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Health Services Utilization Among Older Asian Americans

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Abstract

Older Asian Americans (OAAs) represent one of the largest and the fastest growing older minority populations nationwide. The striking growth and intra-group diversity of OAA underline the urgency for an improved understanding of ethnic Asian groups' health care access and service utilization patterns. This dissertation therefore examines health seeking and utilization behaviors among OAAs. It consists of two studies. The first study used secondary data from the 2011-2012 California Health Interview Survey (CHIS) to explore health service utilization (HSU) patterns among OAAs. Bivariate and multivariate regression analyses were conducted to examine the significant factors associated with physician visits, emergency department (ED) visits, and hospitalization, focusing on psychological distress as the key independent variable. The study findings suggest that psychological distress was associated with the utilization of ED services among older Korean and Chinese Americans. Other significant factors associated with HSU included self-reported health, length of residence in the U.S., and English proficiency. ED encounters may therefore represent opportunities to identify older Korean and Chinese Americans with psychological distress and initiate appropriate treatment.

The second study is a qualitative study that examined culturally-informed perceptions of dementia and barriers/facilitators in accessing/providing dementia-related services from the perspectives of older Korean and Chinese immigrants, their family caregivers, and home care providers. In-depth face-to-face interviewers were conducted with 12 older Asian immigrants and 12 family caregivers. Three semi-structured focus group sessions were conducted with home care professionals and ethnic home health aides. Data were analyzed using the conventional content analysis approach. Six themes emerged: perceptions and attributions of dementia, delayed help-seeking, perceived barriers in accessing care, caregiving burdens, barriers in providing care, and service needs. The findings underscore the importance of culture in shaping perceptions of dementia and related help-seeking behaviors. Culturally and linguistically appropriate training and educational programs should be developed to enhance awareness and knowledge of dementia in the Asian community to facilitate timely help-seeking. Culturally and linguistically appropriate social services are imperative to address the emotional and social needs of older Asian immigrants and their family caregivers.

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ABSTRACT

HEALTH SERVICES UTILIZATION AMONG OLDER ASIAN AMERICANS

Dexia Kong

Yin-Ling Irene Wong

Older Asian Americans (OAAs) represent one of the largest and the fastest growing older minority populations nationwide. The striking growth and intra-group diversity of OAA underline the urgency for an improved understanding of ethnic Asian groups' health care access and service utilization patterns. This dissertation therefore examines health seeking and utilization behaviors among OAAs. It consists of two studies. The first study used secondary data from the 2011-2012 California Health Interview Survey (CHIS) to explore health service utilization (HSU) patterns among OAAs. Bivariate and multivariate regression analyses were conducted to examine the significant factors associated with physician visits, emergency department (ED) visits, and hospitalization, focusing on psychological distress as the key independent variable. The study findings suggest that psychological distress was associated with the utilization of ED services among older Korean and Chinese Americans. Other significant factors associated with HSU included self-reported health, length of residence in the U.S., and English proficiency. ED encounters may therefore represent opportunities to identify older Korean and Chinese Americans with psychological distress and initiate appropriate treatment.

The second study is a qualitative study that examined culturally-informed perceptions of dementia and barriers/facilitators in accessing/providing dementia-related services from the perspectives of older Korean and Chinese immigrants, their family caregivers, and home care providers. In-depth face-to-face interviewers were conducted with 12 older Asian immigrants and 12 family caregivers. Three semi-structured focus group sessions were conducted with home care professionals and ethnic home health aides. Data were analyzed using the conventional content analysis approach. Six themes emerged: perceptions and attributions of dementia, delayed help-seeking, perceived barriers in accessing care, caregiving burdens, barriers in providing care, and service needs. The findings underscore the importance of culture in shaping perceptions of dementia and related help-seeking behaviors. Culturally and linguistically appropriate training and educational programs should be developed to enhance awareness and knowledge of dementia in the Asian community to facilitate timely help-seeking. Culturally and linguistically appropriate social services are imperative to address the emotional and social needs of older Asian immigrants and their family caregivers.

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CHAPTER 1: INTRODUCTION

Background and Significance

According to the Administration on Aging (2015), there were 1.9 million Asians age 65 years or older in 2014, amounting to 4.1 percent of the total older adult population. The number of older Asian Americans (OAAs) is projected to grow to over 8.5 million by 2060, amounting to 9 percent of the total older adult population (Administration on Aging, 2015). OAAs represent the third largest (below to older African Americans and Hispanics) and the fastest growing older minority population nationwide (Administration on Aging, 2010; Hoeffel, Rastogi, Kim, & Hasan, 2012). Between 2000 and 2010, OAAs increased by 68.3% nation-wide, followed by Hispanic (58.2%), Native Hawaiian/Pacific Islander (48.9%), Native American (40.5%), and African American older adults (19.8%) (Administration on Aging, 2010). The dramatic growth of OAAs is a result of the aging of the existing population and a continuous stream of older Asians who immigrate to reunify with their families (Pourat, Lubben, Yu, & Wallace, 2000).

Commonly aggregated as one ethnic group, OAAs feature a vastly diverse population. Based on countries of origin, there are approximately 26 subgroups with distinct demographic characteristics, socio-economic statuses, years lived in the United States (U.S.), immigration histories, health status, and cultural and linguistic backgrounds (Frisbie, Cho, & Hummer, 2001; Kim et al., 2010; T. Kuo & Torres-Gil, 2001; Ryu, Young, & Kwak, 2002; Sentell & Braun, 2012; Zhang & Ta, 2009). The largest older Asian subgroups are Chinese, Filipinos, Asian Indians, Vietnamese, Korean, and

Japanese (Hoeffel et al., 2012). Over 85% of OAAs are foreign-born immigrants (Kim et al., 2010). Despite the striking growth and intra-group diversity of OAA, this population is underrepresented in health research. To address this significant knowledge gap, the purpose of this dissertation was to examine help seeking and health services utilization (HSU) behaviors among OAAs. It consists of two studies.

Purpose and Specific Aims

The first study used secondary data from the 2011-2012 California Health Interview Survey (CHIS) to explore HSU patterns among OAAs. The study aims to address four specific questions: First, what are the factors associated with utilization of three types of health services (physician visits, one or more nights in hospital, and one or more emergency department (ED) visits) by OAAs? Second, what are the factors associated with utilization of the three types of health services in older Korean and Chinese Americans? Third, to what extent is psychological distress associate with utilization of the three types of health services among OAAs? Fourth, to what extent is psychological distress associated with utilization of the three types of health services in older Korean and Chinese Americans? Findings of this study will pinpoint key determinants of utilization of different types of health services which would enable health practitioners and policy makers to develop tailored interventions to reduce health disparities among OAAs. Additionally, the findings could potentially inform the development of effective interventions to reduce unnecessary medical expenditures and promote timely mental health treatments among OAAs.

The second study is a qualitative study examining culturally-informed perceptions of dementia and facilitators/barriers in accessing and providing culturally appropriate services in Korean and Chinese immigrant communities in Philadelphia. Focusing on a specific health condition, the study aims to address three questions: first, what are the perceptions of dementia and barriers/facilitators in accessing care among first-generation older Korean and Chinese immigrants? Second, what are the perceptions of dementia and barriers/facilitators in accessing care among Korean and Chinese family caregivers? Third, what are the perceptions of dementia and barriers/facilitators in providing care in the home among ethnic Asian home care providers? Findings from this study will describe the perceptions of dementia in the Asian community and highlight the gaps in knowledge of the disease, which will enable practitioners to develop culturally appropriate educational interventions to promote the awareness of dementia and encourage early diagnosis and timely treatment. The findings will further our understanding of the barriers and facilitators to accessing/providing dementia care and will be used to develop outreach programming tailored to older Asians and their families. Ultimately, findings of the study will facilitate improved clinical communication and health outcomes for older Asian immigrants with dementia.

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CHAPTER 2: PSYCHOLOGICAL DISTRESS AND HEALTH SERVICES UTILIZATION AMONG OLDER ASIAN AMERICANS

Introduction

With the rapid growth of the OAA population, empirical evidence on their health service utilization (HSU) patterns has been accumulating (Jang, Kim, & Chiriboga, 2005; Miltiades & Wu, 2008; Nguyen, Choi, & Park, 2015; Ryu et al., 2002; Shibusawa & Mui, 2010; Shin, Kim, Juon, Kim, & Kim, 2000; Sohn & Harada, 2004). However, existing studies examining HSU among OAAs focus on physical health needs along with sociodemographic characteristics as the major determinants. Even though psychological distress is reported to be one of the strongest predictors of HSU in the general older adult population, there is scant information on the relationship between psychological distress and HSU among OAAs (Fischer et al., 2002; Huang et al., 2000).

The relationship between psychological distress and HSU is of particular relevance for OAAs for two reasons. First, it has been reported that OAAs are more likely to report symptoms of mental distress and severe mental illness than their white counterparts (Sorkin, Pham, & Ngo-Metzger, 2009; Sorkin, Nguyen, & Ngo-Metzger, 2011). Second, an emerging body of literature suggests OAAs tend to present mainly somatic symptoms of distress due to stigma and culturally determined symptom conceptualization and expressions (Chun, Enomoto, & Sue, 1996; Herrick & Brown, 1998; Leong & Lau, 2001; Yeung, Chang, Gresham, Nierenberg, & Fava, 2004; Zaroff, Davis, Chio, & Madhavan, 2012; Zhang & Ta, 2009). Frequently reported somatic complaints related to distress in Chinese populations include bodily pain, insomnia, fatigue, dizziness, and chest heaviness (Parker, Cheah, & Roy, 2001; Wu, Chi, Plassman, & Guo, 2010). As a result, OAAs with mental disorders are inclined to seek help from general medical care settings where mental illnesses are under-diagnosed and undertreated (Himelhoch, Weller, Wu, Anderson, & Cooper, 2004; E. H. Lin, Carter, & Kleinman, 1985). Considering the possible prevalence of psychological distress and the tendency of somatic presentation of psychological conditions among OAAs, the omission of psychological conditions as a contributing factor of HSU represents a significant knowledge gap (Herrick & Brown, 1998; Leong & Lau, 2001; Yeung et al., 2004; Zaroff et al., 2012).

OAAs who seek medical services for psychological distress represent an indispensable health care concern with substantial fiscal, medical, and psychological implications. These patients undergo unnecessary medical procedures, which lead to delays to appropriate psychiatric treatments and prolonged personal suffering, while the underlying problem remains undertreated (Kirmayer, 2001; Suen & Tusaie, 2004). Furthermore, these patients pose special challenges to physicians in the diagnosis and treatment process (E. H. Lin et al., 1985). However, despite the negative consequences of the tendency to use medical services for psychological distress among OAAs, we have limited understanding of the relationship between psychological distress and HSU in this population.

Guided by Andersen's Behavioral Model of Health Services Use (ABM), this study attempts to bridge this knowledge gap by: 1) determining factors related to utilization of three types of health services (physician visits, nights in hospital, and ED visits) by OAAs as an aggregated group; 2) determining factors associated with utilization of three types of health services in Korean and Chinese subgroups; 3) examining the extent to which psychological distress is related to utilization of three types of health services among OAAs as an aggregated group; and 4) investigating the extent to which psychological distress is associated with utilization of three types of health services in Korean and Chinese subgroups.

Background and Significance

The striking growth of OAA underlines the urgency to understand the health service needs and utilization patterns of this population. OAAs are more likely to perceive their health to be poor than their white counterparts (Min, Rhee, Lee, Rhee, & Tran, 2014; Pourat et al., 2000; Sohn & Harada, 2004). Previous research also suggests that OAAs experience higher rates of functional limitations (Jang et al., 2005; Pourat et al., 2000). Additionally, OAAs are disproportionately affected by several illnesses, such as diabetes, hypertension, tuberculosis, hepatitis B, liver cancer, and coronary heart disease (J. Chen, Vargas-Bustamante, & Ortega, 2013; Min et al., 2014; Ngo-Metzger et al., 2003; Pourat et al., 2000). However, it is well documented that OAAs underutilize health services compared to the general older adult population (Frisbie et al., 2001; Jang et al., 2005; W. T. Liu & Yu, 1985; Ngo-Metzger et al., 2003; Shibusawa & Mui, 2010).

A closer scrutiny of the existing literature reveals that service utilization rates actually vary for different types of health services among OAAs (Ye, Mack, Fry-Johnson, & Parker, 2012). Specifically, OAAs tend to underutilize preventive care (such as regular physician visits and screening services), dental care, and hospice services (W. T. Liu & Yu, 1985; Ngo-Metzger et al., 2003; Saha, Arbelaez, & Cooper, 2003; Sohn & Harada, 2004; Tang, Solomon, & McCracken, 2000; Ye et al., 2012). OAAs are reported to have accrued only half of the general doctor visits used by their white counterparts (W. T. Liu & Yu, 1985). Min and colleagues (2014) further reported that OAAs have the lowest rate of general doctor visits compared to their non-Hispanic White and Hispanic counterparts. Additionally, OAAs have lower cancer screening rates, such as colorectal cancer screening and mammography rates, than whites (Boult & Boult, 1995; J. Y. Chen, Diamant, Pourat, & Kagawa-Singer, 2005). Moreover, OAAs with cancer are substantially less likely to use hospice services compared to their white counterparts (Ngo-Metzger et al., 2003). However, in contrast to the typical underutilization of health services among minority populations, evidence points to higher rates of hospital stays and ED use among Asian Americans (J. Chen et al., 2013; Pourat et al., 2000). According to Liu and Yu (1985), length of hospital stay among AAs is almost triple that of white Americans. Additionally, AAs have the highest rate of ED use compared to any other populations (W. T. Liu & Yu, 1985). Ye and colleagues (2012) reported that foreign-born AAs, who typically underutilize health services, visit the ED as often as their counterparts who are born in the U.S. Although evidence indicates that OAAs accrue low rates of physician and dental visits but high rates of ED visits and hospital stays, empirical evidence on what drives these differences is sparse. The variation in use of specific services requires separate analyses to understand the contributing factors to use of specific services.

Researchers have identified an array of variables that affect the HSU patterns of OAAs, including socio-demographic characteristics, health insurance coverage, health needs, and social network/support (Miltiades & Wu, 2008; Pourat et al., 2000; Ryu et al., 2002; Shibusawa & Mui, 2010; Shin et al., 2000). Additionally, several immigrant-specific factors have been commonly reported to be significant in explaining HSU among OAAs, including English proficiency, years lived in the U.S., and citizenship status (T. Kuo & Torres-Gil, 2001; Pourat et al., 2000; Ryu et al., 2002). Health needs have been consistently reported as the most significant predictor of HSU among OAAs (Pourat et al., 2000; Ryu et al., 2002; Shibusawa & Mui, 2010; Shin et al., 2000). Measures of health needs in these studies include number of chronic conditions, self-reported health status, functional limitations, and number of sick days. However, existing studies with OAAs focus on physical health needs along with various socio-demographic characteristics as the major predictors of HSU. Even though the relationship between psychological distress and HSU is well established in the general population, whether psychological distress affects HSU among OAAs is unknown.

A careful review of the literature with respect to whether psychological conditions are associated with HSU among OAAs yields only two studies. Miltiades and Wu (2008) reported that depression, as measured by the short version of the Center for Epidemiologic Studies Depression Scale (CES-D), was positively associated with the number of physician visits in their sample of 177 older Chinese immigrants in Boston. However, the relationship turned out to be insignificant when other socio-demographic and health characteristics were controlled. Using the same measure of depressive symptoms (CES-D), Pourat and colleagues (1999) reported that the presence of depressive symptoms significantly reduced the likelihood of use of traditional medicine in their 223 older Korean participants. Findings of these two studies are limited by their inclusion of only one Asian ethnic group. Thus, whether the findings could be generalizable to other ethnic Asian groups is unknown. Taken together, empirical evidence on the association between psychological distress and HSU among OAA is scant and fragmentary.

Prevalence of psychological distress among OAAs

Although information on the prevalence of psychological distress among OAAs is limited, previous studies suggest OAAs as an aggregate population are more likely to report mental distress and symptoms indicative of serious mental illness than their white counterparts (B. C. Kuo, Chong, & Joseph, 2008; Sorkin et al., 2009; Sorkin et al., 2011). OAAs have 50% higher odds of reporting psychological distress than their white counterparts after adjusting for socio-demographic and health characteristics (Sorkin et al., 2009). These results that are specific to psychological distress are consistent with findings from previous studies that suggest OAAs are generally more likely to report symptoms indicative of psychiatric problems (Jang et al., 2005; Shibusawa & Mui, 2002). It is further reported that significant subgroup differences exist among Asian subgroups regarding psychological distress (Kim et al., 2010; B. C. Kuo et al., 2008; Sorkin et al., 2011). Overall, all older Asian subgroups are more likely to report distress symptoms than their white counterparts, except for older Japanese Americans (Sorkin et al., 2011). In addition, older Korean, Filipino, and Vietnamese Americans are most likely to report psychological distress, followed by older Chinese, south Asian and Japanese Americans (Kim et al., 2010; Sorkin et al., 2011). Taken together, existing evidence indicates the prevalence of psychological distress may be higher in OAAs and significant subgroup differences exist regarding psychological distress in this population.

Utilization of health services among OAAs with psychological distress

Individuals of Asian descent are more likely to emphasize somatic complaints rather than affect when facing psychological distress than those of European descent (Kung & Lu, 2008; K. Lin & Cheung, 1999; Ryder et al., 2008; Suen & Tusaie, 2004; Zaroff et al., 2012). As a result, instead of seeking services from mental health specialists, Asian populations are inclined to seek help from hospitals, physicians, and traditional medicine for assistance with their mental health concerns (Kung & Lu, 2008; Leong & Lau, 2001; Sorkin et al., 2009; Suen & Tusaie, 2004; Yeung et al., 2004). Existing literature offers three possible explanations for why Asian populations tend to seek general medical services for conditions that are psychological in nature. First, stigma associated with mental illness in Asian cultures is widely cited as a major reason (Ryder et al., 2008; Zaroff et al., 2012). In Asian cultures, mental disorders are attributed to moral defect, personal weakness, sin from previous lives, hereditary defect, and bad upbringing (Pang, 1998; Suen & Tusaie, 2004). Presenting psychological distress as physical discomforts, which are more socially acceptable, is postulated to be a coping mechanism by Asian populations to avoid stigma associated with mental disorders and solicit external help (Kung & Lu, 2008; Leong & Lau, 2001; Zaroff et al., 2012).

Second, culturally informed perceptions of psychological conditions affect help-seeking behaviors regarding distress in Asian populations (Leong & Lau, 2001). Asian cultures perceive the body and the mind as unitary (Pang, 1995). This perception significantly influences the causal attribution of psychological conditions and the resulting help-seeking behaviors (K. Lin & Cheung, 1999). According to Kung (2001), Chinese Americans describe mental disorders as malfunctions of the organs, which logically lead to a higher propensity to seek medical care instead of mental health services for their psychological distress.

Lastly, culturally-informed symptom expression of mental conditions in Asian populations represents another commonly reported explanation of OAAs' tendency to seek general medical care for physiological conditions (Kung & Lu, 2008; Ryder et al., 2008). A qualitative study by Pang (1998) examining the ways older Korean Americans express depressive symptoms reported that the older Korean informants tend to use body-oriented language to express their emotional states. A review of literature suggests that commonly reported symptom expressions regarding distress among Asian immigrants include pain, heaviness in the heart or chest, indigestion, headaches, insomnia, and dizziness (Pang, 1995; Pang, 1998; Ryder et al., 2008). Additionally, Asian cultures consider emotions as private matters and tend to withhold articulation of emotional state and psychological feelings from others (Leong & Lau, 2001; Ryder et al., 2008). This cultural norm further prompts Asian populations to use physical complaints to express psychological distresses (Ryder et al., 2008; Suen & Tusaie, 2004).

Individuals who seek medical services for psychological distress represent an indispensable health care concern with significant fiscal, medical, and psychological implications. These patients undergo unnecessary medical procedures, which lead to delays to receive appropriate psychiatric treatment and prolonged personal suffering (Suen & Tusaie, 2004). Despite the negative consequences to use medical services for psychological distress, existing research on this issue is scant. Especially, even though psychological conditions, such as depression and psychological distress, have been reported to be the strongest predictors of hospital use and doctors' visits in the general population, whether such relationships hold true for OAAs has not been systematically examined (de Boer, Wijker, & de Haes, 1997).

This knowledge gap warrants systematic investigation considering the high prevalence of psychological distress among OAAs and the observed tendency to seek medical services for mental disorders in this population. To address this significant knowledge gap, the present study aims to examine the relationship between psychological distress and HSU in a sample of OAAs. Examining the association between psychological distress and HSU has significant implications for devising effective interventions to reduce unnecessary medical expenditures and promote timely mental health treatments among OAAs. The prevalence of psychological distress and the negative consequences of utilizing medical services to address symptoms that are psychiatric in nature justify the significance of this study.

Conceptual Framework

The present study was guided by the ABM, which is widely recognized as a useful and comprehensive theoretical framework for examining HSU in diverse populations (Andersen, Harada, Chiu, & Makinodan, 1995; Choi, 2011; Wolinsky, 1994). The model was initially developed in the late 1960s to predict and explain families' utilization of formal health services and promote equitable health care access (Andersen, 1995). Although subsequent revisions of the model from 1970s through 1990s proposed the inclusion of health care system factors and external environment characteristics, research applying the behavioral model focuses on the individual determinants of the decision to use formal health service (Andersen, 1995; Andersen & Newman, 2005; Andersen, 2008). According to the model, HSU is a function of individuals' predispositions to use health services (predisposing factors), ability to mobilize resources to obtain such services (enabling factors), and needs for the services (need factors) (Aday & Andersen, 1974; Andersen, 1995; Andersen & Newman, 2005).

Predisposing factors are defined as individual characteristics that relate to different propensities of certain individuals towards more or less use of health services prior to the onset of any specific illnesses (Aday & Andersen, 1974; Andersen & Newman, 2005). Such characteristics include demographic and social structure characteristics, and health beliefs. Demographic characteristics are important predictors of HSU due to the documented relationships between these characteristics and physical needs and illness patterns, which subsequently lead to differences in HSU (Andersen & Newman, 2005). Common measures of demographic characteristics include age, gender, marital status, and past illnesses. Social structure comprises an array of characteristics that represent the social status of an individual (Andersen & Newman, 2005). Commonly used measures of social structure include educational attainment, employment, and ethnicity. Health beliefs are defined as attitudes, values, and knowledge individuals have toward health and health services which affect their perceived health need and use of health services (Andersen, 1995; Andersen & Newman, 2005). According to Andersen and Newman (2005), predisposing factors are not direct reasons for the utilization of health services. Instead, people in different subcategories under each predisposing factor may have different inclinations towards HSU, which subsequently leads to different utilization patterns. In OAA samples, older age, female sex, and higher educational levels, are associated with higher levels of HSU (Pourat et al., 2000; Sohn & Harada, 2004).

Enabling factors refer to resources and means an individual mobilizes to facilitate his/her service utilization (Aday & Andersen, 1974). When individuals are predisposed to use health services, they must have resources and means that permit them to use the services (Andersen & Newman, 2005). Enabling factors not only include resources and means that are available to the individual and his/her family, but also characteristics of the community where the individual resides (Aday & Andersen, 1974; Andersen & Aday, 1978). Indicators that have been used to measure individual/family resources include health insurance coverage, type and access to regular source of care, living arrangement, and social support. Indicators commonly used to measure community resources include rural/urban residence, and health personnel and facilities to population ratios (Aday & Andersen, 1974; Andersen, 1995; Andersen & Newman, 2005). Researchers suggest that OAAs who have health insurance coverage, larger social support networks, more chronic conditions, and poorer self-rated health, have higher levels of HSU (Jang et al., 2005; T. Kuo & Torres-Gil, 2001; Miltiades & Wu, 2008; Shibusawa & Mui, 2010; Sohn & Harada, 2004).

Need factors are conceptualized as perceived needs reported by individuals and professional-evaluated needs (Andersen et al., 1995; Wolinsky, 1994). In addition to the predisposing and enabling factors, individuals must perceive the need for health services for utilization to take place (Andersen & Newman, 2005). Measures of perceived need include self-reported general health, number of disabilities, number of sick days in bed, and self-reported functional status/limitations. Evaluated needs generally contain chronic condition diagnoses (Andersen & Newman, 2005). The need factors are widely reported to be the principal and most significant predictor of HSU (Aday & Andersen, 1974;

Andersen & Newman, 2005). In OAAs, more chronic medical conditions, more basic activities of living difficulties, and fewer instrumental activities of living difficulties, are associated with more physician visits (Jang et al., 2005; Pourat et al., 2000; Shibusawa & Mui, 2010; Sohn & Harada, 2004).

In the behavioral model, utilization of health services is characterized into its type, purpose, and unit of analysis (Aday & Andersen, 1974; Andersen & Newman, 2005). The type of utilization is defined as the kind of services and the providers of such services, such as hospital, physician, dental, and ED (Aday & Andersen, 1974). The purpose of utilization refers to the nature of the services, such as preventive care, illness-related care, and custodial care. Preventive services are efforts to prevent illnesses from happening, such as immunization and screenings. Illness related care include treatments and management of both acute and chronic illnesses. Custodial care refers to services that attend to personal needs of the individual without treating any underlying illnesses, such as personal care. The unit of analysis of utilization refers to whether the focus is contact or volume. Contact is defined as whether or not an individual received the health service under examination during a given period of time. Volume is defined as the number of services received in a given period of time (Aday & Andersen, 1974; Andersen & Newman, 2005). Andersen further (1995) suggested that the individual determinants of utilization have different relative importance depending on the type, purpose, and unit of analysis examined (Aday & Andersen, 1974). Specifically, Andersen (1995) proposed that demographic characteristics and need factors would be the major determinants of hospital stays. Dental services, which are considered to be dispensable, would more likely be explained by social structure and enabling factors. Doctor visits would be explained by all three components of the individual determinants.

Applications of the model in OAAs

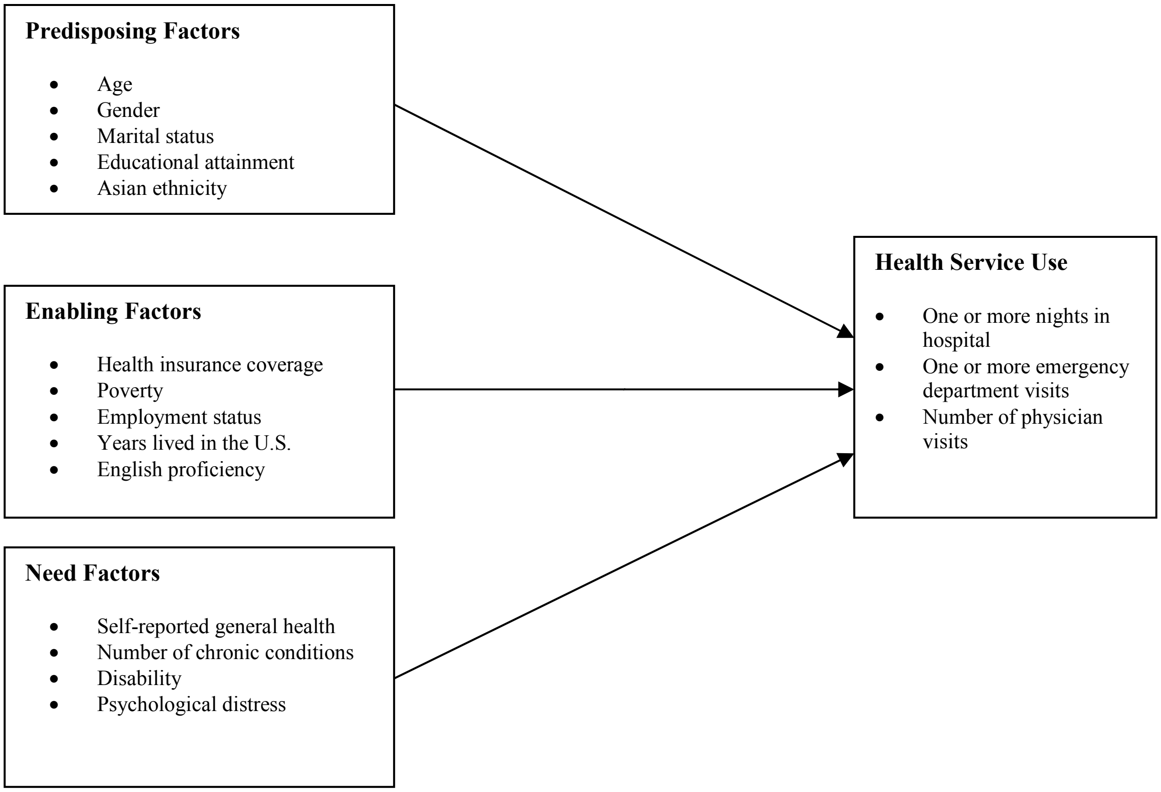
Numerous studies have used the behavioral model to examine HSU among OAAs, including physician visits, hospital stays, emergency department service use, and use of traditional medicine (T. Kuo & Torres-Gil, 2001; Miltiades & Wu, 2008; Nguyen, 2012; Ryu et al., 2002; Shibusawa & Mui, 2010; Sohn & Harada, 2004). Findings of these studies have two suggestions.

First, the existing studies indicate that although enabling factors tend be insignificant in predicting HSU of the general older adult population, these factors are important in explaining HSU among OAAs considering the high uninsured rate in this population (Choi, 2006; T. Kuo & Torres-Gil, 2001; Shibusawa & Mui, 2010; Shin et al., 2000). Chen and colleagues (2005) reported that OAAs have the highest uninsured rates among the older adult population. Although older adults are more likely to be insured than any other age groups due to public health insurance programs such as Medicare and Medicaid, OAAs, especially those who are non-citizen immigrants, are much more likely to lack health insurance than their naturalized or native-born counterparts (Carrasquillo, Carrasquillo, & Shea, 2000). Previous studies reported that enabling factors, especially health insurance coverage and having a regular source of care, are prominent factors associated with use of hospital and ED services and physician visits among OAAs ((T. Kuo & Torres-Gil, 2001; Miltiades & Wu, 2008; Ryu et al., 2002; Shibusawa & Mui, 2010).

Second, several studies have modified the model since it has been recognized that the original behavioral model lacks attention to cultural and structural barriers faced by immigrant populations (T. Kuo & Torres-Gil, 2001; Moon, Lubben, & Villa, 1998; Nguyen, 2012). The modifications emphasize the importance of several immigration-specific factors in HSU research of older Asian populations, such as English proficiency, citizenship status, and years lived in the U.S. Kuo and Torres-Gil (2001) suggested that the inclusion of such factors that are specific to older Asian immigrants significantly improved the amount of variance explained by the model. In order to capture the characteristics that are specific to OAAs which relate to HSU, this study modifies the behavioral model by incorporating two immigration-specific factors, including English proficiency and years lived in the U.S. The modified behavioral model is graphically presented in Figure 1.

To summarize, the present study builds on prior research in three aspects. First, since categorizing Asian subgroups as one ethnic group, such as Asian American/Pacific Islanders, obscures the unique health needs and service utilization patterns of the diverse population, which leads to misleading health service findings and information, the present study conducts subgroup analysis to prevent such erroneous generalizations (Ryu et al., 2002). Second, to bridge a significant knowledge gap, the present study examined the relationship between psychological distress and HSU among OAAs. Last, different from existing studies, most of which focus on one type of health service to examine significant factors associated with service use, three different types of health services were included in this study to assess whether significant predictors of service utilization vary among types of health services. The inclusion of three different types of health services allowed a more comprehensive and nuanced investigation of the relationship between psychological distress and HSU.

Figure 1. The Modified Andersen Behavioral Model of Health Services Utilization



Research Questions and Hypotheses

Research Question 1 (Aggregated group): What are the predisposing, enabling, and need factors associated with utilization of the three types of health services (physician visits, one or more nights in hospital, and one or more ED visit) by OAAs as an aggregated group?

Research Question 2 (Korean and Chinese subgroups): What are the predisposing, enabling, and need factors associated with utilization of the three types of health services (physician visits, one or more nights in hospital, and one or more ED visit) in Korean and Chinese subgroups, respectively?

Research Question 3 (Aggregated group): To what extent is psychological distress associated with utilization of the three types of health services among OAAs as an aggregated group?

> Hypothesis: Psychological distress is positively associated with HSU among OAAs as an aggregated group controlling for the covariates.

Research Question 4 (Korean and Chinese subgroups): To what extent is psychological distress associated with utilization of the three types of health services in Korean and Chinese subgroups?

> Hypothesis: Psychological distress is positively associated with HSU among the two subgroups controlling for the covariates.

Data and Methods

Data source

The California Health Interview Survey (CHIS) is an ongoing cross-sectional statewide health information survey of California's diverse racial and ethnic groups with detailed information on Asian ethnic subgroups (UCLA Center for Health Policy Research, 2014). CHIS has been conducted biennially since 2001. From 2011, CHIS has been conducted annually due to the increased ability to track health information in California and the effort to eliminate potential seasonality in the biennial data (UCLA Center for Health Policy Research, 2014). CHIS collects comprehensive information on the participants' health status, health conditions, health behaviors, health insurance coverage, health care access, and other health related issues (UCLA Center for Health Policy Research, 2014). This study will use the most recent cycle of CHIS data collected between June 2011 and January 2013 available for public use.

The CHIS 2011-2012 employed a dual frame, multi-stage sample design (UCLA Center for Health Policy Research, 2014). Telephone numbers assigned to landline (80%) and cellular services (20%) were included in the random-digit-dial (RDD) sample. For the landline RDD sample, 56 California counties were divided into 44 total sampling strata, including 39 single county strata, three multi-county strata, and two metropolitan county strata (Los Angeles and San Diego) with 14 sub-strata. Within each geographic stratum and sub-stratum, landline telephone numbers were selected, and within each household, one adult respondent who is 18 and older was randomly selected. Geographically targeted oversampling was employed to increase the precision of estimates for ethnic minority population groups (UCLA Center for Health Policy Research, 2014).

A separate cellular services RDD sample was drawn to capture the households without landline telephone services. The cell RDD sample was geographically stratified into 28 strata using telephone area codes. The adult owner of the sampled cell number was selected for the interview. If two or more adult members in a household shared a sampled cell number, one household member was randomly selected for the interview. It took approximately 35 minutes on average to complete the interview. The interviews conducted in non-English languages took longer (UCLA Center for Health Policy Research, 2014). Proxy interviews with an adult household member were conducted for frail and ill older adults. The overall response rate of the 2011-2012 CHIS was 35.1%, which was comparable to other telephone health surveys (UCLA Center for Health Policy Research, 2014).

CHIS data were chosen for three reasons. First, California has the largest older Asian population in the nation (Kim et al., 2010; National Asian Pacific Center on Aging, 2013). CHIS data provide a diverse sample of older Asian populations for health services research. For this study, a subsample of 1201 OAA participants in the 2011-2012 data set provides sufficient statistical power for data analysis. Second, the CHIS interviews were administered in six languages, including English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean. These languages were chosen based on languages that would cover the largest number of Californians who speak limited English as supported by 2000 Census data (UCLA Center for Health Policy Research, 2014). The inclusion of these OAAs who speak limited English is imperative considering the significant impact of language barriers on HSU. Third, unlike other national data sets that aggregate Asian subgroups, CHIS data identify the subgroups which allows for thorough examination of HSU patterns of specific Asian ethnic groups and cross subgroup comparisons.

Study Subjects

The sample for this analysis was extracted from the CHIS Public Use Data Files 2011-2012 (downloaded from http://healthpolicy.ucla.edu/chis/data/public-use-data-file/Pages/2011-2012.aspx). The sample for the analyses was restricted to adults aged 65 years and older who self-reported their ethnicity or race as Asian, including Korean (n=339), Chinese (n=290), Japanese (n=144), Vietnamese (n=241), Filipino (n=112), or others consisted of south Asian, southeast Asian, and other Asian groups or those with multiple Asian ethnicities (n=75). For this study, the sample is comprised of 1,201 OAAs. Subgroup analyses of this study focus on older Korean and Chinese Americans.

The inclusion of older Korean and Chinese Americans in the subgroup analyses is justified for two reasons. First, Korean and Chinese are among the five largest Asian subgroups living in the U.S. (National Asian Pacific Center on Aging, 2013). Second, the two subgroups share similar immigration patterns. Specifically, older Korean and Chinese immigrants came to the U.S. as voluntary immigrants as compared to other Asian subgroups who came as refugees, such as Vietnamese and Filipino (Ishii-Kuntz, 1997; Tsoh et al., 2016; Wong, Yoo, & Stewart, 2007).

Measures

Dependent Variables: Dependent variables include three indicators of HSU, namely one or more nights in hospital in the past 12 months, number of doctor visits in the past 12 months, and one or more ED visits in the past 12 months.

One or more nights in hospital in the past 12 months was measured by the question, "During the past 12 months, altogether how many nights were you in the hospital?" Response was the number of nights in the hospital as reported by the respondent, ranging from 0 to 25 nights. It was coded as a dichotomous variable ("1" if the respondent has spent one or more nights in hospital in the past 12 months and "0" if otherwise) to allow for valid inferential comparisons because using a distribution characterized by a high percentage of zeros (87.6%) to examine volume of service utilization is statistically problematic.

Number of doctor visits in the past 12 months was measured by the question, “During the past 12 months, how many times have you seen a medical doctor?". Response was the number of doctor visits as reported by the respondent, ranging from 0 to 156 times. Number of doctor visits is a count variable in this study.

One or more ED visits in the past 12 months was assessed by the question "During the past 12 months, how many times did you visit a hospital emergency room for your own health"? Response was the number of ED visits as reported by the respondent, ranging from 0 to 10 times and over. Since the majority (83.6%) of the respondents reported that they had no ED visits in the past 12 months, this variable was coded as a dichotomous variable due to the same reason discussed above regarding dichotomizing the nights in hospital variable.

<u>Independent Variable</u>: The primary independent variable was psychological distress, measured by the Kessler 6 (K6) scale. Study participants rated the extent to which they endorsed each scale item on a Likert scale with 4=all of the time, 3=most of the time, 2=some of the time, 1=a little of the time, 0=not at all. The total score, ranging from 0 to 24, was calculated by adding up the assigned scores for the six items in the scale. A higher score indicates a greater level of distress. A score of 6 and above indicates psychological distress, while 13 and above indicates serious mental illness (Sorkin et al., 2009). The scale was administered to all participants. After completion of the scale, all respondents were asked "was there ever a month in the past 12 months when these feelings occurred more often than they did in the past 30 days"? For those who answered no to this screening question, the sum of the assigned scores for the completed K6 Scale was used to assess their psychological distress in the past year. For those who answered

yes to this screening question, the K6 scale was repeated. Then the sums from the two times were compared. The higher value was used to assess these respondents' psychological distress in the past year. Previous studies that used the K6 scale among OAAs reported satisfactory internal consistency (α=0.89) (Kim et al., 2011).

Covariates: Additional covariates included relevant predisposing, enabling, and need factors as suggested in the literature.

Predisposing factors

Age was measured by three dummy variables representing older respondents between 65 and 74 years of age, between 75 and 84 years of age, and 85 and older, with those who were between 65 and 74 years of age coded as the reference category. *Gender* was coded "1" if male and "0" if female. *Marital status* was coded as either married or living with partner (reference category) or widowed, divorced/separated, and never married. *Educational attainment* was measured as either high school education and beyond (coded as 1) or less than a high school education (reference category). *Asian ethnicity* was coded as Korean, Chinese, or people of other ethnic Asian origins, with Koreans coded as the reference category.

Enabling factors

Health insurance coverage was coded "1" if the older respondent was insured, and "0" if otherwise. *Poverty level* was calculated by the reported total annual income of the household as a percent of the Federal Poverty Level (FPL). It was measured by one dummy variable representing 100-199% FPL and above, with 1-99% FPL coded as the reference category. *Employment status* was coded as "1" if employed and "0" if unemployed. *Years lived in the U.S.* was measured by one dummy variable representing 15 or more years of residency in the U.S., with less than 15 years of residency in the U.S. coded as the reference category. *English language proficiency* was measured by one dummy variable coded as either speaking English not well or not at all (coded as 1), or speaking only English or speaking English very well/well (coded as 0).

Need factors

Self-reported health was assessed using a single-item question, "Would you say that in general your health is excellent, very good, good, fair, or poor?" (Coded as 1=Excellent, 2=Very good, 3=Good, 4=Fair, and 5=Poor). *Number of chronic conditions* was constructed by summing the incidence of six chronic medical diagnoses, including asthma, diabetes, high blood pressure, stroke, arthritis, and heart disease. A higher score indicates a greater evaluated medical need, ranging from 0 to 6. *Disability* was assessed by asking older participants whether they had experienced any of five conditions, including blind or deaf, or have a severe vision or hearing problem; difficulty learning, remembering, or concentrating; difficulty dressing, bathing, or getting around the house; difficulty going outside the home alone to shop or visit a doctor's office; and condition that substantially limits one or more basic activities such as walking, climbing stairs, reaching, lifting, or carrying. Older participants who answered yes to any of the five conditions were categorized as "disabled" (coded as 1). Those that answered no to all of the five conditions were categorized as "not disabled" (coded as 0).

Data Analysis Plan

Descriptive statistics were performed on all variables to summarize the sample characteristics. Chi-square and t-tests were conducted to determine whether the sample characteristic differed between the Korean and Chinese samples. To account for CHIS's complex sampling design, replication weights and final weights were used in all statistical analyses to assure accurate population estimates. All analyses were conducted in Stata Version 13.

Research questions 1 and 2. What are the predisposing, enabling, and need factors associated with utilization of the three types of health services (physician visits, one or more nights in hospital, and one or more ED visits) by the aggregated OAAs, and Korean and Chinese subgroups?

To address these questions, a series of bivariate regression analyses were conducted to examine the significance of the independent variables on the three dependent variables without adjusting for the covariates. For the likelihood of having any nights in hospital and ED visits, logistic regressions were conducted to assess their association with each independent variable individually. For the number of doctor visits, Poisson regressions were fitted for each independent variable individually. A p-value of 0.05 was used to determine the significance of the associations in all bivariate models.

Research questions 3 and 4. To what extent is psychological distress associated with utilization of the three types of health services among the aggregated OAAs, and Korean and Chinese subgroups?

To address these questions, three separate multivariate regression models were fitted including the primary independent variable (psychological distress) and other predisposing, enabling, and need factors. For each type of health service, a separate regression model was fitted while controlling for the covariates to determine whether psychological distress was independently associated with the utilization of health services. Logistic regression was used in models with categorical dependent variables (the likelihood of having any nights in hospital or ED visits) while Poisson regression was used with the count-level dependent variable (the number of physician visits). The analyses for the Korean and Chinese subgroups followed the same procedure. A p-value of 0.05 was used to determine the significance of the relationship in all multivariate models. Tolerance values were examined to assess the degree of multicollinearity among independent variables in the multivariate regression models.

Results

Sample Characteristics: Aggregated Sample

The total sample description for OAAs is displayed in Table 1. Of the 1,201 OAAs, 55.5 percent were between 65 and 74 years old, 36.1 percent between 75 and 84, and 8.3 percent were 85 or older. A majority of the sample were female (57.4%), married or living with a partner (54.7%), and had high school or beyond education (76.2%). Korean Americans composed the largest OAA group (28.2%), followed by older Chinese (24.1%), older Vietnamese (20.0%), older Japanese (12.0%), older Filipinos (9.3%), and those from other older Asian ethnicities (6.2%).

Considering the enabling factors, of the sample, only 1.4 percent were uninsured, close to one-third of the respondents lived below the poverty line (0-99 federal poverty line), 88.3% were not employed and 96.6 percent lived in urban areas. Since nearly all participants were insured and lived in urban areas, insurance status and urban/rural residency were removed from the enabling factors in bivariate and multivariate regression analyses. In terms of the immigrant-related factors, a majority of participants reported their ability to speak English as not well or not at all (57.8%), while most were U.S. born or had lived in the U.S. for more than 15 years (91.2%).

For the need factors, overall, more than half (52.3%) of the aggregated OAA reported their health to be at least good, and 47 percent of the sample were disabled. On average, respondents reported that they experienced 2 chronic conditions in the past year (SD=1.2). Psychological distress scores ranged from 0 to 24, with 2.76 mean and 4.1 standard deviation. Finally, in terms of the dependent variables, an overwhelming majority of the sample had no ED visits (83.6%) or nights in the hospital (87.6%). Respondents visited a general medical doctor an average of six times (SD = 7.96) in the past year. The number of physician visits ranged from 0 to 156.

Sample Characteristics: Korean Subsample

Sample characteristics for the Korean and Chinese subgroups are displayed in Table 2. Approximately half of the Korean sample was between 65 and 74 years old, with forty percent between 75 and 84, and 10 percent aged 85 or older. A majority of the older Korean respondents were female (63.7%), married or living with a partner (51.3%), and had high school or beyond education (72.3%). In regard to enabling factors, 50.7 percent of the older Korean subsample lived in poverty. Over ninety percent of the older Korean respondents were not employed. Ninety-two percent of them were U.S. born or had lived in the U.S. for more than 15 years. A large majority of the older Korean respondents reported they spoke English not well or not at all (81.4%). Considering the need factors, 52 percent of the older Korean respondents reported fair or poor health, and over two thirds of them were disabled. On average, older Korean respondents reported that they experienced 2 chronic conditions in the past year (SD=1.1). Psychological distress scores ranged from 0 to 24, with 3.93 mean and 4.84 standard deviation. Finally, in terms of the dependent variables, the vast majority of older Korean respondents had no ED visits (85%) or nights in hospital (88.8%). Approximately 11 percent of the Korean sample had spent one or more nights in hospital. About 15 percent of the older Korean respondents had at least one ED visit in the past year. Older Korean respondents visited a general medical doctor an average of seven times in the past year. The number of physician visits ranged from 0 to 60 with 6.58 standard deviation.

Sample Characteristics: Chinese sample

Over half of the Chinese sample was between 65 and 74 years old, with 37 percent between 75 and 84, and 10 percent aged 85 or older. A majority of older Chinese respondents were female (57.9%), married or living with a partner (57.6%), and had high school or beyond education (76.2%). Considering the enabling factors, approximately 30 percent of older Chinese respondents lived in poverty. About 89 percent of them were not employed. Nearly 85 percent of them had lived in the U.S. for more than 15 years. Two thirds of older Chinese respondents reported they spoke English not well or not at all. For the need factors, 44.8 percent of the older Chinese respondents reported fair or poor health, and 56.2 percent of them were disabled. On average, older Chinese respondents reported that they experienced one chronic condition in the past year (SD=1.2). Psychological distress scores ranged from 0 to 20, with 2.5 mean and 3.65 standard deviation. Finally, in terms of the dependent variables, the vast majority of older Chinese respondents had no ED visits (80.3%) or nights in hospital (85.5%). Older Chinese respondents visited a general medical doctor an average of six times in the past year. The number of physician visits ranged from 0 to 96 with 7.88 standard deviation.

Sample Characteristics: Korean and Chinese Subsample Comparison

Significant group differences were noted between Korean and Chinese subsamples regarding poverty status, employment status, length of residence in the U.S., English proficiency, self-perceived health, disability status, and psychological distress. Older Korean respondents were, on average, poorer, had lived in the U.S. longer, and had lower English proficiency than their Chinese counterparts. In addition, older Korean respondents were more likely to be unemployed, disabled, and perceive their health to be poor than older Chinese respondents. Furthermore, consistent with previous research findings, older Korean respondents reported higher psychological distress during the past year compared to their Chinese counterparts (Chang & Moon, 2016). Considering the utilization of different types of health services, significant group difference was observed only in the number of physician visits. Specifically, in the past year, older Korean respondents accrued more visits to a general medical doctor than their Chinese peers.

Bivariate Analyses: Aggregated Sample

Research Question 1 (Aggregated-group): What are the predisposing, enabling, and need factors associated with utilization of the three types of health services (doctor visits, hospital stays, and ED visits) by OAAs as an aggregated group?

Table 3 presents the association of the three types of health services in the past twelve months with each predisposing, enabling, and need factor. Replication weights and final weights were included in all bivariate analyses to account for CHIS's complex sampling design.

One or more nights in hospital. The results of the bivariate analyses indicated that older age, gender, employment status, longer years lived in the U.S., poorer perceived health, disability status, and more chronic conditions were associated with the likelihood of having any nights in hospital in the past year. Specifically, OAAs who were 85 and over were five times more likely to have spent one or more nights in hospital in the past year compared to those who were between 65 and 74 years old. Furthermore, OAAs who had lived in the U.S. for less than 15 years had three times higher odds to have spent one or more nights in hospital than their counterparts. OAAs who were employed (OR=0.4) were less likely to have spent one or more nights in hospital in the past year. In addition, poorer perceived health was associated with higher odds to have spent at least one night in hospital in the past year among OAAs (OR=1.6). Each additional chronic health condition was associated with approximately two times higher odds to have spent at least one night in hospital in the past year for OAAs. Lastly, OAAs with disability had three times higher odds to have spent one or more nights in hospital in the past year than those without disability.

Number of physician visits. Male sex, unemployed status, poorer perceived health, more chronic conditions, and higher levels of psychological distress were positively associated with the number of physician visits in the past year for OAAs. Specifically, males were expected to have a rate 1.6 times greater for physician visits during the past year compared to females. The rate ratio for physician visits during the past year for OAA who were employed would be expected to decrease by a factor of 0.6. OAAs with poorer self-reported health had more doctor visits in the past year. The rate ratio for physician visits in the past year would be expected to increase by a factor of 1.2 for each additional chronic condition. Moreover, psychological distress was positively associated with the number of physician visits (Incidence rate ratio (IRR) = 1.1).

One or more ED visits. Older age, unemployment status, poorer perceived health, higher number of chronic conditions, disability status, and higher levels of psychological distress were positively associated with having had any ED visits in the past year among OAAs. Specifically, OAAs age 85 or older had 3.2 times higher odds to have one or more ED visits in the past year than those between 65 and 84 years old. OAAs who were not employed had 3.3 times higher odds to have one or more ED visits in the past year than those who were employed. OAAs with disability had 2.6 times higher odds to have visited ED one or more times in the past year than those without disability. Compared to their counterparts, OAA with poorer self-reported health (OR=1.3), higher numbers of chronic conditions (OR=1.3), and higher levels of psychological distress (OR=1.1) were more likely to have at least one ED visit in the past year.

Research Question 2 (Korean and Chinese subgroups): What are the predisposing, enabling, and need factors associated with utilization of the three types of health services (physician visits, one or more nights in hospital, and one or more ED visit) in Korean and Chinese subgroups, respectively?

Bivariate Analyses: Korean Sub-sample

One or more nights in hospital. For older Korean Americans, no predictor was statistically significant at the 0.05 significance level to predict one or more nights in hospital in the past year. Predictors that were significant at the 0.1 significance level included older age and the number of chronic conditions. Specifically, older Korean Americans age 85 or over had 3 times higher odds to have spent one or more nights in hospital in the past year compared to those between 65 and 74 years of age. Additionally, during the same time period, one more chronic health condition increased the odds to have spent one or more nights in hospital in the past year among older Korean Americans by approximately 2 times. Although the predictors did not reach statistical significance, the associated trend differences and high odds ratios warrant attention.

Number of physician visits. Older age, poorer self-reported health, and disability status were associated with more doctor visits in the past year for older Korean Americans. Specifically, older Korean Americans age 85 or over were expected to have a rate 2.73 times higher for physician visits during the past year than those between 65 and 74 years of age. In addition, poorer self-reported health was associated with more physician visits in the past year. Moreover, older Korean Americans with disability were expected to have a rate 1.9 times higher for physician visits in the past year than those who were not disabled.

One or more ED visits. Lower educational levels, higher numbers of chronic conditions, disability status, and higher levels of psychological distress increased the odds to have one or more ED visits in the past year in the Korean sample. Specifically, older Korean Americans who had less than high school education had nearly 7 times higher odds to have one or more ED visits in the past year than those that had high school and beyond education. Additionally, compared to their counterparts, older Korean Americans with more chronic conditions (OR=1.5) and higher levels of psychological distress (OR=1.2) were more likely to have one or more ED visits in the past year.

Bivariate Analyses: Chinese Sub-sample

One or more nights in hospital. Older age, unmarried status, unemployment, longer years in the U.S., poorer self-reported general health, higher numbers of chronic conditions, and disability status were associated with one or more nights in hospital in the past year among older Chinese Americans. Specifically, older Chinese Americans age 85 or older had nearly 4 times higher odds to have spent one or more nights in hospital in the past year, compared to those between 65 and 74 years of age. Compared to older Chinese Americans who were married or living with partners, those who were not married had 2.7 times higher odds to have spent at least one night in hospital in the past year. Furthermore, older Chinese Americans who were not employed had 11 times higher odds to have spent one or more nights in hospital in the past year than those that were employed. Compared to older Chinese Americans who lived in the U.S. for less than 15 years, those who were U.S. born and have lived in the U.S. for more than 15 years had 6 times higher odds to have spent at least one night in hospital in the past year. In addition, older Chinese Americans with disability had 4 times higher odds to have spent one or more nights in hospital in the past year than those without disability. Poorer self-reported health increased the odds to have spent at least one night in hospital (OR = 2.1). One more chronic condition increased the odds to have spent one or more nights in hospital in the past year by 1.8 times.

Number of physician visits. Age, education, employment status, self-reported health, and number of chronic conditions were associated with the number of physician visits in the past year among older Chinese Americans. Specifically, compared to older Chinese Americans age between 65 and 74, the rate ratio for physician visits in the past year would be expected to decrease by a factor of 0.7 for those between 75 and 84 years old. During the same time period, the rate ratio for physician visits for older Chinese Americans who were 85 or older would be expected to decrease by a factor of 0.5 compared to those between 65 and 74 years of age. Compared to older Chinese Americans with less than high school education, the rate ratio for physician visits in the past year would be expected to decrease by a factor of 0.7 among those with high school and beyond education. Compared to older Chinese Americans who were unemployed, the rate ratio for physician visits in the past year among those who were employed would be expected to decrease by a factor of 0.5. Furthermore, poorer self-reported health was associated with more physician visits in the past year among older Chinese Americans (IRR = 1.3). Each additional chronic illness increased the rate ratio for the number of physician visits in the past year by a factor of 1.3.

One or more ED visits. Older Chinese Americans who were older, unemployed, and had higher numbers of chronic conditions had higher odds to have one or more ED visits in the past year. Specifically, older Chinese Americans who age 85 or older had 6 times higher odds to have visited ED at least once in the past year than those between 65 and 74 years old. Compared to older Chinese Americans who were unemployed, those who were employed had lower odds to have visited ED at least one time in the past year (OR=0.06).

Additionally, each additional chronic condition was associated with 1.4 times higher odds to have visited ED at least one time in the past year among older Chinese Americans.

Research Question 3 (Aggregated group): To what extent is psychological distress associated with utilization of the three types of health services among OAAs as an aggregated group?

Multivariate Analyses: Aggregate sample

A series of multivariate regression models were conducted to determine the significant factors associated with the utilization of different types of health services, controlling for the covariates. The results from the multivariate regression models to examine the factors associated with ever stayed one or more nights in hospital for the aggregate sample are displayed in Table 6. Replication weights and final weights were included in all multivariate analyses to account for CHIS's complex sampling design. The tolerance values ranged between 0.87 and 0.92, which were greater than the common threshold of 0.1. Therefore, multicollinearity was not detected in the regression models.

One or more nights in hospital. Age, sex, English proficiency, self-reported health, and number of chronic conditions were associated with one or more nights in hospital in the past year for the aggregated OAA sample. Specifically, controlling for other covariates, OAAs who were 85 and older (OR = 3.7), male (OR = 2.6), and proficient in English (OR = 2.4) were more likely to have spent one or more nights in hospital in the past year than their counterparts. Moreover, while other covariates were controlled for, one additional chronic condition was associated with a 1.3 times higher odds to have spent at least one night in hospital in the past year among OAAs. Similarly, poorer self-reported health was associated with higher odds to have spent one or more nights in hospital in the past year among OAAs (OR = 1.6). Psychological distress was not statistically significant in predicting one or more nights in hospital for OAAs, while other covariates in the model were controlled.

Number of physician visits. Sex, employment status, and self-reported health were associated with the number of physician visits in the past year among the aggregated OAA sample, while other covariates were controlled. Specifically, OAAs who were male (Incidence Rate Ratio=1.6) were more likely to have physician visits in the past year than their counterparts while other predictors were controlled. Controlling for other covariates, OAAs who were employed had a lower rate for physician visits in the past year than those that were unemployed (IRR=0.6). Moreover, poorer self-rated health was associated with a greater number of physician visits. Specifically, a one unit increase in self-reported health (indicating poorer health) increased the incidence rate for physician visits by 18% while holding other covariates constant. Lastly, although psychological distress was statistically significant in the bivariate regression model (p=0.004), it was not significant once other covariates were controlled for (p=0.331).

One or more ED visits. Age, employment status, and English proficiency were associated with having had any ED visits in the past year for OAAs as an aggregated group. Specifically, OAAs age 85 or older (OR = 2.5) were more likely to have one or more ED visits in the past year compared to those between 65 and 74 years old, controlling for other covariates. Additionally, OAAs who were employed were less likely (OR = 0.3) than those who were unemployed to have one or more ED visits in the past year while other covariates in the model were controlled for. Furthermore, compared to

OAAs who spoke English not well or not at all, those that spoke only English or spoke English very well/well had approximately two times higher odds to have one or more ED visits in the past year while holding other covariates constant (OR = 2.3). Put differently, the odds of having one or more ED visits in the past year were positively associated with English proficiency among OAAs. Lastly, psychological distress was not statistically significant.

Research Question 4 (Korean and Chinese subgroups): To what extent is psychological distress associated with utilization of the three types of health services in Korean and Chinese subgroups?

Multivariate Analyses: Korean Sub-sample

One or more nights in hospital. No predictors were significant at the 0.05 significance level for ever spent one or more nights in hospital in the past year for the Korean subsample. Age and length of residence in the U.S. were significant at the 0.1 significance level. Specifically, while other covariates were controlled for, older Korean Americans age 85 or older had 3 times higher odds to have spent one or more nights in hospital in the past year, compared to those between 65 and 74 years old. Moreover, older Korean Americans who were born in the U.S. or those that had lived in the U.S. for more than 15 years were 71% less likely to have spent one or more nights in hospital than those that had lived in the U.S. for less than 15 years (OR = 0.3).

Number of physician visits. Education and self-reported health were associated with the number of physician visits in the past year in the Korean sample. Specifically, compared to older Korean Americans who had less than high school education, those that had high school and beyond education were expected to have a rate 1.7 times greater for physician visits in the past year. In addition, poorer self-reported health was associated with a greater rate for physician visits in the past year (IRR = 1.3).

One or more ED visits. Education and psychological distress were associated with the receipt of one or more ED visits in the past year for the Korean sample. Specifically, older Korean Americans who had high school and beyond education were less likely to have one or more ED visits in the past year compared to those that had less than high school education, while other covariates were controlled for (OR = 0.2). Furthermore, psychological distress was positively associated with the receipt of one or more ED visits in the past year, controlling for other covariates. Specifically, a one unit increase in the psychological distress score was associated with a 10% increase in the odds of having one or more ED visits in the past year among older Korean Americans.

Multivariate Analyses: Chinese sample

One or more nights in hospital. Sex, employment status, length of residence in the U.S., and self-reported health were associated with one or more nights in hospital in the past year among older Chinese Americans. Specifically, while holding other covariates constant, older Chinese Americans who were male (OR=4.6) were more likely to have spent one or more nights in hospital in the past year than their female counterparts. Further, compared to those who were unemployed, older Chinese Americans who were employed (OR = 0.1) were less likely to have spent one or more night in hospital in the past year while other covariates were controlled for. Older Chinese Americans who were born in the U.S. or had lived in the U.S. for more than 15 years had 6.8 times higher odds to have spent one or more nights in hospital in the past year than those who had lived in the U.S. for less than 15 years. Additionally, poorer self-reported health was associated with higher odds (OR = 2.4) to have spent at least one night in hospital in the past year among older Chinese Americans, controlling for other covariates.

Number of physician visits. Age, employment status, self-reported health, number of chronic conditions were associated with the number of physician visits in the past year among older Chinese Americans while other covariates were controlled for. Specifically, while holding other variables constant in the model, older Chinese Americans who were 85 or older had less physician visits than those between 65 and 74 years old (IRR = 0.5). During the same time period, older Chinese Americans between 75 and 84 years of age had less physician visits than those between 65 and 74 years of age (IRR = 0.7). Furthermore, older Chinese Americans who were employed had less physician visits in the past year than those that were unemployed (IRR = 0.5). Poorer self-reported health was associated with more physician visits in the past year among older Chinese Americans while holding other predictors constant (IRR = 1.2). Lastly, each additional chronic condition would be expected to increase the incidence rate for physician visits in the past year by a factor of 1.1 among older Chinese Americans while other predictors in the model were held constant.

One or more ED visits. While other predictors in the model were controlled for, age, employment status, English proficiency, and psychological distress were associated with the receipt of one or more ED visits in the past year among older Chinese Americans. Specifically, older Chinese Americans age 85 and older had approximately 6 times higher odds to have visited ED at least once in the past year than those between 65 and 74 years old. Moreover, compared to older Chinese Americans who were unemployed, those who were employed were less likely to have any ED visits in the past year while other covariates in the model were controlled for (OR = 0.1). Furthermore, older Chinese Americans who spoke only English or spoke English very well/well had 3.4 times higher odds to have one or more ED visits in the past year than those who spoke English not well or not at all. Lastly, a one unit increase in the psychological distress score was associated with a 10% increase in the odds to have one or more ED visits in the past year for older Chinese Americans, while other covariates were held constant.

Discussion

The study reveals several findings with significant practice and policy implications. First, the study findings underline the significant association between psychological distress and ED visits among older Korean and Chinese Americans. Second, the findings underscore the importance of perceived health in the utilization of health services among OAAs. Additionally, the findings highlight the importance of two immigration-related factors, including length of residence in the U.S. and English proficiency in the utilization of the different types of health services.

Psychological distress and HSU

Concordant with previous studies in the general older adult population, the findings suggest that the relationships between psychological distress and the likelihood of having any ED visits among older Korean and Chinese Americans were statistically significant, even after adjusting for medical comorbidities, self-perceived health, disability status, and other covariates (Brokaw & Zaraa, 1991; McCusker, Cardin, Bellavance, & Belzile, 2000; Rottenberg, Jacobs, & Stessman, 2013; Unützer et al., 1997). A prior study in Hong Kong reported similar findings (Chou, Ho, & Chi, 2005).

There are three possible mechanisms underlying the positive association between psychological distress and the likelihood to have any ED visits. First, distress may amplify symptoms of chronic medical illnesses and functional impairment, both of which are predictive of ED visits (Katon & Ciechanowski, 2002). Second, poor adherence to medical treatment regimens and reduced ability to self-manage chronic conditions resulting from distress could lead to deterioration or complication of chronic conditions, which ultimately might increase the likelihood to seek ED services in older Korean and Chinese Americans (DiMatteo, Lepper, & Croghan, 2000; Katon & Ciechanowski, 2002). Lastly, limited access to mental health care among older Asian populations may account for the observed association between psychological distress and ED utilization (Larkin, Claassen, Emond, Pelletier, & Camargo, 2005).

However, in the present study, the association between psychological distress and service utilization held for ED visits for the Korean and Chinese subsamples only. Contrary to previous studies, the relationship between distress and one or more nights in hospital and the number of physician visits were not significant in this study after controlling for other covariates (Kang, Kim, & Kim, 2016; Luber et al., 2001). The lack of such relationship in the present study in unexpected and bears further investigation. Additionally, distress was not associated with ED visits in the aggregated OAA sample. One possible explanation is that the heterogeneities in psychological distress prevalence and severity among Asian subgroups may obfuscate the relationship in the aggregated sample (B. C. Kuo et al., 2008).

Self-reported health and HSU

Congruent with existing studies, the findings underline the significance of perceived health in the number of physician visits and the likelihood of having any night in hospital among OAAs (Choi, 2006; Jang et al., 2005; Pourat et al., 2000). Aside from the fact that no variable was significant for ever spent one or more nights in hospital among older Korean Americans, poorer perceived health was associated with ever spent one or more nights in hospital in the aggregate sample and the Chinese sample. Additionally, poorer perceived health was associated with more physician visits across the three samples (the aggregate OAA sample, the Korean and the Chinese samples). It has been well documented that self-reported health is a powerful predictor of mortality, recovery from illness, and physical functioning among older adults even when other related covariates are controlled for (DeSalvo, Bloser, Reynolds, He, & Muntner, 2006; Y. Lee, 2000). Findings from the present study suggest that perceived health affects utilization of health service above and beyond the effect of the objective measures of health that are currently used in survey studies and clinical settings, such as the number of chronic conditions (DeSalvo et al., 2006; Pourat et al., 2000). Taken together, the findings illustrate the value of a single-item measure of overall health as a useful risk assessment tool that could facilitate health services planning in this population (DeSalvo et al., 2006).

However, perceived health was not significant in all ED models. One plausible explanation is that acute illnesses as well as fall-related injuries may represent stronger determinants of ED service use in this population, which could mitigate the relationship between perceived health and ED use (Gruneir, Silver, & Rochon, 2011). Nevertheless, this finding is inconsistent with previous studies and bears further investigation (Shah, Rathouz, & Chin, 2001).

Immigration-related factors and HSU

Immigration-related factors including length of residence in the U.S. and English proficiency, conceptualized in this study as enabling factors, were associated with HSU for the aggregate sample and the Chinese sample. Specifically, consistent with existing studies, the findings suggest that English proficiency was associated with HSU for the aggregate sample and the Chinese sample (Kim et al., 2011; T. Kuo & Torres-Gil, 2001; Sohn & Harada, 2004). One possible explanation is that OAAs with limited English proficiency may be more inclined to use traditional medicine due to cultural and communication barriers, reducing their utilization of the mainstream health services (Shibusawa & Mui, 2010; Shin et al., 2000; Sohn & Harada, 2004). OAAs that were more proficient in English, on the other hand, would have better access and utilization of mainstream health services.

The findings further indicate that older Chinese Americans who had lived in the U.S. for less than 15 years had higher odds to have spent at least one night in hospital in the past year than those that had lived in the U.S. for more than 15 years. It is possible that older Chinese Americans who had lived in the U.S. for shorter periods of time may have poorer health conditions due to stressors associated with immigration (Sohn & Harada, 2004). However, in the present study, length of residency in the U.S. was significant for one type of health services and for the Chinese sample only.

Concordant with existing studies, older age was associated with the likelihood of having any ED visits in the past year for the aggregated sample and the Chinese sample (Shah, Rathouz, & Chin, 2001; Wolinsky et al., 2008). Another interesting finding from this study is employment status was associated with utilization of all three types of health services in the Chinese sample. This finding is consistent with previous studies that document the beneficial effects of paid work and volunteer work on health in older adults (Luoh & Herzog, 2002). However, it is not clear why such relationship was not significant for the aggregated sample and Korean sample.

Korean and Chinese subgroup differences in HSU

An emerging body of literature warrants the importance to consider subgroup differences in Asian populations in health services research (Chang & Moon, 2016; Ryu et al., 2002). Findings from the present study provide some preliminary evidence of subgroup differences in patterns and predictors of HSU between older Korean and Chinese Americans. For the Chinese sample, sex, employment status, and self-perceived health were significant predictors of ever spent a night in hospital. However, no variables achieved statistical significance for ever spent a night in the hospital for the Korean sample. In the physician visits models, education and self-perceived health were significant predictors for the Korean sample. For the Chinese sample, age, employment status, self-perceived health and number of chronic conditions were statistically significant. In the ED visits models, education, employment status, and distress were significant predictors for the Korean sample. Age, education, employment status, English proficiency, and distress were significant predictors for the Chinese sample.

Taken together, the subgroup analyses indicate that while there are some commonalities between models for the aggregate sample and the Chinese sample, the study identified very few correlates of HSU in the Korean sample. Future investigations on diverse Asian subgroups with larger sample sizes are needed to validate the subgroup differences. Nevertheless, the findings underscore the importance to examine the unique utilization patterns and predictors of health services in specific ethnic groups despite shared cultural heritage and immigration patterns.

Comparing with existing literature

Comparing the findings from this study with those of the existing studies, one conclusion is that evidence on the covariates of HSU has been inconsistent, even for the same type of health service. One major discrepancy between the findings of this study and the previous studies is the effect of disability on HSU. Disability, a proxy measure for functional status in this study, was not significant in any models. Number of basic activities of daily living (ADL) difficulties and number of intermediate activities of daily living difficulties (IADL), which were used as proxy measures for functional status, were reported to be significant predictors of HSU among OAA populations (Pourat et al., 2000). One plausible explanation for this discrepancy is, compared to disability status, numbers of difficulties with ADL and IADL represent a more comprehensive and appropriate assessment of functional status. Number of chronic conditions has been reported to be one of the most significant predictors of HSU in Asian populations (Jang et al., 2005; Shibusawa & Mui, 2010). However, findings from the present study suggest that number of chronic conditions was only associated with ever spent a night in hospital for the aggregated OAAs, and physician visits for older Chinese Americans.

Methodological differences, such as varying analytic strategies and variables examined, and divergent measures of related variables, may account for the observed inconsistencies in the literature (Wolinsky, 1994). Furthermore, most of the existing studies examining HSU among Asian populations are geographically specific, mainly in metropolitan cities with established immigrant communities such as New York City, Chicago, Boston, and Los Angeles (Pourat et al., 2000; Sohn & Harada, 2004). The lack of national data with health care information on Asian subgroups is another key reason for why findings of existing studies regarding patterns and predictors of HSU are inconsistent.

Strengths and Limitations

This study contributes to existing literature in several aspects. First, the study expands the knowledge on the use of health services among older minority populations since existing studies that include Asian subgroups are sparse due to a lack of available HSU data with information on Asian ethnicities for quantitative analyses. Second, the findings that psychological distress was associated with the likelihood to have any ED visits in the past year among older Korean and Chinese Americans, bridge a knowledge gap as this relationship has not been examined in previous research. Moreover, the study systematically examined the significant covariates of both primary and acute care services in OAAs and the two subgroups.

Nevertheless, several limitations should be considered in interpreting the findings from this study. Main limitations of the study stem from the limitations of the data set and the constraints of secondary data analysis. Firstly, the CHIS data are subject to self-report bias among OAAs considering the recall period of one year, especially for data related to utilization of health services. Adding to the limitations is that findings of this study are not generalizable to older Asian populations residing in other geographic areas outside of California where support services are not as established, or other minority older adult populations (Clough, Lee, & Chae, 2013). Future studies are needed to examine potential geographic variations among OAAs regarding HSU. National representative data of OAAs are urgently needed to comprehensively examine the patterns and predictors of HSU and subgroup differences in this population. Additionally, since CHIS is a population-based telephone survey of California's non-institutionalized adults living in households with landline telephone or cellular services, OAAs who live in institutions were excluded from the sample. Health service needs and utilization patterns of such OAAs were thus disregarded in this study. Moreover, since this secondary data analysis only included variables that were available in the CHIS data set, the effects of other variables that may predict utilization of health services in this population, such as health beliefs, health literacy, living arrangement, and social support were not examined (Jang et al., 2005; T. Kuo & Torres-Gil, 2001; Pourat, Lubben, Wallace, & Moon, 1999; Shin et al., 2000; Tsoh et al., 2016). Lastly, because CHIS data is cross-sectional, causal relationships and directionality could not be determined. Longitudinal studies should be conducted to evaluate patterns and predictors of HSU among OAAs over time.

Furthermore, measurement of HSU is limited in this study. HSU during a period of the past 12 months was measured by three self-report questions in the CHIS interview. Research suggests that there may be some degree of inaccuracy in self-reported utilization of health services among the older adult population (Roberts, Bergstralh, Schmidt, & Jacobsen, 1996; Wallihan, Stump, & Callahan, 1999). Although medical record review and claims record data may provide more accurate HSU measures, such cross validation was not available for this study. Nevertheless, one study that compared self-reported utilization of health services and the actual utilization as ascertained from medical records suggested that self-reported utilization were reasonably reliable (Roberts et al., 1996). Furthermore, the nature of physician visits, ED visits, and hospital admissions were not examined in this study. In addition, other types of health services, such as specialist care, traditional medicine, and preventive services, were not addressed in this study. Moreover, insurance status was not included in the regression models in the present study since nearly all OAAs (98.6%) in the sample were insured. Future studies should examine the effect of different types of health insurance on HSU among OAAs, such as Medicare, Medicaid, and private insurance.

Additionally, psychological distress in this study was measured by the Kessler 6 scale. Self-reported distress was not validated by clinical diagnostic instruments. Therefore, the effect of clinical diagnoses of depression on utilization of the types of health services remains unaddressed in this study. Future studies that use psychiatric evaluations of depression are needed to validate the findings from the present study. Furthermore, stigma associated with mental illness among OAAs may have prevented the older participants from reporting psychological distress, leading to potential response bias in the findings (Chang & Moon, 2016). Lastly, the CHIS data do not provide variables that capture the cultural nuances among Korean and Chinese subgroups, such as health beliefs. Without focusing on these cultural differences, interpretability of the difference in findings from the two groups is limited.

Conclusions

Despite the aforementioned limitations, the findings of this study have several health care and policy implications for professionals working with the OAA population. Most importantly, the findings suggest that psychological distress was associated with the utilization of ED services among older Korean and Chinese Americans. Consequently, ED encounters may represent opportunities to identify older Korean and Chinese Americans with psychological distress and initiate appropriate treatment. However, the rapid care process focusing on acute illnesses in the ED precludes the implementation of comprehensive psychiatric assessments (Kumar, Clark, Boudreaux, & Camargo, 2004; Tse, Wong, Lau, Yeung, & Tang, 1999). Brief screening instruments, such as the two-item Patient Health Questionnaire (PHQ-2), may be more favorable by clinicians in the ED settings due to time constraints (T. M. Chen, Huang, Chang, & Chung, 2006; Kumar et al., 2004). Particularly, considering the tendency to somatically present psychological distress in the Korean and Chinese community, such brief instruments should tap into somatic complaints such as fatigue, dizziness, pain, insomnia, change in appetite, which have been reported to be somatic proxies of depression in Asian populations (Sue, Saad, & Chu, 2012). For example, Chen and colleagues (2006) recommended adding a third item to the PHQ-2, asking whether in the past two weeks the participant felt tired or had sleep problems.

The inadequacy of psychosocial services in the ED has been well documented, potentially compromising care outcomes (Aminzadeh & Dalziel, 2002; Sanders, 1992; Tse et al., 1999). Therefore, connection to appropriate psychological services should be made to ensure adequate treatment once psychological needs are identified in older

Korean and Chinese Americans. Meanwhile, educational interventions that could increase awareness about the psychological needs of OAAs among clinical staff in the ED should be implemented. More importantly, the interrelated medical and psychosocial problems among OAAs call for a team approach where mental health and medical professionals collaborate in the ED to improve quality of care for older Korean and Chinese Americans with psychological distress (Adams & Gerson, 2003; Unützer, 2002).

The potentially preventable utilization of ED services among older Chinese and Korean Americans with psychological distress also represents an opportunity for intervention (Rice & Matsuoka, 2004; Sanders, 1992). Psychiatric social workers or nurses that could connect these older patients with appropriate services in the community have been reported to be effective strategies in improving care outcomes without any increase in societal cost (McCusker et al., 2003). To improve quality of care for older Chinese and Korean Americans and reduce preventable utilization of ED in this population, future studies need to adapt and evaluate the effectiveness of such interventions in this population.

More research attention should be devoted to the patterns and predictors of HSU among OAAs, especially older Korean Americans. Population studies focusing on specific Asian groups, such as the Population Study of Chinese Elderly in Chicago, need to be implemented with other Asian subgroups (Dong, Wong, & Simon, 2014). Future studies should disentangle the mechanisms of how psychological distress affects utilization of ED services among OAAs. Additionally, while the findings indicate the heterogeneity in patterns and predictors of HSU among older Asian subgroups, research on less established Asian groups, such as Vietnamese and Cambodian, should be conducted in the future to determine whether their HSU patterns and predictors differ from the more established Asian populations. As the number of OAAs grows rapidly, a thorough understanding of HSU patterns among this population becomes fundamental to provide adequate health services to this diverse population because health services are most effective when tailored to the needs of the target population (Ryu et al., 2002).

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Table 1. Sample characteristics: Aggregated sample

Variables	**Frequency (%)**	**Mean ± *SD* (range)**
Age (65-74)	667(55.5)	
75-84	434(36.1)	
85 and above	100(8.3)	
Gender (Female)	689(57.4)	
Marital status (Married or living with partner)	657(54.7)	
Education (less than high school)	286(23.8)	
Asian ethnicities (Korean)	339(28.2)	
Chinese	290(24.1)	
Others	572(47.6)	
Poverty	405(33.7)	
Employment status (unemployed)	1060(88.3)	
Years lived in the U.S. (less than 15 years)	106(8.8)	
English proficiency (not well/not at all)	694(57.8)	
Self-reported health		3.35 ± 1.21(1,5)
Number of chronic conditions		1.57± 1.16 (0,6)
Disability status (not disabled)	636(53.0)	
Psychological distress		2.76 ± 4.1 (0,24)
One or more nights in hospital		
Yes	149(12.4)	
No	1052(87.6)	
Number of physician visits		6.04 ± 7.96 (0,156)
One or more ED visits		
Yes	197(16.4)	
No	1004(83.6)	

Table 2. Sample characteristics: Korean and Chinese samples

Variables	Korean sample frequency (%)	Chinese sample frequency (%)	χ2/t statistic
Age (65-74), *n (%)*	166 (48.9)	154 (53.1)	
75-84, *n (%)*	138 (40.7)	108 (37.2)	
85 and above, *n (%)*	35 (10.3)	28 (9.7)	1.6
Gender (Female), *n (%)*	216 (63.7)	168 (57.9)	2.2
Marital status (Married or living with partner), *n (%)*	174 (51.3)	167 (57.6)	2.7
Education (less than high school education), *n (%)*	94 (27.7)	69 (23.8)	1.2
Poverty, *n (%)*	172 (50.7)	88 (30.3)	25.5***
Employment status (unemployed), *n (%)*	316 (93.2)	257 (88.6)	4.1*
Years lived in the U.S. (less than 15 years), *n (%)*	27 (8.0)	44(15.2)	7.7**
English proficiency (not well/not at all), *n (%)*	276 (81.4)	177 (61.0)	32.4***
Self-reported health, *mean (SD)*	3.49 (1.3)	3.22 (1.2)	18.7***
Number of chronic conditions, *mean (SD)*	1.51 (1.1)	1.48 (1.2)	9.2
Disability status (disabled), *n (%)*	221 (65.2)	163 (56.2)	5.3**
Psychological distress, *mean (SD)*	3.93 (4.8)	2.50 (3.7)	3.8***
One or more nights in hospital			
Yes, *n (%)*	38 (11.2)	42(14.5)	
No, *n (%)*	301 (88.8)	248(85.5)	0.9
Physician visits, *mean (SD)*	6.98 (6.6)	5.58 (7.8)	4.5***
One or more ED visits			
Yes, *n (%)*	51 (15.0)	57 (19.7)	
No, *n (%)*	288 (85.0)	233 (80.3)	5.8

*p<0.05, **p<0.01, ***p<0.001

Table 3. Measures of association: Aggregated sample

Variables	**One or more nights in hospital**	**Physician visits**	**One or more ED visits**
	Odds ratio	Incidence rate ratio	Odds ratio
Age (65-74)			
75-84	1.1	0.9	1.2
85 and above	5.2**	1.1	3.2**
Gender (Female)	1.8*	1.6**	1.1
Marital status (Married or living with partner)	1.5	0.8	1.3
Asian ethnicities (Korean)			
Chinese	2.1	0.8	1.5
Others	2.1*	0.8	1.7
Education (Less than high school education)	1.3	1.0	0.8
Employment status (Unemployed)	0.4*	0.6**	0.3**
Years lived in the U.S. (less than 15 years)	2.7*	1.2	1.5
English proficiency (not well/not at all)	1.5	0.9	1.6
Poverty	0.8	0.9	1.3
Self-reported health	1.6**	1.2*	1.3*
Disability status (not disabled)	3.2**	1.3	2.6**
Psychological distress	1.0	1.1**	1.1*
Number of chronic conditions	1.7**	1.2**	1.3*

*p<0.05, **p<0.01, ***p<0.001

Table 4. Measures of association: Korean sample

Variables	**One or more nights in hospital**	**Physician visits**	**One or more ED visits**
	Odds ratio	Incidence rate ratio	Odds ratio
Age (65-74)			
75-84	0.9	1.1	0.7
85 and above	3.1	2.7*	2.7
Gender (Female)	0.6	1.2	1.0
Marital status (Married or living with partner)	1.6	1.2	2.0
Education (Less than high school education)	0.4	1.4	0.2**
Employment status (Unemployed)	0.4	0.7	0.8
Years lived in the U.S. (less than 15 years)	0.3	1.5	1.7
English proficiency (not well/not at all)	0.7	1.3	1.2
Poverty	0.7	0.9	0.6
Self-reported health	1.3	1.3*	1.2
Disability status (not disabled)	2.1	1.9*	2.9
Psychological distress	1.1	1.1	1.2*
Number of chronic conditions	1.7	1.1	1.5*

*p<0.05, **p<0.01, ***p<0.001

Table 5. Measures of association: Chinese sample

Variables	**One or more nights in hospital**	**Physician visits**	**One or more ED visits**
	Odds ratio	Incidence rate ratio	Odds ratio
Age (65-74)			
75-84	0.7	0.7*	1.3
85 and above	4.3*	0.5**	5.9**
Gender (Female)	2.0	1.3	1.0
Marital status (Married or living with partner)	2.7*	0.8	2.1
Education (Less than high school education)	1.5	0.7*	0.9
Employment status (Unemployed)	0.1*	0.5**	0.1**
Years lived in the U.S. (less than 15 years)	6.0**	1.1	1.9
English proficiency (not well/not at all)	1.2	0.9	2.0
Poverty	0.5	0.9	1.0
Self-reported health	2.1**	1.3**	1.2
Disability status (not disabled)	4.0**	1.4	2.0
Psychological distress	1.1	1.0	1.1
Number of chronic conditions	1.8*	1.3**	1.4*

*p<0.05, **p<0.01, ***p<0.001

Table 6. Significant factors associated with use of health services: Aggregated sample

Variables	**One or more nights in hospital**	**Physician visits**	**One or more ED visits**
	Odds ratio	Incidence rate ratio	Odds ratio
Age (65-74)			
75-84	0.8	0.8	0.9
85 and above	3.7**	0.9	2.5*
Gender (Female)	2.6**	1.6**	1.4
Marital status (Married or living with partner)	1.6	0.9	1.5
Asian ethnicities (Korean)			
Chinese	2.2	0.8	1.6
Others	1.7	0.8	1.3
Education (Less than high school education)	1.2	1.1	0.7
Employment status (Unemployed)	0.4	0.6*	0.3**
Years lived in the U.S. (less than 15 years)	2.1	1.2	1.2
English proficiency (not well/not at all)	2.4*	1.2	2.3*
Poverty	0.8	0.9	1.7
Self-reported health	1.6**	1.2**	1.3
Disability status (not disabled)	1.7	1.1	1.8
Psychological distress	1.1	1.1	1.1
Number of chronic conditions	1.3*	1.1	1.1

* $p < 0.05$; ** $p < 0.01$; ***$p < 0.001$

Table 7. Significant factors associated with use of health services: Korean sample

Variables	**One or more nights in hospital**	**Physician visits**	**One or more ED visits**
Age (65-74)			
75-84	0.8	1.1	0.6
85 and above	3.1	1.9	1.8
Gender (Female)	0.8	1.3	2.2
Marital status (Married or living with partner)	1.0	1.4	2.5
Education (Less than high school education)	0.5	1.7*	0.2***
Employment status (Unemployed)	0.6	0.8	1.2
Years lived in the U.S. (less than 15 years)	0.3	1.5	2.7
English proficiency (not well/not at all)	0.9	1.3	1.8
Poverty	1.3	0.9	0.9
Self-reported health	0.9	1.3**	0.7
Disability status (not disabled)	1.5	1.5	1.8
Psychological distress	1.0	1.0	1.1*
Number of chronic conditions	1.5	1.1	1.5

* $p < 0.05$; ** $p < 0.01$

Table 8. Significant factors associated with use of health services: Chinese sample

Variables	**One or more nights in hospital**	**Physician visits**	**One or more ED visits**
Age (65-74)			
75-84	0.5	0.7**	1.2
85 and above	3.5	0.5*	6.1**
Gender (Female)	4.6*	1.2	1.4
Marital status (Married or living with partner)	3.1	0.8	1.9
Education (Less than high school education)	1.5	0.7	0.7
Employment status (Unemployed)	0.1*	0.5***	0.1**
Years lived in the U.S. (less than 15 years)	6.8**	1.2	1.3
English proficiency (not well/not at all)	2.6	1.2	3.4*
Poverty	0.5	1.0	1.3
Self-reported health	2.4*	1.2*	1.2
Disability status (not disabled)	1.8	1.2	1.2
Psychological distress	1.0	1.0	1.1*
Number of chronic conditions	1.0	1.1*	1.1

* $p < 0.05$; ** $p < 0.01$

CHAPTER 3: PERCEPTIONS OF DEMENTIA AND CULTURALLY APPROPRIATE SERVICES IN ASIAN COMMUNITIES

Introduction

It is estimated that the age-specific prevalence of dementia among Asian Americans is comparable to that of the general U.S. population (Braun & Browne, 1998; Jones, Chow, & Gatz, 2006). As the number of older Asian immigrants grows rapidly, so does the number of those affected by dementia (Jones et al., 2006). Diverged from Western biomedical perspectives which construct dementia as a biomedical disease, Asian populations tend to view dementia as a consequence of normal aging, psychosocial distress, and traumatizing life experiences (Dilworth-Anderson & Gibson, 2002). This culturally-based explanation of dementia hinders medical and social service utilization in the Asian community, including clinical diagnosis and treatment, and supportive and respite care for family caregivers (Jang, Kim, & Chiriboga, 2010; Jones et al., 2006).

Additionally, in the Asian community, dementia brings stigma, shame, and embarrassment to both the persons with dementia and their family caregivers (S. E. Lee, Diwan, & Yeo, 2010). Such cultural norms in the Asian community further prevent the affected families from reaching out for necessary medical and social interventions until behavioral symptoms become unmanageable, leading to premature institutionalization of older Asian immigrants (Jang et al., 2010; Kagawa-Singer, Shon, & Moon, 2008). Because the limited effective treatments for dementia depend on early diagnosis and interventions, examining perceptions of dementia in the Asian community is indispensable to improving dementia care outcomes among this population (Jones et al., 2006).

A few studies have examined perceptions of dementia among older Asian immigrants and their family caregivers. However, two gaps prevail in existing literature. First, little is known about ethnic Asian home care providers' perceptions of the disease, which may influence the quality of care received by older persons with dementia (Zane, Hatanaka, Park, & Akutsu, 1994). Second, there is scant research on the experience of Asian family caregivers, and their perceived facilitators and barriers in accessing services. To address the aforementioned gaps in the literature, the study aims to: 1) investigate dementia-related perceptions and facilitators/barriers in accessing care among first generation older Korean and Chinese immigrants who have limited English-language proficiency, a population that has been rarely studied in previous research; 2) explore dementia-related perceptions and facilitators/barriers in accessing care among Korean and Chinese family caregivers; and 3) examine perceptions of dementia and facilitators/barriers in providing care among ethnic Asian home care providers (i.e., home health aides, nurses, social workers).

Findings from the study will describe the perceptions of dementia in the Asian community and highlight the gaps in knowledge of the disease, which will inform the development of educational interventions to promote the awareness of dementia and encourage early diagnosis and timely treatment. The findings will further our understanding of the barriers and facilitators to accessing/providing dementia care and will be used to develop outreach programming tailored to older Asians and their families. Ultimately, findings of the study will facilitate improved clinical communication and health outcomes for older Asian immigrants with dementia.

Background and Significance

Prevalence of dementia among older Asians

Dementia, one of the most common and debilitating chronic illnesses among older adults, consists of a group of clinical syndromes characterized by progressive neurological disorders, representing multiple impairments in memory and other cognitive abilities, together with declining functional abilities, and other behavioral and neuropsychiatric problems (American Psychiatric Association, 1994; Gould & Kendall, 2007; D. Liu, Hinton, Tran, Hinton, & Barker, 2008). In a process of cognitive changes, the illness ultimately subsumes the individual, and the individuals experience increasing difficulties managing their daily activities (Perry & O'Connor, 2002).

This terminal illness is anticipated to affect 10% of individuals over 65 years old, and the rate grows exponentially with age, with over 50% of those aged 85 and above having dementia (Gurland et al., 1999). The age-specific prevalence of dementia among Asian Americans is estimated to be comparable to that of the general U.S. population (Braun & Browne, 1998; D. Liu et al., 2008). The proportion of the Asian population aged 65 years or older in the U.S. has continued to increase in recent years. According to the Administration on Aging (2010), there were 1.4 million older Asians (≥65 years of age) in 2010, and the number is projected to grow to over 7.6 million by 2050 (8.6 percent of the total older adult population). The high prevalence of dementia and the increasing number of the older Asian immigrants highlight the critical need for culturally appropriate clinical interventions to help patients understand the illness progression and also support family members caring for people with dementia, who are severely challenged by the increasing care needs of patients.

Perceptions of dementia in Asian communities

Many researchers suggest that different from the Western biomedical perspectives which understand dementia as biomedical diseases, Asian populations are more likely to perceive dementia as consequences of normal aging, psychosocial distress, and traumatizing life experiences (Dilworth-Anderson & Gibson, 2002; Hinton, Franz, & Friend, 2004; Jones et al., 2006; S. E. Lee et al., 2010; Y. Lee & Smith, 2012). The different perceptions of dementia have significant clinical consequences because they influence health behaviors and care outcomes for persons with dementia and their family caregivers (Hinton, Franz, Yeo, & Levkoff, 2005). Viewing dementia symptoms as consequences of normal aging leads to ignoring initial symptoms and limited help-seeking until behavioral symptoms become unmanageable (Hinton et al., 2005; Wu, Lombardo, & Chang, 2010). Particularly, mild cognitive impairments are considered as expected in old age in Asian communities (Sun, Ong, & Burnette, 2012; Wang, 2012).

Older Asian immigrants with dementia experience multiple stigmas similar to those associated with chronic and severe mental illnesses (D. Liu et al., 2008; Sun et al., 2012; Wu et al., 2010). The stigmatized perceptions of dementia are reflected by the derogatory terms used in Asian languages, most of which imply insanity, stupidity, and idiocy (Chiu et al., 2014). Family members and associates of the older Asians with dementia are subject to affiliated stigma (Chee & Levkoff, 2001; D. Liu et al., 2008; Wu et al., 2010). This results in a delay in help-seeking for those experiencing cognitive impairments.

Additionally, it has been documented that certain Asian cultural norms further contribute to delayed help seeking. Filial piety, a central family principle in Korean and Chinese cultures, emphasizes the obligation of adult children to respect and care for their aging parents (Ishii-Kuntz, 1997; Wong, Yoo, & Stewart, 2006). Exhibition of the behavioral symptoms and utilization of external services are interpreted as a failure of filial piety in Korean and Chinese cultures, leading to a profound shame on the family (Chee & Levkoff, 2001; Hinton et al., 2005; D. Liu et al., 2008). To avoid shame and stigmatization, the Asian families tend to avoid public disclosure of their older relatives' dementia related problems by declining formal diagnosis and treatment (Hinton et al., 2005).

These cultural perceptions of dementia impede early diagnosis and timely treatment. Hence, it has become increasingly important to explore differences in the cultural perceptions of dementia in Asian communities. Such information will help design interventions to promote early diagnosis and proper treatment of dementia, timely utilization of services, and improved clinical communication. The present study thus examines perceptions of dementia among older Korean and Chinese immigrants and their families and the barriers and facilitators in accessing services.

The two ethnic Asian subgroups were chosen for three reasons. First, Korean and Chinese Americans are among the five largest Asian groups living in the U.S. (National Asian Pacific Center on Aging, 2013). Second, the aforementioned common cultural values shared by the two cultures that may influence dementia help seeking justified focusing on the two groups in this study (Wong et al., 2006). In addition, older Korean and Chinese immigrants have similar immigration patterns. Specifically, older Korean and Chinese immigrants came to the U.S. as voluntary immigrants as compared to their Vietnamese and Filipino counterparts who came as refugees (Ishii-Kuntz, 1997). Although Japanese Americans as another East Asian group share common cultural norms with Koreans and Chinese, unlike most of their Korean and Chinese counterparts who are foreign-born, most older Japanese Americans are native-born (National Asian Pacific Center on Aging, 2013).

Dementia services in Asian communities

In addition to the perceptions of dementia and related cultural beliefs, the lack of linguistically and culturally appropriate dementia services leads to low utilization of the available dementia services in the Asian community (Hinton et al., 2004; Wu et al., 2010). Mainstream organizations need to understand the unique cultural needs of the community to provide appropriate dementia services (Wu et al., 2010). However, little is known about ethnic home care providers' perceptions of dementia. It has been reported that older Asian immigrants tend to utilize ethnicity-specific health related services from bilingual and bicultural community-based health care programs that are specifically developed to serve Asian populations (Takeuchi, Sue, & Yeh, 1995; Zane et al., 1994). Such ethnic preference is particularly prevalent in older Asian immigrants who have limited English proficiency (Chow, Ross, Fox, Cummings, & Lin, 2000).

The ethnic home care providers, providing home based care to older Asian immigrants on a day-to-day basis, can provide concrete examples and authentic experiences working with persons with dementia and their families and the challenges they experience providing care to the target families. Therefore, incorporating ethnic home care providers' understanding of dementia and the facilitators and barriers in providing care to the target population is imperative. Such information can facilitate changes in the current practice to improve quality of home care serving the Asian community nationwide. Moreover, findings will identify knowledge gaps regarding dementia among ethnic home care professionals, which can help facilitate tailored staff in-service programming to raise awareness of dementia among ethnic home care providers.

To summarize, this qualitative study builds on previous research in several important aspects. The first strength of the present study is the integration of perspectives of the three interviewee types (older Asian immigrants and their family caregivers, and ethnic home care providers). The integration of the perspectives will portray a more holistic and accurate picture of the perceptions and experience of dementia in the community (Speziale, Streubert, & Carpenter, 2011). The multi-perspectival view of dementia and facilitators and barriers in accessing and providing care to older Asian immigrants with dementia is fundamental to improve care outcomes for this population. Particularly, since perceptions of dementia and the facilitators and barriers in providing care to Asian families affected by dementia among home care providers have not been explored in previous research, this study has the potential to bridge a significant knowledge gap in the field. In addition, the inclusion of the multiple perspectives also enhances the trustworthiness of the data. Moreover, the study explores perceptions of dementia and barriers and facilitators in accessing care from a family perspective. Prior research that includes the perspectives of both older immigrants and their family caregivers is scant. The family-based strategy conforms with the filial values in the Asian community (Ho, Friedland, Rappolt, & Noh, 2003). Lastly, the qualitative methodology allowed the participants to convey the complex culturally informed perceptions and beliefs regarding dementia in their own terms.

Methods

Population and settings

The study was conducted in an urban home care agency specializing in the care of older Asian immigrants disadvantaged due to language, cultural and socioeconomic barriers. The agency provides supportive services for older Asians and disabled adults for their personal care to help them stay at home and prevent premature institutionalization. The agency currently provides in-home health care for about 300 older and disabled adults throughout the Philadelphia metropolitan region, among which 29% are Korean, 21% Chinese, 21% Vietnamese, 14% Cambodian, 3% Asian Indian, and 2% Southeast Asian (Penn Asian Senior Services, 2014). The relatively large number of older Asian immigrants served by the agency and the large ethnic Asian staff working at the agency allowed recruitment of the desired sample size.

Sampling and recruitment procedures

Family dyad recruitment: Purposeful sampling was used to recruit older Korean and Chinese immigrants to maximize diversity of experience related to dementia allowing rich and vigorous descriptions. Social workers who have been working with the Korean and Chinese families at the agency identified individuals who met the inclusion criteria and contacted them to ask their permission to be contacted by the investigator for recruitment. Eligible older immigrant participants needed to be: 1) current clients of the agency aged between 80 and 90 who either had: a formal diagnosis of dementia, or memory loss issues and other behavioral symptoms without formal diagnosis of dementia, or no memory loss issues based on the agency's daily updating home care records; 2) first generation Asian immigrants of self-identified Korean or Chinese ethnicity; 3) living in the community. For each older immigrant, a primary family caregiver who was identified as the responsible party as reflected by the agency record, lived in the Philadelphia area, and involved in the care of the older participant was contacted to verify his/her interest in participation. Older immigrants with severe hearing problems and speech impairments making it difficult to complete the interview and those with severe cognitive impairment such that they were unable to comprehend or complete the informed consent process were excluded from the study.

The social workers provided a list of potential participants. The investigator, a native Chinese speaker, contacted older immigrants and family caregivers of Chinese ethnicity to explain the purpose of the study and to verify their interest in participation. Older immigrants and family caregivers of Korean ethnicity were contacted by a doctoral student research assistant (RA), who was a native Korean speaker. The 12 older immigrant participants included 2 Korean and 2 Chinese who had formal diagnoses of dementia based on the agency's home care records, 2 Korean and 2 Chinese with memory loss issues or other behavioral symptoms without formal diagnoses of dementia based on the social workers' knowledge, and 2 Korean and 2 Chinese with no memory loss issues based on the social workers' knowledge. For each of the 12 older immigrant participants, a primary family caregiver was recruited.

Home care professionals recruitment: Convenience sampling was used to recruit home care professionals for the semi-structured focus group. A list of home care professionals with job titles was used to identify the professionals who met the inclusion criteria. Phone calls and emails were made to all eligible participants for recruitment. Eligible professionals needed to: 1) be currently employed by the agency; 2) have experience providing care to older Korean or Chinese immigrants who have dementia or related behavioral symptoms. Administrative office staff who did not provide direct care to the older immigrants were excluded. A final sample of 11 professionals including 3 registered nurses, 5 community outreach coordinators, 2 social workers, and 1 volunteer manager gave consent and completed the semi-structured focus group session.

Ethnic home health aide recruitment: Convenience sampling was used to recruit Korean and Chinese home health aides providing in-home care to older immigrants. A list of home health aides was used to identify aides of Korean and Chinese ethnicity who met the inclusion criteria. Eligible home health aides needed to: 1) be currently employed by the agency; 2) be of self-identified Chinese or Korean ethnicity; 3) have experience providing care to older Korean or Chinese immigrants who have dementia or related behavioral symptoms. Home health aides with less than 3 months of experience caring for older immigrants were excluded. A final sample of 18 home health aides (8 Chinese and 10 Korean) gave consent and completed the semi-structured focus group sessions.

Data collection: Interviews and focus groups

This study was approved by the University of Pennsylvania's Institutional Review Board. Data were collected from April to December, 2014. All participants provided written informed consent prior to data collection (see Appendix A for the informed consent form in English). Demographic information was collected from all participants via a brief survey administered by the interviewers/focus group moderators.

Face-to-face interviews: Upon completion of consent, older immigrants and their family caregivers participated in individual face-to-face interviews separately at their homes using their preferred languages to elicit their perceptions of dementia and facilitators and barriers in accessing care in the home. Considering the strong stigma associated with dementia in the Asian community, one-on-one interviews were conducted to explore dementia-related values, perceptions, and meanings (Hinton, Guo, Hillygus, & Levkoff, 2000). The investigator conducted the interviews with the 6 Chinese family dyads. A bilingual RA, who was a native Korean speaker, conducted the interviews with the 6 Korean family dyads. All interviews were conducted in Asian languages (Korean and Chinese) due to participants' preferences.

A semi-structured interview guide was prepared in English and translated and back translated into Chinese and Korean by master-level bilingual RAs to ascertain accuracy. The translated interview guides were pilot tested with four non-participating family dyads (two Chinese, two Korean) to ensure the items were culturally valid, and conceptually and linguistically appropriate (see Appendix B for the interview guide in English). Possible probing questions were also included in the interview guide to encourage more responses as needed. Examples of questions and probes include: Tell me what you know about dementia. Do you think dementia is an illness? If yes, what makes you think so? If no, what makes you think so? Would you know how to get help for someone who has dementia? What supports and services do you think would be beneficial to older Korean and Chinese immigrants with dementia and/or their families?

The face-to-face interviews lasted for 55 minutes in length on average (interviews with the older immigrants ranged from 32 minutes to 73 minutes, interviews with the family caregivers ranged from 40 minutes to 67 minutes). Participants received $30 at the completion of the interview as a token of appreciation for their participation.

Focus groups: Eleven home care professionals and eighteen ethnic home health aides participated in three focus group sessions facilitated by the investigator and a Korean-speaking RA with qualitative research experience to explore their perceptions of dementia and barriers and facilitators in providing care to the target communities (one session for professional staff, one session for Chinese home health aides, and one session for Korean home health aides). Focus group sessions for professional staff and home health aides were conducted separately to decrease the likelihood of power dynamics which might interfere with participation. The focus group session with the professional staff was conducted in English. The focus group sessions with the home health aides were conducted either in Korean or Chinese based on the participants' ethnicity.

A semi-structured focus group guide was prepared in English and translated into Chinese and Korean and then back translated by master-level bilingual RAs to ascertain accuracy. The translated focus group guides were pilot tested with four non-participating home health aides (two Korean, two Chinese) to ensure the items were culturally valid and conceptually and linguistically appropriate (See Appendix C for the focus group guide in English). Possible probing questions were also included in the focus group guide to encourage more discussions as needed. Examples of questions and probes include: What are your ideas about the cause (or causes) of dementia (or the words interviewee uses)? In your opinion, how are the needs of persons with dementia different from clients without dementia? What are the barriers or challenges to providing services to clients with dementia? their family members? any examples? What additional services do you think would be beneficial to your clients with dementia and/or their families?

The focus group sessions lasted for 115 minutes in length on average (ranged from 95 minutes to 132 minutes). Participants received $45 at the completion of the focus group as a token of appreciation for their participation.

Data analysis

All interviews and focus group sessions were audio-taped, transcribed verbatim, and translated into English (when applicable) for analysis. All transcripts were reviewed against the original audio files for accuracy by bilingual RAs. Data were analyzed using NVivo, a software program for computer-assisted analysis of qualitative data. Conventional content analysis was performed to describe perceptions of dementia and facilitators and barriers in accessing and providing culturally appropriate services among older Korean and Chinese immigrants and their families, and home care providers (Hsieh & Shannon, 2005). This analytical technique allows information to emerge from the data without reliance on existing theories or pre-imposed perspectives. It is most useful in describing a phenomenon for which existing theory or research is limited (Hsieh & Shannon, 2005).

The following steps were taken to analyze the interview and focus group data. First, the primary investigator (DK) reviewed all 27 transcripts repeatedly to achieve a thorough understanding of each transcript as a whole. Next, the PI and a social work scholar with qualitative research experience independently reviewed six transcripts for open-coding and appropriate themes and categories were developed in the process (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). After open-coding of six transcripts, the two coders met to discuss initial impressions of the data, and a preliminary code-book of identified categories and definitions was developed by consensus. The remaining transcripts were then coded independently and the code-book was refined during frequent calibration meetings between the two coders. Once all transcripts had been coded, all categories from the open coding process were reviewed and those with similar meanings were aggregated into higher order categories (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004). Discrepancies were resolved through consensus. The team discussed and finalized the themes that emerged from the data.

Trustworthiness

Several strategies were employed to ensure trustworthiness of the study. Trustworthiness was first ensured by strictly following the steps of conventional qualitative content analysis methodology (Hsieh & Shannon, 2005). Secondly, peer debriefing sessions were performed with a senior researcher with extensive qualitative research experience to examine the transcripts, the findings, and general methodology to enhance credibility of the study. Additionally, two bilingual and bicultural researchers with in-depth knowledge of the Korean and Chinese culture coded the data independently (investigator triangulation) and met frequently to reconcile all coding to increase the rigor of the study.

Transferability was further assured by developing a detailed description of research activities, including protocol development, and data management and analysis procedures, so that the study can be replicated in different ethnic groups, settings, and geographic areas in the future. Lastly, direct verbatim quotations, when appropriate, were included in the findings to enhance transferability (Graneheim & Lundman, 2004).

Findings

Participant characteristics: Face-to face interviews

In terms of the relationship between older immigrants and their family caregivers, of the 12 families that participated in the interviews, 9 were parent-child dyads (5 mother-son, 3 mother-daughter, 1 mother in law-daughter in law) and 3 were spousal dyads. A majority of the family caregivers (n = 10) lived with their care recipients in the same household. Table 1 displays the socio-demographic characteristics of the older immigrants and their family caregivers who completed the face-to-face interviews.

<u>Older immigrants:</u> The vast majority of the older immigrant participants were female (83%), and rated their health to be fair or poor (92%). On average, the older immigrants were 83 years old (ranged from 80 to 88) and had lived in the U.S. for 25 years. The sample had low English proficiency, with all older participants rating their English as fair or poor. Ten older participants (83%) had high school or below education and lived with others. Approximately 33% of the older participants were married.

<u>Family caregivers:</u> On average, the family caregivers were 60 years old (ranged from 47 to 83), and lived in the U.S. for 22 years (ranged from 2 to 40). Of the 12 family caregivers, 58% were female, 75% rated their English proficiency as fair or poor, 50%

rated their health to be fair or poor, and 83% were married. The family caregivers were well-educated, with 75% of participants having completed a high school education or higher. In addition, all family caregiver participants were living with others in the household.

Participant characteristics: Focus groups

Of the 29 focus group participants, 69% were aged 50 or older, approximately 90% were female, and 83% completed a high school education or higher. Regarding ethnicity, all home health aides were of self-reported Korean or Chinese ethnicity, with 2 Caucasian represented in the professional staff (one social worker and one volunteer manager). In addition, the focus group participants had worked in home care for 4 years on average. Table 2 presents the socio-demographic characteristics of the home care providers who participated in the focus groups.

Main themes

Six overarching themes emerged from the data. The following sections present the themes, first the three themes (perceptions and attributions of dementia, delayed help-seeking, and perceived barriers in accessing care) that were shared across the three interviewee groups (older Korean and Chinese immigrants, family caregivers, and home care providers), followed by a theme unique to family caregivers (caregiving burdens), a theme unique to home care providers (barriers in providing care). For each shared theme, findings were organized by the interviewee groups. The last theme, service needs, was presented by the types of identified services. Direct quotations from research participants were included for each theme and subtheme, when appropriate, to illustrate the findings. Table 3 presents the main themes and subthemes discussed by informants.

Theme one: Perceptions and attributions

<u>Perception of dementia: Stigmatization</u>

Dementia was associated with strong stigmas among three respondent groups. The stigmatized perceptions of dementia were reflected by the negative connotations and imagery attached to the condition among the participants.

<u>Older immigrants:</u> Dementia was described as “dummy”, “no point in living”, “silly”, “confused”, “scary”, and “stupid” by older Korean and Chinese immigrants.

> An older Chinese stated*: “It (dementia) makes you stupid…you don’t know anything, isn’t that being stupid? Everyone is afraid of getting it.”*
>
> Another older Chinese participant responded: *“It (dementia) means that I should stop living…what’s the purpose of living? There is no point. Do you think there’s any purpose (to live)? You are a burden to others. If I got dementia, then I wouldn’t want to live anymore. If the doctor diagnosed me with dementia, then it’s over. Why live longer? There is no point…you don’t know anything, it really is no different from being dead. You are no better than a car or a dog.”*
>
> An older Korean participant commented: *“It (dementia) is scarier than cancer because the person doesn’t even die with dementia. You can’t poop, you can’t do anything. How sad is that!”*

<u>Family caregivers:</u> Family caregivers shared similar perspectives. Dementia was most commonly described as “burden”, “having no point in living”, “worse than any other disease”, “pitiful”, and “messy”.

> A Korean family caregiver stated: *“It’s the best that I don’t get this kind of disease (dementia). I am really afraid that I will get it. It (dementia) is worse than any other disease that involves other organs.”*

> A Chinese family caregiver shared: *"I feel that losing things and having dementia is the same logic. A healthy person wouldn't forget things. Dementia is like a vegetative person with no brain…If you tell them what this object is, they can't remember it. They would remember for a second and then forget. Isn't that a sign of stupidity?" The family caregiver continued: ""I also feel that dementia is pretty scary. I got stomach cancer and I didn't feel that it was scary… but dementia, you won't understand anything…why bother living? And you also burden your family."*
>
> Another Chinese family caregiver noted: *"Forgetful is just forgetting. Dementia is becoming dumber…and it's more severe. It should be the next step. Then there is no point in living, that is the bad way of putting it…Dementia is completely not understanding (what is going on). If you talk to them (persons with dementia), it's like playing the piano to a cow. They completely don't understand (laugh)."*

<u>Home care providers:</u> Among home care providers, ethnic home health aides expressed more negative connotations of dementia and persons with dementia than the professional staff, such as social workers and nurses. Most frequently reported negative descriptions of dementia and persons with dementia included "crazy", "child-like", "foolish", "confused", "having no soul", "difficult" and "poor hygiene".

Perspectives shared by Chinese home health aide included:

> *"(persons with dementia) lose control of their emotions. When they want to throw a tantrum, they throw a tantrum…I feel like if a family has a member who has dementia, the people around them all suffer, it can ruin a family since they don't have control or judgment, so they make a mess."*
>
> *"Everyone is scared of dementia patients, one because they are clueless and don't understand anything, also the family members suffer."*
>
> *"They are alive, but it seems like they have no soul. It's just a living body."*
>
> *"Patients with dementia are paranoid and suspicious."*

Korean home health aides shared similar thoughts:

> *"Like our old expression, it looks like being possessed by a ghost. They (dementia patients) say they can hear and see something that ordinary people cannot (hear or see)."*

> *"Persons with dementia are not likely to clean their clothes, not even taking shower."*
>
> *"Dementia is a mental illness."*

Professional staff participants, on the other hand, were less likely to describe dementia with negative connotations than ethnic home health aides. They generally described dementia as brain disorders.

> *"Dementia is a general term for confusion and forgetfulness and things like that."*
>
> *"Dementia can be tested by physical observation and verbalization from the client by a mini mental test or things like that."*
>
> *"Dementia is basically someone you can talk to right now and they can be perfectly normal. Then when you talk to them ten minutes later, they don't remember speaking to you. So it's someone who goes in and out of confusion."*

Perception of dementia: Normal aging

Dementia and memory loss were commonly considered to be normal aging and not requiring medical interventions. The normalizing perceptions of dementia stem from the cultural stereotype that deteriorations in both mental and physical functions are inevitable in old age. Cognitive decline is therefore perceived as normal aging in the Asian community (S. E. Lee, Lee, & Diwan, 2010; Zhan, 2004).

Older immigrants: The perception that dementia was normal aging was prevalent among older Korean and Chinese immigrants. They consider dementia as something anticipated and inevitable in old age.

> An older Chinese participant noted: *"Being forgetful, I feel that it is a natural process of aging. It's difficult to avoid it. But each person is different, some people get it early, and some people get it later. Neither is bad, they are just natural occurrences when you get older."*

> Another older Chinese participant shared: *"Older people will get dumb eventually…that's normal aging for older people, that's how they present. It's natural for older people."*
>
> Perceiving dementia as part of normal aging was also shared by older Korean participants:
>
> *"When you age, it happens naturally. Of course, there is a problem. But it's not enough to get treatment or anything. It's something that occurs naturally as you get older."*
>
> *"You just happen to forget more often as you age."*

Family caregivers: Family caregivers expressed high tolerance of forgetfulness in old age, as they also viewed it as normal.

> A Chinese family caregiver noted: *"I feel like that's just because she is old…Maybe when people get older, it (dementia) just happens."*
>
> Another Chinese family caregiver said: *"I feel that it's the age (that causes dementia). When you get older, one is that some sort of disease can cause dementia, another is that your body is degrading… So from some standpoint it is normal."*
>
> A Korean family caregiver shared: *"I think it's just normal aging. I accept it as normal, but I do worry that my mother keeps forgetting words. So I tell her that I forget words too and that it's normal. I tell her to accept that these (forgetting words) are symptoms of aging."*
>
> Another Korean family caregiver expressed: *"I think as you get older, it's part of the natural aging process."*

Home care providers: Both professional home care staff and home health aides viewed dementia as part of normal aging themselves.

> A coordinator shared: *"We call it 'old-timer' instead of Alzheimer's or dementia. I guess it's for those with old age. We just brush it off as you are old and it's normal."*
>
> Another coordinator shared: *""We consider it as part of aging. If you ask ' what is the cause of dementia', we will usually say aging. For us, 70 is old age."*
>
> A Chinese home health aide noted: *"As people get older, it (dementia) is inevitable."*

> Another Chinese aide commented: *"When we age, it is common to have dementia."*

The providers also discussed how Korean and Chinese families they worked with view dementia as normal aging.

> A Chinese nurse said: *"Some of my clients actually describe their parents with dementia as 'not as sharp as they used to be', or they now become 'forgetful' to the point that they cannot recognize their family members, and it's all related to old age. They don't come out as they have a problem."*

Attributions of dementia: Psychological problems

The participants most frequently attributed dementia to psychological problems, the most common among which included loneliness and social isolation, depression and stress, and adjustment problems.

Older immigrants: Loneliness and social isolation were reported by many older immigrants as important causes of dementia.

> An older Korean participant stated: *"I think people who sit quietly in the house get dementia."*
>
> Another older Korean participant responded: *"You get dementia when you are always alone."*
>
> An older Chinese respondent commented: *"If you stay in your home all day and don't interact with the outside world, the chances of getting the disease (dementia) become higher…If you close yourself inside your home then those things will happen more."*
>
> Another older Chinese participant shared: "*…a lot of older people they don't understand English, their family members who come with them have to find work…then as time goes on, they will develop dementia."*

Depression and stress were another frequently discussed cause of dementia among the older participants.

> An older Chinese participant said: *"you have to be happy. If you are happy, the disease (dementia) will get better. The more depressed you are, the worse."*
>
> Another Chinese participant suggested: *"I feel that it is definitely emotional stress that causes some problems, and you can't work it out."*
>
> An older Korean respondent stated: *"Well, it's probably because of depression. It doesn't matter what age but mostly old age."*
>
> Another Korean participant commented: *"If you continuously have sad thoughts, you get dementia."*

The older respondents also attributed dementia to adjustment problems related to significant life changes, such as migrating to the new country or loss of a spouse.

> One older Chinese participant stated: *"Like a couple who were very close and one spouse passed away, which caused the other to be really sad. He would develop this kind of illness (dementia) from the sadness."*
>
> Another older Chinese respondent responded: *"…when people's living situation suddenly changes, they may get sick, and the brain will get sick too. For instance, I am from the Shan Dong, I don't understand the ABCs. What would I do once I came to the U.S.? Some people who can't get used to the new environment or change will get the disease (dementia)."*

Family caregivers: Social isolation and loneliness were most frequently mentioned by family caregivers as the main cause of dementia.

> A Korean caregiver responded: *"Dementia is lonely – lots of time alone. When you are alone, you don't have many conversations. I think it's a result of loneliness."*
>
> Another Korean caregiver described: *"Some things don't click when you live alone. For example, if you live with children at home you recall more easily the old days when they were younger. When living alone, you slowly become more hesitant to leave the house…it might be fine for some but others will forget who came and went on what days."*
>
> A Chinese caregiver remarked: *"Someone told me that it might be because they come to America and were too lonely and caused them to have dementia. I said that it's definitely lonelier in the U.S., especially for Chinese people in a different country. Younger kids can quickly adapt to the culture and language here…but older people don't. So some people said that it might be due to loneliness, and that they don't use their brain as much, and developed the disease (dementia)."*

Family caregivers also attributed dementia to depression and anxiety.

> A Chinese caregiver stated: *"He is depressed. Slowly this can lead to tantrum with himself or with people around him, and overtime it may lead to dementia."*
>
> Another Chinese caregiver mentioned: *"sometimes I feel like overly anxiousness can lead to dementia."*

<u>Home care providers:</u> Similar to the older participants and their family caregivers, the home care providers mainly attributed dementia to loneliness, depression, adjustment problems, and stress.

> A Chinese nurse articulated: *"With the cases I have experienced…a lot of them complained about loneliness. When they come to the country and their kids are grown-up and work, they live by themselves. Besides the TV, who do they talk to? They can't drive…Loneliness itself can lead to depression, and slowly turning you to confusion, and everything else."*
>
> A Chinese home care coordinator responded: *"Since we are Asian and coming to the U.S. Some older people can have adjustment problems for the total environment changes. And this can induce dementia…I think it (dementia) could be anxiety related adjustment problem."*
>
> A Korean home health aide commented: *"I personally think staying alone causes dementia as I saw my aunt's case. She got dementia after coming to the U.S. She was isolated, did not speak English, and could not drive. So she wasn't able to connect with others. Slowly she got dementia."*
>
> A Chinese home health aide responded: *"It seems like people who reach a certain age, menopause, there appears to be more stress…because during this time you still have your older parents and your children to take care of. You are stuck in the middle, working, taking care of everyone…and like us immigrants we have so many barriers, don't know the language or the environment…Experiencing such stress in the old age will either cause physical ailment or mental ailment. Another reason is that community activities are sparse (for older immigrants)."*

Additionally, the home care providers identified sleep problems as a potential cause of dementia.

> A Korean social worker articulated: *"When I do assessments, I have not met anyone who does not have sleep problems. Every senior says they cannot sleep well…some of them have to take medications to get sleep. So I think the sleep*

> *deprived state can cause them to have forgetfulness and could be one of the reasons."*
>
> A Korean home health aide stated: *"Dementia is also related to insomnia. I think persons with insomnia are more likely to get dementia. Dementia patients are also not likely to sleep well at night, no exception."*

Theme two: Delayed help-seeking

The stigmatized and normalizing perceptions of dementia contributed to delay in help seeking among the affected older immigrants and their family caregivers as evidenced by the experiences shared by the respondents. Particularly, viewing dementia and cognitive changes as normal aging and not requiring medical attention is the major reason for the delayed help-seeking in the Asian community. Older immigrants and their family caregivers discussed the severity threshold that would prompt them to elicit care. The majority reported that they would not seek help until the disease reached its later stages. Furthermore, family caregivers shared that they would not seek help unless they exhaust all resources to care for their older relatives with dementia at home. Home care providers shared similar observations.

<u>Older immigrants:</u> Many older immigrants reported that they would seek help only if the symptoms were frequent or disruptive to their daily life. They provided specific examples of the severity threshold that would prompt them to elicit help.

> One older Chinese participant stated: *"If he can't recognize his spouse, then he needs to go see a doctor."*
>
> Another Chinese participant noted: *"If they don't know how to eat then that's pretty serious. The family should send them to the nursing home."*
>
> An older Korean participant mentioned: *"If my forgetfulness appears more often (I will seek help). For example, if someone told me a story or had a conversation, and I would forget it the next day…or if I think I'm going to the departing flight,*

> *but actually went to an arriving flight. On a scale of 1 to 10, I would not go if it's below a 5".*

Family caregivers: Family caregivers shared a similar perspective on the threshold for help-seeking. A family caregiver eloquently recounted that he would not initiate help-seeking unless memory loss issues affect his mother's ability to function independently.

> *"Her memory loss problem has not gotten severe to the point that it's affecting her life…what I mean by that is that it hasn't affected her ability to take care of herself. For instance, finding her home…not knowing where she is going when she leaves the house or her lifestyle schedule is completely messed up. In those situations then I would feel it's affecting her life, and she is unable to take care of herself. If her mind is clear, she is still able to take care of the basic things in her life... when she should sleep, how to get home when she leaves the house. If she knows these, then it doesn't affect her life. If she forgets these basic things then there is an issue. If it doesn't affect her life, then it's normal".*
>
> Another Chinese caregiver said she would not seek help unless her mother's condition *"gets to the point where she can't even tell what the objects are…or don't know how to get home."*

Several family caregivers shared that they would not seek help until they could not manage their older relatives' conditions at home.

> A Chinese caregiver said: *"Severe means…that I can't handle it anymore at home."*
>
> A Korean caregiver stated: *"If I can't take care of him at home then I would have to think about it (getting help)."*

Home care providers: Home care providers shared similar observations that Asian families generally would not seek care until the disease reaches its later stages.

> *"I see a lot of Asians, specifically Chinese patients. They don't think it (dementia) is a problem until they are acting out in some way, their family will take them to the hospital."*
>
> Another staff responded: *"My feeling about the Asian community is that, they usually don't go to the doctor for check-up until they already hit the stage of late dementia."*

Theme three: Perceived barriers in accessing care

Narratives by older immigrants and family caregivers identified a number of barriers that hindered their help-seeking, including the futility of treatment, reliance on family for care, language barriers, and lack of accessible services.

Perceived barrier: The futility of treatment

Older immigrants: The most frequently reported reason for not seeking services among older immigrant participants was the belief that there was no point in seeking medical services since dementia is not treatable and nothing could be done about it.

> An older Chinese immigrant commented: *"I feel that seeing the doctor wouldn't help…If a person is already confused, even if he sees the doctor, it would be a waste of money and effort. What type of doctor would he see? If it were me, I wouldn't go see any doctor. You are already confused…the brain is bad, what could the doctor do (about it)? Seeing the doctor is no use. I don't think there is a point (to see the doctor)."*
>
> Another Chinese immigrant stated: *"This (dementia) is not a disease… other things, you have to go the doctor and tell him what kind of problems you have. The doctor will pretty much tell you how to treat the disease, but this (dementia) is not curable. For instance, being forgetful, there is no medication for your memory. Dementia-related things aren't things the doctor can help you with. Doctors don't deal with forgetfulness… For example, my forgetfulness – even if I were to tell the doctor, the doctor wouldn't have any methods to help me either… It's not curable."*
>
> A Korean immigrant said: *"Even if I go to the hospital, there would not be any treatment. You can't do anything about it (dementia)."*

Family caregivers: The futility of treatment was also the most commonly reported barrier in accessing services among family caregivers.

> As a Chinese caregiver remarked: *"Do you think the doctor can give you medicine for constantly forgetting? There is no medicine that can help you recover your memory…we feel that this isn't something that medicine can solve. There's no use in telling the doctor. There's no use."*
>
> Another Chinese caregiver shared: *"I know people with dementia need help, but I feel like there are no medications for this type of disease (dementia)…"*

> A Korean caregiver stated: *"You can treat cancer and recover but I don't think you can recover from dementia."*

<u>Perceived barrier: Reliance on family for care</u>

The Asian cultural value of filial piety, which specifies that adult children should respect and care for their aging parents, was commonly endorsed by both older immigrants and family caregivers. As a result, caring for a family member with dementia was considered to be a family responsibility, which consequently limited their willingness to seek or use formal services.

<u>Older immigrants:</u> Older Korean and Chinese immigrants expressed that they expected and preferred to be cared at home by their family members.

> An older Korean immigrant stated: *"It's (taking care of the aging parent) the duty of the child".*
>
> An older Chinese participant responded: *"there is no other way…you have to let the family take care of you. If your family has it (dementia), then you have to take good care of him."*
>
> Another Chinese respondent remarked: *"My health wasn't great and my son can take care of me…he is family so it's easier on me. Having my son taking care of me is easier."*

<u>Family caregivers:</u> Family caregiving was not only preferred and expected by the older immigrants, this cultural expectation was also commonly endorsed by the family caregivers. Family caregivers expressed a strong sense of obligation to care for their family members with dementia or related behavioral symptoms.

> As one Korean caregiver explained: *"We could send her (mother-in-law) to a facility to make our life easier, but she gave birth to my husband and she watched our kids. We would not ask her (to go to a facility), it would be sad. Without her, I would not have a husband and without my husband, I would not have my kids. Because we are family, we have to take care of each other as a community".*

Some caregivers specifically mentioned that family-based caregiving was a cultural tradition in Asian communities.

> A Chinese caregiver stated: *"I have no choice... since it's custom and tradition in China to be respectful and giving to your parents. This type of patients (dementia patients) need to go to the hospital and be seen, and need patient family members to look after them".*
>
> Another Chinese caregiver commented: *"It's (family caregiving) is tradition…For the elderly, you have to be good to them, and you feel that it's your responsibility. You rather take the burden at home…you care for them to the end.. maybe it's a Chinese tradition".*

Perceived barrier: Language barriers

Language barriers further exacerbated the aforementioned cultural barriers in obtaining services. This theme is reflective of the fact that the vast majority of older Korean and Chinese participants and their family caregivers reported their English proficiency as fair or poor. Some remarks from the older immigrants and their family caregivers included:

> *"Everything is good but communication is not good. I cannot speak English or drive a car so I have to learn".*
>
> *"Well, they (older immigrants) aren't able to speak English. Isn't that why they still suffer? Because they can't speak (English)."*
>
> *"There always be a language problem but Koreans also don't see the advertisement for these services."*

Perceived barrier: Lack of accessible services

Older immigrants: The older participants discussed that culturally and linguistically appropriate services were generally lacking in the Asian community, presenting additional barriers to help-seeking.

> An older Korean participant explained: *"Even going to the hospital is too difficult. There isn't room so they have to wait months to go in. I first go to the family doctor and get a referral to go somewhere else, but I can't walk well*

> *because of sciatica. If it hurts a lot I take painkillers. In Korea, if the hospital tells me to get surgery or examination, I do it because everything can be done in the same hospital. But it is different here."*
>
> A Chinese participant commented: *"There are no places for help."*

Family caregivers: Family caregivers also indicated that culturally and linguistically appropriate services were not readily available in the Asian community.

> A Korean caregiver stated: *"A man I know of is over 70 years old and he seemed to have mild dementia. He just stays home and reads books. He was not able to go to this day care center (with Korean staff) because he lived in Delaware."*
>
> Another Korean caregiver articulated: *"A reputable institution (that serves Korean people with dementia) does not seem to exist."*

Theme four: Caregiving burdens

The cultural preference of family caregiving could lead to significant caregiver burden. Family caregivers shared personal reflections on their caregiving experiences and feelings. Caregiving burdens were reported in three areas, including psychological distress, balancing work and caregiving, and high care needs.

Caregiving burdens: Distress

In order to fulfill cultural expectations of family caregiving, many family caregivers experienced significant caregiver burdens, most commonly in the form of psychological distress.

> One Chinese caregiver eloquently put: *"I don't know if I'm just being negative, but Chinese people are taught to be respectful towards our parents and care for them. It's deeply engraved in our upbringing. But it's so tiring…so I have a lot of stress".*
>
> Another Chinese caregiver stated: *"This is my personal experience. The longer the time is, it does seem really hopeless and depressing. When I had to take care of my father, it was the same way. It was so tiring. He would have urinary incontinence and would ruin his pants or have bowel incontinence. I had to make*

> *sure that he was comfortable in those situations. I have done all of that. It is impossible to not feel annoyed or frustrated. I am not that brave. When I went to Hong Kong, my friends said I was so brave and respected me so much, but I just couldn't laugh…I said I was not brave, I didn't have any other way".*
>
> One caregiver shared that she struggled ever since her husband was diagnosed with dementia. She noted: *"I just couldn't take the situation at home…the pressure was too high. After the diagnosis, I started realizing that it was hopeless. He has this disease, and I started slowing recovering and telling myself that it will be okay. All these years, I have struggled through… there was a time when I couldn't take it anymore and went to see a psychologist. I went for a while, then I decided it wasn't right. There is no solution. With the disease (dementia), he will do a lot of senseless things, weird things, and I have to deal with all of them."*

Caregiving burdens: Balancing work and caregiving

Some caregivers who were working shared the challenges they faced in balancing work and caring for their aging parents. One family caregiver had to quit her job to take care of her husband with dementia.

> A Chinese caregiver shared: *"He always gets into arguments with our daughter. I felt that it was not working, so I stopped working and just stayed home to be with him. Then he would often urinate or defecate on the bed, always unhappy, getting angry…At that time I was working, then I stopped working to be with him…so it was a big struggle".*
>
> Another Chinese caregiver remarked: *"I can't take care of everything for her (his mother who has dementia), like I can't take care of everything for my kids either…and then go to work. I would have worked myself to death, right? Now I know what it feels like to care for both aging parents and your kids. I have to care for both, so the road is still long."*
>
> According to a Korean caregiver: *"Initially when I did not have the (home care) services, it was very tiring. I had to do everything for my mom while working full-time".*
>
> A Korean caregiver shared similar experience: *"A lot of Koreans have their own business. If you have a family member with dementia, you can't go to work".*

Caregiving burdens: High care needs

Another source of caregiving burden shared by some family caregivers was the high care needs due to their older relatives' dementia-related problems, such as the need to provide constant care and supervision. Several caregivers explained:

> *"I am a paid family caregiver – 5 hours each day. It feels more than 5 hours… people who do this type of job I do would know that it's very tiring on the nerves. We don't have breaks, and we can't say that we want to rest. I can say that I have vacation time, but in her types of condition, I don't feel safe leaving her alone."*
>
> *"If I have to go out, I ask the home health aide to accompany him. You have to have someone by his side or else it won't be okay. He doesn't know anything. He doesn't know how to turn off the stove so it's very dangerous (to leave him alone). You can't leave him stay at home by himself."*

An older Chinese caregiver who was caring for her husband with dementia said she had to meet the high demand of care despite significant challenges she had experienced. She stated:

> *"Sometimes he can't control his bladder or bowels…especially during the winter when you are wearing a lot of layers, if you have stool on your hands, it will get on so many layers of clothes and it's just a lot of work. You will have to make him take a bath and he moves so slowly. The bathroom, the floor, everywhere is covered with stool. How is that not difficult? Who wants to do this type of stuff, right? But there is no other way (for me)."*

Theme five: Barriers in providing care

Another main theme that emerged from the data was barriers in providing care identified by home care professionals and home health aides. Subthemes included cultural differences, behavioral symptoms, communication barriers, lack of accessible services, and workforce challenges.

Barriers in providing care: Cultural differences

Similar to older immigrants and family caregivers, home care staff discussed that the cultural norm of filial piety in Korean and Chinese communities presented barriers in providing care to this population, as commented by several home care staff:

> According to a Chinese nurse: *"Respect is a big thing in Chinese culture. So as your parent ages and they change their personality… in American culture, changes in personality and things like that, you say "there is something wrong with this person, let's bring them to the doctor". Whereas Asian, when they see their parents, one minute angry one minute happy, they accept it. "This is my parents and they have the right to do so, it is their personality". They don't bring them to the doctor, they just treat them as the way they are".*
>
> Another staff noted: *"If the client has a family taking care of him/her, I feel bad walking into the house because accepting help from the outside is considered as a failure to fulfill filial obligations. They don't want anybody (outsiders) to help."*
>
> *"I think that the biggest barrier is still culture. Even a patient or family caregiver don't want to open the door to other people who are coming to help, then they'll never going to identify, or find out that they have some problems."*

Shame and stigma attached to dementia were identified as another cultural barrier in providing care to the Asian community.

> *"But my opinion is a lot of Chinese feel shameful if their family member has something like dementia or depression. They don't want people to know… That's why a lot of Asian suffer a lot more than Western people because Westerners are more open to get treatment. But Asian – a lot of them cover the problem. Even the family members cover the symptoms…They feel shameful if their family member has dementia."*
>
> *"I have a lot of trouble trying to convince not only the clients, but family… children… and educating them that there is something wrong with their parents, because it is a shame, guilt, and they don't want to lose their independence… The point is that no matter how bad they are, they don't want to accept the fact that there is something wrong with them. They are embarrassed to use a walker and they are embarrassed that they have dementia and need to take medication. The kids are just as embarrassed and not educated as their parents. That to me is definitely cultural barrier".*
>
> *"I'm from Korea and majority of Korean people… even though they are not diagnosed with dementia yet, if they have that kind of problem, they might be worried to see the doctor. Probably they say 'oh you have some mental problem',*

> *but people think that if someone has a mental problem… it's a big deal in Asian society. That's our culture."*
>
> *"Korean people are particularly embarrassed by dementia."*

Denying there was a problem among older immigrants and their family caregivers was identified as another barrier in providing care to older Asian immigrants with dementia.

> *"99% of dementia patients say they are not dementia patients. They even refuse to take medicine for dementia."*
>
> *"I feel like, family members are not likely to accept the fact that their mom or dad has dementia unless the patient has very serious symptoms. I think family members just hate to accept it."*
>
> *"They even hide it (dementia) from home health aides. It's so frustrating. I see the person apparently has dementia, but family members never admit it."*

Barriers in providing care: Behavioral symptoms

Home health aides discussed that behavioral symptoms related to dementia could be particularly challenging. Several home health aides shared that older care recipients with dementia or memory loss issues would accuse them of stealing when they had forgotten where they placed the items.

> A Chinese home health aide said: *"It's just that she would accuse you of doing something when you did not. Sometimes she would say that her stuff is missing, when in reality she just forgot where she misplaced it. She has memory loss, she put the item under her bed, and she had forgotten."*
>
> A Korean aide commented: *"One time my client said I took her clothes that she bought from Korea. I don't want to have them even if she gives it to me… I was so upset. She told it to the agency as if it is true. There was nothing I can do. I thought I would quit this job."*
>
> Another aide explained: *"Many home health aides quitted due to conflict with a female client because of lost items. I did not want to take that case but the agency kept asking me…So when I go to her house, I never take anything with me, just the key, and nothing else. She did not know that she got dementia."*

Home health aides also reported disruptive/aggressive behaviors among the older care recipients with dementia can make their jobs challenging:

> *"I know sometimes she (older client) is not logical, but she yells and insults. That makes my job challenging."*
>
> *"Some patient will insult you."*
>
> *"When I go to do my job as a home health aide, he (older client) thought a prostitute was coming and tried to touch and play…showed that kind of behaviors. That is very hard for me."*

Barriers in providing care: Communication barriers

Communication was another frequently discussed barrier in providing care to older Korean and Chinese immigrants with dementia.

> *"The biggest barrier is of course communication. If they are Chinese, they should have a Chinese aide or nurse. If they are Cambodian, like wise. On top of being confused…trying to communicate in English...I would be confused myself. For a dementia patient, number one, you do not know them. On top of that, you have no idea what they are saying. That to me is the biggest barrier."*
>
> *"It is a communication barrier. When you have someone who is caring for them and who does not have the same cultural background, it can create huge gaps in communication so the communication breakdown is very… can be very bad."*
>
> *"Our day care center, besides myself, the staff speaks Asian languages. We will be serving Asian food. We will have Asian-type of activities – the things Asian people like to do. We are going to have Asian language TV programs… A few years back, we didn't have all these. That was a huge barrier because people who speak different languages didn't want to go to an all American place."*

Barriers in providing care: Lack of accessible services

Home care providers suggested that accessible services were generally lacking in the Asian community. As expressed by several provider participants:

> *"I think in the Asian community, we lack resources where we could go for help. If dementia people act out, we don't know how to deal with it. You will probably have to call 911 first because you don't know what will happen"*

> *"Asian community lacks resources, such as where should I go first…it really needs to some education or some kind of help line as to where I should direct them to and what they should do."*
>
> *"If you don't speak the language, even if you see it (the services) on the paper or TV, you won't understand it. There isn't much Asian-language type of education or training on where the resources are."*

Barriers in providing care: Workforce challenges

Home care providers identified several workforce challenges, including scheduling and matching cognitively impaired older Asian immigrants with willing home health aides. The service coordinators who were responsible in matching home health aides with the older care recipients also noted challenges in the retention of aides.

> *"One of my clients – I feel bad for the home health aide because the client needs help 24/7. I know that. But the client treats the home health aide really badly so the home health aide can't handle the behavior. So they quit constantly. They do not want to go back to the client's house. As a coordinator, I have to replace them because the clients need help. So it is kind of hard to find providers to those types of clients."*
>
> *"Stress is the bigger barrier for the care-taker. If I'm demented, I have no idea what is going on. I am happy as whatever. Whereas, as a caretaker, the stress is horrible. So the question is, how many people can honestly say "yes, I can do it 24/7". So the stress is on care-taker… and that is the barrier. Because it is hard to find a person who can do a great job for these demented patients."*

Theme six: Service needs

Finally, the respondents indentified several unmet needs in the community. The most frequently mentioned services were social and recreational programs for older immigrants, emotional support for family caregivers, education, and respite care.

Service needs: Social and recreational programs for older immigrants

Older immigrants: Culturally and linguistically appropriate day care programs were identified as a needed type of service by older immigrants. Specifically, older Asian immigrants prefer ethnic-specific services provided by bilingual and bicultural professionals that are specifically developed to serve Asian populations. As noted by an older Korean respondent:

> *"A Korean facility that could accommodate Koreans would be great. There are a lot of Koreans here but there isn't a facility like this. Since the elderly don't have cars, it would be expensive but we need somewhere we can go in the morning to do activities and come home at night. We need something like that."*
>
> *Another Korean participant shared similar thoughts: "Because children need to work, we need day care assistance so they can go to work and make a living."*

Socialization was another need, as explained by an older Chinese immigrant:

> *"I really wish for more opportunities to interact with the community, not just with the same age group. Sometimes I like to listen to the younger fellows, it gives me a lot of spirit. Older people can be pessimistic. They can be negative, they just wait for death, one day at a time. Younger people are full of life. If we can communicate and have some interactions, that would be really good."*

Family caregivers: Linguistically and culturally appropriate social and leisure activities were suggested to be helpful by family caregivers.

> *"I feel that if there is an elderly center, it would be good for them to be involved in some activity, to have some interaction opportunities…that will be beneficial to them".*
>
> *"If they can do some activities that are popular in the past in Korea, that would help with dementia".*

Service needs: Emotional support for family caregivers

Additionally, family caregivers expressed the strong need for emotional support. A Chinese family caregiver indicated the desire to connect with other families that suffer from dementia. As the caregiver described:

> *"I want to connect with other Chinese families with this issue (dementia), it's just that I don't know where they are. I was hoping that you could tell me some of their experiences and how they handle things. That way, we know that there are*

> *other people with the same situation and that we are not alone. That way, my dad would feel a little better and I would have less pressure."*

Other family caregivers noted the need to find ways to relieve their stress:

> *"I wish there was something that could just relieve my stress. Because caring for them is very stressful and tiring, and the patients often don't understand… And I think overtime, it gets depressing. I feel like I'm a little depressed myself…It's just that one person who is constantly doing the same work, constantly under so much stress, and there isn't anyone who understands or appreciates you, and (there's) no way to switch or change the situation."*
>
> *"So with a lot of things, I feel a lot of pressure because I can't talk to anyone about it. A lot of things are depending on myself to figure out."*

Service needs: Education

Family caregivers: More education regarding dementia and its progression was identified by the family caregiver participants as an important need in the Asian community. Many family caregivers suggested that the awareness and knowledge of dementia should be raised in the Korean and Chinese communities.

> *"Just spread the word about the disease's characteristics and progression …inform people of how the disease occurs, and how it progresses step by step…have the caregivers be prepared of what will happen".*
>
> *Another caregiver noted "The knowledge on how the disease progresses…if it can be spread to other people, it would be beneficial. Like my father was always so worried and scared (about my mother's condition), if the caregivers knew then they would not be scared".*
>
> *"An agency needs to promote what to do with a patient with Alzheimer's disease (in our community)."*

Home care providers: Home care providers suggested that not only older immigrants, but also professionals who work in the Asian community, such as physicians and home health aides, should receive more education on dementia.

> *"I think the lack of information (is the key issue). You don't know what is dementia versus what is just forgetfulness. And I think we should provide more*

> *information and training for home health aides or primary caregivers. For the general population, there are a whole bunch of foundations, Alzheimer's Association or other research foundations. But those are for the general population and immigrants have no idea what's going on. If you don't have those information and culturally you are very "closed-up" and don't want to talk about it (dementia), you are going to get delayed treatment or misdiagnose problems."*
>
> *"I think within the Asian community, it seems that not just general ordinary not really knowing what is dementia. Even physicians, primary doctors, they sometimes think it is just cultural. They don't even think that this patient may have dementia – they just say 'oh, it's age!' Even the professional people do this. I think we should have more emphasis on not just educating the ordinary people, but also the professionals in the Asian community."*

Service needs: Respite services

Family caregivers also shared that respite services may be helpful.

> *"Another (need) is if the family members are unable to care for them (during the day), hopefully there is a service that can help take care of them. The family then will be able to relax because sometimes I am not able to relax if I know my mom is at home".*
>
> *"If someone could come to the house to look after my mom, clean the house, and make food for her... being able to have someone come in the day to look after her when you need it."*

Discussion

This qualitative study generated in-depth narratives from older Korean and Chinese immigrants, family caregivers, and home care providers regarding culturally informed perceptions of dementia and barriers in accessing/providing dementia-related services. Several findings from this study warrant discussion.

Consistent with previous studies, dementia was described in strikingly stigmatizing and discrediting terms that connote idiocy (S. E. Lee et al., 2010; Yeo, UyenTran, Hikoyeda, & Hinton, 2002; Zhan, 2004). Particularly, the local Korean and Chinese names for dementia are derogatory, both of which imply idiocy and stupidity

(Chiu et al., 2014; D. Liu et al., 2008). Service providers and researchers should avoid reinforcing the stigma attached to dementia by not using such local names. Instead, recent campaigns proposed that terms reflecting the core features of dementia, such as cognitive disorder should be adopted (Chiu et al., 2014). More importantly, the prominent stigmatizing view of dementia and its potential negative impacts underscore the necessity to incorporate stigma-reduction initiatives in any intervention programs or support groups targeting the Asian community (Werner, Goldstein, & Buchbinder, 2010). Moreover, stigma-reduction initiatives regarding dementia should be implemented via professional associations and the media to reduce stigma surrounding the disease in the general population (Werner et al., 2010).

The study findings suggest older Asian immigrant and their family caregivers delay help-seeking until dementia reaches its later stages, often to the point when behavioral symptoms interfere with older immigrants' ability to function independently or such symptoms could not be managed in the family (Hinton et al., 2005; Ikels, 2002; S. E. Lee et al., 2010; Wu et al., 2010). Developing culturally appropriate interventions to encourage early detection and treatment of dementia represents an urgent need in the Asian community because the limited effective treatments for dementia depend on timely interventions (Jang et al., 2010).

The findings further highlight several significant barriers that could potentially contribute to the delayed help-seeking in the Asian community, including culturally determined perceptions and beliefs of dementia, cultural preferences of family caregiving, and structural barriers such as language barriers and lack of accessible services. First, culturally determined perceptions and beliefs of dementia have significant influences on symptom recognition and help-seeking behaviors. Specifically, the findings suggest that dementia and memory loss are commonly perceived as consequences of normal aging in the Asian community. This finding is consistent with existing evidence suggesting that viewing dementia and related symptoms as consequences of aging is more prevalent in ethnic minorities (Gray, Jimenez, Cucciare, Tong, & Gallagher-Thompson, 2009; Hinton et al., 2005; Jones et al., 2006). The normalizing perception presents significant barriers in help-seeking because early symptoms of dementia (i.e. initial cognitive changes) are generally not recognized as problematic (Ikels, 2002; S. E. Lee et al., 2010). Moreover, the findings indicate that the belief that dementia or memory loss issues could not be cured and therefore not worth medical consultations or interventions is common in the Asian community (S. E. Lee et al., 2010). These findings underscore the pressing need for tailored health education and outreach programs targeting this community, particularly in the areas of early signs and symptoms of dementia, the differences between normal aging and dementia, treatment options and available services, to encourage early detection and timely interventions (S. E. Lee et al., 2010; Wu et al., 2010). The findings further indicate that such training and educational programs should also target health and home care providers serving the Asian community. Specifically, health professionals need to be trained in how to discuss dementia related issues in a culturally appropriate way to find out if a patient may be experiencing cognitive decline, how to connect them with existing services, and how to work with families to see that they deserve support.

Additionally, consistent with findings from previous studies, the study findings suggest that filial piety is a prevailing cultural value in the Asian community (Chee &

Levkoff, 2001). It is culturally expected and preferred that older Asian immigrants with dementia be cared at home (Han, Choi, Kim, Lee, & Kim, 2008; Ho et al., 2003). As a result, the Asian community has been reported to underutilize formal services (Aroian, Wu, & Tran, 2005; Ho et al., 2003). Health and social service providers should take into consideration the cultural expectations of family caregiving when working with Asian populations. Especially, the potential psychological strain from the disjuncture between fulfilling the cultural expectations of family caregiving and the inability to provide such care among Asian family members caring for their relative with advanced dementia or other illness deserves research and clinical attentions (Funk, Chappell, & Liu, 2013; Ho et al., 2003).

The study participants further identified structural barriers to help-seeking, including language barriers, and lack of accessible services. Language barriers emerged as a main concern, consistent with findings from a previous report that over 75% of older Korean and Chinese Americans has limited English proficiency despite the fact that a majority of them have been in the U.S. for more than two decades (National Asian Pacific Center on Aging, 2013). Educational materials and health promotion brochures regarding dementia should be more widely available in Asian languages to allow access among Asian families with limited English proficiency. Linguistically appropriate outreach programs are necessary to reach the Asian community.

Another frequently reported barrier was that culturally and linguistically appropriate services were not available in the Asian community (Scharlach et al., 2006; Sun et al., 2012). The types of services that were most frequently identified by the respondents to be helpful (i.e. day care programs, social and recreational activities, family support groups, and respite services) indicate that short-term care programs, which could relinquish some of the caregiving responsibilities while maintaining family-centered care, can be more culturally relevant and effective (Casado & Sacco, 2011; Chee & Levkoff, 2001; Scharlach et al., 2006). In addition, strengthening the capacity of the preexisting ethnic-specific community organizations in providing dementia-related information and services is crucial (Scharlach et al., 2006; Wu et al., 2010).

Finally, contrary to prior studies that suggested Chinese family caregivers were less likely to experience caregiver burden because the cultural norm of filial piety could modify the appraisal of caregiving stressors, the findings from this study indicate that Asian family caregivers experience significant caregiver burdens, particularly in the form of psychological distress (Lai, 2010; Scharlach et al., 2006). The findings further indicate that there are unmet needs for supportive services for the Asian family caregivers, particularly mental health services (Sun et al., 2012). Service providers working with the Asian community should acknowledge the potential caregiving burdens even though family caregiving is culturally considered as obligatory. Furthermore, providing the Korean and Chinese family caregivers who wish to care for relatives with dementia at home with culturally appropriate interventions and supportive services is essential (Lai, 2010).

Limitations

Several limitations should be noted in interpreting the findings from this study. First, since participants in this study were recruited from the Greater Philadelphia area, it is not clear whether the findings could be transferable to older Korean and Chinese immigrants and their families residing in other geographic areas or other ethnic minority populations.

Second, Chinese and Korean families who suffered from severe dementia were not included in this study. Moreover, it is also possible that the families who were experiencing stronger stigma were more likely to refuse to participate in this study, resulting in potential bias in the study sample. Third, the older participants were recruited because they were receiving home care services from the recruiting home care agency. As a result, the findings might not be representative of the experiences of those who were not receiving such services. Moreover, the older informants who had not been formally diagnosed with dementia but were viewed as suffering from memory loss or other behavioral symptoms were based on subjective assessments of social workers in the recruiting home care agency, which may subject to potential bias. Lastly, the older participants in this study were first-generation Korean and Chinese immigrants, it is therefore not clear whether the study findings could be generalizable to their native-born or more acculturated peers.

Implications

Nevertheless, the study findings have important implications for clinical and research practices involving older Asian immigrants with dementia and their families. First, culturally and linguistically appropriate training and educational programs should be developed to enhance awareness and knowledge of dementia in the Asian community to facilitate help-seeking in this community. Special attention should be given to the recognition of early and mild cognitive changes to facilitate timely help-seeking among older Korean and Chinese immigrants and their family caregivers. Such education interventions should also target ethnic home care and health care providers serving the Asian community so that they can assist in raising awareness of dementia and encouraging help-seeking in the community (Lombardo, Wu, Chang, & Hohnstein, 2007; Wu et al., 2010).

The in-depth cultural understandings and beliefs of dementia derived from the narratives could assist health care and social service providers working with the Asian community to establish rapport and better engage the families in the care delivery process (Yeo et al., 2002). Particularly, the mainstream clinicians need to acknowledge and integrate the cultural understandings and beliefs in the care process to enhance trust and satisfaction, both of which have been associated with improved health outcomes (Andrulis & Brach, 2007; Truong, Paradies, & Priest, 2014). Additionally, these findings could inform the development of targeted educational interventions to bring the cultural beliefs regarding dementia into alignment with up-to-date medical knowledge (Gray et al., 2009). Furthermore, clinical professionals and researchers working with the Asian community should be cognizant of the negative images of dementia and related cultural norms/beliefs to formulate culturally appropriate strategies to approach such topics (S. E. Lee et al., 2010).

Lastly, recognizing the importance of family caregiving in the Asian culture and the reported caregiving burdens, providing additional support to empower family caregivers of older Asian immigrants with dementia is imperative (Wu et al., 2010). Social workers are at the forefront to provide individualized counseling and emotional support to help the Asian family caregivers reconcile the potential conflicts between the cultural expectations and feasibility of providing family-based care (Casado & Sacco, 2011). Forming support groups with peer caregivers from the same ethnic background was specifically identified by the study participants as helpful (Wu et al., 2010). In order to develop culturally appropriate interventions, additional qualitative research will be necessary to better understand the preferred types of services that could be most useful to the family caregivers.

The study findings also underscore several important topics warranting future research. First, while the focus of this study was on beliefs and experiences shared by Korean and Chinese participants, there are likely differences between the two groups. Quantitative studies with large representative samples are needed to investigate cross-ethnic and cross-cultural commonalities and differences in perceptions and knowledge of dementia in various Asian subgroups. Second, considering the dynamic nature of culture, future research should examine how the acculturation process modifies cultural beliefs and values regarding dementia, the caregiving experiences, and help-seeking behaviors in the Asian community. Particularly, considering the significant influence of culture on dementia-related perceptions and help-seeking behaviors, the discrepancies in cultural values due to different levels of acculturation across generations may lead to family conflicts unique to the Asian community. Moreover, cultural determinants of the caregiving experiences in Asian communities deserve further research attention. For example, future studies should examine how cultural norms, such as filial piety, could influence stress appraisal and well-being of family caregivers. Larger representative samples of older Korean and Chinese immigrants and their family caregivers with various sociodemographic backgrounds and acculturation levels are needed to address these questions.

Conclusion

The overall goal of this qualitative study was to examine the perceptions of dementia and barriers/facilitators in accessing/providing care from the perspectives of older Korean and Chinese immigrants, their family caregivers, and home care providers. The study findings underscore the importance of culture in shaping perceptions of dementia and related help-seeking behaviors. Training and educational programs should be developed to expand awareness and knowledge of dementia in the Asian community and the need for early treatment. Special attention should be given to symptom recognition in order to facilitate timely help-seeking in this community. Training for formal care providers should also focus on stigma, communication barriers and support in seeking care. Culturally and linguistically appropriate social services are imperative to address the emotional and social needs of older Asian immigrants and their family caregivers.

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Table 9. Sample characteristics: Face-to-face interviews (N=24)

Variables	Older immigrants (N = 12)	Family caregivers (N = 12)
Age, *mean (min, max)*	83.4 (80, 88)	59.9 (47, 83)
Gender, *n (%)*		
Female	10 (83.3)	7 (58.3)
Male	2 (16.7)	5 (41.7)
Years in the U.S., *mean (min, max)*	25.1 (3, 50)	21.5 (2, 40)
English proficiency, *n (%)*		
Very good	0	2 (16.7)
Good	0	1 (8.3)
Fair	3 (25.0)	5 (41.7)
Poor	9 (75.0)	4 (33.3)
Education, *n (%)*		
No formal education	2 (16.7)	1 (8.3)
Less than high school	5 (41.7)	2 (16.7)
High school or GED	3 (25.0)	3 (25.0)
Some college or above	2 (16.7)	6 (50.0)
Marital status, *n (%)*		
Married	4 (33.3)	10 (83.3)
Not married	8 (66.7)	2 (16.7)
Living arrangement, *n (%)*		
Living alone	2 (16.7)	0
Living with others	10 (83.3)	12 (100.0)
Perceived health, *n (%)*		
Excellent, very good, or good	1 (8.3)	6 (50.0)
Fair	3 (25.0)	3 (25.0)
Poor	8 (66.7)	3 (25.0)

Table 10. Sample characteristics: Focus groups (N=29)

Variables	Home care professionals (N = 29)
Age, *n (%)*	
20 - 29	2 (6.9)
30 - 39	3 (10.3)
40 - 49	4 (13.8)
50 - 59	10 (34.5)
60 or older	10 (34.5)
Gender, *n (%)*	
Female	26 (89.7)
Male	3 10.3)
Ethnicity, *n (%)*	
Caucasian	2 (6.9)
Chinese	10 (34.5)
Korean	13 (44.8)
Other Asian	4 (13.8)
Education, *n (%)*	
Less than high school	5 (17.2)
High school and above	24 (82.8)
Years in home care, *mean (min, max)*	4.1 (0.5, 22)
Job title, *n (%)*	
Home health aide	18 (62.1)
Community coordinator	5 (17.2)
Registered nurse	3 (10.3)
Social worker	2 (6.9)
Volunteer manager	1 (3.4)

Table 11. Main themes and subthemes

Main themes	**Subthemes**
Perceptions and attributions	Stigmatization
	Normal aging
	Psychological problems
Delayed help-seeking	Severity threshold to elicit help
Perceived barriers in accessing care	The futility of treatment
	Reliance on family for care
	Language barriers
	Lack of accessible services
Caregiving burdens	Distress
	Balancing work and caregiving
	High care needs
Barriers in providing care	Cultural differences
	Behavioral symptoms
	Communication barriers
	Lack of accessible services
	Workforce challenges
Service needs	Social and recreational programs for older immigrants
	Emotional support for family caregivers
	Education
	Respite services

APPENDIX A: INFORMED CONSENT FORM

You are being asked to be part of a research study exploring perceptions of memory loss and the culturally appropriate services in Asian communities. The study is not supposed to detect a disease, or test a treatment. You are being asked to participate in face-to-face interviews. Your participation in this study is voluntary. The following paragraphs will describe the study, your role as a participant and the risks and benefits associated with participation in the study. We will review this document with you, answer any questions you have and, if you agree to participate, we will ask you to sign it. Please do not sign this consent form if you have any questions or concerns about your participation in the study. You will be given a copy for your records along with our contact information.

Purpose: The purpose of this study is to understand perceptions of memory loss and facilitators and barriers in accessing culturally appropriate care for individuals with memory loss in Asian communities in the Philadelphia area.

Participation: You are being asked to participate in a one time face-to-face interview that will be approximately 90 minutes in duration at places of your choice using your preferred language (Korean, Chinese, or English). During the interview, we will be asking you a series of questions related to your perceptions of memory loss and the various facilitators and barriers in accessing care in the home. We are interested in your views and experience on this topic as individuals. There are, no right or wrong answers to our questions. You can choose not to participate if you don't want to and you can quit the interview at any time if you wish. You do not have to answer all the questions and you should feel free not to comment if you do not feel comfortable sharing your thoughts on any particular question. The agency will not be informed of who participates in the interviews. You (Your loved ones) will lose no benefits or advantages that are now coming to you (them), or would come to you (them) in the future, if you wish not to participate. All the information we collect will be kept strictly confidential. All dissemination activities will only contain quotes with pseudonyms so that identification is impossible.

Risks: The most likely risks are anxiety/stress and inconvenience. First, topics covered in the interviews may cause emotional and psychological distress. All interviewers will approach the topics in a non-suggestive yet supportive and empathetic way to minimize distress. Second, interviews will be conducted at a time and place convenient to you. Finally, loss of confidentiality is judged to be unlikely as the research data collected will only have a research study number to identify the subject, so the risk is not judged to be a major risk.

Benefits: This study does not have any direct benefits for you.

Compensation: You will be given $30 cash in appreciation for your time and effort.

Voluntary: Your participation is completely voluntary. Your participation will not influence your employment and benefits. You will lose no benefits or advantages that are now coming to you, or would come to you in the future, if you wish not to participate. You are not obligated to answer all the questions that are asked during the interview and you are free to withdraw from participation at any point. If you choose to withdraw from the study, you can simply verbally inform the interviewer, at any point prior to or during the interview. However, if you choose to withdraw before we complete the interview we will not be able to reimburse you for your time.

Confidentiality: Your participation in this study is confidential. You are not being required to participate by your agency nor will we reveal to anyone in or outside of your agency who agreed to participate. If you do agree to participate the fact that you participated and your answers will be kept strictly confidential as required by law. Only the research staff will know who chooses to participate and who does not choose to participate. All collected data will be de-identified and securely maintained on a firewall and password protected computer in the PI's office: only the PI, co-PIs, and RAs will have access to the data. Consent forms with names and the participant ID identifier will be locked in the PI's office. We will not report or record any names on the interview notes, transcripts, in research reports or any other publications that arise from this study so that identification is impossible. All contact information that we use to schedule the interviews will be destroyed upon completion of the interviews and will be maintained is a separate locked file cabinet in a locked office or on a firewall, and password protected, limited access computer server.

Time: As a participant in this study, you will be asked to participate in a one-time interview. The interviews will last approximately 90 minutes.

No Costs: You do not have to incur any cost as a result of your participation in this study. In exchange for your time, participants will receive $30 cash once the interview is completed.

Questions/Concerns/Complaints: We hope you will find your participation in the interview interesting and we thank you for your help and cooperation. If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject at any time, you should speak with the Principal Investigator, whose contact information is provided on the first page of this form, or any member of the research team. If the principal investigator or another member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215)898-2614.

You will be asked to sign this form to show that

- the research study and the information above have been discussed with you

- you agree to participate in the study

You will receive a copy of this signed form and the summary of the study that will be discussed with you.

Subject’s Name [print]	Subject’s Signature	Date
Family Caregiver’s Name [print]	Family Caregiver’s Signature	Date
Witness [print]	Witness’ Signature	Date

APPENDIX B: INTERVIEW GUIDE

Introductory Statement:

Thank you very much for taking part in this interview. We appreciate your time and value your participation. This interview will focus on your perception, knowledge, and awareness of memory loss and related services. Your opinions and thoughts are very important. They can help us learn about how to improve the culturally related services for older immigrants with memory loss issues.

Experience of receiving services (Ice-breaker):

How long have you been receiving services from Penn Asian Senior Services (PASSi)? What made you decide to use the services from the agency?

The next couple of questions are about your perception, knowledge, and awareness of memory loss and related services.

Perception of dementia:

1. If someone exhibits extreme forgetfulness, wandering aimlessly, loss of orientation, etc., what does this mean to you? What words do you use to describe a person with these behaviors?
2. What would you do for someone with these behaviors?
3. Tell me what you know about dementia. What are your ideas about the cause (or causes) of dementia (or the words interviewee uses)? What does dementia mean to you? When people say dementia, what words come to mind?
4. Do you think dementia is an illness? If yes, what makes you think so? If no, what makes you think so?

Knowledge of dementia and inclination for seeking treatment:

Next, I will describe four different situations and then ask you some questions. It is NOT that you or anyone in your family are like this. You can answer these questions based on your own judgment.

a. Someone in your family or someone you are close to experiences memory loss that disrupts daily life. For example, forgetting important dates or events; asking for the same information over and over; increasingly needing to rely on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. How would you interpret this? Would you seek medical consultation (If so, could you tell me why? If not, could you tell me why not?) What else would you do? Have you ever experienced this yourself?
b. Someone in your family or someone you are close to experiences confusion with time or place. For example, losing track of dates, seasons and the passage of

time; having trouble understanding something if it is not happening immediately; or forgetting where they are or how they got there. How would you interpret this? Would you seek medical consultation (If so, could you tell me why? If not, could you tell me why not?) What else would you do? Have you ever experienced this yourself?

c. Someone in your family or someone you are close to experiences new problems with words in speaking or writing. For example, having trouble following or joining a conversation, stopping in the middle of a conversation and having no idea how to continue or repeating themselves. Or struggling with vocabulary, having problems finding the right word or calling things by the wrong name. How would you interpret this? Would you seek medical consultation (If so, could you tell me why? If not, could you tell me why not?) What else would you do? Have you ever experienced this yourself?

d. Someone in your family or someone you are close to misplaces things/items and accuses others of stealing these things/items. And it keeps occurring more frequently over time. How would you interpret this? Would you seek medical consultation (If so, could you tell me why? If not, could you tell me why not?) What else would you do? Have you ever experienced this yourself?

Awareness of dementia and dementia-related services (including barriers & facilitators):

1. Have you ever experienced any symptoms that you think might be symptoms of dementia yourself?

   If yes, *ask sub question 1.1.*

   If no, what makes you think you don't have any dementia symptoms?

   Sub question 1.1: Would you briefly describe your symptoms? Have you sought medical consultation to address these symptoms? If yes, what kind of medical consultation? When and why you decided to seek medical consultation? If not, can you tell me why you have not sought medical consultation to address the symptoms you mentioned?

2. Would you know how to get help for someone who has dementia? If yes, would you elaborate a little bit about how to get such help? If no, are you aware of the following services and organizations that provide help: diagnostic services for memory problems (memory clinics); organizations that provide information on memory loss (Alzheimer's Association); community based older adult services (adult day care center, senior center, etc); home care (home health care, caregiver support group) and institutional care (nursing home, assisted living, etc)?

3. Do you personally know someone (can be you, your friends, relatives, co-workers, neighbors etc.) who has reached out for dementia services?

   Yes _______(If yes, ask sub question 3.1.) No ________(If no, ask sub question 3.2.)

Sub questions:

3.1. If yes, what were their or your experiences like? (probe: Why he/she decided to seek help? Was it difficult for you, your friends etc. to get help? If yes, what made it difficult to get help? Anything else? If no, what helps in regard to getting help? Anything else?)

3.2. If not, can you please share with me why you (your friends or relatives with dementia etc.) have (has) not reached out for services? (probe: things related to Chinese society/culture, feeling of shame, lack of knowledge of organizations/agencies, even have knowledge, difficult to get to these organizations, no extra money to use services), any examples?

4. For clients with no symptoms and those with symptoms but no diagnosis, ask: What are the situations in which you would consider requesting medical consultation to address the symptoms we described as Dementia? What are the situations in which you would consider requesting help from agencies providing dementia-related services?

   For clients with formal dementia diagnosis, ask: what made you to seek medical consultation to address your memory loss issues and other dementia related symptoms that you mentioned? Were you involved in the decision making process? In what ways?

Closing question:

5. What supports and services do you think would be beneficial to older Korean and Chinese immigrants with dementia and/or their families? Anything else?

APPENDIX C: FOCUS GROUP GUIDE

Ice Breaker/Opening Questions

1. How long have you been working at PASSi?
2. What is your role/what do you do?

Next I would like to ask you some questions about clients and families dealing with memory loss.

5. If someone exhibits extreme forgetfulness, wandering, searching, etc., what does this mean to you? What words do you use?
6. What are your ideas about the cause (or causes) of dementia (or the words interviewee uses)? Probe: How does dementia affect the mind and body?
7. In your opinion, how are the needs of persons with dementia different from clients without dementia?
8. How do you feel when you work with these clients? Their family members?
9. What are the barriers or challenges to providing services to clients with dementia? their family members? (probe: cultural factors, perception, stigma, etc), any examples?
10. How do you manage these challenges and barriers?
11. What are the facilitators in providing services to clients with dementia?
12. What additional services do you think would be beneficial to your clients with dementia and/or their families? (probe: services that are not currently provided by PASSi, or other agencies)