment and reason, delusions, and hallucinations. Additionally, dementia can be complicated by outside factors contributing to a state of excess disability. The presence of other illnesses or sensory impairment and external stressors can exacerbate the management of dementia (U.S. Congress, Office of Technology Assessment, 1987).

Care-giving

The costs of caring for a patient with Alzheimer's disease or a related disorder can be staggering, not only in terms of money, but in its effect on family members. Although approximately 25 percent of elders with dementing disorders are institutionalized, the remaining 75 percent are cared for in the community (Gilhooly & Birren, 1986). Many AD patients live in their own home with their spouse or other relative as care-giver. Others live in the home of family members, often children, while those in the early stages of dementia may live alone under close supervision of relatives or other care-givers. The victim may live up to 20 years after a diagnosis of AD is made; however, the average survival time is approximately seven years.

At-home care for impaired individuals is conservatively estimated at \$12,000 per year. The average cost of nursing-home care is \$22,000 annually (Altman, 1987; Coughlin & Liu, 1989; U.S. Congress, Office of Technology Assessment, 1987). Fiscally, the longer an AD patient remains in a residential setting, the less the cost for family members. Taxpayers benefit as well because federal and state governments are estimated to spend 10 to 15 percent of overall costs of long-term care for dementia patients, or \$8.5 billion per year. Diagnoses alone can cost up to \$1 billion annually, with drug treatment and medical management running over \$10 billion in 1983 (U.S. Congress, Office of Technology Assessment, 1987).

There is no way to estimate the cost in terms of loss in family members' incomes or the toll that care-giving takes on the physical and mental health of the care-givers. Several studies have profiled the care-giver of frail elderly. Horowitz (1985a, 1985b) and Horowitz and Doorof (1982) have described the primary care-giver as either a female spouse in her 70s who is also in poor health, or, if a spouse is not available, a daughter or daughter-in-law not living in the same household. This stereotyped gender-appropriate behavior excludes most sons, unless no female sibling can serve as care-giver. Sons tend to provide less extensive support to older parents (Horowitz, 1985b). This tendency is most pronounced in domestic tasks, especially food preparation (Stoller, 1983). In analyzing the 1982 *Long-Term Care Survey*, Stone, Cafferata, and Sangl (no

date), found that the majority of care-givers (71.5 percent) were women (wives or daughters). Approximately 13 percent were husbands. The average age of the care-giver was 57.3, with 25 percent of the total care-givers being 65 to 74 years of age, and about 10 percent being 75 or older. Female care-givers who are employed often have to quit or cut back on their work to continue in the role of care-giver.

Special problems which women face as care-givers are well documented. Women are typically nurturing, often younger than the men they marry, and live longer (Crossman, London, & Barry, 1981). Increasingly, women are caught in the middle; they are middle-aged, in the middle generation, in the middle of roles competing for time and energy, and in the middle of competing values of care for the elderly and working outside the home (Brody, 1981). They are placed in the difficult role of being a parent to their own parent (Brody, Johnsen, Fulcomer & Lang, 1983; Cicirelli, 1986).

Women caring for impaired spouses face problems similar to those of adult daughters engaged in parent-care. Fengler and Goodrich (1979) have observed that the overall morale of wives of disabled men was higher when they were not employed full-time and when they perceived their income as adequate. The resentfulness of some women was attributed to their feeling trapped in care-giving when they thought there would finally be time for themselves (Fitting, Rabins, Lucas & Eastham, 1986; Pruchno & Resch, 1989).

Inseparable from women's special problems are those of burden and strain experienced to some degree by all care-givers. The health of the care-giver, often poor and deteriorating, is of prime concern. Failing health of the care-giver and feelings of burden with constant care are associated with nursing-home placement of the patient, with seeking more formal supports, or with requesting help from family members (Chenoweth & Spencer, 1986; Johnson, 1983; Johnson & Catalano, 1983; Zarit, Todd & Zarit, 1986). Other contributing problems include insufficient sleep, depression, fatigue, and feelings of guilt of care-givers, plus incontinence, combative behavior, and angry outbursts of the AD patient (Farkas, 1980).

The strain of parent-care is the expected and accepted norm, with the role never decreasing as with child-care, only increasing until the parent dies (Brody, 1985). Burden has been related to many factors, not just to the severity of symptoms, and may be experienced differently by individual care-givers or by the same care-givers in different situations (Cantor, 1983; Chenoweth & Spencer, 1986; Cicirelli, 1986; Fengler & Goodrich, 1979; George & Gwyther, 1986; Motenko, 1989; Zarit, Todd & Zarit, 1986). The worst strain for care-givers may be emotional; the closer the bond, the more stressful the care-giver role (Cantor, 1983). The meaning of the care-giver role may be more important in predicting care-giver burden than the duration or severity of the patient's symptoms (Motenko, 1989).

In order for family care-giving to be effective, the care-giver must develop skills for providing care, learn coping mechanisms, and get respite from the care-giving (Cicirelli, 1986). There may, however, be an increase in care-giver's tolerance to problem behaviors as AD progresses (Zarit & Anthony, 1986). Annoying activities such as wandering, paranoia, and restlessness may decrease as the disease worsens, thus enabling coping mechanisms to develop in the care-giver.

The burden of care-giving has been found to be lessened by some intervention programs. The most frequently recommended intervention supported by public monies is the regular provision of respite care, to grant care-givers time for other activities or time alone (Baldwin, 1987; Cantor, 1983; Cicirelli, 1986; Crossman, London & Barry, 1981; Fengler & Goodrich, 1979; Horowitz, 1985a; Mace & Rabins, 1981; Pynoos & Stacey, 1986; Rakowski & Clark, 1985; Sommers & Shields, 1987). Respite care may take the form of homemaker/sitting services in the care-receiver's own home, day-care or camps for patients, or day-care for the patients accompanied by the care-giver to share experiences and learn new skills from other care-givers (Cicirelli, 1986).

Support groups for care-givers have also been highly recommended (Cantor, 1983; Clark & Rakowski, 1983; Crossman, London, & Barry, 1981; Horowitz, 1985a; Lazarus, Cooper, Cohler & Dysken, 1981; Mace & Rabins, 1981; Zarit, Reeve & Bach-Peterson, 1980). These care-giver groups traditionally meet without the patients at senior centers or other public facilities to share experiences and coping skills. Support groups for care-givers have been found to be very beneficial.

There has been no evidence of abandonment of the frail elderly by their family members. To the contrary, most researchers have remarked on the willingness of family to assume responsibility for care-giving and/or the appropriateness of the family over institutions to care for a frail or demented member of the family (Brody, Johnsen, Fulcomer & Lang, 1983; Cicirelli, 1986; Hanson, Sauer & Seelbach, 1983; Horowitz, 1985a, 1985b; Johnson, 1983; Johnson & Catalano, 1983; Mace & Rabins, 1981; Motenko, 1989; Pratt, Schmall & Wright, 1987; Sommers & Shields, 1987; Zarit & Anthony, 1986).

Environment

Design guidelines of environments for the elderly and disabled have been extensively developed (Green, 1975; Obenland & Blumenthal, 1978; Zeisel, Epp & Demos, 1977), usually suggesting that the physical needs of the elderly differ from other segments of the population. More recent research and design guidelines have emphasized the concept of universal or adaptable housing design which promotes safety and convenience for all age groups through the use of such features as wider doorways and lever handles (Bostrom, Mace & Long, 1987; Dean, 1987; Gunn, 1988). These guidelines, whether for housing the elderly or for universal design, tend to emphasize the physical capabilities of the residents. Due to the advancing age of many AD patients, adaptations for physical impairments may be appropriate. They do not, however, address the critical issue of cognitive impairment among AD and dementia patients, many of whom are not physically impaired. For example, controls at the front of the kitchen range are hardly a comfort to the care-giver of an AD patient who turns the elements on and forgets to turn them off; grab bars in the bathroom are of little consequence for the able-bodied AD patient who delights in stopping up the lavatory drain to flood the room or who unwinds whole rolls of toilet paper; lever handles for the doors will not stop the wanderer who gets lost in his own neighborhood.

Research on environmental needs specific to AD patients and their care-givers is relatively new, and needs are difficult to articulate due to the differing reactions of patients at varying stages of the disease. Also, adaptations that are effective for one patient may not work for another. In the case of AD patients, the environment may be an important factor in care-giving as well as the self-functioning of the patient. The interaction of values with personal, situational, and environmental factors in determining filial behavior are not yet fully understood (Brody, 1985). Some housing characteristics, however, may be correlated with a family's willingness to care for an elderly relative (Struyk & Katsura, 1988). Because of their inability to learn and retain new information, dementia patients may show greater impairment in unfamiliar settings; in their own homes familiar cues may trigger well-established habits (Zarit, Reeve & Bach-Peterson, 1980).

Mace and Rabins, in their popular 1981 book for caregivers of AD patients, *The 36-Hour Day*, make many practical suggestions for modifying the home, such as locking away power tools and medications, keeping clutter to a minimum to reduce falls and fire hazards, installing gates at stair tops, and lowering the water heater temperature to prevent scalds and burns. Powers (1989) recommends specific items to purchase or to modify home health-care, such as ramps, wide doorways, wheel chairs, and bedside commodes. Common problems have been noted for all frail elderly in residences, including scatter rugs, electric and telephone cords, insufficient lighting, low ovens and shelves, and narrow hallways and entrances (Pynoos, Cohen, Davis & Bernhardt, 1987).

Much of the research on environmental intervention for the cognitively impaired eld-

erly has been conducted in institutional settings; however, the results of many of these studies would apply equally to the home environment. For example, wandering has been characterized as unique to geriatric facilities, offering a potential source of harm to the wanderer, as well as legal liability for facility administrators (Weisman, 1987). Institutional solutions, such as creating a courtyard next to the ward in a Veterans Administration Hospital (Cornbleth, 1977) would also be suitable for the AD patient living at home. In addition, nursing-home experience has shown that reducing noise and visual distraction helps patients who are confused by multiple stimuli (Schafer, 1985). The difficulties of discriminating color have also been found to be intensified by dementia, making the elimination of prints and patterns on floors, walls, and furniture beneficial. Doorways camouflaged with barriers, room-dividers, or pieces of fabric may also help reduce wandering of AD patients (Namazi, Rosner & Calkins, 1989; Schafer, 1985).

Changes in the aging process and how they affect one's sensory abilities in adapting to the environment have been identified (Andreasen, 1985; Calkins, 1988; Coons, 1987; Fozard, 1981; Hayter, 1983). The use of nonglare surfaces, warm and bright colors, sharply contrasting colors on edges of steps and counters, carpeting to reduce glare, textured fabrics, and handrails has been promoted. Hiatt (1980) has suggested the use of landmarks and cues to assist in way-finding. She has also suggested that the use of floor plans, words, and numerals in signage may be more effective with dementia patients than the use of symbols. Lawton (1981), however, has stated that to date there is no empirical evidence affirming that aids are effective in way-finding for dementia patients.

Hiatt (1987) has given specific recommendations on designing nursing homes and AD units to accommodate wandering behavior and to promote appropriate interactions between patients. She has expressed caution in the use of color, noting that color is an abstract idea, and people with memory impairment have greater difficulty relying on abstract memory (Hiatt, 1981). In *Design for Dementia*, Calkins (1988) has given a comprehensive summary of AD, with special regard to designing institutional environments. She has also indicated considerations for patients still at home, suggesting the modification of environmental demands so that AD persons can compensate for their declining ability to adapt. Emphasis is placed on the role of the physical environment in achieving behavioral goals in relation to way-finding, personalization to maintain self-image, safety and security for persons with varying levels of cognitive and physical impairment, and competence in daily activities.

Not all research has involved institutional settings. One study of primary care-givers has indicated a wide prevalence of spatial and navigational barriers in homes and has concluded that efforts for elderly care-giving could be enhanced by providing solutions to spatial barriers, especially in three generation households where the barriers were most common (Noelker, 1982). Shroyer, Anderson, Hutton, and Dobbs (1989) have observed the activity and the type and placement of furnishings in living rooms, bedrooms, kitchens, and bathrooms. They have found that for AD patients, large, sheltering chairs were preferred and that kitchens and bathrooms posed the most problems. Safety considerations, highly reflective surfaces, lack of contrast between elements, and potentially dangerous control elements reduce the AD patient's competence in both kitchens and bathrooms. Some television programs have also been found to contribute to confusion and distress, and glare increases disorientation. Possessions, however, have been found to contribute to psychological well-being.

Pynoos and Ohta (1988) have observed changes in functioning for AD Patients and their care-givers with environmental intervention. Up to \$100 worth of modifications were made in individual homes, and respondents were asked pre- and post-questions regarding effectiveness of modifications on relieving burden. These features (grab bars, ramps, etc.) were not found to reduce burden, a global stress measure. The results, however, did suggest that low-cost interventions made tasks easier and safer and alleviated some care-giver concerns. A result of this research was *The Caring Home Book-*

let, written for Alzheimer's care-givers, offering them specific strategies for solving problems at home (Pynoos, Cohen & Lucas, 1988). Many of the environmental modifications suggested for AD patients would be inappropriate for the elderly population in general. For example, mirrors are often removed from the home to prevent catastrophic reactions. Glass doors must be clearly marked or covered to prevent the AD patient from repeatedly walking into them. Lights may need to be turned on while it is still daylight to prevent a reaction referred to as "sundowning," a negative catastrophic reaction which may be triggered by darkness or by a sudden change in lighting levels. Clothing may need to be stored away with only one change of clothes left out at a time, and prized possessions which can no longer jog a failed memory must be locked away so they will not be broken.

The potential utilization of the physical environment has hardly been realized (Calkins, 1988). There may be several reasons why the environment has been under-used in home care: People often assume nothing can be done; there are few existing role models or examples; the environment is considered insignificant compared to group activities, such as therapy; control of the environment is presumed to be the responsibility of experts such as architects; many individuals value the status quo and resist change, particularly in their own homes; and health professionals have not stressed environment as part of the support system (Hiatt, 1983).

A Proposed Environmental Model

A review of the literature regarding the problems of AD patients and their environments clearly indicates that this segment of the aging population may not fit into the typical image of appropriate housing for the elderly. According to the person-environment congruence theory, in order to maintain well-being the environment must be congruent with the person's individual needs (Kahana, 1982). As a person's needs and capabilities change, resulting in lack of congruence, the environment must be adapted to maintain well-being. For AD patients and others suffering from cognitive impairment, the environment may need to be adapted more rapidly or differently than for others with gradually deteriorating physical capabilities.

The complexity of the environment can be equated to Maslow's (1943, 1970) hierarchy of human needs. At the lowest level of environmental complexity are the physiological and safety needs essential to human survival. The middle of the scale includes the need for love and belonging and the need for esteem. The highest needs include self-actualization, the need to know and understand, and aesthetic needs, which are most likely to be met by more complex environments.

If the complexity of the environment is examined throughout the lifespan in relation to adaptations for maintaining person-environment congruence, a model of this relationship evolves. This model is shown in Figure 1. In infancy, an environment of relatively low complexity can meet the basic physiological and safety needs as well as the need for love and belonging a child needs to grow and thrive. As a child matures, the complexity of his/her environment must also adapt to include the higher levels of needs which continue throughout the adult years. As a person ages, these needs do not decline appreciably, provided the individual remains physically and cognitively intact. Physical impairment alone may require the adaptation of the environment to somewhat less complex levels; however, the needs for esteem and love and belonging remain intact, as well as the safety and physiological needs. Patients suffering from AD and related disorders, however, may eventually regress to the lowest levels of environmental complexity as the disease progresses to its final stages, where only safety and physiological needs can be met.

The competing demands of environmental complexity may conflict in households shared by an AD patient and other family members. Maintaining the environmental complexity level appropriate for younger or nonimpaired household members may jeopardize the safety and well-being of the AD patient. Simplifying the environment to the level

of relocation and after the seven-month interval. Previous work with the elderly and the ability to empathize with prospective residents were two factors that provided the builder the knowledge and foresight to create an environment which met the needs of the residents. This match between needs and features, emphasized by Brennan, Moos, and Lemke (1988), was the basis for design decisions.

In designing Oakwood Apartments, the builder implemented several techniques which may relate to the high levels of satisfaction expressed by residents:

1. Apartment units were designed to be very fuel-efficient through the use of solar heat and the inclusion of floor registers instead of ceiling vents. This not only reduced living expenses, but also made the units more comfortable.

2. Residents were given the option of painting, wallpapering, and choosing their own draperies. They were not forced to live with someone else's choices. With an increased feeling of control over their environments, residents may feel greater satisfaction and less stress. This conclusion is supported by findings from studies conducted by Schulz and Brenner (1977).

3. Recreational facilities were provided in the basement of the building. This area was used frequently by residents for exercise as well as socialization. This "neutral territory", as described by the builder, was instrumental in the formation of new friendships because it provided social opportunities for those who were inhibited by the idea of visiting in another person's apartment. Lawton (1975) suggested that new social opportunities may be important as the elderly may be experiencing the loss of a role in society.

4. Extra storage space was provided in the basement of the building as well as in garages. This provision eliminated the need to give things away that many elderly people face when they move to a smaller home.

5. Other facilities were also provided in the basement. A guest bedroom was provided for overnight visitors. A small kitchen was located downstairs for residents' use. This was often used for big family gatherings or informal social meetings. These facilities allow residents to continue entertaining and socializing in the manner to which they are accustomed, unhampered by lack of space or resources.

The builder managed and maintained the building himself. He provided some services that were also attractive to the residents.

1. Residents felt free to be away from their homes for extended periods because they were confident their homes would be safe and well maintained. All yard work and maintenance was handled by the staff.

2. A free van ride to the nearest large town was offered once a week by the staff. This allowed residents time to shop, eat lunch, and take care of other errands that were necessary. This service was very popular with the residents, particularly during the winter months when they did not want to drive themselves because of adverse road conditions.

Overall, the Oakwood project appeared to be a successful one. Through his excellent planning and the resulting design, the builder-designer was able to provide an environment which fit the needs of the residents very well. Future projects for the independent, older adult could benefit from this example of cooperation between the builder and the user.

Future research should focus on similar testing with larger groups. By doing this, one may be able to pinpoint specific factors which lead to stress in the environment as well as changes in attitude and stress levels over time.

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