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Out of Time: the perceived loss of self in dementia patients in the United Kingdom and United States

A Thesis submitted in partial satisfaction of the requirements for the degree Master of Arts

in

Anthropology

by

Julia K. Sloane

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2017
The Thesis of Julia K. Sloane is approved and it is acceptable in quality and form for publication on microfilm or electronically:

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Chair

University of California, San Diego

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ABSTRACT OF THE THESIS

Out of Time: the perceived loss of self in dementia patients in the United Kingdom and United States

by

Julia K. Sloane

Master of Arts in Anthropology
University of California, San Diego, 2017
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This thesis examines the phenomenological aspects of dementia patients who are living out their lives with decreasing lucidity in the world around them. Popular tropes surrounding dementia consider the diagnosis a living death sentence. In this paper, I hope to illustrate the lived-experience of individuals suffering from the disease and combatting the opinion that they have lost their personhood in a culture idealizing autonomy and
independence. I propose using Douglas Hollan’s framework of selfscapes to better conceptualize the embodied experience of dementia. In so doing, I will expose the flaws of Bourdieu’s *habitus* for the phenomenological consideration of individuals who may be temporally dislocated from “objective reality” and explore how the phenomenological misperception of Cartesian dualities encourage the decline of personhood in anthropological paradigms of embodiment.

Keywords: Psychological Anthropology, Geronpsychology, Phenomenology, Dementia, Personhood, Selfscape, Embodiment
Introduction

Home is where one starts from. As we grow older/ The world becomes stranger, the pattern more complicated/ Of dead and living. Not the intense moment/ Isolated, with no before and after,/ But a lifetime burning in every moment/ And not the lifetime of one man only/ But of old stones that cannot be deciphered

T.S. Eliot

T.S. Eliot paints an image of an age in which the realities of an individual’s past, present and inevitable future exist simultaneously in the mind’s eye. Impending degeneration is as strong of a player in the construction of subjective experience as the memory of one’s first romance or her current physical condition. Death has joined Life’s theatrical stage to construct a nouveau cirque display embodying all of life's joys and fears while hindering a comprehensive and linear path of consciousness. So too do we see this drama play out in the halls of retirement homes and elderly communities whose players burn in each moment while dementia withholds the safety of a logical train of thought. Quotidian patterns are confused as older individuals strive to perform a consistent yet time-altered self and their caretakers fight to keep them from physical harm. In the following pages, I will address the cultural constructions of elder care and the implications thereof on a person with dementia’s (PWD) lived-experience of the world.

Casting the experience of aging and cognitive decline through an anthropological perspective allows us to view the entire bio-psycho-social process while considering the
cultural frameworks that shape its expression. Only with this level of awareness are we able to become sensitive to the cycle of making and re-making personhood that plagues people with dementia daily. Aging into a new life stage can be viewed as a liminal process of depersonalization characterized by loss, dissolution, and dispossession followed by repersonalization in which one reorients, inhabits, chooses and revels in being a unique individual with a storied past. Unfortunately, all too often, repersonalization is complicated by physical and mental maladies and individuals find themselves stagnating in loss.

Crucial to understanding this cycle is examining the cultural context in which aging takes place. As Jay Sokolovsky (2009) explains, "Cultural perceptions of older adulthood, or old age, link changes in the person's physical being (reduction of work capacity, beginning of menopause) with social changes (such as the birth of grandchildren) to create a culturally defined sense of oldness" (3). The impact such a sense has on the embodiment of “oldness” thus proves a worthy pursuit of thought in elucidating the lived experience of individuals afflicted with a cognitive disease strongly marked by age. Contributing to literature concerning phenomenological perspectives on the anthropology of aging and disease, this piece attempts to understand the lived-experience of dementia patients and propose an alternate trope to that of dementia as a living death sentence.

In the following pages, I aim to articulate how embodiment paradigms of the self can help us understand the lived-experience of people with dementia who frequently find themselves at odds with their “former” selves, or the selves their loved-ones expect of them. Anthropologists, psychologists, and philosophers have long debated what is meant by a “self” and how this subject-object is composed in the world and the psyche. To first
develop an understanding of how the self is constructed and reconstructed, I will employ the Hallowellian understanding of the self. From there, I will discuss how the self is experienced and disrupted by disease and age using Douglas Hollan’s discussion of the selfscape, Bourdieu’s theory of *habitus* and Thomas Csordas’ meditation on the embodiment paradigm in anthropology. As it is thoroughly impossible to consider the lived-experience of a person with dementia without hearing from a person with dementia, I have sought the United States and United Kingdom oriented phenomenological data through voices of people with dementia in documentary accounts, personal blogs, and recorded conversations between multiple people with dementia discussing their disorder and existence. I also consider data gathered in a peer-reviewed ethnographic study at a retirement home in the United Kingdom. I will later contrast this phenomenology of dementia with accounts of aging and dementia experience in India, as documented by the ethnographic works of anthropologists Sarah Lamb and Lawrence Cohen.

Chapter 1: Dementia

Recent years have seen a dramatic rise in the world’s population with people aging longer than ever before thanks to novel medical treatments and pharmaceutical development alongside a declining fertility rate. "Worldwide, the population aged 80 and over is projected to more than triple between 2015 and 2050, from 126.5 million to 446.6 million” (US Census Bureau: 11). Unfortunately, this trend has come at a cost. The U.S. Census Bureau found that subjective well-being followed a U-shape trajectory over the life course of citizens in Western/developed nations, meaning that after reaching a peak of
well-being and contentment in mid-life, the majority of people began to lose the feelings of satisfaction that they had previously cultivated (US Census Bureau: 50). Further, aging has opened avenues for new modes of being in senescence and disease. The aging person finds herself confronted with a changing world, a changing body and, a changing self.

![World Population Trend](image)

**Source:** Population Reference Bureau

**Figure 1: World Population Trend**

A number of diseases have become associated with aging and display a similar set of side-effects – cognitive decline, memory loss, and an inability to communicate effectively, that together are considered under the umbrella of “dementia.” Due to this inability to communicate and cognitive confusion, the popular narrative surrounding people with dementia (PWD) paints them as resigned to a waking death. Despite this, PWD have taken to various forms of media in efforts to minimize the depersonalization
that is intimately linked to the disease. In this paper, I will consider the voices of dementia patients in the United States and United Kingdom to develop a keener understanding of the phenomenological aspects of existing in this world with dementia among the popular trope of a “living death.”

As with all groups, the most important thing to understand when studying PWD is that each individual has a unique experience and expression of the disease. If you have met one person with dementia, you have met one person with dementia. The multiple diseases that cause symptoms of dementia include Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. As different diseases affect the brain in unique ways, the experience of dementia is colored strongly by which mental domains are attacked and when. For example, in patients with Alzheimer’s disease, memory impairment is the most prominent symptom, whereas patients with vascular dementia are more likely to have difficulty with executive functioning (Smits, et. al 2014: 1051).

Too, there are a myriad of hidden factors leading to decline rates that researchers have yet to fully uncover. In a brave interview with the online magazine Folks, Kim Ovard, a 52-year-old woman living with dementia with Lewy bodies compares finding her diagnosis to “playing whack-a-mole” in an article entitled “I’m Still Here: What It’s Like To Live With Dementia” (2016). Ovard explains that, “Every day is different, so it’s tough to put your finger on it. All we know is that we’re not ourselves anymore… We become a kind of masquerader, where we try to hide the mistakes we’re making.” What Ovard calls “mistakes” may be innocent enough behaviors in and of themselves, such as wandering
around a parking lot, but they do not match the culturally-constructed behaviors that others are comfortable accepting. In this sense, dementia is very much a cultural disease. Further, these mistakes break the continuity of familiar behavior that reinforces a person’s sense of self and trust in her own body.

1.2 Cultural framework of aging in the United States and United Kingdom

In the industrialized West, an obsession with the maintenance of independence and avoidance of being perceived of as a burden are key to depersonalizing the aging experience of older adults as they lose privileges such as driving, living alone, and administering one’s own medications. For individuals who were raised with a deep sense of value in productivity and self-management, these changes can be psychologically devastating, particularly when the only appropriate cultural space with which to replace them is senescence and disability. Personhood and dementia is becomingly increasingly popular among anthropologists interested in identity and cognition. Anthropologist Elana Buch has offered insight into how elderly attempt to maintain feelings of personhood through aging-in-place practices, for example. Buch illustrates the relationships older Chicagoans develop with their caregivers and the manners of presentation and performativity that allow for illusions of independence often occasionally complicating relationships with caretakers (2015).

Through the framework of Westernized cultures, such as the United States, an older person's inability to perform the tasks that she had spent the past few decades doing may diminish her feelings of self-worth while portraying her as a needy or negatively dependent
on the community. A dementia patient is put in the position of repeatedly recreating her identity and relationship to the outside world as her cognitive skills decline. As we face an increasingly older population, countries and cultures throughout the world will have to learn how to care for the growing amount of people coming-of-age with dementia humanely. The necessary paradigm shift involved in this evolution may be especially difficult for Western nations that have linked morality and worth to productivity and individuality.

Chapter 2: Building towards cultural phenomenologies of dementia

2.1 Self

Kim Ovard echoes the narratives of thousands of dementia patients who insist that they are no longer themselves, but still there. One typically thinks of “losing” her self as a temporary state, perhaps brought about through religious invocation or artistic expression. One is momentarily overcome by a sense of uncontrollable energy overtaking one’s actions and self-awareness. In the context of dementia, the expected loss of self is irreversible with levels of awareness sporadic and varied. So, what then is the self? And just how important is awareness?

Emerging out of the Culture and Personality School which emphasized personhood and a relatively structural narrative of human development, Irving Hallowell determined the self is “a concept that remains closer to the phenomenological facts that reflect man’s sense of self-awareness as a generic psychological attribute” (Hallowell 1955:80). He emphasized the role of the “self” as an “object in a world of objects” for the perpetuation
of a culture. As a “culturally-constituted” object, the self operates as a currency of cultural propagation, and the media in which human beings experience and live in the world. It is the culturally-constituted self that perceives, interprets and, navigates the world, human relationships, and perhaps most importantly, its self, by way of reflection. The self-aware person then, is familiar with this energy, these patterns, this historicity, that is implicated at our most basic understanding of who we are in the world. I contend that it is this familiar sense that is cognitively misaligned when a person “loses” her self, and the consideration of self-awareness must be unfolded to consider behavioral familiarity.

Self-awareness is necessary for the reflection and continuous making and remaking that engenders personhood in a world of objects. The reflection process allows individuals to meditate on their selves as beings in the world and their orientations to objects and entities outside of their selves. In fact, the self requires outside orientations to become self-aware. In discussing his notion of selfscapes, Douglas Hollan reflects on Hallowell’s enforcement of self-awareness as a “social product” recalling:

a person’s sense of self is greatly influenced by what is reflected back to him or her by the evaluations and expectations of others and that all people become the repositories of such reflections. (2014:176).

This has great implications for PWD who are removed from familiar social surroundings, relationships, and what Hallowell would have termed their “behavioral environments.” This break in familiarity can occur abruptly for people who are moved to special care units upon diagnosis where almost literally everything is different from not only what one is familiar with, but from how one has ever expected to live as a being in the world.
For most dementia patients in the US and UK who are moved to care units, they are restricted from moving about freely, placed on a cafeteria diet, cared for by strangers, and isolated from family and friends. The most tragic part of this is that it happens after the brain seems unable to integrate new orientations to the world into self-awareness. Here is where I believe self-awareness requires modifying. As a “culturally-constituted” object, the self operates as a currency of cultural propagation, but as a culturally-constituted subject, it is the media in which human beings experience and live in the world. As Thomas Csordas contends, a methodological approach to self-embodiment requires that “the body is not an object to be studied in relation to culture, but is to be considered as the subject of culture, or in other words as the existential grounds of culture” (Csordas 1988:5). Accordingly, self-awareness requires the added nuance of familiarity to impart the embodied feeling of the “self” in each moment.

Csordas notes, “Perception is a key element in Hallowell’s definition of the self as self-awareness, the recognition of oneself as an ‘object in a world of objects’” (Csordas 1988:6). Perceived familiarity of objects is one level of awareness, but perceived familiarity of behavioral patterns in a subject of culture concerns a deeper examination of phenomenology. One to which I will turn now.

As part of the network HBO’s “Project Alzheimer’s,” a documentary entitled “The Lost Memory Tapes” vividly illustrates an instance in which advanced dementia devastates the perceptual reality of an older woman. In addition to temporal dislocation, a person with dementia may perceive hallucinations as existing in their reality. In a memory-care unit for advanced dementia patients, a woman with dementia is terrified of the snakes on her
wheelchair, snakes that only she can see. While her caretaker attempts in vain to explain that the snakes are part of her imagination and not reality, the woman laments her isolation in a world others cannot understand. As her caretaker moves her to her bed from the snake-infested wheelchair, she responds to the attempts to bring her into a shared reality, crying, “You try to make it so simple, but it’s not. It’s not.” While hallucinations are an entirely separate meditation on reality, the revelation that her experience is not “simple” is important. As Csordas advises, “far from being constant, perception is by nature indeterminate. There is always more than meets the eye, and perception can never outrun itself or exhaust the possibilities of what it perceives” (8). Reality is a multi-fold experience that becomes increasingly harder to share when perceptual boundaries are shifting, as in the case of dementia.

2.2 Cartesian deaths

Following a phenomenological approach to embodiment, let us now turn to the consideration of practice through a modified version of Bourdieu’s concept of the habitus. Multiple scholars warn of the danger in overlooking the iterative nature of the self throughout an individual’s life. As George Devereux explains, “to our mind, the crux of mental health is not adjustment but the capacity for constant readjustment” (1956:41). The necessity to continually reconstitute the self is what leads to the ultimate breakdown of continuity for many people with dementia, who find their bodies out of harmony with their minds creating a strong sense of Cartesian duality. Bourdieu considers the metaphysical
structure enabling this reconstitution of self to be the *habitus*, which is constructed around “past conditions which have produced the principle of their production, that is, by the actual outcome of identical or interchangeable past practices” (Bourdieu 1977:72). Through this cyclic production and reinforcement of logical actions, the *habitus* becomes “the universalizing mediation which causes an individual agent’s practices, without either explicit reason or signifying intent, to be none to less ‘sensible’ and ‘reasonable’” (Bourdieu 1977: 79). Despite the fact that the person herself may be unaware of practices that she has developed being repeatedly scaffolded onto and adjusted to fit new situations, her “reasonable” behavior, and continuity of self are dependent on this unconscious process.

Dementia is well-known for withholding the memories of select past conditions, however. Thus, when the demented *habitus* is left to interpret perception, a uniquely-informed subject may arise in every perceptual encounter which becomes highly dependent upon the subject’s state of mind. In other words, a temporally-dislocated *habitus* emerges from the body of the unfamiliar self. This is the crux of social and behavioral misunderstandings between caretakers and people with dementia. Bourdieu goes on to emphasize that the “homogeneity” of *habitus* among members of a group, facilitates communication, understanding, and a reasonable expectation of behavior among other group members. However, when the setting is a retirement community, and the actors in play have not experienced analogous “conditions of existence” (which make practice immediately intelligible), the stage is rife for misunderstanding and unconscious
depersonalization of the person with dementia, whose reality is not perceived as representative of objective conditions.

Though in other circumstances, this lack of habitus harmony may lead all parties involved to unconsciously depersonalize their interlocutor, interactions with a PWD may be more one-sided, as she herself, is out of harmony with a contemporary habitus consistent with her own group, or even her own past. As Kim Ovard describes her experience, “I get angry. I curse, ad cursing is not me, but I know my disease is acting up more than usual when I do. I lose empathy, I find the wrong things funny, and I say things that I don’t know what I’m saying” (Andrew 2016).

To recall Eliot at the beginning of this paper, “As we grow older/ The world becomes stranger, the pattern more complicated/ Of dead and living.” Dementia introduces an inconsistency of self-patterning that has a great effect on the PWD’s personhood as their sense of self is weakened through the decaying executive functioning of mental and memorial reinforcements. A dissonant selfscape adds to the confusion as the conscious subject may be temporally or environmentally misaligned with the present.

Interviews suggest that the expectation of dementia is interpreted through a broken habitus, creating a Cartesian-like duality with the death of the mind occurring before death of the body. People with and without the disorder find themselves believing in an eventual point of no return, after which they will have nothing left of their selves to contribute to the world and will be nothing but a burden on their loved ones. In a filmed therapy session for the documentary The Memory Loss Tapes, a 63-year-old man with AD, Joe Potocny
shares his expectation for his future with the disorder, including his firm belief that there will be a threshold that he will eventually cross at which point he will lose himself entirely.

I told Lynne, and the kids that when it gets to the point where I feel that I’m stepping over the line, going to become a totally different person – that they would all be given a hug and kiss and said goodbye to and I will leave and I will take care of it. (Joe Potocny, Memory Loss Tapes)

For Joe, the loss of his mind is not worth the physical existence of his body, or the embarrassment it may cause his memory. If he is unable to continue to contribute in anyway, his existence is not worth the burden it would place on his family and friends. The concept of being a burden, spurs an enormous amount of anxiety surrounding dementia progression in the United States and the United Kingdom, which I will return to later. Joe also expresses an assumption that his existence could not possibly experience anything worthwhile that may motivate him to stay alive.

The idea of a point of no return is echoed repeatedly throughout the dementia experience discourse. The author of Kim Ovard’s Folks interview writes that Ms. Ovard “will tell you about the fear she carries each day as she anticipates the morning when she will awake fully entrapped by the disease, no longer aware that she has it” (Andrew 2016). Though Ms. Ovard herself speaks relatively optimistically, she admits openly to feeling that she has no control over her own brain, but is “just at its mercy.” There is a sense that the disease has taken over the body as bits of the conscious and agentive brain are “shaved away” until the brain itself becomes a traitor to the mind and thwarts the subjects attempts to control and recognize thoughts and actions. Of course, the body still behaves and is affected by
the surrounding environment but the patterns of behavior are not recognized by the self as familiar leading to cognitive dissonance in a previously established mode of being in the world.

Thus, it looks to be the bolstering of a faux Cartesian duality that serves as the point of no return for many dementia patients, and sadly their caretakers. Millett notes that when a caretaker “begins to perceive a loss of ‘self’ (or personhood) in those they care for, there are frequently implications for the kind of care being given and consequently the welfare of the person with dementia” (Millett 2011:515). The “loss of self” is a lack of familiarity of behavioral patterns and is recursively destructive as caretakers reinforce that the PWD’s expressions are strange and not arising from the self.

2.3 Death of trust

Trust in the body is one of the first things to go when dementia takes hold of a person. The body becomes an unpredictable battlefield that could change the mood, control, and lived-experience of the subjective self at any moment. When members of the family and, friends, are increasingly disturbed by the unfamiliar volatility of the PWD’s daily experience, her sense of distrust in bodily-self-performance grows, and the faux Cartesian duality between the mind and body is strengthened. As dementia progresses, and she begins to lose awareness of basic bodily needs – such as using the bathroom, leading to further complications (e.g. Urinary Tract Infections), caregivers may have a better idea of what the body needs than the person inside of it. The body has become an object among
subjects in the world. Personhood has been stripped from the unpredictable habitus for the very reason that it is unfamiliar to the self. The communicative links that made the person in a body the best translator for that body’s needs have been broken and in societies where physical health and safety often ranks above mental well-being, this confusion is enough to pronounce the PWD a danger.

Unsurprisingly, this lack of trust is also extremely affective for the self, causing avoidance behaviors that disrupt behavioral patterns at a conscious level for the PWD. Joe Potocny, whose therapy session was discussed earlier, bemoans, “I have grown afraid to leave my own house because I am not sure that even going to the mailbox, I will stop and remember to come back”!

Along with the death of trust in their physical bodies, PWD face sporadic mood changes that disrupt the familiar level of self-awareness and predictability of behavior. As Clare, et. al. (2008) reported of dementia patients in residential communities in the United Kingdom, “the psychological impact of being in this situation was characterized by uncertainty and lack of control or self-determination” (718). These changes in daily living are often characterized by loss.

2.2 Embodied mind and selfscape

Following Heinz Kohut, Douglas Hollan takes up criticism of Freudian psychoanalysis’ “experience-far” approach to the psyche, believing a cultural phenomenological approach to the self is key to empathy and psychological understanding of a person’s lived experience, and the self-other relationship. Hollan defines “selfscape”
as the “self system’s implicit moment by moment mapping of its own representations of its own past embodied experiences onto the space and time of the contemporary culturally constituted world” (2014: 182). This system allows for infinitely more combinations of authentic self-behavior than that of the *habitus*. As opposed to the carefully structured *habitus*, selfscapes consider the malleability of human experience and plasticity of cognitive abilities while the *habitus* is primarily concerned with the “durable dispositions, in the organisms (which one can, if one wishes, call individuals)” (85) that are consistently reproduced in the “convergent experiences which give a social environment its physiognomy” (86). Thus, selfscapes match far closer to the dementia experience than *habitus* is able to, primarily due to the consideration of embodied memories and emotions. The inconsistency of memory, here, does not help to find familiarity in the self, but it does account for the actions of the self and offers a possibility of maintaining personhood.

Hollan describes one’s relationship with her self and another as existing in a “phenomenal field” in which the self “is actually created in each instant” (2014:324). Retirement communities maintain their own “contemporary culturally constituted world”, particularly in special memory needs “neighborhoods.” For a brain that already has trouble assigning temporally accurate culturally acceptable presentations of the self, it is not necessarily possible to become fluent in an entirely new, and constantly changing culture that exerts feelings of being controlled under the guise of care. Hollan echoes Hallowell’s call to “first understand what the world looks and feels like from the actor’s point of view… otherwise we risk misunderstanding or pathologizing behavior” (Hollan 2014:177). The problem comes when the person interacting with the PWD does not recognize a
consistent actor as such. With the human brain shrouded in mystery, there is no rational way of knowing the level of lucidity a PWD is experiencing in any given moment. Further, a break with the outside world or “objective reality” causes layered difficulties when communication barriers abound and behavioral environments clash. Culturally aberrant behaviors, such as wandering into inappropriate locations, collecting and hiding things, becoming unreasonably angry, or scared are bound to frighten neuro-typical people in proximity, yet with an understanding of the selfscape’s plasticity, perhaps a level of personhood may be maintained, or renewed for a person with dementia. Unfortunately, these behaviors may also frighten the people performing them and a theoretical understanding of selfhood may provide less comfort to those struggling to understand.

2.3 Self, Other & the “phenomenal field”

Embodied practices are not only shaped by the contemporary psycho-bio-socio-cultural situation of the person but may see the revival of biased psycho-bio-socio-cultural ghosts including meanings and values that may no longer be accurate to the person’s surrounding reality but had a significant hold on her psyche in her past. As Hollan remarks:

The particularities of our culturally, socially, and politically influenced encounters with others help determine which ghosts haunt us, which are stirred in our encounters with others, and which cultural forms are used to manifest and articulate them. (2014:190).

This makes the construction and experience of the “phenomenal field” highly dependent on the PWD’s relationship to her interlocutor, her current mental temporal orientation and her
physical needs. Not only are PWD uncertain about their own moods and behaviors, but they are uncertain about the motives and intentions of those surrounding them. In residential communities, where PWD may be interacting frequently with other PWD, or different people in general, the phenomenal field is complicated even further. “Actors act in environments not just of competing norms, values, desires, and institutions, but ones in which the people around them have been affected by, and affect, these various elements in different ways” (Hollan 2014:191). In fact, this may in part be one of the appeals of giving PWD companion robots who are not negatively influenced by their environment on a mooded level that may be contagious to other humans. As Clare, Rowlands, Bruce, et al. observed, “living with a group of other people who all had their own difficulties could be stressful, irritating, frustrating, or distressing” (717). Frequent visitors of elderly care centers in Japan have expressed this feeling in relation to an experimental companion bot that resided in the center for a 3.5 months. As one Mrs. S. explained, “Even in our daily lives, if I said good morning to someone and he/she doesn’t answer I feel uneasy all day long. I think, ‘Did I make him/her angry?’ But when Robovie replies to me cheerfully, I feel happy” (Sabelli, et al. 2011:40). As noted before, elderly centers are rife with misunderstandings, and when these occur on an emotional level, can be quite devastating.

A person with dementia may also feel her contribution to the community is overlooked due to her illness creating a lack of hope that she might once again share an intersubjective reality. As a woman in a retirement community in the UK bemoaned, “if I was wanted by anybody, I’d go, and I could be quite useful. But nobody knows that I want a job” (Clare, et al. 2008:714). PWD often find themselves foregoing their own personhood
in order to make sense of the dearth of family contact. The sense of worthlessness deriving from mistrust in one’s own body, the physical separation from loved ones, and an inability to follow lifelong behavioral patterns or contribute satisfactorily to the community strongly reinforces the trope of dementia killing the self before the body. As one of Clare, et al.’s participants reflected, “It’s all a lot of rubbish, and I’m a lot of rubbish now” (716).

Here we see, again, that the culturally-constituted fear of burden is interpreted as a living death sentence. For some, living as a burden on loved ones is worse than death. One woman in the United Kingdom, explains of her family, “I don’t want them to think that they’re putting themselves out for me, because it’s, you’ve had, I’ve had my life and it’s not fair to take other people’s lives away from them” (Clare, et al. 2008: 716). Foregoing personhood, or deciding that one’s life value is no longer on par with her loved ones, may serve as a defense mechanism to make sense of the new and unfamiliar situation she continuously finds herself in. For residents in this UK nursing home, eventually “an attitude of acceptance involved the notion that younger family members had their own lives and could not be expected to devote much time to visiting the home” (Clare, et al. 2008:716). That said, the same study found that there was still a strong desire to affirm “one’s own sense of identity” (716). This could come in reflections on one’s own past but also “feeling sorry for, others who were perceived as less well off or as lacking family relationships” (717). This reflection allowed individuals to exercise gratitude for what they did have left, or even what they had had at some point in their lives.
Chapter 3: An alternate cultural framework for aging

3.1 India

So far in this paper, I have discussed the difficult situation of living with dementia in the United Kingdom and the United States while maintaining a sense of self. I further demonstrated how the fears and difficulties surrounding these individuals were culturally-constructed in relation to the ideals of independence and autonomy that pervade Western societies. What may be phrased as a Western sense of oldness (following Sokolovsky’s terminology) is overwhelmingly colored by the fear of being a burden, the loss of previously patterned behaviors, and the idea that aged life is unproductive, unattractive, and thus less valuable than younger life. To contrast this deterioration-centric view of aging that influences Western oldness, I will now briefly visit the landscape of aging in India.

The make-up of a family is itself a cultural construct, and as such, we see values and customs of the host culture reflected in family life. The traditional anthropological cultural narrative of India emphasizes an extended family that is tight with feelings and obligations of interconnectedness. This interconnectedness is experienced through the concept of *maya* in which family members consider each other interwoven in a network of inter-being essential for identity and self-understanding. In Sarah Lamb’s beautiful ethnography of older women in Bengal India, she described *maya* as a “web of attachments, affections, jealousies, and love that in Bengalis’ eyes make up social relations” (Lamb 2000: 28). Where Western cultures see the promotion of an idealized self
as distinct and individual from other persons, Indian cultures have traditionally emphasized the opposite. In fact, Lamb illustrates the difficulties with living and aging as related to the difficulties of separating one’s self from the loved ones that have become her home in the earthly world. *Maya* can ultimately work to one’s detriment. If she has retained too many tight connections in life, it may be difficult for her spirit to pass on. Thus, as one ages, it is wise for her to loosen connections with the earthly world through such actions as renunciation and isolation, moving ever further away from her personhood. That said, in her eyes, the decreasing levels of personhood are not necessarily hurtful to her subjective well-being.

In Asian nations, a premium is traditionally placed on family-operated elder care and family-oriented cohabitation. Indian kinship responsibilities place the parents of the husband at the top of familial priorities. The wife understands and expects this from the beginning of the marriage. There are certainly idiosyncrasies in the level of respect paid to this arrangement, but the concept is firmly rooted in traditional practice (Lamb 2009). With the rise of Indian expats working in other countries and sending money home, family dynamics have had to evolve and fewer elderly are finding it possible to live a traditional retirement with their children in India. This has led to the contentious creation of retirement communities in larger metropolitan areas, such as Kolkata.

In fact, retirement communities may make more cultural sense in India than in Western counterparts. As Sarah Lamb elucidates about the gendered experience of widowhood amongst women in Kolkata, an essential part of the aging process involves loosening (or destroying) earthly ties of *maya* (translated to mean love), such as those to
family and home. In this environment, logic suggests culturally appropriate aging would support the proliferation of retirement homes and wandering as a means of maintaining disconnectedness with worldly ties as the traditional aged Hindu ascetic demonstrates.

Multiple elder homes have taken up this particular moral viewpoint as an attraction of living in a retirement community but there are still a lot of mixed feelings in the firmly rooted family-centric society. Many people consider allowing one’s parent to live in a retirement home away from family to be a blatant disregard for tradition on behalf of the younger generation, a terribly negative aspect of modernity (Lamb 2009). Even so, some communities are picking up ground and framing their services in the cultural tradition of seva – or service to elderly. This is especially appealing to residents who do not have nearby family or children of their own from whom they may receive seva. Additionally, most of these institutions maintain spiritual centers and temples that further support an older person’s spiritual preparation for leaving the earthly plane. Still, the resistance to living outside of a family home in life’s later years is strong enough that this option is distressing for many people. Further, these homes do not provide care for older people experiencing significant or debilitating cognitive decline, such as those with Alzheimer’s and other forms of dementia. Meaning, if a person in a retirement home develops symptoms of dementia, that person again becomes the responsibility of the family, and sent back home (Lamb 2009).

In India, the apparent aimlessness of wandering elders is not cause for concern as is often felt in UK and US. Dementia behavior that becomes problematic is that which casts negative light on the family’s ability to care for their relative appropriately. Lawrence
Cohen (1998) speaks to the importance of social situations and expectations in consideration of caring for elders after pursuing a lengthy study with a population in Varanasi, India. Arguing against strict explanatory models, Cohen claims such attempts "miss the specificity of explanation itself as a situated social practice" (318). Why an older person's behavior is aberrant depends heavily on the social situation in which she is acting. This variance, then, leaves room for questions of morality and care.

Varanasi families may be left to explain their relative’s behaviors within the family and society at large. Indian dementia narratives may place blame for an individual’s troublesome behavior on her “Bad Family” (Cohen 1998). When an older person is allowed to exhibit rude behavior towards neighbors and villagers during her escapades, wandering becomes a cause for familial concern as it directly endangers the family’s collective reputation. If these actions are disruptive enough, neighbors may come to suspect maltreatment of the elder and blame the family. As an important side-note, this example depicts how culturally-dependent caretaker stressors may be which as we saw earlier have significant impacts on the person with dementia herself. Ultimately, the family must invent alternative explanations for aberrant behavior to combat the outsider narrative of the “Bad Family.”

It is important to recognize that cultural frameworks drastically impact the impression of moral character on individuals in cognitive decline and their families. The existence of hundreds of religions around the world demonstrates the human desire to make sense of life and the causality behind momentous events such as aging and death. People are frequently uncomfortable with deviations that cannot be logically explained and
dementia-induced behavior can be far from logical flying in complete disregard for previous behavior and temporally-accurate orientations.

Conclusion: Revisiting the cultural phenomenology of dementia

One of the many odd things about memories is that they don’t live in one single location – there is no single cell that houses a single episodic memory, rather varied sensorial triggers may unearth dormant memories, preferences, even communicative abilities. This is especially true of music which has successfully reanimated people who have very advanced dementia. Social worker Dan Cohen, has seen this remarkable repersonalization engendered quite simply by the exposure to music. After spending years journeying across the United States to bring music to people with dementia in retirement communities, Cohen has set up the Alive Inside Foundation that has now brought music to 4000 nursing homes in the United States returning long-lost memories and a sense of self and personhood to PWD who had unconsciously resigned to live out their death sentence anonymously. Music and memory is an important area of research that may elucidate more about how sensorial triggers reinvigorate dormant selfscapes.

In this paper, I emphasized the importance of cultural conceptions of the self in shaping the embodied experience of dementia. Aging individuals in the UK and US struggled with the perceived loss of independence associated with requiring extra help in daily life, which further engendered feelings of being a burden on loved ones. PWD are likely to internalize a loss of personhood commensurate with feelings of lacking self-worth
or importance. Our old friend Joe Potocny wrote a good-bye letter in preparation for his eventual death that read: “I know some of my family will read this; others won’t. Same as friends, and so on, because they are as caught up in their own lives and mine is not important in the Grand Scheme of things. Goodbye.”

Though accounts of phenomenological experiences of dementia in India are beyond the current reach of this researcher, I hope to have shown how significantly cultural attitudes towards aging can shape the psychological well-being of those in their later years. Dementia is a confused and confusing disease and the subjective well-being of those experiencing these conditions ought to be careful considered in practices of care. That said, aging itself is a process that many people struggle with regardless of cognitive ability. In India, we saw how framing retirement homes in a spiritually and culturally consistent manner can empower older people as they seek peace in their final years. In the United States, we saw how sensorial triggers such as music can restore personhood and engender serenity in PWD who have long been separated from their familiar sense of self. Thus, I believe anthropological discourse on aging provides hope for the elderly suffering from loss of personhood.

I have also argued here that self-awareness is not holistic enough of a consideration in the study of selfhood. One must find familiarity in her behavioral patterns and self-attributes. Without levels of familiar self-awareness, the concept of awareness is too shallow a critique in understanding selfhood. Further, caretakers inability to find familiarity in behavioral patterns and stylings of a person with dementia reinforce the distance she may feel between her body and self. This faux Cartesian-duality is responsible
for instilling the belief in an eventual point of no return, after which a PWD is neither alive, nor dead. Bolstering the concept of a living-death sentence is harmful to the person with dementia and any hope she may have for a positive subjective well-being. To dig more deeply into embodiment of dementia, I have recommended analysis through Douglas Hollan’s proposal of the selfscape as opposed to Bourdieu’s well-loved concept of the *habitus* which falls short when considering bodies with missing memories. The selfscape allows us to see how a person can relate to various levels of herself without the durability of culturally curated behavioral patterning.

Finally, I discussed cultural conceptions of aging in India to exemplify alternate modes of being in the world as an aged person and the strong influence one’s behavioral environment exerts upon her well-being. As Sarah Lamb advises, “Perspectives on aging from outside North America such as from India can help to illuminate the cultural and ideological elements of successful aging models” (2014: 42). In this vein, perhaps the ability of music to realign the self with familiar cultural and ideological elements of her *self* and identity may improve the experience of aging with and without dementia worldwide.


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