

*Green in the body, honey in the heart:
Exploring the roles of nature and friendship in long-term
healthcare*

rachel betesh
center for environmental studies

brown university
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Acknowledgments

“Nature has given us two eyes, two ears, and but one tongue—to the end that we may see
and hear more than we speak.” - Socrates

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Executive Summary

This thesis is an argument for subtlety, compassion, and creativity—all of which facilitate the seeing and making of connections. As a written document it is built by connections made between disciplines and as a realized idea it is reinforced by connections developed between human beings.

My research focuses on community-based gardening in long-term healthcare facilities, a concept which forges an unlikely connection between what is wild and what is often deemed sterile. Residential long-term care is a highly regulated system whose purpose is to provide medical and social support to elderly, chronically ill, or disabled people who can no longer live independently. The current “long-term care crisis” receiving significant media coverage hinges on two obstacles faced by the long-term care system: the need for *more* care and the need for *better* care. The former is a result of the gradual aging of the United States population. The latter is fueled and made public by the advocacy movement for improved “quality of life” in long-term care. Citing significant organizational, regulatory, social, and interpersonal flaws in the lived experience of long-term care, advocates call for ethical accountability as well as innovative approaches to health and wellbeing.

One such innovative approach is horticultural therapy, the use of plants and gardening for rehabilitative purposes. Though its principle belief that interaction with the natural world is a source of therapy and empowerment is widely accepted, its official practice is not currently reimbursable by Medicaid. Horticultural therapy is often instigated and carried out on a project-by-project basis by registered nurses, occupational therapists, or social workers. The “Eden Alternative” template for long-term care reform incorporates the concept of horticultural therapy through its inclusion of plants-- as well as pets and childcare-- in the nursing home. Dr. William Thomas, the founder of the Eden Alternative, explains that all three offer much-needed opportunities for residents to give care instead of simply receiving it.

The case study application of this thesis used a community-based garden as an activity for growth, interaction, and fun at Sunrise House, a long-term care facility for people living with HIV/AIDS in Providence, Rhode Island. I worked with residents and staff to grow organic vegetables and flower gardens on the property. Through structured workshops as well as unstructured, one-on-one “garden time,” nearly all of the residents participated in a full season of planting, maintaining, harvesting, and cooking from the garden. Using participant observation memos and tape-recorded interviews, I maintained a record of the meanings and benefits of the garden for members of the Sunrise House community.

The findings of the case study at Sunrise House suggest that a garden, in addition to its basic value as an enjoyable activity, also carries distinct significance in its ability to strengthen connections that are often strained in the lived experience of urban long-term care residents. First, the garden defies the relegation of “nature” to pristine, rural places, instead bringing beauty, agriculture, and a sense of discovery to a piece of lawn smaller than a parking lot. As a forum for interaction, visible activity, and resident pride, the garden helps build community with neighbors and volunteers. With magnificent beauty and abundant produce, the garden also instills a feeling of luxury—without requiring significant monetary input. In a system and setting which can easily characterize

residents as “receivers” of care, the garden offers unique opportunities to nurture, share, and *give* to both plants and other people. Finally, the garden’s cycles, metaphors, and chances to learn are a source of spiritual and mental health—and a reminder of life’s interactive potential. Among residents and staff members at Sunrise House, the garden was so enjoyed and appreciated that its continuation next season is already assumed and planned for.

I align myself with advocates for “better” care in a recommendation that long-term care reform should emphasize positive incentives and innovation, not simply more regulation. As an example of such innovation, I advocate low-cost, community-based gardens on the grounds of long-term care facilities as a physical and experiential forum for interaction, integration, and growth (and fresh tomatoes). My broader recommendations include the training of medical professionals to be as aware of social and interpersonal health as they are of the functions of the body. I also recommend that long-term care facilities seek out and encourage community interaction, reaching out beyond facility walls rather than giving them a new coat of paint. Community members must meet facilities and residents halfway by acknowledging the true worth and gifts of the elderly and chronically ill.

The realization of these recommendations would ideally cultivate a more functional, visible niche for the elderly and chronically ill who are part of our communities. Over time and with momentum, long-term care facilities might one day be associated with the growth of food and flowers. This is a revolutionary vision, full of life, and it is the opinion of this writer that each snapdragon planted towards it is a revolutionary act.

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I

Introduction

Any ecologist will tell you that the health of an ecosystem rests on the co-functioning of its many parts, and-- perhaps in implicit tribute-- the academic field of Environmental Studies is often contingent upon developing connections across a variety of disciplines. In this paper I will develop a series of connections, resulting in more of a web than a straight line. This, too, emulates the logic of natural life.

First, I will describe long-term healthcare: its history, its legacy, its current state of reform. It is a description inevitably constructed with bricks of legislation, statistics, and analysis, but my intention is to emphasize throughout that long-term care ought to be conceptualized as a human-centered framework.

At what seems to be the opposite extreme, a garden is best described with colors, textures, and visible manifestations of growth and blooming. Statistics of germination would be ancillary, and man-made laws are irrelevant to root development and ripening.

At first glance then, long-term care and gardening are an awkward pair; the former is cautious about rigidity and standards, while the latter tends naturally towards wildness and free form. But in this paper, I do present them as a pair, challenging the initial incongruity between them. Opposites attract, and often need each other. For background, I will introduce and discuss horticultural therapy, the deliberate use of plants and gardening for mental and physical rehabilitation, as well as some specific cases of horticultural therapy in practice. The most prominent of these is the Eden Alternative, a

nursing-home reform template created by Dr. William Thomas. The case study of this paper presents my own experience bringing gardening to a long-term care setting.

What long-term care and gardening do have in common is that their written descriptions leave much unsaid; both ought to be seen and touched and experienced before they are judged. Accordingly, I emphasize throughout this paper that a sense of community, integration, and visibility are paramount to understanding the lived experience of long-term care residents. I believe that ultimately, it is the cultivation of this understanding that must be the foundation of reforming long-term care in the United States.

II

Literature Review

We live with the awareness that there are numbers and machines too vast to comprehend and complexities so minute that our eyes alone cannot perceive them. Ours is a world with deficits, double helixes, and still dandelions growing in the cracks of the sidewalk. An instance which speaks of both the big and small: the United States government expends roughly \$1.6 trillion annually on health services (Cowan et al 2004), a figure whose sheer magnitude is an indicator of the vastness and complexity not only of the 296,536,581 human bodies within our political boundaries (U.S. Census Bureau 2005) but of the systems which have been put in place over the years to care for them. Thirty-three percent of this spending is through the Centers for Medicaid and Medicare Services, which is the primary provider of care for the physically disabled, low-income families, and those over the age of 65 (Program Information on Medicare, Medicaid, SCHIP, and

other programs of the Centers for Medicare and Medicaid Services 2002). Though some of these services are in acute care hospitals, Medicare and Medicaid finance much of the long-term care system, which can best be defined as the set of health and social services delivered over a sustained period of time to people who do not have the necessary capacity required for personal, independent care (Wallace 2003). Today's long-term care category includes the nation's 17,000 nursing homes (Wood 2003), an estimated 38,000 assisted-living facilities for the elderly (Hawes 1999), and additional facilities specialized for people with chronic diseases or physical and developmental disabilities. Ideally, recipients of long-term care live with as much dignity and independence as possible; in reality, their experience often reflects the pressured ambiguity with which long-term care settings straddle the multiple roles of home, hospital, and often for-profit business as well.

This wide span of services and clientele is part of the legacy of long-term care and the American health care system, which has been stretched from its inception by the changing needs of those it was created to care for and by social events and epidemiological phenomena that filled beds and rooms with new residents and their new needs. As the population requiring long-term care changes or grows, the system must react and develop accordingly.

A Brief History of Long-Term Care

Though unregulated poorhouses in the United States served as institutional homes for the displaced sick and elderly as early as the 1800's (Stevenson 2005), the system has since then developed from a largely unsupervised community service to a giant of legislation and bureaucracy. Characterized as a "regulatory octopus" by legal and ethical

healthcare expert Marshall B. Kapp (Kapp 2001), the long-term care system began its era of federal government regulation with the passage of the Social Security Act (SSA) of 1935, which was created and ratified based on the findings of the Committee on Economic Security submitted in the same year. Though some states offered cash assistance to the unemployed elderly in the early part of the 20th century, most programs had collapsed under the economic pressure of the Depression, revealing the need for a comprehensive, reliable federal system. The SSA included the Old Age Insurance Act (OAI), the precursor to Social Security, and the Old Age Assistance Act (OAA), which laid the groundwork for Medicaid. Because the existing poorhouses had been found to be drastically less efficient economically than remaining at home with family or friends, the OAA prohibited payment to people living in publicly-run homes; as a result, private, for-profit nursing home institutions-- able to receive OAA payments for their residents-- began to multiply as viable businesses (Stevenson 2005). In the seventy years since the SSA, congress has passed and amended several acts regarding long-term health care, including the Kerr-Mills bill of 1960, which offered financial assistance to the “medically needy” for the first time (Committee on Nursing Home Regulation 1986). In 1965, the enactment of Medicare and Medicaid legislation greatly expanded federal funding for nursing homes (Committee on Nursing Home Regulation 1986). The Omnibus Reconciliation Act (OBRA) of 1987 instituted several measures and reforms including the mandatory use of a Resident Assessment Tool for quality of care as well as a drastic reduction in the use of physical restraints. (Blumenthal 2003).

Today’s long-term care system, an incarnation based on decades of legislation, currently faces a major set of changes in the populations who directly need its services.

The first difference is in quantity: the gradual aging of the United States population, led by the “baby boomer” cohort born in the years 1946-1964, will account for a projected near-doubling increase in the number of senior citizens from today’s 37 million to 71 million in 2031 (National Academy for Social Insurance 2004). In Rhode Island, as in many other states, sheer numbers will overwhelm the long-term care system which is currently in place, even with the rise in popularity and construction of residential assisted-living facilities. On February 28, 2005, a study released by the SHAPE Foundation, a research group financed by Blue Cross & Blue Shield of Rhode Island, announced its prediction that within 25 years the needs of the state’s aging population will have significantly outgrown the capacity of the hospital and nursing home system (Freyer 2005).

The second change, though less quantifiable, is as formidable in inevitable force: the movement of advocacy for *better* care, often referred to with the phrase “quality of life.” Characterizing this shift in expectation, Margaret P. Calkins, president of the IDEAS Institute, a research endeavor to provide solutions that improve the lives of older adults, explains (Calkins 2002):

Traditionally, nursing homes have been organized around the efficient provision of physical care to frail and impaired individuals. In the future, the focus won’t be on the provision of care services (which is an ‘input’ to the system) but on the quality of life of the residents (ultimate output).

It is this change, and its sweeping undercurrent of basic human wellbeing, which presents long-term care, the greater healthcare system, and our entire society with a challenge to rethink the place of its members whose unifying characteristic is some level of medical dependency in daily living—whether due to age, illness, or disability.

Innovative approaches and solutions are needed to move towards this projected better model of care for the long-term care population.

What is Quality of Life?

Increasingly, quality of life (QOL) in long-term care facilities has been the topic of debate both in scholarly journals and mass media, partly in response to reports of substandard care in the current system. This national phenomenon's most recent local manifestation was the high-profile media exposé of the disturbing case of Germaine Morsilli—an 87-year-old former factory worker from Pawtucket who died from complications of severe bedsores in October 2004 at Hillside Health Center in Providence (MacKay 2005)—send a sufficiently jarring message to spark public interest in what life is like for our “institutionalized elderly,” and how that life could or should be different.

As a result, QOL rhetoric is becoming more common, but providing a precise definition is difficult because it deals with quality and not quantity. According to “Healthy People 2010: Understanding and Improving Health,” a vision of the United States Department of Health and Human Services, “health-related quality of life” is a reflection of “a personal sense of physical and mental health and the ability to react to factors in the physical and social environments” (Department of Health and Human Services 2003). Moving even further away from the traditionally measurable approach, Dr. William Thomas, founder of the Eden Alternative model for progressive nursing home care discussed later in this paper, explains good QOL as “living a life that is full and fully human” (Thomas and Johansson 2003). Improving the Quality of Care in Nursing Homes, a study put out by the National Institute for Health, emphasizes feelings

of “self-worth and self-esteem” (Committee on Nursing Home Regulation 1986) in QOL. It is a subjective concept more difficult to calculate than, for example, life expectancy, and reflects a confluence of factors. The lived experience of the long-term care resident is one impacted not only by the direct ailments of disease, disability, or old age, but by the interplay of economic, organizational, regulatory, and distinct social issues related to long-term care.

“The Regulatory Octopus,” Its Economic Tentacle, and Quality of Life

Marshall B. Kapp explains his “regulatory octopus” image of long-term nursing facility care as an amalgamation consisting of voluntary forms of accreditation by private agencies, internal and external utilization review of Medicaid services, quality assurance mechanisms such as the Resident Assessment Tool codified by OBRA, and the threat of criminal prosecution in the event of abuse or malpractice (Kapp 2001). Together, all of these limbs create a spider web of sorts to catch the weak links in long-term care provision. Critics of this set-up point out that the regulatory system is structured only to punish poor behavior, without recognizing or rewarding good behavior and sound management (Committee on Nursing Home Regulation 1986). What Kapp elucidates is that the regulatory costs to an individual facility are ultimately borne by its residents. As regulatory costs increase, a general decreased quality of care ensues due to staffing cutbacks, as does a lessened availability of highly valuable but non-mandated activities (Kapp 2001). Echoing this criticism, the National Citizens’ Coalition on Nursing Home Reform has insisted that “the regulatory system should be focused on what we do *for the residents* who live in nursing homes, *not about* what we do to providers” (Kapp 2001).

Regulation meets economics in the controversial realm of reimbursement, where services are deemed either worthy or unworthy of Medicaid funding. In Autonomy and Long Term Care, George Agich delineates the negative effect of reimbursement policy on resident quality of life, explaining that reimbursement rewards the efficient provision of specific, discrete services rather than the overall quality of care or life for the resident. Reimbursement is most often granted for assistance in performing “activities of daily living” (ADL); emptying a bedpan, for example, is an act that a nursing facility can put on its bill. Sitting and talking with one resident after emptying her bedpan- as opposed to moving quickly on to the next room to empty the maximum number of bedpans in one hour—is not a service which appears on the bill, which often effectively discourages it. The total reimbursement for *recognized* services is what funds much of the nursing home, and the result is a routinized atmosphere, highly regimented and mechanized (Agich 1993). Innovations in resident-centered care are primarily seen only in private-pay nursing homes serving the wealthiest market of elderly residents, where the looming limits of reimbursement do not hold such a tight grip on daily life (Blumenthal 2003).

Another economic tentacle related to reimbursement’s stretching of long-term care resources is the troublingly high staff turnover rate in long-term care facilities. Though residents frequently cite their relationships with staff as one of the integral factors in their quality of life, the importance of the nurses and nurse aides is not reflected by their place on the economic totem pole nor in the amount of authority they have to make decisions in nursing home care. For registered nurses, a job in a long-term care facility is the lowest-paying position in the field (“Registered Nurses” U.S. Department of Labor 2005). In a 2002 survey of 6,991 facilities, the American Health Care

Association found a national average staff turnover rate in nursing facilities of 76% per year (Blumenthal 2003).

Bruce C. Vladeck, whose 1980 book Unloving Care: The Nursing Home Tragedy was instrumental in bringing the problems of long-term care to public judgment, served as administrator of the Health Care Financing Administration, now CMS, for almost three years. Intimate with what he describes as an ongoing and losing battle to save money in providing long-term care, he suggests that “maybe we would all be better off if we put some of the cost arguments aside, at least while trying to think of how to design better service delivery systems. I recommend we try first to figure out what quality care is and then figure out how to pay for it in a way that is politically acceptable” (Blumenthal 2003).

Social and Interpersonal Factors in QOL

A discussion of pertinent economics, legislation, and statistics is unsettling not only because of their very real shortcomings when it comes to long-term care but because the resident for whom the system exists is neither a number nor a congressional act nor a newspaper article. Residents and patients are people first and foremost. It is a choice we make as a society to see the sick and elderly as a burden rather than a resource; and leanings toward the former take severe psychological tolls on the lives of those who have thus been marginalized. Taking Vladeck’s advice into account, reformers and advocates may also note that allowing concerns of perfecting cost and quantity to precede quality is misguided.

Research aimed at understanding the *social* experience of long-term care residents offers valuable insight into the existing problems and what constitutes a successful solution. Dr. William Thomas identifies the three major barriers to health in an American nursing home as loneliness, helplessness, and boredom, all three of which are exacerbated if not created by the conventional nursing facility model: a building where old, sick people are taken care of by nurses (Thomas 1994). Loneliness and isolation occur both with respect to the happenings of the world outside facility walls, often worsened for residents who rarely have visitors, as well as within the social dynamic of the nursing home community. Renee Rose Shield's ethnography of an American nursing home describes the clear, rarely crossed social boundaries between its three groups: residents, nurses, and social workers. The resident population is further stratified between those who are cognitively healthy and those with dementia and other psychological impairments (Shield 1988).

Improving Quality of Care in Nursing Homes addresses the problem of loneliness due to isolation from community members outside the walls of the nursing home by advocating for increased community involvement. This would include facility-organized resident participation in events and activities outside of the home as well as facility-fostered visits of individual volunteers, schools, and special interest groups (Committee on Nursing Home Regulation 1986).

In "The Nursing Home of the Future: Are You Ready?" Margaret Calkins asserts that quality of life is quality medical care combined with autonomy and meaningful social interactions. Calkins cautions against "facelifts" which simply add a fireplace or paint the walls blue, and instead offers six guiding principles for quality of life: 1) respect

individualized needs and desires; 2) honor life patterns and achievements; 3) support opportunities for continued growth; 4) enable continued productive contributions to the community; 5) encourage meaningful connections with community; and 6) foster fun (Calkins 2002). Calkins is backed up on moral grounds by biomedical ethicist L. Turner, who calls for “the consideration of the many incremental steps that can be taken to make hospitals, geriatric facilities and other healthcare institutions more human, decent, aesthetically and spiritually satisfying moral habitats” (Turner 2002).

The Eden Alternative: A Prominent Face in Long-Term Care Reform

With his trademarked Eden Alternative model, Thomas poses a solution which almost directly answers Turner’s call and incorporates many of the aforementioned ideas about quality of life in a self-described “radically non-medical way of thinking about nursing homes” (Thomas 1994). First piloted in 1991 at Chase Memorial Nursing Home in New Berlin, New York (Thomas 1994), the Eden Alternative seeks to change the very way in which long-term care facilities are managed and run in order to create an environment in which the obstacles to “a full and fully human life” are preemptively mitigated. Loneliness, the first obstacle, can be assuaged with companionship, particularly with the spontaneous and interesting company of plants, animals, and children. A child, a cat, and a begonia also provide an antidote to helplessness, the second major ailment, which stems from being a passive recipient of care with no opportunity to assume the role of caregiver. Boredom, too, is answered by the presence of spontaneity and variety, two underrepresented factors in the atmosphere of conformity and compliance created by the conventional nursing home (Thomas and Johansson 2003). In

addition to the core concepts of companionship, spontaneity, and the opportunity to give care, Thomas calls for reform in “employee empowerment,” restructuring for increased autonomy in scheduling and encouraging staff involvement in activities beyond those clinical duties reimbursed by Medicaid (Thomas 1994).

The pilot study at Chase Memorial Nursing Home showed that residents in an Eden Alternative facility not only reported higher life satisfaction but also revealed a decrease in need for and prescription of the psychotropic, mood-altering drugs so rampantly used in medical care for the elderly in the United States. By 1993, Chase Memorial had an overall 10% decrease in psychotropic drug prescriptions (Thomas 1994). And in comparison with a nearby nursing home with a similar size and cultural demographic, Chase Memorial’s total average drug cost per resident per day steadily dropped over the course of two years (Thomas 1994). Creating a holistic habitat with social and natural- not solely medical- approaches to wellness slowly eroded resident dependency on pharmaceutical remedies. Analyzing these findings for policy implications, Thomas asserts that if all American nursing homes achieved even half the reduction in drug prescription that Chase Memorial did between 1991 and 1993, it would cut health care costs by \$1.25 billion a year (Thomas 1994), a figure which grows when factors such as a documented increase in staff retention and a high level of community volunteer involvement are taken into account (Thomas 1994).

Initial success and positive press has led to a growing interest in replicating the Eden Alternative model in facilities across the country; 238 facilities nationwide now bear a logo of “Eden-ization,” (Thomas and Johansson 2003) and Thomas is spearheading an empire of sorts, replete with speaking tours, an associate training

program, and a retreat center in upstate New York (“The Eden Alternative,” www.edenalt.com). Thomas’ projects have found an interested audience in mainstream discourse on quality of life, most recently appearing in an April 2005 article in The New York Times entitled “The New Nursing Home, Emphasis on Home.” Photographs of comfortable, home-like furnishings and interview quotes from satisfied residents in one of Thomas’ “Green House” facilities accompany statistical data about long-term care and its current state of change (Hamilton 2005).

In less than fifteen years, the Eden Alternative has made familiar what were once radical ideas about long-term care: that residents deserve satisfying social and spiritual habitats; and its implementation furthermore suggests an object lesson- facilities that choose to “Eden-ize” have much to gain in terms of profit and public relations. The evolution of Thomas’ work, while serving as a milestone in the dynamics of long-term care, must be taken as an example of reform but not as its entirety. Long-term care has as much to learn from the Eden Alternative’s individual components as it does from the amalgamated, trademarked whole.

Nature-based and Horticultural Therapy: Principles and Practice

The role of plants and gardens in the Eden Alternative model represents the broader concept of horticultural therapy, which is the use of nature, both cultivated and wild, for therapeutic or rehabilitative purposes. In “Greening Healthcare: Practicing as if the Natural Environment Really Mattered,” Katherine Irvine and Sara Warbler explain that “interaction [with nature] may be understood as a continuum from passive to active” (Irvine and Warbler 2002), and indeed horticultural therapy is simply an umbrella term

for a deep-rooted concept and its subsequent tailoring to different populations and individuals. Much like “quality of life,” “nature” cannot be reduced to a semantic definition—and like quality, its profound effect can neither be served on a tray nor administered from a bottle and instead must be accompanied with a standard of care and attention to personal interests and needs.

Proponents of horticultural therapy draw on psychological research about the deep relationship between humans and the rest of the natural world, the keystone of which is socio-biologist Edward O. Wilson’s “biophilia hypothesis” that there is an innate, biologically-based emotional affiliation of humans to other living organisms (Wilson 1993). In The Experience of Nature: A Psychological Perspective, Rachel and Stephen Kaplan review twenty years worth of studies, finding a general human preference for settings dominated by nature over those which are primarily man-made (Kaplan and Kaplan 1989). Explanations for this phenomenon include the attention restoration theory (ART) of cognitive science, which suggests that interaction with nature is important for mental functioning and enhances ability to learn new information and solve problems. Similarly, the stress response theory purports that interaction with nature counteracts negative physiological effects of stress (Irvine and Warbler 2002).

Wilson’s biophilia necessarily applies to all human beings, but its implications for those with special physical or emotional needs are amplified. The conditions of being sick or elderly-- particularly when combined with Thomas’ factors of loneliness, depression, decreased autonomy, and boredom—echo with the possibilities of the stress response theory mentioned above. Where the conventional model of care attempts to alleviate this stress with medication-- or ignores it entirely-- nature-based therapy is a

gentle, effective alternative. When brought into the long-term care setting, horticultural therapy's greatest strength is perhaps its introduction of wildness into an otherwise sterile environment: the distinct shapes and smells of leaf, stem, and fruit among white walls, curtains, and disinfectant. A daffodil bulb in a pot on a windowsill, so long as it is cared for properly, does not discriminate in blooming; its caregiver can be aged and weak, or HIV-positive, or mentally handicapped, and still the petals will come in full color.

Horticulture and gardening furthermore fall within Mihalyi Csikszentmihalyi's behavioral psychology category of "flow" activities. Originally posited in 1991 and often revisited since then, Csikszentmihalyi's theory characterizes those activities which are enjoyable and satisfying-- producing an optimal mental state referred to as "flow." "Flow" activities are generally self-directed and independent of external factors, and can often reinstate a sense of control or power. In a study of loneliness in older adults, Donna Rane-Szostak and Kaye Ann Herth summarize the eight key elements of a "flow" activity (Rane-Szostak and Herth 1995):

The first five elements are antecedents: flow activities require concentration, clear goals, immediate feedback, effortless involvement, and a chance for completion. The last three elements of the flow experience are outcomes. The experience should lead to an altered sense of time duration, a sense of control over one's own actions, and the emergence of a stronger sense of self.

In keeping with these tenets, a garden requires and invites a broad range of activities, often detail-oriented, and yields tangible outcomes—cherry tomatoes and perhaps even tomato sauce, as well as satisfyingly dirty fingernails. Because the

gardener's sense of success is intimately linked with sunlight, water, and the subsequent growth of a seedling, the necessary patience of gardening lends itself to new appreciation for time and its changes. "A stronger sense of self" and other intangible benefits of horticultural therapy are explained more clearly in individual research studies.

Certified horticultural therapist Dee Liberatore McGuire's 1997 case study entitled "Implementing Horticultural Therapy into a Geriatric Long-term Care Facility" outlines the goals and outcomes of the program she organized at Meridian Perring Parkway Nursing Facility in Maryland. McGuire's program incorporated various activities including flower arranging; a garden club for those interested in low-impact indoor and outdoor gardening; and one-on-one "flower visits" with bed-ridden residents. After a six month trial period McGuire's main observations included increased alertness and improvement in cognitive and social functioning and a distinct satisfaction among residents with the opportunity to exchange cut flowers as gifts for their friends, visiting family members, and favorite nurses (McGuire 1997).

In "The Meaning of Gardening and the Effects on Perceived Well-Being of a Garden Project on Diverse Populations of Elders," nurse Diane Heliker and her co-authors express the findings of a three-month structured gardening program with two culturally-diverse groups of elders. Heliker's hypothesis extends the person-plant relationship with the theory that community, too, is an extremely valuable and integral benefit of gardening (Heliker 2000):

Gardening with others results in increased communication, socialization, sense of commitment, and responsibility to the group. The experience of gardening occurs within a restful,

noncompetitive environment and allows the development of a community of mutual caring and being cared for.

Using standardized instrument questionnaires and semi-structured one-on-one “garden interviews,” Heliker and her research team found thematic patterns in the meaning of gardening for the participants, most notably gardening as perceived spiritual healing and as a trigger for personal memories and family legacies. One participant remarked that “it [gardening] keeps me on my feet and moving. . .it’s the only place you can get your hands dirty and your heart clean.” (Heliker 2000). Heliker’s study is particularly pertinent in consideration of the true cultural and socioeconomic diversity of long-term care residents in the United States; one of her groups was largely African-American elders with working-class backgrounds whose parents or grandparents had been farmers, while the other was made up of middle-class elders whose exposure to horticulture was often limited to a World War II “victory garden.” Though their responses and triggered memories were different, the overall theme of connection was widespread (Heliker 2000).

Social worker and occupational therapist Caryl Gurski’s experience working with elders affected by Alzheimer’s disease and other dementias revealed that gardening resulted in greater self-esteem, interest in the future, awareness of the environment, and increased participation in other activities of daily life. Gurski emphasizes that horticultural therapy should be designed with a focus on the functional abilities of an individual rather than on his or her functional deficits and that the collaborative relationship between a volunteer or therapist and the client is of paramount importance (Gurski 2004).

In a different format than that of the aforementioned studies, Rebecca Reynolds' Bring Me the Ocean is a resonating personal account of the work of her Massachusetts-based non-profit organization Animals as Intermediaries (AAI). AAI workers travel to hospitals, nursing homes, and boarding schools for abused children with "nature" in tow, whether golden retrievers, pine boughs, hay bales, giant sunflowers, or buckets of seaweed and saltwater. Often creating full-room displays with themes like "Autumn" or "Ocean," Reynolds attempts to offer familiar smells and sounds to the institutionalized elderly and the sensation of a summer day to an HIV-positive toddler who may never know its reality. Reynolds' chapter-long success stories are compelling in their simplicity and grounded-ness; an object which seems commonplace in the woods becomes a powerful, nearly magical presence in a hospital room, and elderly residents who have rarely spoken to staff members suddenly begin to share anecdotes of their childhood by the sea (Reynolds 1995).

Reynolds communicates her work with a distinct message that horticultural therapy is more than a research finding or a series of clinical trials; it is an idea-turned-activity, reviving the biophilia which E.O. Wilson might point out is as present, albeit dormant, in a long-term care resident as it is kinetic in a backpacker on the Appalachian Trail. What seems abstract in a textbook is concrete and convincing in a series of true stories. Horticultural therapy is an exchange between people and the rest of the natural world, between one person and another with a strip of oak bark or a grapevine as the starting and giving point. Beyond that fundamental concept, the rest is circumstantial; nature-based therapy should take the cues of the people involved, the resources present,

and whatever the season happens to be. It is a thoroughly flexible and applicable practice that requires creativity and commitment more than it does financial capital.

III

Case Study: A Community-Based Garden Project at Sunrise House

Methods

Informed by the existing literature, my research focuses on understanding the role that nature-based, community-oriented gardening can play in the lived experience of residents in long-term care. This topic called for a descriptive, phenomenological study that was qualitative by design, rooted in the assumption that the answer to such a question must be sought in the “real world” of long-term care rather than in books, laboratories, and surveys. This research project was designed with an emphasis on personal interaction in response to the fact that social isolation is one of the undeniable, recurrent flaws in the long-term care system.

The time span of this research lent itself to a case study strategy: working closely with one group of residents at one facility during one garden season in an attempt to gain insight on the broader community of long-term care. I chose Sunrise House, an assisted-living facility for adults living with HIV/AIDS in Providence, Rhode Island-- though it is just as accurate to say that Sunrise House chose me.

I first came to Sunrise House as a volunteer landscaper and flower gardener in the fall of 2004. It is a small, inviting community of ten residents and several staff members. In November, the administrator mentioned to me that several residents had expressed

interest in having a vegetable garden. As I accepted the responsibility of organizing this enterprise with the residents, I decided to also undertake it as research.

The ten residents of Sunrise House, true to the diverse and gradual effects of the disease they have in common, are of varying levels of health and physical ability. Some are well enough to work part-time and others rarely go beyond the front porch. They are middle-aged men and women, born in Mexico, Providence, Puerto Rico, and Boston, among other places. All of them live from disability check to disability check, which amounts to approximately \$636 a month. What they share is this place to call home: a quiet assisted-living setting under the auspices of AIDS Care Ocean State. Living at Sunrise House means access to 24-hour nursing care, a part-time social worker, escorts to and from treatment at the Miriam Hospital complex, two communal kitchens, and private bedrooms.

Our goal was to maintain well-kept, functional vegetable and flower gardens for the enjoyment and usage of residents and staff. “The garden” was actually a series of many plots: in the backyard; along the perimeter of the house facing the street; and in wheelchair-accessible raised planter boxes. Challenging the barrier between man-made and natural, we planted cucumber vines to grow up and into chain link fences, and put eggplant and pepper plants into recycled five-gallon plastic buckets. A map of the Sunrise House gardens can be seen as Appendix 1. (*to be inserted*)

Multiple factors informed the emphases of the garden program. I approached my work at Sunrise House from the perspective of an Environmental Studies concentrator, an experienced urban farmer, a believer in thoughtful human relationships and in the value of community. My work approached *me* with its own added dimensions: the specific

importance of nutrition for chronically ill people; the perceived and actual limitations imposed on nutrition by economic status; and the respectfulness required in working with people who have “good” and “bad” days.

The garden program had both structured and unstructured components. Examples of the former were seed starting workshops and three “Cooking with Food from the Garden” classes. The actual preparation, planting, weeding, harvesting, and exploring could be best described as “consistently spontaneous”: frequent yet unscheduled. Though highly encouraged, involvement in garden activities was completely optional, and ranged from the carpentry of building planter boxes to starting marigold seeds indoors to talking about a remembered grandmother’s cucumber patch while sitting outside smoking a cigarette. As phrased by Irvine and Warbler in their aforementioned article, “interaction [with nature] may be understood as a continuum from passive to active” (Irvine and Warbler, 2002). From March through September of 2005, I was at Sunrise House several times each week and sometimes twice daily during the summer months. While I sometimes made “garden dates” with a specific resident, our work more often stemmed from spur-of-the-moment engagement. If Pete was sitting on the porch when I arrived, I would ask him if he wanted to plant carrot seeds with me. With regular visits to Sunrise House in the morning, afternoon, evening, and on weekends, this proved to be a successful model for involving residents without rigidity. Simply put, participation in this project was defined broadly enough to ensure that each individual, on his or her own terms, would indeed be a participant.

Creating a healthy garden from what was once a patch of grassy lawn requires hard work and some materials. In procuring resources for the garden I turned to the many

communities which Sunrise House can consider itself to be part of, and emphasized this sense of belonging to the residents. Our organic seeds were donated by Seeds of Change, Inc., and High Mowing Seeds. The four cubic yards of rich black compost that built up the sandy Sunrise House soil was donated by Earth Care Farm in Charlestown, RI. Vegetable and flower seedlings were donated in May by the Southside Community Land Trust. AIDS Care Ocean State volunteers were integral in doing some of the physical labor that was inappropriate for the residents. A generous grant through the Brown University Swearer Center for Public Service allowed us to purchase lumber and garden tools.

Data were collected using two strategies: participant observation and in-depth interviews. I kept a series of confidential memos, written after I had left Sunrise House for the day, chronicling important points of what I thought, felt, heard, saw, and said in the company of the residents and staff while working in the garden. My participant observation checklist can be seen as Appendix 2.

The foundation of my participant observation was simply *being at* Sunrise House. As I spent more time there, had conversations with more members of its community, and was treated as a familiar person, my interactions and observations became deeper and more meaningful. My frequent presence meant that like everyone else, I was someone to tease and be teased by; that my absence for a few days was noticed and my subsequent return warmly acknowledged. Gradual acceptance into the community enriched the written memos, which chronicle not only the construction of a garden, but the subtle profundities of chronic illness, human friendship, and the receptiveness of the residents to the natural world.

The second data collection strategy was in-depth interviewing. Interviews were conducted and tape-recorded with the seven residents who were still living at Sunrise House by the end of the garden season. For several weeks in August and September I carried a tape-recorder, batteries, informed consent forms, and an interview protocol with me when I went to Sunrise House. I had told the residents beforehand that I wanted to talk about their experiences “in the garden.” Our conversations used a standard interview protocol as a springboard (Appendix 3), but often followed relevant and interesting tangents. Residents were eager to be interviewed but were often shy about speaking into the tape recorder; as part of the interview process, they were asked to create their own alias for use in the interview and in any written record of the garden. Being referred to as “Priscilla” proved to be an effective way of lightening up the process of interviewing for someone who had always wanted to be named Priscilla. Interviews with individualized protocols were also conducted with the facility administrator and a long-time staff member. Below is a list of the chosen aliases of residents and staff members whom I quote and refer to directly in the body of this study.

<i>Residents</i>	<i>Staff</i>
Henry	Charlie (driver and maintenance man)
Luis	Marilyn (administrator)
Pete	Nancy (CNA)
Sherrie	Maripa (CNA)
Mary Ann	Olivia (CNA)
Hank	David (CNA)
Priscilla	Marisol (CNA)
Eddie	Polly (CNA)
Gabriel	
Jay	

The taped interviews, transcribed as Microsoft Word documents, and the participant observation memos were carefully read and coded. Codes represented themes and patterns that seemed to consistently represent the feelings and actions of the residents regarding their respective relationships to gardening; the surrounding neighborhood and greater community; and the natural world. The list of codes (see Appendix 4) was the backbone from which the main and ancillary patterns were analyzed and interpreted.

Qualitative researchers commonly seek multiple insights into a phenomenon rather than a concrete answer to a specific question. As phrased by Gretchen B. Rossman and Sharon F. Rallis in their research guide, Learning in the Field, qualitative researchers “search for truths, not Truth” (Rossman and Rallis 2003). The truths I observed over the course of this research have been closely linked with my reflexive role in the project. One

of the consistent patterns revealed in the interviews and memos was how directly each resident associated the garden with me as an individual, and the many instances of residents “giving care” to me: with food, compliments, hugs, recipes, and a reflector for my bicycle. My findings are therefore highly contextualized, and my aim in presenting them is to describe the sensitivity to beauty and life which I saw and shared with the people at Sunrise House. The applicability of my conclusions to the entire long-term care system lies in the powerful combination of nature and friendship which underpinned this research, its analysis, and its conclusions.

Statement of Ethics

A researcher who seeks to gather and interpret data about the lives of other people can treat them as subjects to be observed and reported on or as active stakeholders in the research process. Community-based participatory research, or CBPR, redefines social research itself by redefining the role of the “human subjects” referred to in the traditional academic institution. As an evolving field of research, CBPR is accompanied by its own set of ethical principles beyond those of the Institutional Review Board (IRB). Not unlike the concept of quality of life discussed earlier in this paper, CBPR ethics present a challenge to the very idea of standardization because they are more qualitatively than quantitatively based—and more to be strived for than to be achieved, accomplished, or checked off.

The garden project at Sunrise House was a potent collaboration between myself, residents, and staff and in itself was a combination of study and action. I undertook this research project with the approval of the Brown University IRB as required by law and additionally in keeping with certain universal CBPR principles (Appendix 4). My own

personal understanding of ethics is as a thoughtfulness to be revisited with every step of research. Though not a legal requirement, the ethical guidelines of CBPR served to define the way I interacted with the people at Sunrise House, recognized my own role in the project, and interpreted the data that filled up notebook paper, word documents, and audio tapes. Just as ethical consideration must precede and evolve with research, I preface my findings with a section called “ethics” and hope that the academic institution continues to embrace this crucial component of research with human participants.

Findings

The garden at Sunrise House, though small in square footage, provided a contextual experience for developing and revealing multiple links between estranged “opposites.” Ultimately, this thesis is an argument for subtlety, for a proactive softening of the thick lines that sometimes divide fluid continuums into perceived opposites and alienating extremes. When we define with words like “living” and “dying,” “natural” and “unnatural,” “urban” and “rural,” “old” and “young,” we turn clay into brick; when we act and think unarmed with these words and their stigmas, we find ourselves suddenly dealing not with concrete, but with a much more approachable medium. The six major themes of this study construct and support a notion of interconnectedness that both ecology and sociology have often posited. In addition, these findings emphasize that while both environmental and healthcare-related “problems” seem daunting and staggering, they are simply instances of a currently broken connection. The solution is only a more sophisticated version of tying shoelaces: we simply have to pick up and reunite the loose ends.

Accordingly, the findings section of this study describes in detail how the garden at Sunrise House challenged the idea of polarization and extremes, and instead developed connection and reconciliation. The garden project can best be understood through its relationship with six sets of perceived opposites: nature and the city; the individual and the community; simplicity and luxury; giving and receiving care; being sick and being healthy; and, ultimately, living and dying.

Nature and the City

The association of the natural world with pristine wilderness is anachronistic; not only because areas of pristine wilderness are fewer and further between than in the days of Muir or Thoreau, but because of a realization that nature overlaps with the brick and concrete that were once deemed separate from it. If the gingko trees that line city streets are less grandiose than a mountain range, they compensate in their distinct ability to live and thrive amongst humans and the human-made. The immediacy of the gingko tree is a component of the environmental justice movement, which emphasizes the importance of keeping “nature” accessible to all people-- not only those who can by foot or car visit the deep woods and the sea.

A garden, even in its most tame and manicured incarnation, is inherently wild. And unlike a mountain or a lake, a garden can easily be created and maintained in a space the size of a lawn or a parking lot, or even smaller. Urban gardens, like gingko trees, can be healthy, happy parts of the city ecosystem, cohabitating amiably with coffee shops and office buildings.

The Sunrise House garden in Providence, like any garden in an urban area, is a visual and experiential statement about what belongs in a city. Climbing vines of purple flowers and rows of bean plants offer visual contrast to the surrounding sidewalks and the constant presence of cranes and bulldozers in the paved hospital complex across the street. For passing cars and pedestrians as well as residents, the garden is a striking yet unobtrusive reminder that nature is *in* the city.

Correspondingly, and in keeping with the aforementioned research of Rachel and Stephen Kaplan, a resident named Jay described how the garden at Sunrise House impacts his experience of urban living:

For me to have a house, and live in a place where I can see tomatoes, I can see eggplants that I never saw before, green collards growing—has been something beautiful and a great experience. Because I don't feel much like I'm living in a jungle made out of blocks and cement. But I'm still living in a place where there are green areas around, and it's very peaceful to see that.

Jay's singling out of tomatoes, eggplants, and collard greens may represent the additional significance that food-producing plants carry, distinct from the beauty of lilies and roses. At Sunrise House we had full backyard plots of collard greens, kale, peppers, and cucumbers, but took care to plant tomatillos, beans, and tomatoes in the more visible front gardens as well, which had previously held only perennial flowers. The ripening Brandywine tomatoes and the yellow blossoms of tomatillo plants held their own next to pink roses and hydrangeas. The presence of food on stems rather than supermarket shelves, and in the most visible part of a residential property, speaks a loud truth in the din of food production and consumption in this country. Food comes first from the

ground, not a truck or a display case, and can come from the ground of one's own yard rather than some distant rural field.

At Sunrise House especially, the importance of food amongst flowers was appreciated and noted by residents and staff alike. Residents who live on disability allowance and CNA's working night shifts and multiple jobs to support their families are under enough financial pressure to value the function of food over the beauty of flowers—and made that fact clear to me. After a planting session in early June, I sat on the front porch with Luis and Eddie, both of whom grew up in agrarian Puerto Rico, and Nancy, a cheerful and unapologetically outspoken CNA. As I pointed out the newly planted pattern of snapdragons and poppies, Nancy asked, “When are we gonna plant okra? And more collard greens?!” Definitively, she told me that flowers were okay, but we had to grow food: “We need something we can eat!” Luis and Eddie nodded in agreement. The presence of food plants in our garden, initiated on principle and increased by demand, was a way for residents and staff to use and view nature as something that could provide a needed commodity. A vegetable garden in the city is not simply a form of luxury or eye-candy but a resource for meeting basic human needs. I will revisit this idea of the garden as food source in a later section about the role of the garden in the physical health of the residents.

In addition to the usual garden suspects: flowers and vegetables, our use of organic growing methods at Sunrise House added a third dimension of exposure to the natural world. First, in mid-May, large piles of black compost were brought by truck from Earth Care Farm in Charlestown, RI. While shoveling the compost from the bed of the truck I excitedly put handfuls of the rich soil into the palms of suspicious residents. I

pointed out the earthworms and sea shell fragments within the crumbly dark compost, and informed everyone that elephant dung from the zoo downtown was an invisible ingredient. Similarly, I brought haybales one at a time in the basket of my bike to use for mulching the beds. Gradually, the Sunrise House property came to include not only the recognizable garden but its natural precursors and cousins, all of the forms of life that organic agriculture uses in place of Miracle-Gro and chemical-based pesticides. Residents inquired about surprising deliveries with curiosity and interest, and came to expect that something which seemed nonsensical would be followed by an explanation of natural function. This was an ongoing opportunity for the residents to discover the surprises inherent in the natural world, and for me to see them again with new eyes.

Previous experience and interaction with nature, horticulture, and agriculture varied among the residents. Some grew up in the rural tropics, others in South Providence. Many reported that a mother or grandmother kept a garden, and Priscilla recounted fond memories of visiting her aunt's farm in the South. In several conversations, Pete described in great detail his months of "living in the woods near Warwick" when he was homeless before coming to Sunrise House. He swore to me that if necessary, he could survive in the woods with a tent, a spool of string, and a knife.

The present reality for these residents is that they rarely leave Providence. Some of them rarely leave 8th street. One of the implicit goals of the garden was to defy the possibility that this lack of geographical exposure translates into a lack of interaction with the natural world. If people cannot get to "nature" as it exists in mountains and forests, "nature" must come to them—in some other, more portable form. Priscilla remarked that when working in the garden, especially when both she and I were wearing "farmer jeans"

(overalls), “it felt like I was in the country.” Similarly, Jay laughed when he told me that with the garden now at Sunrise House, “it’s like living in a farm, when you are not in a farm, you are in your backyard!” Both of these sentiments represent the garden as a bridge between the perceived distant place where nature resides and the immediate, urban setting.

Marilyn, the administrator, noted that Sunrise House had never before offered an ongoing activity to its residents that was based outdoors or that focused on building a sense of “connection with the earth.” The garden did just that, in the process redefining nature as an urban-friendly entity, and naturalizing the city as a quietly wild place.

The Individual and the Community

Just as the concept of “nature” must envelop and accept its urban parts, so too must a community embrace its individuals. And though individualism and independence are prized parts of American culture, it is the interaction and cooperation among such individuals—not their isolation- - which ultimately reveals the gifts and needs of each person.

Like “quality of life,” “nature,” and other key concepts in this paper, “community” cannot be strictly defined; it is an unquantifiable yet enormously important idea. For the individuals who call Sunrise House home, community is largely made up of the other residents and the staff members who come and go. Though some have family members and friends who visit occasionally, Marilyn pointed out that through intersecting circumstances of HIV/AIDS, poverty, homosexuality and/or drug addiction, “many of them [the residents] have worn their friends out, or their families out. . . there’s

a lot of emotional support needed.” This emotional support is considered one of the services officially offered by Sunrise House as well as by case managers assigned to each resident through AIDS Care Ocean State and the Department of Health and Human Services. Unofficially, residents’ support systems come from the daily interactions that make them feel that they are part of something bigger than themselves.

If community is based on affinity or shared characteristics, it may be viewed not as a finite grouping but as a series of concentric circles. The residents’ most immediate community, besides family members, is made up of each other. A larger perspective includes the staff as well. The presence of volunteers, and the garden program in particular, emphasize the fact that residents belong to still wider communities: the surrounding Summit neighborhood; Providence; the state of Rhode Island; and the charismatic urban agriculture movement which is so vibrant in this city.

Just as the garden is a traveling representative of nature at Sunrise House, so are volunteers representative of community. In a sense, a fresh-faced volunteer is making a house call to let residents know that they are cared for and valued. Marilyn explained that the presence of volunteers reminds residents that there is a certain amount of commitment made to them, and that volunteers from all walks of life expose residents to new perspectives and new approaches for how to cope with problems. Residents value the social company of new, friendly people. The garden program attracted volunteers to Sunrise House: my friends and I who came to help; a community service crew of Providence College students; and people who heard about the garden through AIDS Care Ocean State and Volunteer Center of Rhode Island. Among the residents, Jay’s

perspective on the importance of such volunteers at Sunrise House was strikingly eloquent:

People who are very sick, they lose their relationship with the people, with the society, with the community, because they don't go out. They are just so sick and feeling so sick. Then, when people come to their house, they are living again. They are not so miserable, feeling sick. But they are interacting, seeing people, they are being visited and they are doing activities. It doesn't feel like they do much, they just move one plant or they look at the plant, but for them-- for us-- it's important. . . Yeah, to be alive means to be with other people: to share with other people. . . Okay, we are sick but we are not dead. And as long as we are still able to communicate we need somebody to communicate [with]. And if we can't go out and communicate, it's good that other people come and communicate with us.

While the maintenance of the garden brought volunteers into the internal Sunrise House community, the garden itself encouraged a greater sense of external community with other people in the neighborhood. Sunrise House is located across from a bustling hospital complex and within a relatively quiet, residential area. The sidewalks are frequented by dogs and their owners, babies being pushed in strollers, and older adults out walking for exercise. It has always been the case that people *walk by* Sunrise House; but the garden and its interesting beauty is what makes people stop to look and talk with residents. In all of my interviews with residents, interaction with neighbors was mentioned as a prominent component of the garden experience.

This type of interaction—passersby complimenting the garden, asking about it—is distinct for the residents because it places them in a position of pride and ownership.

As Pete explained:

I always get compliments, *always*, you get a compliment from people. . . that go by and say, ‘What a *beautiful* garden,’ and it just brings more pride to the house, class to the house, and beauty to the house.

Priscilla, too, described her experience of telling nurses at Miriam Hospital about the garden when she was there for surgery over the summer and how attractive the garden was to passersby:

I spoke about our garden [to the nurses at Miriam Hospital]. And they was like, ‘wow.’ And I said, ‘whatever kind of garden you want, we have it!’ I mean when people walk by, they stop because it’ll *make* you stop. If you don’t want to stop—it’ll *make* you stop. And look and see, you know. It wasn’t like that last year. But it was here this year, and many more to come.

My own experience with neighbors, passing pedestrians and motorists was also significant. From April through September, I was kneeling in the garden, pruning roses, harvesting ground cherries and basil, or pushing a wheelbarrow of compost back and forth. Though I am clearly not a resident, I must have become a familiar image to passersby, who greeted me warmly and commented on how well things were shaping up. Mack, who lives directly across the street, often watched me working from his 2nd floor deck. After a couple of months, he came over and asked me to show him around the various gardens. He marveled at the tiny eggplants, saying he had never seen the plant itself before. I sent him home with a bunch of collard greens to cook and eat and

promised him tomatoes later in the season. While the residents felt a sense of pride in their home, I too felt an intense satisfaction at the visible display of both gardening and volunteerism—two things that are often best advertised by example.

Investing in the bonds that connect people to each other is a crucial way to create an environment of support, interest, and caring. For the residents, the garden offered many opportunities to feel like contributing members of multiple communities; for neighbors, it was a comfortable way to reach out and feel connected to the people at Sunrise House. Marilyn was adamant that community is a key message of the garden:

It takes the community to take care of it, it took a community to start it, it took a community to clear the land. And it's *built* that sense of community. It's given some people some common ground that probably none of the other activities have done.

People living in long-term care must feel confident in their communities if they are to feel confident in themselves as individuals. The garden at Sunrise House profoundly and consistently reinforced the human relationships that create this qualitative concept of “community.” On a broader level, an attractive, approachable outdoor garden is a small but effective step towards a greater goal: increasing visibility and integration of the elderly and chronically ill who are often unseen when within the walls of the facilities they call home. A three-year old living near 8th street need not be afraid of the man in a wheelchair who sits outside Sunrise House, and the sunflowers that stand between them offer common ground for a smile.

Simplicity and Luxury

Luxury is most often associated with money; simplicity is equated with plainness and lack of sophistication. They are certainly considered antonyms rather than synonyms,

but the garden suggests otherwise. We started the garden season with a yard still barren from winter, a pile of compost, and some seedlings that to anyone but a horticulturist or farmer look as much like weeds as anything else. It seemed a fairly modest foundation. The planters we had specially built and designed were a source of some novelty, but for the most part, the basic ingredients seemed as far from beauty and food as flour is from bread.

By the end of the summer, we were surrounded by exquisite colors, smells, and soft petals; eating red, flavorful tomatoes; and crushing cinnamon basil between our hands. Residents who smoke cigarettes outside all year round were suddenly doing so amidst blue morning glories and towering amaranth. This metamorphosis from plainness to magnificence cost only time, water, and sunlight. And while “luxury” may initially seem a melodramatic description, it is grounded in both the literal and metaphorical ways that the garden yielded richness for everyone at Sunrise House.

In a very direct sense, the garden was a way to save money, in that it provided food at no cost. As previously mentioned, financial pressure is a definite reality for residents and even some staff members. At Sunrise House, residents are expected to pay for their own groceries using money from disability, savings, or family members. Often they give a small shopping list and some cash to Charlie, the chauffeur of sorts, who then drives to Shawe’s and picks up the needed items. These lists more often consist of instant macaroni and cheese, frozen dinners, and English muffins than anything else. Some, like Jay and Priscilla, responded that they have always included some fresh vegetables as part of their grocery list. But whether people have paid for produce in the past or not, all

residents were eating food from the garden this summer. When I asked Pete why he liked the cucumbers from the garden, he answered me honestly:

Well, let's start this way, they save me money, which I appreciate, I mean not that cucumbers are expensive but anything that you can save, even if it's a penny. . . because I am on disability and you only get, as anybody would know, so much allowance on disability.

Marilyn gave me a more exact figure: a monthly disability check is for a total of \$636. Sunrise House rent is on a sliding scale, but residents' most looming financial pressure is the possibility of getting sick. For people living with HIV/AIDS, unexpected ailments and infections are a reality, and an expensive one. As Sherrie once told me, "I can't afford to get sick."

So if every penny counts, then so does every cucumber, every tomato. And unlike the periodic deliveries of macaroni and canned goods from the Rhode Island Community Food Bank, the produce from the garden is not donated charity but earned reward. There is a difference there.

The second dimension of this luxury of free produce is abundance: buying peppers at the store you might take one or two; but when they're ripening throughout your backyard you suddenly find yourself with as many peppers as you want as opposed to as many as you can afford. Jay, who loves to cook his native Mexican food, excitedly describes the effect of the garden's abundance on his eating habits:

I used to buy spinach and other vegetables, like tomatoes. Tomatoes were so expensive and now that I have been growing [them], I love to eat them like that (holding his arms out like a giant basket)! In a tomato salad, in a tomato sandwich. And, oh, I make my salsa! (laughing) I love salsa! And I use the tomatoes a lot with that.

Through the garden, the residents have been exposed to a luxury of freshness and abundance that is usually enjoyed only by farmers and gardeners. The tastiness of our garden produce was exclaimed upon repeatedly throughout the season: “the taste of those cucumbers is just out of this world!”

Abstractly speaking, the beauty of the garden was so noticeable and so appreciated as to constitute a richness and depth at Sunrise House that is not present with only sidewalks and grass medians. One afternoon, Pete, Luis and I were sitting on the porch when we noticed a monarch butterfly resting in one of the empty plant pots. Luis called Gabriel and Charlie over to see. This sharing of beautiful observations was characteristic of the garden season. Priscilla told me about a similar experience:

There’s certain plants that I’ve been looking at and I said, ‘wow, you know, the sunflower—it’s very huge!’(laughing). . .I just mentioned to one of the staff, ‘wow, do you see how fast the sunflower grew?!’ So we walked over and she says, ‘yeah,’ she says, ‘now look at the other flowers!’

Sherrie, who often speaks in metaphors with poetic forthrightness, articulated a more introspective relationship with the beauty of the garden:

The garden reminds me of stories. You know what I’m saying? They do look like little storybooks when you’ve got gardens. . . It’s so, it’s so dreamlike, you know? Fantasy land. And this may sound crazy, I even think—believe it or not—I think about Alice in Wonderland when I see a garden. You know, a whole bunch of flowers—they’re all like magic to me. That’s what flowers bring out to me.

Specific instances of “beauty appreciation” add up to a general sentiment that the garden is a valuable resource not only because of its translation into grocery-dollars-saved but in the intrinsic splendor of its colors, shapes, textures, and meanings.

Giving and Receiving Care

Among other services, Sunrise House residents receive their disability checks and Medicaid from the government; donated groceries from the food bank; daily care from nursing staff; frequent care from social workers; and occasional care from physicians. But as Shield and Thomas have pointed out, *receiving* care is not enough; it is the opportunity to *give* which enables a “full and fully human life” (Thomas and Johansson 2003; Shield 1988). This is a profound realization in long-term care. With the Eden Alternative, Thomas created opportunities for giving with day-care programs, fish tanks, and potted plants. At Sunrise House, the garden enabled residents to give care not only directly to plants as in Thomas’ model but, more subtly, to humans as well.

One of the traditional premises of horticultural therapy is its linking of people who need to give care with plants that receive care-- and show the benefits of care in their growth and blooming. As in Thomas’ findings, Sunrise House residents took gardening as an opportunity to be responsible for another living thing-- an opportunity they rarely have. Many of these instances were reminiscent of previous research findings on horticultural therapy: referring to the plants as “babies” and noting with pride how they grew; treating seeds and seedlings with extreme gentleness due to an expressed concern about “hurting” them through rough handling; and seeking out my help and advice to

“cure” sick houseplants. Marilyn noted that one of the main benefits to the residents of the garden program was this fulfilled opportunity to nurture:

One of the things I think that moved me most is how well the residents took care of nurturing the plants they got. . .in fact there was nurturing exhibited by some residents whom I’d never seen show that before.

Though Marilyn was referring to the benefit of giving care to the plants specifically, the Sunrise House garden program noticeably highlighted other dimensions of care less prominent in the literature review but as significant in their implications. The experience of having a garden program at Sunrise House afforded residents not one but three recipients of their care: the plants, yes, but also the nursing staff-- and me.

As stated earlier, most Sunrise House residents do not leave the property very often; their fairly insular community is comprised of other residents, nurses, and CNA’s. As a result, interactions between residents and staff members have both medical and social importance. Nursing staff play an integral role in the provision and maintenance of medical care by reminding residents to take their daily pills, escorting them to the hospital for treatment, and assisting with various activities of daily living. It is the constant, reliable presence of the nursing staff members—justified and paid for on grounds of medical need—which renders them part of a crucial social fabric for the residents. Residents are well aware of staff members’ schedules: who’s on duty Tuesday night, when Olivia is returning from visiting her family in the Haiti, and how nervous David is for his impending wedding. Residents and staff members often take cigarette breaks together, and on several summer nights I found myself sitting in the glow of a porch light with a couple of residents and a staff member, laughing and telling stories. The nursing staff of Sunrise House *gives* care to the residents, both by fulfilling the duties

for which they are paid and by allowing themselves to be known and treated as individuals, often like friends. This giving is a gift readily received by the residents.

Luis is the most physically disabled of all the residents; he can only leave his wheelchair with assistance and his left side was severely weakened by a stroke. The nursing staff is responsible for helping him bathe and dress, and all of his meals are cooked for him. In an interview, he agreed that he enjoyed helping in the garden but broke out into an earnest smile when he added, "I believe they [the nurses] enjoyed it even a little bit more than I did!" When I asked why he felt that way, he said it was because "they were always out here asking me to pick tomatoes and cucumbers so they can make a salad." The garden provided an opportunity for reciprocity; Luis often has to ask a staff member for a cup of water or for help using the bathroom, and now the staff can ask *him* to bring in tomatoes from the front yard.

Later in the summer, Luis was hospitalized for several days with a chronic foot infection. I visited him twice with a bouquet of fresh flowers cut from our garden to keep by his bed. The hospital nurses on the floor commented on how beautiful, colorful, and unusual the arrangements were: striped marigolds, hibiscus, snapdragons, and basil in contrast to the traditional carnations, daisies, or roses. When Luis returned to Sunrise House he asked that we pick a bouquet together to bring to those nurses because they had so loved the flowers. We picked a nice arrangement and went together to deliver them. Luis proudly held them in his lap and presented them to the fourth floor nurses with a smile.

On a July afternoon, Pete watched from the porch as I showed Olivia, a Haitian-American CNA, the various plants that were growing in the planters alongside the

driveway. Excitedly, she laughed to tell me that basil grows in Haiti “like grass,” and that her mother and aunts used it to make hot tea and to give a nice aroma to water for mopping floors. Overhearing the conversation, Pete called out: “Take some home! Yeah, we’ve got lots of it, take some!” Like Luis, Pete relies somewhat heavily on daily assistance from nursing staff, and was perhaps eager to offer something—even basil—in return.

Jay is the most independent of the residents; he works part-time, volunteers, and can do physical labor on a “good day.” He is known among staff, residents, and administrators as a kind, generous, easygoing person. Jay becomes visibly joyful when he has the opportunity to share, and the garden—its beauty, novelty, and abundance—is no exception. He emphasized in an interview his enjoyment in showing the garden to nursing staff specifically:

There is something that I never gonna forget—the faces they [the staff] have when they walk and they saw the plants [and said]: ‘wow! Those have eggplants!’ And they says to me, ‘wow, how many tomatoes you have!’ (laughing) . . .they never know what we able to grow; the green collards, they said ‘those green collards are big. We go to markets but we never see the plants, what it looks [like].’

The garden is as much of a source of interest-- and food-- for the nursing staff as it is for the residents. Anything that makes Sunrise House a more enjoyable workplace for the staff seems to also be an indirect service to the residents who are under their care, an idea reminiscent of the Eden Alternative as well.

Maripa, a Ghanaian CNA, asked me in early May to show her what had been planted. She said “That will be great!” and made me promise that in August there would

be enough tomatoes for everyone. As the season went on, she often picked cherry tomatoes and ground cherries and put them in bowls on the kitchen table.

Nancy, a CNA who often worked long night shifts, was so excited about the backyard bed of collard greens that she shook my hand and made me coffee in the morning before she left.

In July, Marisol, personal attendant to Sherrie and Pete, took home some giant zucchini and served it to her family for dinner, breaded and fried. When I asked her to explain the recipe to me, she promised that she would make it at Sunrise House to show everyone. This was perhaps the most noticeable way that staff chose to be part of the garden season: though they treated the outdoor garden work as the responsibility of me and the residents, they eagerly volunteered to cook with the harvested produce. Each of the three cooking workshops was led by a different volunteer staff member, with me as obedient organizer and residents as assistants. As Marilyn pointed out in an interview:

The staff welcomes the residents' impact and effort into the garden, and the staff is kind of looking forward to being the people that do the actual cooking, like David wants to do the eggplant parmesan. . . So the staff was instrumental in coming forward and filling that gap in—"Oh this is my mother's recipe for this, so let's cook it and we'll have it all from our own garden."

This was certainly the case with Polly, an African-American CNA with a sarcastic sense of humor. She authoritatively led the workshop on how to make fried green tomatoes using her grandmother's recipe. During the workshop, she and Priscilla reminisced together about their respective childhood experiences growing up in a single-mother household with very little money or food. They laughed boisterously at the

memory of eating oatmeal for days at a time. Again, the multi-dimensional relationship and shared experiences between residents and staff contribute to a sense of community and warmth at Sunrise House; the garden and its memory-triggering capacity were a source of such sharing.

Volunteerism is sometimes misunderstood as a one-sided, altruistic act when in truth it is reciprocal. The residents and staff at Sunrise House re-taught this lesson to me; their generosity in accepting me as part of their community made me feel as much a recipient of care as a giver, if not moreso. The social dynamic at Sunrise House is one of banter and lightheartedness. Residents and staff call each other by nicknames, play practical jokes on one another, and generally seek out and find reasons to laugh. About six weeks into my time as a volunteer at Sunrise House, I was given my first nickname: “Granola Head,” which was later joined by “Skachel,” “Raquel,” “Madame LeFleur,” and of course “Honey,” “Sweetheart,” and “Baby.”

Residents implicitly and explicitly expressed that I was an important part of what made the garden an enjoyable activity. Luis pointed out that working in the garden *with me* was fun and educational:

Especially with you, cause you’re so easygoing and we stopped to explain things about the garden. Things that I didn’t even know.

Luis’ frequent efforts to help in the garden were particularly poignant because of his physical limitations. On the day when I brought discarded pottery from a RISD studio to be crushed for drainage fragments, no one was visibly around but Luis. He wheeled himself over, watched what I was doing, and used his one good arm to throw big shards from the height of his wheelchair to the ground. Then he bent over, picked up the broken

pieces, and collected them in a bucket to be used later on. “Luis,” I said, “how come you’re so good to me?” He laughed and said, “I gotta help you, ‘cause you work so hard.”

Over the course of the season, residents found ways to care for me with tangible gifts as well: a reflector for my bicycle, lunch, breakfast, coffee, and hugs. Jay even insisted, against my polite refusals, that I take home some of the groceries that came from the food bank. Knowing that I am a vegetarian, he convinced me that no one at Sunrise House would ever eat the whole wheat spinach pasta and that I should really take it. Seeing that this was a way for Jay to give care and not just receive it, I eventually accepted.

The garden at Sunrise House was firsthand experience of what Thomas so convincingly presented in Nature, Hope, and Nursing Homes: offering opportunities to *give* is a radical and important innovation to be made in long-term care. While I sometimes take this privilege of giving for granted in my own life, the residents reminded me of its value in their clear enjoyment of the experience of caring-- for plants, nursing staff, and me.

Being Sick and Being Healthy

Though any thesaurus will assure you that “sickness” is the decided opposite of “health,” its confidence in the dichotomy is purely for the sake of semantics. In lived experience, the tension between the two is an interplay whose balance shifts each day. Especially when understanding health as a mental and spiritual as well as physical state, it is unlikely that any person could ever be completely “sick” or completely “healthy.”

With this holistic view of wellness, even those who are labeled “chronically ill” are highly capable of being healthy individuals.

Particularly in the case of HIV/AIDS, societal acceptance and medical developments have enabled health and sickness to co-exist. In recounting a brief history of Sunrise House, Marilyn noted its transition from being a place where people with HIV/AIDS came to die with dignity to being a place where people *live* with HIV/AIDS. This epidemiological development, the result of heavily funded medical research, is made possible by the antiretroviral cocktails and pill medleys that people with HIV/AIDS must take every day to simulate a functioning immune system. At Sunrise House, the most common announcement over the intercom is to ask a resident to come to “the med room” to get his pills. Often, these medications have serious side effects: lethargy, extreme sensitivity to sunlight, and harmful liver damage. This irony is part of the tenuous divide between sickness and health that is a familiar part of daily life for Sunrise House residents. They are used to it, and I had to become accustomed to it myself. As mentioned in the Methodology section, scheduled work in the garden was revealed to be inappropriate for a setting where health is erratic.

But in an environment where sickness is so unpredictable and so dreaded, health—even in small doses—becomes all that much more valuable. One of the important roles of the garden was as a source of health for the residents, both physically, mentally, and spiritually.

The time span of this study, not to mention my lack of credentials, prevented an in-depth analysis of the nutritional impact on residents’ health from eating garden vegetables. But the fact that residents were eating and enjoying fresh vegetables—

excellent sources of nutrients, vitamins, and minerals—is significant because it symbolizes the incorporation of these foods into their diets and consciousnesses. The head nurse at Sunrise House, whose credentials *do* allow for nutritional advising, reported that the immediacy of the garden was helpful to her in encouraging residents to consume more fruits and vegetables. The free, proximate source turned a big leap into a small one: as Priscilla said, “when I want fresh vegetables, I just go to my backyard garden and start picking.” Even if the physical impact is not immediate, the garden is an introduction to eating healthier food. Marilyn emphasized that the garden, and the cooking classes in particular, encouraged residents to try something new:

I think some of the residents have never tasted fresh vegetables. I think they’ve never bought a fresh vegetable at a store. I think they don’t have any idea what it tastes like. I think that people are reluctant to buy in the store because of the price. And the fact that they’re unfamiliar with the proper way to cook it. Or because, I recall one person saying a couple of weeks ago that he didn’t like summer squash, because his mother used to just boil it, and mash it, you know? And what we did was we did the summer squash on the grill, and it was wonderful! You couldn’t get him to stop eating it.

Whether because of the head nurse’s encouragement or not, residents seemed certain that fresh vegetables were healthy for them. Hank, a man of few words, was matter of fact: “I like eating fresh vegetables: it’s good for you. It’s good for you.” Jay told me how and why he began cooking with collard greens from the garden:

I use them for my chicken soup. I always cut them up, I boil them first, and after when I have the chicken soup ready I put them in there. . . because I was reading a men’s fitness magazine, it says that the collards

greens they have a lot of vitamins. . . Yeah, they are very healthy, and I've been eating them and using them a lot.

Sherrie went further to associate the merit of vegetables from the garden with their contrast from processed food:

I much love eating fresh vegetables and sure, everything today is all quick-quick-quick, but then you're not getting the nutrients that you really need. Maybe quick is *quick* but it's not healthy. I don't think so. But when it's fresh, and straight from the garden, it's like it's God's food, that's how I look at it, you know I don't know if other people look at it like that. But it's food from the earth as I should say. And it's natural. And natural to me means to have everything it should have, not things that it didn't have, you know that's why I like vegetables like that.

The fact that residents eat fresh vegetables and believe that they are healthy is perhaps an overlap between physical and mental health. In this and in other ways, the garden, its maintenance, and its produce had psychological benefits for the residents.

Marilyn and Charlie both noted that they believe what residents need most is a reason to get up and do something, even for ten minutes at a time. A sense of purpose is important for most people, but for Sunrise House residents it may be even more critical. With so many unstructured hours in a day, they may easily be preoccupied with the difficulties and limitations in their lives. Psychological research studies examining people in long-term care have often found high incidence of depression, which has in turn been linked to idleness (Rane-Szostak and Herth 1995).

Though this was not a psychological investigation, I did observe that for the most part, residents were unoccupied when I crossed paths with them outside or when I sought

them out in their individual rooms. Residents stand outside to smoke cigarettes and talk to each other. Indoors they are likely to be watching television, resting, and sometimes eating. Notable exceptions are Jay, who works part-time, and Eddie, who goes to the gym to work out several times a week. Hank and Mary Ann are sometimes picked up by friends or family members to go to church. In an environment where, as Charlie put it, “there’s just a *lot* of hanging out,” a stimulating activity that lends itself to short spurts of energy and attention span is extremely worthwhile. This was a significant contribution of the garden. It was easy for me to invite Gabriel to follow up his cigarette break with ten minutes of planting beans. This was likely to lead into another ten minutes of talking about the beans his mother grew in Puerto Rico. Jay, whose general tendency to fill his time with structured activity illustrates his attitude, offered a very direct connection between working in the garden and keeping busy:

It [working in the garden] is an activity that helped me to not think about my illness, and my problems, but I just spend time doing something that I really enjoyed, and I’m rewarded with that when I eat them [the vegetables]. . . because it [working in the garden] doesn’t give me time to complain. I keep my mind busy in what I have to do to make the plant grow.

Priscilla, in less detail, stated that working in the garden “made me feel better; seeing stuff that grew in a short time.” Her appreciation of the relationship between the plant life cycle and her own feeling about health, even life, is an indication of a realm more aptly understood as spiritual rather than mental. The connection between spirituality and the garden was a repeated pattern in garden work as well as in interviews.

The combination of an activity that deals with the germination, life, and dying of plants with people who themselves have an above-average intimacy with their own mortality unsurprisingly yielded many conversations about life and death in the abstract as well as personal perspectives. In contrast with previous work I've done with high school students and nature-based activities, residents were highly sympathetic to the cycles of plant life and very receptive to connecting those cycles with parallels in human experience. During conversations in the garden, I mentioned this potential parallel only loosely in order to respect the residents' privacy and comfort. However, I found that they were likely to suggest such parallels on their own while we were in the midst of garden work. For example, when a whole tray of pepper seedlings dried up and died indoors in April, Luis watched me dump out the remains into the front perennial garden. I explained that they "didn't make it" and that fortunately, even though they would not get to become full-grown plants they would now decompose, becoming part of the soil that would feed other plants. This is a basic premise of soil science; for Luis, it seemed instantly to be a metaphor: "It would be nice if people could be like that, too," he said.

Sherrie, too, ascribed spiritual merit to the plants and flowers of our garden. She adamantly felt that they were "generous," and that they did not care about anything but giving beauty to the world. She often used the word "miracle," to describe things observed and discovered in the garden, such as the seed pods of the rose of Sharon bushes or the tiny germinated carrot seedlings. She in turn related the beauty of the flowers in the garden to her memories of similarly meaningful beauty, and finally to the beauty that the flowers bring out in her:

Just the beauty of the flowers in the yard brings out a lot of spirit in you. . . It's such a wonderful feeling. It brings me back, when I see

things like that, to when I was a kid getting up early in the morning all the spring flowers in the yard, and the smells of the flowers, that's what I like—it's just a thing of beauty. . They [the flowers] also bring out gentleness. And it also brings out warmth. That's what I like about flowers anyway, and to learn how to grow and how to feed them, is a big thing for me.

Hank's sometimes fervent Christianity is well-known among the residents. He is soft-spoken but speaks clearly and surely about the existence and power of God. One day I sat with Hank on the stoop and saved zinnia seeds—the dried out petals from the spent flowers. We picked off petals and dropped them into a bucket that sat between us, and I told him of my own particular partiality to seed-saving as a garden activity because of its cyclical nature. He responded that seed-saving is one more piece of evidence that God exists. Later, in an interview, I asked him to restate his feelings about how the garden might be connected to God. He said:

We just didn't appear. God created us, and plants, and stuff of that nature . . . to make a long story short they [plants] will show you that there is a god, a higher power. . .And all the planting, things like that, and gardening: that's part of God's plan. He likes people to grow things that He made. There's a creator upon all this stuff, I know there is! Human beings didn't just appear out of air, they were made by something, they were made by God.

When considered as a whole, the garden presents multiple, if intangible, opportunities for health. In a setting where health is earned through an all-too-tangible medley of pills and appointments, subtle means to challenge sickness are precious

counterparts. Literally, the produce of the garden offers much-needed nutritional value to the body. The act of gardening offers health to the mind and spirit in the form of engrossment, symbolism, and metaphors to human experience.

Living and Dying

The starker dichotomy of living and dying is less casually spoken of at Sunrise House than that of health and sickness, but it does inevitably surface. As a community, Sunrise House does have to see death, though because of its assisted-living status it is not considered a place where people come to die. Death remains in the domain of the nursing home, and over the years past residents have been moved to nursing homes in other parts of the city when their dependency on daily assistance exceeds what is offered, or intended, at Sunrise House. In September, Luis was transferred against his wishes to a nursing home in South Providence, after living at Sunrise House for over eight years. Staff and other residents accepted this event as inevitable and appropriate due to Luis' high level of disability. When I visit him in his new home, Luis still tells me that he hopes one day he will be given a second chance to move back into Sunrise House. His "someday" attitude implies that even with a stigmatized relocation to the nursing home, he does not feel that the end of his life is immediate.

Internalizing the way they are spoken to and treated by healthcare professionals, family members, and society as a whole, residents in long-term care may tend to perceive themselves as closer to "dying" than the average person. Sunrise House residents openly admit that their health is more precarious, but they tend to resist being associated with death itself. They are most certainly alive, and their cognizance of that fact is part of what

makes their company so profound. Jay's comment that "we are sick, but we are not *dead*," is poignant not only because of its frankness but also because he laughed as he said it. His laughter, to me, expressed his surprise that anyone could think otherwise.

Actual death-- loss of human life-- did affect the Sunrise House community once during the garden season. On the day that we had scheduled the first seed-starting activity, Marilyn called me to cancel, explaining that Henry, a resident, had died in his sleep the night before. She told me that everyone was in a state of shock and we would have to try seed-starting another time. Henry had raked leaves with me all through the Fall and we had planned to build planters together in a few months. For me, too, it was a shock to be reminded of the very real relationship between death and the residents I had come to know. After a week, people and schedules at Sunrise House were functioning as usual. After two weeks, Henry's room was occupied by Mary Ann, a new resident from Burundi.

Two months later, when the planters Henry had intended to build were finally constructed, it was a joint effort between me, Pete, and Charlie. As the largest planter took shape, Pete joked that it would make a nice coffin. "Will you build one like this for me, one day?" he asked Charlie. They laughed and agreed that at any rate it would beat the corrugated cardboard coffin in which Henry had been carried out of his room, out of the house, and to the morgue. Overall, it seems there is little money, time, or energy to spare for the sake of death and mourning. It is only brought up as another source of banter.

Pete's combined characteristics of poor health and sarcastic lightheartedness make for a daily approach to living that leaves death for later. His maxim, "I live one day at a time, I take it one day at a time," was echoed by other residents as well. But what I

observed throughout the garden season was that residents value and need both the past and the future in addition to what the present offers. Ultimately, the confluence of all three informed my understanding of what makes “a full and fully human life.”

Each resident at Sunrise House has had a childhood, a family, several homes, and several jobs. Some have had spouses or children, or drug problems, or have spent time in prison. Just because they now live, slightly isolated, at Sunrise House does not render the earlier chapters of their lives irrelevant. Acknowledgment of the past is the first component of a fully human life; the opportunity to value and share one’s memories, whether positive or painful, is a validation of lived experience.

Several factors made the garden a place where talking about the past was comfortable and relevant. The first, of course, is having a listener—me—which again reiterates the importance of human companionship as part of horticultural therapy. But gardening is distinct because of its tranquil, interesting tasks conducive to quiet company as well as conversation. Planting, weeding, and watering are direct; an accompanying conversation is optional and low-pressure. It can include long monologues and long pauses. On separate occasions of garden work, Pete, Luis, Jay, and Priscilla recounted thorough renditions of their respective life histories. Sherrie, Eddie, and Hank, though less thorough in their storytelling, offered many anecdotes.

Sharing of life stories was often triggered by the task at hand. During the early phases of spring planting, I asked residents if they had any experiences with gardening as children. This initial connection to the past easily opened up a portal for free association. For example, Priscilla responded that her mother had a full garden in South Providence when she was growing up. First describing those remembered vegetables, she eventually

told me of the poverty which motivated her single mother to grow food in the yard; of the many houses they lived in; and of the circumstances which ultimately caused Priscilla to run away from home at the age of fourteen. Luis told me how his childhood neighbors called his father “loco” for the attention he lavished on his pumpkin garden. Jay spoke fondly of his gardening grandmother who was a traditional healer in rural Mexico.

Whether the childhood landscape was South Providence, Warwick, Mexico, or Puerto Rico, a connection could always be made from the plants in front of us to a garden of the past, or a farm, or a favorite tropical tree. This unobtrusive opening of the door to memory led to sharing of stories that had nothing whatsoever to do with gardening. It was a pattern that repeated itself with most of the residents.

Ethnic and familial recipes played a distinct role in incorporating the past into the present of our garden season. As already mentioned, staff were enthusiastic about sharing inherited secrets of cooking eggplant and collard greens. Residents, too, connected the food in the yard to meals they were served by parents and grandparents.

In keeping with Pete’s “one day at a time” philosophy, the present is an important part of a fully human life, particularly in its capacity to infuse daily living with experiences of pride, caring, and stimulation. The garden’s ability to make a person feel that they are part of the present is in part explained in the above sections about community and care. In addition, garden work offers an opportunity for residents to experience a sense of accomplishment. Setting and achieving goals reminds residents that they are, and can be, productive rather than idle, sedentary, or bored. With a backyard garden, they can do so without crossing the mental and physical boundary of leaving the

property, taking a bus, and risking the possibility that they might suddenly feel tired or sick when far from home.

Residents were encouraged to bring themselves to the garden, to contribute what skills they already possessed as well as learn new ones. Jay, of course, is an avid gardener, and was able to directly use his knowledge of staking tomato plants. In an interview, he emphasized the satisfaction of being able to harvest the food for dinner.

For Pete, who shunned most plant-centered garden work, the chance to use power tools and make planters was clearly invigorating and validating. Sketching the plans and drilling holes, he reminded me that this was how he made his living as a carpenter before he got sick. Once built, Pete took great pride in showing visitors how sturdy the planters were. Pete also considered himself the unofficial security guard of the garden:

When I can I usually take a look around to make sure everything's fine with it [the garden] and make sure nobody plays with it. And anybody that comes here that I don't know, I make sure that they do not mess with the garden and also, people that walk by, I'm always eyeing them to make sure that they don't pick a flower (laughing). . . Yes, well you know I don't try to be a big intimidator, but if they do I tell them please don't do that, because we worked very hard on this, and it's not there to be picked, it's there to be seen.

While Jay and Pete brought physical skills to the garden, Sherrie and I agreed that her contribution was more about insight than labor. Sherrie is bright-eyed and quick-witted but is often weak and tired. She carries herself gingerly and was unable to do any garden work that involved bending. During an interview, I mentioned that I had

noticed and admired her “way with words” over the course of the season; she often spoke in metaphors and made poetic, insightful comments about the garden. She smiled and agreed, acknowledging that this characteristic, indeed, is a skill to be valued:

Hey, thank you! . . . A lot of times I *do* see things in things that other people may not see, you know—and I like that part of me too.

In addition to valuing their own contributions of personality and past experience, most residents sought out and appreciated opportunities to learn new skills and gain knowledge about gardening.

Residents, staff, and visitors alike commented that it was fascinating to simply see the vegetables they recognized from the supermarket now growing on stems and leaves that they had never seen before. The baby eggplants, in particular, were exclaimed upon with amazement. Realizing that the smell of fresh oregano is an integral factor in the aroma of pizza was another exciting discovery. We also grew some foods in the garden that no one at Sunrise House had ever seen or tasted, such as ground cherries, a sweet relative of the tomato. When they began to ripen I convinced everyone to eat at least one or two and describe what it tasted like. Answers ranged from “apples” to “pears” to “just different.” Priscilla liked the idea of using basil for tea, as advertised by Olivia the Haitian CNA, so much that she began doing for herself several times a week. The amount of informal learning and teaching that takes place in the garden is remarkable. Though the structured workshops were successful, residents are much more receptive to one new and interesting fact at a time in a casual manner. Accordingly, it is rare for me *not* to approach a resident sitting outside with a petal, a leaf, or a handful of soil and a sentence that starts with “Did you know. . .?”

The level of curiosity and desire to learn displayed by the residents can be understood as interest in the present and future: a feeling that life is dynamic. By asking questions and listening to the answers, by tasting a new fruit or agreeing to touch an earthworm, residents acknowledge that their world is still interactive. Marilyn explained to me that from her point of view as an administrator, an activity or program is successful if it allows residents to either use skills that they rarely get a chance to share or to develop new skills that help them better cope with their lives. The garden certainly satisfied both of these criteria.

Looking forward to the future is perhaps the most privileged component of a fully human life, but only if the future is perceived to span decades-- as college students are so often encouraged to believe. For residents, the future might be tomorrow, next week, or next month; some certainly shy away from talking about next year. Regardless of the length of "the future," allowing its very existence to play a role in one's life is a statement that life may very well keep happening and is therefore worth investing in.

Gardening is about investing, waiting, watching, and seeing. Seeds are often used in metaphors because in truth the concept of planting one is profound: though it is not a tomato now, it will become one. It takes foresight and belief to take that first step. Our work in the spring was accompanied by a feeling that there would be satisfaction, beauty, and harvest later on. This investment in the even the short-term future is a wonderful thing to bring to long-term care.

On a broader level, my interviews with the residents and staff included a final question about what we could grow or do differently next year. Hank, who had been only passively involved, said earnestly that next year he wanted to participate more in the

garden. Priscilla decided that she wanted her own personal plot. Marilyn spoke of having enough tomatoes to make and preserve “Sunrise House Tomato Sauce.” Charlie told me he thought we should level the entire backyard and turn it into one giant vegetable garden. Now, in November, we’ve pulled up all of the plants and are raking leaves again, spreading compost over the beds to ensure that they are ready in the spring. In addition to all it has yielded in one season, the garden now assumes a distinct role as something to look forward to. Its cycles are easy to grab hold of.

The particulars of a “full and fully human life” depend largely on the human who lives it, but the importance of past, present, and future seem constant. Leaving death for later, the garden – so full of living things-- lends some of that life to its gardeners, offering opportunities to think back, think forward, and enjoy what lies between.

V

Conclusions and Recommendations

When I started this project, I did not have to research how to grow tomatoes and basil or read about the wisdom, care, and worth of elderly and chronically ill people; these were things I already knew. What sent me to the library was my curiosity about the current state of long-term care and the field of horticultural therapy. Though there is much I have yet to learn, I finish this thesis process familiar with a few of the key figures in this broad community of discourse: Vladeck, Thomas, Relf, Kapp, Lewis, and more. Aligning myself with the observations of these highly-credentialed sociologists, ethicists, and physicians, I too recommend with certainty that a long-term care movement under

pressure to improve needs innovation, not simply more regulation. Un-credentialed, I also offer my own caveats to what innovation means.

From the top down, “the regulatory octopus” of long-term care must realize the limitations of its tentacled approach to living. Kapp remarks that the current regulatory system exists mostly to punish and “weed out the bad” from long-term care facilities. There ought to be an increase in top-down incentives and rewards for creating and maintaining environments in which residents are both healthy and happy. “Healthy and happy” is another way of labeling the elusive “Quality of Life,” which needs to be ever more integrated in long-term care. A focus on social and interpersonal wellbeing in long-term healthcare should not be the domain of sociologists looking on from outside; like making sure the pills are taken on time and the bed is made, quality of life is a responsibility of physicians, nurses, nurse aides, and administrators. Training for medical professionals, from the entry-level aide to the most specialized physician, should further incorporate social and interpersonal health needs into the curriculum. Without due awareness of mental, spiritual, and experiential factors which significantly impact the life of a human being, medicine functions with a dangerous blind spot.

As the day-to-day overseers of long-term care facilities, administrators bear considerable responsibility for cultivating quality of life. They are in the best position to rethink and redefine the very concept of recreational activity, to facilitate opportunities for activity that does more than just occupy minutes or hours of the day. Bingo and movie-watching could be supplemented or even replaced by community outreach and interaction, making the walls of the nursing home more permeable to what surrounds them.

In addition, it is my opinion that advocacy and advance in this area are sorely misguided if they target or reach only an upper class clientele. Private nursing homes adopting the Eden Alternative benefit those residents who can afford the fees required to live there. Quality of life is a right, not a luxury. Long-term care facilities serving those whose only source of income is Social Security or Disability are the ones most susceptible to the cuts and criteria of Medicaid. If reimbursement is still the first step or the bottom line, then the ingredients that make life full and fully human must be reimbursable. Standardizing those ingredients may be a difficult and certainly ironic task, but perhaps it is worth a try. Enabling a more even ratio of nurses to residents would be an excellent first step. Appropriate recognition and empowerment of nurses and nurse aides who care for sick, elderly, or disabled people will likely reduce the high turnover rate in the field and reinforce a sense of continuity and community for residents.

Though I respect and have been inspired by the tenets of the Eden Alternative, I believe that creative and direct programs initiated from within an individual facility will probably be more successful, and more personal, than ideas superimposed from a template or a trademark. In this respect, bottom-up innovation is ideal. I therefore encourage others who are interested in long-term care community gardens to work *with* members of a particular facility in creating a customized program based on the needs and desires of residents and staff. This sense of individuality rather than standardization is important in maintaining the aura of pride, creativity, and ownership which characterized the garden program at Sunrise House.

Still it is neither the top-down nor the bottom-up improvement in long-term care which I feel is most crucial or most in need of advocacy. Rather it is the “from-all-sides”

approach. The watchful eye of regulators and even the earnest attempts of administrators would be augmented tenfold by the involvement, input, and interest of everyone who has ever or will ever grow old, get sick, or need help. Whether termed “society” or “community,” we simply need a revolution in the way we perceive and treat aging and illness-- in ourselves as well as in others. Growing old or needing assistance in daily living ought not to be dreaded; long-term care in the media does not have to be a horror story of bedsores and boredom with quotes from ombudsmen and analysts rather than residents. I continue to learn firsthand that there is no magic involved in discovering an alternative image of life as an elderly or chronically ill person. It is the presence of the very real people who live that life daily which is most powerful, and given a chance, least intimidating. Visibility and integration will eventually lead to acceptance and appreciation—with could soon be followed by quality of life-- but people of all ages must meet long-term care halfway. Recognizing and learning from the elderly and chronically ill people who live right in our communities is revolutionary.

Enter here the idea of a community-based garden on the grounds of a long-term care facility. The case study at Sunrise House suggests that a garden, in addition to its basic value as an enjoyable activity, also carries distinct significance in its ability to strengthen connections that are often strained in the lived experience of urban long-term care residents. First, the garden defies the relegation of “nature” to pristine, rural places, instead bringing beauty, agriculture, and a sense of discovery to a piece of lawn smaller than a parking lot. As a forum for interaction, visible activity, and resident pride, the garden helps build community with neighbors and volunteers. With magnificent beauty and abundant produce, the garden also instills a feeling of luxury—without requiring

significant monetary input. In a system and setting which can easily characterize residents as “receivers” of care, the garden offers unique opportunities to nurture, share, and *give* to both plants and other people. Finally, the garden’s cycles, metaphors, and opportunities to learn are a source of spiritual and mental health—and a reminder of life’s interactive potential. Among residents and staff members at Sunrise House, the garden was so enjoyed and appreciated that its continuation next season is already assumed and planned for.

At Sunrise House, the effects and benefits of community-based gardening may well deepen and develop over the course of a second season. Furthermore, its success could be expanded and customized at other facilities. Encouraged to think about sustainability and application, I started this project with a vision of a network of such gardens. A cooperative effort among residents, staff, and community members to grow food and flowers at many long-term care facilities could re-establish the lessons learned at Sunrise House and provide new insights as well. I like to imagine that one day, gardens and residential long-term care could even be synonymous, that children could go to a nursing home to eat fresh cherry tomatoes grown by elderly people. It is a powerful idea of building bridges across the perceived rifts between life and death; sickness and health; nature and the city; communities and the individuals that make them; givers and receivers of care. This vision invites not only administrators and nurses but neighbors and urban agricultural activists to develop community gardens which honor the kinetic and potential energy of people who have lived, and are still living.

In addition to Dr. William Thomas, Bruce Vladeck, and Marshall Kapp, I would invite John Muir, Henry David Thoreau, Rachel Carson, and William Cronin to visit

these gardens and look carefully to see their respective reflections in them.

Environmentalism is dynamic; it is a movement and an academic area that relies heavily on creativity and resourcefulness. As humans we constantly redefine what “nature” is, why it moves us, and what our role is within it. What long-term care reform and environmentalism have in common is an emphasis on healing something whose wholeness leaves room for interpretation. A city is no more something to be afraid of than a wrinkle or an arthritic joint: it just takes some adjustment. Environmentalism must keep pushing at the seams of its own definition and associations, and strive to value neither man over land, water, and animals nor land, water, and animals over man; its task instead is to promote the remembered concept that nature values all of these parts equally.

Similarly, long-term care does not need to choose between medical or social, interpersonal health but must try to balance all of the components of a fully healthy and human life.

A recurring, important caveat is that both environmentalism and long-term care reform are at risk of distortedly targeting and reaching only the middle and upper classes. In doing so, the proverbial ceiling is raised ever higher while the floor remains too low for comfort. Community-based solutions are powerful in environmentalism and long-term care reform because they require effort, not capital and because they are therefore applicable where capital is lacking.

In this web of recommendations, the least quantifiable is also the most important of all, a theme that this paper, its author, and perhaps its readers have grown accustomed to. Life—ecosystems, compost, aging, waking up—is something to be proud of. No ailment or circumstance should cause a human being to feel otherwise, and often

relationships with other people are the best reinforcement of this truth. When we invest in life and in human relationships, we are in a sense emulating what the natural world does best: interacting with and being impacted by what surrounds us, and makes us whole.

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Appendix B

Participant Observation Checklist

- Facial expressions
- Resident's behavior after accomplishing a garden task—planting; harvesting; doing a job no one else wanted to do
- Cooperation between two or more residents in a garden project
- Time of day when resident likes to work in the garden
- Does it become part of their daily or weekly routine somehow?
- Preferred tasks
- Willingness to share knowledge and expertise with others in the garden; styles of teaching, listening, learning
- Changes in participation (amount or quality) over course of the season
- Length of time spent at once in garden activities
- Interactions between residents and neighbors/passersby
- How residents describe garden activities, etc when talking to nurses and staff
- Patterns of spontaneous conversation in the garden
 - Talk about the past?
 - About health/ how they feel that day?
 - No talk at all?

Appendix C

In-Depth Interview Prompts

Reflecting on the season

1. What is your favorite part of being part of the garden?
- Dirt under your fingernails? Being responsible for a living thing? Spending time outside? Harvesting? Eating the produce? Learning new things? Ladybugs? Sitting and enjoying? Cooking?
2. What was your favorite plant or area in the garden this summer? What is special about it?
3. How did people walking by on the street react to the garden? Did you ever talk to anyone about it or show them the garden? How did that make you feel?
4. How do you think the people on our street and in the neighborhood feel about the garden?
5. Does Sunrise House feel like your home?
6. Did you spend about as much time gardening as you expected to when we started the seeds back in April? More? Less? Why?
7. Did you feel that the garden was a place for you to spend quiet time by yourself? A place to work together and talk to me and the other residents?
8. Can you describe a certain memory or experience that stands out when you think back on this season and everything we did?
9. All of us participated in the garden but we didn't all do the same things. What do you think was the most valuable thing you brought to the effort? What are some of your personal characteristics that you think make you a good gardener?
10. Did you spend more time outside this summer, compared to other summers?

Health

11. Do you feel that the time you spent in the garden had any impact on your physical health and wellness? If yes, how so?
12. How did working in the garden affect your energy level?
13. Were there days when you did not feel physically well enough to participate in the garden? How did that feel?
14. Do you feel that the time you spent in the garden had any impact on your emotional or mental health? If yes, how so?

Thinking about the future

15. When the outdoor garden is put to sleep for the winter, how do you think we could keep learning about gardens and plant care?
16. Do you think we should start the outdoor garden back up in the Spring? If we do, do you have any new dreams or wild ideas for next season? What would you like to grow or do?

Growing food crops

17. How does the taste of the homegrown compare to the store-bought?
18. Our garden was organic. Have you ever bought organic produce in the store?
19. What did you think of our cooking classes?

Appendix D

Community-based Participatory Research Guidelines

1. Lessons from previous research harms are important to designing more sensitive research in communities
2. Research designs should come out of consultation with the community
3. Informed Consent must be conducted with communities
4. Cultural sensitivity and competence are integral to understanding the experiences of community members