HeartMind of Alzheimer's disease

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HEARTMIND OF ALZHEIMER’S DISEASE

by

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DEDICATION

I would like to dedicate this thesis to the elders at Greater Boston Golden Age Center and in loving memory to Dr. Diane Weiner.
ACKNOWLEDGMENTS

I would like to thank all of the amazing people who helped make this thesis possible. In particular, I would like to thank my wonderful professors Drs. Diane Weiner, Nicole Newendorp, and Hee-Young Park for their continuous support and encouragement. I also would like to recognize Nancy Eng at the Chinese Historical Society and Catherine Chang at the Greater Boston Golden Age Center for their friendship and invaluable insights. Finally, I want to acknowledge Drs. Lance Laird and Linda Barnes, my professors in the Medical Anthropology and Cross-Cultural Practice program.
HEARTMIND OF ALZHEIMER’S DISEASE

SUSAN KING

ABSTRACT

Using Scheper-Hughes and Locke’s “Mindful Body” (1987) as a theoretical framework, this thesis seeks to examine how Alzheimer’s disease (1) impacts Chinese and Taiwanese American elders and their caregivers, (2) is felt through the relationships and social interactions of the Chinese and Taiwanese American individuals interviewed, and (3) is experienced through the complex overlapping of culture, politics, and institutions in Boston and beyond. In order to understand the impact of Alzheimer’s disease on Chinese and Taiwanese American families living in Boston, qualitative interviews of health care professionals, community members, Chinese and Taiwanese American elderly, and Alzheimer’s disease caregivers were conducted and analyzed. Furthermore, participant observation at a Chinese American adult day health center, dementia review meetings, and various public lectures on Alzheimer’s disease and the Chinese and Taiwanese American communities were attended. This case study demonstrates that for the Chinese and Taiwanese American communities, Alzheimer’s disease is a social disease. It exists within family relationships of elder and caregiver, and for families, it is the gradual degeneration of these relationships that is at the heart of meaning of this illness’ lived-experience.
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Table 1. List of participants, their various identities, and type of participation in thesis 28
LIST OF ABBREVIATIONS

AD................................................................. Alzheimer’s disease
BMC ............................................................... Boston Medical Center
BU ................................................................. Boston University
BU’s ADC ..................................................... Boston University’s Alzheimer’s disease Center
FHS ............................................................... Framingham Heart Study
JADC ............................................................... Jade Adult Day Center
QMC ............................................................... Quincy Medical Center
CHAPTER 1: INTRODUCTION

“It gets swept under the carpet,” my friend explained in a frustrated tone.

“Nobody talks about it. There’s a problem, but he’s my grandfather- it’s not respectful,” she added. We were sitting inside a small white-walled exam room in a university neurology clinic waiting for the next patient to arrive. Every Friday, we shadowed our research mentor in his clinic, and during the down times between patients, we discussed how neurology trickled beyond our professional lives into our personal ones. My friend, a first generation Chinese American, grew up in a house with her parents, sister, and both sets of grandparents. They were planning a month-long trip to visit extended family and friends in China, including a detour to her grandfather’s home village. She did not seem very enthusiastic about the planned sightseeing events, which made me curious. Why not be excited to travel?

My friend explained that traveling with her family meant accommodating her grandparents. Accommodation meant physical, dietary, and social limitations. For example, excursions had to be wheelchair accessible with limited walking. Her grandparents only ate Chinese food so that even in European countries, they would locate Chinese restaurants or buy groceries to make food. Also, her grandparents had final say on which sites to visit such as her grandfather’s village, which held little interest for my friend who wanted to see more globally-recognized historical landmarks. She approached these limitations with a practical perspective, her disappointment curtailed by her feelings of love and respect for her grandparents.
This trip wasn’t for her; it was for her grandparents, in particular her grandfather. Her grandfather had Alzheimer’s disease, although no one in her family labeled it as such. My friend explained that he was often mentally confused, not his usual sharp self, and had difficulty managing daily tasks like bathing. But, instead of talking about these changes, which alarmed my friend, the rest of her family responded by planning a trip to China. The trip was meant to renew old familial relationships and reconnect her grandfather with his roots. I think it was also a way of crossing generations, showing my friend and her sister the places her grandfather had grown up in and giving meaning to her grandfather’s struggle to rise above socioeconomic challenges to become a nationally renowned mathematician and engineer. Her family may not have directly addressed her grandfather’s growing cognitive deficits, but I realized they were trying to find healing in other ways.

My experiences listening to patients and families cope with progressive neurological disease together with my friend’s story about her grandfather made me want to learn more about how Alzheimer’s disease impacts Chinese American family dynamics. Also, how might the medical and healthcare community provide better care and support for such families? Past studies have shown that Chinese American families delay or do not seek clinical help for Alzheimer’s disease (Braun and Browne 1998; Chow et al. 2000). This has resulted in broad public assumptions that Alzheimer’s
disease is not a significant health issue within the Chinese American community\(^1\); that Chinese American elders are somehow mentally healthier than the general population (Casado and Leung 2002; Tanjasiri, Wallace, and Shibata 1995). However, according to the CDC, Alzheimer’s disease is among the top ten causes of death among Asian American elderly and may indirectly contribute to a number of health concerns such as depression (Heron 2011). Likewise, in Boston, despite growing numbers of elderly Chinese Americans, Alzheimer’s disease remains a health issue “swept under the carpet” in the public discourse.

Originally, this thesis research set out to examine in a case study how Alzheimer’s disease in Boston Chinese American elderly affects family dynamics and medical decision-making. But, as I began to talk with members of the Chinese and Taiwanese American communities\(^2\) in Boston, interview health workers and family members of elders with Alzheimer’s disease, and spend time with Chinese and Taiwanese American elderly, the focus shifted away from the medical decision-making process. Instead, this thesis takes a deeper look at how Alzheimer’s disease affects the nature of relationships within multiple contexts (e.g. individual, family, community) and the ways families

\(^1\) “Community” is used broadly here within a national context; however, the Chinese American community represents a diverse web of groups that will be discussed further in the Background & Methods chapters.

\(^2\) “Communities” are used here in a broad local (Greater Boston Area) context, but as noted in the previous footnote, in fact, encapsulates a variety of heterogeneous sub-groups (e.g. generational sub-groups). I will elaborate further on the meaning of “community” as it is used in this thesis in the Background & Methods chapters.
coped with these new dynamics. In particular, through this case study, I argue that the need to find ways to reshape or reconnect relationships and family identities is an important part of coping with Alzheimer’s disease. For example, my friend’s family trip to her grandfather’s village in China brings to mind this theme. This focus better sets the groundwork for understanding potential ways of healing as well as constructing practical interventions for Alzheimer’s disease and dementia within Boston’s Chinese American communities.

*From the Personal to the Collective*

Although I have chosen to look at a more individualized and personal understanding of Alzheimer’s disease within a small part of Boston’s Chinese and Taiwanese American communities, I want to suggest that this case study’s findings may have broader implications for practical interventions within these communities. Cohen, in his ethnography of Alzheimer’s disease in India and the United States, states “old bodies serve as a critical site in the constitution of collective meaning and practice” (2000:4). Thus, Cohen views old bodies’ lived experience of Alzheimer’s disease as representative of more than the individual, but a collective, whether between old body and caregiver, family, or nation. For example, he asks if the pathology of Alzheimer’s disease a clinical disease (as often viewed in the West) or a ‘bad family’ (India)? How might old bodies with Alzheimer’s disease reinforce the American psyche’s perspective that “memory is the key to the self” and feed a national anxiety of getting old (Cohen 2000)? Similarly, I believe that the personal experiences of Alzheimer’s disease put forth
by the individuals I interviewed and spent time with have some collective meaning, a voice in the public discourse.

**Connections to Alzheimer’s Disease Research**

This thesis expands upon current public health and anthropological research on Alzheimer’s disease within Chinese communities in a few key ways. First, most Alzheimer’s disease research has focused on West Coast communities of Chinese Americans or families in China (Braun and Browne 1998; Chao et al. 2011; Chiu and Zhang 2000; Chow et al. 2002; Chung 2001; Elliot et al. 1996; Gallagher-Thompson et al. 2006; Ikels 1998; Jones, Chow, and Gatz 2006). West Coast Chinese American communities such as those in San Francisco, CA, have a different history and culture compared to East Coast communities like Boston’s. For example, San Francisco’s community is larger and historically older compared with Boston’s, meaning that elder and Alzheimer’s disease care resources for Chinese Americans tend to be more extensive and well-established. Boston’s Chinese American and Taiwanese communities are newer and constantly in flux, composed of students, factory workers, restaurant owners, working professionals, and elderly parents immigrating from China, Hong Kong, and Taiwan to join their adult children among others (Eng 2012; Hinton and Levkoff 1999; Newendorp 2011).

Second, my thesis seeks to include both emic and etic perspectives such as the biomedical and the family, the outside researcher and the community member, the elder and caregiver. On the other hand, Alzheimer’s disease research within Boston’s Chinese
American communities has chosen to focus primarily on emic or etic perspectives. I argue that this reinforces fractured conceptions of Alzheimer’s disease. For example, Hinton & Levkoff also looked at Alzheimer’s disease in Boston’s Chinese American community, but they focused on caregiver narratives (1999). I interviewed caregivers but also wanted to give voice to the Chinese American elderly, themselves, since a significant amount of Alzheimer’s disease research already chooses to construct experience of Alzheimer’s disease solely from caregiver perspectives. This over reliance on caregiver perspectives tends to subconsciously relegate Alzheimer’s disease elders to a secondary entity, contributing to perceptions that such elders somehow lack selfhood (Cohen 2000). Thus, I felt it was important to touch on both emic and etic perspectives within this thesis.

Third, in an effort to determine why Chinese American families are less likely to seek out clinical care for Alzheimer’s, medical anthropology and public health studies often set up culture as a “barrier” to care (Hinton et al. 2000). I want to step away from this inadvertently adversarial framework and realign clinical care to the same side as Chinese American communities, looking at how culture may be used as a strength. Likewise, I sought to understand the current biomedical discourse of Alzheimer’s disease as it is incorporated within parts of Boston’s Chinese American communities and how it relates to family experiences of dementia. Ultimately, both clinical and community group goals are the same: how to provide the best support for families with elders affected by Alzheimer’s. Thus, it makes sense to re-conceptualize biomedical and
Chinese American meanings of Alzheimer’s disease as interrelated parts of a bigger framework utilized by families.

Conceptual Frameworks

In this thesis, I discuss how Alzheimer’s disease is about disrupting, shifting, and renewing of relationships. I explore the nature of these relationships, connections, and boundaries within the contexts of: (1) self, (2) interpersonal, and (3) community. As mentioned in the previous section, one such relationship is between conceptual frameworks of Alzheimer’s, specifically biomedical and sociocultural or Chinese American frameworks. Often in the public discourse these conceptual frameworks appear to be at odds with one another. For example, Cohen describes the “biomedicalization of dementia” as a “reduction of alternate frameworks”, the impetus of which is due to biomedicine or as he argues perhaps something more complex: practices of culture and political economy (Cohen 2000). Essentially, this creates a division between clinical and social constructs of Alzheimer’s disease. How might disrupted relationships between conceptual frameworks of Alzheimer’s disease be shifted and renewed? I hope to show through this thesis that we need to recognize a holistic conceptual framework of Alzheimer’s disease that is more in touch with individual Chinese American experiences that tend to mix biomedical, social, and political

3 These conceptual frameworks will be described further in the Background chapter and analytic chapters.
constructs fluidly. In order to create more effective interventions and models of care for Alzheimer’s disease within Chinese American communities, this is the first step.

**Theory & Structure**

Progressive chronic illnesses, such as Alzheimer’s, impact families on multiple levels. In order to understand this inherent complexity within my thesis research, I am using an interpretation of Schepër-Hughes and Lock’s theoretical model of “mindful body” (1987). The “mindful body” is a holistic concept that seeks to incorporate three aspects of the body in health and sickness. First, the individual body is a phenomenological exploration of illness experience. Second, the social body examines social embodiment of illness. And third, the body politic seeks to understand how structures from community institutions to national governments and global policy wield control and power over our bodies. In the following paragraphs, I will outline my interpretation of each “body” within the context of my thesis research, providing the reader with a roadmap for each chapter.

Chapter two or “Background” orients the reader within the social, medical, and political conceptual spaces that I will construct the “mindful body” of Alzheimer’s disease within and highlights the ways in which these spaces overlap and fuse. It starts with the building where I spent most of my time as a participant observer, the Jade Adult Day Center or JADC. The building housing the JADC is a perfect example of how social, medical and political spaces are integrated together, since it contains a public school, health center, community facility, and elderly residence all in one. I take a
moment to look at the infusion of biomedicine and Chinese health perceptions with regards to Alzheimer’s disease, both within this space and in the medical anthropology literature. Next, by noting the sociopolitical history behind the JADC, I expand outwards to look at broader context of the history of the Chinese American communities in Boston. The history of Chinatown is a story of neighborhoods and the families living in them. Through this discussion, I return back to sociocultural spaces of Chinese American families in Boston, multigenerational households and elderly housing, such as the elderly residences in the JADC building.

Chapter three, “Uncertainty in Alzheimer’s”, examines Alzheimer’s disease at the level of the individual body. I look at how a predominant theme of “uncertainty” characterizes many of the Chinese American elders’, caregivers’, and health professionals’ experiences of Alzheimer’s. In particular, I argue that uncertainty emerges from the liminal nature of Alzheimer’s, revealing false dichotomies of real-unreal, visible-invisible, normal-abnormal, body-mind, and disease-illness. In the latter half of this chapter, I focus in on perceptions of the self in Alzheimer’s. In what ways is it constructed and deconstructed? Where does it exist? How does this relate back to the underlying theme of uncertainty? I argue that the Alzheimer’s disease self emerges between elder and caregiver. Alzheimer’s disease is a social disease embedded within relationships. I examine this further in the next chapter.

In chapter four, “In Relation”, I look at the relationship between elders with Alzheimer’s disease and their caregivers, part of the social body. First, I ask what are
some of the values infused within family and elder-caregiver relationships? How might these values shape the sense of loss and consequent pain experienced by Alzheimer’s disease families? Next, I examine the ways Chinese American family relationships are experienced when elders develop Alzheimer’s. For example, what roles do expectations and feelings of responsibility play? What kind of conflicts may or may not arise? Finally, I look at how families seek to address these conflicts, specifically to re-establish or maintain family harmony. Also, how might these stories help clinicians and community workers better support the needs of such Chinese American families?

Chapter five focuses on the role of institutions, education, and policy on Boston Chinese American families’ experience of Alzheimer’s, the body politic. It shifts discussion from family relationships to consider how broader community relationships may be used to influence models of care and social constructions of Alzheimer’s. I started this introduction with a story about my friend’s grandfather who has Alzheimer’s disease and the ways her family sought healing. Through my thesis research, I found myself thinking more about her story and how renewal of relationships, connections between generations, crossing international borders, clinical and cultural brokerage are all part of healing. At the end of this chapter, I attempt to synthesize these thoughts through a possible community-based intervention proposal. My research shows that the breakdown or disharmony of relationships is a source of loss and pain within the Chinese American families I interviewed. Thus, I feel rebuilding or rather reshaping relationships more positively should be a beginning point for how to better support elders with
Alzheimer’s disease and loved ones within Boston’s Chinese American and Taiwanese American communities.

Finally, Chapter six or “Conclusion” reviews my key findings for each section, holistically looking at the relationships among individual, interpersonal, and community layers to the larger picture of how Alzheimer’s disease impacts family dynamics in parts of the Chinese American and Taiwanese American communities of Boston. Through this thesis, I have sought to reconnect conceptual frameworks of Alzheimer’s disease to personal experiences in an attempt to start a conversation about better community-based support for Chinese American and Taiwanese American families living in Boston areas. I argue that renewal and reshaping of relationships constructively within the self, between family members, and among families and community organizations are all important processes of coping and healing. While this thesis is a case study focusing on Boston Chinese American and Taiwanese American experiences of Alzheimer’s, some of the core themes may represent basic human experience of dementia and therefore might be useful to consider for future research and application beyond this small project. I hope this thesis is a spark for conversation about Alzheimer’s disease within the public discourse, bringing it out from “under the carpet”.

CHAPTER 2: BACKGROUND

“In 1967, or ’68, when the new Quincy School was planned, unbeknownst to the community, New England Medical Center had been talking to the City about playing a role at the new Quincy School, because the new Quincy School was going to be a community school- which would not only house a school but a community facility, and the community facility was a health facility”

-- Catherine Cheung (1995)

This section will review the social, medical, and political spaces that situate and form the context of my thesis research. Much of my thesis examines the integrated relationship between the concrete and abstract, including the neurologic and psychiatric, the physical body and subjective self, and within Scheper-Hughes & Lock’s theory of “mindful body”. While the social, medical, and political spaces I review are conceptual, as the above quote suggests, they are grounded in the physical architecture of Chinatown and one community building in particular. Thus, I will use this building as a basis to organize and explore the conceptual social, medical, and political spaces covered in this section.

The community facility Catherine Cheung describes is the site where the Jade Adult Day Center, or JADC, is located. I spent most of my participant observation at the JADC, so it holds particular importance to my thesis findings. The first time I visited the JADC, I circled the building twice before guessing and choosing a random entrance. It’s an irregularly shaped brick structure that houses a public school, Chinatown community health clinic, elderly residence towers, and Jade Community Center. The JADC is
located on the second floor of the community center section, and except for the labeled white transport vans parked out front it is easy to assume one is at the wrong address.

Here is an excerpt from my field notes describing my second visit:

At first I tried the door for the Towers, but it was locked with a small black card reader to the right of the glass doors. This is not my first time at the Jade Community Center, but this building always confuses me. It seems like the brick and concrete building is an octopus - it houses the Quincy School, the Chinatown Community Clinic, the Jade Community Center, and the Towers (senior housing). The building itself has a high-rise residential tower, an indented middle for the clinic, and a boxy part to the left by the thruway that is the school section. The back of the building is tiered with glimpses of trees and walls of plants, the tiers blending into each other with ramps. I have yet to explore this section of the building, but it reminds me of secret gardens. The entrance to the Jade Community Center confuses me somewhat, which is why I always end up trying the Towers first. The small wrought-metal gate is unobtrusively to the right of the residential entrance, and it opens onto a curvy walkway lined with hostas and other tropical-looking plants. There is a small stone fountain. I think “Asian Zen Garden” when I see it.

There is a white door open at the end of the walkway. However, when you first step in, it seems like you wandered into the wrong door-like you entered the kitchen area or the back service entrance rather than the front. For all I know, that’s what I’ve been doing all along, but because I can’t read the Chinese writing, I don’t realize the front entrance is on the other side of the building. Yet, I don’t think so. The walls are an aqua whitewashed blue- so is the concrete floor (making it seem industrial). The ceiling is high, with wide shelves lining the walls, and
fluorescent machine lights overhead. In the middle is a large pool table with a crimson-felt surface. Three older men (white hair, balding, bit of paunch, spindly arms, slightly stooped) are playing a game. They don’t even notice me as I slip past into the door to the right.

Now, I’m in a cafeteria-like room with red and gold Chinese paper ornaments hanging from the ceiling. There are bulletin boards on the walls and long cafeteria faux-wood tables running lengthwise down the room. I notice a couple of old women whom I smile at and nod my head. They return my smile but continue their conversation in Chinese (Toisanese? Cantonese? Mandarin?). I pass through a doorway on the opposite wall, entering a burnt-orange corridor with half of it filled with a wheelchair ramp. This goes to the right and when you turn the corner, you are in front of three black elevators with red leather club chairs opposite. Above the chairs is a community bulletin board, and I spy my research poster already tacked up above a diabetes poster.

The next room is an atrium-like space with a sunk-in sitting area to the right, lined by large green lounge chairs. This is the entry area of the Towers I had originally tried to come into when I was outside. A few elderly men and women are hanging out; canes and walkers momentarily abandoned. Again, I smile, shyly murmur “Ni hao” and walk to the left near the “management offices”. I had thought I remembered more bulletin boards, but when I rounded the narrow corner, it was just another office. So, I turned back and retraced my steps back to where the elevators were.

Instead of the elevators I headed straight for the door to the stairs. The narrow, concrete stairway was white-washed with the same high gloss pale blue paint as the pool-room. I went up one floor, finding a helpful placard that proclaimed “Adult Day Center” in gold lettering. I entered a
narrow hallway with dark green carpet and walked to the left and into a large common room with lower ceilings than the room downstairs, but still big spaces. This room was filled with four large circular wood-laminate tables, each surrounded with green-seated chairs almost all occupied by elderly Chinese Americans, men and women, walkers, canes, a wheelchair.

My field notes may appear to describe a maze-like building, and as a new visitor, this is exactly how it appeared to me. However, my point isn’t to orient readers within the building, but rather to demonstrate how this building is an amalgamation of spaces. The community, health, and residential areas intimately flow together. I only peripherally explored the school section, but this too was welded into the rest of the building. In the next section, I step from physical structure to conceptual space.

“The community facility was a health facility”

Similar to the building I described above, the social and medical spaces are intertwined and hybrid. The Chinatown Community Clinic acts as a basic health facility for many of the elders I met. The clinicians speak fluent Chinese dialects including Mandarin, Cantonese, and Toisanese, making it a familiar environment compared with the much larger Tufts Medical Center which stands only a couple of blocks away. However, psychiatrists oversee elders with Alzheimer’s disease and dementia since there is no neurologist on staff. Literature shows that a common belief among Chinese and Chinese Americans is that Alzheimer’s disease is a mental health condition and not a neurological disease (Braun and Browne 1998; Yeo 2006). Psychiatric disorders are
much more likely to be perceived as shameful and something to be hidden within the Chinese American community (Yang 2007; Zhong 2011). Elliot et al suggest that this view of Alzheimer’s disease may be one reason it is stigmatized within the community, and families put off seeking medical care (1996; Zhan 2004). However, as I will explain, the issue is not so clear-cut.

First, it is important to understand that both cognitive and behavioral symptoms characterize Alzheimer’s disease and dementia. From the biomedical perspective, Alzheimer’s disease is a progressive, degenerative neurological disease characterized by protein “plaques and tangles” which build up within the brain, causing dementia and other deficits (Rodgers 2003). Symptoms may include memory loss, language deficits such as aphasia, disturbance of executive function (planning and executing tasks, impulse control, etc.), and significant impairment of social or occupational function (Rodgers 2003).

Aging is the biggest risk factor for Alzheimer’s disease; however, it is not inevitable with old age (Alzheimer’s Disease Fact Sheet 2006). A neurologist may diagnose Alzheimer’s disease using a simple clinical exam such as the mini-mental status exam, but neuropsychological testing is more appropriate for an in depth understanding of an individual’s stage of disease and specific deficits, combining quantitative and qualitative observations (Elliott and Di Minno 2006; Folstein, Folstein, and McHugh 1975). Also, psychiatric help may be useful for finding strategies to cope with behavioral changes like angry outbursts or for caregivers to unburden pent up stress. Furthermore,
the underlying causes of Alzheimer’s disease are not well understood. Progression of Alzheimer’s disease and dementia are closely correlated with mental health issues such as social isolation, depression, and maladaptation to sudden life changes like moving into a nursing home (Stern 2012). On the other hand, high education (“cognitive reserves”), active lifestyle, and strong social support are negatively correlated with progression of Alzheimer’s disease (Stern 2012).

Often behavioral changes associated with Alzheimer’s disease are most upsetting and remarkable for Chinese American families. Hinton & Levkoff note that in the Chinese American families they interviewed, early symptoms of Alzheimer’s disease such as memory and cognitive deficits were not seen as “particularly ominous or noteworthy” (1999:463). Families’ tend to not seek outside help until significant disability is seen in elders with more advanced Alzheimer’s disease (Chow et al. 2002; Hinton and Levkoff 1999; Sheng, Law, and Yeung 2009). Ikels states that early Alzheimer’s disease cognitive losses “are less salient and less significant for contemporary elderly Chinese and their family members than the later stages of personality change that disrupt the correct performance of social roles” (2002:249). She argues this on the basis of cultural Chinese conceptions of self, which do not “prioritize the cognitive domain”, but rather focus on appropriate social interaction (Ikels 2002).

However, an exception might be when an elderly individual’s social interactions and personality are defined by high education and intellectual facility. Ikels notes that in this case “decline of an elder...is much more quickly noticed by and painful to both the
affected individual and the family. Co-workers and family members will go to considerable lengths to keep up the pretense that nothing is wrong” (1998:277). Here, Ikels hints that stigmatization of Alzheimer’s disease is also wrapped up in denial and sociocultural guidelines of respect (cf., Jones, Chow, and Gatz 2006).

Much of the medical anthropology literature on Alzheimer’s disease within Chinese American communities specifically looks at why Chinese health perceptions may act as a “cultural barrier” for early awareness and help-seeking (Jones, Chow, and Gatz 2006). The above discussion outlines a few of these perceptions such as stigmatization of Alzheimer’s disease as a mental health issue (Hinton et al. 2000). Elliot et al argue that many Chinese Americans perceive Alzheimer’s disease as part of “normal aging” (1996). Hinton & Levkoff note that this perception is reinforced by Boston Chinatown health practitioners who are portrayed as “advocates of traditional Chinese views of old age that normalize old age confusion and dependency” (1999:463). They state that the health practitioners, thinking little could be done medically, felt it was better not to “burden” families’ with the stigmatizing label of Alzheimer’s disease and instead use “reassuring” traditional explanations that normalized symptoms (Hinton and Levkoff 1999).

I also find it interesting how Alzheimer’s disease seems to be “normalized” within traditional Chinese health conceptions as a vascular condition. For example, rates and awareness of vascular dementia outnumber diagnoses of Alzheimer’s disease dementia within China, although with recent public health efforts these statistics may be changing.
(Chen 2004). In historical Chinese medicine, the body is seen as a system of interconnected vessels through which qi, a fluid-vapor described in terms of yin or yang, flows and interacts with the body. The biomedical vascular system was part of this qi system (Epler 1988). Thus, vascular origins of dementia may be better understood and accepted within traditional Chinese health conceptions of illness.

Bachelor-town

In Catherine Cheung’s quote at the beginning of the chapter, she notes that the New England Medical Center was in talks with the city of Boston “unbeknownst to the [Chinese American] community” (1995). Biomedical hegemony over traditional Chinese health perceptions is embodied in the medical institution’s takeover of Chinatown. The history of Chinese Americans in Boston is shaped by waves of immigration, but also by exercise of political power over the community. The usurpation of the Chinese American community by medical centers like New England Medical Center and Tufts University during the late 1960’s and early 1970’s demonstrates this.

In the following paragraphs, I will give a general history of the Chinese American communities in Boston, highlighting the parts that have influenced families, elderly, and health perceptions. My multiple discussions with Ann, a volunteer historian at the Chinese American Historical Society, guide this overview of Chinatown’s history. She provided me with a wonderful overview of Chinese immigration to Boston, including book references, and also directed me towards several oral histories of Chinese American women, one of whom is the founder of the JADC. In addition to Ann’s helpful
information, I have incorporated information from a talk given by Tunney Lee, MIT professor of urban planning, who described Chinatown as a community that is “as ordinary as any, as complex as any, and as changing as any”.

The first immigrants from China to Boston, arriving during the 1800’s, were sailors from merchant ships in China (exporting Chinese porcelain expressly made for Americans) (Lee 2013). The next groups were students (from Guangzhou and Toisan areas) brought by missionaries (Rhoads 2011). Ann mentioned a Chinese man who graduated from Yale as one of the first records of such students. They came to the US to be educated and then return to China to ‘modernize it’. Some of the students were as young as eight years old. Pictures of these young schoolboys shipping off from China may be found in the *Chinese in Boston* book, a photo-history of Chinese Americans in Boston (To 2008).

Immigrants fell into different socioeconomic groups, such as the students and the workers (sailors, laundry, restaurant). Ann also talked about the shoe factory workers (North Adams) who were brought in as strike-breakers in 1870 from the west coast of the US (they had probably been railroad builders) (Lee 2008). Before they arrived, these workers expected violence. However, upon arriving, the crowd was so fascinated by them because they were of Asian origin (a rarity), that the reception was not as antagonistic as one might predict. They apparently made friends with the locals and fit in surprisingly well considering they were strikebreakers. After the shoe factory in North Adams closed down, most of the Chinese workers left the Boston area. For example,
there is a historical record of one strike-breaker who moved to Florida and developed a frost-proof variety of orange (Lee 2008).

In the early 1900's, Chinatown, located on the Boston waterfront, was mostly populated by Syrians and Lebanese, who eventually moved inland to suburbs as they became more economically prosperous. Chinatown was a less than savory area until the 1970's (in part because of political relegation of adult businesses to the area, “the combat zone”). Ann noted that it was rife with prostitution, "xxx" movies, and described as a “bachelor-town”. She explained that due to the Chinese Exclusion Act of 1882, Chinese families forcibly became trans-national, with men working in Boston while wives and children remained in China, Hong Kong and Taiwan. On the other hand, Chinatown has always been a complex community, with many good aspects beyond the less savory ones. As Tunney Lee notes, starting in the 1900’s, it became a thriving sociocultural center for Chinese immigrants, filled with restaurants and laundry businesses as well as organizations such as family associations, created to help new Chinese residents survive (Lee 2013).

Today, now that many in the Chinatown community are doing better, they have also moved to the suburbs of Lexington, Brookline, and Newton. Some "empty-nesters", however, are now moving back to Chinatown, specifically into the higher rent condos being built, such as places along Tremont Street overlooking Boston Common. Near the Common, they are close enough to enjoy the community, the food, the Asian groceries, but are not living in the heart of Chinatown. However, such return moves are a luxury,
literally, since tensions have continued to build in recent years as gentrification and luxury developments threaten to make Chinatown too costly for current Chinese American residents (Liu and Geron 2008).

Ann mentioned that when the over-street railroad tracks existed over Beach Street and Harrison Avenue, the spaces under them were darker, not inviting, nor safe for families and businesses. But, with urban renewal beginning in the 1950’s, they were taken down, and businesses started up, raising the living conditions of the neighborhood. Urban renewal ushered in new conflict as well as the birth of Chinatown activism (Liu and Geron 2008). For example, the mass displacement of Hudson street occupants for the thruway construction, the Central Artery, led to families leaving for Dorchester, Quincy, southeast Brookline, as well as for Lexington and Newton (better school systems for those able to afford these suburbs) (Lee 2013). An overview of this displacement on the Asian American Civic Association’s website describes the community as “crippled” (AACA 2014). Again, community split into two economic classes: the workers and the professionals. One group was displaced and moved out unwillingly; while the other chose suburbs based on the privilege of education.

Also in the 1950’s, Chinatown’s identity as a ‘bachelor-town’ began to change. According to the Asian American Civic Association of Boston’s website, the repeal of the anti-Chinese immigrant legislation finally permitted entry of women and children, allowing family reunification (2014). At the same time, political turmoil in China created a new wave of immigration of families from Hong Kong, increasing the Chinese
population in Boston. However, the 1960’s and ’70’s saw more upheaval for families within the community with the Mass Pike Extension Project eating up real estate in Chinatown (Lee 2013). The results of this can be seen today as the JADC building, once centrally located, now rests on the cusp of the interstate. In addition to division by Mass Pike construction, Tufts University and New England Medical Center began aggressively buying up buildings and land in the Chinatown area, continuing into the 1980’s (Li et al. 2013; To 2008). As gentrification in Chinatown grew, community advocates developed the Chinatown Master Plan of 1990 (recently updated in 2010), which sought to curb such invasive developments by imposing height limitations and reaffirming Chinatown as a cultural and economic center (Li et al. 2013).

The political takeover of Chinatown area sparked the creation of a variety of advocacy groups to support the besieged yet growing Chinese American community in Chinatown, including the Asian American Civic Association, the Chinese Progressive Association, and the Chinese Economic Development Council (AACA 2014; Liu and Geron 2008; To 2008). This strong history of social justice and grass roots Chinese American community activism continues to grow today. For example, recent protests against gentrification of Chinatown such as the influx of luxury housing projects, included a community sit-in at the Mayor’s office in 2004 to return a parcel of Chinatown land to the community and a Chinatown rally in 2013 against housing threats (Lalwani 2013). Thus, Chinatown retains a core residential heart and community spirit despite outside political forces.
Past to Present

In summary, I want to point out three key ways the history of Chinatown is relevant for understanding current experiences of Alzheimer’s disease in Chinese American families living in the Boston area. First, historical immigration policies and patterns have created two populations of Chinese Americans in Boston which persist today: (1) educated professionals of higher socioeconomic status and acculturation into biomedical perspectives and (2) workers of low socioeconomic status with less English language proficiency and exposure to biomedical culture. Second, the invasion of community space by Tufts and New England Medical Centers has both forced biomedicine into the lives of many Chinese Americans in Boston, but has also created feelings of distrust that are still being repaired today. For example, the Chinatown Coalition (TCC), a community advocacy group and public forum appears to be both buffer and reconciliatory group between medical institutions, the City of Boston, and the Chinese American community. Their website states “TCC has enabled members to address issues of mutual concern such as welfare and immigration reform, economic development, public safety, public health and quality of life issues” (The Chinatown Coalition 2014). Third, physical division of the community by political construction projects and aggressive takeover by medical institutions reduced affordable local housing, giving many families little choice of whether or not to live multi-generationally or even in Chinatown.

Living arrangements, whether with family or “independently” in elderly housing, alters experiences of Chinese American elderly with Alzheimer’s disease, influencing
issues of socialization, caregiving expectations, and generational tensions (Lee and Hong-kin 2005; Smith and Hung 2012). When Ruth Moy, who founded the JADC, sought to create elderly housing for Chinese Americans in Boston, she ran up against political stonewalls. In her oral history (2011), she states,

“Yes, because I used to have such a hard time with the funding sources which would say to me, ‘well, the Chinese take care of their own.’ And I spent so much time explaining that they are not here, their families. However, when they are in this country, in those days, you know people offered their house, and they had small apartments, and the elderly just have to be, you know, they all lived together. And so it was very overcrowded. And they really couldn’t stay there any longer, when the children grew up, there was no place, not enough room, and so they, all thought to live in elderly houses.”

Ruth later adds that the elderly housing served multiple purposes, “having a place to go to for socialization, and, a little help with services, but I think mostly it was just to get away from home”. Her interviewer compares Ruth’s vision of elderly housing with a “village back home”. It’s a hybrid space. Today, building hybrid community facilities, such as the school-clinic-residential-community center the JADC is part of, represents a transition and compromise between cultural values, historical multigenerational living arrangements, health care, and familial socioeconomic pressures. For example, in a recent New York Times article, the creation of hybrid community facilities for seniors such as the one found in Boston’s Chinatown, has been proposed as a solution for cultural Chinese American desires to care for elders respectfully while adjusting for economic and social pressures which make caregiving difficult (Vega 2014). On the other hand, such facilities demonstrate shifting health perceptions among Chinese American families
and increased incorporation of biomedical care practices within traditional health care practices.

Through this background chapter, I have sought to give a general overview of perspectives in current medical anthropology literature on Alzheimer’s disease and Chinese Americans as well as a sociocultural historical context of families living in the Chinese American community of Boston. In both sections, I demonstrated the ways social, medical, and political conceptual spaces overlap and hybridize, creating new formations in which the whole is more than the parts and yet still retains aspects of the parts. The way I refer to hybridization of spaces is similar to Escobar’s idea of hybrid cultures; processes of construction are simultaneously reflexive and creative (Escobar 2012). These conceptual spaces form the context of the rest of my thesis research just as the community facility in Chinatown acted as the setting for my participant observation of elders with Alzheimer’s disease and health care workers. In the next chapter, I will detail my methods such as participant observation as well as some reflections and insights gleaned from the process of my thesis research.
CHAPTER 3: METHODS

The People

My research question revolves around not only how Alzheimer’s disease impacts families but also how families, health care providers, and the broader Boston Chinese American communities think about Alzheimer’s disease and dementia. Thus, my original research plan was to interview three distinct groups of people: families with an elderly relative with Alzheimer’s disease or related-dementia, families with an unaffected elder, and community activists and health care providers. However, as my research progressed, I found that the lines between these categories were continuously blurred. For example, many of the community activists and health care providers I met with talked not only about their role in the community but also from their own personal experience belonging to a Chinese American family in Boston. Some of the family members affected by Alzheimer’s disease also had dual roles in the community as medical interpreters or community organization board members. Finally, one of the ‘forgetful’ elders I came to know through my time at a community adult day center (the JADC) could also fall under the category as a health provider since before retirement he was a Traditional Chinese Medicine doctor who had worked for years both in China and Boston. I think the realization that the people I have come to know through this project cannot fit into socio-scientific categories is important. It shows that people have plural roles and cultural worlds which they seek to make sense of and incorporate into their understanding of Alzheimer’s disease: a different type of medical pluralism.
Table 1. List of participants, their various identities, and type of participation in thesis

<table>
<thead>
<tr>
<th>Participant Name</th>
<th>Elder Caregiver</th>
<th>Family</th>
<th>Community Activist</th>
<th>Health Care Provider</th>
<th># of Interviews</th>
<th>PO</th>
</tr>
</thead>
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<td></td>
<td></td>
<td>2</td>
<td>X</td>
</tr>
<tr>
<td>Thomas</td>
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<td></td>
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<tr>
<td>Stephanie</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>3</td>
<td>X</td>
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<tr>
<td>Dr. Mick</td>
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<tr>
<td>Lin</td>
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<tr>
<td>Mona</td>
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<td>X</td>
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<tr>
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<tr>
<td>Pete</td>
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<td></td>
<td>X</td>
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<tr>
<td>Aba</td>
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<td>Doctor Chin</td>
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<td>X</td>
</tr>
<tr>
<td>Grandpa</td>
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<tr>
<td>Sarah</td>
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<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Dr. Chang</td>
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<td>1</td>
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</tr>
</tbody>
</table>

As introduced in the Background chapter, I want to emphasize that the Chinese American population in Boston consists of a web of heterogeneous communities that are made up of many sub-groups. Some of these sub-groups include generational groups
(both age and also immigration history), regional groups (family history e.g. Taiwan, Hong Kong, Guangdong, Toisan, Beijing, and other parts of mainland China but also where in the US families originate from e.g. West Coast or East Coast, Quincy, Chinatown Center, Brookline, etc.), language and education groups (e.g. dialects, multiple languages, level of education, type of education, place of education), socioeconomic groups (e.g. family economic status, students, retirees, social involvement with community organizations and activities), and other numerous sub-groups. These groups often overlap and blend further adding to the rich diversity of the Chinese American and Taiwanese American communities of Boston.

This thesis is a case study of select parts of these Chinese American and Taiwanese American communities, mostly determined by access. First, as a non-Chinese speaker, I was limited to speaking with individuals who either were English speakers or English-Chinese interpreters for Chinese speakers. Second, most of the people I interviewed belonged to higher socioeconomic echelon and tended to be more acclimated to American culture. While I spoke both to immigrants (some more recent <2 years and others long-term >20 years), second, and third generation individuals, most were well educated, having earned college degrees. I interviewed people whose families (or themselves) had connections with Taiwan, Hong Kong, Guangzhou, Toisan, and Beijing, representing broad regional backgrounds. Furthermore, there were significant generational differences such as some elders I came to know who had grown up under British Colonial rule in Hong Kong compared with a younger nurse who had emigrated from Taiwan for college. Likewise, many of the people I interviewed had diverse reasons
for coming to live in Boston. For example, some came for education, others to join family members, some had been born and raised in the area, and others relocated to Boston from other parts of the United States.

Thus, this case study covers personal experiences of select parts of the larger Chinese American and Taiwanese American communities and is not representative of those, for example, who are non-English speaking restaurant workers, among others. This thesis is meant to examine the specific ways Alzheimer’s disease affects relationships and life worlds of the individuals I interviewed and spent time with, and I hope it leads to new conversations and perhaps further research into other parts of the Chinese American and Taiwanese American communities that I could not access.

**The Places**

I started off selecting two Boston areas, Chinatown and Quincy, since they not only represent two centers for the Chinese American population in Boston, but they also demonstrate a shift in time with Quincy often referred to as “the new Chinatown”. I am interested in multigenerational families, and I believe Chinatown and Quincy in some ways are multigenerational cities for Chinese Americans living in Boston. However, like the broken down distinctions between the people groupings, the divisions between the two localities began to erode with further investigation. For example, many of the 2nd and 3rd generations of Chinese Americans who were born and grew up in Chinatown have moved away from this center and now live in the surrounding areas such as South End and Quincy as well as the fringe along Tremont Street by Boston Common.
Likewise, many new immigrants or first generation Chinese Americans living in Boston might live in Quincy with their families but they spend most of their daytime in Chinatown working in the restaurants and seeking services from the major community organizations created to help immigrants navigate the new cultural world of Boston.

In order to recruit participants and get to know Chinatown and Quincy areas, I reached out to a number of community organizations such as Quincy Asian Resources, Inc., South Shore Elder Services, Greater Boston Chinese Golden Age Center, Chinese Historical Society of New England (CHSNE), etc. While I found some of these organizations on my own through initial web searches, I was directed to most of them through informant recommendations. I was able to recognize key community members by the frequency other informants mentioned them as ‘a good person to get in touch with’. As the summer passed, I found myself with a large list of contacts whom I would have loved to speak with if I had had enough time. But, due to the time constraints of my research, I was forced to focus on only a small fraction. This experience has taught me that with further exploration and time, I may develop a richer picture of what it means to grow old as a Chinese American living in Boston. This thesis is just a beginning.

Finally, I initially sought out health providers at Boston Medical Center (BMC) and Quincy Medical Center (QMC). In particular, I focused on Boston University’s Alzheimer’s Disease Center (BU’s ADC) and QMC’s Manet Community Health Center, a satellite community clinic of BU that serves the Chinese American community predominantly. However, I discovered that instead of the ADC, the dementia section of
the Framingham Heart Study (FHS), also part of BMC, was a better fit for participant observation. The group was smaller and covered fewer cases with more details, perhaps since the FHS has data tracing back a few generations whereas the ADC is just developing a longitudinal patient database. Also, one reason in particular I was interested in FHS was because they are collaborating with Chinese researchers to set up a similar longitudinal dementia study in China. Thus, I was able to glimpse how Alzheimer’s disease is seen in China from the clinical perspective and some of the trans-cultural challenges regarding clinical research of dementia.

I also found that instead of trying to shadow a physician at QMC’s Manet Health Center, which focuses on primary care, for my research purposes, it was better to focus on participant observation at a Chinatown adult day center (the JADC) and interviews with a neurologist at BMC, researchers at the Alzheimer’s Association, medical interpreters from QMC, and nurses who work with “forgetful” elders in Chinatown. These participant observations and interviews gave me targeted insight into how elderly Chinese Americans and their families interact with health providers. Also, they show how medical professionals involved in Alzheimer’s disease care think about dementia and in particular how they believe Alzheimer’s disease impacts Boston-area Chinese American families.

**Recruitment**

I recruited participants in two ways: using flyers and through snowball methodology. Overall, I found that fliers were useful only as a form of large business
card for people to get my contact information. For the most part, the individuals I interviewed got in contact with me after being introduced to my project and me through another informant, essentially snow-ball methodology. Thus, word of mouth and meeting people in person while spending time in Chinatown and Quincy was far more effective than posting fliers at key community centers.

There are two main explanations for this result. First, my fliers were in English since I was seeking to recruit English-speakers only initially. I do not speak Mandarin, Cantonese, or Toisanese, the main languages spoken within the Chinese American communities in Boston. However, although many individuals in these communities may speak English, they primarily speak a form of Chinese, and are more likely to read notices posted in Chinese. For example, I noticed on one community bulletin board where I posted my flier, it was the only one written in English. Second, I think personal recommendations are more effective to start a relationship than a flier. I found that despite emailing certain informants regarding my research project, it wasn’t until they heard about me from someone else whom they trusted that they were more open to talking with me. As an outsider from an institution not heavily involved in the Chinese American community (like Tufts Medical Center for example), I needed more than an abbreviated flier to open otherwise private doors. However, as mentioned before, once I started talking to community members and getting to know Chinatown and Quincy on a personal level, I found most people very responsive.
Data Collection & Sources

The bulk of my data comes from official interviews and participant observation collected over the course of the summer of 2012. I interviewed ten participants for a total of fourteen interviews (four individuals I interviewed twice, see Table 1) and informally interviewed at least six others. As mentioned in the earlier section, although I had originally planned to interview a minimum of five people in each of my three groups (Alzheimer’s disease families, non-Alzheimer’s disease families, and community activists and/or health care providers) for a total of fifteen participants, I found a great deal of overlap between the groups as I started talking with people. Thus, most of the community activists and/or health care providers I interviewed also belong to the non-Alzheimer’s disease family group, etc. Also, although I was not able to interview as many families affected by Alzheimer’s disease as originally planned, I had the opportunity to observe and spend time with a group of “forgetful” Chinese American elders three days a week for over a month. This participant observation at a Chinatown adult day center (the JADC) has provided a valuable perspective that was at first missing from my research project: that of the elder her/himself.

Initially, I attempted to formally interview some of the cognitively healthy Chinese American elders with the aid of a medical interpreter who was also a nurse at the Day Center. However, after three attempts which fizzled during the consent process, I realized that the long, Chinese consent form was extremely off-putting to the elderly participants. They found it confusing, not fully understanding that this wasn’t a medical interview (the only time they had experienced such a consent form was in a doctor’s
office), or they balked at being voice-recorded by some strange outsider. I became close to each of these three participants through my later participant observation, and found that they were happy to talk with me casually after I spent more time with them. It was the combination of unfamiliar researcher plus long medical consent form that had stymied my earlier attempt to interview the elders.

When not interviewing participants, I filled my time with participant observation (PO). The two most important PO opportunities were my meetings with the FHS clinical research team and days at the Chinatown adult day center. For these two PO, I went multiple times over the course of the summer, for a more in depth experience. For example, I joined the FHS clinical dementia research team for their “dementia review” meetings every 2-3 weeks over the course of the summer. During these meetings, staff included 4-5 research assistants, the research director, and a neurologist. One meeting was with a larger group of FHS clinical staff including pathologists and a number of stroke doctors and two other meetings included a Chinese clinical research team who are seeking to construct a longitudinal clinical study similar to FHS in China. The FHS PO was important for understanding medical decisions and construction of Alzheimer’s disease from the biomedical clinical perspective. Also, it provided a good comparison for how biomedicine perceives Alzheimer’s disease cross-culturally here in Boston and in China.

On the other hand, over the month of August, I was at the JADC for the most part from 9:30am-2:30pm three times a week. There are 30 Chinese American elders who go
to this day center, and they range in their cognitive awareness and physical independence. The elders were divided into four groups, one of which I consistently sat with and joined in with daily activities such as coloring, learning English, physical exercises, and eating lunch. Since only one of the elders spoke conversational English, I was often accompanied by one of the English-speaking staff members who was familiar with the elders and whom I had spoken with extensively about my research project goals and needs. The elders in my group were mostly in initial stages of “forgetfulness” and were relatively cognitively unimpaired (as determined by a staff nurse). However, each individual was distinct in his or her deficits and degree of cognitive awareness, offering a broad perspective. Ultimately, I feel the opportunity of PO at the adult day center was better than short official interviews with the elders. This PO gave me a better idea of what their day-to-day lives are like. Also, as I became more familiar with them, they opened up to me more about their lives and even invited questions to help my research project. Overall, it was richer experience than what I had originally planned.

I also attended a number of community and clinical events as part of PO. Although, these were singular events such as talks, presentations, and celebrations. For example, I attended a talk by MIT urban studies professor, Tunney Lee, who is known for his contributions to the Boston Chinatown Master Plan, sponsored by CHSNE at the Boston Public Library. I also joined medical students, residents, and fellows for a general medical presentation of Alzheimer’s disease at BMC. I sat in on one of The Chinatown Coalition’s monthly meetings in which a public health survey of the Chinese American communities was reviewed (conducted by Tuft Medical Center’s Asian Health...
Initiative). I attended Chinatown celebrations for New Year’s and the August Moon Festival. Also, I enjoyed walking through a calligraphy and drawing exhibition at the Quincy Public Library that was put together with the efforts of Pete, an Asian Elders Outreach Worker, and members (young and old) of the Chinese American and Taiwanese American communities around Quincy.

Other sources of data for this thesis include what I learned during informal conversations with contacts. These conversations were vital for my understanding of the fabric of the Chinese American community living in Boston such as learning about the history of Boston’s Chinatown during a walking tour or speaking with a street vendor about her experience living in the area. Also, I spoke with various community organization leaders such as staff at the Boston Chinatown Neighborhood Center and Chinese Progressive Association giving me an idea of different Chinatown community outreach programs ranging from children’s health programs to ballroom dancing for elders. Finally, I spoke with two executive members of the Alzheimer’s Association Boston chapter, to learn more about how this national organization is involved (or not involved) with the Chinese American and Taiwanese American communities in Boston.

To supplement this data, I also conducted an extensive literature review focusing on medical anthropology theory such as explanatory models as well as research studies related to Chinese American experience of Alzheimer’s disease. Furthermore, I collected a number of local pamphlets, news articles, and videos that were aimed at the Boston Chinese American communities and discussed aging issues, Alzheimer’s disease, and
families. Finally, I read a number of oral histories of Chinese American women who grew up in Chinatown. A number were directly pertinent to my project such as one women who later was instrumental in setting up the Chinatown adult day center I spent so much time as a participant observer in. Others touched on doctor-patient cultural issues and how families interacted with one another, particularly grandparent-adult child relationships.

**Overall**

My field research evolved throughout the summer as I became more familiar with Boston-area Chinese American communities and came to recognize constraints on my research such as time limitations and language barriers. However, overall, I have collected a wide number of perspectives through interviews, participant observation, informal conversations, media, research literature, and oral histories. In this thesis, I attempt to knit together these perspectives into an in depth examination of how Alzheimer’s disease in an elderly relative affects family dynamics. The variety of sources and experiences aid in teasing apart the three main layers of perspectives: individual, interpersonal, and community, which I use to build my conclusions. Finally, the Boston University School of Medicine Institutional Review Board approved this thesis research. And, in order to protect confidentiality, names of people and places were changed.
CHAPTER 4: UNCERTAINTY IN ALZHEIMER’S DISEASE

Sitting on a grey-painted metal fold-up chair tucked into the corner of Stephanie’s cubicle at the JADC, I pushed some brown rice kernels off to the edge of my Styrofoam plate. The lunch ladies always gave me heaping mounds of rice next to equally large servings of meat stir-fry and steamed vegetables. During lunch, I would sit with Stephanie and listen to her stories about being a nurse, her observations of the elders under her care, and her own personal feelings about living as a Taiwanese American in Boston.

During this particular lunch, we were talking about how dementia or “forgetfulness” impacted the elders differently, especially when comparing superficial impressions with truly getting to know them. She felt Alzheimer’s disease had hidden qualities, sometimes positive and sometimes negative. “Things aren’t what they seem often” she mused. Alzheimer’s disease, like many neurological illnesses, is superficially invisible. At first glance, you would not be able to tell the difference between the elders sitting around faux-wood tables in this second floor room to the seniors who eat downstairs in the community room. Even after brief conversations with many of the elders, you might just assume they were older (one lady was 103 years old!), perhaps physically more feeble (the walls were lined with walkers) in comparison to the 60-something year old ladies who practiced Chinese fan dances in the first floor community room. Aging may mask or excuse memory lapses, behavioral changes such as “crankiness”, disorientation, and other signs of Alzheimer’s, blurring lines between what
is normal and what is not (Sun, Ong, and Burnette 2012). This invisibility of Alzheimer’s disease adds to the confusion and uncertainty surrounding it.

In this chapter, I analyze how various phenomenological expressions of confusion and uncertainty develop in part because of liminality within Alzheimer’s disease. Turner, a cultural anthropologist interested in ritual and performance, initially describes liminality as “coincidence of opposite processes and notions in a single representation characterizes the peculiar unity of the liminal: that which is neither this nor that, yet it is both” and “they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (1964; 1969). Within medical anthropology, this definition of liminality has expanded to refer not only to grey zones created by static categories and periods of disease, but also to encompass the paradoxes inherent in dynamic processes of chronic illness. For example, Little et al. in their analysis of cancer patient experiences characterize liminality as “an enduring and variable state...something of the nature of the subjective experience of illness” (Little et al. 1998:1490). Likewise, this chapter examines the multidimensional nature of subjective experience of Alzheimer’s disease within a part of the Chinese American communities of Boston. In particular, one recurrent question I will address is: where is the self in Alzheimer’s? I choose “where” instead of “what” since I feel the “self in context” must be seen as a single entity in order to represent the liminality inherent in Alzheimer’s. The Alzheimer’s disease self represents a fluid process rather than a state of being; a dynamic expression of lived experience tethered to a moment.
As outlined in the introduction, I am using Lock and Scheper-Hughes’ construct of ‘mindful body’ as a basic theoretical framework and roadmap. This chapter focuses on the “individual body” or “phenomenological sense of the lived experience of the body-self...the constituent parts...and their relations to each other, and the ways in which the body is received and experienced in health and sickness...” (Scheper-Hughes and Lock 1987:7). In Scheper-Hughes & Lock’s description of this first body in their model, they compare conceptions of the body derived from Cartesian legacy of dualism with other more “sociocentric” and interdependent views of the self (1986; 1987). These two conceptions likewise are classified as western compared with non-western. In this chapter, I will demonstrate that the liminality of Alzheimer’s disease furthermore exists because of the hybridization of these different bodily conceptions within the Chinese American communities. The adoption of biomedical perspectives of disease fuses and flows into sociocultural Chinese perspectives of illness. Thus, many of the families and members of the community I spoke with found it difficult to sum-up in a few words what Alzheimer’s disease meant to them.

The lack of a useful Chinese (Mandarin, Cantonese, or Toisanese) translation for “Alzheimer’s disease” illustrates this uncertainty. On the one hand, the more commonly used, older Chinese term is tainted by stigma (and therefore avoided), and on the other hand, the newer term is overly biomedicalized to the point of being barely known even by majority of clinicians working with Chinese communities, let alone average families.

And then there’s an issue with the name of Alzheimer’s in Chinese [mhm]. Um, they said they are like retard- it’s the name in Chinese
has the same meaning as a retard! So, when you see the name and you call them ‘you have retard-disease’, or something, of course they will think of ‘oh, you’re a retard!’ So, that’s the name and that’s the issue of the name and they just changed it last year! Like officially changed it to like, um, the name Alzheimer’s is ‘degenerative disease of the brain’ in Chinese. So, so to clear it up, but people don’t really like this name, they don’t really understand is, what it really is is a degenerative disease. - Liz (Young Chinese American Medical Interpreter)

So, though, um, so that’s also a problem. I know that one of my colleagues at Peking Union Medical College that’s one of the things that she’s been trying to do is actually educate the medical profession. And you are not even just talking about the physicians you are obviously talking about the other health care providers in the system. - Celia (Chinese American Dementia Researcher)

During my time at the JADC, Stephanie referred to Alzheimer’s disease in Chinese as “forgetfulness” even though for her and the families I spoke with, memory was only a small part of the overall pathology. Instead, it was the context of memory loss, the voids that seeped into relationships and changed behavioral patterns, which seemed most important. Finding a single way of communicating this meaning of Alzheimer’s disease proved difficult. As I consider this issue of a Chinese term for “Alzheimer’s disease”, I am reminded of a quote in Scheper-Hughes & Lock. They state, “we lack a precise vocabulary with which to deal with mind-body-society interactions and so are left suspended in hyphens, testifying to the disconnectedness of our thoughts” (1987:10). Lived experience of Alzheimer’s disease within Boston’s Chinese American communities in many ways can be described as “suspended in hyphens”, with the surface
issue of uncertain terminology reflecting deeper depths surrounding the Alzheimer’s disease self.

_A ‘Unique’ Disease_

Alzheimer’s disease is a progressively degenerative illness shrouded in confusion and uncertainties. Many of these uncertainties arise in part from a Cartesian mind-body legacy of dichotomies persistent in biomedical and western cultures today. Schepers-Hughes & Lock argue that within the clinic, there has been a tendency to focus overly much on the material body at the cost of biopsychosocial consequences (1986; 1987). They recall a story of a medical student who wanted to know the “real” cause behind a woman’s chronic, debilitating headaches, noting, “the medical student, like many of her classmates, interpreted the stream of social information as extraneous and irrelevant to the real medical diagnosis” (1987:8). According to Schepers-Hughes & Lock, part of the legacy of mind-body dualism is the creation and persistence of other false disease dichotomies of real-unreal, visible-invisible, and normal-abnormal. In my thesis research, I found that many of the uncertainties expressed by the individuals I interviewed sprang from these dichotomies. Alzheimer’s disease paradoxically both embraces these dichotomies while also defying them. In this chapter, I highlight the most significant of these uncertainties that recurred in my interviews and how they relate back to issues of realness, invisibility, and normality.

I look at how the onset of Alzheimer’s disease often appears invisible, masked by normal aging. Consequently, there is confusion within Chinese American families as to
how and when to best care for elders. Many of the cognitive and behavioral changes that occur with dementia such as irritation, difficulty carrying out tasks, and poor hygiene may be dismissed as an elder’s aging self instead of disease process (Hinton and Levkoff 1999). In order to illustrate this point, I am providing two quotes which both bring up the visibility of stroke compared to Alzheimer’s disease:

And particularly because, ah, dementia and Alzheimer’s disease, specifically, is so insidious in its onset, so it’s not like a stroke. Like I think stroke you are not going to have these problems, you had a stroke. The fact that you have cognitive issues after the stroke is a residual of the stroke, but it’s a known event, it’s an obvious event. And I think the problem with dementia is that it overlaps with what we see in normal aging which is we do have a reduction in our cognitive facility with age. And, um, some people have it greater than others- within the normal range. So, how do you differentiate that, um, from, you know, something that’s really, um, signaling an imminent progressive dementia. I think that, that that’s probably unique to dementia as a medical disease compared to maybe some of these other ones. – Celia

I remember before he have the stroke, it didn’t dawn on me he had Alzheimer’s. Okay, because I used to take my parents to vacation every year..... So, at that trip I sat with my dad, and then he pointed out all the little houses and said ‘oh, you know, Mona you are from there, that was our little old village. Do you remember, you liked catching fish?’ Huh, but I have never been to China... Because you know my, I was, I said to my dad, ‘I have never been to China’, I said ‘I was born in Hong Kong.’ ‘No! you were born in London! Remember you were born in London, and then you went to Japan to study.’ I said, ‘Nooo.’ It didn’t dawn on me.

And I said, ‘Mom, why dad talk like that?’ My mom said, ‘Oh, he told me he wanted to quit cigarette, it was like a week ago’. I said ‘how you doing?’ ‘Well since then, he never have one’. I said, ‘does this have something to do with the cigarette? He got so confused!’ Like I said it didn’t dawn on me Alzheimer’s-it did not dawn on me. So I thought, hum. The next day, he was
okay. I said ‘Dad, did you remember you calling the little houses—' you know, I was living there?’ ‘You must be crazy!’ I say, oooh- I was crazy, alright. I said ‘Dad, remember you told me I was born in London?’ He said ‘No! No, you were born in Hong Kong! Under British Colonial.’ I said, ‘Yeah, under British Colonial! So, why did you say I was born in London?’ ‘No- I did not say that!’ I said oh, okay, so that mean I lie, okay. Maybe I was dreaming so I don’t remember. So, I’ll just, like, cover...

I call my brothers up and I say, ‘John, do me a favor, call the primary doctor, okay, dad has a, you know, episode’.... So, my brother call and doctor say, oh, he, he guessing is ‘oh, sounds like your dad is having early Alzheimer’s’.... Now, back in Boston, so, I took my father to see a doctor and then they said, they gave him some tests, but every single test they gave him answered ‘no problem!’....nothing wrong, they say, he’s fine... ‘I can’t really diagnose any of the Alzheimer’s, but from the behavior, okay, I can tell he maybe started.’ I say, ‘Okay, so what am I supposed to do then?’ He said, ‘Well, there’s nothing you really can do, just keep talking to him, reminding him, you know, of things’. – Mona (Chinese American Caregiver)

From the clinical perspective, as Celia argues, dementia is “insidious”; it skims the line symptomatically between normal and abnormal aging. It stealthily creeps up with no identifiable start point, no single biological “event” of origin such as neurologic stroke possesses. Likewise, Mona isn’t aware of any neurologic illness with her father until he has a stroke. Hinton & Levkoff, who collected narratives of Chinese American Alzheimer’s disease caregivers in Boston, suggest that for families onset is not recognized because of its overlap with cultural conceptions of normal aging (1999). After her father’s stroke, Mona’s perception of what is normal shifts. Suddenly, his sporadic moments of confusion take on a new ominous meaning. She consults her
siblings and the family doctor to find out more, however his condition remains invisible and something only “guessed” at.

I spent a number of mornings observing “dementia review” meetings with a local clinical research group. One purpose of these meetings was to review study participants’ exhaustive neuropsychological and clinical evaluations to determine the timeline of Alzheimer’s disease for each individual. I found it remarkable how much clinical detective work was needed to come up with a ‘probable’ or ‘estimated’ start of dementia. Again, there were no absolutes, only educated guesses to separate normal from pathology.

Onset of Alzheimer’s disease is a continuum, and thus, it is not truly possible to separate the normal and abnormal symptoms. Instead, they overlap and become a matter of subjective, qualitative degrees. For example, during one review, an individual showed poor naming and word generation. One researcher, Thomas, thought the scores from a college graduate should be higher and therefore reflected onset of cognitive impairment. However, Celia, who leads this group, brought up that the participant was an engineer. She argued, “I don’t want to be biased but my father was an engineer and all my father’s friends were engineers, and they had language issues...and they were good engineers!” They debated back and forth and finally decided to move on to results of the clock test. Thomas noted the participant had correctly gotten all the “elements” (hands, circle, and numbers) but took three minutes to draw it, perhaps indicating an issue. The attending neurologist laughed saying, “okay, maybe he’s an engineer”, referring to the fact that he
didn’t have as much difficulty on the numbers-based task of the clock. Thomas began to wonder if they could contact the family to determine if the participant had long-standing language difficulties. This discussion continued for a while longer without resolution. I think this conclusion is apt since resolution isn’t something elders with Alzheimer’s disease or their families can expect whether it is a clear indication of onset or even post-mortem ruling of Alzheimer’s disease. The visible-invisible and normal-abnormal dichotomies intercross leaving educated guesses and uncertainty.

Paradoxically, Alzheimer’s disease has gained notoriety in part because of this uncertainty and, as Celia in the quote above describes it, “unique” nature. According to the Alzheimer’s Association, “[Alzheimer’s disease is] the only cause of death among the top 10 in the United States that cannot be prevented, cured, or even slowed”. Part of the reason Alzheimer’s disease ‘cannot be prevented, cured, or even slowed’ is because biomedicine hasn’t fully grasped the nature of Alzheimer’s disease even at a biological level. Thus, the desire to recognize, to pin down the nature of Alzheimer’s, has gradually replaced the clinical obsession to find a cure. Celia’s team of researchers and the dementia review meetings are part of this biomedical imperative. Within Chinese American communities, Elliot et al note that a large focus of Alzheimer’s disease research likewise is figuring out ways for families to recognize Alzheimer’s disease early on as abnormal (1996). However, similar to Mona’s and her father’s experience as shown earlier, many Chinese American families do not necessarily see Alzheimer’s disease as a string of cognitive and clinical symptoms examined in dementia review
meetings but rather through interactions and behaviors. For Mona, recognition of onset becomes overshadowed by the practical question of “what am I supposed to do?”

**The Role of Stigma**

Stigmatization of Alzheimer’s disease as a psychiatric condition keeps it hidden while families seek to project appearances of “normality”. Studies have shown that Alzheimer’s disease within the Chinese and Chinese American communities is often considered a mental health illness instead of a neurological disease (Chiu and Zhang 2000; Elliot et al. 1996; Hinton and Levkoff 1999; Ikels 1998). Every person I interviewed also brought this issue up. For example, Celia states,

So, I, I think, um, I think though what they [Chinese Americans] bring with them is this bias that, uh, cognitive impairment in general is much more of a mental disorder.

Elliot et al (1996) also argue that stigmatization of Alzheimer’s disease as a psychiatric condition within the Chinese American community results in few members of the community seeking help outside the family for coping strategies and treatment options. From the clinical perspective this is problematic. From a broader perspective, it is another way Alzheimer’s disease experienced within Chinese American communities is invisible even to health practitioners.

Jackson (2005), in his examination of experiences of chronic pain, suggests that liminality and uncertainty play a role in stigmatization. He argues that the uncertainty of origin of chronic pain lying ‘betwixt and between’ the psychological and physical, its
chronicity, and its invisibility to others, including health care practitioners, all contribute 
to its stigmatization as an illness. He notes that liminality, embodying defiance of 
classification, is seen as aberrant, polluting, and threatening; “the main source of 
stigmatization in chronic pain is inappropriate pain behavior” (Jackson 2005:339). 
Likewise, Celia relates,

Well, I think it’s just that you are talking about some abnormal behavior and I think it’s just this principle that you are not going to air out the fact your elderly person whom you’re supposed to show ultimate respect to is having some abnormal behavior.

On the other hand, I find it interesting that in the case of my research, the division between psychological and physical (neurological) is purposely drawn in order to reduce stigmatization. Neurological disease is categorized as “normal” while psychiatric conditions represents the “abnormal”. This method of de-stigmatizing Alzheimer’s disease is similar to Sontag’s proposal that reification of illness, or ‘sanitizing’ it through representation as pure biomedical disease, may help reduce negative social connotations and expectations that illness as metaphor introduces (1978). However, Taussig (1980) argues that reification of illness is not possible. Illness, even as represented as biomedical disease, is not without social connotations and cannot be isolated from subjectivity. I agree with Taussig, but feel it is more complicated. In interviews of caregivers and health workers, I found that labeling Alzheimer’s disease as a “disease process” does appear to reduce some of the stigma connected with its name. For example, Mona noted with a smile that,
We are more westernized, so we feeling, it’s okay, it’s just a disease and stuff, he’s old, it’s okay, as long as he’s healthy, he’s happy, it’s fine.

Initially, it seems paradoxical when Mona mentions that her elderly father is healthy while also having Alzheimer’s disease. But, again, this represents the blurring and variability between normal and abnormal depending on context. For her and her father, Alzheimer’s disease has become part of his lived experience, a new normal. However, it does not change the negative connotations of behaviors considered socially inappropriate within the family. Families such as Mona’s continue to feel that such behavioral changes in their elders are private matters. Celia further reflects on this additional part,

So I think for instance, with the- the problems in the clinical situation with respect to dementia [right] is the fact that- one, there has to be, uh, already in place the understanding that dementia is a neurologic disorder [mhm] and not a mental disorder... but then on top of that, this idea that you, you keep close to the vest any behaviors that are not really seen as normal. Because you don’t want to embarrass or in any way show disrespect, ah, to your elderly, ah, family member.

As a result, stigmatization shifts from being about negative connotations associated with mental illness to more about breaking sociocultural behavioral rules by exposing Alzheimer’s disease family members to public censure. In Cohen’s ethnography of Alzheimer’s in India, he discusses how lived experience of old bodies is framed in “language of inappropriateness” (Cohen 2000). It embodies a pathology of the family rather than of clinical disease. Thus, old, irrational bodies cast moral judgment
and social censure on families, making such old bodies something shameful and to be hidden. Similarly, Alzheimer’s disease within these Chinese American families remains hidden.

Furthermore, the low awareness of Alzheimer’s disease in Chinese American families contributes to persistence of stereotypes such as the “healthy Chinese elder” and to the lack of support given to the community from outside. For example, I spoke with representatives of the Alzheimer’s Association (AA) in Boston and found that unlike other minority groups such as African American and Latino communities, there were no special programs directed towards the Chinese American community. Chinese American families rarely sought them out or used their helpline, so the AA had little information on what needs the community might have.

**Alzheimer’s Disease is an Illness**

Eisenberg et al defines illness as the patient’s subjective experience of pathology (1977). Much of the pain and loss associated with Alzheimer’s disease is embodied in the subjective experience. Likewise, the progression of Alzheimer’s, while invisible in many aspects, becomes notable through interactions and relationships, perceptions that color our subjectivity. For example, Biehl, Good, and Kleinman in their explorations of subjectivity in ethnography observe that it is “the dynamic and unsolved tension between the bodily, self, and social/political processes that, we hold, is at the core of subjectivity...Of particular concern are the inward re-workings of the world and the consequences of people’s actions toward themselves and toward others” (2007:15).
describes the body-in-the-world as interactive (“product and agent”) and in flux, but also composed of many different influences.

Furthermore, Biehl, Good and Kleinman argue that “a more substantial conceptualization of cultural experience is in order, one in which the collective and the individual are intertwined and run together and in which power and meaning are not placed in theoretical opposition but are shown to be intimately linked in an intersubjective matrix.” (2007:14). In this instance, experience, individuals, and reflexivity all are complex compositions with many influential elements. In turn, these three multifaceted conceptions weave together and result in what they describe as the “fractured nature of subjectivity”. I will continue to explore more integrated issues of subjectivity in the next chapter, however, for this chapter I want to focus on how it relates to the main two individual-collective bodies impacted by Alzheimer’s: the elder and caregiver.

As introduced earlier in this chapter, much of the confusion, uncertainty, and invisibility of Alzheimer’s disease are due to difficulties distinguishing between what is disease and what may be normal changes in personality due to age. Celia, Thomas, and the neurologist’s debate about engineer’s personalities and poor language skills illustrates the murkiness surrounding Alzheimer’s disease “deficits”. When talking with dementia researchers from China, Celia emphasized the importance of the subjective and qualitative observations as key for understanding the nature of Alzheimer’s disease. She argued that quantitative and statistical data such as time to complete a neuropsychological
test or scores become meaningless without the subjective context. Did a person complete the word recall slowly because of pathological deficit or is it part of who they are normally? Likewise, Stephanie observed that among the elderly and their family members there is the initial assumption that negative behaviors are a reflection of personality in old age,

Umm, yeah, because I think for most of people, they think once you get older, of course you will be like forgetful and some of them, umm, this disease process will cause you to have more irritation episode, [mmhm] you’re more easily to get angry, or like verbal abuse and those kinds of symptoms. [mmhm] Um, it’s hard for the clients themself or the family to be aware that it is a disease process. They will think ‘oh that’s normal’ and ‘that’s what their personality is’. [mm] So, it’s hard, um, for you to ask them.

Another point I want to bring attention to is the variability in the ways Alzheimer’s disease interacts with personality. First, while significant research attention is focused on negative behavioral changes since these are the greatest source of concern for families, these changes may hide surprising aspects of personality (Ikels 2002; Liu et al. 2012). In order to illustrate this variability, I will draw from my field notes of participant observation at the JADC to introduce a few of the elders I came to know.

“They are surprising”, Stephanie said. “How so?” I asked. “His handwriting is so beautiful. I noticed it the other day when we were doing word exercises. He must have been a teacher or professor. Highly educated. The letters were so elegant.” - excerpt from JADC field notes
Stephanie is describing Aba, a tall, wiry man with closely cropped, thinning grey hair, stooping shoulders, and an easy smile. Out of all of the “clients” in the JADC, Aba’s Alzheimer’s disease was most apparent. He was easily confused, had difficulty speaking cogently, and perseverated behaviors such as clapping. In particular, he had difficulty following directions such as keeping his hearing aids in place until it was time to go home at 2pm. Stephanie patiently worked with him to remind him to wear the hearing aids. Otherwise, communication with him, already difficult, became almost impossible. Furthermore, the hearing aids were expensive and his tendency to remove them had apparently resulted in more than one lost pair, to the family’s dismay. Often when people left the room, Aba would get up to leave too, thinking it was time to go home. He would wave at me and say “bye! bye!” before turning towards the door. The caregivers would quickly guide him back to his chair, pointing at the clock, and explaining it wasn’t time yet to go home. This would happen more than 10 times an hour until the van home arrived at 2pm. But, Aba’s severe Alzheimer’s disease obscured inherent talents such as his elegant penmanship that in other individuals may have been recognized earlier.

On the other hand, sometimes personality masks Alzheimer’s disease that unless one knows the individual well, may remain invisible. I called the elder I was closest with at JADC, Grandma. She reminded me a lot of my own maternal grandmother who had passed away at 93 years old when I was in seventh grade. Like my real grandmother, Grandma took me under her wing. She made sure there was always a spot available next to her, and when I would arrive in the morning, she would pat the tablemat and urge me
to “sit! sit!” Grandma, was originally from Taiwan, so she spoke Mandarin Chinese instead of Toisanese or Cantonese like the majority of JADC elderly, making her somewhat of an outsider. Also, in order to communicate better with her Chinese American grandchildren, she had learned some English and readily engaged me in conversation. She also helped to interpret for me amongst the other elderly at the table, keeping me in the loop whenever Stephanie could not be near to help me.

We would talk about Chinese food. How I loved all the different vegetables and sauces, and how she would make “Chinese pizza” with her granddaughter when she was home from college. She also took care of me during the afternoon Cantonese Bingo sessions. The elders would use pennies to bet on their boards. I think the first time I played, Grandma saw a chance to double her penny loot by betting for me and thus having twice the chance of winning. Unfortunately, I was still learning Cantonese, so my understanding of the rapid-fire number announcements put me at a significant disadvantage. Grandma didn’t bet for me again after that time, but she always kept an eye on my board in case I missed a called out number. Without her help and inclusiveness, I probably would not have been able to interact with and get to know the elders at my table. By the time I finished my summer research, all the elders at my table would help me keep an eye on my bingo board, and I was even able to win twice.

In all my interactions with her, grandma appeared perfectly normal. She was quite old, in her late 80’s, but her eyes always twinkled with intelligence and warmth. As far as I knew, her deficits were mostly physical. She told me she used to walk around
Boston Common in the mornings with a friend, but now, she was too physically tired to venture out much except when family visited. Over the course of the summer, she became enrolled in the dinner program, in which a take home meal was prepared for her, indicating that she was having difficulty with daily living tasks.

It was not until the end of the summer that I realized she had Alzheimer’s. It was subtle at first, we would repeat cooking conversations, with her asking me questions that I had answered the previous day and the day before that. In my mind, I didn’t dwell on it since it seemed easier to believe it was due to her limited English and my limited Mandarin. However, one day we were talking more about walking around Chinatown, and she casually mentioned that she didn’t venture out as much anymore because she’d become confused. With some gentle probing questions, I discovered that the main reason she had stopped her morning walks wasn’t due to physical infirmity but rather because she had started to get lost on “familiar” streets, leaving her feeling distressed and anxious about leaving her apartment complex. Still, she mused, “I’m lucky. I speak English”. Alzheimer’s disease was slowly limiting her world, but despite her inner anxieties, she outwardly remained hopeful and upbeat. It was in the context of Alzheimer’s disease where I truly recognized how strong Grandma is.

Briefly, I want to highlight a second way variability characterizes Alzheimer’s disease illness experiences. This time, instead of focusing on the elders, I will look at caregiver experiences. Variability compounds uncertainty among caregivers. Over time, Alzheimer’s disease demonstrates a progressive decline, often characterized as a ‘loss of
self” (Herskovits 2009). But, it was the day to day or week to week fluctuations in personality of elders which both pained and gave hope to the caregivers I interviewed.

For example, Celia explains,

Yeah I think so [approach loved ones with uncertainty]. Because you don’t know who you are going to see today. And I think that’s obviously more towards the end stages of the disease, I think, you know. I think at the beginning stages, I- I’m going to imagine that there’s some, a little bit of denial that goes on in the hopes that, because the symptoms aren’t as evident all the time, that maybe, you know, it won’t be as bad.

And because there is variability, you know, you always hear about the good days and the bad days. So, I always wonder if sort of, you know, when people, for instance, if their parents are in the nursing home, I wonder if they go in with any trepidation. Or, or hope! You know, right, either way.... ‘I hope this is a good day... let it be a good day...’ Maybe they get to the point where they pray it will be a good day, you know?

The second quote captures this case of ‘uncertainty’. Prior to visiting elders, Celia considers the trepidation intermingled with hope felt by family as to whether their loved ones would be the ones who had raised them compared with those altered by dementia. One daughter-caregiver I spoke with, Lin, described her father’s personality as meticulously tidy, taking care of his clothing with pride. However, she recalled that on ‘bad days’, he would have stains on his shirt from spilled meals, his cotton pants would be rumpled and smelly, and most importantly, her father would not seem to notice or mind. Each time she visited, she hoped to find the father of her memories, proud of his appearance, self-aware; she dreaded and feared this other dementia-stricken father who

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betrayed her memories with his own self-forgetfulness. Thus, it was the variability and uncertainty of her father’s state that became so disturbing to her.

Constructions of Self

In the previous section, I separated elder and caregiver subjective experiences of Alzheimer’s. Much of ethnographic literature also separates these two narratives. However, there is an underlying struggle over ‘identity’ that characterizes both types of ethnography. Specifically, there is tension when the caregiver is used as the main narrative voice, which in turn denies elderly Alzheimer’s disease subjects any ‘self’. For example, in narratives of Chinese American caregivers from Boston, Alzheimer’s disease selves are described as “dead alive loved one” and “less than fully human” (Hinton and Levkoff 1999). However, paradoxically, the caregiver’s self or identity may become increasingly defined by their caregiving obligations even as the subjects of their care, the elders, lose their ‘identity’ in the eyes of the caregiver. Similarly, Cohen describes the loss of identity in Alzheimer’s disease as connected to issues of dependency. I also found that during interviews and participant observation, caregivers described Alzheimer’s disease as a loss of self, sometimes characterizing it as a process of infantilization or dehumanization. For example, Liz vividly recalls her childhood conceptions of elders with Alzheimer’s:

Because people in Hong Kong really mess that up, I really think that as Parkinson’s, like drooling, involuntary movement, like forgetful, wandering around the street, there’s something like, because when you watch TV it’s, um, they really picture Alzheimer’s patient or Parkinson’s patient in the same-like figure-
wandering, drooling, you sew your name, the family members will get a piece of cloth and write your name and your telephone number and your address down and sew it inside. [oh, so if you get lost you can..] Yeah [...be found again] Yeah, ‘cause we don’t have the medical band or something, you know the medical bracelet that has your info and stuff (coughs). We don’t really have that, but rather they really sew it to every single layer of the cloth, the clothing, which works! Yeah. So, so that’s the picture of me, growing up in Hong Kong and seeing how people picture Alzheimer’s.

Her image of Alzheimer’s disease is jumbled together with other neurodegenerative diseases like Parkinson’s, and the way she describes labeling elders reminds me of parents labeling their children’s clothes before sending them to camp or school. It implies an inability to be responsible for one’s self. While I would consider this loss of ‘independence of self’ disturbing, among many of the individuals I interviewed, the idea that elders become dependent and childlike is not abnormal. Hinton & Levkoff (1999) also observed this among the Chinese American caregivers they interviewed. They suggest that it “may be due in part to traditional Chinese views of old age as a time when some people may become more confused and childlike” (Hinton and Levkoff 1999:463). Ikels also brings up the point that in Confucian tradition, independence is not necessarily linked to adulthood as it is in Western cultures but being “responsible” for others is a “marker of adulthood” (1998; Kertzer 1989). During old age, it is seen as normal to rely on adult children (Ikels 1998). On the other hand, I learned that the loss of self as a process of dehumanization to a “body” is very upsetting for family members. I was struck by one comment Celia made to me about being able to
tell which families were Alzheimer’s disease families when she called them to ask about postmortem brain donations. She said,

> And I, I realize that they said their goodbyes a long time ago, they had to. Cause the person who’s left isn’t the person that they had that connection to. So, I think the body still remains, and I think the memory of that person still remains, but by the time of death it seems like a lot of their mourning process has already been worked through.

Scheper-Hughes & Lock discuss Oliver Sacks’ clinical narratives about neurodegenerative diseases and loss of “humanness”. They relate, “Sacks’ message throughout his poignant medical case histories is that humanness is not dependent upon rationality or intelligence-- i.e., an intact mind. There is, he suggests, something intangible, a soul-force or mind-self that produces humans even under the most devastating assaults on the brain...” (1987:17). Ikels, in her review of Confucian philosophy of the self and its impact on Chinese American perceptions of dementia, notes that “the heart/mind [xin] encompasses a dual concept of the self that is broader than ‘one who thinks rationally’ and symbolically locates it outside the brain...correct performance of social roles serves both as the means of developing the self and as a demonstration that the self is still ‘there’” (2002:249). Similar to Ikels, in the above quote, Celia points out that it is the loss of interpersonal connection that dehumanizes the Alzheimer’s disease self into a body.

> Alzheimer’s disease elder and caregiver experiences are interdependent. As noted earlier, Biehl, Good, and Kleinman write that subjective experience is where “the
collective and the individual are intertwined”. Cohen also notes construction of meaning of Alzheimer’s, such as “an embodiment of anxiety”, requires two bodies (Cohen 2000). Likewise, in Alzheimer’s, the self is constructed between elder and caregiver. Each voice represents a part of a whole, and it is their relationship that constructs the self. This is similar to how Scheper-Hughes & Lock describe complementary holistic thinking “in which the relationship of the parts to the whole is emphasized” (1987:12). They give an example of Chinese yin/yang cosmology to explain how dynamic equilibrium characterizes cosmic relationships and, I believe, the elder-caregiver relationship. The Alzheimer’s disease self therefore exists within such a dynamic equilibrium, and disease and abnormality become evident when the relationship becomes disharmonious. I will explore specific examples of this in the next chapter.
CHAPTER 5: IN RELATION

In this chapter, I examine how Alzheimer’s disease is experienced through relationships, in particular the elder-caregiver relationship. This chapter is organized into three major sections, values, conflicts, and harmony, which encompass central themes that emerged from my interview analyses and participant observation. In the first section, “values”, I discuss expressions of conscientiousness and family devotion, recurrent themes. Both of these themes are grounded in Chinese cultural ideals, specifically, ren (compassion or humaneness) and xiao (filial devotion). In the second section, “conflicts”, I describe how Alzheimer’s disease in the context of these values leads to conflicts or social disturbances within Chinese American families. Finally, in the third section, “harmony”, I look at some of the ways families seek to preserve harmony in the face of social problems within the experience of Alzheimer’s.

This chapter is loosely based on Scheper-Hughes & Lock’s second body, the social body (1987). They state, “social relations are also understood as a key contributor to individual health and illness. In short, the body is seen as a unitary, integrated aspect of self and social relations” (1987:21). I argued in the last chapter that the Alzheimer’s disease body-self experientially exists between and within the Chinese American elder-caregiver relationship. This social relationship is what comes to create humanness in the face of “de-humanizing” Alzheimer’s disease. Some of the questions I explore through examples are to what extent or how are cultural ideals embodied in the social relationship formed through Alzheimer’s disease? Also, what might reflection on personal
experiences reveal about the nature of the relationship between cultural ideals and the values or themes expressed by family members, health care providers, and elders?

**Values**

“If the ancient Chinese perception is right that we are not born fully human, but only become so as we cultivate ourselves and our relations with others -- and that we must do so in a threatening world where things often go terribly wrong and where what we are able to control is very limited -- then caregiving is one of those relationships and practices of self-cultivation that make us, even as we experience our limits and failures, more human.”

- Arthur Kleinman from *Caregiving: the odyssey of becoming more human* (2009)

In the analysis of elder-caregiver and Chinese American family relationships, two main values or themes emerged again and again from interviews: conscientiousness and family devotion. These two values are interrelated and grounded in Chinese cultural ideals of ren and xiao. Ren, a Confucian ideal expanded upon by Mencius, may be understood as compassion or humaneness (Hagen 2007). SUNY Plattsburgh’s website on terms in Asian Philosophy breaks down the various meanings of ren within the Confucian Analects and Mencius (2007). It may mean “to see things from other people’s perspectives, and then to do one’s best for them with that in mind” (Analects 6.30), “to be human” (Mencius 7B16), “taking on a burden on behalf of those loved” (Analects Zengzi), and “a duty to act appropriately in relation to others” (Peerenboom: 44) (Hagen 2007).
The ideal of *ren*, implying compassion and benevolence, is closely related to the theme of conscientiousness within my thesis research. During my participant observation at the JADC, I noticed many acts of benevolence among the elders and well as towards myself. For example, Grandma’s care of me during lunchtime such as her making sure I always had a napkin and piece of fruit even if it meant giving me hers. Similarly, the elders looked out for each other, such as when Aba, in confusion, would get up to leave too early, the other elders would speak up, warning the health workers, and would reach out, urging him to sit down again. During my interview with Pete, an Asian American elder services outreach worker, he enthusiastically described his job as fulfilling stating, 

But, when you work in the community... and ah, you find out (pause) ah, if you can help the others [mm-hm]. You know, with your skill, your knowledge, and your experience [hm]. And, that is better than anything on earth!

For Pete, it was the human connectedness and being able to help others that are at the core of his elder services position. Pete felt similarly to the message within Kleinman’s quote at the beginning of this section. He believes that his role as a community caregiver was part of his own self-cultivation. Tu Wei-ming, a Confucian humanist scholar, writes about self-cultivation and ‘being human’ another way, “Concretely, for Confucians, in learning to be human beings by cultivating the capacity to empathize with the negative feelings of one’s closest kin -- namely, by directly referring to our own hearts and mind -- we should understand the reasonableness of the following dictum: ‘Do not do unto others what I would not what others to do unto me!’” (1985). The theme of conscientiousness
not only encompassed acts of compassion, but also equally important it meant inaction as a form of benevolence. In other words, it meant not doing or saying something that would put someone else in an awkward position or would require someone to do something for you. In this sense, it created a screen between what was appropriate public and private social behavior. For example, Celia noted,

That’s right! So, you don’t even tell them in the first place because even though you are not asking for help, [mhm] by sharing that you are in a situation that needs help, [mhm] you’re then putting them in a position of needing to then offer help.

Stephanie framed this issue in terms of elder-neglect when I asked her about privacy boundaries and what kinds of family issues Chinese American elderly felt was okay to speak about with others. She replied,

Both [facts and emotional stuff]. So, for example, if like my children is not treating me well of course I won’t willing to share this with others, my friends. So it’s both, either the emotion or if the childrens like outstanding or not, both. So, if it’s a little bit negative they won’t be that willing to, you know, share with other people.

The issue of what was appropriate to discuss publicly compared with privately is related to burden. Being conscientious meant not placing obligations of action or feelings of burden onto those around one. For example, Celia elaborates,

So, my own experience is that you- you- you don’t talk about anything that’s really, um, private and part of the reason, particularly when you have difficulties going on is that you don’t want to burden someone else with your problems. There is that aspect of it as well. Um, you know, I always think of... the Chinese way is always worrying about the impact on the- on the
person on the other person, right? [sort of conscientious?] Yeah. And so, it’s, you know, it’s, everybody has their burdens. Everybody has things that they are dealing with, you don’t want to burden someone else with yours- cause they already have enough [mm, right]. So, I think there’s that part of it- there’s a consideration, I don’t know that Americans always understand that part [right], but there’s actually a very strong... you know, aspect of being considerate to the other person.... that comes with sort of not sharing a lot of your, um, you know, difficult.

Not wanting to burden or cause worry for those around one was a common feeling expressed by the Chinese American elderly living in Chinatown & Quincy, according to Pete the elder services outreach worker I interviewed. Often times, burden came with economic costs for families. It was more than moral endurance that both Kleinman and Hinton & Levkoff use as a theoretical construction for caregiving narratives (Hinton and Levkoff 1999; Kleinman 2012). For example Pete described why many elders put off seeking medical care of Alzheimer’s disease issues,

They don’t want to go to see the primary physician. [mm-hm] Because they feel like ah, “well, ah, if I go to see the doctor and my children have to take a day off, they losing their income, and ah, and I been telling them I’m fine, I’m perfectly fine.

Stephanie also mentions how elders try to be considerate of family. She notes, “they don’t want to have to give the children troubles by you know calling them all the time, complaining all the time, something like that”. Alzheimer’s disease creates a situation where elders don’t want to burden or communicate problems to family, resulting in distancing of relationships. Mok et al also found this in their interviews with elderly Chinese Americans with early-stage Alzheimer’s disease. They noted that elders felt a
loss of intimacy with family members while protective behaviors increased (Mok et al. 2007). Even from the perspective of health care professionals, such as Stephanie, families were protected from burden,

So, and, it just really depends, we just do our best not to upset the family- because a lot of family members they got upset sometimes, they think that um it’s like come on they don’t want to hear the bad things about their own parents. So, we don’t really like call every time, we do our like documentations you know everything

Closely related to the value of conscientiousness and cultural ideal of ren is a theme of family devotion. Ren encompasses the five cardinal relationships: ruler-subject, parent-child (xiao), husband-wife, elder brother-younger brother, and friend-friend (Ikels 2002). Xiao, or filial devotion, not only refers to providing support for parents, but also doing so in a respectful way (Ikels 2002). Often, I found echoes of this ideal xiao being expressed in terms of moral responsibility, respect, or care for elders. For example, Celia related themes of consideration and privacy with respectfulness, stating, “you keep close to the vest any behaviors that are not really seen as normal. Because you don’t want to embarrass or in any way show disrespect, ah, to your elderly, ah, family member.” She told me a story of her mother-in-law who was showing signs of dementia. In particular Celia was concerned about her siblings-in-law not taking away the elderly woman’s car keys and even letting her drive their teenage children to music lessons despite the fact she would become easily confused and disoriented. Celia saw her in-laws denial as a form of not wanting to show disrespect for their elderly mother.
On the other hand, Stephanie mentioned her childhood education in Taiwan, “so it’s like, it’s moral, like um you shouldn’t let go of your loved ones, you have to try everything, and if... if you just let go, it’s just ah kind of like- disrespectful... yeah.” The notions of respect and morality in the context of family devotion are part of public or social guidelines. According to Lee & Hong-kin, filial devotion involves reciprocity but also “keeping the family’s honor by one’s achievements” (2005:190). Likewise, in their analysis of Boston Chinese American Alzheimer’s disease caregiver narratives, Hinton & Levkoff note “the Wong’s story and those of several other Chinese-American families we interviewed focused on managing old-age disabilities and on the moral behavior of family members” (1999:465).

With regards to responsibility, interviewees focused on management and family cooperation in care of elderly. Often, this meant delegating specific tasks and in some circumstances, extended family such as in-laws stepped in to fulfill responsibilities. For example, Stephanie recalled,

No, usually it’s direct- like their son or their daughters... [natural son or daughters] Yeah, but we have some cases that, um, I think the sons they are all busy at work, so always it’s the in-laws taking care of the elderlies. So, one in-laws is in charge of like, um, paying her rent or something like that and the other in-laws is in charge of like medical appointments and all. So, when you know which issue you have you call which in-laws.

Thus, family devotion expressed through responsibilities and daily management was often organized within the available family members. I found it interesting when one caregiver, Mona, noted that her father, who has Alzheimer’s disease, loves dim sum; so
she and her siblings (seven of them) coordinate to divvy up the weekdays with different siblings accompanying their elderly father to dim sum every day. Stephanie & Liz both observed that coordination often followed a gendered hierarchy with sons acting as the point person. In part, Stephanie explained this tended to be based on some of the elders’ preference for their sons over their daughters,

Umm... So, that’s similar to the- those that I’ve been telling you because they care more about the son so, at that point, if that’s the case in the family, son will become the one that make the decision compared with others and girls. Yeah. And usually, it’s the oldest son like make most of the decisions.

So, for example, um, like here if... a couple of them, if I have to talk to I talk to the biggest son ‘cause he will ask the other siblings to do the things or you know he’s in charge to ask the other ones, this one to do this the other one to do that, and they will listen to him.

However, other than Pete, most of the caregivers I interviewed were in fact women. It was interesting to note that in their families, the main caregiver or point person for their elder’s health issues tended to be more dependent on proximity, availability, and financial stability. This point is important because, often in the health literature it is simple to make the leap from cultural ideals to stereotyped behavior or pictures of Chinese American caregiving relationships. However, when looking at personal experiences of these caregiving relationships, it becomes evident that the picture is much more complex. Cultural ideals, political-economic pressures, and physical limitations all were embodied in the nature of caregiving relationships, at times creating
conflict. For example, Lin, a caregiver for her mother, who has late-stage Alzheimer’s disease, described how she came to be in charge despite the fact that she is the only sibling who lives in the east coast. She noted that her eldest sister was in her seventies with a husband in his eighties, and physically could not become the main caregiver. Her younger sister had recently lost her husband and used his life insurance money to pay for assisted living near her home for their ill mother. However, Lin related that her younger sister didn’t fulfill her promise to visit their mother regularly due to emotional distress. Their mother, unable to remember the younger sister’s father had passed away would always ask about him, which upset the younger sister. Lin also vaguely mentioned a third sister, but she appeared to be disconnected from family decisions, so the responsibility fell onto Lin to fly her mother across country from California to Boston to care for her at home. In their study of Canadian Chinese Alzheimer’s disease caregivers, Spitzer et al, argue that there is a cultural expectation of women, daughters in particular, being responsible for daily caregiving tasks of elders with Alzheimer’s disease (2003). Such gendered expectations contribute to caregiver stress and fatigue, particularly in immigrant Chinese women (Spitzer et al. 2003). Expectations within families, created in part from residual sociocultural ideals of ren and xiao, is one source of conflict I will explore in the next section.

Conflicts

In this section, I will review the conflicts pertaining to Alzheimer’s disease experiences which families and caregivers focused on the most. I found these conflicts to
fall under overlapping categories of generational expectations, independence vs.
dependence, burden vs. responsibility, home vs. institutional care, and “traditional” vs.
“Americanized” ways. While I recorded numerous examples of conflicts or social
disruptions within these categories, given space restraints of this thesis, I will highlight
only some of the most poignant and recurrent stories I heard.

Examples of generational expectations involved stories of lost communication,
inability to relate culturally, and a sense of displacement. Lee & Hong-kin look at elderly
expectations of reciprocal support of younger generations, stating, “many older persons
had a strong perception of reciprocity of care, and felt they should be taken care of by
their children and to try to live under one roof is often regarded as the most appropriate
choice for them...they need somebody to be concerned for them...” (2005:201). Those I
interviewed mentioned this sentiment frequently. For example, Stephanie noted “like, for
Chinese they will think- a lot of them- like for older generations they will think that ‘oh,
my son have to take care of me when I get old’.” Elderly expectations of care often were
simple concern shown by children inquiring after their wellbeing or calling to check up
on them regularly. Sarah, the director of the JADC, recalled how some elders under her
care would wait for phone calls from their children, becoming more upset and frustrated
as time passed with no word. She emphasized how she would speak with elders,
explaining to them that it wasn’t lack of concern by adult children but rather other time
constraints such as full-time jobs and children which made it difficult to call regularly.
Also, she would encourage the elders to be more proactive, urging them to make phone
calls to children themselves when they missed them, instead of expecting family to call
them. Sarah perceived expectations based on ideal social and moral guides of child-parent behaviors to be negative and outdated. Stephanie spoke of her own family mentioning this as well,

Yeah, like, my grandparents, they’re- my grandma in Taiwan- she... yeah, cause, I don’t know if it’s that generation or what? They’re expecting the children or grandchildren will call them all the times and sometimes they just hold it and they just counting how many times my children have called me for the past... past month or something like that [mhm]. And they won’t say anything, they won’t complain like, they won’t complain directly to the person ‘why you don’t call me or why you don’t contact me’, but they hold it up in themself and feeling oh, is there something wrong or they just complain to other, like other friends or other children like ‘why this one doesn’t call me’, like that...

On the other hand, Pete describes generational conflict in the households of elderly Chinese Americans within the community as a combination between cultural-generational differences but also a gradual displacement of elders from active participants within families as their health erodes,

Especially in the ah Chinese way, they love to live with their family member. But in then, aah, from my past experience, I also notice that (pause) when they live with their- say for example, when they caring for the younger generations. [mm-hm] And everything work out very well. [right] Theey, caring for the younger generations, and then when they go to school, and aah, so their duty has been shifted, instead of caring for, for the, the, ah, the grandchildren, [mm-hm] Now, they shift their job into doing some household chore [I see]. Meal preparation [mm-hm]. Aaah, some of time, sometimes they do some laundry. And, ah, so it’s, it’s still good. [mm-hm] But, then, when (pause) they getting older, aaah, the, physical... activities slow down, the motions slow down. [mm-hm] And, ah... so, they will come across say... when... when they want to watch the TV, maybe the younger generations
doesn’t like it. [aah] So, [they can be protective of their cartoons] yeah, [laugh] they, they, they, can create a little bit of conflict.

He explains that smaller spaces of multigenerational households inevitably lead to conflict whether over TV time or necessity of frequent trips to the bathroom (vs. teenager hair care time). Elders begin to feel helpless and isolated as grandchildren grow up. Mok et al also found that as family communication broke down, Chinese American elders with Alzheimer’s disease began to perpetuate silences feeling that “they were considered useless” (2007:597). Consequently, Pete urges the elders who come to him to change expectations and consider living independently. He argues that by living independently of adult children and grandchildren, Chinese American elders not only have their own space on their own time, but also family interactions become more special and meaningful for both elders and grandkids.

In the context of Alzheimer’s disease, however, independence vs. dependence isn’t always a choice for elderly Chinese Americans. While as Ikels points out, there is a cultural expectation that Chinese elderly will become more dependent as they age, the reality isn’t always positively thought of, “old age when one is like a dog, forced to beg for one’s food and lucky not to be kicked” (2002:249). Often elderly while accepting care still want to be in charge of decisions about their lives such as when to seek medical help or social services. For example, Stephanie describes a common experience of Alzheimer’s disease among the elders under her care,
They think they take showers by themselves everyday [mmhm] but it’s obvious for us to notice that everyday maybe she wears the same clothes everyday [mm], without changing, and we can smell it. But, the elders themself thinks that ‘oh, I wash my clothes-hand wash my clothes everyday [mm], and I take shower everyday why you have to telling me that I am not doing it right’ [mmhm]-that kind of, you know, concerns comes up, comes up a lot, yeah. So, it’s hard like when they live togeth- ah, they live alone. And no family member is able to, you know, visit them every day [mmhm], and you just notice that problem and they refuse to receive any care.

Furthermore, Lin, a caregiver for her mom, notes,

And she has lost her ability to choose, very simple things, do you want to drink water? or do you want to- very simple things- eat now or later? Cannot make the choice. So, I don’t ask her anymore, ‘oh, let’s go eat’ you know, because she gets really-pretty upset, because it hurts her ego, that she cannot make the choice, if if you keep asking her, then she gets angry.

I hope to illustrate through both Stephanie’s and Lin’s quotes that independence and dependence are carefully balanced within elder-caregiver relationships. Significant dependence is perceived as negative for relationships, often frustrating for both elders and caregivers. Independence is seen positively in most circumstances; however, it also acts as a barrier for care of elders with progressive dementia. Thus, Alzheimer’s disease often tips this balance between independence and dependence, with families seeking to re-establish new equilibriums, restoring harmony in relationships.
Harmony

During early-stages of Alzheimer’s, many families often glossed over elders’ health problems and incorporated various ways of compensating until social and behavioral issues could no longer be handled within the family. For example, Lin described an interaction between her son and mother before she realized her mother had Alzheimer’s. Lin’s mother usually drove herself to her Buddhist temple every week, however one week, Lin’s son offered to take her. He started to drive, following MapQuest directions, but Lin’s mother became confused and agitated. Lin recalls the result,

And then she said ‘it’s wrong!’ and got really upset, so my son had to follow her direction, of course got nowhere, and eventually they had to come back.

Even though Lin’s son knew his grandmother didn’t know where she was, he followed her driving directions. Other ways of compensation included setting up routines and visual cues as evidence for confused elders. Routines revolving around particular times of day were a frequent coping strategy to alleviate angry outbursts or agitation. For example, Stephanie consistently worked with Aba, who often correlated meals with taking out his hearing aids, to instead link 1 pm with an OK time to take them out. As Alzheimer’s disease affected elders more severely, caregivers needed to spend more time working with them. Two caregivers I interview, Mona and Lin, both described their care in terms of “conning” and “coaxing”. They felt there was a certain level of trickery involved in taking care of daily tasks such as showers. Lin describes this,
My sister hired a professional to bring her here. Kind of con her. Well, even taking a shower, we have to kind of con her [laughs], like, really! yeah.” - “I just have to be a con person, I don’t know.” “Because, you- I cannot say it smells. That’ll make her really angry. [laughs]” “tiny step tiny step in order to take a shower”.

Likewise, Mona would lure her wandering father into her car after he “escaped” several times in winter without a coat with promises of “char siu” and family brunch at his favorite dim sum place.

He keeps smiling, doesn’t say anything, he keep looking at my car, he doesn’t recognize me. So, I take off my coat and gave it to him, and say ‘dad, it’s really cold! Do you want to go in my car?”’ He keeps staring at my car. And I say, “you know we always go to dim sum? you know right? you like char siu ba” “yeah, I like char siu ba” “yeah, okay, so you want to go to dim sum? did you want to go in my car? to dim sum?” “yeah, I can go in your car”.

I heard other stories bordering closer to desperation from Liz during her time as a Chinese medical interpreter at Quincy Medical Center Emergency Department (ED). She recalled one elderly gentleman with Alzheimer’s disease being dropped off at the ED by his exhausted son, completely confused and upset since he thought he was going to dim sum not the hospital. These experiences were deeply upsetting to caregivers and usually were a result of no other alternative. The individuals I interviewed would laugh about the stories, but describe themselves and their other family members as in tears during the moments. These moments were representative of both breaking down of relationships but also of caregiver attempts to maintain them.
Kleinman describes caregiving as a complex relationship and moral experience that makes one “more human” (2009). While he is referring to the self-cultivation of caregivers, in my research, I found that “humanness” is found within the relationship between caregiver and elder with Alzheimer’s. Humanness within this relationship is outlined through expressed values or themes of conscientiousness (derived from ren) and family devotion (derived from xiao), given shape through conflicts of generational and cultural expectations and issues of independence-dependence, and shaded by caregiver attempts to maintain harmony within families through denial, compensation, and “conning” or white lies. It is this humanness that forms the dynamic equilibrium of the Alzheimer’s disease self. Tu Wei-ming describes learning to be human as learning “to be sensitive to an ever-expanding network of relationships” (1985). In this sense, understanding humanness in Alzheimer’s disease may be found in the broader context of relationships. In the next chapter, I will shift outward to consider how relationships within the context of Alzheimer’s disease and my thesis research are interconnected.
CHAPTER 6: RECIPROCITY

The prior two chapters focus on relationships involving the self and between elder and caregiver. In this chapter, I shift outward to consider the relationships between Alzheimer’s disease families (or elders or caregivers) and institutions, community organizations, and other “political” bodies. What is the nature of social support for the families I spoke with and how do health providers and community activists envision their roles in this relationship? How have models of care and social support for families affected by Alzheimer’s disease in this part of Boston’s Chinese American communities been influenced by ‘convenient’ stereotypes?

In the Background chapter, I quoted Ruth Moy’s oral history in which she recalls the difficulties of obtaining public funding for elderly housing in Chinatown (what later developed into the community building where the JADC is located). She talks about the pervasive stereotype among government officials that the “Chinese take care of their own” and neither require nor want ‘outside’ social support (Moy 2011). Such stereotypes are often used as political excuses for benign neglect of Chinese American communities, resulting in less funding for resources and outreach programs (Yeo 2006). For example, Pete is the sole outreach worker for Asian American elders living in the Greater Boston Area, despite Asian Americans representing one of the fastest growing minority groups in Boston.

Also, historically, political forces on Boston’s Chinatown have not only been neglectful but at times antagonistic towards the community, favoring policies of
in institutional and luxury development encroachment (Li et al. 2013). The Medical institutions, in particular, do not have good history of social support and care for families in Boston’s Chinatown, instead acting as community aggressors (Lee 2013).

Consequently, social support for Chinatown residents has had to come from within. This has resulted in a number of strong community organizations dedicated to serving the needs, including health needs, of Boston Chinese American and Taiwanese communities (Liu and Geron 2008). For example, the CPA and BCNC both offer health-related social activities like the Chinatown Bike-a-thon and nutritional workshops for Chinese American youth. In the first half of this chapter, I will focus on two main parts of the social relationships between Alzheimer’s disease families and institutions or community organizations: resources and education. In the second half, I consider a possible role for community-based interventions, proposing one potential intervention based on findings from this case study.

**Resources & Education**

Resources mentioned by those I interviewed included improved ‘health literacy’ about Alzheimer’s disease (what it is but more importantly how families can care for those affected), adult day health services that didn’t culturally isolate elders, and most important better availability of language resources. Language barriers were connected both to elders reluctance to seek outside help from community institutions not in Chinatown or Quincy as well as caregiver stress. Chinese American elders, not able to speak much English, found themselves isolated from broader institutions of social
support and healthcare that cater to other elderly communities in Boston (Zhan 2004). At times this culminated in drastic actions, particularly the use of ambulances. For example, Sarah, director of JADC, noted that one of the elderly living in the building would call an ambulance when he needed to go to Tuft’s Medical Center ER, despite it only be a few blocks away. She explained that he did so because he knew he would have access to an interpreter if he went in an ambulance. In another story about ambulances, Liz, a nurse and medical interpreter at Quincy Medical Center, discussed the lack of resources to address “caregiver fatigue”. She spoke about how some over-stressed family members, unable to cope with responsibilities of non-stop caregiving, would ‘dump’ elders onto medical institutions out of desperation. For example, Liz told me this story of one of her Alzheimer’s disease patients:

Their kids are kind of fatigued from helping them make their appointments to arrange their medications…those kind of things…everything if they don’t speak English. You have to find resource to help them from how to prepare meals, home health aides, how to stop them from wandering around the street. I’ve had a patient, who, um, who has Alzheimer’s, and he was incontinent. And, um, the son just called the ambulance just send him to the hospital and then leave. Twice. Like within two weeks. Twice! And he said, he’s just a mess, I don’t want to deal with him, bye. And that kind of frustrates doctors too. When it’s a Chinese elderly who doesn’t speak any English and he has Alzheimer’s, is really frustrating. Because when you get an interpreter there’s the hope you can help him with the language, but you can’t. So, that frustrates them a lot.

Language barriers exacerbated caregiver stress by making them the only viable link between elders with Alzheimer’s disease and outside social support institutions. Liz reasoned that with resources such as better availability of language-appropriate material
for elderly and other caregiving services specific for the Chinese American population, caregivers would better be able to manage new full-time responsibilities without as much burnout.

When asked about the ways community organizations, such as the JADC, primarily provide social support for Alzheimer’s disease families, Stephanie, Sarah, and Liz brought up the need for better “health literacy” and education. However most of the education programs they mentioned were general, biomedical Alzheimer’s disease information series, not originally made for Chinese American families. It seemed that simple translation of these health literacy programs into Chinese was supposed to suffice for adaptation for local residents. However, I believe that this may further foster feelings of disconnect between families and medical institutions. When I asked further why they chose these programs that seemed to lack cultural relevance for their target audience, I discovered that it was easier to obtain funding for evidence-based research programs (EBR). EBR are programs that have been ‘vetted’ through a critical mass of clinical research trials. This becomes problematic when considering which communities these programs were tested in, and whether such mainstream-oriented programs may be useful for application in minority communities.

An alternative to EBR programs are community-based research programs (CBPR), which are developed grass-roots style through the community (Dong et al. 2010). In Boston, whose Chinatown already has a strong history of community activism, albeit directed more towards economic and housing policies than healthcare, CBPR
programs might be a better way to develop a connection between elders with Alzheimer’s disease, caregivers, and institutions of social support. In the second half of this chapter, I introduce an example of a potential community-based intervention. Although, funding is a concern for many institutions and organizations of social support within Chinatown, I hope to show that CBPR programs do not have to be costly as long as there are engaged community members.

**HeartMind Intervention**

Listening to different members of Boston’s Chinese American community discuss the impact of Alzheimer’s disease, I realized that a major source of suffering was in the disruption of relationships. I feel three relationships were particularly important, specifically those between: (1) the Chinese families and biomedical health community, (2) different generations of family members, and (3) Chinese elders and their caregivers. Thus, I suggest that any future Alzheimer’s disease intervention within the Chinese American community should work towards healing these core relationships.

The first step in creating an intervention should be to focus on the ‘divisions’ between Chinese families and the biomedical health community and bring all members of the community together in a constructive dialogue. In my research, I found that biomedicine framed the issue of Alzheimer’s disease in the Chinese community as overcoming various cultural barriers such as mis-categorizations of Alzheimer’s disease as a psychiatric disorder instead of neurologic or the emphasis on behavioral symptoms instead of cognitive ones. On the other hand, Chinese family members focused on daily
struggles to maintain social harmony within the family and feeling like the health community had little to offer them. Similar to Erwin et al (2010), I think one strategy might be to remove ‘culture’ as an entity that separates the two communities in their goal to provide care for elders with Alzheimer’s disease and instead reform ‘culture’ as a hybridization in flux which can be an asset in finding a solution. For example, holistic Chinese conceptions of the body such as *xin* (heartmind), which does not separate cognitive from the emotional within the body, can also be representative of the community body itself. Heart might represent the Chinese families and their concern for elders while mind may refer to the biomedical health workers. In reality, these two groups are not so separate; many of the Chinese family members I interviewed also worked as medical interpreters, nurses, and neuropsychologists and everyone I interviewed spoke about the social costs of Alzheimer’s disease. Thus, as Kitagawa-Singer (2009) proposes, reframing the problem can be helpful when looking for a way to find healing. The intervention should step away from how to ‘educate’ Chinese American families to view the problem in a biomedical framework, but instead focus on the common issue of broken social relationships.

Recently, there has been a proliferation of ‘creative expressions’ interventions to address health issues such as Alzheimer’s disease. ‘Creative expressions’ programs include art therapy, photovoice (cameras are given to subjects to give ‘voice’ to otherwise ‘invisible’ or ‘unheard’ groups), reminiscing, dance, and other nontraditional therapies (Desouza 2007). These programs focus on fostering relationships (Fritsch et al. 2009). One storytelling intervention used in middle- to late-stage Alzheimer’s disease patients is
called TimeSlips. Fritsch et al describe it as “highly innovative in that it taps preserved abilities (e.g. resident’s creativity), rather than focusing on participants diminishing capacities, by using creative storytelling to engage residents and help them communicate with each other and their caregivers” (2009:119). Essentially, groups of elders with Alzheimer’s disease are given a picture that they then use to create a story. Caregivers are instrumental in creating a ‘failure-free’ environment in which elders feel it is okay to offer any ideas about the picture. Caregivers also are responsible for compiling the elders’ ideas and merging them together into a united story. The story is then returned to the elders for discussion and sharing with family (Fritsch et al. 2009). The goals are to empower elders with Alzheimer’s disease in social engagement and develop positive relationships between elders and caregivers.

I am taking this TimeSlips program idea as a starting point to address the specific types of negatively impacted relationships within the Boston Chinese American community. I believe an important part of adapting the program is transforming it into a CBPR program, thereby becoming co-investigators with involved community organizations.

Dong et al in their analysis of a CBPR study of Chinese elders’ health perceptions in Chicago sum up successful interventions as “relevant to the community’s needs” (2010). As an outsider in many ways to Boston’s Chinese American community, I am definitely not as knowledgeable about the complexity and ongoing changes of the ‘community’s needs as its members are. Developing a relevant intervention for
Alzheimer’s disease therefore hinges on collaborations with important community organizations. As introduced in the Background chapter, I found it interesting that the building housing the main Chinese American senior center program in Boston, the JADC, also contains a public school and community health clinic, three important community organizations. It seemed to me that this building with its physical barriers between younger generations, elders, and health workers was metaphorically illustrative of the blocked relationships between these groups. Thus, I believe that engagement of each of these organizations within the building is the next step towards a meaningful intervention.

I would like to involve each group: elders, health caregivers, and younger generations in some aspect of the TimeSlips project. For example, one way of addressing intergenerational relationships might be commissioning the public school’s art students to produce a number of pictures. The subject matter of these pictures can be decided on in dialogues between the JADC caregivers, public school teachers, and students with the medical anthropologist facilitating discussions. For easier involvement of students, middle school-age students and older might be the most practical, but these are details that should ultimately be discussed with school leaders. Zeldin et al review various CBPR interventions aimed at fostering intergenerational relationships and note that “community programs, including out-of-school and after-school programs for youth are an important context where this intergenerational isolation can be bridged” (2005:2). Also, another study found that TimeSlips may improve elder-young adult relationships through highlighting the retained abilities of elders with Alzheimer’s disease, combating
tendencies to trivialize patients with Alzheimer’s disease (George et al. 2011). Therefore, I think bringing all involved parties together in the planning stages is important to figuring out potential benefits and reciprocity between groups. The pictures created by the school students will then be brought to the Chinese elders at the JADC. This initially indirect collaboration between the generations serves to sidestep structural issues like language barriers and availability of free time.

The next phase in the intervention will involve the anthropologist working with caregivers to create an open and positive environment and strengthening elder-caregiver relationships as partners in ‘group story-telling’. Alzheimer’s disease patient-caregiver relationships are often seen unilaterally with the patient slowly de-humanized and the caregiver increasingly the focus of health workers’ treatment efforts (Herskovits 2009; Hinton and Levkoff 1999). Using Freire’s concept of praxis, or social empowerment of the oppressed through “reflection and action upon the world”, may help reset the often skewed power relationship between elders with Alzheimer’s disease and caregivers (Freire and Macedo 2000). In the group storytelling, elders become empowered to share their ideas while caregivers retreat into roles of learning and listening (George et al. 2011). An anthropologist might act as a mediator during group storytelling and may take on a greater role to facilitate caregivers’ process of weaving ideas together into coherent stories.

The final phase is the process of sharing the matched stories and pictures. Sabloff discusses the relevance of applied anthropology though its accessibility (2011). He
argues that if anthropologists only share new concepts within academic circles, this stunts growth. Therefore, the platforms which ideas are presented should take into account modern and creative ways of communication that are used by the communities. Thus, in order to reach younger generations, developing an ongoing community project blog pairing the scanned student artwork with the elders’ & caregivers’ stories might be one idea. Also, in order to reach the working families of children and elders, creating small booklets that can be brought home and shared amongst family members is another possibility. Finally, for many of the elders who also live in the JADC building, a gallery exhibition within the community center where all involved individuals can come together to view the artwork and matching stories at their leisure may be best. In all presentations, as the anthropologist, I need to make sure that issues such as language differences are taken into account so that all partners have equal access to the final products.

I believe that the process of developing this CBPR project should be dynamic with ongoing feedback between the public school students and teachers, elders, caregivers, and health care providers. The tone should be positive with Chinese culture as an asset, not a barrier to Alzheimer’s disease care. During my thesis research, I attended a calligraphy exhibit organized by Pete, the elder services outreach worker serving the Asian American community of Boston. During my interview with him, he focused on how the exhibit was a way to empower elderly volunteers including those with Alzheimer’s. Furthermore, he envisioned the exhibit as a way for families to positively interact with one another,
And for those people who might need a little bit more attention say I ask the family member to join in too [hm]. So, basically, they are the one who taking care of- the, the, (pause) the family member, [mm-hm] but then try to get the family member to come out, to make them feel- good. [mm-hm] So, it work very well!

Finally, this intervention is in many ways a first step towards healing Alzheimer’s disease social relationships within the Chinese American community but it may also serve to start dialogues about other relationships both within the Chinese American community and between it and other Boston communities. For example, Liz brought up her frustration over the growing divide between the educated, professional Chinese Americans and the lower socioeconomic, less acculturated Chinese Americans. She felt that despite there being a significant amount of Chinese health professionals living and working in Boston, few of them wanted to identify or associate with the Chinese community. Among the elderly Chinese Americans I spent time with at the JADC, who were mostly first generation immigrants, there was a feeling that younger generations were rejecting their cultural values and identities. As Escobar (2012) discusses, it should be socially reasonable to recognize hybrid selves within communities and, in fact, see such multiplicities and expansions of self-identities as a strength.

I developed this intervention in part as part of wanting to give back to the individuals with the Chinese American communities I came to know through my fieldwork. While examining the impact of Alzheimer’s disease on relationships, I found myself reconsidering the nature of my own relationship as a researcher working with the
Chinese American community in Boston. Consequently, I have learned that in order to make my research relevant and meaningful it must be anchored in my partnerships and personal interactions with the individuals of this community.
CHAPTER 7: CONCLUSION

This thesis research has revolved around relationships. I began by asking how Alzheimer’s disease impacts family dynamics within Boston’s Chinese & Taiwanese American communities. However, I came to realize how interconnected family dynamics were to social, medical, and institutional dynamics within the broader Chinese American community. Scheper-Hughes and Lock describe the holistic concept of balanced complementarity within Chinese philosophy noting,

“The evolving tradition of ancient Chinese medicine borrowed the yin/yang cosmology from the Taoists and from Confucianism a concern with social ethics, moral conduct, and the importance of maintaining harmonious relations among individual, family, and state. Conceptions of the healthy body were patterned after the healthy state: in both there is an emphasis on order, harmony, balance, and hierarchy within the context of mutual interdependencies.” (1987:12)

Likewise, the unhealthy body, such as one with Alzheimer’s disease, might be the inner sphere within larger concentric spheres of unhealthy family, community, and world.

Tu Wei-ming’s Confucian humanism relates to these thesis findings. It emphasizes the relevance of relationships, as part of a dynamic process, over parts themselves (Wei-ming 2012). I used Scheper-Hughes & Lock’s theoretical concept of “mindful body” to organize my analyses of Alzheimer’s disease within Boston’s Chinese American community into three parts or “bodies”: the individual body, social body, and body politic. In chapter four, I describe how “uncertainty” is embodied within the liminal
nature of Alzheimer’s disease. Also, I attempt to unravel relationships of false
dichotomies of real-unreal, visible-invisible, normal-abnormal within the context of
Chinese American subjective experience of Alzheimer’s disease.

In chapter five, I focus on understandings of values of ren and xiao within the
elder-caregiver relationship such as conscientiousness, compassion, burden and
responsibility, and levels of `family devotion. From these values, tensions involving
generational expectations, views of independence-dependence, forms of caring, and
cultural perceptions simmer and disrupt family dynamics. In the latter part, I look at how
families cope with these tensions with a spectrum of strategies ranging from denial and
compensation, roundabout communication, white lies and conning, to day health
programs and social services. In chapter six, I look at ways broader community,
education, and research involvement may be a basis of healing in families with elders
who have Alzheimer’s disease. I reflect on the issue of reciprocity within the context of
my fieldwork and suggest a potential intervention based on TimeSlips programs for
patients with Alzheimer’s disease.

Through these analytic chapters, I hope to build up a bigger picture of how the
dynamic, multi-dimensional relationships interact with and build off of one another.
According to Tu Wei-Ming, “The self is never an isolated individual but a center of
relationships...community is never separate from the self” (2012:78). Likewise, I see the
“individual body” never truly separate from “social body” or “body politic” inside of
Scheper-Hughes & Lock’s “mindful body”. It is not the bodies themselves that are
important but the nature of the relationships among them. In this thesis research, one of the main findings that emerged is that it is the disrupted social relationships among elder and family member-caregiver, families and health professionals, biomedical, social, and community institutions are a significant source of pain, loss, and anxiety of Alzheimer’s disease. In order to be effective, future interventions need to identify and address these disrupted relationships.
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University of Michigan, LSA Honors Program, Concentrator in Biopsychology & Cognitive Science (BS), Minor in Anthrobiology — 2002-2006

Study Abroad in Edinburgh, Scotland at the University of Edinburgh, SUISS Program — Summer 2004

Study Abroad in Florence, Italy at the Accademia Italiana — Winter 2004

PROFESSIONAL EXPERIENCE

Jenk’s Vestibular Physiology Lab with Dr. Richard Lewis — 2014-present
Investigating the relationship between dizziness and migraine

Daroff-Dell’Osso Lab with Dr. John Leigh, Louis Stokes VA, Cleveland, OH — 2009-2011
Researched neurological diseases through eye movements

Patient Care Assistant for Pediatric Anesthesia Care Unit, Mott Children’s Hospital, University of Michigan — 2006-2009
Coordinated clinical care of post-anesthesia pediatric patients, successfully completed nurse’s aide training

Dr. Barbara Smuts Animal Behavior Research Lab, University of Michigan — 2005-2006 & Summer 2008
Examined canine dominance and aggression in play behavior

Dr. Kent Berridge Biopsychology Lab, University of Michigan — 2004-2006
Investigated effect of opioids in the amygdala on taste reactivity and eating behavior; neural mapping of nucleus accumbens in rats

Dr. Robert Baker Lab, Marine Biological Laboratories, Woods Hole, MA — Summer 2005
Explored squid embryo cultivation and development

Dr. Daniel Eitzman Cardiology/Internal Medicine Lab, University of Michigan — 2002-2004
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Created database of the effects of rehabilitation methods on pulmonary embolism and deep venous thrombosis in brain injury patients

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Also contributed to:

*Effect of midbrain disease on synkinesis of vertical saccades, disjunctive horizontal saccades and vergence* (Piccione E, King SA, Leigh RJ)

*Effect of cerebral hemispheric lesions on the amplitude and direction of saccades to double-step stimuli* (Naasan G, King SA, Leigh RJ)

*Influence of orbital eye position on vertical saccades in progressive supranuclear palsy (PSP)* (Schneider RM, Chen AL, King SA, Leigh RJ)

*Saccadic palsy following cardiac surgery: Effects of blinks* (Sawyer RN, Chen AL, King SA, Leigh RJ)

*Tests of two hypotheses for saccade-vergence interactions: Effects of internuclear ophthalmoplegia* (Chen AL, Ramat S, Serra A, King SA, Leigh RJ)

Society for Neuroscience (2010 San Diego, CA) *Changing your mind: Cerebellar disorders and the double-step saccade task* (King SA, Chen AL, Naasan G, Joshi AC, Serra A, Leigh RJ)