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Alzheimer's

Special Care Units

Submitted by John Zeisel, Hearthstone Alzheimer Care, Lexington, Mass.



The research presented in this submission does not involve the design of a specific place. Rather, it involves the design of a place type, namely, Special Care Units and Assisted Living Treatment Residences for people with Alzheimer's disease and related dementias. Currently, there are approximately 10,000 special care units in U.S. nursing homes and residential facilities and it is likely that another 10,000 or more new special care units (SCUs) and day care programs will be established in the coming years.

People with Alzheimer's and other dementing illnesses have extreme difficulty understanding and negotiating their environments, and there is substantial evidence that elements of the physical environment can either interfere with or support a resident's highest potential level of functioning. Moreover, many professionals and researchers believe that an appropriate physical environment can be an effective therapeutic element in the delivery of quality care and quality of life for individuals with Alzheimer's disease and related dementing illnesses. But while special care units typically cost more than one million dollars to construct, and renovated units can cost hundreds of thousands of dollars, these funds are being spent on designs whose effectiveness has never been validated.

The study *Assisted Living Treatment Residences for People with Alzheimer's Disease* was carried out in thirty special care Alzheimer's units in nursing homes in New England. The client (funder) was the National Institutes of Health and the National Institute on Aging (NIH/NIA) under its Small Business Innovations Research (SBIR) program. The research team consisted of an interdisciplinary group that was headed by John Zeisel of Hearthstone Alzheimer Care; the team brought together a psychologist, gerontologist, and researchers. The scope of the research was no mean feat — to determine if and how environmental design

affects the health and functioning of patients with Alzheimer's disease. It was an attempt to bring environmental-design research to the level of provable science.

A key reason for the lack of previous research is the intrinsic methodological difficulty of research in this field. Each special care unit is different from the next, and no one facility has more than a small number of residents. The five year study occurred in three phases. Phase I entailed the development of a testable model of interaction between the physical environment and the quality of life and health outcomes. The research team employed the established Delphi technique to build on the collective expertise of leaders in the field of dementia care and design, including their ethnographic and scientific research. (The Delphi technique is a method whereby research is distributed to a panel of experts who are then asked to re-evaluate the "untested complex hypothesis" based on the shared data; the method was used to determine which independent environmental variables would be tested.)

During Phase II of the research (1995-6), the team focused on developing reliable and valid measures for gathering data on the independent, mediating and outcomes variables. Instrument testing took place in thirty participating special care units throughout New England. Phase III (1996-7) then gave the team a chance to gather comprehensive health data on over 400 residents in fifteen of the thirty special care units. Final data analysis demonstrated that environmental factors have clear health and quality of life effects, independent of other quality care characteristics, which in effect, translate into the specific design interventions below.

1. Unobtrusive and secure exits reduce paranoid delusions, the sum of misidentification syndrome and paranoid delusions and social withdrawal. For example, in SCUs with exits that met the criteria for high quality, doors were painted the same color as the walls or as other residential doors in the SCU. The doors were located along the side of the hallways and were therefore less visible to residents than if they had been located at the end of hallways, where they tended to invite residents to use them to leave. Similarly, doors should be fitted with little or no hardware, which sends a clear message to residents to use the exits and leave the buildings.
2. Increased bedroom privacy and "away spaces" in common areas reduce verbal agitation among residents, physical agitation and aggression together, and misidentification syndrome and paranoid delusions.

facing page: **A typical bedroom in a Special Care Residence.**

Photo: Anton Grassl

this page: **A Music Room at the end of a hallway provides destination cue and adds to residents sensory awareness.**

Photo: John Zeisel

3. A manageable number and variety of common spaces in SCUs reduces physical agitation. Sometimes, too many common rooms could result in confusion. SCUs with a small number of rooms, for example a dining room, living room, activity room, and staff office, appeared to be more understandable and manageable by both staff and residents. A factor that affects this is the variety of decor, colors and surfaces.
4. Sensory environments where sights and sounds are controlled, yet understandable by residents, reduce misidentification syndrome of self and others. However, they tend to increase social withdrawal.
5. Supportiveness for resident autonomy through a safe, prosthetic environment reduced misidentification syndrome.
6. Aggression among people with Alzheimer's is reduced with the development of an environment-behavior model, which includes eight concepts — exit control, wandering paths, individual spaces, common spaces, outdoor freedom, residential character, autonomy support and sensory comprehension. The higher the quality on all eight environment variables combined, the more aggression and depression are reduced.

With great effort, this project was able to determine which design features and combinations of design features actually improve life quality and health outcomes for residents of specialized Alzheimer's environments.

Retreat Social Area. The enclosed living room with hassock provides a socio-petal gathering place that reduces social withdrawal.

Photo: Anton Grassl



This unique achievement in the field potentially impacts not only millions of dollars of construction, but also the regulations and approaches to care for this population.

The project also developed a unique research methodology that successfully addresses the difficulty of studying these facilities. This project adapted post-occupancy evaluation methods that have been developed for elderly and health care environments, using the latest bar-code reader and computer technology, to collect data to verify the relationship of the physical environments in SCUs to resident outcomes.

The long-term objective of *Assisted Living Treatment Residences for People with Alzheimer's Disease* is to develop a system of design criteria and tools that various care settings, including homes, adult day health centers, residential-care and nursing-care facilities, can use to create effective therapeutic environments for such individuals. Specifically, based on testing and modifying the therapeutic efficacy of the set of design criteria that the principal investigators developed over the last five years, the project will produce a manual and computerized data collection forms. When customized, each user will be able to complete a post-occupancy evaluation and/or design process for a therapeutic care environment. Families, facilities and design professionals will be able to purchase this system to evaluate existing, or to renovate or create new therapeutic environments.

Todd W. Bressi, Robert A. Gonzalez

Jury Comments

Clare Cooper Marcus: This is an excellent example of a very comprehensive multi-method piece of research, connecting design with actual health outcomes of Alzheimer's patients. It has very specific usable design applications, so in a way, it's exactly the sort of thing we were hoping for. This is absolutely the most comprehensive piece of research ever done, I think, on any user type-building, where they have documented many cases the physical facilities, then the staff reports on how the building is used, observation from the residents, resident profiles. They do a very fancy bit of statistical research that connects all these variables with the actual design of the place, and come up with some clear guidelines about how such facilities should be designed — what should be avoided in terms of confusing people whose memory losses are already pretty bad, and what should be included. It is not a case study of one place, that's what's interesting, it's a case study of many places using the same method.

Lawrence Halprin: There has been much discussion about the relationship between memories, which has much to do with a patient's early memories, and how they can adapt to that environment.

Clare Cooper Marcus: So you put in childhood things.

Lawrence Halprin: Yes, and also, you have a soda fountain, because when they were kids, they went to the soda fountain.

Clare Cooper Marcus: You put in flowers that were common in the 40s when they were children. I went to one recently where in the garden they had a 1950s red polished Buick in the garden, and the radio works, and couple go out and sit in it, and they go for a ride. They turn on the radio; and there's a spigot nearby with a sponge, and one man goes out everyday and washes the car down.

Donlyn Lyndon: My one hesitation about this project is that while there is an incredible amount of good serious ongoing research here, it is not put together with any of the organizing imagery that gets you into the research to connect with it. It doesn't surface illustrations that really are galvanized in the way that you just did.

Clare Cooper Marcus: Remember, this is written by researchers, so it's not making the leap into design that you might wish, but then, that's not what they do. It's going an awfully long way.

Lawrence Halprin: It doesn't take it to the other level, is what you're saying, of what you should do as a result of all this.

Samina Quraeshi: It does give criteria for how to deal with the disease, which they have done exhaustive pieces to organize how to take you through it; and they did talk about, even in the design submission, they talked about criteria to deal with it. The disappointing thing is that the photographs are of very ordinary environments, and not the Buick example.

Gary Hack: My first impression was that this is really symptomatic of one of the problems of doing environmental research, which is that results get reported in ways that a designer has a hard time making something out of it. Even the photographs aren't annotated, or in any way interpreted. I would have thought that one thing we've learned about environmental behavior research, is that the key thing is translating, making the connection.

But then I came to a somewhat different conclusion, which is that, these people are informing the administrators of homes and physicians and others, who are the real clients. The argument they're making is that the environment is actually a therapeutic device. In that sense, this is a very different way to go about the process of making better environments, which is to persuade people who are the clients that it's needed. Then, the designers get the room to try to innovative things.

Donlyn Lyndon: That's an extremely important point. One of the things about this is that it is connected research; it's connected with people who are going to be making change. It isn't something which sits off on the side and makes pot-shots. It's engaged.

Clare Cooper Marcus: This research has proved beyond a doubt that certain designs generate more agitated behavior, and certain designs make more people calmer. They've shown that environmental design is a treatment modality for Alzheimer's disease, not just drugs. The design actually affects the outcome. And that's astonishing.

This is a big issue now in terms of policy. It's a disease that is hugely increasing. More and more facilities are being built. And it's a user group which is tremendously impacted by their surroundings; whether the physical environment is right or wrong really impacts their mental health, the degree of violence.

Lawrence Halprin: This does something that I had not really thought about before. If you research something about health, and investigate how people with a disease react to alternate ways of being, then you could end up learning not how to cure people with drugs, but how the environment could help them accept their situation. It seems to me that a lot of the other research that we do about the environment is shallow compared to that.

I like this because it really digs deep into the human condition on a number of levels, and then gives you materials from which you can then derive what you should do to help people. This is a role model for environmental research on all kinds of levels of health and conditions that could lead us to all kinds of remarkably new ideas.

The other projects we've selected are beautiful, but this is very profound — especially what could come out of this as an idea, as a broader approach.