The Cultural Context of Aging

WORLDWIDE PERSPECTIVES

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CHAPTER 44

Beyond the Institution: Dementia Care and the Promise of the Green House Project

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Liberating dreams are those which keep you vigilant in a sometimes miserable existence.

They are the dreams you know when you lose yourself in a book, enjoy a piece of music, dream about falling in love. Liberating dreams hate all those things that keep us grounded in life.... and we emerge rejuvenated from any liberating dream.

.... the non-liberating dream ... is the dream which.... advertising tries to sell you.... telling you you will achieve happiness if you buy....

The nonliberating dream is everywhere today.... Everyone is selling it.

Vassilis Vassilikos 1996

The long-term care industry in the United States is facing a crisis. Not only is there increasing difficulty meeting the needs of a growing population of elders, but the very quality of existing care remains poor in many facilities in spite of two decades of efforts to correct shortcomings (see Polivka this volume, this section). The year 2007 marked the twenty-year anniversary of the federal Nursing Home Reform Act (as part of OBRA 87), which put in place historic regulations to address serious issues of neglect and abuse in nursing homes and to establish standards to promote both quality of care and quality of life.[1] Unfortunately, extensive noncompliance with those standards, chronic understaffing and turnover and ongoing confusion, even among professionals, about what actually constitutes quality have impeded the realization of OBRA 87's promise, particularly in dementia care (McLean 2007a).

During these same twenty years, the visionary work of British psychologist Thomas Kitwood (1989, 1997), and others, has led to optimistic reconceptualization of the person with dementia and her care (cf. Shomaker 1987; Sabat and Harré 1992; Hughes 2001). This has placed new emphasis on the *person* with dementia, as a dignified social being with a will and ability to meaningfully

communicate even late in the illness (Killick and Allan 2001; McLean 2007b). It has also encouraged a shift from *instrumental* care, focused on custodial maintenance and medicalized *control* of the body and behaviors (as *symptoms*), to a person-centered approach to *quality of life* and understanding behaviors in the context of the person's life experience. The very locus of dementia care in a medicalized institutional setting, like a nursing home, has also been questioned since many elders with dementia lack other pressing needs for ongoing medical attention. Such settings nurture neither care receiver nor giver and may be viewed as depressing by families, who often prefer smaller homelike settings (Greene et al. 1998; Hodder 2004).

THE BIRTH OF A CULTURE CHANGE MOVEMENT

In the United States, these shifts have been promoted by advocacy organizations like the National Citizen's Coalition for Nursing Home Reform (NCCNHR) and innovative providers and other advocates of "culture change" (CC), largely through a group called the Pioneer Network.[2] More recently, the Centers for Medicare and Medicaid Services (CMS), which serve as both the federal regulatory body and the major funder for long term care, have also encouraged the adoption of CC reforms consonant with the goals of OBRA 87.

This changing climate has sparked consumer demand for new "person-centered" care, and many new "dreams" are being fashioned and marketed as person-centered approaches in long-term care (McLean 2007c). Some, like PACE (Program of All Inclusive Care for the Elderly), provide a full spectrum of long-term care directly in the home and the community. Others offer new caregiving models and training approaches for long-term care facilities, such as "dementia care mapping" (Innes 2003),[3] innovations for humanizing nursing homes like the "Eden Alternative" (Thomas 1996),[4] and new designs for creating smaller, more sociable "neighborhoods" or "households" in a larger residential unit (Shields and Norton 2006).[5] Promoting privacy, individualized care and respect for the dignity of each resident, many of these options have appealed to private-paying families, often seeking assisted living options developed for elders less physically and cognitively impaired than those now typically in nursing homes (Eckert and Morgan 2001; Ball et al. 2005). Others, like Green Houses (GH), developed by physician William Thomas, founder of the Eden Alternative, were intended to virtually replace[6] nursing homes of the future and were designed for all elders, regardless of income, as a "wonderful kind of dream idea" (Thomas 2004; Thomas this section; Kane et al. 2007).

This chapter will consider the potential of the Green House Project (GHP) as a liberating dream for persons with dementia, who constitute a majority of people in nursing homes today. I begin by briefly describing the unique problems and care needs of people with dementia. Then, I offer conclusions from my own research comparing a dementia unit dominated by a biomedical approach to one with a more holistic, person-focused one. Pulling from my case studies and other work on person-sustaining environments, I then consider

the potential of Green Houses for long-term dementia care in the future (see Thomas this volume).

DEMENTIA AND THE CARE NEEDS OF AFFECTED PERSONS

Senile dementia is considered a progressive disorder of older persons (sixty-five and older) that varies in symptomatology, rate of decline and length and course of illness from three to twenty years (Richter and Richter 2002:35; see also Traphagan this section). Most common impairments occur in cognition (thought processes and organization), language, behavior, orientation to time and place and often mood. The ability to recognize and use objects may also be impaired. Taken together, these changes affect people's activities of daily living as well (ADLs and IADLs).[7] Memory (short term and, later, possibly long term) is affected, leading to distortions in the sequencing of events. This shatters the person's confidence about the past and produces a sense of fragmentation of self. Moving to an unfamiliar institutional setting often exacerbates confusion and fragmentation and promotes cognitive and social decline. Over time, persons with dementia may develop problems recognizing those who had been close to them, fracturing relational ties to loved ones as well. In very advanced dementia, incontinence, hallucinations and the inability to speak, walk and swallow often occur. This typically necessitates additional care and may involve increasing resistance from the elder, unless effective, trusting relations are established with the caregiver.

Impairments can be frightening to elders, particularly earlier in the illness when they have the most awareness and fears of what might follow; this creates a need as well for considerable emotional support. Recognizing failing abilities may lead to loss of self-confidence and self-esteem, especially as others become aware of these. Incontinence may bring shame and further erode self-esteem, and efforts to hide accidents may make the person appear even more impaired.

Elders with dementia respond in different ways to their growing dependence on others; wishes to retain independence may affect their willingness to accept help from caregivers. Those who have been independent may be especially aggressive with caregivers who come to cleanse or toilet them. Their responses have typically been interpreted as *symptoms* of their disease, not as the understandable effort to retain some control and independence. Confusion, related to memory losses and fragmentation, often leads an elder to display behaviors that appear disturbed.

Given the multiple personal and social losses that occur in dementia, its most profound impact is in shattering the person's sense of self, history and relationships—the defining elements of personhood. This is why researchers have long urged that the most pressing needs of someone with dementia are *for person work* through an enduring relationship with a supportive caregiver (Gubrium 1975; Kuhn 2002:165–66; Eggers, Norberg and Ekman 2005:343). Yet regulations, staffing levels and institutional prescripts have continued to place emphasis instead on standard physical and custodial *body work.*

My own observational research, summarized in the following discussion, found dramatic differences between residents on two identical, innovatively designed units with different approaches to care—a biomedicalized approach emphasizing *body work* and a *person-centered* approach where disturbed behaviors were viewed as more than just symptoms. I introduce this material for three reasons. First, I want to illustrate that physical models and structural designs alone are no guarantee of quality care; the underlying philosophy and values make greater difference in optimizing dementia care. Second, the unit that allowed for better care and resident outcomes adopted a philosophy of care consonant with that of the GHP. Finally, the care issues raised by the cases in both units provide serious care challenges. This offers an opportunity to consider the capacity of the GHP for handling them.

RESEARCH OF TWO SPECIAL CARE UNITS: THE HISTORIC SLEY UNITS

Setting of the Units: The First Special Care Units in the United States

In 1992–1994, I conducted research on the first two special care units in the United States designed with special environmental features to help people with mild dementia maintain their autonomy and cognitive and functional capacities. The units opened in 1974 due to pioneering efforts of Powell Lawton.[8] By the mid 1960s, Lawton and his colleagues had already envisioned an environment that challenged standard "dehumanizing" custodial care conducted "in the name of easing the effort of staff and maintaining cleanliness at all costs" (Liebowitz et al. 1979:59–61).[9] Extremely innovative for its time, this new approach was the product of a decade of research, years of planning and considerable input from international experts in gerontology, geriatrics and architecture, and of staff, families and residents.

The units were designed to compensate for deficits, while offering stimulation to help residents maintain existing capacities. Special design features, such as color-coding of rooms (to enable residents to locate them) served as visual memory aids to enable the residents to negotiate the environment (Liebowitz 1976). An open floor plan allowing visibility of activities was intended to socially cue people's memories, spark interest to engage in activities and passively stimulate residents for possible therapeutic effect (Liebowitz et al. 1979). A kitchen for cooking activities, pleasant lighting features, bright color schemes and a gazebo with safe plants were included to add meaning to elders' lives and provide cognitive stimulation (Cohen and Kirsten 1992:131). Residents dined together in one section of the floor around large tables.

By the time of my study, however, the intended use of the innovative floor plan, with all its special features, had dramatically changed, together with the level of impairment of residents who occupied the units. Many of the special design features, like the color coding of rooms and the kitchen, were either

gone or in disuse. The gazebo was now used strictly by staff as a getaway, and residents were forbidden to go there. As residents became more impaired, the open design resounded with noise they produced, compounded by other institutional sounds from staff and visitors, the loudspeaker and the floor cleaners. To avoid conflict during meals, residents were now seated alone, or at the same small table with another resident. As residents became more cognitively impaired and less ambulatory, a number of demographic, fiscal and institutional factors conspired against preserving the original plan. The vision, energies, wisdom and dreams of the early planners were no longer benefiting the elders, who, like their families and most of the staff, knew little of the units' illustrious beginnings. The value of special care units themselves as superior facilities to support persons with dementia also was called into question. In one of his last published articles, Powell Lawton himself concluded that special care units could not be distinguished for offering better care (2001:158).

CASE STUDIES

Background to My Study

By the time I began studying the units, researchers were beginning to suggest that behavioral disturbances (BDs), such as fighting with caregivers, which were previously regarded as disease *symptoms*, might actually have some reasonable basis in the person's struggle to regain lost autonomy. Other BDs, such as repetition or agitation, might reflect the person's struggles both with cognitive impairment and the loss of social regard by others. Typically, confusion, evidenced by "wandering," had been seen only as a symptom. However, studies were beginning to suggest that a person did not wander aimlessly, but toward a familiar place, like "home," for example, to prepare her husband's dinner, or the bus stop to meet her children, forgetting that her husband had died or that the children were now adults. It was as if the resident found herself in a time warp.[10] So while the behavior seemed to lack sense in the present context, it clearly had some historical relevance in past contexts. Thus, behaviors that had been regarded as meaningless were beginning to gain credence as plausible efforts to *communicate* genuine needs, maintain a sense of self or revive personal stories (Sabat and Harré 1992; Hughes 2001).

One goal of my work was to study problematic behaviors in the contexts in which they had occurred—locations (the resident's room or dinner table), conditions (being pressured to wake up), persons involved (a family, nurse, NA) and time (upon waking, before dinner)—and the resolution (staff intervention, family involvement) that followed. I also tried to learn about the history of the person and more recent events that might have affected the behavior. To do so, I talked with the person (if possible), the family and staff and read their medical records.

The units each housed forty residents and were identical in design and admissions criteria: severe dementia and BDs (often verbal or physical aggressiveness). Their residents were the most severely impaired in the nursing home,

whose disturbed behaviors led to their admission there. The median age on Sley 1 was 86.5 and 88.5 on Sley 2. Both units had somewhat higher than usual portions of female residents, with 80 percent females on Sley 1 and 85 percent on Sley 2.[11] Both units also enjoyed similar staffing levels: a head nurse (an RN) on the day shift, responsible for setting the philosophy and organizing the delivery of care; a nurse who served as care manager on all shifts and during weekends, responsible for supervising staff and dispensing medicine and treatments; five Nurse Assistants (NAs) during the morning and evening shifts and one or two at night; a part-time bathing assistant; and professional staff (physician and physician assistant, psychiatrist, activities specialist, nutritionist and social worker) who regularly visited the units.

However, more residents on Sley 1 were ambulatory and somewhat more behaviorally disturbed than on Sley 2, and the unit overall seemed noisier. After visiting the two units, I also discovered differences in the tenure of staff and residents and evidence of differing philosophies of care by the head nurse, who was responsible for structuring and prioritizing care. These differences, I felt, warranted a comparative study as they might contribute to differences in the residents' behaviors. I thus decided to split my time on the two units, spending nine to ten months on Sley 1 and then the same amount of time on Sley 2. I began by conducting general observations of the lives of the residents, their families and the staff. After a couple of months on each unit, the staff helped me select seven residents with severe BDs to study intensively over all shifts for one month each. The following focuses on one case study from each of the Sley units as an example for comparing the two approaches to care. In addition, I offer a second particularly challenging case from Sley 2 in considering the demands on the GH as a long-term care model.

Sley 1: Margaret—Unquieting Noise

> My greatest fear is the inability to take care of myself ever.
> They made this lovely place for the people, but it isn't though.

Margaret was the first person I came to know on Sley 1. During my first months there, she would regularly roll her wheelchair over to chat. Despite some confusion from her dementia, she was very pleasant and welcomed company. She was also socially sensitive with me, taking care not to interrupt me if I looked busy. The first time we met, she asked where she could find the trolley station, as it was getting late and her mother might worry. I explained I was new here and did not know. On later visits, she described her mother's lovely flower garden or the book club over which she had presided. At eighty-nine, she had survived two husbands and was childless. However, her brother and sister-in-law were very concerned for her and visited her frequently.

Margaret had lived in the nursing home complex for eight years, first in an apartment and, after her arthritis worsened, in a nursing unit. Previously independent, this move upset her. She lacked dementia at the time, but moving

symbolized loss of autonomy and led to depression. A few years later, following hip surgery, she declined cognitively as well. During her last year on her unit, she began to call out loudly to staff when she was hungry or uncomfortable. This disturbed other residents, and she was placed on a small dosage of an antipsychotic medication (20 mg of Mellaril[R]) and transferred to Sley 1 several months before I started my research.

Except for her occasional calling out, Margaret was not seen as a difficult resident. However, during baths, she would cry out loudly, and her cries were becoming more intense and generalized to other times. Her sister-in-law, who was a social worker, asked to observe her bath to see if she could find some triggers to Margaret's screaming. She found that Margaret started screaming only if she got water in her ears. To prevent this from happening, her sister-in-law brought in a rubber sunbonnet she had purchased on a trip to a tropical island specifically for Margaret. It fit snugly around Margaret's head and blocked her ears from the water. Much to her surprise, Hazel, the head nurse, could not promise it would be used.

Hazel later explained to me that locating the bonnet and using it was just too time-consuming for Rhonda, the part-time bathing assistant who bathed eight residents a day. Rhonda had to complete the eight baths within 3.75 hours or the nursing home would have to pay her benefits, which they tried to avoid. If she exceeded her allotted time, her evaluation would suffer and she could risk losing her job. Rather than let another resident delay in getting a bath, or leave bathing to the already overworked nursing assistant, Hazel encouraged Rhonda to complete her standard bathing tasks, skin checks, vital signs and dressing routines rather than to spend time with the sunbonnet, even if it improved Margaret's bath. Indeed, the one time that Rhonda tried it, Margaret was calmer and did not scream. Still, to Hazel, Margaret's problem was much larger than anything that could be solved by a "localized environmental accommodation," since to her, it stemmed directly from the dementia. It remains unclear whether the bonnet would have made a more lasting difference since Hazel no longer permitted Rhonda to use it.

Around this same time, a six-month psychiatric consultation, required by OBRA, led to a series of medication changes that exacerbated Margaret's symptoms. In keeping with OBRA's mandate to use milder psychiatric medications and smaller dosages, the psychiatrist switched Margaret to Buspar[R], a milder antipsychotic medication, which took six weeks to take effect. Almost immediately, Margaret complained about dizziness. She became intolerant of other residents and started yelling incessantly. With every medication change, her condition worsened. She became more confused and could no longer converse, recognize her family or feed herself. When other medications were added, she began to hallucinate. Her family insisted that she be returned to her original medication, and after twenty-nine changes and a nine-fold increase from her original dosage of Mellaril, she temporarily improved, although not to her previous level.

Then suddenly, she declined sharply. She tightly shut her eyes and just shouted or sang loudly, shutting out the world. Her brother appreciated the

existential quality of her new behavior, which effectively separated her from an environment of which she would say, even in her deteriorated state, "I don't like this place; it's the *whole* thing I don't like." Hazel and her staff did not acknowledge the validity of Margaret's perceptions; to them, her decline was the predictable outcome of someone with dementia. However, for Margaret, constrained as she was, her increasingly pervasive outbursts were her only available means of articulating her existential condition.[12] Outbursts of this quality were not amenable to silencing via magic bullets.

Sley 2: Mrs. Fine—the Wicked Witch of the West

> I have nothing—just this, while they have a very big house.
> That is their world, and this is mine; I like it here.

When she was first entering the nursing home three years earlier, Mrs. Fine scored only four out of thirty possible points in the mini-mental status exam (MMSE) and another cognitive test.[13] Mrs. Fine stated that her husband had died a year before, when it was actually twenty years, and she seemed confused and hostile. At eighty-five, she had endured the loss of a second close male companion, six hospitalizations, a stroke and a broken hip. Left with a severe speech impediment and the inability to walk, she became depressed, more cognitively impaired and began to hallucinate. These led to brief psychiatric hospitalizations, which her daughter ended because she could not bear the artificial effects of the antidepressant on her mother: "I wanted my critical mother back!" While this endeared her to her daughter, it gained her the reputation in the nursing home as the "wicked witch of the west."

Mrs. Fine had lived on two other units before Sley 2, becoming increasingly aggressive. A tranquilizer at her previous unit disturbed her gait and she was restrained in her wheelchair. She began to disrobe in public, became incontinent and was in need of total hygienic and grooming care. At that point, she was transferred to Sley 2. Jenny, the head nurse there, determined that Mrs. Fine's anger stemmed from her awareness of her loss of control and dependence on others. She secured Mrs. Fine's cooperation for physical rehabilitation. As Mrs. Fine began walking again with the aid of a walker, her mood improved, so she was taken off the tranquilizer. An observant NA saw her remove her diaper to go to the bathroom and after additional assessment, she was deemed continent and the staff were alerted not to use diapers. They were also asked to respect Mrs. Fine's wishes to gain help with hygienic care only in the evening, the only time she wanted it. Mrs. Fine improved so markedly that staff visiting from other units could not even recognize her.

Because she had significantly improved, her family encouraged staff to transfer her to a unit with higher-functioning residents. After moving, she declined and once again was restrained in her wheelchair. She returned once again to Sley 2, this time to a highly coveted private room. With patience from the staff, she restored some autonomy, gained confidence and resumed walking

independently. Her speech *aphasia* (difficulty in finding words)—brought on by a stroke—had worsened, but the staff were patient and supportive of her efforts to talk. However, following hospitalization, due to a possible stroke, she became more aggressive again and also became obsessed with photographs of family members and with fears for the safety of her daughter. She also became paranoid about others going through her belongings and seemed more deeply depressed. The psychiatrist and unit physician disagreed about how to handle this. The physician had known Mrs. Fine since her initial admission to the home and felt her behavior was only marginally more extreme than before and that the unit staff could handle it. He did not want to risk her losing functional improvement by introducing psychotropic medications.

The psychiatrist was also aware of risks in using antipsychotic medications with elderly patients, especially when dementia is involved. Tranquilizers can lead to dizziness and falls and even have disinhibiting effects, like disrobing. Antidepressants can also increase agitation or confusion. Still, the psychiatrist did not like to see Mrs. Fine suffer, so she convinced the unit physician to start Mrs. Fine on an antidepressant. In fact, Mrs. Fine's mood did improve, her depression lifted, and her paranoia diminished. She also viewed the nursing home more positively: "I like it here; I have two good doctors here." Her mini-mental status exam showed higher functioning than at any time since her admission several years earlier, and she developed a strong relationship with the psychiatrist. However, a month later, after another hospitalization for a urinary tract infection (UTI), she became irritable, so her physician withdrew the antidepressant, but her mood remained unchanged. "This," he insisted "is just Mrs. Fine."

A few weeks later, she was looking quite content, glad to be back from the hospital, but disappointed that her daughter had not yet visited her. However, this time, instead of worrying that her daughter was dead, she calmly observed that it did not really matter "as long as she's okay."

Mrs. Fine told me she had torn off a sign from her door. The sign, "Nurse in Charge," had been placed on her door because of a suspected infectious virus she might be carrying. "I just tore the 'Nurse in Charge' sign off my door," because, she confidently explained, *"I'm* in charge."

"You are protesting?" I asked.

"Yes," she firmly stated.

It appeared she was back to her old spunky self.

CONTRASTS AND IMPLICATIONS OF THE TWO APPROACHES

In contrast to the staff of Sley 1, who disregarded Margaret's complaints, those of Sley 2 not only responded to Mrs. Fine's wishes, but also were attuned to her history, personality and preferences. This led them to design and adjust her care so as to maximize her functional capacities while supporting her as a *person*, with all her foibles, including her occasionally sour disposition. Her treatment team were even willing to revisit possibilities like physical therapy, years after other clinicians had abandoned it as an option, to help her restore

some independence, viewing this as vital for increasing her quality of life. This involved *working with* Mrs. Fine to help her attain greater well-being. The head nurse could look beyond the dementia and try to understand Mrs. Fine's anger as legitimate in light of the loss of her highly valued independence. This was in striking contrast to Mrs. Fine's experience at previous units, which like Margaret's, "treated" her existential protests as medical symptoms needing containment and restraint.

Rather than suppress Mrs. Fine's expressions of anger, her care team appreciated their legitimacy. To improve her functioning, they tried to determine, and then move to correct, what stimulated her disruptive behaviors. This approach served to preserve—not pathologize and suppress—the obdurate, cantankerous person, however difficult, who had always been that way. It also helped her function at a level unimaginable by staff from other units.

At Sley 1, residents' behaviors were attributed entirely to medical causes, and their *personal* needs were invalidated or relegated as secondary to the *instrumental* needs of the staff and institution to efficiently complete care tasks. What differentiated care on Sley 2 from Sley 1 was the willingness of the staff to see residents as *persons*, beyond their dementia, and to flexibly organize care to identify and correct not only medical problems, but excess disability[14] not related to the dementia, like vision problems, to optimize their life quality (McLean 2007b:23).

In yet another particularly challenging case in Sley 2, the care team expended extraordinary effort in helping Mrs. Gold, a woman who had become very unsteady and whose sleep pattern had become reversed. To protect her, staff initially restrained her in bed, but after she climbed over the bedrails and injured herself, her physician gradually withdrew her medications, which he suspected had increased her unsteadiness. Meanwhile, nursing staff gave her one-on-one attention and used less invasive protection, like a floor-level bed, and naturally tired her out by walking with her while conducting their rounds. This was time consuming, and one nurse did quit, but the situation was resolved within two months. Through experimentation and devoted personal attention, the staff restored her ambulation, sleep routine and calmness, without placing her at risk. While the demands on the staff were immense, so were the positive outcomes.

The challenge is to develop person-centered care that may be high intensity at times, but sufficiently productive that both the resident and staff are rewarded. This requires adequate staff to prevent burnout and skilled specialists to guide an optimal outcome. Any model of residential care, like the Green House, that offers skilled nursing care must be able to address such complex challenges in promoting quality of life for residents, even during difficult periods.

THE GREEN HOUSE PROJECT (GHP)

GHP is an innovative approach to long-term care that, under federal regulations, fully qualifies as skilled nursing home provision.[14] Green Houses were

deliberately developed to meet regulatory and reimbursement criteria to be accessible even to the indigent elderly. Green Houses, however, were designed as intentional communities that depart radically from traditional nursing homes both structurally (in physical environment and organization of care) and philosophically. Green Houses were developed by William Thomas, founder of the Eden Alternative, a previous "culture change" (CC) approach designed to humanize nursing homes by promoting relationships and life. Eden intended to eliminate loneliness, helplessness and boredom in residents, to bring life through plants, animals and children to the home and to empower both residents and frontline staff to make everyday decisions. Despite the international popularity of the Eden Alternative, Thomas found progress to culture change slow, evaluations unimpressive, and by 1999 he became convinced of the need to fully redesign the nursing home from the beginning in order to effect the kinds of changes he had in mind.

What initially motivated Thomas to design these CC initiatives was his encounter with an elder at a nursing home where he worked in the early 1990s. As he prepared to leave her bedside, she grabbed his arm and uttered, "I'm so lonely" (Thomas 2004:180). From that haunting moment, he has been on his own CC journey, with the mission of liberating elders from institutional existence, promoting instead a new world vision of interdependence and well-being among generations, what he calls "eldertopia." This involves sustaining and protecting elders, who in turn impart wisdom and foresight to the community (see Thomas this section).

For Thomas, the GHP was one vehicle toward achieving this vision, an "opportunity ... to transform the *dream* of a warm, loving, nurturing sanctuary into a specific *innovation* that can change how we age" (Thomas 2004:222). These affect size, design, conception of residents' needs, staffing roles and delivery of expert services. Green Houses are designed as places where assistance with daily living and clinical care are available, but where the focus is not on care, but on life and relationships. Thus, by design, it redirects attention from the instrumental care task in the realm of timed work, to the person in the realm of life as nonprescriptively lived (cf. McLean 2007a).

To achieve this, he adopted a philosophy emphasizing residents' strengths and freedom to choose, used the principles of *warm* (small and nonhierarchical), *smart* (technology to foster well-being) and *green* (connection to the living world) in designing the physical environment. To create a new notion of care in this setting, Thomas evoked the mythical creature of the Shahbaz, the royal falcon who stood as protector, sustainer and nurturer of people, as the model for the *assistant* or helper of elders. He was careful, however, to distinguish *protection* (as a form of reciprocal support for those cherished) from the *restraint* and control more common in nursing home care (Thomas 2004:259–261). *Sustenance* involved friendship, homemaking and the pleasure of sharing food (what he calls *convivium*). *Nurturance* above all was relational, holding the capacity for mutual fulfillment in carrying out even the most mundane routines. Through mutual cooperation with elders, the Shabaz is invested in the enormous charge of creating a new societal understanding of elderhood.

Structurally, the GH is deliberately small[15]—a self-contained house for seven to ten residents. Ideally, it is located in a neighborhood and blends in architecturally with other homes. Up to ten private bedrooms with full bathrooms surround the heart of the home—the hearth room and kitchen. Food is cooked in the kitchen, as one would expect in one's home, and residents can participate in preparation and delight in the sensuousness of the smells of food cooking. Because of the small distance of travel to the kitchen and other places within the home, mobility is encouraged and wheelchairs are often not needed. Safety features are built in, and there is access to an outdoor garden and patio. The appearance of medical apparatuses is deliberately avoided by eliminating medication charts (keeping residents' medication cabinets in their own rooms instead), replacing a visible nurse's station with a closed-off den and using wireless call systems and silent pagers. Each bedroom has a track for a ceiling lift to assist with lifting residents from their bed to a wheel chair. The Green House may incorporate smart technology as well, to enhance communication, for example, using interactive television to connect with remote family (Rabig et al. 2006:534). But while the Green House may have the markers of a home, Thomas is clear that it is "not a family dwelling," but a particular kind of "intentional community" (2004:232).

In contrast to those in nursing homes, elders in a GH retain control over such vital daily activities as when to get up, bathe, eat and sleep, preserving the *sanctity of lived time* (McLean 2007a). Residents engage in activities whenever they want, as part of life, not as a "billable service." Elders and Shahbazim participate together in life by eating, talking, engaging in activities and even playing together (Rabig et al. 2006:534–35). They are supported physically, emotionally and spiritually. Importantly, the hope was to engage the broader community as well.

The Shahbazim are housekeepers and caregivers in the broadest sense, responsible for cooking, cleaning and laundry, as well as personal care and nurturance. Beyond CNA (certified nursing assistant) training, they receive 120 hours of training in the GH philosophy. There are two Shahbazim during the day and evening shifts and one during the night shift, accounting for forty hours for ten residents. In a typical nursing home where CNAs conduct rounds, this would amount to four hours per resident. In a Green House, it is both less and more—less, since with her other obligations, the Shahbaz is less likely to spend four hours exclusively with one resident; more, because residents can be in the presence of a Shahbaz a full twenty-four-hour period if they wish. The Shahbazim[16] are supervised by an administrator ("guide"), rather than by nurses, to avoid the traditional hierarchy in nursing relations. To break down existing professional hierarchies and organizational rigidity, Thomas made Shahbazim central to life in Green Houses and removed professionals from any nonclinical decision-making. The clinical support team (nurses, a medical director, social worker, activities specialist, dietician and other therapists) visit on a schedule dictated by regulatory mandates and needs for assessment and treatment, but are expected to "behave as guests." This further identifies the Green House as a home, not a clinical space.

PROMISES (AND CAVEATS)

Because GHP is young and little research is yet available on it, my observations will be largely speculative. Early findings from the study in Tupelo, Mississippi, of the first Green Houses, however, are promising. Self-reported quality of life measures of residents in GHs were superior to those at the two nursing homes with which they were compared.[17] On quality of care, GH residents equaled those of nursing homes and showed less decline in late-loss ADL functioning. Surprisingly, though, they showed more incontinence. Although Green Houses do not emphasize structured activities, in seven areas they equaled the comparison group (Kane et al. 2007). Anecdotal evidence is even more telling. One woman, who was viewed as too impaired and unresponsive to actually benefit from a Green House environment, was transferred there from her 140-bed nursing home at her family's request. Upon arriving at the Green House, she perked up immediately and continued to improve, talking and singing again, going from being fed pureed foods to feeding herself whole foods and gaining a spark of life (Baker 2007:88–89). Still, the original study showed that one resident was asked to leave and another returned to the nursing home (Kane et al. 2007:833). It would be worth exploring why these removals occurred in order to gain insight as to what the issues were that led the residents to leave and how well the model might be able to better address these in the future.

The GHP has succeeded in removing the medical wrappings and institutional controls that have oppressed life in nursing homes for decades. By radically reconfiguring not just the physical structure, but also the power relations between the supervisory and rank nursing staff and the pace of life within, it has enabled possibilities for elders to reconnect with their world and reinvigorate their lives. By refashioning CNAs as venerable homemakers, it has invested these women with enormous responsibility to sustain a portion of society's frail elders, to nurture relations and protect elders as those one cherishes. Yet Shahbazim begin as strangers to elders, lacking a shared history. Some will nonetheless embrace this responsibility out of sheer grace and desire for growth; others may come to this with time—or, they will not. Indeed, the success of eldertopia, as advanced within GHs, relies mainly, if not entirely, on the Shahbazim. Yet while invested with immense social responsibility for *all* of us, Shahbazim—often women of color and of modest backgrounds[18]—continue to be paid quite poorly (Baker 2007). Thus their accepting this charge is no small feat, aspiring toward what philosopher Charles Taylor has called "a new horizon of meaning," that they are part of a larger whole both socially and spiritually (1991). But how are the rest of us to be involved?

In Tupelo, GHs were integrated into regular neighborhoods, providing greater opportunity for social inclusion and intergenerational relationships within a broader community beyond strictly the Shahbazim. However, some GHs are being planned to be built on campuses of long-term care facilities, thus limiting broader social integration and perpetuating an association with a

medicalized and geriatric-segregated establishment. Beyond the resident-Shahbazim relation, the GHP has not developed ways of creating the intergenerational reciprocity eldertopia seeks to promote, perhaps to avoid overly prescribing it. Nonetheless, unlike small owner-operated board and care homes, Shahbazim are less likely to gain access to informal supports (family, friends and neighbors) available to the owner-operators who live on the premises of their board and care home unless they are also part of the community (Eckert and Morgan 2001). Identifying nonprofessional staff as the core staff of the Green Houses reinforces the nonmedicalized aspects of daily life and combined resident/Shahbazim control over everyday decision-making, with help from the guide as needed. Still, some losses may result from this arrangement, such as the reduction of exposure of residents to exceptional clinicians, like Jenny, of Sley 2, whose insights helped reduce Mrs. Fine's excess disabilities and increased her autonomy. In addition, the move away from a medical model, while vital for the everyday life of residents, may lead to false dismissal of signs of genuine medical conditions (Baker 2007:77).

Implications for Dementia

Despite these potential limitations, the GHP has worked at reversing a mindset that ignores elders' needs as secondary to institutional prescripts. For elders with dementia, whose aberrant behaviors have long been pathologized as senseless symptoms of their disease and ignored, this is no less than revolutionary. Further, in redefining itself as a genuine home, not a place of shift work and rounds, the Green House frees elders and Shabahzim alike to enjoy the tempo of life as lived. Here *relationships* reign supreme and central to life quality. For the person with dementia, such relationships perpetuate meaning-making in their lives and validate both their fragile identities and their enduring need to engage meaningfully with their world (Frank 2005:177). This is therapeutic to someone whose impaired memory disrupts their sense of a unified self. Shahbazim can effectively restore that sense by continuing to acknowledge the elder. Indeed, in dementia, quality of life depends on the sense of self-esteem and belonging that derive from meaningfully relating with others (Nolan et al. 2002:200–201).

Some elders are privileged to remain in their own homes, where a sense of personal meaning and belonging has been fostered over their entire life course (Stafford Part V). For those who lack this privilege, the Green House may provide a substitute locus for home. In fact, for some people the experience of home—or of a home yearned for—is not attached to an external place at all, but to an interior space of personal security and social connectedness (Reed-Danahay 2001:60). This may be why, in the absence of these positive conditions, an elder *already* in her home may still longingly cry out for it (Frank 2005). Thus, emotional connections to the referents of home may matter even more to the elder than the actual physical site (Brent 1999:78).

How, then, might the Green House Project succeed in fostering social connectedness? It is less likely to do so by creating a generic sense of "hominess"

in the environment than by providing ongoing opportunities for each elder to make meaningful connections to both past and present (Post 2006:226). These connections help to preserve a positive social identity and to fend off insecurity, social isolation and depression (cf. Williams 2002:145). As a potentially healing environment, the Green House can help maintain identity in dementia by sparking cognitive, sensorial (e.g., by smelling favorite foods cooking) and emotional experiences that recall past memories. These can be compared against experiences in other settings (Williams 2002:148), or enable the construction of new meanings through new relationships and experiences. Such experiences, together with the sense of freedom and privacy, reinforce the delicate sense of being at "home" with one's self (Frank 2005:184, 187–188), so vital to well-being in dementia (Williams 2002:145–146, 148). Finally, insofar as the Green House "shelters daydreaming" and "protects the dreamer ... to dream in peace," it reinforces meaningful continuity with the past: "it is because our memories of former home-places are relived as daydreams that these home-places of the past remain in us for all time" (Bachelard 1994:6).[19]

CONCLUSION

As the Pioneer Network gains force, many more homes are promoting person-centered care, often through remodeling to appear more homelike and appealing. While many of these homes are run by individuals or groups that have been on the forefront of change, or welcoming of it, others may see this more as a necessary marketing scheme. What is unique about the GHP is that its vision was matched with a design to reach those whose economic situations could never afford access to this kind of model. Thus, it has the makings of a broadly liberating dream. Of course, the GH is not the first to do this; Quaker facilities predated even OBRA in working to validate and dignify all elders, no matter how impaired (McLean 2007b:241–42).[20]

Dreams, though, are actualized by real people in real circumstances; they are never universally guaranteed no matter how liberating the possibilities. Thus, in the final analysis, it is people themselves (Shahbazim, guides, administrators, residents, families, policy-makers and the public) who will determine the extent to which the GH—and other CC models—will or will not be liberating and sustainable. Some will decide whether to preserve or alter the initial model to meet the needs of those who live and work there, as they strive to make the GH financially sustainable. Already, Cedars, the nonprofit owner of the four GHs in Tupelo, has built six more GHs, but with twelve beds, not the six to ten beds Thomas had in mind. To actualize his dream-idea, Thomas stayed within CMS costs. Yet to fully deliver its dream to elders with varying skilled-care needs, the GHP may need to build in additional help in exceptional circumstances, as with Mrs. Gold on Sley 2, where intensive individual staff support for two months helped her to ride out a difficult period. The challenge is to accommodate residents like her without overburdening staff and other residents; this may demand higher funding. With its call to support the human

spirit, rather than to make profits, it is not surprising that GH and CC have been promoted mainly by nonprofit faith-based organizations (Baker 2007:3). One thing is for sure. The call for CC will not die, as CC agents are mobilizing internationally[21] to realize a dream of better life for elders. How this will be realized in particular contexts, both locally and internationally, will be something anthropologists will surely wish to follow and help to inform for future initiatives.

NOTES

1. The Nursing Home Reform Act, as part of the 1987 Omnibus Reconciliation Act (OBRA 87), intended to address neglect and abuse in nursing homes, but also to establish standards of care and compliance. These standards addressed quality of life by obligating nursing homes to provide "the highest practicable physical, mental, and psychosocial well-being" of residents (Turnham 2001). While heroic in intent, even with success in several areas such as restraint reduction and continual efforts to improve regulations and compliance, it has fallen short of its goals. For further elaboration on its shortcomings, see *Faces of Neglect* by NCCNHR. See www.nccnhr.org/action_center/ 366_1994_12825.cfm (accessed on August 15, 2008).

2. Although reformers had long complained about conditions in institutionalized homes for the aged (e.g., Henry 1963), the "culture change" movement finally gained momentum when a group of "pioneers" of nursing home reform gathered in Rochester, New York, in 1992 and again in 1997. In 2000, the group named themselves the "Pioneer Network," and have gained influence with consumers, care facilities and policy makers. For more information on its history, see www.pioneernetwork.net/who-we-are/our-history.php (accessed on August 15, 2008).

3. Dementia Care Mapping is an intensive observational method used to determine quality of dementia services on the basis of specific indicators of quality of life (Capstick 2003:11–22). It was developed by Kitwood and colleagues, the Bradford Dementia Group, UK.

4. The Eden Alternative was a new concept in nursing home care and philosophy, developed by William Thomas to tackle "loneliness, helplessness and boredom" through a habitat that engaged people in the "green" noninstitutional world of plants, animals and children. It challenged the hierarchical model of institutional organization and returned control to the direct caregivers (Thomas 1996; 2004:179–90). This model has been very successful internationally with at least 300 registered "edenized" homes. See www.edenalt.org (accessed on August 15, 2008).

5. *Neighborhoods* refer to structural divisions within nursing homes, which serve as smaller clusters of residents (about twelve per neighborhood). Each is further divided into two "houses," consisting of residents' rooms surrounding a kitchen, den and formal living room. This innovation was developed by Charlene Boyd and the staff of Providence Mount St. Vincent, in Seattle, Washington. However, in more vulgarized commercially exploitative forms, a simple door is said to divide a wing into neighborhoods, without further structural or conceptual changes.

6. By 2025, Thomas envisions a system of home and community care with 100,000 Green Houses and a few leftover nursing homes. In five years, fifty Green Houses have opened (Kane et al. 2007:839).

7. ADLs are Activities of Daily Living—personal care routines like combing one's hair; IADLs are Independent Activities of Daily Living—more complex chores like balancing a checkbook.

8. Powell Lawton was probably the most influential psychologist in reconceptualizing environmental designs for optimizing cognition and dementia care in the United States. He forged efforts to understand the impact of environment on the care and quality of life of those in nursing homes and conducted innovative research on ways to evaluate these impacts.

9. This was the type of care that Jules Henry had decried in *Culture against Man* in 1963.

10. I thank Deanna Trakas for this metaphor.

11. Most homes average around 75 percent women.

12. I thank Robert Rubinstein for this observation.

13. The difference in Mrs. Fine's performance went beyond the tests to her disposition toward being tested as well as to actual differences in her cognitive status during times of testing.

14. States have ultimate jurisdiction over classification of long-term residence. In those states where skilled nursing certification is not allowed, GHP allows them to be built as assisted living facilities. See CMS letter, December 21, 2006 from www.ncbcapitalimpact.org/default.aspx?id=414 (accessed on August 15, 2008).

15. Smaller facilities have been associated with less anxiety and depression in residents (Rabig et al. 2006:534), especially those with dementia.

16. The word *shahbaz* is Persian and a singular form of the assistant he calls the "midwife of elderhood." *Shahbazim* uses the Hebrew "im" ending to create the plural form, to capture a mixture of traditions in a novel blend, like the Green House itself (Thomas 2004:239, 255).

17. There were four Green Houses with ten residents each; two were dementia-specific. The comparison nursing homes were owned by the same nonprofit organization, and one of the homes shared their administration with the Green Houses (Kane et al. 2007).

18. Because Green Houses in many states qualify for Medicaid grants, many Green House residents may share backgrounds with the Shahbazim, in contrast to residents in private homes.

19. Cited in Brent (1999:72).

20. Quakers are a religious society that accepts the fundamental divinity in all things. This includes extremely frail and demented persons. Long before the CC movement began, Quakers had designed long-term care to support the dignity and respect of both care receiver and caregiver in demedicalized settings. Quaker-sponsored facilities such as Chandler Hall, in Newtown, Pennsylvania, have also pioneered in intergenerational programs with on-site child care and development facilities See www.chandlerhall.org (accessed on August 15, 2008). In addition, since 1973, Kendal, in Longwood, Pennsylvania, has promoted an "Untie the Elderly" movement to eliminate the use of both physical and chemical restraints. See http://ute.kendaloutreach.org/learning/learning.aspx (accessed on August 15, 2008).

21. In Ireland, on December 5–6, 2007, CC experts Steve Shields and LaVrene Norton, at workshops organized by the Health Service Executive and the National Council on Ageing and Older People, were enthusiastically received for their ideas on transforming care in the Irish context.