Health Outcomes

Improvements from Alzheimer Care Design

John Zeisel, Ph.D.

As Alzheimer's disease becomes the most extensive and expensive disease in the world, the need to broaden the definition of treatment becomes more and more necessary. Medications are presently the first, and often the last, step in "treatment." But medications alone offer meager solace for the millions of people who live daily with this degenerative disease. The world they live in becomes increasingly strange and their behavior increasingly erratic. In order for most people with this disease to live lives that tend toward normalcy, a mix of pharmacological with non-pharmacological are necessary. Therapeutic settings, activities that make up for cognitive deficits, family involvement, and caregiver approaches must augment medications. One non-pharmacological treatment modality is a physical environment that helps people find their way, jogs their memory, and keeps them safe.

This paper recounts an investigative journey to discover what are the components of a multi-approach treatment for Alzheimer's disease, what role the physical environment plays in treatment, and what effects the physical environment has on the behaviors of people with Alzheimer's disease. This paper describes and links the work of a small group of investigators and practitioners over the last decade of the 20th century (Zeisel, Hyde, Levkoff 1994; Hyde 1987; Zeisel, 199?; Zeisel and Raia, 2000; Zeisel, Silverstein, Hyde, Powell, and Holmes, 2001).

A new paradigm was needed

The journey starts with the establishment of a paradigm of care for Alzheimer's disease that is not exclusively pharmacological. Raia and Konig-Coste first established this "habilitation" therapy approach in the early nineties (Raia and Konig-Coste, 199?), re-focusing attention from re-habilitation which infers regaining aptitude to habilitation which emphasizes living life with existing abilities. This shift in treatment paradigm, later elaborated by Zeisel and Raia (2001) with emphasis on non-pharmacological treatments linked to our growing understanding of neuroscience, parallels historical advances in other diseases

> "..physicians routinely treat people with diseases for which there are no cures. People with cancer, multiple sclerosis, or Lou Gehrig's disease receive treatment and medical attention even though there is no cure for their maladies. Alzheimer's patients deserve no less." (Winograd and Jarvik, 1987)

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The new paradigm focused on minimizing the symptoms of Alzheimer's disease and related dementias, rather than focusing only on a search for a cure.

> ... despite lack of medications to reverse the underlying etiology, physicians need not feel helpless or hopeless, because management strategies do exist that can help treat the manifestations of this disease. Incurable does not mean untreatable. As with other chronic diseases, such as diabetes mellitus, congestive heart failure, or degenerative arthritis, curative remedies for the underlying disorder do not exist. Treatment is often symptomatic rather than pathology-specific. *(pp. 6-7)*

Including Alzheimer's in the same class of diseases as cancer, multiple sclerosis, diabetes, congestive heart failure, and degenerative arthritis places Alzheimer's in the realm of the medically and psychosocially understandable and manageable. Making this link turns Alzheimer's into a treatable, although incurable, disease rather than the hopeless condition it and these other diseases were thought to be a century ago. This seemingly simple shift can bring back to the realm of the living tens of millions of people worldwide who our limited thinking has condemned to a limbo in which they are merely waiting to die.

Acceptance of the new label

The new broader definition and label of "treatment" that includes the physical environment is subtly being accepted by the professions as well as the research community. A recent widely distributed pharmaceutical industry health guide reflects this approach:

> *AD Can be Treated*[1]
> Although there is no cure for Alzheimer's disease at this time, there is much that can be done to manage the disease and to treat its symptoms to provide a better quality of life for those afflicted and their caregivers. (p. 4)
>
> In addition to medication to treat the symptoms of AD, physical exercise and social activity are important in maintaining overall good health, as is proper nutrition.
>
> Calm structured surroundings may also help the afflicted person to continue functioning as well as possible for as long as possible. Modifications to the living environment can help the afflicted person maintain comfort and dignity (p. 6)

The idea that behavior of caregivers can be considered treatment is also appearing in scholarly research articles by established researchers. Barry Reisberg and his colleagues at New York University Medical Center discuss "treatment" for Alzheimer's disease in a 1998 article[2]:

> A stage 6 AD patient who is frustrated or mistreated will frequently respond with what has been termed a "catastrophic reaction"…A stage 5 or 6 AD patient who is insecure, whose pride has been wounded, or who experiences their current life as intolerable, will frequently develop delusions. We might consider *treating* the AD patient's catastrophic reactions by removing the sources of frustration or mistreatment [and] we might use "delusion therapy" in AD to explore and *treat* the source of the AD patient's insecurity, wounded pride, etc. (pp. 16-17)

This shift in paradigm set the stage for seriously considering the role of the physical environment as one treatment for Alzheimer's disease.

Other diseases and illnesses in the last century have moved from hopeless condition to manageable disease: diabetes, manic depression, and now AIDS. But each has become a treatable disease through the use of proper medication, life style changes, diet, and environmental design. Alzheimer's is now at this point, and the role of

[1] America's Pharmaceutical Companies. *Alzheimer's Disease: A Health Guide*. Washington, DC, 1997.

[2] Reisberg B, Franssen E, Souren LEM, Auer S, & Kenowsky S *Progression of Alzheimer's disease: variability and consistency: ontogenic models, their applicability and relevance. J Neural Transm* (1998) [Suppl] 53: 9-20

the physical environment in treatment is becoming more evident.

The brain's physiology and Alzheimer's Disease

As Zeisel and Raia point out (2000) "Alzheimer's disease tends to begin in the medial temporal lobe, then spreads to other regions of the brain. Alzheimer's disease tends to affect most severely the association cortex of the parietal, temporal and frontal lobes and the cingulate cortex of the brain. By contrast, the motor cortex and major sensory areas are less affected. Memory dysfunction, emotional and personality changes tend to arise from damage to the limbic system – the hippocampus and amygdala – while damage to the temporo-parieto-occipital association cortex results in different forms of language, visual, and movement disorders. Social graces and habitual personality traits are relatively preserved until late in the disease."

The four lobes of the brain are differentially affected during Alzheimer's disease, as the following table demonstrates:

Non-pharmacological Alzheimer's Treatment Matrix

(The amygdala[3] in the brain retains the person's ability to sense emotion & mood; therefore the major treatment goal is to maintain positive emotion.)

Brain Dysfunction	Functional loss	Treatment Approach	Treatment Actions
Naturally Mapped Enrivonment			
Parietal & Occipital Lobes[4]	lack of cognitive map & vision	How environment communicates to residents by speaking for itself/cueing.	• speaks for itself • directs cognition (cueing) • archetypal spaces • links into what is lost last
Accepting Residents' Frame of Reference			
Hippocampal Complex	being in the present, with no past or future	How we communicate to residents by participating in their definition of the situation.	• never say "no" • participate in patient's reality • reduce fear
ADL Success Assistance			
Frontal Lobe[v]	loss of executive function – ability to sequence tasks – motor function	How we approach ADLs to create independence and enhance mood. The way they are done is as important as getting them accomplished.	• use ADL to bring about a positive emotion – participate in daily life routine • limit excess disability – don't do too much for residents
Therapeutic Activities			
Frontal Lobe[6]	loss of impulse control & social norms	How we therapeutically structure activitites to increase relationships, belonging to the group & individuation.	• the main treatment therapy • use activities to keep cognition that still remains from being lost
Multiple Communication Modalitites			
Anterior & Medial Temporal Lobes	loss of language & detailed memory	How we link into the way residents perceive, feel & process information to enhance whatever types of memory are preserved.	• verbally & hysically structure things so residents can "see" them • employ music, art, visual objects & hugs
Self-control Behaviors			
Frontal lobe[7]	loss of ability to place meaning & reality – no ability to soothe themselves	Strategies to avoid negative behaviors – agitation, confusion, hallucination – to react positively to negative behaviors & to support positive behaviors	• react positively yourself to prevent causing problematic behaviors • structure the environment to provide meaning • can't change behavior by words – change yourself

[3] Goleman D. *Emotional Intelligence* New York: Bantam Books, 1995, p.13–29, 297–300.

Physical Environment: A main Treatment Domains

Naturally Mapped Physical Environment[8] Treatment can be a physical environment that promotes safety and reduces fear by directing cognition even without the person's awareness. The literature is replete with environmental intervention strategies that have proven effective in improving resident behavior.[9,10,11,12] The environment is like prosthesis for those who have difficulty carrying a cognitive map. By being self-evident it compensates for neurological losses. The environment has what Donald Norman calls "natural mapping" in which the environment itself contains the knowledge necessary for its correct use, rather than relying on knowledge held in the head of the user.[13] Design adaptations and enhancements work by reducing demands on the person's already challenged perception, thus dramatically improving levels of functioning. More importantly, by promoting feelings of security, mastery and belonging, they lessen the frustrations that often result in behavioral outbursts.

The physical environment of care provides the setting for the simultaneous application of treatment in each of these domains.

the other side of the door, the greater independence will the resident have in his safe environment.

2. ***Walking Paths*** One of the symptoms of Alzheimer's disease for certain people is the desire to walk, perhaps looking for something without knowing precisely what. While aimless wandering can be a problem for staff in a facility that has no place for this activity, a well-designed pathway can transform wandering into walking. A pathway can achieve this goal if it is interesting and does not dead end. Such a pathway need not be a specially designed circular track, but rather can be the thoughtful connection of corridors that pass through common areas, and connect up again to corridors going in another direction. Interest along the path is important so that those walking always have some goal in sight – the next interesting picture, view or plant. And interest at the end of the path, a social space or a fireplace, provides a place to walk to, a destination that gives purpose to the trips.

3. ***Common Spaces*** Residents in Alzheimer's assisted-living facilities spend almost all their time in the facility and together. To satisfy their need for diversity and reduce boredom and agitation it is essential to have at least two if not three different common spaces – dining room, kitchen, living room, foyer. The more the settings of these rooms are different and interesting, the easier it is for staff to manage smaller family-like activities there and for residents to feel stimulated by the differences in ambiance they can sense.

4. ***Private Areas*** Because residents spend so much time together, they also need places to be alone, to avoid the pressures of social interaction. Just because someone is demented does not mean that they can stand being together with others 24 hours a day. Individual spaces residents can use to get away by themselves can include private bedrooms or small out-of-the-way corner sitting areas in a living room or garden. Places like this can also be used by residents with visiting family members who just need to sit together quietly. Private areas are also places residents and their families use to decorate and furnish personally, thus creating a soothing mood that triggers positive memories.

5. ***Healing Gardens*** Not every residence is able to provide its residents with a safe and secure outdoor area immediately adjacent to the residential area. Yet this ideal gives residents a sense of nature, weather and plants. If nothing else, Alzheimer's residents enjoy being outdoors and are relaxed by being able to get out of the confinement they feel inside. Yet a healing garden is even more than a place to get out, it is a sanctuary where a basic drive to have contact with normal forces can be met.

If such an amenity is not easily provided, for example if the residential area is on an upper floor of an urban building, designers and operators need to arrange alternatives. One possibility is to have an outdoor area nearby that residents can use regularly accompanied by staff – on grade or on a roof patio. When such an arrangement is to be made, the path there and back must be thought through carefully to avoid creating anxiety and a breakdown in safety.

6. ***Residentiality*** Home, fireplace, front porch, garden are residential environmental design elements that create positive mood in residents by touching deep seated memories. The familiarity of residential furniture, spaces, decorations and lighting fixtures relaxes everyone in Alzheimer's facilities – residents, their families, and staff members. Managing the size of features to be residential – a scale people can relate to and grasp easily – can be soothing itself. A refrigerator, a window, a small room, a small group gathering are all familiar, understandable and manageable elements for demented residents and everyone with whom they interact.

7. ***Independence*** Details in the environment such as handrails and floors that prevent slips

and falls contribute to the independence and autonomy of residents, because they support each person's ability to do things on their own. It may seem obvious that a toilet so low that it prevents an older person from standing up alone limits independence, but it does. Any non-prosthetic or unsafe design element has this effect. The safer the environment, the more likely staff are to permit residents to move about by themselves and make independent choices.

8. ***Comprehensibility*** Alzheimer's residents are not confused by everything around them. When the sounds, sights and smells they experience are familiar, they can cope with them and enjoy them. A common myth and mistake in design for dementia care is that if everything is sedate and bland, residents will be soothed. This is not the case. Soothing can be anxietyproducing if taken to an extreme. What is needed is to create enough activity to keep residents interested, and to make sure that the activity provided is understandable to them. Colors are fine, and traditional patterns for wallpaper are better than abstract patterns. A television is fine, with recorded films that have fewer rapid changes for advertisements are more satisfying than random violence and loud noises from the television. Comprehensibility comes from sensible, common-sense management

The final step in this journey of exploration is not complete. In a study supported by Grant AG12343 from the US National Institutes of Health/National Institute on Aging, a research team building on the earlier environmental model carried out research to determine correlations between certain physical environment characteristics, and health outcomes. As yet unpublished, the study's aim was to determine if there are systematic correlates between various design conditions and patient behavior in long-term care residences.

A reliable and valid Environmental Scoring Scale was generated and applied to 15 Nursing Home Special Care Alzheimer's Units. Behavioral and health data were gathered for nearly all of the patients being cared for in these settings. Hierarchical Linear Modeling statistical analysis techniques were employed, controlling for potentially confounding unit-scale factors such as level of staff training, Alzheimer focus of the organization's mission, and size of the unit, and for individual factors including stage of disease, age, medication usage, and length of stay in the unit. Significant correlates were found between specific environmental characteristics and patient anxiety, aggression, withdrawal, depression, and psychological problems.

Anxiety & Aggression tend to be lower in settings with greater bedroom privacy & with more personalization in bedrooms. Other correlates: Residents who had more problems falling down had greater anxiety and aggression. Residents who had problems with Activities of Daily Living had less anxiety and aggression.

Social withdrawal is reduced in settings with limited numbers of common spaces each of which has a unique character. Other correlates: In larger facilities residents tend to withdraw less. The longer residents live in a facility, the more likely they are to withdraw socially. This may be related to the progression of the disease.

Depression is reduced in settings with camouflaged exits that have electronic locks rather than alarms and delays. Other correlates: Women residents are more likely to be depressed than men. Greater depression is also positively related to taking anti-psychotic medications.

Aggression – verbal and physical together –is reduced in settings that are more residential then institutional. Other correlates: Men tend to be more aggressive than women.

Physical aggression does not appear to be affected by environmental design characteristics. Other correlates: The fewer problems residents have with carrying out Activities of Daily Living (ADLs) the greater the likelihood that they are physically aggressive.

Verbal aggression is reduced in settings where residents understand more of the sensory input they receive, and where the sensory input is controlled. Other correlates: The greater the staff ratio, the less verbal aggression there was. There

was more verbal aggression where residents fell more, where they were more anxious, were older, and took more anti-psychotic medications.

Psychological problems were lower where there was more privacy and personalization & where residents could understand the sensory environment. But improved walking paths were correlated with increased psychological problems. This requires more research. Other correlates: In facilities with a particularly Alzheimer's capable mission, there were fewer psychological problems.

In sum, this design for health journey is a continuous one to which many people are contributing through research, design, analysis, and practice. Each of us has to decide, based on our own understanding and analysis of a wide variety of data, whether environment can help treat certain diseases. In the case of Alzheimer's disease my colleagues and I believe the data to overwhelmingly demonstrate that environmental design can improve both the quality of life and health outcomes of those with this disease.

REFERENCES

This paper has drawn on a series of related articles written and co-authored by John Zeisel. These include:

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[4] This reference suggests that wayfinding loss is associated with damage to the parietal lobes. Frank J. ***Alzheimer's Disease: The Silent Epidemic.*** Minneapolis: Lerner Publications, p. 30.

[5] Frank J. ***Alzheimer's Disease: The Silent Epidemic.*** Minneapolis: Lerner Publications, p. 30.

[6] Albert MS. *Assessment of Cognitive Dysfunction.* In Albert MS, Moss MB, eds. ***Geriatric Neuropsychology.*** New York: The Guilford Press, 1988, p.68.

[7] This association is related to that of impulse control and thus is supported by Albert MS. *Assessment of Cognitive Dysfunction.* In Albert MS, Moss MB, eds. ***Geriatric Neuropsychology.*** New York: The Guilford Press, 1988, p.68.

The following reference associates the neocortex—"the thinking brain" (p. 14)—in the prefrontal lobes with controlling feelings from the amygdala, specifically the left prefrontal lobe (p. 26) in Goleman, Daniel ***Emotional Intelligence*** Bantam Books, New York (1995) Part One-Ch. 2 pp. 13-29

[14]For a fuller discussion of these criteria see Zeisel, John, Hyde, Joan and Levkoff, Sue, (1994). *Best Practices: An Environment Behavior (E-B) Model of physical design for special care units*, **In The Journal of Alzheimer's Disease Vol. 9, No 2, pp. 4-21,**