Making a Difference: Resident-Focused Models for Memory Care Facilities

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Winds of Change

For well over 30 years, design professionals have been aware of the growing proportion of the general adult assisted living facilities, for those who are challenged with different forms of dementia. The most common of these geriatric dementias is Alzheimer's disease (AD). A current estimate maintains that AD is affecting 5% of the population between the ages of 65 and 74 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003).

Incredible strides have been made in the knowledgebase for treatment and care of the residents challenged with AD. Empathetic and positive treatment guidelines have been developed for adult-living facilities as well as guidelines for shoring up the fragmented families stretched and stressed by this disease (Manepalli, Desai, & Sharma, 2009). The care facilities and operators are now retooling the construction guidelines to embrace this notion of care (Facilities Guidelines Institute, 2010). Multilayered efforts are being made by a cross section of professionals to create a new place: a place called home.

The song "Forever Young," written by Bob Dylan in 1974, poignantly expresses this aging pandemic in its call for society to be "forever young." Perhaps at 33, Dylan was beginning to see the shift in the cohort he was very much a part of, the aging of the "baby boomer" generation. It was a demographic he was right in the middle of when he penned the lyric for the song, a clarion prayer for strength, community, and honesty in the inevitable face of aging and death. His lyrics speak to the dignity of human condition when faced with change and death, the ultimate transition.

Whether one is a physician, operator, builder, architect, or interior designer, we are all tasked by future generations to get it right before this generation passes. How will we know whether our assumptions are correct and the decisions we made in implementing new design, business, and care models were correct? One of the primary tools available to the senior care and design professionals is critical participant observation. This type of reflective scrutiny is based on the observer embedding himself into the AD culture in an attempt to experience what the resident is experiencing. With empathetic, methodical, and consistent cyclical review, new models of treatment, management, and design will be developed and evaluated over time. It is time that is creating is the growing pressure to find solutions for the population shift from individuals who have been independently productive to those who require around-the-clock supervision and care. The demographic bubble is reaching critical mass. Bob Dylan is now 71 years old. He along with his burgeoning cohort of baby boomers may well overwhelm our health care and adult care infrastructure (Wahl, Rick, Paul, & Warner, 2004). It is time to develop a flexible, affordable model that will address the current needs of the baby boomer as well as anticipate the needs of future generations. It will be a model that will facilitate compassionate care for the individual and recognize the value of the nuclear family as it knits its disparate parts into a place called home.

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Strong Foundation

What can designers- and operators-assisted living and dementia care facilities do to create this place, this new home? First and foremost engaged professionals need to arm themselves with multidisciplinary sources of information. Fortunately, responsible and caring individuals have worked hard to generate a body of knowledge based on research, critical thinking, and creativity in the field of adult care (Tharp, 2009). This knowledge, filtered through analytical participant observation, will create the foundation on which this "place" will be built. It will be a refined mixture of common sense, evidence-based data, and understanding of the AD culture.

The word culture is loosely defined as the attitudes and behaviors and social patterns that are characteristic of a social group (American Heritage Dictionary of the English Language, 2011). Historically, anthropologists have imbedded themselves in other cultures, as well as various age groups within those cultures, to identify idiosyncratic traits and expressions of that culture to get a better understanding of greater humanity. Caretakers, operators, and designers of AD facilities must also continue to place themselves in the role of participant observers, working through the never-ending cycle of gathering information, evaluating that information, and finally developing useful treatment programs. The importance of the collaborative involvement of the medical, adult health care, and designers cannot be overstressed.

This continuous, holistic review of adult care methodologies, in the field, will provide the real-world foundation for improvement and excellence in treatment models and programs designed for the aging population (Altman, 2011).

Know the Truth

What have we learned in the treatment and care of AD and other dementias in the past 30 years is substantial. The scope of this essay will be limited to a succinct overview of what has filtered through the long process of research, trials of success and failure, and are considered some of the current accepted standards of design for the AD care unit. As a degreed Anthropologist, licensed Interior Designer (ID5268), and a supporting family member, I have spent countless hours at the bedside of three grandparents and a mother as they gradually declined. I have acquired both professional and first-hand knowledge in understanding the challenges faced by the elderly and impaired. My personal perspective has also been shaped by managing Dystonia (DRD), a movement disorder that primarily affects the movement, hand skill, and posture of the body. Learning to cope with this disorder and being an engaged caretaker for two generations of parents gives me a unique insight. The way I practice design has been enhanced tremendously by my life experience. I would encourage other allied professionals to spend time, energy, and imagination trying to understand the impact of AD in a deeper level, the user level. It would behoove all of us to imagine the experience of being a resident in an AD-assisted living community.

However, understanding what the resident is experiencing alone is not enough. The placemakers (operators, builders, architects, and interior designers) need to be mindful of their role as educators as well as implementers. Managing the expectations of what almost universally becomes a fragmented family is one of the keys to the successful transition of the resident. This partnering with the family will be critical in cases where anxiety, guilt, and depression accompany the introduction of the new AD resident into the assisted living center community.

P E R S P E C T I V E

Whether one is a physician, operator, builder, architect, or interior designer, we are all tasked by future generations to get it right before this generation passes. How will we know whether our assumptions are correct and the decisions we made in implementing new design, business, and care models were correct?

William Faulkner wrote in his 1932 novel *Light in August*, "Memory believes before knowing remembers." What was Faulkner trying to express? The past represents a collective body of experience. This collective experience provides a base point for future experience. This place of believing, this hard to find place, must be understood. It is a special place in all of us filled with life's memories of friends, places, and treasures of the past. That is where the work begins, before knowing remembers. It is a reflection on the power of memory. The tools we derive from this knowledge can be described as memory anchors. Memory is one of the last things a resident may be aware of and one of the first things the design team should consider.

I remember my mother Helen asking me, after a long arduous period in hospice lying in her uncomfortable bed in her shared suite to pray that the Creator take her that night. She was weary of the body and mind she felt trapped in. Although conflicted by her request, I did as she asked and knelt beside her bed, praying with her out loud that she be taken that very night and that she was ready for the next adventure. I was surprised when I felt her tug on my sleeve and whisper in her slow Alabama accent, "I don't believe I am ready quite yet." Then she smiled. Something had reminded her that life was good after all. That is the way it works sometimes. Memory believes and we smile.

I have heard similar stories from other families. How the resident's or a family member's personality or behavior can transform almost instantaneously, seemingly gone and then reappear before our very eyes. It is incumbent on us, as design and construction professionals, to understand how important memory is to the AD resident. Even to the last moment. That is why experts in caring for residents challenged by AD work so hard to create cues to bring back these memories. Indicators and evidence all underscore the value of incorporating the memory anchors into the design of these life centers.

The list of symptoms of the resident challenged by AD must be overlaid with the knowledge that each case is unique. The experiential emphasis of many of the care unit programs is a good place to begin the discussion of the design of the physical plant, the facility. Yet there is no typical. The question that arises from a programmatic perspective is how do we translate this knowledge of uniqueness into a constructible, well-programmed place? One of the answers is that the "place" must have flexibility designed into it, supporting activities that can be altered and changed as meets the needs of the unique resident.

Imagine the sets in a theater stage production, compounded with orchestrated experiences of color, texture, aroma, sound, and light. All designed to help the resident to feel safer, less anxious, rested, and healthy for as long as possible. The fit for the resident will be constantly changing as the decline of the AD resident's mental capacity continues through there residency, eventually resulting in death. This void that exists between the abilities of the residence will change over time. As the resident does less and less for herself, the caretakers and operators of the new home will fill the generated gap by implementing stage-appropriate social and maintenance protocol. The adult care industry has labeled the diminishing abilities of the residence and increased caretaker duties "aging in place" (Malkin, 2008). If designed well, the facility will support the fluid and shifting role of the caretaker. It will also protect the resident's sense of self and contribute to a dignified aging in place.

Build a Ladder to the Stars

Knowing we want to provide a place to fully support those with AD does not make it clear where to start. Where does the design team begin? We touched on the idea of observation. Accepting the validity of this

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is almost common sense when taken in the light of evidence-based results. It is helpful to approach this programming phase from a macro to micro perspective, from the desired community experience to the specific needs of the residents and the caretakers.

Currently, programming models are being discussed that encourage the development of communities within the community. These ''sub'' neighborhoods might be structured around similar interests, professions, and regions. These similarities, memory anchors or activators, would be the result of in-depth interviews with families and residents to identify the optimum resident experience, as well as compatibility with potential subneighborhood resident (Zeisel, 2006). The identification of life interests when combined with personality characteristic and identification of the level (stage) of AD progression will be necessary before the operators and caretakers will be able to structure a successful care program. Again, this process stresses the careful collection of information and the observation of family and resident responses. From this collection of personal information and information of what works and does not work for most AD residents, we begin the task of creating the resident's new home.

The successful AD care facility will provide a nurturing place. This ''place'' will ideally provide for the individual residents' need, facility's cultural structure, and be supported by the physical expression of the new environment. To better understand these qualities, they can be organized as individual aspects, cultural aspects, and environmental aspects.

Individual aspects are those that are focused on the individual resident's unique needs. These needs can be indentified through personal and family interviews, visits to the resident's immediate past home. These aspects might include the following:

- Real choices for the residents in unit plans, amenity packages, and neighborhoods.
- Remind and connect the resident with the intellectual construct of home.
- Meet unique needs of the individual: physically, socially, and spiritually.
- Identify the proclivities of the memory care resident and design with them in mind.

Cultural aspects are based on those needs that involve interface with the environment and other residents or staff in the facility and could include the following:

- Designed mindfully for the unique age requirements of hearing, sight, smell, and tactile experiences.
- Support emotional health and well-being of the resident, family, and friends.
- Reinforce the family connection and educate the family as well as resident providing complete information regarding programs and benefits of these programs.
- Be safe and secure.
- Reinforce independence and active living.
- Have a hospice program in place that would meet the needs of the resident and family, while interfacing with needs of the community and caretakers when they grieve.
- Collaborate with the development team to fabricate areas that will meet the requirements of programs that create a sense of purpose, achievement, and accomplishment.

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The physical environmental aspects of the facility are based on information collected from interviews, observations, and research of the resident past woven into the jurisdictional guidelines and standards of care. These would be expressed through interior and exterior architecture of the facility and could include the following:

- Design a unique and individual surrounding. The visual theme would be inspired by the resident's past and personal experiences.
- Provide the resident with opportunities for solitude and dignity, accessible through personal choice.
- Provide the resident with spaces for social interaction, accessible through personal choice.
- Protect the resident from physical trauma, social or environmental in nature.
- Utilize light, natural and artificial to benefit the resident.
- Provide engaging outdoor areas where there are opportunities for group socialization and activities as well as solitude.
- Build in spaces for staff retreat and meditation.
- Provide spaces, elements, and view vistas that engage the resident and do not encourage the thought to leave.
- Support the ability to change elements in the future.
- Include clear simple way-finding cues in the architecture and color.
- Be mindful of the importance of color from the elderly perspective.
- Select furnishings, accessories, and finishes that address the realities of the AD resident facility, including but not limited to soiling, flammability, fluid barriers, accidental impact, and antimicrobial finishes. Be aware that bed requirements for the aged are unique and specify accordingly.
- Develop the proposed facility around a sustainable model.

An understanding of the aforementioned list of spatial programming and cultural and resident care protocol provides the designer with a body of critical information. If these factors are carefully incorporated into the design process, the design and care teams will have an environmental and cultural structure that will be more flexible and effective in caring for the residents and families managing the symptoms and impact of AD.

Climb on Every Rung

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What we do know now and can currently influence the process of refinement and construction for a new generation of AD facilities. Units that will be able to provide a place uniquely responsive to the umbrella of ailments described as dementia, including AD. The development of this process, like climbing a ladder is best done methodically and safely, one rung at a time, carefully assessing through observation and collection of evidence-based information. Fully understanding the needs and behaviors of the AD resident is critical to design. Missing any of the rungs might result in falling short of the expectations of the caretaker, resident, and resident's family. The facility must reflect a clear understanding of federal, state, and jurisdictional regulatory guidelines. It must be responsive to the behavioral tendencies of the AD resident. Most notably the following:

- Emotional fluctuations and states, including depression, anger, and paranoia/suspicion.
- Physical tendencies such as repetitive behaviors, wandering, hoarding, intimacy and sexuality, violence, and catastrophic reactions.
- Hygiene, nutrition, and wellness issues.

The key to developing solutions can often be found through a process of observation and methodical analysis. This process is a precursor to evidence-based design.

An example of how a facility designer would deal with wandering behavior would be to observe within the facility and actually study the wandering resident's behavior pattern. In one of the facilities I have visited, there was a patient hovering in an offset corridor outside of the caretaker's station range of vision. The entry point to the ward had two doors with glass lights. When the caretaker unlocked the door remotely two things occurred, an indicator light went off and a subtle bell tone announced the opening. Yet, I noticed the resident started moving toward the door before the light or bell announcement occurred. The cue that started the wanderer toward the secured entry was the movement of the caretaker when she dropped her head to speak into a microphone assembly to identify the visitor. When the caretaker executed the entry ritual, the resident walked with eyes carefully toward the junction of the floor and wall, no other eye contact. She usually made it to the door right as it was being opened by the visitor. Depending on the caretaker, the wanderer would either be called back (sometimes successfully) or escorted away from the door.

I witnessed this movement ritual several times and never saw the resident escape. I asked the caretaker about the behavioral pattern and was told the wandering resident had only slipped out a couple of times. After the conversation, I realized the caretakers felt that the procedure was successfully managing the symptom. In fact, the conditions for success should have been reviewed with an eye to modify the behavioral pattern. The ritual itself created purpose but ended in the resident's failure to achieve the desired goal, escape. Could this pattern have been shifted with alternative design strategies? From the caretaker's perspective, time and attention were spent on the recurring ritual, ultimately hurting staff productivity. Some creative thinking would suggest alternate solutions that would not result in lost productivity. Perhaps if the door was placed so the resident was not aware of the entry/exit activity, the need for behavioral response and staff inefficiency would likely be eliminated. A less expensive solution would be to use doors without the inset glazing so that no outdoor activity would beckon the wandering escape-minded resident. A simpler possible solution would be developing a modification to the caretakers cue behaviors and security speaker system. The key to develop solutions can often be found through a process of observation and methodical analysis. This process is a precursor to evidence-based design.

Do for Others and Let Others Do for You

In my time in the adult care facilities as an observer, art therapy instructor, and family member, I have noticed the very real value in empathetic connection with the residents, particularly as they face the reality of death. I have participated in discussions with adult care professionals in matters of senior adult environments and lifestyles. The closeness of death was difficult for some to face without someone near by. These are the quiet moments where family and individual dignity must be protected. At the end of their lives, my grandparents and mother benefited from hospice, a final stage care system. Hospice care may begin when the resident shows common signs and symptoms that typically indicate when she is entering the final stages of life (Cummings & Frank, 2002). It is a system built around family and faith and affirms life. It does not hasten or postpone death. Rather, it accepts death as the final stage of life with compassion and support. A thorough understanding of this process will benefit the design and care team in modeling an improved social and environmental memory care model. There may be significant procedures that require review and thought on this issue. Questions regarding the impact of death on other resident ''neighborhood'' members would ideally be addressed at a minimum with staff caretakers and operators. Issues such as grief management for staff and residents, dignified treatment of remains, and remains transportation routes should be discussed in the programming phase of design.

The operators, caregivers, and design team need to collaborate carefully to create a productive, safe, and healing environment. Design will not alleviate resident symptoms, but evidence suggests that the well-designed facility can effectively diminish the intensity of these symptoms, contributing to overall wellness. Being fully informed regarding the state of the art in treatment methodology, activity trends, outdoor space, and garden designs is imperative. Fortunately thanks to the work of individuals such as Elizabeth C. Crawley (1999), Victor Reigner (2002), Claire Cooper Marcus and Barnes (1999), Uriel Cohen and Day (1993), and many others, the design community has been endowed with a growing collection of information and evidence-based information that has not traditionally been available. Using the tool of participant observation to assist in the design of a new facility or modify an existing facility can minimize the impact of most behavioral tendencies of the residents through the understanding of them. 1912 Nobel Prize winner Alexis Carrel was fascinated by the process of aging or senescence. In the delivery of his Nobel acceptance on wound research he stated, "a few observations and much reasoning lead to error, many observations and a little reasoning lead to the truth."

Accurate observation and self-monitoring procedures will give the AD-assisted care facility's operators, staff, caretakers, and design team a consistently better understanding of their procedure's effectiveness and reveal new potential procedures that the community can benefit from. These collected observations will build the body of information and reveal new and better treatment alternatives for the care and design of the AD-assisted living communities. It is imperative that the process of creating newer, more effective models, and post-occupancy observations be pushed aggressively. These new facilities can be models of compassion, safety, and care if we collectively will it. Suffering can be alleviated now. I cannot think of a higher reason to design, construct, and create these environments. Can you?

May you build a ladder to the stars
And climb on every rung,
May you stay forever young.

Taken from Lyric to "Forever Young," Bob Dylan (1974)*

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