Individuality in Place-making at End-of-Life: Gerontopia

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ABSTRACT
Focusing on the individuality of human beings in end-of-life settings, this paper seeks to elevate the discussion on meaning of place through design. Commonly, designers' concern for function, form, and space is in designing for the average user in aggregate. Useful social research provides a broad theoretical backdrop relating to environments and aging. Unfortunately, little work exists that can be extrapolated for the uniqueness of individuals engaged with their environment during the process of dying. Yet, in hospice settings, the power of place is tremendous.

This paper addresses approaches in studying place using reported data from three previous qualitative studies completed by the author. For hospice patients, the deathbed is where the individual exerts preferences and desires for a wide range of connectedness to their environment. Beyond meeting functional requirements, symbols of individual history and connectedness imbued with meaningful personal treasures empower identity and belonging. Deathbed settings are enhanced with opportunities for individual control and preferences that enable independence and contentment. Furthermore, these deathbed places are saturated with options for multiple sensory feedbacks that calm, comfort, and reassure.

The weighted personal value of place is captured in the author's term *Gerontopia*—the place where we want to grow old and die. Coined from the Greek roots *geron* referring to "old age" and *topia* meaning "a place", a Gerontopia is characterized by individual preferences and choices for highly individualized and familiar environments which meaningfully unite personal lives to place. Designers are well equipped to work with individuals as optimal, ideal places are visualized, romantic aesthetics are contemplated, and meaningful places are created.

Promoting place-making into design practice begins with listening to the voices of patients and caregivers. The words at first are ineffable and idiosyncratic impressions, individual imaginations, and personal interpretations to describe meaningful inhabitation. At some point, the images become "concretized" as Norberg-Schulz explains basic properties of existence become "visible" as a concrete, local situation.

A graphical place-making model is illustrated for future research and practice. The model reflects social research theory and maps individual characteristics throughout the life span where meaning of place takes central stage. Specifically, the model graphs the following:

- Individual competence and fit with environment (Pastalan, 1982; Lawton and Nahemow,1973),
- Cultural/personal/social makeup of an individual (Altman and Chemers, 1980; Canter 1997),
- Change during the life span (Lawton and Nahemow,1973; Canter 1997),
- Level of meaning and connectedness to place (Tofle,2009; Tofle and Park,2009), and
- Variation of lifespan slopes.

Utilizing both objective and subjective perspectives, the thinking and the feeling, the designer's modus operandi is enhanced in creating meaningful places for end-of-life. The combination of these perspectives seeks to capture the essence of *Gerontopia*—the place where we want to grow old and die.

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INTRODUCTION

Focusing on the individuality of human beings in end-of-life settings, this paper seeks to elevate the discussion on meaning of place through design. Individual meaning of place tends to follow a designer's concern for function, form, and space in designing for the average user in aggregate. While there is useful social research in designing for aging adults, little work exists that can be extrapolated for the individuality of the dynamic aging and dying process when place-making plays a powerful role.

Utilizing both objective and subjective perspectives, the thinking and the feeling, the designer's *modus operandi* for creating end-of-life settings can be enhanced. The combination of these perspectives seeks to capture the essence of *Gerontopia*—the place where we want to grow old and die.

Background Perspectives and Inquiry

1. *Paradigms of social research to understand people in aggregate.*

Social science research examines people in aggregate who inhabit and use the spaces of architecture. Work traditionally referred to as "environment and behavior research", utilizes three environmental adaptation paradigms that are helpful in understanding meaning of place: environmental adaptation, opportunity structure, and sociocultural (Canter,1997). The first, *environmental adaptation* is exemplified in the well established competence-press model initiated by Lawton and Nahemow (1973). That is, the more vulnerable people are with failing health and low competence, the more impact or *press* the environment has on them. The five domains of competence (Lawton and Nahemow, 1973) are: biological health, sensory-perceptual functioning, motor skills, cognitive skills, and ego strength. Competence is described as the theoretical upper limit of a person's capacity to function. Environmental press refers to the demands placed on a person. Adaptation level is where press is in balance for a particular level of competence.

This work stems from the earlier work of Kurt Lewin's (1936) conceptualization of the person-environment interaction and optimal aging: B = f (P,E) where behavior is the function of both the person and the environment. In the competence and environmental press model, behavior is a result of a person with a particular competence in an environment of a specific press level. Behaviors exist on a positive-negative continuum and are observable with the behaviors and affect levels.

The impact of an environmental press is greater as personal competence diminishes. Commonly, the competence-press model provides good justification for functional accommodations in the environment to compensate for low competence. That is, designers specify practical prosthetic equipment and design architectural modifications for functional and sensory disabilities. As a criticism, the competence-press model is less helpful in addressing meaning and cognitive parameters of how an environment can contribute to a person's quality of life.

The second paradigm described by Canter is *opportunity structure* with a focus on the

> options for action that the environment makes available and how people can select or manipulate settings to make possible those patterns of behavior, or styles of life, to which they aspire (p. 112).

Symbolic interactionism (Blumer 1969; Herman and Reynolds 1994) embraces the importance of meaning in one's environment and the symbols that are used for the purpose of communication. A criticism of symbolic interaction theory is the trap where styles get substituted for substance.

The third paradigm recognized by Saegeret and Winkel (1990) is *sociocultural* where

> The person as a social agent seeks and creates meanings in the environment…. The paradigm…explicitly recognizes that environmental meanings and actions are not solely individual constructions (p. 452,465).

An example of a broadened sociocultural perspective on meaning of place is the Altman and Chemers (1980; *Culture and Environment*) framework. Their model includes:

(1) environmental outcomes (built environment, homes, farms, cities);

(2) environmental behaviors and processes (privacy, personal space, territoriality, crowding);

(3) environmental cognitions (perception, coding, memory, judgments);

(4) environmental orientations and world views (cosmology, religion, values, norms);

(5) natural environment (topography, climate, flora, fauna). (p.10)

Again examining people in aggregate, but in a dynamic view of time, Pastalan (1982) describes the Loss Continuum Model where aging is viewed as a progressive series of losses that reduces one's social participation. There is a shrinking of the environment with age and losses in health. In young adulthood individuals may be healthy; later life is marked with increasing physical decline; and the greatest physical limitations are among those who are home bound or receiving institutional care.

These three social research paradigms provide the context of aging and environment. Rather than designing for the average user in aggregate, the challenge is to design for individuality where place can be rewarding and empowering.

2. Aging, place-making, and changing individuals.

Over the course of a life span there are usually multiple moves to different houses and geographical locations. Nearing late life, some elders wish to "age in place" by making house modifications. In the best of situations, there is a good "fit" (Lawton and Nahemow, 1973) between them and their residence. The component of change over time is embraced in Lawton's *competence-press model* and helps to explain the aging process with increased disabilities and a growing reliance on the environment. How rapid the afflictions and disabilities occur in the life span are, of course individual and happen at different chronological ages.

From protective crib to the deathbed, over the course of the life span from early childhood to frail elderly, the demands of the environment vary widely. People not only experience changes in their buildings and in themselves, they also experience the struggle to accommodate the complexity of these changes happening simultaneously. When a person experiences disabilities in ambulation and sight, ideally their environment can be adjusted to compensate. When individuals have disabilities and they are without resources to make environmental changes, their competence in performing activities of daily living are impeded.

Because of actual or anticipated problems, individuals may choose to relocate because of a combination of exacerbating reasons—economic security, family crisis, a desire to move closer to family and support services, and comfort (Oswald, Shilling, Wahl, & Gang, 2002; DeJong, Wilmoth, Angel, & Cornwell, 1995). When there is not this good "fit," relocation can be seen as a result of push and pull factors. According to Gonyea, for example, push factors are "the life events or circumstances that loosen an individual's attachment to his or her current residence and lead him or her to consider relocation" (2006:563).

Just as buildings change use and change occupants, experience adaptations, and become dilapidated, people change in the type and intensity of activities they can perform, their financial and health capacities, aspirations, and attachment to place. When individuals relocate, the process of place-making also begins again. Place attachment is a process, not frozen in time, but evolves over time and takes on meaning at different rates for different individuals. It is our individual accumulated experiences that create place attachment during a life span.

Gerontopia

1. Approaches in studying place: Outsideness and insideness

Outsideness. Two approaches to studying place are "outsideness" and "insideness" (Seamon,1979; Buttimer, 1977). The outsider's view is a detached observer and the insider's view is grounded in everyday experiences. Using what could be called an outside perspective, Canter provides a framework built on the theory that place experience combines individual, social, and cultural processes in the *facet theory* to quantitatively test hypotheses about place experiences.

> Evaluation of places are the products of assessing how the components of places combine to help people achieve a variety of objectives…. (T)he acoustics of a concert hall might be hypothesized as being the best predictor of the evaluation of most other aspects of the place…. It would be identifiable from an empirical structure that revealed variables that had high average correlations with all the other variables. The fundamental hypothesis here is that there will actually be variables that have a high average correlation with many other aspects of evaluation, rather than there being a lot of separate groupings of intercorrelations. …these variables are likely to be central to the configuration as well as having a conceptual centrality to the experience of that place. (Canter, 1997:137-138).

Insideness. Designers are more educated in creating environments than in facilitating meaning in them. They are generally more adept at the objective thinking required in modifying functional inadequacies than being in touch with an individual's subjective feelings and interpretations of how the environment could meaningfully enable and empower connectedness.

As human beings, we have a level of understanding that at times can be powerfully meaningful. We are aware of places at moments of significant life defining events. We can remember the specifics of where we learned to ride a bike and had our first kiss. A residence can be the embodiment of joyful memories providing comfort throughout life and in the dying process. In a recent study of the author's, when a 91 year old woman was asked what she was most proud of, she said,

> Well of course I'm proud of my children, but I'm really proud of this house where I have lived since I was married just after War II…this is where I raised my children and it's still a wonderful place for me now that I'm old. My bedroom is where I want to die—it would be a good ending.

In the last stages of life, family members often use photos and memorabilia of meaningful places to remind loved ones of pleasant experiences and emotions. A dying person eventually loses consciousness and awareness of their environment. If the patient is fortunate to have loving family and caregivers nearby, awareness of the environment

continues to be important to them to carry out the wishes of their loved one past the time when a person is conscious. As in symbolic interactionism, the meaning of one's life can be exhibited in the environment and its symbols serve the purpose of communication. Symbols are useful to patients and also to visiting family and friends to tell life stories as trophies, portraits, and newspaper articles communicate life's benchmarks.

Being able to interpret the core of an individual's aspirations for the deathbed is what one would like throughout one's life—an intimate place which is familiar, comfortable, and nurturing. Hospice individuals and family members are in the unique situation of planning the place of the deathbed. In the process of this decision making, emotional connections to a setting and the "spirit of the place" matter to a hospice patient.

Genius loci refers to a location's distinctive atmosphere, or spirit of place. The term is derived from Roman mythology where *genius loci* was the protective spirit of a place. The spirit of the place where a hospice patient may choose to die has profound implications for place-making and is studied as phenomenology. Christian Norberg-Schulz's *Genius Loci: Towards a Phenomenology of Architecture* says…(poetry) concretizes basic properties of existence.

> 'Concretize' here means to make the general 'visible' as a concrete, local situation. In doing this, the poem moves to the opposite direction of scientific thought. Whereas science departs from the 'given', poetry brings us back to the concrete things, uncovering the meanings inherent in the life-world (1979, p. 10; Norberg-Schulz, 1963).

From the inside perspective, a poem can capture the sounds, sights, and nostalgia of personal preferences:

> When I am old, I will dwell at the windowsill.
> Near a family genealogy—photos, pillows and pearls.
> Recall history as nostalgia; sweeten knowledge that was suppressed; regenerate legend for the hereafter.
> The lessons of life are best remembered while rocking in a creaking rocking chair.
> Telling folktales, swaying back and forth. life is simple, life is predictable.
> From past to present, from present to past. I know this place, I call it home.
>
> When death comes close, I still want to dwell at the windowsill.
> Too weak to chew an apple, a knowing caregiver scrapes the pulp with the round of a spoon to feed.
> Like mother scraped, when I was sick, like I scraped for my babies, before teeth.
> Respiration labored, words slurred, caregivers take a feverish hand.
> The illumination now darker, oxygen more scarce.
> Begin and end in the horizontal bed. Alpha and omega: birth and death.
> Glorious and savage rites. And the capricious globe whirls.
> I know this place—where death comes, my eyes will close. My last home. (Brent,1999: p 63)

Relph (1976) argues that places have meaning in direct proportion to the degree that one feels inside that place. Insideness has the deepest experience of place involving an unself-conscious immersion in place. It is the empathic insider, according to Buttimer (1977), who is best able to mediate between people who live in places and those who plan for those places.

2. Connectedness for individuals in end-of-life care.

Substantial differences exist between states and the number of people who die in hospitals, private housing, and nursing homes. According to the Center for Gerontology and Health Care Research (2004), nearly 50 % of Americans who died from chronic illnesses in 2001 died in the hospital, 23% died at their house, and 23.2% died in a nursing home.

Anticipating one's end of life, hospice patients and their family members are challenged to plan the place of death. Last Acts (2002), a coalition of more than 400 organizations, recommends facilitating a patient's death in his or her preferred location. The priority given to preferred location reflects the end-of-life movement empowering patients and families to control the decision-making process in preparing the physical setting where death occurs for terminally ill patients.

Healthcare providers and volunteers serving as trained hospice caregivers were interviewed by the author. Original data was collected and reported in qualitative studies of (1) elders in long term care (Brent,1999), (2) hospice caregivers in institutional and private dwellings (Tofle,2009), and (3) comparisons of hospice caregivers in private dwellings in the U.S. and Korea (Tofle and Park, 2009). Hospice patients and caregivers described the ideal place for dying by associating it with places where they experienced delight, comparing it to places travelled, analyzing attributes of both the private dwelling and institutions, arguing for a place that afforded closeness to loved ones and pets.

Focusing on hospice patients and their caregivers, individuals exert preferences for the place where they would like to be in that last stage of life. The meaning of this connectedness assumes a wide range of possibilities. In the qualitative study of hospice caregivers, the strong desire for connectedness was demonstrated in:

- Connecting with the outside world (telephone, email, Skype, favorite music, television, radio, video-taping)
- Connecting with nature (windows and balconies with natural light and a view, plants, protective pets, linens air-dried outside, snow and falling rain, garden, flowering plants from bulbs decades old from family, flowers fresh picked from garden)

• Connecting with people (visiting with friends dropping by and helping with chores, mail delivery, family routines, journal writing, singing & reciting poetry with family, "Skyping" for visual connection, watching neighborhood passersby and children building snowmen from window)
• Connecting with home (being part of holiday celebrations and traditions, privacy, freedom to do what you want)
• Connecting with memorabilia giving identity (acknowledgements of a rich life lived—sentimental gifts from loved ones triggering memories, hand-stitched patchwork quilt of childhood dresses, heirloom linens, photographs of loved ones and places travelled, souvenirs, legacy journals, art, cards, valentines, beauty queen crown, wedding ring & jewellery, trophies)
• Connecting with spiritual transcendence (sunsets, rainbows, candlelit meals, view to nature, religious materials, burning incense) (Tofle, 2009).

Hospice caregivers gave examples of how the environment empowered. Specific examples were organized by themes of meaning, control/preference, and sensory perception as described below:
• Meaning. Pets and family members curled up and snuggling with patient on hospital bed, "altars" with religious items, heir-loom blankets and pillowcases, out-of-season Christmas trees with decorative wrapped presents….
• Control/preference. Operable windows for fresh air, dictating letters, audio-video taping, keeping "legacy journals", speaker telephone and boom box with favorite music, the disguising of a make-shift potty, being able to sleep without being disturbed….
• Sensory perception. View to the outdoors; photos and plants, stroking the fur of pets, listening to others play piano, being able to cry, moan, and scream without being heard by neighbors ….

In a follow-up study of hospice caregivers in Korea, similar results were found with some differences in cultural expression. End-of-life care was in dense Korean apartment high rises and connection to nature was achieved by going to an apartment's balcony, individuals preferred to sleep on the floor, and the smell of burning incense contributed to the comfort of the dying individual.

3. *Elevating the meaning of place in end-of-life care through design.*

Unlike those of us who may not choose our final place, terminally ill individuals and their family members are faced with wrenching questions of where that last place will be located and what it will be like. For a small number of individuals, the purpose-built hospice facility is an option for end-of-life care. Hospice architects Scott and Valins (1999) considered quality of life such as windows with a view; acoustics to facilitate reflection, spiritual meditation, and intimate discussion; surfaces that facilitate posting joyful family photos; close connections to nature and aromas of home cooking; patient control of daylight and music; and other patient-driven choices and means of control that relate to privacy and independence, sensory stimulation, and connections with family and friends. More recently, Verderber and Refuerzo offer illustrations of existing hospice facilities with case studies and narratives confirming the positive role of the purpose-built hospice in *Innovations in Hospice Architecture* (2006).

Beyond function, space, and form, interior designers and architects give emphasis to the subjective and achievable goals of aesthetics. The natural environment contributes to realizing the goals of aesthetics and is often associated with having the ability to comfort and transcend. In addition, Kaplan (2009) argues that nature contributes to well being:

> There is a substantial body of research that has shown the role that natural environments can play to offset such mental fatigue; many studies have also shown that such natural settings need not be large, nor is it necessary to be physically situated in them. Even a few trees in the view from the window can make a substantial difference in well being and behavior (page 2).

The terms *place identity*, *sense of place*, and *place attachment* are described by Kopec (2006) in making the argument that interior designers and architects can facilitate meaning of place and place-making. When people incorporate a place into their larger concept of their own identities or sense of self, they achieve place identity. When people have a level of comfort and feel of safety associated with a place, it translates to a sense of belonging and people can achieve a sense of place. When people form an emotional bond with their immediate social and physical environment, they achieve place attachment.

Unfortunately, for most hospice patients, purpose-built hospice facilities are unavailable and place-making is left up to patients and their families. In this process of place-making, all the issues of the designed environment come into play. Patience, communication, ability to afford individual requests, and the level of support from family and friends contribute to place-making.

More than the parameters of function, form, and space, discussion is often trumped by emotional considerations.

Utilizing both objective and subjective feeling, the *modus operandi* for end-of-life settings can be enhanced.

The combination of these thinking and feeling perspectives seeks to capture the essence of *Gerontopia*—the place where we want to grow old and die. Coined from the Greek roots "geron" referring to old age and "topia" meaning a place, they are characterized by individual preferences for highly individualized and familiar environments which meaningfully connects personal lives to place. Designers are well equipped to work with individuals as optimal, ideal places are visualized, romantic aesthetics are contemplated, and meaningful places are created.

Gerontopias are not listed as most beautiful homes or prototypes to be built. Gerontopias do not have checklists with vintage memorabilia or catalogues of best fixtures and furnishings to specify. Promoting place-making into design practice begins with listening to the voices of local users. At first the words are ineffable and idiosyncratic impressions, individual imaginations, and personal interpretations to describe meaningful inhabitation. The words may focus on what is their impression of a pleasant setting, aesthetic beauty, and emotional fulfilment. At some point, the images become *concretized* as Norberg-Schulz explains basic properties of existence become "visible" as a concrete, local situation.

Beyond identifying the characteristics of where one would like to grow old and die, a graphical model of Gerontopia is provided for future research and practice. The *Lifespan Model: Place Connectedness & Competence* is unique in that it reflects a way to map the characteristics of individuals as follows (*Figure 1*):

- *Individual competence and fit with environment* (Pastalan, 1982; Lawton and Nahemow,1973). Slopes are illustrated as plotted curves for three individuals A,B, & C.

- *Cultural/personal/social makeup of an individual* (Altman and Chemers, 1980; Canter 1997). Individuals' characteristics are illustrated as disks.

- *Change during the life span* (Lawton and Nahemow,1973; Canter 1997). The x axis represents time from birth to death.

- *Level of meaning and connectedness to place* (Tofle,2009; Tofle & Park,2009). The y axis represents connectedness through knowing as conscious appreciation of place.

- *Variation of lifespan slopes.* Gerontopia is achieved with ideal place connectedness, competence, and "good fit" between person and

place during the life span as represented by an upward slope for individual *A*. In this ideal situation, modifications are achieved, competence is good, and memories of place connectedness continue to accumulate. Alternatively, variations of downward slopes represent "poor fit" between person and place for individuals *B* and *C* when modifications are not made, competence declines, and connectedness to place diminishes with time and eventual death.
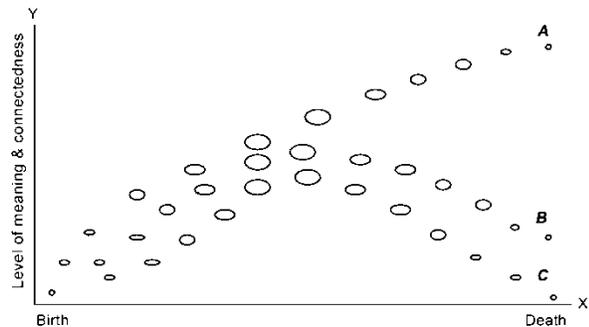
Figure 1: Lifespan Model of Place Connectedness and Competence

The ideal situation is our best hope. In this case, the places where individuals want to grow old and die evolves over time with new experiences. While there are declines in health with aging, the environment adapts to be supportive and the individual continues to be aware, appreciate, conscious of, and connected to the environment that nurtures, enables, and empowers.

The worst situation represents our greatest fears. In this case, individuals experience health declines with aging but the environment fails to be supportive and individuals find themselves alone in residences that are empty, devoid of any positive symbols or benchmarks from their life, and television noises ineffectively fill the emptiness of the housing space.

Conclusions

Demonstrating that hospice settings benefit from the power of place, this study suggests a close relationship of the design of place, connectedness, belonging, and competence thereby framing future research with this design strategy. Furthermore, the formulation of Gerontopia can be a construct operationalized by identified variables. Beyond meeting functional requirements, an argument is made to emphasize individual history and connectedness imbued with meaningful personal treasures that empower identity and belonging. These settings may be enhanced with opportunities for individual control and preferences that enable independence and contentment. And, they may be saturated with multiple sensory feedbacks that calm, comfort,

and reassure. Architects, interior designers, caregivers, and patients themselves are challenged to elevate the meaning of place by grasping its individuality and the notion of Gerontopia—where we want to grow old and die. Stressing the individuality of aging and dying, ultimately, the real designers are the dwellers themselves. As Heidegger says, dwelling is the essence of being, humans dwell in place.

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