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Re-examining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers

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Abstract

Prior literature emphasizes that Asian Americans with dementia may be particularly vulnerable to the stigma of chronic mental illness. However, there is a dearth of empirical research to support this claim. This study examines the relationship of stigma and dementia in 32 qualitative interviews with Chinese and Vietnamese family caregivers. Stigma was a common theme in the interviews (91%). Further analysis of stigma revealed two sources: chronic mental illness stigma and stigma reflecting negative stereotypes of aging or the aged. Chinese and Vietnamese cultural views of normal aging are not a unitary category but accommodate different trajectories of aging, some more and some less desired. When applied to persons with dementia, a “normalized” but negative trajectory of aging carried with it significant stigma that was distinct from but in addition to the stigma of chronic and severe mental illness. Older Chinese and Vietnamese with dementia are thus at risk of experiencing multiple stigmas that include but go beyond the stigma associated with chronic and severe mental illness.

INTRODUCTION

Understanding whether and how stigma affects older Asian Americans with dementia and their families is timely for several reasons. Dementia is one of the most common and disabling conditions to afflict older adults, and available data suggest that the prevalence of dementia among Asian Americans is comparable to the prevalence in Caucasians (Manly & Mayeux 2004). The rapidly growing Asian American elderly population in the US is projected to increase by more than 300% between 2000 and 2050 (Barnes & Bennett 2002). Since age increases the risk of developing Alzheimer’s disease and related degenerative dementias, the prevalence of dementing illness among Asian Americans is also projected to increase.

Stigma, in particular the stigma of chronic mental illness, has been identified as an important issue for Asian Americans with dementia and their families (Gallagher-Thompson et al 2000; Lin 1980), yet there is a paucity of empirical research addressing this issue, particularly that draws on the narratives and perspectives of Asian American families themselves. The overall goal of this study is to examine the relationship of stigma and dementia from the perspective of Chinese and Vietnamese family caregivers.

Defining Stigma

The concept of stigma is notoriously difficult to define. In his seminal work, Goffman noted that the Greeks “originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman 1963). He went on to formulate his own somewhat broader definition of stigma as “an attribute that makes [the person] different from others in the category of persons available for him to be, and of a less desirable kind... He is thus reduced in our minds from a whole and usual person to a tainted and discounted one.” Goffman also identified three types of stigma – bodily abominations (e.g. missing limbs), moral incapacities (e.g. ‘bad’ behaviors or thoughts), and tribal stigma or stigma ‘courtesy’ of one’s affiliation with stigmatized others (e.g., with family or friends who are ‘criminal’ or ‘crazy’, or from a particular ethnic group or locale). These three types of stigma may occur singly or in concert with one another. Thus, stigma can occur for multiple reasons simultaneously.

In other theoretical work on stigma since Goffman’s initial formulation, other descriptions of stigma have been offered. For example, stigmatization may also occur when people possess or are thought to possess “some attribute or characteristic that conveys a social identity that is devalued in a particular social context” (Crocker et al 1998). Sociologist Bruce Link stands out in his attempt to specify the stigma process, including the distinguishing and labeling of difference, associating those differences with negative attributes, separating “us” from “them,” and finally status loss and discrimination all occurring within a power situation (Link & Phelan 2001). The definition of stigma remains difficult, however, as “stigma is a broader and more inclusive concept than any one of these processes (Major & O’Brien 2005).

Stigma and dementia

As interpreted through the lens of biomedicine, senile change may reflect the clinical syndrome of dementia, which can be caused by a variety of pathological processes, including degenerative brain diseases such as Alzheimer’s disease, Lewy Body dementia, and fronto-temporal dementia. While the clinical syndrome of dementia as defined in biomedical nosologies emphasize the importance of cognitive symptoms sufficient to cause a decline in functioning, behavioral and psychological symptoms have historically been recognized as an important part of the clinical presentation. Thus, stigma may be triggered by dementia-related changes in cognition (e.g. increased forgetfulness), behavioral symptoms (e.g. depression or hallucinations), or from disability itself as they are manifested, experienced, and responded to in specific sociocultural contexts.

There is a body of work in anthropology and sociology on dementia that is relevant to consideration of the relationship of stigma and dementia (Whitehouse et al, 2005; Leibing and Cohen 2006). Much of this work focuses on lay categories the map roughly to the biomedical concept of dementia or Alzheimer’s disease. To a large extent, this work builds on Goffman’s seminal observation that stigma is damaging because it undermines the “moral status” of the afflicted individual. Herskovits and Mitteness show, for example, that stigmatization of persons with dementia occurs in part because those with the condition transgress core Anglo European-American cultural values of mastery, productivity, self-control, and independence (1994). In contrast to the person embodying these values, the person with Alzheimer’s is viewed as less than fully human and may die a “social death” (Cohen 1998; Herkovitts 1999). In Japan, the moral status of the older person is defined in terms of his or her ability to maintain social connections within a circle of family, friends and acquaintances (Traphagan 1998). The moral status of the person who is labeled as senile (boke) is degraded not only because they fail to maintain social connections in a reciprocal and culturally expected way, but also because they viewed as personally responsible for their actions and hence their condition. This observation parallels in certain respects with the observation of Hinton et al that in Chinese families senility

may be stigmatized because it signifies the “unbalanced” and therefore “undisciplined” person (Hinton et al, 2001). In his ethnographic study of senility in India, Cohen finds that senility may signify the “bad family” and also reflects on the moral status of the larger society (Cohen 1998). As an interesting contrast to the studies mentioned above, work by Henderson with the American Indians shows that the very behavioral symptoms that may lead to stigmatization of older persons in other cultural contexts actually elevate the status of older Indians because they are viewed as “supernatural” manifestations (2002). These cross-cultural studies show that it is not only the moral status of the individual, but also the family or the larger society that may be threatened by senility.

Stigma and dementia in the context of Chinese and Vietnamese cultures

There is, however, an interesting tension in the literature on stigma among Chinese and Vietnamese with dementia. On the one hand, some have suggested that Asian American elderly with dementia may be particularly vulnerable to the stigma of severe mental illness, resulting in increased suffering and delayed help-seeking (Braun & Browne 1998; Guo et al 2000; Yeo & Gallagher-Thompson 1996). A cross-ethnic study of knowledge of Alzheimer’s disease found that significantly more Asian Americans (53%) than Anglos (16%) endorsed the item that “Alzheimer’s is a form of insanity” (Ayalon & Areal 2004). Persons with dementia may be vulnerable to the stigma of severe mental illness (i.e. schizophrenia) because they share a set of similar behavioral symptoms (e.g. depression, delusions, hallucinations, agitation).

Germane to these studies of Asian Americans and dementia stigma, empirical work with Asian groups in North America and Asia have furthered the understanding of stigma in relation to a specific (Asian) culture and setting or condition (mental illness). Arthur Kleinman (Kleinman et al 1995) and more recently Lawrence Yang (Yang 2005) have argued for the specification of Asian cultural dimensions of stigma, through the importance of key concepts such as *diu lian* (loss of face). The afflicted person and family members experience “loss of face,” which is felt both individually as shame or guilt and interpersonally as a loss of status within the larger community. In their more culturally sensitive reading of stigma as a moral category, the stigma of chronic illness and its consequences are experienced not only by the individual but also by the entire family (Chin 1992; Gold 1992).

In the mental health field, early studies emphasized the tendency of Chinese families to sequester the mentally ill at home and to delay seeking formal help because of the deeply discrediting effect of severe mental illness for the entire family. Recent work has broadened our understanding of the experience and social consequences of stigma from the perspective of Chinese with schizophrenia. Lee and colleagues (2005) outline four key domains in the social experience of stigma by persons with schizophrenia: (1) work-related stigma (e.g. loss of job or prestige), (2) interpersonal stigma (e.g. family and friends being afraid of the person and/or increasing their social distance), (3) concealment and anticipated stigmatization (e.g. efforts to hide the diagnosis from family or friends), and (4) emotional reactions to stigmatization (e.g.. fear and anxiety).

On the other hand, studies conducted in the US, China, and other parts of Asia emphasize the strong tendency of Asian Americans, particularly Chinese, to view dementia as a normal part of the aging process. From this perspective, cultural expectations of aging create a “buffer” that may result in little if any stigmatization of the person with dementia. Ikels suggests that cultural concepts, such as filial piety and normative views of aging as a “second childhood” may result in a tendency for Chinese to accept dementia as a normal part of the aging process (1989 (2002)). She concludes that lack of biomedicalization, specifically the lack of familiarity with concepts such as Alzheimer’s disease and dementia, reduced expectations, and cultural stereotypes of the elderly conspired to “normalize” the symptoms of dementia, leading to less fear, stigma, and caregiver burden in China compared with the US. A previous analysis of

Chinese interviews, including a subset from this study, found that Chinese caregivers often viewed dementia-related changes as a normal part of the aging process (Hinton & Levkoff 1999). Furthermore, this study found in contrast to the Irish American and African-American caregivers, Chinese caregivers were much less likely to view dementia in terms of “loss of self,” a very common trope in studies of European-American cultures.

Taken together, prior work suggests that there is considerable cross-cultural and cross-ethnic variation in the cultural meanings of dementia. Furthermore, dementia-related changes may result in stigmatization because it threatens cultural values that are associated with what it means to be “fully human” or to “age well” but may also have the potential to elevate the moral status of the afflicted individual. In addition, within any given cultural context, a variety of cultural models or explanatory frames may be available to interpret the variety of cognitive, behavioral, and functional symptoms that are part of the clinical presentation of dementia.

Research Questions

Despite the importance of stigma for the health of Asian American elderly, surprisingly little empirical research – qualitative or quantitative – addresses this tension in the literature or tackles the impact of stigma and dementia on the daily lives of older Asian Americans and their families. This paper aims to address this gap in the literature through an analysis of narrative data from qualitative interviews with Chinese American and Vietnamese American families in Boston and northern California respectively. Our research sought to answer the following set of related questions: How often does stigma emerge as a theme in these narratives? When stigma emerges, is it predominantly in the form of the stigma of chronic mental illness or does it take other forms? What are the implications of these findings for research and clinical practice involving Chinese Americans and Vietnamese Americans specifically (and Asian Americans more generally) with dementia and their families? As noted by others, research that examines how stigma is experienced by those it affects – in this case, the person with dementia and his or her family – is vital if we are to understand the social and cultural aspects of stigma as an interpersonal process (Kleinman et al 1995).

METHODS

Setting

The data were collected from 1994 to 1997 in two qualitative studies conducted as part of an exploratory center grant funded by the National Institute on Aging. The methods of participant selection are described elsewhere (Hinton & Levkoff 1999; Yeo et al 2001). The goal of the overall study was to compare the meanings families assign to dementing illness and help-seeking responses associated with the care of a relative with dementia across different ethnic groups. The two Asian American groups who participated in this larger study are the focus of this paper, i.e. Chinese American caregivers living in the Boston and Springfield areas of Massachusetts (n=23) and Vietnamese caregivers (n=9) who were identified in the San Francisco Bay Area of California. For one Vietnamese elder with dementia, two family caregivers were interviewed separately.

Participants

This convenience sample of Chinese and Vietnamese caregivers was recruited from primary care physicians and nurses, a larger home health program, Alzheimer support groups, home health agencies, adult day health centers, and nursing homes. To be eligible, caregivers had to be adult family members who provided substantial day-to-day care for a family member age 55 and older with a dementia. In addition, the caregiver needed to be fluent in one of more of the following languages: English, Vietnamese, Mandarin, Cantonese, or Toishanese. The person with dementia needed to be community dwelling or have been institutionalized within

the prior year and formally diagnosed with dementia or suffering from significant memory problems according to the referring agency, clinician, or family member.

Procedures

Face-to-face interviews were conducted in the caregivers' native language and in the setting of their choice – usually the caregiver's home. The interviewer used in-depth qualitative interviewing techniques, using an interview guide that included a list of topics a set of questions on the meanings they attributed to their relative's dementia. Most interviews lasted from 1 to 2 hours in a single visit; all were audio taped and later transcribed. All interviewers were trained and supervised by the senior author (LH). To control costs, Chinese interviews and half the Vietnamese interviews were translated in one-step from audiotapes to written English.

Data analysis

Analysis of the narrative data followed standard qualitative procedures involved multiple steps (Bernard 2005; Miles and Huberman 1994). First, the interviews were read in their entirety by the first author (DL) and open-coded for instances of stigma appearing in the text. The results of this preliminary analysis were discussed at a research team meeting that involved three of the authors (LH, JB, DL). Next, a general definition of stigma and a narrower definition of the stigma of chronic mental illness were developed by three of the authors (DL, JB, LH). Our general definition of stigma specified the following five types of evidence of stigma along with detailed examples of each type: (1) non-biomedical labels with negative connotations are applied to the person with dementia, (2) discrediting stereotypes, (3) negative emotional and social responses to the person with dementia/family, (4) loss of status or discrimination due to their diagnosis, and (5) other examples that do not fit well with the above categories. Using the general definitions, two of the authors (DL and CT) as well as two research assistants performed the coding.

Interviews with instances of stigma were further coded independently to determine if they fit the definition of stigma due to severe mental illness and discrepancies resolved through a group consensus process. The stigma of chronic and severe mental illness was further coded if there was (a) the use (or rejection) of terms or descriptors that connote chronic mental illness (e.g. "crazy"), (b) emphasis on guilt/shame and moral failure of the person or the family, (c) fear of the person with dementia, and (d) attempts to conceal the person with dementia or their diagnosis from others. Each interview was coded by two persons independently to determine if dementia stigma was present or absent. A meeting was held to review the results of the coding, and disagreement between the two coders was then resolved using a group consensus process.

RESULTS

Participant Characteristics

While the Chinese and Vietnamese in the sample had distinct migration histories and experiences (see table of caregiver characteristics), these were consistent with the general migration patterns reported for these Asian groups into the US throughout the 20th century (Fawcett and Carino 1987; Gold 1992; Rumbaut 1991). Chinese and Japanese migration to the US, mainly for economic purposes, has been occurring for decades longer than has migration by other South and Southeast Asian groups, including Vietnamese, who began arriving in large numbers, mainly as refugees, beginning from 1970. Four of the 23 (17%) Chinese elders in the sample, all four of whom had been here for over 30 years at the time of the interview, had arrived in the US with their caregiver. Most Chinese elders, however, preceded their caregiver's arrival by approximately five or more years. At the time of interview, the majority (87%) of Chinese caregivers had been in the US for more than 20 years. Before settling in the US, some

20% of Chinese were born or had lived outside China before migrating to the US. In contrast, all the Vietnamese in the sample migrated along with their caregivers; only two of the nine (22%) arrived in the first wave of Vietnamese immigrants in the late 1970's. This first wave of Vietnamese refugees tended to be wealthier, better educated and more politically active than the later waves. At the time of the interview, the majority (78%) of Vietnamese participants had been in the US an average of five years, and only one caregiver in this group had ever lived outside Vietnam or the US.

Consistent with the pattern of caregiving for elderly found in the general US population, 21 (66%) of the 32 caregivers were women. The majority of caregivers were daughters or daughters-in-law and only 6 (19%) were spouses. The mean age of caregivers was 50 (three missing). Eighteen (60%) of the caregivers were living with the person with dementia at the time of the interview.

Prevalence of Stigma as a Theme Stigma was coded in 29 (91%) of the 32 interviews, including 22 (96%) of the Chinese interviews and seven (78%) of the Vietnamese interviews. Among the 29 interviews coded for stigma, 15 (52%) exhibited codes for the stigma of chronic and severe mental illness; in 14 (48%) the stigma of chronic and severe mental illness was absent but other forms of stigma were present. Next, we describe these two broad categories of dementia stigma in more depth, using examples from the interviews.

Stigma related to chronic and severe mental illness—In this section, we describe examples from both Chinese and Vietnamese interviews of dementia-related stigma that resemble the stigma of chronic and severe mental illness in three important respects: illness labeling, etiological beliefs, and personal/social consequences and experience of illness. “At that time (in China), we didn’t know it’s dementia. We thought that they have mental problem, being crazy. My mom told me what had happened to them, but I still didn’t know what it is. Later, I moved to HK [Hong Kong] and worked in an elderly health center. I started to know more about it [dementia] since I had met many elders who have this illness. Dementia is because of the brain shrinking, later people will act like a child and weird behavior happened. Some people don’t know about dementia and say they are crazy.” (41 year old daughter, ID no. 10) This daughter described how her own view of dementia changed, from that of heavily stigmatized mental illness (i.e. “being crazy”) to an explanation of abnormal behavior as a product of the “shrinking brain.” This quote highlights the importance of the stigma of mental illness for many of the caregivers we interviewed. In these interviews, dementia is labeled in ways that provide a direct link with stigmatized mental illness. This occurred in a number of interesting ways. Some caregivers made a connection between biomedical terms, such as Alzheimer’s disease or dementia, and chronic and severe mental illness. For example, when asked by the interviewer what the term “dementia” means, one daughter caregiver replied that people in the Chinese community thought it was “just going crazy or they think it’s just, you know, it’s the same thing as schizophrenia.” (31 year old daughter, ID no. 14) This caregiver herself adhered to a more biomedical view of dementia, which she actively contrasted with the views of others in the community. She discussed feeling “looked down upon” by the community because people took her mother’s illness as a sign that the daughter had failed to take proper care of her mother (i.e. was not appropriately filial). In other cases, the caregivers themselves appeared to have internalized the view that the conditions of the person they were caring for was akin to mental illness. For example, when asked to describe what the term “Alzheimer’s disease” meant to her, another Chinese caregiver said, “The person can not be able to think. The person acts like a person suffering from a mental disorder.” (64 year old third wife, ID no. 3)

In conjunction with labeling dementia as mental illness, many caregivers identified a cause for their relative’s dementia. In his study of caregivers of persons with schizophrenia in China,

Phillips (Phillips et al. 2000) found that family members most frequently attributed the illness to psychosocial stressors (i.e. interpersonal conflict, traumatic losses, poor upbringing) and personal characteristics of the care receiver (i.e. personality problems, thinking too much, substance abuse). These interviews provide evidence of a similar pattern of attribution for dementia. For example, when asked why her mother-in-law has dementia, one caregiver replied, "Because she always said that her parents didn't like her when she was young. They liked boys instead. Her parents were doctors in a village and they liked her elder brother very much. Her family was very feudal, and she wasn't open minded. Once she grew up and got married but didn't have good marriage. She had to worry and do many things and got much pressure, which always affects her. Since she thinks too much and makes her brain go crazy." (38 year old daughter-in-law, ID no. 6) This caregiver sought answers for her mother-in-law's dementia in a set of explanations that link dementia, psychosocial explanations, and "craziness" or chronic and severe mental illness.

"Thinking too much" emerges as a common attribution in this set of Vietnamese and Chinese interviews; it is a kind of thinking that involves excessive brooding and rumination, anxiety, and emotional uneasiness. For example, when a Vietnamese caregiver (42 year old wife, ID no. 24) was asked what caused dementia, she replied that "those who do a lot of mental work" and those who become "mentally exhausted" get dementia. Another Vietnamese caregiver (34 year old son, ID no. 30) attributed the causes of his mother's dementia to "too many worries." The cultural meaning of this explanation can be found in traditional East Asian medicine and Confucianism, traditions that are important among both Chinese and Vietnamese people. Traditional Chinese and Vietnamese views of health place emphasis on the holism of mind with body and the importance of balance and harmony to promote health and prevent illness (Lin 1980;Phan and Silove 1999). Previous research with this data set found that emphasis on "thinking too much" implied some degree of moral failure of the afflicted person (Hinton et al. 2001). This moral failure may also extend to family members. The son of a demented Chinese elder blamed his wife for contributing to his mother's disease: "If they [wife and mother] could get along, then we could live together, therefore she [mother] would not be lonely. I believe her illness wouldn't have happened." (47 year old son, ID no. 4) The wife of another Chinese elder told us, "Sometimes I don't feel happy either because it was me who brought him here. I don't know if it's my fault or it's just our life. I am eating all those bad fruits I planted myself." (58 year old wife, ID no. 8) Here, the older man's wife suggested not only that the disruption of relocation may have unduly psycho-socially stressed her husband such that he later developed dementia, but also that this was a moral failing on her part.

The social experience and responses to the person and family somewhat resembles what has been described in the literature in association with chronic and severe mental illness. Shame and "loss of face" emerged as important experiential themes in these interviews. In some cases, the shame was triggered by public display of abnormal behavior. For example, when the caregiver mentioned above was asked directly if his mother's illness ever makes him "lose face" publicly, he replied, "Often. She talks something nonsense which we don't know what she talks about." (47 year old son, ID no. 4) Erosion of the social network, highlighted in much of the literature on schizophrenia in Chinese culture, was also present. In one case, a daughter caregiver felt that her Chinese father's dementia made it difficult to form friendships and even implied that it would harm her chances to marry: "I can't make friends or boyfriend because I am afraid that they won't like my father or look down on him." (50 year old daughter, ID no. 5) The lack of social contact can also be due to a fear of contagion. A daughter-in-law mentioned that people avoided the older Chinese woman "because she has cancer, dementia, they are afraid to it will spread." (38 year old daughter in-law, ID no. 6). A son said that his wife "thinks that the kids would get the same disease transmitted from their grandmother if they get too close to her. So she doesn't allow them to come here. Now, when I bring my kids here, I have to keep this from being known by my wife." (47 year old son, ID no. 4) Attempts at concealment

may be used to deflect the stigma of chronic and severe mental illness. The wife of an elderly Chinese man who exhibited behavioral symptoms such as running around undressed after urination, said, “I couldn’t tell anyone about this, even to his daughters.” (64 year old third wife, ID no. 3). Another caregiver said he never met any elderly with dementia in China and mused, “Maybe you don’t see them because they always in the house.” (32 year old grandson, ID no. 18). The above examples describe facets of the stigma of chronic and severe mental illness uncovered in these interviews about demented older care recipients.

Stigma related to negative stereotypes of aging—In describing her mother who has dementia, one Chinese American woman told us: “She is like the very old. It is not like she is in her hundreds. But she doesn’t remember things. But when I see these crazy people, they are about in their sixties. There is a kid too, about teenage... She is like a machine, there is a missing part. It is not a crazy machine.” (48 year old daughter, ID no. 16) By emphasizing how her mother is both similar and dissimilar to other “crazy people”, this caregiver highlights the salience of the stigma of chronic and severe mental illness for Chinese with dementia while revealing a cultural alternative to understanding dementia. In this alternative, dementia-related changes become a normalized and expected part of the aging process that manifests in those at advanced ages (i.e. a person/machine with worn-down parts, close to 100 years old). As we have discussed elsewhere (Hinton 1999), the reference to the aging mind/body as a machine, common in both the Vietnamese and Chinese interviews, is a culturally shaped metaphor that emphasizes holism and the inevitability of deterioration. The stereotyping of old age as a time of mental confusion was also underscored by the following Vietnamese caregiver: “There were times that I did not think my mother was getting old. But when she started to become confused, then I realized that she was old. Because in Vietnam, confused people were old people.” (51 year old daughter, ID #28) These quotes also underscore age-related interpretation of cognitive and functional change: for the “very old”, it is normal for memory to fail, but in someone who is in their “sixties”, this would signal something abnormal. Thus, no matter their actual chronological age, older adults who have declined cognitively would be labeled as “confused” by Vietnamese and Chinese caregivers, or simply be called “old.” These findings are consistent with a number of studies that highlight the “normalization” of functional and cognitive decline among older Chinese with dementia (Elliott et al. 1996; Hinton et al. 1999; Ikels 2002).

Our informants made clear distinctions between older persons who had “aged well” and those who had aged less well. People with dementia appeared to fall into the latter category. The disability, cognitive decline, and even the behavioral changes of older persons with dementia were thus viewed as a less desired trajectory of aging, while simultaneously an understandable and normal part of the aging process. A growing dependence on others and difficult or strange behaviors of the person with dementia were thus attributed to their becoming “childish,” “confused,” “foolish,” or just “difficult”. As one caregiver told us, “She, the elderly, was baby number one.” (52 year old son, ID no. 15). Describing her mother, another Chinese caregiver said, “Her behavior is just like a child.” (50 year old daughter, ID no. 5)

The view of older persons as “confused” or “childish” may also result in a kind of social distancing, on the assumption that the person with dementia is incompetent in all domains of life. There may be decreased attempts to communicate with the older care recipient because “the person doesn’t understand anyway” or the older person may be discouraged from talking especially in the presence of people from outside the family or household. The older person also may no longer be included in social activities on the grounds of inconvenience rather than fear of contagion. This often results in exclusion of that person from social interactions such as visits by family members or playing Mahjong, activities that otherwise would be highly valued within the context of Chinese and Vietnamese cultures. One caregiver, in response to the interviewer’s question about whether her daughter visited her Chinese grandmother who has dementia, said, “No. Because my mother doesn’t even recognize her. She [caregiver’s

daughter] once said, 'I have been there once and grandma doesn't recognize me.' So I said to her [caregiver's daughter] if she doesn't recognize you, don't go." (48 year old daughter, ID no. 16) Another caregiver noted that her Chinese mother was no longer welcome at the Mahjong tables: "People did not want to play with her because she is slow and people who play Mahjong like to be quick." (51 year old daughter, ID no. 20) The exclusion from Mahjong is poignant because it is a game deeply rooted in Chinese culture and is as much a valued form of social interaction as a pastime.

Ultimately, this negative stereotyping of aging may be internalized, leading older people to view themselves as being of less value. Reflecting on her Chinese mother's view of herself, one caregiver said: "She says that her memory is bad because of her old age and she's become useless." (38 year old daughter-in-law, ID no. 6) This last comment is alarming in view of the high rates of suicide among older Asian American women in the US. Data compiled by the National Center for Health Statistics of the Centers for Disease Control and Prevention shows in 1995, there were 8.6 suicides per 100,000 people among Asian Pacific Islander women over age 65, compared with 5.8 suicides for age-matched white women and 2.1 suicides for age-matched African-American women (Chung 2004). While the comment about becoming "useless," may be one of culturally understood self-deprecation, it nonetheless offers an insight to how this Chinese care receiver with dementia has chosen to describe herself; she pairs her perceived uselessness not just with older age but with its attendant memory problems.

The model for treatment of the elderly in Chinese culture is described by Charlotte Ikels (2002) as a "parent-child contract." The roots of the contract are both cultural and political: Confucian notions of filial piety and the social positioning of the elderly as deserving of respect and obedience are strengthened by Chinese government policies limiting housing and relocation. Children, especially the eldest son, are held responsible for an elderly parent's care on both a personal level and public level: he wishes to set an example for his own children while avoiding public censure for not being filial. Ikels' use of the word "contract" connotes a reciprocal relationship. It is understood that in return for food and housing, the elderly will provide services, such as taking care of children or helping with housework. In this way, the balance of power between the generations is preserved and the generations are linked by both birth and interpersonal relationships.

In contrast to this contract, the theme of decreased status of the elderly emerges from the interviews. As noted above, caregivers frequently described the elder as like a "baby" or "child". One Chinese daughter caregiver stated, "He was a hero to me before, now he can't even do something simple." (50 year old daughter, ID no. 5) Older people frequently are no longer able or allowed to cook or take care of children. Those with moderate to severe memory loss might no longer remember or be able to recount coherently stories of the past. When asked if the Chinese mother with dementia held any *di wei* (social status, connoting that due to respect or political power) within the home, a son's response was simply "No." (48 year old daughter, ID no. 16) Throughout this process of recognizing an elder's diminished capacity to sustain the demands of a social contract based on respect and mutual obligation, however, the older person's familial label of "mother" or "father" remains intact. In answering the interviewer's question as to why she was not tired of caring for her Chinese father, a daughter simply replied, "Because he is my father." (50 year old daughter, ID no. 5) This suggests that while the older care recipient's status as an elder is diminished due to the symptoms of dementia, the "parent-child contract" is not eliminated. The individual identities and relative social positioning/generational status of both caregiver and care receiver have been preserved.

Coupled with the changed status of the elderly within the household is an increasingly negative perception of aging in general. Several caregivers echoed this sentiment: "So I say, seeing the elderly grow old like that, even I fear old age." (53 year old son, ID no. 17) In response to the

question: “After many years of caring for your mother, have you changed your point of view on aging?” a Chinese family caregiver said, “It is a scary process; I often tell myself that I don’t want to grow old. [Laugh] When I get to that point I will ask Dr. Jack Kevorkian² to give me an injection.” (48 year old daughter, ID no. 22) This quotation highlights some degree of fear about aging itself.

In contrast to mental illness, where the family as much as the demented elder experienced the stigma, our research suggests that these negative stereotypes of aging have more of an impact on the person with dementia than on the family. These stereotypes are, in our view, distinct from chronic and severe mental illness, but they carry with them the potential to lead to an “erosion of full adult personhood” (Luborsky 1994).

DISCUSSION

We have examined the effects of dementia on the lives of caregivers and care receivers among an urban, immigrant population, with a range in degrees of acculturation. The main finding of this study is that dementia may place older Chinese and Vietnamese at risk of multiple stigmas that include but go beyond that associated with chronic and severe mental illness. The stigma of chronic and severe mental illness was associated with varying degrees of individual incapacity and moral failure. In Goffman’s terms, this represents two forms of stigma—bodily abominations (the behavioral and cognitive symptoms attributed to mental illness) and blemishes of character (the attribution of moral failure as a cause of disease). In addition, an older person who is labeled a “crazy” may be interpreted as a sign that the family—in either the present or past—has failed to live up to its filial obligations. In this way, dementia becomes a sign of the family’s moral failure, an example of what Goffman referred to as tribal stigma.

In addition to the stigma of chronic and severe mental illness, we have identified a stigma of aging that reflects negative stereotypes of aging and the aged. This suggests the need for future studies of these and other Asian cultures to broaden their investigation to include other possible sources of stigma, such as negative stereotypes of aging and older persons. In Chinese, dementia is *lao nian chi dai zheng*. Two phrases lie within the disease name: *lao nian* is translated literally as “old year” and *chi dai* is translated as dementia or slow-witted. The juxtaposition of these two phrases highlights the tension that exists in current literature, as previously discussed: the tendency to view dementia as part of aging and the derogatory label of dementia. Our finding of the negative stereotypes of aging reveals that individual suffering can begin with just *lao* (old), before the full label of dementia is applied. Descriptors such as “childish” or “foolish”, while not as heavily stigmatizing as “craziness” are pejorative nonetheless. “Aging poorly” appeared more often to be associated with stigmatization of the person with dementia, rather than with stigmatization of the family. The labeling of elderly this way appears to sanction what theorists highlight: the ignoring, excluding, and neglecting of the (stigmatized) older person. Not visiting parents was more common in this sample than one might expect according to the “parent–child contract.” i.e., less filial behavior than might be expected was present in this data set. Dementia symptoms revoke the reciprocal nature of the contract, leading to a loss of the elder’s traditional status position within the household’s social structure. This change, now unequal and against the elderly, establishes a power scheme on which Link’s stigma process may begin to unfold.

We suggest that the category of “normal aging”, so prevalent in discussions surrounding aging, Chinese, and dementia (Hinton and Levkoff 1999), needs to be re-examined. Our informants clearly recognized that some older people age without experiencing significant deterioration of their mental faculties or behavioral change. Chinese and Vietnamese cultural views of normal aging are not a unitary category but accommodate different trajectories of aging, some more and some less desired. Far from being value-free, we found that when applied to persons

with dementia, this negative but “normalized” trajectory of aging carried with it a soft stigma that was distinct from that of chronic and severe mental illness. Our presentation of stigma and dementia among older Chinese and Vietnamese Americans, as existing in different forms across different generations, is shaped by powerful cultural constructs. Despite major contextual differences in the migration and subsequent acculturation experiences of these two groups, their responses to dementia appear to be shaped by similar cultural constructs. Given this foundation, we propose that what is “at stake”, to use Kleinman’s term, in the experience of dementia among some Chinese and Vietnamese families is the moral status of the family. Confucian ideas of the body and illness, for example, may lead to a view of illness as a sign of the moral status of the afflicted person because he or she has failed to exert appropriate discipline or respect. A loss in moral status manifests both as the intangible feeling of “loss of face” within the eyes of the community and the tangible fading of social network. The “loss of face” becomes internalized and expressed, in our interviews, as a sense of shame among family caregivers, who often are wives or adult children. Some caregivers, desperately in need of more support from their social networks, find those networks fading away as both family members and others visit less often. In some cases, this was to be due to fear of contagion while in other cases it seemed to flow from the sense of the diminished personhood of the afflicted elders. Our data suggest that dementia stigma has the potential to amplify suffering for family caregivers as well as the person with dementia and to obstruct other processes, such as social support.

This study has a number of possible limitations. First, as stated above, our participants consisted of immigrants living in limited socio-geographic areas: the urban environments of Boston and the San Francisco Bay Area. Our samples from these moderately wealthy areas of the US may not be representative of people in suburban or rural areas, or in other socioeconomic circumstances. Even within the participants, there is diversity in immigration history and the individual travails (of both caregiver and care receiver) faced through changing political regimes. Generalizability may be limited, too, because the Chinese and Vietnamese families who were experiencing more intense stigma in connection with dementia may have been more reluctant to participate in an interview study, biasing our sample in the direction of cases with less intense stigma. Related, our informants were identified because of their demented relative’s participation in formal services (i.e. clinics, adult day health programs) and thus the samples may be different from those who choose not to participate in such services. The size of this sample, particularly the Vietnamese subgroup, although acceptable within an exploratory qualitative framework, is modest, and makes for caution in generalizing findings. Almost all the interviews were translated from spoken Chinese to written English in one-step with the original tapes were not available for this analysis. This limited our ability to define with more precision some specific idioms and linguistic nuances that might deepen the cultural analysis.

In addition, our data were collected almost a decade ago, when Asian American communities may have been more insulated from biomedical models of Alzheimer’s disease and related dementias. With the development of the cholinesterase inhibitors in the mid-1990s, for example, there was a much more concerted effort to reach out to minority communities, including Asian Americans. Yet there is strong evidence this study’s findings remain relevant today. A recent study by Ayalon and Arean (2004) found that a majority of Asian Americans respondents viewed Alzheimer’s disease as a form of “craziness.” In what is arguably the most widely read book on ethnicity and dementia, republished in 2006, authors of the chapter on Chinese Americans conclude that despite efforts to outreach to the community, Alzheimer’s is often viewed in terms of normal aging or “craziness” (Yeo and Gallagher-Thompson 2006). Anecdotal reports from a variety of social, healthcare and welfare service workers also support our argument that professionals today face similar barriers to providing outreach to

these families as they did a decade ago. Thus these data remain as relevant now as they were when initially collected.

Our findings have important clinical and research applications. Like Yang (2007), we suggest the need for more research on Chinese American, Vietnamese American, and other Asian American cultures that takes a more dynamic and process-oriented view of stigma. This may help the dementia field to move beyond the dichotomy between the stigmas of chronic and severe mental illness and “normal aging” to engage how these meanings are intertwined, negotiated and responded to by family members. Herskovits has written on the stigma of aging in relation to Alzheimer’s Disease in a nonspecific though largely Western culture (Herskovits 1995). This, along with previous work on the stigma of health conditions culturally defined to be “normal” in old age, such as urinary incontinence (Mitteneß and Barker 1995), may provide a framework with which to broach the subject among the various Asian American populations. In this study, we observed a fair degree of variability in the intensity of felt stigma across families that we were unable to account for. It might be productive, for example, to compare and contrast families who manifest high and low stigma in the context of similar degrees of cognitive and behavioral disturbance in their elderly family member. This might help to illuminate the varied processes and social contexts of responding to and coping with these situations. Such directions in future research may illuminate more “successful” adaptation to behavior and cognitive change. While the focus of this paper has been on themes shared by the Chinese and Vietnamese participants, there are likely to be important differences as well. Further research, ideally more ethnographic, would help better characterize each ethnic group and provide richer data to perform cross-cultural analyses.

We hope that this paper will stimulate a re-examination of what the perceptions of the elderly in Chinese and Vietnamese cultures are, and how these may be protective, stigmatizing, or reinforce a negative trajectory. Our work also highlights the need to examine the cultural meanings associated with dementia among these and other Asian American cultures as a moving target, evolving through interaction with the mainstream media and developing technologies and scientific discourses.

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Table 1

Characteristics of participants (CG= caregiver, CR= care receiver, N/A = not available)

| ID # | Gender of CR | Age of CG | Relationship to CR | Education of CG | Brief Migration History |
|------|--------------|-----------|-------------------------------------|---------------------|---|
| 1 | Female | N/A | Daughter | College+ | CR was born in China but moved to Taiwan during the Communist takeover. CG was born in Taiwan. The CG came to Boston in 1984. CR came some time after. |
| 2 | Female | 52 | Son | Some high school | CR was born in Canton and lived in Hong Kong. CG was born in Shanghai. CG immigrated in 1974 and CR came 5 years later. |
| 3 | Male | 64 | Third wife | Some high school | CR was born in Guangdong, China. CG was born in Bangkok, Thailand. CR immigrated 50+ years ago. CG immigrated 7 years ago. |
| 4 | Female | 47 | Son | Some college | CR and CG were born in Guangzhou, China. CG immigrated 13 years ago, and CR immigrated 1 year prior. |
| 5 | Male | 50 | Daughter | 8th grade or less | CR was born in Guangdong, China. CG immigrated in 1989 and CR immigrated in 1993. Currently live in Boston. |
| 6 | Female | 38 | Daughter-in-law | High school | CG and CR both born in Guangdong, China. CG moved to Boston in 1985 and CR moved to Boston in 1986. |
| 7 | Male | 64 | Wife | High school | CG and CR were born in Canton, China. CR came to Boston in 1954. CG and their two daughters came in 1961. |
| 8 | Male | 58 | Wife | Some high school | CR and CG were born in Guang Dong, China. CG and CR came to the States in 1990. CG states she is now "an American". |
| 9 | Female | N/A | Daughter | N/A | CG and CR were born in Toishan, China. CG and CR "have been living in Boston for about 30 years." |
| 10 | Female | 41 | Daughter | High school | CR and CG born in were born in Shan Tou, China. CR came to the US in 1984. CG moved to Boston in 1994. |
| 11 | Female | 63 | Son | 8th grade or less | CR was born in China "Canton.. Toison..", CG was born in Toisan and came to the US in 1986. |
| 12 | Female | 56 | Daughter-in-law | Vocational training | CG was born in Malaysia, lived in Hong Kong, and came to the US in 1964. CR was born in China and came to the US in when "she was over 10 and married in Boston." |
| 13 | Female | 57 | Son | Some college | CG and CR were born in Toishan. CG came to US in 1968 and CR came in 1967. |
| 14 | Female | 31 | Daughter | College+ | CG was born in Lima, Peru. CR was born in Canton, China and moved to Peru in 1960. CG and CR immigrated Boston in 1969. |
| 15 | Female | 52 (CG1) | Son (CG1) and daughter-in-law (CG2) | High school | CR was born in Hong Kong. CG1 and CG2 both state they immigrated from Burma. CR immigrated before CG1 and CG2 who arrived in 1974. |
| 16 | Female | 48 | Daughter | 8th grade or less | CR and CG were born in China and lived in Hong Kong. They immigrated 10+ years ago and live in Boston |
| 17 | Female | 53 (CG1) | Son (CG1) and daughter-in-law (CG2) | Some high school | CR was born in Guangdong, China. CG1 and CG2 lived in Vietnam, but identify themselves as Chinese. They immigrated in 1979. CR immigrated in 1975. They live in Boston. |

| ID # | Gender of CR | Age of CG | Relationship to CR | Education of CG | Brief Migration History |
|------|--------------|-----------|---|---------------------|--|
| 18 | Female | 32 (CG1) | Grandson(CG1) and grandson's wife (CG2) | College+ | CR was born in Taiwan, but lived in Hong Kong for a period during Communist invasion. CG1 and CG2 were born in China. CR immigrated to U.S. in 1960s. CG1 and CG2 immigrated in 1989–1990. |
| 19 | Female | N/A | Son (CG1) and daughter-in-law (CG2) | N/A | CR was born in Canton, China and immigrated to Boston in 1938. CG information is not available |
| 20 | Female | 51 | Daughter | College+ | CR was born in Fujian, China. CG was born in Burma. CG and CR immigrated to Boston sometime prior to 1984. |
| 21 | Female | 40 | Daughter | College+ | CR was born in China, and lived in Taipei, Taiwan. CR immigrated 5 years ago. It is unclear when CG immigrated to Boston. |
| 22 | Female | 48 | Daughter | High school | N/A. Interview conducted in Boston. |
| 23 | Female | 47 | Daughter | High school | CR is from China. CG is from Hong Kong and immigrated in 1963 to Mississippi. Unclear when CR immigrated. |
| 24 | Male | 42 | Wife | Some college | CG and CR are from Vietnam. They immigrated to Concord, CA in 1993. |
| 25 | Female | 56 | Daughter | High school | CR is from Vietnam. CG is from Vietnam and has lived in Thailand and France. CR immigrated in 1975. It is unclear how long CG and CR have resided in San Francisco area. |
| 26 | Female | 42 | Great-niece | High school | CR is from southern Vietnam. CG immigrated to San Jose in 1991. Unclear when CR immigrated. |
| 27 | Male | 44 | Daughter | N/A | CG and CR are both from Vietnam. They immigrated in 1988. |
| 28 | Female | 51 | Daughter | College+ | CG is from southern Vietnam. CG and CR immigrated in 1992. They reside in Orange County |
| 29 | Female | 29 | Adopted daughter | Vocational training | CG and CR were born in Vietnam. They immigrated in 1991 through the Amer-Asian children program. At time of interview, CR was deceased. |
| 30 | Female | 34 | Son | High school | CG and CR were born in Vietnam. Interview was conducted in San Jose. |
| 31 | Female | 78 | Husband | N/A | CG and CR were born in Vietnam. CG immigrated in 1977. Unclear when CR immigrated. Interview was conducted in San Jose. |
| 32 | Female | 70 | Husband | 8th grade or less | CG and CR were born in Vietnam. They immigrated in 1992 through Children Journey. |