Perceptions of caregiving and health services use among Korean American family caregivers of older adults

Mihee Chung
Portland, OR

BSN, the Armed Forces Nursing Academy, Republic of Korea, 1992
MSN, University of Virginia, 2015

A Dissertation presented to the Graduate Faculty of the University of Virginia in Candidacy for the Degree of Doctor of Philosophy in the Graduate School of Art and Science

Department of Nursing

University of Virginia
May, 2019

Ishan C. Williams, Chair of the dissertation committee
Jeanita Richardson
Cathy Campbell
Jeongok Logan

ACKNOWLEDGEMENTS

I would like to acknowledge the members of my dissertation committee for their guidance and support. I am especially grateful to my committee chair and academic advisor, Dr. Williams, for her continuous encouragement and support throughout the dissertation research project. Also, special thanks to the Aging Research Team (ART) for helping me with funding for the project. I would like to send my gratitude to all my participants who willingly shared their lives. Special thanks to the Deans, all faculty members, and staff at School of Nursing. Thank you to all my classmates and friends at UVA. To ones who I failed to mention, I extended my full-hearted gratitude to you all.

DEDICATION

To the Lord God, who has walked with me throughout my life and provided me whenever I was in need and who has shown me steadfast love through your angels, my church family and friends all around the world.

To my family in Seoul and New York, especially my dearest niece Rachel, with love, who has been suffering with endless proof reading, I really am thankful for your patience and trust in me even when I was in doubt of myself.

To my husband, my best friend, and love, Jong Ho and my daughter, Youngsuh, both of you are just the best gifts from God to me! I am just so blessed. Thank you and love you!

TABLE OF CONTENTS

Concept Analysis: Perceived Stigma in Dementia

Perceptions of caregiving and healthcare uses among Korean American family caregivers of older adults: Qualitative descriptive study with thematic analysis

CHAPTER 1

INTRODUCTION

Family caregivers are the backbone of care in older adults in the U.S, and family caregivers have reduced the cost of care for older adults tremendously by keeping them in the community setting (National Alliance for Caregiving and AARP, 2015). Greater than 80 % of older adults in the U. S. have at least one family/ informal caregiver to assist them in maintaining their daily living (Kasper et al., 2015). When family caregivers provide in home daily living assistance for older adults, the physical workload, time management issues, and financial burdens, may cause physical and psychological stresses that may put these caregivers at a greater risk of developing cardiovascular disease, depression, or other adverse health conditions (Burgener et al., 2013; Laditka et al., 2012; 1989; Mannion, 2008). Many studies have revealed there is underutilization of healthcare services by caregivers of older adults, even though they are a vulnerable population who need more medical attention (Casado & Lee, 2012; Haralambous et al., 2014; Laditka et al., 2009). There are also other issues among certain populations, such as cultural traditions, that further prevent the utilization of healthcare services. One of these populations are the Asian American caregivers of older adults, including Korean Americans who have a deep layer of cultural tradition, which may hinder them from using healthcare services. Different cultural beliefs put Asian Americans, including Korean Americans, at a more vulnerable status regarding the use of health services. In addition, a unique cultural background, such as face saving, can result an increase stigmatization of asking for outside help. Cultural beliefs in Korean Americans, impact of perceived stigma, and health service utilization may be correlated. However, not many studies have been conducted to understand Korean Americans' perceptions of caregiving roles and what factors drive their health behavior related to their cultural background.

Thus, the primary purpose of this study is to explore the personal experiences and perceptions of caregiving among Korean Americans caring for older adults, who are age 65 and older. Based on the literature, caregiving of older adults is physically, mentally and financially challenging (Alzheimer's Association, 2018; Laditka et al., 2012; Mannion, 2008). These challenges may influence the health status of caregivers negatively, including those of Korean American descent. Exploring the individual's experience and perception of caregiving can expand our knowledge and understanding of what influences their help seeking behaviors and add to the existing evidence of the cultural influence on one's caregiving role.

The second purpose of the study is to explore negative and positive reactions to the caregiving role. Acknowledging their reactions to caregiving can help researchers build the necessary foundation in terms of understanding the intervention necessary to decrease the negative impact of the caregiving of older adults. It is also of interest to better understand whether caring for someone can influence how caregivers utilize health resources in terms of maintaining a good health status for themselves and for their care recipients as well.

The specific aims of this study are: (1) to explore the perceptions of caregiving and its consequences among Korean American caregivers of older adults, (2) to explore the negative and positive reactions to caregiving, and (3) to describe the factors that contribute to their use of health care services.

This study consists of three manuscripts. The first manuscript was a literature review of help-seeking behaviors of caregivers of people with dementia (PwD). Factors affecting help-seeking behaviors of caregivers of PwD among the general population were explained. The second manuscript was a concept analysis, where the antecedents, attributes, consequences, and empirical referents were analyzed from the existing literature to differentiate the clear meaning of perceived stigma with other types of stigma such as family-, self-, public- or structural stigma among people who are affected by Alzheimer's disease and related dementia (ADRD) were explored. This was done in order to better understand the relationship and increase communication between people who are involved with PwD, such as caregivers, nurses, physicians, and researchers. Finally, the last manuscript explored the perceptions of the caregiving role, challenges, strategies to overcome those challenges, and healthcare services use among Korean American caregivers. Through these three manuscripts, clinicians and researchers may expand their knowledge on caregivers of PwD and ADRD, so they can utilize this new knowledge to perform better care and further development of assessment and interventions necessary to improve the quality of life of people who are affected by ADRD.

Definition of Key Terms

Informal (Family) Caregiver: an unpaid individual such as a spouse, family member, friend, or neighbor, who is involved in assisting the care-recipient with activities of daily living and/or medical tasks. They typically spend an average of 24.4 hours per week providing care (Family Caregiver Alliance, 2016; National Alliance for Caregiving and AARP, 2015).

Health Service Utilization: "the quantification or description of the use of services by persons for the purpose of preventing and curing health problems, promoting maintenance of health and well-being, or obtaining information about one's health status and prognosis (Gellman & Turner, 2013, p. 909)."

Asian American (Korean-American): A person who claims their origins in any of the countries from the Far East, Southeast Asia, or the Indian subcontinent. Korean American refers in the same way to a person having origins in Korea, including persons who indicate their race as “Korean” or “Korean American” (Census.gov, 2010).

Help-Seeking Behavior: An act or behavior looking or searching for a relief in response to changes in health. The direction of this act is based on the interpretation of the problem by a person who is the subject of the help-seeking process (Cornally & McCarthy, 2011)

References

Alzheimer’s Association (2018). Alzheimer’s disease Facts and Figures. Retrieved from https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia*, *14*(5), 609-632. Doi: 10.1177/1471301213504202

Casado, B. L., & Lee, S. E. (2012). Access barriers to and unmet needs for home- and community-based services among older Korean Americans. *Home Health Care Services Quarterly,* 31, 219-242. Doi: 10. 1080/01621424.2012.703540

Gellman & Turner, 2013, p. 909).”

Haralambous, B., Dow, B., Tinney, J., Lin, X., Blackberry, I., Rayner, V., Lee, S., Vrantsidis, F., Lautenschlager, N., & LoGiudice, D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers. *Journal of Cross Culture Gerontology,* 26, 69-86.

Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs, 10* (2015), 1642-1649. Doi: 10. 1377/hlthaff.2015.0536

Laditka, S.B., Tseng, W., Price, A.E., Ivey, S.L., Friedman, D.B., Liu, R., Wu, B., Logsdon, R. G., & Beard, R.L. (2012). Beliefs about promoting cognitive health among Filipino Americans who care for persons with dementia. *International Journal of Aging and Human Development, 75*, 3, 273-296 doi: http://dx.doi.org/10.2190/AG.75.3.d

Mannion, E. (2008). Alzheimer's disease: the psychological and physical effects of the caregivers' role. Part1. *Nursing Older People*, *20*, 4, 27-32

National Alliance for Caregiving and AARP, 2015

U.S. Census Bureau population Division (2013) Annual estimate the resident population retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk

CHAPTER 2

RESEARCH PROPOSAL

Statement of the Problem

Family caregivers are the backbone of the care of older adults in the U.S, and those workforce have reduced the cost for older adults tremendously by keeping them in the community setting. When family caregivers provide care for maintaining the activities of daily life of older adults at their home, physical workload, time management, and financial burden could cause physical and psychological stresses that may put them under the risk of developing cardiovascular disease, depression, or other adverse health conditions from caregiving. There are many studies that revealed the underutilization of healthcare services by caregivers of older adults even though they are such a vulnerable population who need more attention. Among them, there are Asian American caregivers of older adults including Korean Americans who have an additional layer of cultural tradition which may hinders them from healthcare service utilization. However, not many studies included those groups to understand in depth to their perceptions of caregiving roles and what factors drive their health behavior.

Purpose of the Study

The primary purpose of this study was to explore the personal experiences and perceptions of caregiving among Korean American caregivers of older adults who are age 65 and older. Exploring the individual’s experience and perception of caregiving can expand our knowledge and understanding of what influences their health behaviors and add to the existing evidence of the cultural influence on one’s caregiving role.

The second purpose of the study was to explore coping strategies including negative and positive reactions to the caregiving role. Acknowledging their strategies used to cope with caregiving can help researchers build the foundation in which they have to begin to decrease the negative impact of caregiving on adult caregivers.

The specific aims of this study were: (1) to explore the perceptions of caregiving and its consequences among Korean American caregivers of older adults, (2) to explore the perceptions of challenges to their caregiving role and what coping strategies are used, and (3) to describe the factors that contribute to their use of health care services.

Significance of study

In the U.S, there were 46.2 million Americans aged 65 and over in 2014, and it will be more than double by 2060 (US department of Health and Human Services, 2015). Among this fast growing population, more than eighty percent of older adults have at least one or more family or informal caregivers to maintain their activities of daily life (Kasper et al., 2015). As the number of older adults increases, the number of caregivers for them increases as well. Previous studies showed that family caregivers have more physical and emotional stress from caregiving than non-caregivers that could negatively affect to the state of the public health (Grunfeld et al., 2004; Musich et al., 2017; Paekh et al., 2017; Schulz & Beach, 1999). Furthermore, previous studies revealed that older adults and their family caregivers underutilize the healthcare services compared to non-caregivers, particularly among Asian Americans including Korean Americans who are under the influence of their own cultural beliefs (Casado & Lee, 2012; Han et al, 2008; Park et al., 2004). Based on what is known, healthcare providers should acknowledge the health issues and underutilization of healthcare services among Korean American caregivers; they also need to develop culturally tailored educational materials and instruments to promote their health behaviors and to prevent the health disparity among this group. However, there are scarce studies regarding healthcare service utilization among Korean American older adults and their family caregivers (Jang, Kim, & Chiriboga, 2010; Lee, Lee, & Diwan, 2010). Given the situation, Korean caregivers need to be further examined to better understand how they perceive their role as a caregiver and what affects their healthcare service utilization.

Review of the Literature

This section contains a description of key concepts; older adults, informal caregivers, caregiving and the impact of caregiving for older adults including caregivers' underutilization of health care services, and literature examining Asian Americans including Korean American caregivers. The evidence provided illustrated the importance of this proposal, and explain why it is essential to better understand the target population in terms of promotion of public health by addressing the issues among ethnic minority groups.

Key Concepts in the Study

Older Adults. In the US, population of age 65 and over is 46.2 million. By 2060, that same population will be approximately 98 million, more than double the current amount (US Department of Health and Human Services, 2015). Among them, Asian Americans consist of 5.6 percent which is 1.9 million, which is projected to increase to be 8.5 million by 2060 (US Census Bureau, 2012). Older adults among Asian American grew four times faster than in the general population between 2000 and 2010, forty-three percent versus nine percent (US Census Bureau, 2012). To prevent the health disparity among this racial and ethnic minority group, more attention may need to be given to this group.

Informal (Family) Caregiver. Informal caregivers are people who are involved in assisting a person's activities of daily living or instrumental activities of daily living to maintain one's daily life without monetary rewards, and they usually provide care in care recipient's home (Family Caregiver Alliance, 2016). There are about 34.2 million caregivers of an adult age 50 or older (National Alliance for Caregiving and AARP, 2015, Caregiving in the US). Among them, approximately fifteen percent of caregivers were categorized as caregivers of older adults (Musich et al., 2016) and about ten percent of caregivers were caring for someone with dementia (Alzheimer's Association, 2017). According to Kasper and colleagues, persons with dementia were receiving more help with activities compared to ones without dementia (Kasper et al., 2015). The value that informal caregivers provide exceeded the value of paid home care and that save approximately $470 billion healthcare expenditure (Family Caregiver Alliance, 2016). The report by the National Alliance for Caregiving and AARP, which lists caregivers by race and ethnicity, shows that sixty-two percent were White, thirteen percent were African American, seventeen percent were Hispanic, and six percent were Asian Americans.

Caregiving. Research shows that more than 90% of caregivers provide activities of daily living (ADLs) and more than 40% perform medical or nursing tasks because most of them do not have any other options or they think it is their responsibility (Kasper et al., 2015). More than 60% reported that they are responsible for making decisions regarding the care recipient's treatment, communicating with healthcare professionals, and advocating for the care recipient (Family Caregiver Alliance, 2016).

Asian Americans (Korean Americans). Asian American adults consist of 5.6 percent (17.3 million) of the total US population (US Census, 2012) and 1.9 million, which is four percent of the total US population, are age 65 and over (US Department of Health and Human

Services, 2015). The Asian American population is expected to increase to 8.5 million by 2060 (US Department of Health and Human Service, 2015). Among them, Korean Americans are the fourth largest group (Lee & Choi, 2012; Lee & Smith, 2012). Thirty percent of Asian American caregivers, including Korean American caregivers, reported having caregiver burden with an average of working 16 hours per week (Alzheimer's Association. 2015).

Cultural Beliefs and Norms. Most Asian Americans' cultural beliefs are based on Confucianism, specifically filial piety or filial responsibility (Dai, 1998; Lai, 2010). They share many common cultural beliefs, which influence their caregiving and their help-seeking (McCleary & Blain, 2013). For example, they consider dementia symptoms as part of normal aging, and that normalization hinders them from seeking healthcare providers. Filial piety is a fundamental value in Confucianism; adult children should respect their parents and should support them in old age physically and financially when they cannot afford themselves. This concept includes reciprocity, which means to repay their parents for the parental support they received until they were fully grown (Lai, 2010). In terms of caregiving, due to the influence of Confucianism, the first choice of the caregivers of older adults is most likely the oldest son's wife among Korean/ Korean Americans (Youn et al., 1999). On the other hand, most of the primary caregivers among Americans are mostly spouse or daughter (Gatz, Bengtson, & Blum, 1991 in Youn et al., 1999).

There is another cultural norm, "face-saving," which considers exposing negative family events as shameful and embarrassing. For example, members of the family do not want to disclose their family member's mental illness because it will ruin or dishonor their family name (Smith & Kobayashi, 2002, in Lee et al., 2010). That may result the family caregivers' low utilization of healthcare services due to the stigma. Sun and colleagues (2014) found that

Chinese American caregivers of older adults with dementia have a lack of communication and initiative in seeking help (Sun et al., 2014). In their study, caregivers addressed stigma as one of the barriers to seeking help. The stigma addressed in this study may be involved with face saving.

Filial piety. Filial piety is one of the Confucian principles that has three important elements: respecting and loving parents, bringing no dishonor to parents, and taking good care of parents (Dai & Diamond, 1998). In this family centered cultural construction, children are expected to sacrifice their own interest physically, financially, and socially for the benefit of their parents or family as a responsibility (Dai & Diamond, 1998). There are four conceptual components of filial piety: (1) concern for parental health, (2) financially supporting parents, (3) fulfilling the housing needs of parents, and (4) respect for parental authority. Filial piety is the central theme in caregiving in many different ethnicities as a responsibility or obligation to parents, and it can influence the caregiving appraisal, caregiving burden, and caregiver's utilization of healthcare services (Lai, 2010). Family caregivers, particularly adult children caregivers, may avoid seeking help due to saving family face or avoid social stigma. When their parent is ill, family caregiver try to keep the one at their home because taking good care of their parents at home is regarded a good practice of the filial piety (Lai, 2010).

Familism. "Refers to strong identification and solidarity of individuals with their family as well as strong normative feelings of allegiance, dedication, reciprocity, and attachment to their family members, both nuclear and extended (Knight & Sayegh, 2010, p. 7)." Familism is multidimensional, with subcomponents that may have differential impacts on caregiving (Knight & Sayegh, 2010). The subcomponents of familism are family obligation (obligation to provide caregiving for family members); support from the family (expectation of support from family members when needed); and family as referents (rules about how life should be lived derived from the family) (Knight & Sayegh, 2010). In a review of cross-cultural comparisons of familism among dementia family caregivers, Knight and colleagues (2002) found that familism was associated with acculturation to the Western value of individualism. The lowest levels of familism were found in White American samples, followed by African American, Japanese American, Korean American, Latino American, and Korean samples. Familism may affect the coping strategies negatively which may lead to worse outcomes among caregivers (Knight & Sayegh, 2010)

Acculturation. Acculturation is the process of assimilating oneself to the new culture (Berry, 1998; Marshall, 1990). In other words, it is the process of changing one's values, behaviors, or attitudes. All immigrants might experience this process and they may have different levels of acculturation with different levels of stress. Berry categorized acculturation as integration, assimilation, marginalization, rejection (Berry, 1998). However, acculturation is an on-going process in one's life in a new culture. The levels of acculturation may affect many aspects of ones' lives. For example, low acculturation levels with high Asian values can increase psychological distress and adjustment issues (Suinn, 2010). Different levels of acculturation between family members might also increase family conflicts or emotional problems (Suinn, 2010).

Impact of Caregiving and Healthcare Utilization. Caregiving of older adults involves assisting activities of daily living including dressing, feeding, bathing and helping in- and out of the bed in which they have to put much time and effort to maintain their care recipients' need. Family caregivers spent average 24 hour per week for providing care for their care recipients and among those family caregivers, the ones who reside with their care recipients work prolonged hours of average 40 hours per week (National Alliance for Caregiving and AARP, 2015). Because their time unable to separable from their care recipients', they may feel overwhelmed emotionally than who are living separately. The previous studies found that caregivers have higher morbidity and mortality risks than non-caregivers (Grunfeld et al., 2004; Musich et al., 2017; Paekh et al., 2017; Schulz & Beach, 1999). They have higher prevalence of depression, cardiovascular disease and diabetes (Bruce et al., 2008; Burgener et al., 2013; Laditka et al., 2012; Link et al., 1986; Mannion, 2008). Grunfeld and colleagues revealed that caregivers had equal to or greater psychological morbidity than care recipients who were suffering from breast cancer (Grunfeld et al., 2004). Parekh and colleagues showed that thirty percent of caregivers experienced health problems related to caregiving (Parekh et al., 2017). All of these studies showed that caregiving affects caregivers' physical and psychological health. To enhance caregivers' health status, more attention should be given to these populations.

One factor that may affect caregivers' well-being is health care utilization. Previous studies showed that family caregivers underutilize the formal care resources compare to the non-caregivers, as well as having a low awareness of healthcare services that are available for them (Boots et al., 2015; Casado & Lee, 2012; Musich et al., 2016). Boots and colleagues (2015) found that family caregivers of persons with dementia expressed fear of rejection and low acceptance from their ethnic society, which hindered them from seeking help (Boots et al., 2015). Burgener and colleagues (2013) support this finding that fear of negative response and social isolation might be a caregivers' stressor, which may influence their healthcare utilization.

This phenomenon-underutilization of healthcare services- is pertinent among Korean American older adults. Korean Americans as a group with highest uninsured rate among the subgroups of Asian Americans may affect their underutilization of healthcare services (The

Kaiser Family Foundation, 2008). In addition, Kwak and colleagues (2007) found that some Korean American older adults and their caregivers underutilized healthcare resources, such as palliative care and hospice services for their family members during the end of life. Reports also illustrated limited use of mental health services for older adults with cognitive impairment due to the belief of fulfilling their moral duty as adult children in terms of filial piety (Kwak et al., 2007; Lee et al., 2014). Including Kwak and colleagues' study, previous studies' identified factors that influence caregivers' attitude toward healthcare services are familism, filial piety, differences in food, and language barrier (Han et al., 2008; Kwak et al., 2007; Lee et al., 2014; Park et al., 2004; Youn et al., 2004). Cultural influences, described above may have a significant impact on how Korean American caregivers use health care services.

Summary

As the population of older adults continue to increase rapidly, the numbers of caregivers for them will also need to increase. While they are caring for their family members, evidence has shown that caregivers are under physical and emotional stresses, which may lead them to develop various health issues that may incur noticeable financial costs. In addition, previous studies revealed that caregivers underutilize healthcare services and have limited awareness of available resources. More importantly, caregivers from ethnic minority groups may have more factors hindering them from seeking healthcare services, such as language barriers and their own cultural beliefs-filial piety, familism and face saving- and norms around caring for their loved ones. Healthcare professionals should recognize such barriers and cultural context to understand what their needs are. To better understand these phenomena among Korean American caregivers, this proposed study will explore how Korean American caregivers perceive caregiving around their role, coping strategies, and healthcare utilization.

Research Methodology

Research Design

A qualitative descriptive approach with thematic analysis was used with semi-structured interviews to describe and explore Korean-American caregivers' perceptions and experiences of caregiving and health service uses. Qualitative descriptive approach was used because this method can help us to understand the cultural nuances and personal impact of caregiving by adapting a person-centered and holistic perspective (Holloway & Wheeler, 2014). Furthermore, a qualitative descriptive method was chosen because it is "the method of choice when straight descriptions of phenomena are desired" (Sandelowski, 2000, p. 334). According to Sandelowski (2000), the qualitative descriptive approach facilitates a comprehensive summary of an event in our daily lives which was a good fit to understand caregivers of older adults.

Additionally, the qualitative descriptive approach can stay closer to the data than other qualitative method. In other words, qualitative descriptive approach requires low inference, which researchers put much of their interpretive opinion to the event they observed or experienced (Sandelowski, 2000). Considering all the benefits mentioned above, the qualitative descriptive approach was the best fit for this proposal.

Pilot Study

To examine the feasibility and interview guide in terms of cultural context and validity a pilot study was conducted. With the approval of University of Virginia Institutional review board (IRB) (IRB#2016-0431-00), the primary investigator (PI) recruited the participants from the metro New York and Northern Virginia area by posting flyers and contacted local Korean American senior center coordinator, and church pastor. Period of recruiting and data collection was between December 10th, 2016 and March 31, 2017. Inclusion criteria was 1) Age 18 and older, 2) be a family member/partner, 3) reside with or have contact with a person who is diagnosed with dementia (vascular, Lewy-body, Alzheimer's) at least twice a week, and 4) be self-identified as Korean-American. The targeted range of sample size was three to 20. The PI screened and set an appointment for the interview after the participants contacted and showed the interest in the study. All interviews were conducted in Korean. All were recorded and transcribed verbatim and translated into English.

Results. There were four participants who contacted and four were included in the pilot study. One was a spouse and three were adult child caregivers. Range of their age was 44 to 81. All were bicultural status in terms of the level of acculturation, which means all of them were assimilated to the western culture while they still keep their old culture. Only one interview was held at the participant's home and the rest were at the local coffee shop or bakery.

Conclusions. Different recruitment strategy was considered to engage more participants such as revising inclusion criteria, modifying the terms on the flyer and emails to the personnel of local Korean community centers and conduct in-person recruitment to provide more education regarding the study at the local Korean churches or senior centers. Include local Korean newspaper and social network sites were other options, such as including the group sites of any local Korean churches on Facebook. Han and colleagues found that utilizing ethnic media was effective when recruiting hard to reach population (Han et al., 2007). By changing the inclusion criteria number three (reside with or have contact with a person who is diagnosed with dementia (vascular, Lewy-body, Alzheimer's) at least twice a week) into the family member/partner who are caring for older adults produced better outcome in terms of recruitment. Interview guide was revisited to broaden up the contents to ask experiences of caregiving in general to specific concerns or challenges of caregiving.

Data Collection Procedures

Participants and Setting. The target population was Korean American family caregivers of older adults, no matter which generation they are. Participants were recruited by purposive, non-probability, convenience sampling methods and the snowball technique, from the Metro New York area and Northern Virginia where a majority of Korean immigrants reside (Yeo & Gallagher-Thompson, 2006, p 246; Yoon et al., 2016). According to the US. Census Bureau, 9% and 4.8% of Korean Americans are living in both metro New York and Virginia, respectively (U.S Census, 2010). They are second and fourth place in population wise following after California, New Jersey, and Texas. Northern Virginia was selected because of the vicinity to the PI in terms of feasibility.

Sample Size. Based on the sample characteristics and suggestions from literatures (Lee & Smith, 2012; Lee & Yim, 2012; Moore & Cahill, 2013; Navab et al., 2013; O'Sullivan et al., 2014; Park et al., 2004; Prorok et al., 2013; Sun, 2014) and with the revision of inclusion criteria after the pilot study, sample range twenty to forty seemed appropriate for this proposal. However, interviews were continued to be gathered until saturation (means there are no more new concept or repeatedly shown similar concepts) has been reached (Creswell, 2016, p110). Guest et al.(2006) asserted in their experimental study that small samples like three can be enough within a homogeneous population who share a particular cultural context. Furthermore, Magilvy and Thomas (2009) suggested the sample range for qualitative descriptive study from three to twenty (Magilvy & Thomas, 2009).

Recruitment. IRB-approved emails were sent to the leaders of organizations, churches or clinics, such as the Korean American Senior Centers or Korean-American clinics in targeted areas. In particular, churches are one of the most successful place to recruit participant (Han et la., 2007), the PI primarily contacted the pastors of the local churches as well as the local senior centers to set up a booth to hand out information about the study. Flyers that also indicate the incentive for participating ($10 value of local grocery store gift card) the study were posted in multiple places within the Korean community, such as Korean churches, Korean grocery stores, and Korean senior centers, and clinics. A sign-up sheet was provided for people who want more information and then the PI contacted them to see if they were eligible for the study. Individuals also contacted the PI directly from the contact information listed on the flyer. The PI have utilized the social network sites, such as the site of local Korean churches or local Korean communities on the Facebook and Kakaotalk by posting the flyer to promote recruiting. Kakaotalk is the worldwide social network that the majority of Koreans are using as a way of communicate. One last strategy was the use of snowballing technique (Creswell, 2016, p 109). When one interview was completed, the PI askd whether the participant can suggest other volunteers for the PI to contact. The PI contacted and screened them by using the inclusion criteria.

Inclusion criteria were 1) Age 18 and older, 2) be a family member/relative who is caring for older adult age 65 years and over, 3) reside with or contact with older adult at least twice a week, and 4) be self-identified as Korean or Korean American. Once they were selected as a participant, the PI set an appointment for the interview.

Data Collection. ***Informed Consent and Survey.*** Once participants verbally agreed to participate in this study (participants contacted the PI through the various contacts that were provided on the flyers and to the leaders of the communities or in person at the information booth), the PI contacted each of them and arranged an appointment to elicit informed consent (Korean/English version available). Study participants have completed/signed a consent to participate in the study prior to the collection of any research data which was needed to confirm confidentiality and participants' voluntary participation. To increase the number of participants, the PI had set up a table in the facilities/ churches to explain about the study to the candidate of the study to get a verbal consent. The PI have conducted the whole process including consent and interview process, which means the participants received the consent form and signed before they have an interview.

At the beginning of the interview session, the revised Participant Information Form (PIF) was completed by participants after they have completed the written consent form. The PIF includes basic demographic information and characteristics of participants such as the type of health insurance, relationship to the care recipient, and the length of caregiving, but this form was revised to better fit the population of interest. It was a self-reported questionnaire and estimated completion time was approximately 5 to 10 minutes.

Interviews. Face-to-face interviews, with semi-structured interview protocol, in either Korean or English based on participant preference, was conducted by the PI. The semi-structured interview questions were focused on the experience of caregivers. Furthermore, the interviewer could manipulate the sequence of questions depending on each participant's reaction.

According to Holloway and Wheeler (2010), "interview studies have contributed to the understanding of participants and the wider culture. In health research, interviewing provides the basis both for exploring colleagues' perspectives and clients' interpretations" (Holloway & Wheeler, 2010, pp. 87). Participants can express their thought freely within semi-structured interviews while researchers can have the freedom to prompt for more information. Thus, both researcher and participants were satisfied with this method of data collection.

The interview took approximately 60 to 90 minutes. They were audio-recorded. Participants were asked open-ended questions about their experiences as caregivers of older adults. General questions, such as “please tell me about your experience from taking care of your parents/spouse" and questions that asks any challenges or experiences that hinder or promote their seeking help, were included. Interview questions were developed the PI adapted from past studies. It was revised after the pilot study to broaden the spectrum of question to caregivers of older adults. The PI made notes during and after each interview (See Appendix A). After interviews were completed, the participants received the local grocery store gift card ($ 10) for appreciation of participating in the study.

Data Analysis Strategy

Thematic Analysis (TA) was used for three specific aims because TA is a method for “identifying, analyzing, and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail” (Braun & Clarke, 2006, p. 6). Braun and Clarke asserted that TA is the first qualitative method of analysis that researchers should learn. TA is the basis for conducting many other forms of qualitative analysis. One of the benefits to conducting TA was flexibility. With or without the theoretical framework, TA provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex account of data (Braun & Clarke, 2006). For these reasons, TA was the best fit for this proposal.

The PI adapted the seven steps of thematic analysis as stated by Braun and Clarke (2006). The PI (1) read and re-read the transcript to become familiar with the data, (2) generated initial codes, in this process, PI have conducted open coding, (3) during the second coding, focused coding was conducted, (4) categorized and searched for themes, (5) reviewed themes, (6) defined and named themes, and (7) produced the report. This process was repeated by the PI and another researcher.

Recorded interviews were transcribed verbatim and analyzed. After analysis, codes and excerpts were translated into English. The codes and excerpts of the first five interview transcripts were translated into English and sent to the bilingual researcher to ensure the accuracy and validity. The software Dedoose provided by the institute was used for storing, sorting, retrieving, and coding data. Dedoose was chosen because it is web-based and user-friendly.

Reliability and Validity

To add to the rigor, conceptual and methodological verification were done by member checking such as sharing coding and categorizing processes with other researchers or discussing them with a qualitative expert. To ensure rigor and validity, the PI have confirmed the contents with the informants for member checking and during the coding process, the PI has sent the English translated codes and excerpts of the first five interviews to the bilingual researcher to check the accurate translation including the nuance of the meaning of the codes. Also, the proposal was presented at the conference to have the peer feedback to ensure credibility (Shenton, 2004).

Study Limitations

The convenience sampling method would be a limitation, in that there was a possibility of sampling bias and social desirability bias. Also, findings from a small sample size from metropolitan New York area and Virginia had a limited transferability to the Korean-American population as a whole. Since this study is a cross-sectional study, research results were limited to understand the perceptions caregiving and health service uses of caregivers of older adults among Korean-American over time. To strengthen the study, a future study should plan to increase the sample size or include participants from other Asian countries, such as China, Vietnam, or India, and last, including different geographical areas within the US to increase the transferability.

Protection of Human Subjects

University Institutional Review Board-Social and Behavioral Sciences (IRB-SBS) approval was sought since this study involved interacting with individuals and assessing individual characteristics or behavior including perception, cognition, cultural beliefs and social behavior. Since the IRB-SBS has been approved for the pilot study for the dissertation study (IRB# 2016-0431-00), the PI has submitted a modification to address the expanded dissertation research.

A minimal risk existed in this study because this study was descriptive in nature, based on participants' personal thoughts such as perception and experiences and data were collected through face-to-face interview, self-report questionnaire and no other intervention or interaction with other personnel. Some subjects may have been subjectively sensitive to participants because they were discussing the care of loved ones. In the context of those discussions topics such as stereotype, labeling, and discrimination could aroused and caused emotional distress while they were sharing their experiences during the interview. The PI has provided resources such as the coordinator of elder care support group at the local senior center or church. This study included "risk-sensitive" participants of the minority group, and probability of harm occurring is minimal.

To minimize the risks, the PI ensured that the participants fully understand the purpose of this study and processes in detail in either Korean or English, including participants' right regarding participation and withdrawal during the study (Creswell, 2016, pp.51). The PI was attentive to both verbal and nonverbal cues for signs of physical or emotional distress. Any adverse reactions noted during the participation was supposed to be reported to the Institutional Review Board (IRB) of the University of Virginia within the respective time frames outlined.

Inclusion criteria for the study was defined as 1) being Age 18 and older, 2) being a family member/relative who is caring for an older adult age 65 and over, 3) residing with or contact with a care recipient at least twice a week, and 4) being self-identified as Korean or Korean American. Exclusion criteria was defined as being an immigrant from other countries and speaking other languages. There was no additional staff other than PI; thus no staff training plan was needed. The participants who belong to a vulnerable population such as children, prisoners or persons with impaired decisional capacity were not included in this study because participants should be family caregivers' of older adults, not patients themselves.

To minimize the potential for the loss of confidentiality, demographic survey and transcripts of the interview were stored separately in a locked file cabinet in a locked office in the School of Nursing separate from the consent forms that was locked. Participants were assigned unique identification numbers that are linked to transcripts and Participant Information Form (PIFs). The cross reference sheet was stored with the consent forms. Only the documents with identified numbers were used for data analyses. After recordings and verbatim transcripts are completed, all audio files were destroyed, six months after data collection.

References

Alzheimer's Association. (2015). Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 11*(3), 332-384. Doi: https://doi.org/10.1016/j.jalz.2015.02.003

Alzheimer's Association (2016). Alzheimer's disease facts and figures.

Retrieved from http://www.alz.org/alzheimers_disease_facts_and_figures.asp

Alzheimer's disease International (2012). World Alzheimer report 2012: Overcoming the stigma of dementia. Retrieved from https://www.alz.org/documents_custom/world_report_2012_final.pdf Bayer, A. (2012). Progress in diagnosis and management of Alzheimer's disease. *Quality in Ageing and Older Adults, 13*(3), 189-196.

Barnett, J. H., Lewis, L., Blackwell, A. D., & Taylor, M. (2014). Early intervention in Alzheimer's disease: A health economic study of the effects of diagnostic timing. *BioMed Central Neurology, 2014* (14), 101-109.

Berry, J.W. (1997). Immigration, acculturation, and adaptation. *Applied Psychology: An International Review, 46* (1), 5-68.

Boots, L.M., Wolfs, C. G., Verhey, F. J., Kempen, G. I., & de Vugt, M. E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *International Psychogeriatrics, 27* (6), 927-936. Doi: 10. 1017/s1041610214002804

Boughtwood, K., Shanley, C., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., &Rowland, J. (2011). Culturally and linguistically diverse (CALD) families dealing with dementia: An examination of the experiences and perceptions of multicultural community link workers. *Journal of Cross Culture gerontology, 26,* 365-377. doi 10.1007/s10823-011-9155-9

Boustani, M.A., Justiss., Frame, A., Austrom, M. G., Perkins, A. J., Cai, X.,…Hendrie, H. C. (2011). Caregiver and noncaregiver attitudes toward dementia screening. *Journal of the American Geriatric Society, 59,* 681-686. Doi: 10.1111/j.1532-5415.2011.03327

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. Doi: 10.1191/1478088706qp063oa

Bruce, J. M., Mcquiggan, M., Williams, V., Westervelt, H., & Tremont, G. (2013). Burden among spousal and child caregivers of patients with mild cognitive impairment. *Dementia and Geriatric Cognitive Disorders, 25,* 385-390. doi: 10.1159/000122587

Burgener, S.C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease, Alzheimer's dementia and Parkinson's disease. *Dementia, 7*(1), 31-53. Doi: 10.1177/1471301207085366

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., Liu, M. F., Riley, R., Einhorn, C. J., Fitzsimmons, S., & Hahn-Swanson, C. (2015). Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part I. *Dementia*, *14*(5), 589-618. Doi: 10.1177/1471301213508399

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia*, *14*(5), 609-632. Doi: 10.1177/1471301213504202

Castro, F. G., Marsiglia, F. F., Kulis, S., & Kellison, J. G. (2010). Lifetime segmented assimilation trajectories and health outcomes in Latino and other community residents. *American Journal of Public Health, 100* (4), 669-676.

Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice, 7,* 48-67.

Corrigan, P. W., Druss, B. G., & Perlick, D. A. (2014). The impact of mental illness stigma on seeking and participating in mental health care. *Psychological Science in the Public Interest, 15* (2), 37-70. Doi: 10. 1177/1529100614531398

Crellin, N. E., Orrel, M., McDermott, O., & Charlesworth, G. (2014). Self-efficacy and health-related quality of life in family carers of people with dementia: A systematic review. *Aging & Mental Health, 18* (8), 954-969. Doi: 10. 1080/13607863.2014.915921

Creswell, J. W. (2016). *30 Essential skills for the qualitative researcher.* Thousand Oaks, CA: SAGE Publication, INC.

Dai, Y. (1998). Filial piety. *Journal of Gerontological Nursing, 24* (3), 13-18

Dai, B., Mao, Z., Mei, J., Levkoff, S., Wang H., Pacheco, M., & Wu, B. (2013). Caregivers in China: Knowledge of mild cognitive impairment. PLoS ONE, 8 (1), e53928. Doi: 10. 1371/ journal. Pone. 0053928

Dalky, H. F. (2012). Mental illness stigma reduction interventions: Review of intervention trials. *Western Journal of Nursing Research, 34*(4), 520-547. Doi: 10.1177/0193945911400638

Daly, L., McCarron, M., Higgins, A., & McCallion, P. (2012). ‘Sustaining place’-a grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *Journal of Clinical Nursing, 21,* 501-512. Doi:10.1111/jocn.1203

Dartigues, J.F. (2011). Alzheimer's disease: Early diagnosis. *La Revue Practician, 61*(7), 926-930.

Dignani, L., Toccaceli, A., Guarinoni, G., Ptrucci, C. & Lancia, L. (2015). Quality of life in chronic obstructive pulmonary disease: An evolutionary concept analysis. *Nursing Forum, 50* (3), 201-213.

Family Caregiver Alliance (2006). *Caregiver assessment: Voices and Views from the field. Report from a national consensus development conference (Vol II).* San Francisco.

Folkman, S., Lazarus, R., Dunkel-Schetter, C., DeLongis, A., & Cruen, R. J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology, 50* (5), 992-1003.

Gellman, M. D., & Turner, J. R. (2013). Health Care Utilization. In Encyclopedia of Behavioral Medicine (pp. 909-910). New York, NY: Springer New York.

Golberstein, E., Eisenberg, D., Gollust, S. E. (2008). Perceived stigma and mental health care seeking, *Psychiatric Services, 59* (4), 392-399. http://ps.psychiatryonline.org/doi/10.1176/ps.2008.59.4.392

Guest, G., Bunce, A., Johnson, L. (2006). How many interviews are enough? : An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82. Doi: 10. 1177/1525822x05279903

Han, H. R., Choi, Y. J., Kim, M. T., Lee, J. E., & Kim, K. B. (2008). Experiences and challenges of informal caregiving for Korean immigrants. *Journal of Advanced Nursing, 63*(5), 517-526. Doi: 10.1111/j.1365-2648. 2008.04746.x

Hayes, J., Zimmerman, M.K., & Boylstein, C. (2010). Responding to symptoms of Alzheimer's disease: Husbands, wives, and the gendered dynamics of recognition and disclosure. *Qualitative health Research, 20,* 1101-1115. doi: 10.1177/1049732310369559

Holloway, I., & Wheeler, S. (2009). *Qualitative research in nursing and healthcare (3rd Ed).* Chichester, UK: Wiley-Blackwell.

Hseuh, K. H. (2001). Family caregiving experience and health status among Chinese in the United States. PhD dissertation. Ann Arbor, MI: UMI Dissertation Services, ProQuest Information and Learning.

Hughes, T., Tyler, K., Danner, D., & Carter, A. (2009). African American caregivers: An exploration of pathways and barriers to a diagnosis of Alzheimer's disease for a family member with dementia. *Dementia, 8,* 95-116. doi: 10.1177/1471301208099048

Ivey, S.L., Laditka, S.B., Price, A.E., Tseng, W., Beard, R.L., Liu, R.,…Logsdon, R.G. (2012). Experiences and concerns of family caregivers providing support to people with dementia: A cross-cultural perspective. *Dementia, 12*(6), 806-820. doi: 10.1177/1471301212446872

Jang, Y., Kim, G., & Chiriboga, D. (2010). Knowledge of Alzheimer's disease, feelings of shame, and awareness of services among Korean American elders. *Journal of Aging and Health, 22*(4), 419-433. Doi: 10.1177/0898264309360672

Jang, Y., Park, N. S., Chiriboga, D., Yoon, H., Ko, J., Lee, J., & Kim, M. (2016). Risk factors for social isolation in older Korean Americans. *Journal of Aging and Health, 28* (1), 3-18. Doi: 10. 1177/0898264315584578

Jimenez, M.A.V., Jaen, M.C., Garcia, M.V., & Barahona-Alvarez, H. (2013). Decision-making in older people with dementia. *Clinical Gerontology, 23,* 307-316.

Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs, 10* (2015), 1642-1649. Doi: 10. 1377/hlthaff.2015.0536

Karnieli-Miller, O., Perlick, D. A., Nelson, A., Mattias, K., Corrigan, P., & Roe, D. (2013). Family members of persons living with a serious mental illness: Experiences and efforts to cope with stigma. *Journal of Mental Health, 22*(3), 254-262. Doi: 10. 3109/09638237.2013.779368

Kim, J., Ashing-Giwa, K. T., Singer, M. K., & Tejero, J. S. (2006). Breast cancer among Asian Americans: Is acculturation related to health-related quality of life? Oncology Nursing Forum, 33 (6), E90-E99.

Kim, J., & Dattilo, J. (2011). Education and recreation activities of older Asian immigrants. *Educational Gerontology, 37*, 336-350. Doi: 10. 1080/03601271003609058

Kiral, K., Ozge, A., Sungur, M.A., & Tasdelen, B. (2013). Detection of memory impairment in a community-based system: A collaborative study. *Health & Social Work, 38*(2), 89-96.

Knight, B. G., Robinson, G. S., Longmire, C. V., Chung, M., Nakao, K., & Kim, J. H. (2002). Cross cultural issues in caregiving for persons with dementia: Do familism values reduce burden and distress? Ageing International, 27 (3), 70-94.

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. Journal of Gerontology: Psychological Sciences, 65B(1), 5-13. Doi: 10. 1093/geronb/gbp096.

Kuo, L., & Shyu, Y. L. (2010). Process of ambivalent normalization: Experience of family caregivers of elders with mild cognitive impairment in Taiwan. *Journal of Clinical Nursing, 19,* 3477-3484. doi: 10.1111/j.1365-2702. 2010.03240. x

Laditka, S.B., Corwin, S.J., Laditka, J.N., Liu, R., Tseng, W., Wu, B.,…Ivey, S.L. (2009). Attitudes about aging well among a diverse group of older Americans: Implications for promoting cognitive health. *The Gerontologist, 49*(S1), 30-39.

Lai, D. W. L. (2010). Filial piety, caregiving appraisal, and caregiving burden. *Research on Aging, 32* (2), 200-223. Doi: 10.1177/0164027509351475

Lee, Y., & Choi, S. (2012). Korean American dementia caregivers' attitudes toward caregiving: The role of social network versus satisfaction with social support. Doi: 10.1177/0733464811431163

Lee, S. E., Lee, H. Y., & Diwan, S. (2010). What do Korean American immigrants know about Alzheimer's disease (AD): The impact of acculturation and exposure to the disease on AD knowledge. *International Journal of Geriatric Psychiatry, 25,* 66-73. Doi: 10.1002/gps.2299.

Lee, Y., & Smith, L. (2012). Qualitative research on Korean American dementia caregivers' perception of caregiving: Heterogeneity between spouse caregivers and child caregivers. *Journal of Human Behavior in the Social Environment,* 22, 115-129. Doi: 10.1080/10911359.2012.646840

Lee, Y., & Yim, N. (2012). Korean American dementia family caregivers' experience of a psychoeducational support group: Investigation of role of culture. *Social Work with Groups, 36,* 13-26. Doi: 10.1080/01609513.2012.724214

Leung, K.K., Finlay, J., Silvius, J.L., Koehn, S., McCleary, L., Cohen, C.A.,…Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health and Social Care in the Community, 19*(4), 372-381. doi: 10.1111/j.1365-2524.2010.00982.x

Lim, J., Yi, J. & Zebrack, B. (2008). Acculturation, social support, and quality of life for Korean immigrant breast and gynecological cancer survivors. *Ethnicity & Health, 13* (3), 243-260.

Link, B. G., Cullen, F. T., Struening, E., & Shrout, P.E. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review,* 54, 400-423. Retrieved from http://www.jstor.org/stable/2095613

Liu, D., Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (2008). Re-examining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross Cultural Gerontology, 23*(3), 283-299. Doi: 10.1007/s10823-008-9075-5

Mannion, E. (2008). Alzheimer's disease: The psychological and physical effects of the caregivers' role. Part1. *Nursing Older People, 20*(4), 27-32.

Marshall, P. A. (1990). Cultural influences on perceived quality of life. Seminars in Oncology Nursing, 6 (4), 278-284.

McCleary, L., & Blain, J. (2013). Cultural values and family caregiving for persons with dementia. *Indian Journal of Gerontology, 27*(1), 178-201.

Miles, M.B., Huberman, A. M., & Saldaňa, J. (2014). *Qualitative data analysis: A methods sourcebook (3rd Ed.).* Los Angeles, CA: SAGE Publications, Inc.

Milne, A. (2010). Dementia screening and early diagnosis: The case for and against. *Health, Risk, & Society, 12* (1), 65-76.

Mittal, D., Sullivan, G., Allee, E., & Corrigan, P. (2012). Empirical studies of self-stigma reduction strategies: A critical review of the literature. *Psychiatric Services*, *63*(10), 974-981. Doi: 10.1176/appi.ps.201100459

Miyawaki, C.E. (2015). A review of ethnicity, culture, and acculturation among Asian caregivers of older adults (2000-2012). *SAGE open* doi: 10. 1177/2158244014566365

Moore, V., & Cahill, S. (2013). Diagnosis and disclosure of dementia: A comparative qualitative study of Irish and Swedish general practitioners. Aging & Mental Health, 17(1), 77-84. Doi: 10.1080/13607863.2012.692763

Morgan, D.G., Walls-Ingram, S., Cammer, A., O'Connell, M.E., Crossley, M., Bello-Haas,…Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine, 102,* 111-118. Http;//dx.doi.org/10.1016/j.socscimed.2013.11.023

Morhardt, D., Pereyra, M., & Iris, M. (2010). Seeking a diagnosis for memory problems: The experiences of caregivers and families in 5 limited English proficiency communities. *Alzheimer Disease and Associated Disorders*, 24(3), s42-s48.

Musich, S., Wang, S. S., Kraemer, S., Hawkins, K., & Wicker, E. (2017). Caregivers for older adults: Prevalence, characteristics, and health care utilization and expenditures. *Geriatric Nursing, 38* (2017), 9-16. Doi: http://dx.doi.org/10.1016/j.gerinurse.2016.06.017

Navab, E., Negarandeh, R., Peyrovi, H., & Navab, P. (2013). Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneutic study. *Nursing and Health Science, 15,* 201-206. Doi: 10.1111/nhs.12017

Nourhashemi, F., Ousset, P.J., Gillette-Guyonnet, S., Cantet, C., Andrieu, S., & Vellas, B. (2008). A 2-year follow-up of 233 very mild (CDR 0.5) Alzheimer's disease patients (REAL.FR cohort). *International Journal of Geriatric Psychiatry,* 23, 460-465.

Okie, S. (2011). Confronting Alzheimer's disease. *New England Journal of Medicine,* 365(12), 1069-1072.

O'Sullivan, G., Hocking, C., & Spence, D. (2014). Dementia: The need for attitudinal change. *Dementia, 13*(4), 484-497. Doi: 10.1177/1471301213478241

Park, M., Butcher, H. S., & Maas, M. L. (2004). A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility. *Research in Nursing & Health, 27,* 345-356.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30 (5), 583-594.

Perlick, D. A., Wilber, C. H., Nelson, A. H., Huntington, B., Mattias, K., Holman, C. S., …Corrigan, P. W. (2011). In our own voice-faimly companion: Reducing self-stigma of family members of persons with serious mental illness. *Psychiatric Services, 62* (12), 1456-1462.

Polit, D. F. & Beck, C. T. (2012). *Nursing Research: Generating and assessing evidence for nursing practice (9th Ed.).* Philadelphia, PA: Lippincott Williams & Wilkins.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C.P. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's & Dementia,* 9(1), 63-75.

Prorok, J. C., Horgan, S., & Seitz, D. P. (2001). Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. *Canadian Medical Association Journal.* 1-12. Doi:10.1503 /cmaj.121795

Regan, J.L., Bhattacharyya, S., Kevern, P., & Rana, T. (2013). A systematic review of religion and dementia care pathways in black and minority ethnic populations. *Mental Health, Religion & Culture,* 16(1), 1-15.

Ribas, A. C., & Lam, C. S. (2010). Social support and quality of life among Latinos with mental illness. *Journal of Nourvous and Mental Disease, 198* (2), 137-143. DOI: 10.1097/NMD.0b013e3181cc522d

Riley, R., Burgener, S. & Buckwalter, K. C. (2014). Anxiety and stigma in dementia. *Nursing Clinics of North America, 49,* 213-231. Doi: 10. 1016/j.cnur.2014

Salgado, H., Castaňeda, S. F., Talavera, G. A. & Lindsay, S. P. (2012). The role of social support and acculturative stress in health-related quality of life among day laborers in Northern San Diego. *Journal of Immigrant Minority Health, 14,* 379-385. Doi: 10.1007/s10903-011-9568-0

Sandelowski, M. (2000).Whatever happened to qualitative description? *Research in Nursing & Health, 2000* (23), 334-340.

Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research, 14*(10), 1366-1386.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 2010* (33), 77-84

Schulz, R., Cook, T. B., Beach, S. R., Lingler, J. H., Marire, L. M., Monin, J. K., & Czaja, S. J. (2013). Magnitude and causes of bias among family caregivers rating Alzheimer Disease patients. *American Journal of Geriatric Psychology, 21*, 14-25.

Spector, A., Orrell, M., Schepers, A., & Shanahan, N. (2011). A systematic review of 'knowledge of dementia' outcome measures. *Ageing Research Reviews, 11,* 67-77.

Suinn, R. M. (2010). Reviewing acculturation and Asian Americans: How acculturation affects health, adjustment, school achievement, and counseling. *Asican American Journal of Psychology, 1* (1), 5-17. Doi: 10. 1037/a0018798

Suinn, R. M., Ahuna, C., & Khoo, G. (1992). The Suinn-Lew Asian Self-Identity Acculturation Scale: Concurrent and factorial validation. Educational & Psychological Measurement, 52(4), 1041-1046.

Sun, F. (2014). Caregiving stress and coping: A thematic analysis of Chinese family caregivers of persons with dementia. *Dementia, 13* (6), 803-818. Doi: 10.1177/1471301213485593

Sun, F., Mutlu, A., & Coon, D. (2014). Service barriers faced by Chinese American families with a dementia relative: Perspectives from family caregivers and service professionals. *Clinical Gerontologist, 37* (2), 120-138. Doi: 10.1080/07317115.2013.868848

Sun, F., Ong, R. & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans. American Journal of Alzheimer’s Disease & Other Dementias, 27 (1), 13-22. Doi: 10.1177/1533317512438224

The Henry J. Kaiser Family Foundation. (2008). Race, ethnicity & health care: Fact sheet. *Asian & Pacific Islander American Health Forum*. Retrieved from https://kaiserfamilyfoundation.files.wordpress.com/2013/01/7745.pdf

Tremont, G. (2011). Family caregiving in dementia. *Medical Health Research,* February, *94*(2), 36-38.

Urizar, G.G., & Sears, S.F. (2006). Psychosocial and cultural influences on cardiovascular health and quality of life among Hispanic cardiac patients in South Florida. *Journal of Behavioral Medicine, 29* (3), 255-268. Doi: 10.1007/s10865-006-9050-y

U.S. Census Bureau. (2012). The Asian American Population: 2010. Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf

US Department of Health and Human Services (2015). Statistical profile of Asian older Americans aged 65+. Retrieved on May 8 from https://aoa.acl.gov/aging_statistics/minority_aging/facts-on-API-Elderly2008-plain_format.aspx

U.S. Department of Health and Human Services. Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving. Washington, DC. Retrieved December 28, 2015 from: https://aspe.hhs.gov/sites/default/files/pdf/77146/NHATS-IC.pdf; 2014

Watari, K. F., & Gatz, M. (2004). Pathways to care for Alzheimer's disease among Korean Americans. *Cultural Diversity and Ethnic Minority Psychology, 10*(1), 23-38.

Werner, P. (2014). Stigma and Alzheimer's disease: A systematic review of evidence, theory, and methods. In Corrigan, Patrick W. (Ed). (2014). The stigma of disease and disability: Understanding causes and overcoming injustices (pp. 223-244). Washington, DC, US: American Psychological Association, xi, 319 pp. http://dx.doi.org/10.1037/14297-012

Werner, P., & Heinik, J. (2004). Intentions of first-degree relatives of patients with Alzheimer's disease to seek a cognitive status examination. *International Journal of Geriatric Psychiatry, 19,* 479-486. Doi: 10.1002/gps.1120

Werner, P., & Heinik, J. (2008). Stigma by association and Alzheimer's disease. *Aging & Mental Health, 12*(1), 92-99.

Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qualitative Health research, 20* (2), 159-169. Doi: 10. 1177/1049732309358330Werner, p., & Heinik, J. (2008). Stigma by association and Alzheimer's disease. *Aging & Mental Health, 12* (1), 92-99.

Werner, P., Mittelman, M.S., Goldstein, D., & Heinik, J. (2011). Family stigma and caregiver burden in Alzheimer's disease. *The Gerontologist, 52*(1), 89-97. Doi: 10.1093/geront/gnr117

Xiao, L.D., Habel, L., & De Bellis, A. (2015). Perceived challenges in dementia care by Vietnamese family caregivers and care workers in South Australia. *Journal of Cross Cultural Gerontology, 30*, 333-352. Doi: 10.1007/s10823-015-9264-y

Yeo, G., & Gallagher-Thompson, D. (2006). *Ethnicity and the dementias (2nd Ed.).* New Your, NY: Routledge.

Yoon, H., Chatters, L., Kao, T. A., Saint-Arnault, D., & Northouse, L. (2016). Factors affecting quality of life for Korean American cancer survivors: An integrative review. Oncology Nursing Forum, 43 (3), E132-E142. Doi: 10.1188/16.ONF.E132-E142

Youn, G., Knight, B. G., Jeong, H., & Benton, D. (1999). Differences in familism values and caregiving outcomes among Korean, Korean American, and White American dementia caregivers. *Psychology and Aging, 14* (3), 355-364.

CHAPTER 3

MANUSCRIPT ONE

Factors Affecting Help-seeking Behavior among Family Caregivers of People with Dementia: An Integrative Literature Review

To be submitted to *The Journal of Gerontological Nursing*

Mihee Chung, PhD (c), RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
mc2by@virginia.edu, 1-508-963-3018
Jeongok Logan, PhD, RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
jl3zj@virginia.edu, 1-434-924-0082
Cathy Campbell, PhD, RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
clc5t@virginia.edu, 1-434-243-6789
Ishan C. Williams, PhD, FGSA
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
icw8t@virginia.edu, 1-434-924-0480

Abstract

Alzheimer's disease and related dementia (ADRD) is a rapidly growing disease among older adults. More than half of the Persons with Dementia (PwD) are not formally diagnosed, often suffering under physical and emotional strain without any treatment. As a result, it is critical to understand what triggers or hinders help-seeking behavior among this population. This review examined evidence related to help-seeking for caregivers of PwD to understand the barriers and facilitators to seeking support services for their loved one. Twenty-seven relevant publications meeting the inclusion criteria were selected. Three categories of barriers to help-seeking among family caregivers of PwD were identified: individual, structural, and cultural. To promote help-seeking among PwD and their caregivers, education regarding dementia etiology, symptoms, and progression of the disease, and available treatment resources is needed. Furthermore, culturally and linguistically tailored resources may be necessary.

Introduction

Dementia, specifically Alzheimer's disease, is a rapidly growing global pandemic (Alzheimer's Association, 2018; Regan, Bhattacharyya, Kevern & Rana, 2013). An estimated 46.8 million people in the world are living with dementia (Prince et al., 2015) and among the affected population, less than half of the cases were diagnosed as Alzheimer's Disease and related dementia (ADRD) (Morgan et al., 2014). By 2030, the number of people having dementia is expected to increase to about 74 million and 131.5 million by 2050 (Prince et al., 2015). In the United States, there are currently 5.7 million people with ADRD, and this number is projected to increase to 13.8 million by 2050 (Alzheimer's Association, 2018). As of 2015, 110,561 Americans died from AD, which makes it the 6th leading cause of death in the United States and the 5th leading cause of death among people 65 years and over (Alzheimer's Association, 2018; Hughes, Tyler, Danner, & Carter, 2009).

In 2017, more than 16 million people, most of the family members, provided unpaid care for persons with ADRD (PwD), which was calculated to be 18.4 billion hours of care that was valued at $232 billion (Alzheimer's Association, 2018; Laditka et al., 2012). Caregivers of PwD experience higher levels of stress than caregivers of persons without dementia, which may cause both mental and physical illnesses such as cardiovascular disease, decreased immune function, and depression (Alzheimer's Association, 2018; Laditka et al., 2012; Mannion, 2008). For that reason, approximately eleven billion U.S. dollars per year were spent on the physical and emotional toll on caregivers' of older adults with ADRD (Alzheimer's Association, 2018).

Even though the importance of early diagnosis is addressed by many researchers, ADRD are still frequently left undiagnosed among many in the general population (Alzheimer's Association, 2018; Amjad et al., 2018; Bayer, 2012; Jimenez, Jaen, Garcia, & Barahona-

Alvarez, 2013; Kiral, Ozge, Sungur, & Tascelen, 2013; Nourhashemi et al., 2008; Okie, 2011; Wahlster, Niederlander, Kriza, Schaller, & Kolominsky-Rabas, 2013). According to Dartigues (2011), only one out of every three patients is diagnosed in the early stage of dementia and estimated time from detecting memory problems to seeking medical care ranged from one to almost three years (Leung et al., 2011; Xiao, Habel, & De Bellis, 2015). Without a diagnosis, patients are not eligible to have well-timed treatments such as pharmacological drugs, psychosocial interventions, and counseling support for patients and family members (Kuo & Shyu, 2010; Morgan et al., 2014). When these treatments are given during the early stages of AD, it may slow down the disease progression more effectively than at a later stage of the disease (Hughes et al., 2009). Thus, early diagnosis is critical to improving the quality of life for both PwD and their caregivers. Furthermore, in the early stage, PwD are more actively involved in their care plans and activities while they can contribute to the decision choices that are being made (Hughes et al., 2009). To promote early diagnosis, understanding what affects their help-seeking behavior is essential.

According to the Alzheimer’s Association report (2018), early diagnosis of AD for the current US population could save 7.9 trillion dollars (Alzheimer’s Association, 2018). In addition to the economic benefit of an early diagnosis of ADRD, family members have more time to adjust to their roles as caregivers and to educate themselves regarding the disease trajectory and the resources available to them (de Vugt & Verhey, 2013; Dubois, Padovani, Scheltens, Rossi, & Dell’Agnell, 2015; Hughes et al., 2009; Morgan et al., 2014). Further, because early diagnosis and proper treatment may reveal a reversible cause of the disease and assist PwD, and their caregivers in identifying needed support to enhance the quality of life for them both (Alzheimer’s Association, 2018; Leung et al., 2011), seeking healthcare or resources for their unknown condition is critical.

Time strain may be an issue for caregivers of ADRD. Obtaining a cognitive evaluation and diagnosis may be a cumbersome process regarding time, effort, and expenditure for both PwD and family caregivers. According to the annual report of the Alzheimer’s Association (2018), family caregivers of ADRD spend about twenty hours per week, and six out of 10 caregivers are employed, while they are caring for their family members (Alzheimer’s Association, 2018). Furthermore, financial constraints and adverse effects of the reimbursement system can affect caregivers’ seeking of a healthcare provider (Dubois, Padovani, Scheltens, Rossi, & Dell’Agnello, 2015). This is especially true for family members who have had previous experiences with AD as they tend to delay seeking a diagnosis because they learned from their experiences that the efficacy of AD treatment is low because of the disease process (Rapp, 2014). To promote family caregivers of PwD’s help-seeking behavior, understanding factors, which facilitate and hinder, in addition to those factors mentioned above, is important.

Conceptual Framework

An individual’s health-related behaviors may be determined by what one knows or how they perceive the disease and its process (Hochbaum, 1958). The interacting variables of demographic factors, knowledge, and education each affect and individual’s perception which influences one’s decision making related to help-seeking behaviors. To better understand one’s own belief about health and disease, one must disentangle what is known as reality versus a perception. These factors may influence decision making related to help-seeking behaviors that are important in managing this disease. As a result, to promote early diagnosis of ADRD, learning about caregivers’ perceptions about the disease, their knowledge about the progression of the disease and their experiences throughout the caregiving are important. In this integrative review, the factors that are facilitating and hindering help-seeking behaviors among family caregivers of PwD were examined.

Methods

Four digitalized databases, Cumulative Index to Nursing & Allied Health Literature (CINAHL), Ovid Medline, PsychInfo, and Web of Science, were searched for the literature relevant to the keywords: “family caregiver” or “caregivers”, and, “help-seeking” or “help-seeking behavior” or “healthcare utilization” or “health behavior”, and “Dementia”. A total of 177 manuscripts were identified. All articles on the list were exported to RefWorks for further data management. Thirty-three duplicates were removed from the list, and 116 articles were removed after the title and abstract screen. Finally, 28 articles were retrieved after inclusion/ exclusion criteria were applied. Inclusion criteria included 1) peer-reviewed articles, 2) written in English, 3) published from 2008 to 2018, and 4) relevant to keywords. Articles were excluded if the studies were 1) reviews of the disease and treatment, 2) review of the literature, 3) editorials, 4) not relevant to dementia or caregiving, and 5) focused on pathophysiological issues. Among 28 full-text articles, eight were removed because the main focus of the articles was irrelevant for the purpose of the review although they were included based on the keywords. Additionally, seven studies were found by manually searching the reference lists of journal articles identified. As a result, a total of 27 articles were selected to be included in this integrative review (See Figure 1).

Results

Twenty-seven peer-reviewed studies were selected. Of the 27 studies, 19 studies were conducted with a qualitative design and eight studies used a quantitative design. The studies were conducted in four different countries; USA (14), Canada (5), Australia (6), and UK (2). Ten studies were conducted with participants including ethnic minority groups: African American, Chinese, Korean, and Vietnamese. The majority of the participants were White (59.4 %) and female (62.1 %). Among the rest, 18. 1 % were Asian. Sample sizes of the studies in the review ranged from eight to 1,369.

Most of the studies explored hindering factors more than facilitating factors. Facilitating factors were categorized into three groups: The level of knowledge, caregiver's levels of stress, and caregivers' demographics. Hindering factors were categorized into three groups: Individual, structural, and cultural factors. These will be further described below.

Facilitating Factors

In terms of facilitating factors, the level of knowledge, caregiver's levels of stress, and gender were key findings. Five studies included within the review found that the level of knowledge was the most prominent factor to help-seeking among family caregivers of PwD (Casado, Hong, & Lee, 2018; Haralambous et al., 2014; Morhardt, Pereyra, & Iris, 2010; Morgan et al., 2014; Noureldin, Murawski, Mason, Hyner, & Plake, 2017). For example, Casado and colleagues (2018) found that AD knowledge reduces the negative perceptions around ADRD. When PwD and their caregivers have more knowledge, they may have more positive attitudes toward seeking health providers. Further, early education regarding the disease and available healthcare system may enable caregivers seeking help (Haralambous et al., 2014).

Caregivers' levels of stress or anxiety were found as facilitating factors (Bergman, Haley, & Small, 2011; Mukadam, Cooper, Basit, & Livingston, 2011). Bergman and colleagues found that caregivers who are most distressed in bereavement utilized formal services (Bergman et al., 2011). Also, caregivers who have more physical and emotional stress and have anxiety regarding care recipients' safety or opinion of others tend to seek formal care more than those who are not (Mukadam et al., 2011).

The third facilitating factor was the caregiver's demographic factors such as gender and ethnicity (Brown & Chen, 2008; Casado, Hong, & Lee, 2018; Lee & Casado, 2011; Hayes, Zimmerman, & Boylstein, 2010). The study by Brown and Chen revealed that caregiver husbands are slower than caregiver wives to notice cognitive symptoms, but they are quicker to seek for help from outside of the family and utilize healthcare providers during early stages of the disease (Brown & Chen, 2008; Hayes et al., 2010). Contrary to the norm that most Asian American adults have a negative attitude towards dementia care (Casado et al., 2018; McCleary et al., 2012; Sun, Mutlu, & Coon, 2014; Xiao et al., 2015), in one study by Casado et al. showed Korean Americans have a positive attitude towards seeking help regarding dementia care (Casado et al., 2011). This may add the influence of ethnic background not only as a hindering factor but also facilitating factor.

Hindering Factors

Individual characteristics. Multiple studies (n=12) revealed that lack of knowledge was a major reason among caregivers of PwD to defer seeking help (Haralambous et al., 2014; Hughes et al., 2009; Koehn et al., 2012; Lee et al., 2017; Leung et al., 2011; McCleary et al., 2012; Morhardt et al. 2010; Mukadam et al., 2011; Robinson et al., 2012; Stockwell-Smith, Kellett, & Moyle, 2010; Werner et al., 2017; Xiao et al., 2015). Limited understanding of dementia symptoms, diagnosis, and treatment can delay seeking help variously. According to Leung and colleagues (2011), caregivers do not seek formal help because they are not aware of the early symptoms of AD. Also, the study by Hughes and colleagues (2009) showed that a lack of knowledge about AD prior to initial symptom recognition delayed African Americans caregivers' seeking healthcare providers. Additionally, a majority of the Hispanic American participants did not regard AD as seriously as their White counterparts, which may be due to the lack of knowledge about AD (Van Liew, Wooldridge, Kothari, & Cronan, 2014).

Normalization of dementia symptoms is another factor related to the low level of knowledge that prevents caregivers from seeking help (Leung et al., 2011; McCleary et al., 2012; Morhardt, Pereyra, & Iris, 2010; Mukadam, Cooper, Basit, & Livingston, 2011; Van Liew, Wooldridge, Kothari, & Cronan, 2014; Xiao et al., 2015). Even though family caregivers of PwD notice early symptoms of dementia, they regard them as normal aging symptoms (normalization), so they live without taking any action. Some family caregivers believe that the dementia symptoms are caused by stress; thus they do not search for the assistance of healthcare but wait until the problem is resolved (Morhardt et al., 2010). Uncertainty can be caused by not knowing about the disease progression, treatment, and the formal healthcare system (Leung et al., 2011; Mukadam et al. 2011). When family caregivers notice the symptoms, they are not sure if they are related to the disease or normal aging. Also, they are not certain about available resources and the effectiveness of the treatments, so they wait until they desperately need help from outside of the family. Both normalization and uncertainty may stem from a lack of knowledge. They may be prevented by educating the lay public regarding the symptoms and treatment of ADRD.

Gender is another factor that influences caregivers' seeking help (Brown & Chen, 2008; Gainey, Payne, & Kropf, 2010). Female caregivers usually notice the symptoms of dementia earlier than male caregivers, but the coping strategy they apply is avoidance, which delays seeking help, which results in beginning the treatment later (Brown & Chen, 2008; Gainey et al., 2010).

Structural characteristics. The lack of healthcare resources was found in five studies as a major structural characteristic. Lack of community-based resources or inaccessibility of services can discourage caregivers from utilizing services (Forbes et al., 2012; Lee et al., 2017; McCleary et al., 2012). Furthermore, the complexity of the service system, travel required getting to services, and lack of culturally appropriate services or trained providers hinder caregivers from seeking services (Haralambous et al., 2014; Lee et al., 2017; Van Liew et al., 2014). Specifically, family caregivers who are relatively new immigrants experience more difficulty in seeking help than caregivers of the non-immigrant group in a similar situation (Koehn et al., 2012; Sun et al., 2014).

Other structural characteristics may include challenging environments such as remote geographical areas and communities with poorer socioeconomic status. Communities in rural areas often lack of adequate community-based services and supports, which can hinder caregivers from approaching to health services (Forbes et al., 2012; Gainey et al., 2010). Also, the caregivers from the communities with a low socioeconomic status showed lower rates of the formal service utilization (Gainey et al., 2010). Given this lack of healthcare resources and lack of utilization in rural areas, ways to promote help-seeking across environmental and socio-economical settings need to be addressed.

Cultural characteristics. Caregivers of people who are members of ethnic minority groups, especially Asian Americans including Korean Americans, have different hindering factors. Different cultural beliefs such as filial piety (Haralambous et al., 2014; Koehn et al., 2012; Mukadam et al., 2011; Sun et al., 2014; Van Liew et al., 2014; Xiao et al., 2015), the level of acculturation (Xiao et al., 2015), stigma (Forbes et al., 2012; C; McCleary et al., 2012; Robinson et al., 2012), and language barrier (Haralambous et al., 2014; Lee et al., 2017; Xiao et al., 2015) affect caregivers' help-seeking..

Caregivers from Asian countries such as China, Korea, and Vietnam strongly believe that caring for old parents is an obligation or reciprocal family responsibility (Haralambous et al., 2014; Mukadam et al., 2011; Stockwell-Smith et al., 2010). Furthermore, caregivers who are more acculturated to the western culture, are typically more flexible in terms of the family obligation, and are often more knowledgeable about the available healthcare resources in their community (Xiao et al., 2015). Thus, cultural characteristics, filial piety, acculturation, and may affect caregivers' decision making to utilize health services.

Stigma may affect family caregivers' help-seeking as well. The stigma associated with dementia makes family caregivers reluctant to disclose the disease due to the fear of embarrassment (Forbes et al., 2012; C; McCleary et al., 2012; Robinson et al., 2012). Lee and Casado (2011) described that two-thirds of the participants believed that dementia was a form of insanity that could stigmatize PwD and their family caregivers. However, contrary to common Asian cultural norms, their study showed that Korean Americans were willing to seek and accept help from outside of the family in dementia care because their values about elder care may have deviated from traditional values and the perceptions of the seriousness of a disease and burden outweighed the shame from the stigma (Lee & Casado, 2011).

Lastluy, having a language barrier (English as a second language) was mentioned as a barrier for family caregivers (Haralambous et al., 2014; Lee et al., 2017; Xiao et al., 2015). According to Lee and colleagues, most of the Korean American family caregivers did not search for dementia-related information written in English, which led them to delay seeking help to go through the further process to be diagnosed (Lee et al., 2017). In relation to the language barrier, some family caregivers of ethnic minority groups showed a lack of trust for health care providers or of information about the healthcare system (Mukadam et al., 2011; Phillipson & Jones, 2012; Phillipson, Magee, & Jones, 2013; Werner et al., 2017). Overall, the language barrier may be the big challenge to address among many immigrants, in terms of the access to healthcare and further processes.

Discussion

The purpose of this review of the literature was to explore the facilitating and hindering factors affecting the help-seeking behavior of the family caregivers of PwD. The Key findings of this review were the importance of caregivers' level of knowledge, gender, and cultural belief related to help-seeking behavior such as filial piety and stigma.

The impact of the level of knowledge among individuals on help-seeking behavior may emphasize the importance of the caregiver's understanding of the disease and available resources. This result is aligned with studies in the past (Devoy & Simpson, 2017; Neary & Mahoney, 2005) in which the authors found that a lack of knowledge about dementia was a primary barrier to early diagnosis. Furthermore, knowledge of disease can be an influential factor in deciding whether to seek help when caregivers of PwD notice symptoms of cognitive impairment among ethnic minority groups as well (Casado et al., 2018; Sayegh & Knight, 2013).

Well-informed caregivers may have more of a positive attitude towards seeking help from formal services than those who are not (Casado et al., 2018).

Under the umbrella of the level of knowledge, normalization is another identified factor (Devoy & Simpson, 2017; Eustace et al., 2007; Jang, Kim, & Chiriboga, 2012; Kuo & Shiu, 2010; Neary & Mahoney, 2005; Riva et al., 2012). In those studies, caregivers thought the ADRD symptoms, especially memory loss, were caused not by disease, but by stress, depression, trauma, life hardships, old age, and medication side effects. That biased attitude towards dementia symptoms led them to not seek formal healthcare (Morhardt et al., 2010).

Normalization is not only the caregivers' issue but care providers' as well. According to Kiral and colleagues, normalization was a hindering factor among healthcare providers (2013). In this study, primary care physicians fail to diagnose the early stage of disease due to time constraints and normalization. The lack of time during patient visits makes physicians defer the proper cognitive assessment, which results in mild cognitive impairment being considered a part of normal aging (Kiral et al., 2013). To solve this problem, accurate, simple, and cost-effective diagnostic tools for general practice physicians should be developed for an easy approach to detecting cognitive impairment. The standardized Mini-Mental State Examination (SMMSE) is a sensitive and brief screening tool for early detection of ADRD. Even though it was originally developed as a bedside screening tool, it is quite useful for someone at risk for ADRD (Petersen et al., 2001). This instrument may promote the early diagnosis of ADRD. Continuous updates about available evaluating instruments such as the positron emission tomography (PET) imaging or the cerebrospinal fluid (CSF) test should be provided to healthcare providers (Alzheimer's Association, 2018). Emerging evidence supports the fact that researchers can, by combining brain imaging analysis with a neuropsychological assessment, detect with remarkable sensitivity incipient dementia in individuals with mild cognitive impairment (MCI) (de Vugt & Verhey, 2013). This evidence also supports the importance of regular screening to early identify individuals with ADRD.

Caregivers' gender may be an important factor that should be addressed by researchers and healthcare providers. As mentioned above, female caregivers of PwD are slow in seeking help. This may result in female caregivers dealing with hardship longer than male caregivers (Alzheimer's Association, 2018). Furthermore, Poysti and colleagues (2012) showed that female caregivers have higher depression scores than male caregivers after they measured both male and female caregivers' depression scales in their study (Poysti et al., 2012). This was supported by Robinson and colleagues in the scoping review study; women experienced higher levels of burden than men did (Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014). Female caregivers' not taking care of their own health is evidenced by the fact that the majority of female caregivers self-rated their health status as poor (Mannion, 2008). This evidence supports that gender is an important moderator of caregivers' help-seeking behavior, and healthcare providers should pay more attention to female caregivers to promote better health management.

Cultural beliefs and ethnicity are other barriers that should be addressed. In certain cultures or ethnic minority groups such as Korean Americans or Hispanics, taking care of ill parents is a normal role for children caregivers due to filial piety (Han, Choi, Kim, Lee, & Kim, 2008; Van Liew et al., 2014). Filial piety is one of the core principles in Confucianism which emphasizes the importance of serving parents (Dai, 1988; Lai, 2010; Han et al., 2008). Furthermore, Chinese Americans believe practicing filial piety can help them to keep their family harmony (Sun, Ong, & Burnette, 2012). Thus, family caregivers, especially adult children caregivers among may try to keep control of caregiving at home to keep the family harmony, which can lead to delays in the definitive diagnosis of their parents. Hispanic American culture has a similar background in which children generally have obligations to take care of their ill parents (Hughes et al., 2009; Van Liew et al., 2014). They believe that they are repaying their parents by taking care of them. They may consider that bringing their ill parent to a health care professional to assess their cognitive function is being disrespectful to their parents. Therefore, they may try to keep their ill parent home as long as possible. Healthcare providers may have to be aware of those cultural influences when they encounter PwD and their caregivers from ethnic minority groups so that they can provide proper education with culturally tailored materials.

While a majority of the studies within the review pointed out the negative impact of culture among ethnic minority groups, positive attitudes toward seeking help among minority groups in dementia care were also noticed (Casado et al., 2018; Koehn et al., 2012). These support previous studies that were conducted with ethnic minority populations (Casado et al., 2015; Jang, Chiriboga, Allen, Kwak, & Haley, 2012). Jang and colleagues revealed that Korean Americans have a favorable attitude toward formal care (2012) and the result of this review support their study specifically among caregivers of PwD. This phenomenon may be explained by the increased public awareness of ADRD. Even though few studies showed a favorable attitude toward formal care among ethnic minority groups, finding more positive aspects and reinforcing them may increase PwD and their caregivers' utilization of healthcare services.

Another consistent finding with this review is that stigma has been a prominent issue as a help-seeking barrier. It is in line with Burgener and colleagues' study (Burgener, Buckwalter, Perkhounkova, & Liu, 2015). In their study, they revealed that perceived stigma increases the caregivers' stress due to the consequences of stigma, such as social isolation (Burgener et al., 2015). This phenomenon is prominent among ethnic minorities, especially among Asian

Americans who are under the influence of their unique culture (Lee, Lee, & Diwan, 2009). Because disclosing their parents' illness, especially dementia which is regarded as a mental illness, would be dishonoring their good family name, children caregivers are reluctant to disclose their parent's illness to seek help (Neary & Mahoney, 2005; Schrauf & Iris, 2011; Van Wezel et al., 2018).

However, the stigma would be less influential if there was more public awareness about ADRD. Education about the disease coupled with early detection and diagnosis may reduce the stigma and social isolation caused by the lack of knowledge or the misperception regarding dementia (Ivey et al., 2012; Riva et al., 2012). Participation in a community memory screening and education program has shown a decrease in family caregivers' stigma and isolation (Lawrence et al., 2003). In addition, Parveen and colleagues found that dementia education given to adolescent students prevent the development of stigmatizing views. Thus, lay public education regarding reducing stigma is important (Parveen, Farina, Shafiq, Hughes, L, & Griffiths, 2018).

Although the majority of studies in this review primarily included White samples (59.4 %), there is ample evidences that suggest the need to acknowledge and tailored interventions to promote help-seeking by race/ethnicity factors as well. Literatures suggested a customized education regarding each barrier, finding in-depth knowledge of variables related to the specific ethnicity may fill the gap in current studies (Haralambous et al., 2014; Hayes et al., 2010; Ivey et al., 2012; McCleary et al., 2012). Moreover, more attention has been given to ethnic minority groups during the last decade, however, further studies are needed to explore the affecting factors of help-seeking behaviors among Asian Americans in particular.

The prevalence of ADRD is different among different races and ethnicities. The study by Matthews and colleagues showed that there were significant disparities in the prevalence of

ADRD among different races and ethnicities (Matthews, Xu, Gaglioti, Holt, Croft, Mack, & McGuire, 2018). The U.S. Department of Health and Human Services reported that race and ethnicity are a risk factor for AD and asserted the necessity of decreasing disparities in the National plan to address Alzheimer's disease 2018 update (U.S. Department of Health and Human Services, 2018). The prevalence of PwD was highest among African Americans (14.7 %) followed by Hispanics (12.9%). The prevalence of Asian Americans were 10.1% which was lower than other ethnicities. However, Asian Americans are the fastest growing ethnic group among age 65 and older, with 1.5 million in 2010 and a projected population of 8.1 million by 2050 (U.S. Census Bureau Population Division, 2013). Furthermore, the number of Asian American caregivers may be underestimated because the survey used English instead of the immigrant's native languages and people with limited access or no telephone access might be excluded. That means there may be more Asian American family caregivers than what was estimated and who are suffering from caregivers' burden or strain.

In addition, Asian Americans are likely to underutilize services in general, especially caregivers of PwD since they perceive it as a stigmatized mental illness as mentioned above (Laditka et al., 2009). Therefore, finding factors that influence caregivers' help-seeking behavior in the Asian American population is important. The sooner family caregivers use the healthcare services available for their family members with dementia, the less caregiver strain they will experience.

Conclusion

The majority of the studies emphasized the importance of education regarding ADRD because the most noticeable barrier that delayed early diagnosis of ADRD was the lack of knowledge and related factors such as normalization and stigma. Tailored education for the caregivers of a different ethnicities, cultural background, gender, and language is important to make the pathway to diagnosis shorter, which will increase the quality of life for both PwD and their caregivers. Furthermore, to develop a proper plan to decrease the disparity, better understanding of its underlying causes, as well as identifying ways to support racial and ethnic minority families during the disease process, are crucial.

References

Alzheimer's Association (2018). Alzheimer's disease Facts and Figures. Retrieved from https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf

Amjad, H., Roth, D. L., Sheehan, O. C., Lyketsos, C. G., Wolff, J. L., & Samus, Q. M. (2018). Underdiagnosis of dementia: An observational study of patterns in diagnosis and awareness in US older adults. *Journal of General Internal medicine, 33*(7), 1131-1138. Doi: 10. 1007/s11606-018-4377-y

Bayer, A. (2012). Progress in diagnosis and management of Alzheimer's disease, *Quality in Ageing and Older Adults, 13,* 3, 189-196

Bergman, E. J., Haley, W. E., & Small, B. J. (2011). Who uses bereavement services? An examination of service use by bereaved dementia caregivers. *Aging & Mental Health, 15* (4), 531-540.

Brown, J. & Chen, S. (2008) Help-seeking patterns of older spousal caregivers of older adults with dementia. *Issues in Mental Health Nursing,* 29, 839-852.

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. Dementia, 14(5), 609-632. Doi: 10.1177/1471301213504202

Casado, B. L., Hong, M., & Lee, S. E. (2018). Attitudes toward Alzheimer's care-seeking among Korean Americans: Effects of knowledge, stigma, and subjective norm. *The Gerontologist, 58* (2). E25-e34.

Casado, B. L., Lee, S. E., Hong, M. & Hong, S. (2015). The experience of family caregivers of older Korean Americans with dementia symptoms. *Clinical Gerontologist,* 38, 32-48. Doi: 10. 1080/07317115.2014.970316

Dai, Y. (1998). Filial piety. *Journal of Gerontological Nursing, 24* (3), 13-18.

Dartigues, J.F. (2011). Alzheimer's disease: early diagnosis, *La Revue Practician, 61(7),* 926-930.

Devoy, S., & Simpson, E. E. A. (2017). Help-seeking intentions for early dementia diagnosis in a sample of Irish adults. *Aging & Mental Health, 21* (8), 870-878. Doi: http:// dx.doi.org/10.1080/13607863.2016.1179262

De Vugt, M.E. & Verhey, R.J. (2013). The impact of early dementia diagnosis and intervention on informal caregivers, *Progress in Neurobiology,* 110, 54-62

Dubois, B., Padovani, A., Scheltens, P., Rossi, A., & Dell'Agnello, G. (2015). Timely diagnosis for Alzheimer's disease: A literature review on benefits and challenges. *Journal of Alzheimer's disease, 49* (2016), 617-631. Doi: 10.3233/JAD-150692

Eustace, A., Bruce, I., Coen, R., Cunningham, C., Walsh, C., Walsh, J. B., Coakley, D., & Lawlor, B. A. (2007). Behavioral disturbance triggers recognition of dementia by family informants. *International Journal of Geriatric Psychiatry,* 22, 574-579. Doi: 10.1002/gps.1718

Feldman, L., Wilcock, J., Thune-Boyle, I., & Lliffe, S. (2017). Explaining the effects of symptom attribution by carers on help-seeking for individuals living with dementia. *Dementia, 16* (3), 375-387.

Forbes, D. A. Finkelstein, S., Blake, C. M., Gibson, M., Morgan, D. G., Markle-Reid, M., Culum, I., & Thiessen E. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: An interpretive descriptive study. *Rural and Remote Health, 12*(2001), 1-15.

Gainey, R. R., Payne, B. K., & Kropf, N. (2010). Neighborhood disadvantage and refusal of formal services among cases reported to adult protection services. *Journal of Evidence-Based Social Work,* 7, 348-360.

Han, H., Choi, Y. J., Kim, M. T., Lee, J. E., & Kim, K. B. (2008). Experiences and challenges of informal caregiving for Korean immigrants. *Journal of Advanced Nursing,63* (5), 517-526. Doi: 10.1111/j.1365-2648.2008.04746.x

Haralambous, B., Dow, B., Tinney, J., Lin, X., Blackberry, I., Rayner, V., Lee, S., Vrantsidis, F., Lautenschlager, N., & LoGiudice, D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers. *Journal of Cross Culture Gerontology,* 26, 69-86.

Hayes, J., Zimmerman, M.K., & Boylstein, C. (2010). Responding to symptoms of Alzheimer’s disease: Husbands, wives, and the gendered dynamics of recognition and disclosure. *Qualitative Health Research, 20,* 1101-1115

Hochbaum, G.M. (1958). Public participation in medical screening programs: A sociopsychological study, Washington, DC: US Government Printing Office.

Hughes, T., Tyler, K., Danner, D. & Carter, A. (2009). African American caregivers: an exploration of pathways and barriers to a diagnosis of Alzheimer's disease for a family member with dementia. *Dementia, 8,* 95-116 doi: 10.1177/1471301208099048

Ivey, S.L., Laditka, S.B., Price, A.E., Tseng, W., Beard, R.L., Liu, R., Fetterman, D., Wu, B., & Logsdon, R.G. (2012). Experiences and concerns of family caregivers providing support to people with dementia: a cross-cultural perspective. *Dementia*, *12,* 6, 806-820 doi: 10.1177./1471301212446872

Jang, Y., Chiriboga, D. A., Allen, J. Y., Kwak, J., & Haley, W. E. (2012). Willingness of older Korean-American adults to use hospice. *Journal of the American Geriatrics Society, 58* (2), 352-356. doi.org/10.1111/j.1532-5415.2009.02684.x

Jang, Y., Kim, G., & Chiriboga, D. (2010). Knowledge of Alzheimer's Disease, feeling of shame, and awareness of services among Korean American Elders. *Journal of Aging Health, 22* (4), 419-433. Doi: 10. 1177/0898264309360672

Jimenez, M.A.V., Jaen, M.C., Garcia, M.V. & Barahona-Alvarez, H. (2013). Decision-making in older people with dementia, *Clinical Gerontology, 23,* 307-316

Kiral, K., Ozge, A., Sungur, M.A. & Tascelen, B. (2013). *Health & Social Work, 38*, 2, 89-96

Koehn, S., McCleary, L., Garcia, L., Spence, M., Jarvis, P., & Drummond, N. (2012). Understanding Chinese-Canadian pathways to a diagnosis of dementia through a critical-constructionist *26, 44-54. Journal of Aging Studies,* Kuo, L. & Shyu, Y. L. (2010). Process of ambivalent normalization: experience of family caregivers of elders with mild cognitive impairment in Taiwan. *Journal of Clinical Nursing, 19,* 3477-3484 doi: 10.1111/j.1365-2702.2010.03240.x

Laditka, S.B., Tseng, W., Price, A.E., Ivey, S.L., Friedman, D.B., Liu, R., Wu, B., Logsdon, R. G., & Beard, R.L. (2012). Beliefs about promoting cognitive health among Filipino Americans who care for persons with dementia. *International Journal of Aging and Human Development, 75*, 3, 273-296 doi: http://dx.doi.org/10.2190/AG.75.3.d

Lai, D. W. L. (2010). Filial piety, caregiving appraisal, and caregiving burden. *Research on Aging, 32* (2), 200-223. Doi: 10.1177/0164027509351475

Lawrence, J.M., Davidoff, D.A., Katt-Lloyd, D., Connell, A., Berlow, Y.A. & Savoie, A. (2003). Is large-scale community memory screening feasible? Experience from a regional memory-screening day, *Journal of American Geriatric Society*, 51, 1072-1078

Lee, S. E., & Casado, B. L. (2011). Attitudes toward community services use in dementia care among Korean Americans. *Clinical Gerontologist*, 34, 271-286.

Lee, S. E., Lee, H. Y., & Diwan, S. (2009). What do Korean American immigrants know about Alzheimer's disease (AD)? The impact of acculturation and exposure to the disease on AD knowledge. *International Journal of Geriatric Psychiatry*, *2010* (25), 66-73. Doi: 10.1002/gps.2299

Lee, J., Nguyen, H., Park, J., Tran, L., Nguyen, T., & Huynh, Y. (2017). Usage of computers and smartphones to develop dementia care education program for Asian American family caregivers. *Healthcare Informatics Research, 23,* (4), 338-342.

Leung, K. K., Finlay, J., Silvius, J. L., Koehn, S., McCleary, L., Cohen, C. A., … Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health and Social Care in the Community, 19* (4), 372-381.

Mannion, E. (2008). Alzheimer’s disease: the psychological and physical effects of the caregivers’ role. Part1. *Nursing Older People, 20,* 4, 27-32

McCleary, L., Persaud, M., Hum, S., Pimlott, N. JG., Cohen, C. A., Koehn, S., Dalziel, W B.,…, & Garcia, L. (2012). Pathways to dementia diagnosis among South Asian Canadians, *Dementia 12* (6), 769-789.

Morhardt, D., Pereyra, M. & Iris, M. (2010). Seeking a diagnosis for memory problems: the experiences of caregivers and families in 5 limited English proficiency communities. *Alzheimer Disease and Associated Disorders, 24,* 3, s42-s48

Morgan, D. G., Walls-Ingram, S., Cammer, A., O'Connel, M. E., Crossley, M., Dal Bello-Haas, V., Forbes, D., Innes, A., Kirk, A., & Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine,* 102, 111-118.

Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics, 23*(7), 1070-1077.

Neary, S.R., & Mahoney, D.F. (2005). Dementia caregiving: The experiences of Hispanic/Latino caregivers, Journal of Transcultural Nursing, 16, 2, 163-170

Noureldin, M., Murawski, M. M., Mason, H. L., Hyner, G. C., & Plake, K. S. (2017). The association between family caregivers' involvement in managing older adults' medications and caregivers' information-seeking behavior. *Journal of the American Pharmacists Association,* 57, 170-177.

Nourhashemi, F., Ousset, P.J., Gillette-Guyonnet, S., Cantet, C., Andrieu, S. & Vellas, B. (2008). A 2-year follow-up of 233 very mild (CDR 0.5) Alzheimer's disease patients (REAL.FR cohort), *International Journal of Geriatric Psychiatry,* 23, 460-465

Okie, S. (2011). Confronting Alzheimer's disease, *New England Journal of Medicine, 365,* 12, 1069-1072

Parveen, S., Farina, N., Shafiq, S., Hughes, L. J., & Griffiths, A. W. (2018). What do adolescent perceive to be key features of an effective dementia education and awareness initiative? *Dementia, 0* (0), 1-11. Doi: 10.1177/1471301218807559

Petersen, R.C., Stevens, J. C., Ganguli, M., Tangalos, E. G., Cummings, J.L., & DeKosky, s. T. (2001). Practice parameter: Early detection of dementia: Mild cognitive impairment (an evidence-based review) Report of the quality standards subcommittee of the American Academy of Neurology. *Neurology,* 56, 1133-1142.

Phillipson, L., & Jones, S. C. (2012). Use of day centers for respite by help-seeking caregivers of individuals with dementia. *Journal of Gerontological Nursing, 38* (4), 24-34.

Phillipson, L., Magee, C., & Jones, S. C. (2013). Why carers of people with dementia do not utilize out-of-home respite services. *Health and Social Care in the Community, 21* (4), 411-422.

Poysti, M. M., Laakkonen, M., Strandberg, T., Savikko, N., Tilvis, R. S., Eloniemi-Sulkava, U., & Pitkal, K. H. (2012). Gender differences in dementia spousal caregiving. *International Journal of Alzheimer's disease, 2012* (162960), 1-5. Doi: 10.1155/2012/162960

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W. & Ferri, C.P. (2013). The global prevalence of dementia: A systematic review and meta analysis, *Alzheimer's & Dementia, 9,* 1, 63-75

Regan, J.L., Bhattacharyya, S., Kevern, P., & Rana, T. (2013). A systematic review of religion and dementia care pathways in black and minority ethnic populations, *Mental Health, Religion & Culture, 16* (1), 1-15

Rapp, T. (2014). Patients' diagnosis decisions in Alzheimer's disease: The influence of family factors. *Social Science & Medicine, 118*, 9-16. Doi: 10.1016/j.socscimed. 2014.07.052

Riva, M., Caratozzolo, S., Zanetti, M., Chilovi, B. V., Padovani, A., & Rozzini L. (2012). Knowledge and attitudes about Alzheimer's disease in the lay public: influence of caregiving experience and other socio-demographic factors in an Italian sample. *Aging Clinical and Experimental Research, 24* (5), 509-516. doi-org.proxy01.its.virginia.edu/10.3275/8366

Robinson, A., Lea, E., Hemmings, L., Vosper, G., McCann, D., Weeding, F., & Rumble, R. (2012). Seeking respite: Issues around the use of day respite care for the carers of people with dementia. *Aging & Society,* 32, 196-218

Robinson, C. A., Bottorff, J. L., Pesut, B., Oliffe, J. L., & Tomlinson, J. (2014). The male face of caregiving: A scoping review of men caring for a person with dementia. American Journal of Men's Health, 8 (5), 409-426. Doi: 10.1177/1557988313519671

Sayegh, P., & Knight, B. G. (2012). Cross-cultural differences in dementia: the Sociocultural health belief model. *International Psychogeriatrics*, *25* (4), 517-530. Doi: 10.1017/S104161021200213x

Schrauf, R.W., & Iris, M. (2011). Very long pathways to diagnosis among African Americans and Hispanics with memory and behavioral problems associated with dementia, *Dementia, 11,* 6, 743-763

Stockwell-Smith, G., Kellett, U., & Moyle, W. (2010). Why carers of frail older people are not using available respite services: An Australian study. *Journal of Clinical Nursing*, 19, 2057-2064.

Sun, F., Mutlu, A. & Coon, D. (2014). Service barriers faced by Chinese American families with a dementia relative: Perspectives from family caregivers and service professionals. *Clinical Gerontologist*, 37, 120-138.

Sun, F., Ong, R. & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans. American Journal of *Alzheimer's Disease & Other Dementias, 27* (1), 13-22. Doi: 10.1177/1533317512438224

U.S. Census Bureau population Division (2013) Annual estimate the resident population retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk

U.S. Department of Health and Human Services (2018). National plan to address Alzheimer's disease: 2018 update. Retrieved from https://aspe.hhs.gov/system/files/pdf/259581/NatPlan2018.pdf on December 19, 2018.

Van Liew, C., Wooldridge, J. S., Kothari, D. J., & Cronan, T. A. (2014). Ethnic differences in perceptions of Alzheimer's disease: Implications for seeking assistance in caring for an ill parent. *Californian Journal of Health Promotion, 12* (1), 71-82.

Van Wezel, N., Francke, A. L., Acun, E. K., Deville, W. L. J. M., van Grondelle, N. J., & Blom, M. M. (2018). Explanatory models and openness about dementia in migrant communities: A qualitative study among female family carers. *Dementia-International Journal of Social Research and Practice, 17*(7), 840-857. doi:10.1177/1471301216655236

Wahlster, P., Niederlander, C., Kriza, C., Schaller, S. & Kolominsky-Rabas, P.L. (2013). Clinical assessment of Amyloid imaging in Alzheimer's disease: A systematic review of the literature, *Dementia and Geriatric Cognitive Disorders*, 36, 263-278.

Werner, N. E., Stainslawski, B., Marx, K. A., Watkins, D. C., Kobayashi, M., Kales, H., & Gitlin, L. N. (2017). Getting what they need when they need it: Identifying barriers to information needs of family caregivers to manage dementia-related behavioral symptoms. *Applied Clinical Informatics,* 8, 191-205.

Xiao, L. D., Habel, L., & De Bellis, A. (2015). Perceived challenges in dementia care by Vietnamese family caregivers and care workers in South Australia. *Journal of Cross Cultural Gerontology*, 30, 333-352.

Appendix A.

Table. 1. Summary of Articles

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
Bergman et al. (2011), USA	To examine factors associated with the bereavement service utilization of dementia caregivers	Quantitative, secondary data analysis	N=224, family caregivers, mostly White, females (Male: n=35, Female: n=189) average age = 63yrs	• 1 in 3 utilized bereavement services. • The most distressed in bereavement are seeking out, utilizing services. • Educational effort to inform regarding services are needed.	Secondary data: No causality can be demonstrated. Self-reported response bias
Brown & Chen (2008), USA	To examine similarities and differences in help-seeking patterns to understand the processes underlying decisions regarding resource use.	Qualitative, descriptive, secondary analysis	N=20 spouse caregivers (Male: n=9, Female: n=11)	• Wives were passive in seeking help and care for themselves. • Both underutilize available community resources. • Service should be gender specific, and public education regarding the availability of	Limited generalizability due to the small sample size and sample homogeneity.

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				services is necessary.	
Casado et al. (2018), USA	To examine attitudes toward care-seeking for AD among Korean Americans and identified factors affecting their attitudes	Quantitative, cross-sectional survey	N=234 Korean American (KA) adults Majority: female (60.7%) married (81.4%), the mean age of 54 years, college degrees (49.1%)	• Positive attitudes among KAs toward seeking care. • The majority believed in a stigma of pity toward PwD, AD knowledge moderates the effect of the subjective norm on attitudes toward seeking care. • Public education that promotes a better understanding of AD and the importance of seeking appropriate care among KAs is needed.	Cross-sectional survey; cannot establish causal relationships. Limited generalizability due to the purposive sampling method in a geographically defined area. Social desirability bias
Feldman et al. (2017), UK	To investigate the effects of carer attributions on help-	Quantitative, interview survey	N=84, caregivers of PwD	• Memory loss was the most commonly reported	Recall bias; self-selected group and findings were

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
	seeking behaviour for people with dementia		(3/4 female; Male: n=21, Female: n=63, average age: 66years, 86% married,49% spouse, 87% White)	symptom that caused concern, but behavioral and psychological symptoms were prominent at onset. • Public awareness about the range of symptoms suggestive of dementia is needed.	based on their recall
Forbes et al. (2012), Canada	To examine healthcare practitioners, care partners, and PWD's information needs, how these change over time, and how they access, assess, and apply the knowledge	qualitative interpretive descriptive approach, interviews	N=33, care partners were mostly female (Male: n=11, Female: n=22)	• Lack of community-based resources and stigma in small rural communities and the tradition of independence are barriers to help-seeking. • Adequate resources and forms of information are needed to decrease the stigma so that a	Limited generalization; participants' experiences may differ from those who are not included in the study.

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				diagnosis and treatment is received promptly.	
Gainey et al. (2010), USA	To address interactions between caregivers' service utilization, neighborhood context, and the presence of Alzheimer's/dementia	Quantitative secondary data analysis	N=751, average age= 71.15 years, 2/3 female (Male: n=232, Female: n=514)	• Service acceptance is lower among the people who are living in disadvantaged neighborhoods, female, and poorer SES. • It may be appropriate to focus on neighborhoods rather than specific individual regarding dementia education.	Limited generalization due to the limited geographic area.
Haralambous et al. (2014), Australia	To determine the barriers and enablers to accessing CDAMS for people with dementia and their families of Chinese	Qualitative, focus groups, thematic analysis	13 caregivers (Male: n= 2, Female: n= 11, children CG: n= 11)	• Barriers: individual: stress, knowledge deficit, language barrier, and cultural belief including stigma	Limited generalization: Findings are specific to those two communities and small size

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
	and Vietnamese backgrounds.			• Enabler: Information, knowledge, and education. • Engaging the family to understand the culture, and linking communities to services are important.	
Hayes et al. (2010), USA	To explore how the gender of the spouse caregiver of dementia patient works on initial detection, reaction, and help-seeking behaviors	Qualitative design, intensive interview	N = 28 caregivers (Male: n=13, Female: n=15)	• Female caregivers are slower to seek help than male caregivers. • A culturally tailored as well as gender-specific education is needed.	Not generalizable due to the small sample size
Hughes et al. (2009), USA	Examine the perception of AD and experiences of African American (AA) caregivers from recognition of symptom to the formal diagnosis:	Qualitative, face to face, semi-structured interviews	N = 17, AA caregivers (Male: n=3, Female: n=14) Average age = 59.8years	• Barriers: Lack of knowledge about a formal health care system, perceptions of disease severity, and susceptibility	Limited generalization; small convenient sample in one ethnicity

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
	factors that influence the decision to seek a formal diagnosis				
Ivey et al. (2012), USA	Examine the differences in daily life experiences of informal caregivers of persons with dementia in White and Filipino group	Qualitative method design, focus group interview	N = 75, AD caregivers in 4 states : Filipino (n= 25), White (n=50) Average age=58 years, 90 % were female.	• Most stressful factor in both ethnic groups was recipients' cognition decline • Emotional reaction in Whites was guilt and frustration; in Filipino Americans feeling as if learning from caregiving; • Common coping strategy in both groups: Seeking help from friends and family; • Both groups described adapting their lives by limiting social interactions • Culturally tailored education and	Limited generalization: convenient sample, most were women, only two ethnic groups were included

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				support is needed to promote early diagnosis and reduce the stigma and social isolation	
Koehn et al. (2012), Canada	To understand the experiences throughout the pathway from the perspectives of Chinese-Canadian dyads of persons with dementia and their caregivers	qualitative, semi-structured interview, phenomenological exercise	N=20, PwD & caregivers (Male: n= 9, Female: n= 11)	• The traditional family structures and cultural beliefs, and the lack of knowledge delayed help-seeking. • Outreach to ethnocultural minority communities and invest in the sustainability or expansion of programs in the targeted community, as well as strategic use of ethnic media, is recommended.	Limited generalizations: small sample and researcher's own biases during the interviews; they reflected each interviewer's familiarity with the subject.

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
Lee & Casado (2011), USA	To examine attitudes toward community services use	Quantitative, questionnaire survey	N= 209, first-generation Korean Americans. Male: 49.8 %, Female: 50.2 %	• Contrary to the traditional Asian cultural norm, Korean Americans were willing to accept help from outside the family in a dementia caregiving situation. • 66% agreed the stigma exist regarding dementia, but the stress and suffering as caregivers may lead them to seek help.	Limited generalizations: the convenient sampling and geographically defined sample
Lee at al. (2017), USA	To identify smartphone and computer usage among family caregivers of dementia patients to develop dementia care education programs	Quantitative, survey	N= 35, family caregivers (15 Korean American, 20 Vietnamese American, mostly female) Male: n=4, Female: n=31	• Most of the ethnic minority family CGs did not search for dementia-related information written in English, and they were not aware of local associations or	Limited generalizations: small sample size, specific geographic area

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				resources related to Alzheimer's or dementia. • With the widespread use of smartphones among AA, smartphone-based interventions could address the unmet needs of many dementia family CGs who cannot leave home to take advantage of in-class education.	
Leung et al. (2011), Canada	To explore the perceptions and experiences of problem recognition, and the process of obtaining a diagnosis among the carers of dementia	Qualitative, semi-structured interviews	N=13, (6 PwD, 7CGs, mainly spouses) Male: n=6, Female: n=7	• Pathways of AD: Aware of memory problems, attributing meanings to symptoms, initiating help-seeking, acknowledging the severity of cognitive changes and	Limited generalizations: small size Volunteer bias; may reflect the experiences of a specific subset of individuals who are proactive and socially engaged. Recall bias: Retrospective interviews

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				obtaining a definitive diagnosis • Needed the intervention for promoting early help-seeking for dementia for both caregivers and individuals with dementia • Healthcare provider should be aware of uncertainty, normalization, acknowledgment, stigma, fear, and social withdrawal related to the diagnosis of AD	
McCleary et al. (2012), Canada	To explore experiences of South Asian Canadian with dementia and carers	Qualitative, descriptive, semi-structured interviews, in-depth, content analysis	N=14, family caregivers and PwD Male: n=5, Female: n=9	• Normalization, lack of knowledge, inaccessibility of services, and stigma of mental illness negatively influence service use in the general population and	

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				other cultural groups. • Targeting education and outreach to South Asians is needed because they may be less knowledgeable about dementia than their ethnic majority counterparts.	
Morhardt et al. (2010), USA	Examine the conceptualization of dementia in 5 limited English- proficiency (LEP)caregivers of dementia; Examine the reasons for hindering/seeking a cognitive impairment evaluation for their family members	Qualitative method design; observation, interview	N = 50, family caregivers (10 from each LEP community; Arab, Assyrian, Bosnian, Hindi, and Urdu), Female: n=36, Male: n =14 mean years length of stay in U.S.=15.5	• The belief of memory loss and AD; normalization with stress, depression, trauma, life hardships, old age, medication side effects caused memory loss • Caregivers who wanted cure/slow the disease sought evaluation • Further health promotion and	No causality can be demonstrated: small, convenient sample. The profound stigma of AD in these communities made data collecting challenge.

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				education is needed to increase awareness of the AD progress and benefits of early treatment and care	
Morgan et al. (2014), Canada	Examine the reasons for hindering/seeking a cognitive impairment evaluation for their family members	longitudinal, retrospective and prospective qualitative research design	N=46, informal caregivers of PwD Male: n = 15, Female: n = 31,	• Clinic day interview: Pursuing knowledge about patients' progress was the major theme that participants shared. • After 6 months: acceptance and moving forward in the patients' disease progress was the main response. • Family caregivers wait to plan for the treatment and plan on a diagnosis.	Limited generalizations: Selective sample; volunteer bias

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				• Better public awareness of the early signs and symptoms of dementia is needed: healthcare provider should be aware of the importance of education	
Mukadam et al. (2011), UK	To explore the link between attitudes to help-seeking for dementia and the help-seeking pathway in the minority ethnic(ME) and the indigenous population	qualitative with semi-structured interviews	N=18, caregivers (6 White, 7 Asian, 5 Black), Male: n= 5, Female: n = 13	Hindering factor: Cultural expectations: Familial responsibility, lack of knowledge including normalization, lack of trust of information in the healthcare system Facilitating factor: severe symptoms that CGS could not cope, safety, other people noticing problems Further work should explore whether an intervention can modify the attitudes	Limited generalizations: small size, specific ethnic groups.

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
Noureldin et al. (2017), USA	To explore the association between family caregivers' involvement in managing care recipients' medications and their information-seeking behavior and the sources used by them	Quantitative, secondary data analysis	N=1369 Male: n= 450 Female: n = 919	Facilitating factor: the positive relationship between CGs' involvement in assisting care recipients' medication and help-seeking. Needs for health care providers to play a more proactive role in assessing CGs' information needs and providing individualized education related medication management	No causality can be demonstrated: Retrospective study analyzing a secondary dataset, cross-sectional survey data.
Phillipson & Jones (2012), Canada	To explore and describe the behavioral, normative, and control beliefs of caregivers of individuals with dementia in relation to their use of out-of-home day centers	qualitative approach, semi-structured interviews, focus group	N=36 caregivers Male: n=10, Female: n=26	CGs don't perceive respite center beneficial for CRs. Facilitating factor: positive caregiving norms (gains from social interaction or mental stimulation, enhancing or improving the quality of life of both). The nurse should encourage service uses and emphasizing potential benefits for both CGs and CRs.	Limited generalizations: Small sample size

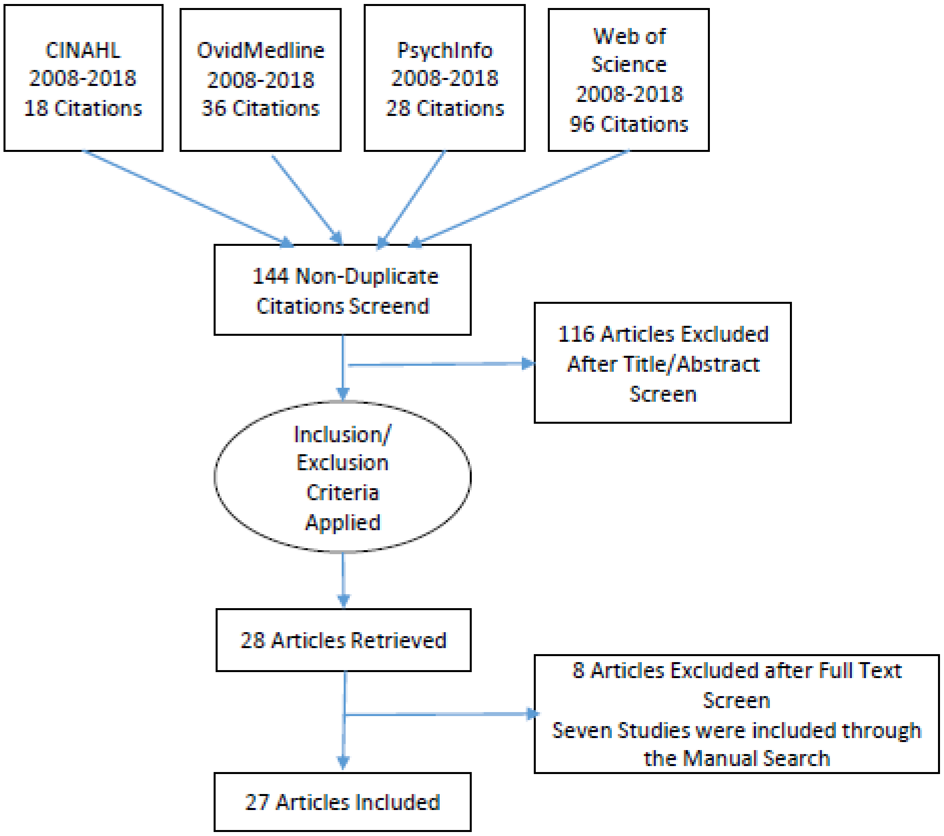
Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
Phillipson et al. (2013), Canada	To investigate the carers' beliefs regarding out of home respite services	quantitative	N=113, mainly female, spouse (Male: n=40, Female: n=73)	Hindering factor: CR's reluctance or refusal and the belief that service use would result in negative outcomes for the CR. Service beliefs should be addressed through service development and promotion that emphasizes benefits for both CGs and CRs.	Limited generalizations: Small convenient sample and specific characteristics of the sample
Robinson et al. (2012), Australia	To identify issues around the use of day respite care, focusing on barriers to attendance and strategies to facilitate attendance	qualitative study, telephone interviews, semi-structured interview	N=27, 78% female (Male: n=6, Female: n=21), average age= 78 years	Hindering factor to use day respite care: lack of knowledge, stigma Reliable information sources and strategies to help caregivers are important	Limited generalizations: Restricted geographic area, small sample size
Stockwell-Smith et al. (2010), Australia	To explore the limiting and motivating factors that influence carers' use of respite services	qualitative, focus groups	N=16, mainly female and spouses (Male: n=5, Female: n=11)	Hindering factor: Reciprocity, fear, lack of knowledge Service delivery changes that engages and promotes user control and fosters genuine participatory relations between informal and professional carer may	Limited generalizations: Lack of cultural diversity

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
				improve uptake of respite services	
Sun et al. (2014), USA	To explore the service barriers perceived by Chinese American families with a dementia patient and their strategies to eliminate these barriers.	Qualitative, focus group, content analysis	N=12 (6, professionals, 6 family caregivers, mainly female) Male: n=5, Female: n=10	Structural and cultural barriers (i.e., lack of culturally tailored services, different values, and norms) To prevent these barriers, families, and professionals to be educated about disease and healthcare systems	
Van Liew et al. (2014), USA	To examine ethnic differences in ratings of condition severity, need for medical assistance, and the likelihood of hiring Healthcare Advocate (HCA) for ill, an elderly parent in the different situation	Quantitative method; MANCOVA	N = 974, (52.5% female, 74.2% White, 5.8% Black, 8.4% Asian, 11.6% Hispanic) Male: n=464, Female: n=511	Differences were seen between Hispanic and White participants in severity rating and seeking assistance; Hispanic participants did not regard AD as serious as Whites. Culturally sensitive education regarding AD needed especially for the Hispanic population; Synergistic medico-familial care would be a good fit for cultural backgrounds.	No differences in all outcomes between Black, Asian-American, and White; Differences were seen between Hispanic and White participants in severity rating and seeking assistance; Hispanic participants did

Author(year), Country	Purpose/Aims	Research Methods	Participant Characteristics	Findings/Implication	Limitations
					not regard AD as serious as Whites Random number sequence was used to prevent selection bias.
Werner et al. (2017), USA	To identify barriers to meeting caregivers' information needs related to the management of dementia-related behavioral symptoms, and overcome barriers	qualitative, focus groups, content analysis	N=52, mainly female and White Male: n=17, Female: n=35	Nine barriers to access information on behavioral symptoms using web-based platform. Caregivers need sociotechnical system interactions/timely access to information.	Limited generalizations: One geographical area
Xiao et al. (2015), Australia	To explore the perceived challenges of dementia care from Vietnamese family caregivers and workers	qualitative, in-depth interviews	N= 13 (6 family caregivers, 7 care workers, Female: n=10, Male: n=3)	Hindering factors: normalization, lack of knowledge, providers' negative attitudes towards the diagnosis, family stigma, and level of acculturation. Individualized dementia caregiver supports are needed to overcome stigma related to dementia.	Limited generalizations: One Vietnamese community organization; volunteer bias

Appendix B.

Figure 1. PRISMA Flow Diagram



CHAPTER 4

MANUSCRIPT TWO

Concept Analysis: Perceived Stigma in Dementia

To be submitted to *the Nursing Forum*

Mihee Chung, PhD (c), RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
mc2by@virginia.edu, 1-508-963-3018
Cathy Campbell, PhD, RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
clc5t@virginia.edu, 1-434-243-6789
Jeongok Logan, PhD, RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
jl3zj@virginia.edu, 1-434-924-0082
Ishan C. Williams, PhD, FGSA
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
icw8t@virginia.edu, 1-434-924-0480

Abstract

Background: Stigma, negative associations due to a particular circumstance, has been associated with those who have been diagnosed with a mental health illness. In particular, people who are diagnosed with dementia have often been perceived inadequately, due to the perceived stigma related to dementia. Stigma affects family caregivers' quality of life and often preventing open discussion and encouraging their help-seeking behaviors to get a diagnosis in a timely manner and to seek supportive services throughout the disease trajectory.

Aim: To report a concept analysis of perceived stigma related to Persons with Dementia (PwD) and their caregivers.

Design: A Concept analysis.

Data Source: Four databases (CINAHL, OvidMedline, PsychINFO, and Web of Science) were searched with the keywords "perceived stigma" or "stigma" and "dementia" and "caregivers." After the inclusion/exclusion criteria were applied, fifty one empirical studies were selected.

Methods: Guided by Walker and Avant's method

Results: Four attributes of perceived stigma were synthesized; negative emotional reaction, living on the margin, inequality, and losing what's normal. Consequences including intermediate and long-term outcomes were extracted.

Conclusion: This concept analysis offers a clear view of the concept of perceived stigma that can help nurses understand the phenomenon and help researchers to develop an instrument measuring stigma and stigma reduction interventions. Also, better communication between different levels of providers and researchers is needed.

Introduction

In the United States, there are currently 5.7 million people with Alzheimer's disease and related dementia (ADRD), and this number is projected to increase to 13.8 million by 2050 (Alzheimer's Association, 2018). The prevalence of ADRD is different between races and ethnicities. In the study by Matthews and colleagues regarding the prevalence of ADRD, there are significant disparities among different races and ethnicities (Matthews, Xu, Gaglioti, Holt, Croft, Mack, & McGuire, 2018). Department of Health and Human Services claimed that race or ethnicity is a risk factor for AD and the 2018 update of the national plan to address Alzheimer's disease asserted the necessity of decreasing disparities in AD (U.S. Department of Health and Human Services, 2018).

As the number of persons with dementia (PwD) is growing rapidly, the number of families caring for them is increasing as well, and both need support from formal healthcare services because the PwD's cognitive and behavioral deterioration may cause a substantial strain. However, despite the benefits of the early diagnosis of ADRD, less than 50 percent of PwD are formally diagnosed due to a lack of knowledge and stigma (Amjad et al., 2018). Stigma, especially, is a prominent cause of delayed help-seeking among PwD and their caregivers (Forbes et al., 2012; Haralambous et al., 2014; McCleary et al., 2012; Robinson et al., 2012). The pervasiveness of stigma, as well as the importance of its reduction for public health, were emphasized by the Alzheimer's disease International in their report (Alzheimer's Disease International, 2012). Also, there are many studies that have attempted to understand the impact of stigma and efforts to develop a scale to measure stigma. However, not many assessment tools were developed regarding stigma, especially stigma among PwD and their caregivers (Stevelink, Wu, Voorend, & van Brakel, 2012). Thus, it is necessary to examine a clear definition, attributes, antecedents, and consequences of perceived stigma among PwD and their caregivers to have clearly defined empirical referents for designing measurements that examine perceived stigma.

The Purpose and Aims of Concept Analysis

The purpose of this study was to analyze the concept of perceived stigma among persons with dementia and their caregivers. The most frequently used stigmas in previous research are courtesy-stigma, family-stigma, and stigma by association (See Table 1; Goffman, 1963; Link & Phelan, 2001; National Alliance on Mental Illness, 2019). However, limiting stigma to those concepts may not explain the perceived stigma clearly among those suffering from cognitive impairment.

The process of perceived stigma in dementia caregiving often begins when PwD and caregivers perceive others’ reaction to the disease or when PwD displays behavioral/cognitive symptoms (Burgener et al., 2015). Assuming that perceived stigma is more subjective than other stigmas, measuring this concept objectively may be a challenge. Thus, it is necessary to analyze the concept further. Perceived stigma may affect the decision making process involved with seeking help or participating in social activities. It also may affect the quality of life of caregivers and the older adult with the condition. In such manner, perceived stigma can be an influential variable in caregiving research.

Thus, this concept analysis can be used to help in the development of an operational definition and attributes to understand perceived stigma in dementia caregiving (Walker & Avant, 2005). Ultimately, it can be used to develop a research instrument in order to measure the concept among this caregiving population. The specific aims of this concept analysis are to 1) define the clear meaning of perceived stigma based on the literature, 2) define its attributes, 3) identify its antecedents and consequences, and 4) describe its empirical referents.

Data Sources

A literature search was conducted by searching four databases: Ovid Medline, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsychINFO, and Web of Science. Manual searching on the bibliographies of retrieved articles was completed as well. Search terms were “perceived stigma” or “stigma” and “dementia” and “caregivers.” To obtain the most number of relevant evidence related to stigma, studies were searched from 1963, the year Goffman defined the concept of stigma (Goffman, 1963). Inclusion criteria were written in English, studies related to dementia, caregivers, and stigma, and exclusion criteria were editorials, reviews, letters, guidelines, non-English language, studies that only focused on the symptoms or policies, and not relevant to dementia. A total of 149 literatures were retrieved after an initial search, and 32 duplicates were excluded. After abstracts were reviewed and inclusion/exclusion criteria were applied, 50 studies were selected.

Concept Analysis Method

The concept analysis is guided by the work of Walker and Avant (2005) which is a modified analysis procedure of Wilson’s classic concept analysis procedure (1963). There are eight steps: 1) select a concept, 2) determine the aims or purposes of analysis, 3) identify all uses of the concept that you can discover, 4) determine the defining attributes, 5) identify a model case, 6) identify borderline, related, contrary, invented, and illegitimate cases, 7) identify antecedents and consequences, and 8) define empirical referents. This method was selected because it is the easiest to understand and master for research beginners, and these eight steps are sufficient to capture the essence of the concept with the iterative process. Walker and Avant asserted that the iterative nature of the eight steps could yield more precise analysis of the concept (Walker & Avant, 2005). The author scrutinized 50 selected empirical studies to identify the defining attributes, antecedents, consequences, and define empirical referents. Then, cases were built upon the author's clinical experiences with PwD and their caregivers.

Results

Identify All Uses of the Concept

Definition of the concept. The definition of "perceived stigma" was searched from several dictionaries. Unfortunately, there was no definition of the combination of "perceived" and "stigma." However, the definition of *stigma* was present in many dictionaries. "Stigma" originated from the Latin word "stigma, *pl.* stigmata" and Greek word "stigmatos", meaning mark, puncture, and a tattoo with its figurative meaning, "a mark of disgrace" (Thesaurus.com, 2015).

In the Merriam-Webster online dictionary (2015), the meaning of stigma is "a set of negative and often unfair beliefs that a society or group of people have about something" and the online Oxford English Dictionary (2015) defines stigma as "a mark of disgrace associated with a particular circumstance, quality, or person." The second definition of stigma in the Oxford Dictionary was derived from the Christian tradition, which is, "marks corresponding to those left on Jesus' body by the Crucifixion, said to have been impressed by divine favor on the bodies of St. Francis of Assisi and others." The third definition in the Oxford dictionary was the use in Medicine, "a visible sign or characteristic of a disease."

In the online American Heritage Dictionary (2015), the definitions of stigma were more comprehensive. They were “an association of disgrace or public disapproval with something, such as an action or condition,” “*Medicine* A visible indicator of disease, small body mark, especially a birthmark or scar, that is congenital or indicative of a condition or disease,” “*Psychology* A bleeding spot on the skin considered to be a manifestation of conversion reaction,” “*Christianity* Bodily marks, sores, or sensations of pain corresponding in location to the crucifixion wounds of Jesus, believed to be given as divine recognition of devotion.”

The definition of *perceived* in the Merriam-Webster online dictionary (2015) is “become aware or conscious of something; come to realize or understand.” Synonyms of *perceive* are discern, recognize, see, distinguish, realize, grasp, understand, identify, comprehend, appreciate, and sense (Merriam-Webster online dictionary, 2015). All of these definitions combine to define perceived stigma in the context of dementia as being aware of disgrace or public disapproval related to one’s or family member’s dementia symptoms or diagnosis.

The meaning in that context is similar to how Goffman, a renowned sociologist, defined stigma in his book, ‘Stigma: Notes on the management of spoiled identity,’ in 1963. Stigma is a complex individual experience in which manifestations of diseases and social environments interact to affect personal identity and, ultimately, sense of self (Link & Phelan, 2001; Goffman, 1963). Goffman (1963) also defined stigma as “an attribute that is deeply discrediting, from a whole and usual person to a tainted, discounted one” (pp. 3). Stigma can be classified in a couple of different ways such as experienced- and perceived- stigma versus public-, self-, family-, and structural stigma (Goffman, 1963; Corrigan, Druss, & Perlick, 2014).

The concept uses in various disciplines regarding dementia. Uses of stigma were noticed in various disciplines. In Sociology, stigma is a multifaceted concept, and there are various ways to define this concept (Phillipson, Magee, Jones, Reis, & Skaldzien, 2015). According to Link and Phelan (2001), stigma is a process that encompasses many concepts such as labeling, stereotyping, separation, discrimination and negative use of power. Fear of discrimination due to a lack of knowledge affects people with dementia and their caregivers' help-seeking behavior (Moore & Cahill, 2013; Stokes et al., 2012). Stigma influences not just people with dementia but also influences family caregivers (Forbes et al., 2011; Haralambous et al., 2014; McCleary et al., 2012; Robinson et al., 2012). In terms of the family caregivers of PwD, ethnic minority groups have faced more challenges due to their unique cultures from their own countries (Sun, Mutlu, & Coon, 2014; Werner, Goldstein, & Buchbinder, 2010). According to Sun *et al.* (2014), Chinese Americans utilize fewer healthcare resources due to barriers such as language and cultural differences that lead them to be more likely stigmatized than the general population (Sun et al., 2014).

In psychology, stigma refers to "prejudicial views or negative stereotypes that individuals or groups hold about people with certain distinguishing characteristics or attributes, and has been widely investigated in conditions such as depression and HIV/AIDS" (Phillipson et al., 2014, pp.158). Stigma has been related to help-seeking behavior that can cause delayed diagnosis and treatment (Forbes et al., 2011; Haralambous et al., 2014; McCleary et al., 2012; Robinson et al., 2012).

In medicine, stigma, as a mark of disgrace, is associated with a certain circumstance, or person (O'Sullivan, Hocking, & Spence, 2014; Phillipson et al., 2014). Early detection and screening for dementia can offer a better quality of life through pharmacotherapy and other interventions; stigma is one of the barriers that hinder PwD and their caregivers from seeking healthcare (Boustani et al., 2011). A stigmatizing perception of AD was shown among ethnic minority groups such as Korean Americans or Chinese Americans because they regard AD as a status of insanity (Lee, Lee, & Diwan, 2012).

In nursing, the concept of stigma is used as one of the help-seeking barriers in certain distinguishing conditions such as mental illness, HIV/AIDS, and other chronic diseases (Bull, Boaz, & Sjostedt, 2014; Burgener et al., 2015; Daly, McCarron, Higgins, & McCallion, 2013). Notably, among people with dementia and their caregivers, concerns of rejection from others can increase stress and caregiver burden (Riley et al., 2014). All those aspects lead to a delayed diagnosis that causes high mortality and lower quality of life (Burgener et al., 2015).

Theoretical uses of the concept. From the analysis, two theoretical uses of the concept were found (Burgener et al., 2015; Werner, Mittelman, Goldstein, & Heinik, 2011). In the Modified Labeling Theory, Link and his colleagues (1989) delineated the stereotype, labeling, stigmatization, and the consequences of this phenomenon such as negative consequences of self-esteem. In the theory, people who have mental illness or people who are associated with someone who is mentally ill, perceive and internalize themselves as devalued or disgraced. Once one is labeled, responses such as secrecy, withdrawal, and educating others to protect oneself will take place. When one fails this step, negative impact on the social network or lower self-esteem will occur, and one becomes vulnerable to a future disorder or present disease (Link, Cullen, Struening, & Shrout, 1989).

Stigma was used in the attribution theory as reflecting a process in which cognitive or causal attributions or stereotypes lead to emotional reactions (e.g., shame, fear, and pity) and behavioral consequences or discrimination (Corrigan, 2000 in Werner et al., 2011). This theory became a framework to develop a structured quantitative questionnaire, the Family Stigma in Alzheimer’s Disease Scale (FS-AD; Werner et al., 2011).

Empirical use of the concept. Empirical use of the concept of perceived stigma were noted among various disciplines. In sociology, perceived stigma was used to mean worthlessness, discrimination, interpersonal interaction, social relationship, concealment, structural discriminations, assignment of guilt, and assignment of shame (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). In medicine, the concept was used to mean perceived harms (Boustani, 2011). In psychology and nursing, perceived stigma was used to measure social rejection, financial insecurity, internalized shame, and social isolation. Many studies from different discipline seem to share empirical uses (Boustani et al., 2011; Burgener et al., 2015; Link et al., 1989; Riley, 2012). Because not many studies distinguished the perceived stigma from general concept of stigma, finding attributes of perceived stigma to build the empirical referents are crucial.

Identification of Defining Attributes

According to Rodger and Knafl (2000), the attributes of characteristics of the concept represent “a real definition that makes it possible to identify situations that fall under the concept” (pp. 256). It is the most important part of concept analysis in which the analyst will pursue the broadest insight into the concept (Walker & Avant, 2005). As a result, there were four attributes of perceived stigma categorized from the analysis. They include a negative emotional reaction, living on the margin, inequality, and losing what is normal.

Negative emotional reaction. It is characterized by the stigmatized persons’ internal reaction to the antecedents. That is the most direct and primary attribute that can be recognized from the stigmatization. It includes humiliation (Navab, Negarandeh, Peyrovi, & Navab, 2013;O’Sullivan et al., 2014), embarrassment (De Mamani, Weintraub, Maura, De Andino, & Brown, 2018; Hsiao, Liu, Xu, Huang, & Chi, 2016; Mackenzie, 2006; O’Sullivan et al., 2014;

Werner et al., 2010), shame (Burgener et al., 2015; Guo, Levy, Hinton, Weitzman & Levoff, 2000; Innes, Abela, & Scerri, 2011; Lee et al., 2012; Moore & Cahill, 2013; Navab et al., 2013; O'Sullivan et al., 2014; Phillipson et al., 2015; Werner et al., 2011; Zhan, 2004), being left in the shadows (Harland et al., 2017; Stokes, Combes, & Stokes, 2012), vulnerableness (Burgener et al., 2015), fear (Forbes et al., 2011; Werner et al., 2010), feelings of unworthiness (Liu et al., 2008; Mackenzie, 2006; Wiersma et al., 2016), and condemnation (Mackenzie, 2006).

Losing what is normal. It is the internal and social level of reaction to the antecedent, characterized by a deeper impact in affected one's life than negative emotional reaction. It includes loss of autonomy (Boustani et al., 2011; Cheston et al., 2016; Devlin et al., 2007; Devoy & Simpson, 2017; Phillipson et al., 2014), weakness (Boots et al., 2015; Moor & Cahill, 2013), disruption of family cohesion (Moor & Cahill, 2013; Sun et al., 2013), feeling unbalanced (Liu et al., 2008; Sun et al., 2013), social death (Hoppe, 2018; Van Gorp & Vercruysse, 2012), and losing face (Xiao et al., 2015). Once PwD and their caregivers perceive that they are stigmatized, they feel vulnerable as if their relationships in their circle of society is ruined due to a loss of family dignity and/or independence who may appear judgmental.

Living on the margin. It can be defined when PwD or their caregivers perceive their social status getting narrow after they have internalized the social label of dementia. It includes marginalization (Daly, McCarron, Higgings, & McCallion, 2012; Evans, Harrison-Dening, & Read, 2018; Mackenzie, 2006), the anticipation of social rejection (Burgener et al., 2008; O'Sullivan et al., 2014; Phillipson et al., 2015; Van Wezel et al., 2018), a gradual loss of social status (Devlin, MacAskill, & Stead, 2007; Devoy, & Simpson, 2017; Lockeridge & Simpson, 2012), and a feeling of denial (Devlin et al., 2007).

Inequality. It is the attribute at the social level. In other words, inequality is the attribute that PwD and their caregivers perceive from society. It includes discrimination (Dai et al., 2013; Liu et al., 2008; Phillipson et al., 2015; Werner & Heinik, 2008), being devalued (Burgener et al., 2008; Burgener et al., 2015; Cheston et al., 2016; Navab et al., 2013; Sun et al., 2014), labeling (Burgener et al., 2008; O'Sullivan et al., 2014; Phillipson et al., 2015), negative social attitude toward PwD and their caregivers (Burgener et al., 2008; Burgener et al., 2015; Edward Voss, & Iliffe, 2014; O'Sullivan et al., 2014; Riley et al., 2014), and prejudice (O'Sullivan et al., 2014; Sun et al., 2014; Werner et al., 2011; Werner & Hess, 2016; Xiao, Habel, & Bellis, 2015).

As the antecedents trigger attributes of perceived stigma, these four characteristics influence each other, leading to consequences such as avoidance, fear, anxiety, social isolation, and delay in timely diagnosis.

Construction of model case and additional cases

Model Case. A model case is "an example of the use of the concept that demonstrates all the defining attributes of the concept. It should be a pure and paradigmatic example" (Walker & Avant, 2005, pp. 174). Below is an example of a model case which is produced by the author's clinical experiences with PwD and their caregivers. Mr. Kim and Sue showed perspectives of dementia which included fear of social rejection, discrimination, and disruption of family cohesion and dignity. All four attributes were included in this case.

Mr. Kim is a 73-year-old man who's having Alzheimer's disease with symptoms of deterioration of his cognitive and physical function. He had been hiding his significant memory loss from his wife, Sue, for a year because he did not want to ruin their social life; they hosted a weekly Bible study group and threw potluck parties for the church small group and had other family gatherings. On top of that, he didn't share his condition with his coworkers because he believed when they found out his condition, they would fire him. When Sue recognized his symptoms, she hesitated to seek help because she was worried about damaging her family's dignity.

Borderline Case. Borderline cases are "those examples or instances that contain most of the defining attributes of the concept being examined but not all of them. They may contain most or even all of the defining characteristics but differ substantially in one of them" (Walker & Avant, 2005, pp. 175). This case represents a borderline case. Mr. Kim recognized the stereotype of dementia or negative attitude of society, but he found support from his family and knew his symptoms were not from himself, but from the disease. Some, but not all, of the attributes were shown in this case.

Mr. Kim is a 73-year-old man who was diagnosed as having Alzheimer's disease due to the deterioration of his cognitive and physical function. He had been hiding his significant memory loss from his wife, Sue, for six months because he did not want to disturb their life including hosting weekly Bible studies and potluck parties for the small group of their church. On top of that, Mr. Kim did not want to lose his part-time job at the grocery store because he believed that he would be fired if people found out his status. When Sue recognized his symptoms, she summoned all family members and discussed his condition. During the discussion, he said, "Even though I have some problem in my daily life, I will be all right because I have all of you who care for me. Moreover, I know it is not me but the process of the disease that gives me problems."

Related Case. Related cases are "instances of concepts that are similar or related to the concept being studied but that do not contain all the defining attributes" (Walker & Avant, 2005, pp. 176). The following case represents a related case, in which Tom was covering the situation because he felt shameful. That is similar to perceived stigma, or it can even be one of the consequences of perceived stigma.

Anna, a 70-year-old woman, came to the primary care physician with her husband, Tom, for the symptoms of memory loss and incontinence. Tom said, “Anna has been like this for a while, but I could not come to you because I was worried and felt ashamed about my situation.”

Contrary Case. Contrary cases are clear examples of “not the concept” (Walker & Avant, 2005, pp. 177). This case represents a contrary case. Bob was positive about his diagnosis and getting support from his family and friends. Thus, he did not perceive any stigma; rather he was showing coping and empowerment in this case.

Bob is a 73-year-old man who was diagnosed as having Alzheimer’s disease due to the deterioration of his cognitive and physical function. He and his wife, Holly, recognized his symptoms six months ago and summoned a whole family meeting. After discussing his condition, they decided to visit his physician for dementia screening. He told Holly, “Thank goodness that I now know what my problem is! I will ask for prayer from my friends at the church!”

Determination of antecedents and consequences

Antecedents are ones that initiate the concept and lead to the consequences (Walker & Avant, 2005). Prior to the beginning of the process of perceived stigma, certain phenomena that initiate the process of stigmatization among PwD and their caregivers must occur. Those phenomena are recognition of the symptoms (Daly et al., 2012; Lockeridge & Simpson, 2012; Navab et al., 2013; Stokes et al., 2012; Sun et al., 2014; Werner et al., 2010), dementia screening

(Boustani et al., 2011; Phillipson et al., 2015), other's reaction and connotation (Daly et al., 2012; Harland et al., 2017; Hoppe, 2018), deterioration of family members' functional and cognitive status (Forbes et al., 2011; Hsiao et al., 2016; Liu et al., 2008; Van Wezel et al., 2018; Werner et al., 2008; Werner et al., 2010), diagnosis of dementia (Boots et al., 2015; Burgener et al., 2015; O'Sullivan et al., 2014; Phillipson et al., 2014; Riley et al., 2014; Sun et al., 2013, Werner et al., 2010), and disclosure (Guo et al., 2000; Lee et al., 2012; Mackenzie, 2006). Others are a lack of anonymity (Forbes et al., 2011), uncertainty (Devlin et al., 2007; Innes et al., 2011), a feeling of failure (Liu et al., 2008) and tiredness (Evans et al., 2018). Antecedents of the perceived stigma come from various directions including society, results of the formal care process, and the PwD or family caregiver themselves.

According to Walker and Avant (2005), "consequences are those events or incidents that occur as a result of the occurrence of the concept- in other words, the outcomes of the concept" (Walker & Avant, 2005, pp. 179). The consequences from the analysis were categorized to intermediate outcomes and long-term outcomes.

Intermediate outcomes include avoidance (Burgener et al., 2015; Harland et al., 2017; Hsias et al., 2016; Lee et al., 2012; Phillipson et al., 2015; Sun et al., 2013), concealment (Hoppe, 2018; Liu et al., Mackenzie, 2006 ;Sun et al., 2014; Werner et al., 2010), withdrawal (Boustani et al., 2011; Burgener et al., 2015; Lee et al., 2012; Lockeridge & Simpson, 2013; Moore & Cahill, 2013; O'Sullivan et al., 2014; Phillipson et al., 2014; Riley et al., 2014; Sotkes et al., 2012; Werner et al., 2011), secrecy (Boustani et al., 2011; Burgener et al., 2015; Devoy & Simpson, 2017; Hsiao et al., 2016; Lee et al., 2012; Lockeridge & Simpson, 2012; Moore & Cahill, 2013; OSullivan et al., 2014; Phillipson et al., 2014; Riley et al., 2014; Sotkes et al., 2012; Werner et al., 2011), loss of independence (Boustani et al., 2011; Burgener et al., 2015;

Riley et al., 2014), distress (Lockeridge & Simpson, 2012; Phillipson et al., 2014), anxiety (Burgener et al. 2015; Devlin et al., 2007; Mackenzie, 2006; O'Sullivan et al., 2014; Riley et al., 2014), a sense of shame (Burgener et al., 2015; Navab et al., 2013; O'Sullivan et al., 2014; Riley et al., 2014; Sun et al., 2013), guilt (De Mamani et al., 2018), denial (Devlin et al., 2007), Fear (Devlin et al., 2007; Guo et al., 2000), discrimination (Werner & Hess, 2016) and a sense of hopelessness (Devoy & Simpson, 2017; O'Sullivan et al., 2014).

When the intermediate outcomes are not timely treated, long-term outcomes, such as depression (Boustani et al., 2011; Dai et al., 2013; O'Sullivan et al., 2014), delayed timely diagnosis and treatment, social isolation, heavier caregiver burden, and lower quality of life, will appear (Boustani et al., 2011; Burgener et al., 2015; Devlin et al., 2007; Elliott; Guo et al., 2000; Harland; Lee et al., 2012; Lockeridge & Simpson, 2012; Moor & Cahill, 2013; O'Sullivan et al., 2014; .Phillipson et al., 2015; Riley et al., 2014; Stokes et al., 2012; Sun et al., 2013; Van Gorp & Vercruysse, 2012; Werner et al., 2010; Xiao et al., 2015).

Determination of empirical referents

When the defining concept and defining attributes are highly abstract, empirical referents are necessary. Walker and Avant states

> Determining the empirical referents for the defining attributes is the final step in a concept analysis. They are useful in instrument development because they are clearly linked to the theoretical base of the concept; they are useful in practice because they provide the clinician with clear, observable phenomena by which to determine the existence of the concept in particular clients. (Walker & Avant, 2005, pp.179)

Humiliation, embarrassment, vulnerableness should be included as empirical referent to measure a negative emotional reaction. Loss of autonomy, feeling unbalanced can measure losing what is normal, and the anticipation of social rejection can be used to measure living on the margin attribute. The last, negative social attitude can be the empirical referent to measure inequality.

From this analysis, three scales for measuring the concept of stigma were recognized: The Modified Stigma Impact Scale (MSIS: Burgener & Berger, 2008; Riley, Burgener, & Buckwalter, 2015), the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC: Boustani et al, 2011; Phillipson et al., 2014; Phillipson et al., 2015), and the Affiliate Stigma Scale (Mak et al, 2008).

Burgener and Berger (2008) revised the Stigma Impact Scale by Fife and Wright (2000) in 2008 to measure perceived stigma in PwD. The Modified Stigma Impact Scale includes four subscales with 24 items in total. Scores range from 0 to 96. A higher score indicates a higher perceived stigma. Cronbach's alpha is .92.

The Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) questionnaire is the second scale. Guided by the health belief model, it was developed by the Indiana University Center for Aging Research team to capture the acceptance and perceived harms and benefits of dementia screening (Boustani et al., 2011). It has five domains with 34-items. The internal consistency has a Cronbach alpha range of 0.58 to 0.89.

The last scale is the Affiliate Stigma Scale. It was originally developed by Mak and colleagues (2008 in Chang, Su, & Lin, 2016) to assess the self-stigma of a caregiver providing care to a family member with a mental illness or intellectual disability. It has 22 items rated on a

4-point Likert scale with three domains (cognitive = 7 items, affect = 7 items, and behavior = 8 items); a higher score indicates a higher level of affiliate stigma. Cronbach's alpha ranges from 0.85 to 0.94 (Chang et al., 2016).

Discussion

Summary of the findings

The purpose of this concept analysis was to define attributes, antecedents, consequences, and its empirical referents of perceived stigma to help health care providers, including nurse researchers, to pursue a better understanding of the phenomena and ultimately enable better communication between each other. From the analysis, four categories of attributes were found, as well as antecedents and consequences (see Figure 1). Among four categories of attribute, each part covers internal (negative emotional reactions), and social (losing what is normal, living on the margin, and inequality) aspects.

Implications for Nursing Research, Theory and Practice

As stigma evolves as a concept and theory, analyzing perceived stigma and having a clear understanding of it may help nurses and healthcare providers have a better plan for tailored care of PwD and their caregivers who come from various backgrounds.

To be a good clinician, nurses should hold holistic perspectives of clients as well as their caregivers to understand the physical and psychological consequences of stigmatization. This analysis can provide a deeper understanding of the process of perceived stigma to give clinicians a thorough view. As many researches pointed out, stigma's pervasive impact on lives of PwD and their caregivers cannot be ignored (Alzheimer's Disease International, 2012: Burgener et al., 2015). Thus, acknowledging the perceived stigma among the affected populations and planning to help them learn how to overcome by using various methods such as education and counseling is needed.

Nursing researchers can continue to develop instruments that measure perceived stigma, which may help to develop interventions to reduce perceived stigma. They can also develop structured education with several different versions to fit care recipients who have different sociocultural backgrounds. By having a clear understanding and empirical referent of perceived stigma, healthcare providers can have better communications when they discuss care plans or develop the instruments used to measure perceived stigma.

Study Limitations

This concept analysis has limitations. First, there could be a researcher's bias because attributes of the perceived stigma were categorized only by the primary author. It would be better to have another researcher who can do this process separately and make a consensus to decrease the bias (Walker & Avant, 2005). Also, out of 50 empirical studies, only six studies utilized perceived stigma as a concept, six used family stigma or associate stigma and the remaining articles did not define the types of stigma. The author analyzed and defined the attributes of perceived stigma, but there can still be overlaps between perceived stigma and the broader concept of stigma, making it difficult to understand which is primary. Furthermore, studies included in the analysis were conducted from several different countries (US, UK, Canada, China, Norway, Iran, Netherland, Ireland, and Israel), but cultural factors were not considered during the analysis.

In spite of these limitations, this analysis is one of the first to compile the literature in this way regarding perceived stigma with a lot of rich data. As it mentioned above, the impact of perceived stigma in dementia caregiving cannot be neglected. As perceived stigma is more subjective than other stigmas, it is important to have a tool to measure this concept objectively, and this study offers the components for that matter. Thus, it can be used to develop an instrument to measure stigma and to operationalize perceived stigma.

References

Alzheimer's Association (2014). Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/alzheimers_disease_facts_and_figures.asp

Alzheimer's Disease International (2012). World Alzheimer Report 2012: Overcoming the stigma of dementia. Retrieved from https://www.google.com/#q=world+alzheimer+international+overcoming+the+stigma+of+dementia

Baldwin, M. A. (2008). Concept analysis as a method of inquiry. *Nurse Researcher*, 15(2), 49-58. Retrieved from http://journals.rcni.com/doi/abs/10.7748/nr2008.01.15.2.49.c6329?url_ver=Z39.88-2003&rfr_id=ori%3Arid%3Acrossref.org&rfr_dat=cr_pub%3Dpubmed&

Boots, L. M., Wolfs, C.A.G., Verhey, F.R.J., Kempen, G. I., & de Vugt, M.E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *International Psychogeriatrics, 27*(6), 927-936. Doi:10/1017/S1041610214002804

Boustani, M.S., Justiss, M. D., Frame, A., Ausrom, M. G., Perkins, A. J., Cai, X., ..., & Hendrie, H. C. (2011). Caregiver and noncaregiver attitudes toward dementia screening. *Journal of American Geriatric Society, 59,* 681-686. Doi: 10.1111/j.1532-5415.2011.03327.x

Bull, M. J., Boaz, L., & Sjostedt, J. M. (2014). Public health model identifies recruitment barriers among older adults with delirium and dementia. *Public Health Nursing, 31*(1), 79-87. doi:10.1111/phn.12075

Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer’s dementia and Parkinson’s Disease. *Dementia: The International Journal of Social Research and Practice, 7* (1), 31-53. https://doi.org/10.1177/1471301207085366

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia*, *14*(5), 609-632. Doi: 10.1177/1471301213504202

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F., Riley, R., Einhorn, C. J., ... Hahn-Swanson, C. (2015). Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part I. *Dementia*, *14*(5), 589-608. Doi: 10.1177/1471301213508399

Casado, B. L., Hong, M., & Lee, S. E. (2018). Attitudes toward Alzheimer’s care-seeking among Korean Americans: Effects of knowledge, stigma, and subjective norm. *Gerontologist, 58*(2), E25-E34. doi:10.1093/geront/gnw253

Chang, C., Su, J., & Lin, C. (2016). Using the affiliate stigma scale with caregivers of people with dementia: Psychometric evaluation. *Alzheimers Research & Therapy, 8*, 45. doi:10.1186/s13195-016-0213-y

Corrigan, P. W., Druss, B. G., & Perlick, D. A. (2014). The impact of mental illness stigma on seeking and participating in mental health care. *Psychological Science in the Public Interest, 15* (2), 37-70. Doi: DOI: 10.1177/1529100614531398

Daly, L., McCarron, M., Higgings, A., & McCallion, P. (2012). ‘Sustaining place’ – A grounded theory of how informal carers of people with dementia manage alterations to relationships within their social worlds. *Journal of Clinical Nursing, 22,* 501-512. Doi: 10.1111/jocn.12003

De Mamani, A. W., Weintraub, M. J., Maura, J., De Andino, A. M., & Brown, C. A. (2018). Stigma, expressed emotion, and quality of life in caregivers of individuals with dementia. *Family Process, 57*(3), 694-706. doi:10.1111/famp.12325

Edwards, R., Voss, S., & Iliffe, S. (2014). Education about dementia in primary care: Is person-centredness the key? *Dementia: The International Journal of Social Research and Practice, 13*(1), 111-119. doi:10.1177/1471301212451381

Evans, S. C., Harrison-Dening, K., & Read, K. (2018). Towards the end of life: An in-depth exploration of the role of admiral nursing in dementia care (innovative practice). *Dementia (14713012), 17*(2), 244-251. doi:10.1177/1471301216636485

Forbes, D., Ward-Griffin, C., Kloseck, M., Mendelsohn, M., St-Amant, O., DeForge, R., & Clark, K. (2011). 'Her world gets smaller and smaller with nothing to look forward to': Dimensions of social inclusion and exclusion among rural dementia care networks. *Online Journal of Rural Nursing & Health Care, 11*(2), 27-42. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip&db=c8h&AN=104277452&site=ehost-live

Guo, Z., Levy, B. R., Hinton, W. L., Weitzman, P. F., & Levkoff, S. E. (2000). The power of labels: Recruiting dementia-affected Chinese American elders and their caregivers. *Journal of Mental Health and Aging*, *6*(1), 103-112.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster Inc.

Hansen, A., Hauge, S., & Bergland, A. (2016). Balancing the use of language to enable care: A qualitative study of oral and written language used in assessments and allocations of community healthcare services for persons with dementia. *BMC Health Services Research, 16*(1), 391. doi:https://dx.doi.org/10.1186/s12913-016-1659-0

Haralambous, B., Dow, B., Tinney, J., Lin, X., Blackberry, I., Rayner, V., Lee, S., Vrantsidis, F., Lautenschlager, N., & LoGiudice, D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers. *Journal of Cross Culture Gerontology,* 26, 69-86.

Harland, J., Bath, P. A., Wainwright, A., & Seymour, J. (2017). Making sense of dementia A phenomenographic study of the information behaviours of people diagnosed with dementia. *Aslib Journal of Information Management, 69*(3), 261-277. doi:10.1108/AJIM-08-2016-0141

Hayes, J., Zimmerman, M.K., & Boylstein, C. (2010). Responding to symptoms of Alzheimer’s disease: Husbands, wives, and the gendered dynamics of recognition and disclosure. *Qualitative health Research, 20,* 1101-1115. doi: 10.1177/1049732310369

Hughes, T., Tyler, K., Danner, D., & Carter, A. (2009). African American caregivers: An exploration of pathways and barriers to a diagnosis of Alzheimer's disease for a family member with dementia. *Dementia, 8,* 95-116. doi: 10.1177/1471301208099048

Innes, A., Abela, S., & Scerri, C. (2011). The organisation of dementia care by families in malta: The experiences of family caregivers. *Dementia (14713012), 10*(2), 165-184. doi:10.1177/1471301211398988

Jung, S. H., & Kim, H. J. (2012). Perceived stigma and quality of life of individuals diagnosed with schizophrenia and receiving psychiatric rehabilitation services: A comparison between the clubhouse model and rehabilitation skills training model in South Korea. *Psychiatric Rehabilitation Journal, 35* (6), 460-465. Doi: 10.1037/h0094589

Lee, S.E., Lee, H. Y., & Diwan, S. (2010). What do Korean American immigrants know about Alzheimer's disease (AD)? The impact of acculturation and exposure to the disease on AD knowledge. *International Journal of Geriatric Psychiatriy,* 25, 66-73. Doi: 10.1002/gps.2299

Leung, K.K., Finlay, J., Silvius, J.L., Koehn, S., McCleary, L., Cohen, C.A.,…Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health and Social Care in the Community, 19*(4), 372-381. doi: 10.1111/j.1365-2524.2010.00982.x

Link, B., Cullen, F., Struening, E., Shrout, P., & Dohrenwend, B. (1989). A Modified Labeling Theory approach to mental disorders: An empirical assessment. American Sociological Review, 54, 400-423.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma, *Annual Reviews of Sociology, 27,*363-385.

Retrieved from http://www.jstor.org/stable/2678626?seq=1#page_scan_tab_contents

Liu, D., Hinton, L., Tran, C., Hinton, D., Barker, J. C., Liu, D., . . . Barker, J. C. (2008). Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology, 23*(3), 283-299. doi:10.1007/s10823-008-9075-5

Lockeridge, S., & Simpson, J. (2012). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia, 12* (5), 635-651. Doi: 10.1177/1471301212440878

McCleary, L., Persaud, M., Hum, S., Pimlott, N. JG., Cohen, C. A., Koehn, S., Dalziel, W B.,…, & Garcia, L. (2012). Pathways to dementia diagnosis among South Asian Canadians, *Dementia 12* (6), 769-789.

Moore, V., & Cahill, S. (2013). Diagnosis and disclosure of dementia-A comparative qualitative study of Irish and Swedish general practitioners. *Aging & Mental Health, 17*(1), 77-84. Doi:10.1080/13607863.2012.692763

Morgan, D.G., Walls-Ingram, S., Cammer, A., O'Connell, M.E., Crossley, M., Bello-Haas,…Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine*, 102, 111-118. Doi: 10.1016/j.socscimed.2013.11.023

Morhardt, D., Pereyra, M., & Iris, M. (2010). Seeking a diagnosis for memory problems: The experiences of caregivers and families in 5 limited English proficiency communities. *Alzheimer Disease & Associated Disorders, 24*(Suppl), S42-8. doi:https://dx.doi.org/10.1097/WAD.0b013e3181f14ad5

Navab, E., Negarandeh, R., Peyrovi, H., & Navab, P. (2013). Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneutic study. *Nursing and Health Science, 15,* 201-206. Doi:10.1111/nhs.12017

O'Sullivan, G., Hocking, C., & Spence, D. (2014). Dementia: The need for attitudinal change, *Dementia, 13*(4), 483-497. Doi: 10.1177/1471301213478241

Oyebode, J. R., Bradley, P., & Allen, J. L. (2013). Relatives' experiences of frontal-variant frontotemporal dementia. *Qualitative Health Research*, *23*(2), 156-166. doi:10.1177/1049732312466294

Phillipson, L., Magee, C. A., Jones, S. C., & Skladzien, E. (2014). Correlates of dementia attitudes in a sample of middle-aged Australian adults. *Australian Journal on Ageing, 33*(3), 158-163. Doi: 10.1111/j.1741-6612.2012.00624.x

Phillipson, L., Magee, C. A., Jones, S. C., Reis, S., & Skaldzien, E. (2015). Dementia attitudes and help-seeking intentions: An investigation of responses to two scenarios of an experience of the early signs of dementia. *Aging & Mental Health, 19*(11), 968-977. Doi: 10.1080/13607863.2014.995588

Rapp, T. (2014). Patients' diagnosis decisions in Alzheimer's disease: The influence of family factors. *Social Science & Medicine, 118,* 9-16. Doi: 10.1016/j.socscimed. 2014.07.052

Richardson, T. J., Lee, S. J., Berg-Weger, M., & Grossberg, G. T. (2013). Caregiver health: Health of caregivers of Alzheimer's and other dementia patients. *Current Psychiatry Report, 15*(367), 1-7. Doi: 10.1007/s11920-013-0367-2

Riley, R., Bergener, S., & Buckwalter, K. C. (2014). Anxiety and stigma in dementia: A treat to aging in place. *Nursing Clinic America, 49*, 213-231. Doi:10.1016/j.cnur.2014.02.008

Robinson, A., Lea, E., Hemmings, L., Vosper, G., McCann, D., Weeding, F., & Rumble, R. (2012). Seeking respite: Issues around the use of day respite care for the carers of people with dementia. *Aging & Society,* 32, 196-218

Rodger, B. L., & Knafl, K. A. (2000). *Concept development in nursing: Foundations, techniques, and applications* (2nd Ed, pp.256). Philadelphia, PA: W.B. Saunders Company,

Roland, K. P., & Chappell, N. L. (2017). Relationship and stage of dementia differences in caregiver perspectives on the meaning of activity. *Dementia (14713012), 16*(2), 178-191. doi:10.1177/1471301215586287

Stevelink, S. A. M., Wu, I. C., Voorend, C. G. N. V., & van Brakel, W. H. (2012). The psychometric assessment of internalized stigma instrument: A systematic review. *Stigma Research and Action, 2* (2), 100-118. Doi: 10. 5463/SRA.vlil.11

Stigma (n. d.). American Heritage Dictionary Retrieved November 2, 2015, from http://www.yourdictionary.com/stigma#americanheritage

Stigma (n. d.). Merriam-Webster Dictionary. Retrieved November 2, 2015, from http://www.merriam-webster.com/dictionary/stigma

Stigma (n. d.) Oxford English Dictionary. Retrieved November 2, 2015, from http://www.oed.com/view/Entry/190242?redirectedFrom=stigma#eid

Stigma (n.d.). Roget's 21st Century Thesaurus, Third Edition. Retrieved from http://thesaurus.com/browse/stigma?s=t

Stigma (n. d.). Wikipedia Free Encyclopedia. Retrieved December 1, 2015, from https://en.wikipedia.org/wiki/Social_stigma

Stokes, L. A, Combos, H., & Stokes, G. (2012). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia, 13* (1), 59-78. Doi: 10.1177/1471301212447157

Sun, F., Gao, X., & Coon, D. W. (2013). Perceived threat of Alzheimer's disease among Chinese American older adults: The role of Alzheimer's disease literacy. *Journal of Gerontology, 70*(2), 245-255. Doi: 10/1093/geronb/gbt095

Sun, F., Mutlu, A., & Coon, D. (2014). Service barriers faced by Chinese American families with a dementia relative: Perspectives from family caregivers and service professionals. *Clinical Gerontologist, 37*(2), 120-138. Doi: 10.1080/07317115.2013.868848

Tremont, G. (2011). Family care giving in dementia. *Medical Health Research,* February, *94*(2), 36-38.

U.S. Department of Health and Human Services (2018). National plan to address Alzheimer's disease: 2018 update. Retrieved from https://aspe.hhs.gov/system/files/pdf/259581/NatPlan2018.pdf on December 19, 2018.

Vickrey, B. G., Strickland, T. L., Fitten, L. J., Adams, G. R., Ortiz, F., & Hays, R. D. (2007). Ethnic variations in dementia caregiving from focus groups. *Journal of Human Behavior* *in the Social Environment, 15*(2), 233-249. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip&db=c8h&AN=105881497&site=ehost-live

Walker, L. O., & Avant, K. C. (2005). *Strategies for theory construction in nursing* (6th ed). Upper Saddle River, New Jersey: Pearson Prentice Hall.

Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qualitative Health Research, 20* (2), 159-169. Doi: 10.1177/1049732309358330

Werner, P., & Heinik, J. (2008). Stigma by association and Alzheimer's disease. *Aging & Mental Health, 12*(1), 92-99. doi:10.1080/13607860701616325

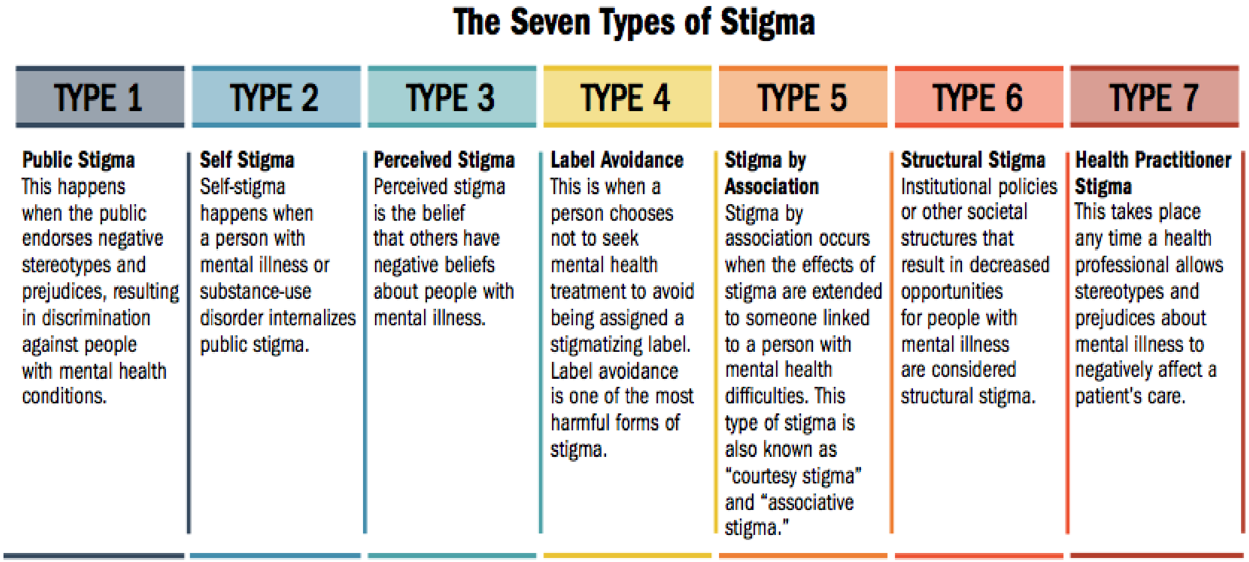
Werner, P., & Hess, A. (2016). Examining courtesy stigma among foreign health care workers caring for persons with Alzheimer's disease: A focus group study. *Home Health Care Services Quarterly, 35*(2), 69-85. doi:10.1080/01621424.2016.1227011

Werner, P., Mittelman, M.S., Goldstein, D., & Heinik, J. (2011). Family stigma and caregiver burden in Alzheimer's disease. *The Gerontologist, 52* (1), 89-97. Doi:10.1093/geront/gnr117

Yang, L. H., Link, B. G., & Phelan, J. C. (2008). Stigma measurement approaches: Conceptual origins and current applications.In J. Arboleda-Florez & N. Sartorius (Eds), *Understanding the stigma of mental illness* (pp.175-192). West Sussex, England: John Wiley & Sons Ltd.

Zhan, L. (2004). Caring for family members with Alzheimer's disease: Perspectives from Chinese American caregivers. *Journal of Gerontological Nursing, 30*(8), 19-29. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&AuthType=ip&db=c8h&AN=106663663&site=ehost-live

Table 1. Types of Stigma

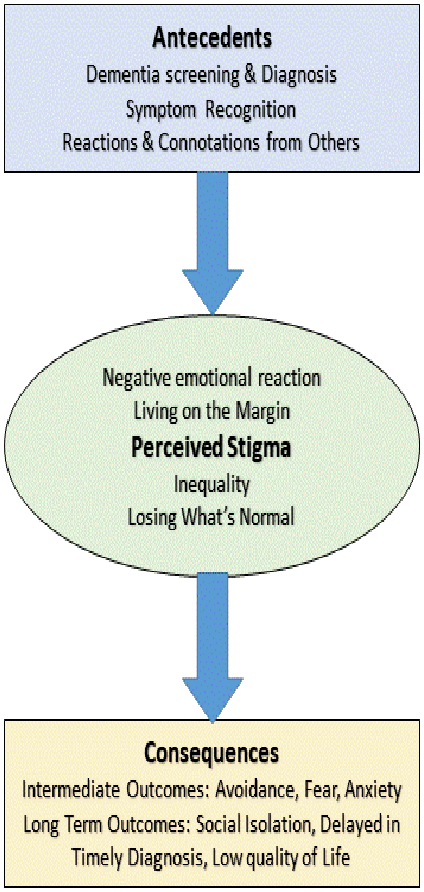


The Seven Types of Stigma

TYPE 1	TYPE 2	TYPE 3	TYPE 4	TYPE 5	TYPE 6	TYPE 7
Public Stigma This happens when the public endorses negative stereotypes and prejudices, resulting in discrimination against people with mental health conditions.	**Self Stigma** Self-stigma happens when a person with mental illness or substance-use disorder internalizes public stigma.	**Perceived Stigma** Perceived stigma is the belief that others have negative beliefs about people with mental illness.	**Label Avoidance** This is when a person chooses not to seek mental health treatment to avoid being assigned a stigmatizing label. Label avoidance is one of the most harmful forms of stigma.	**Stigma by Association** Stigma by association occurs when the effects of stigma are extended to someone linked to a person with mental health difficulties. This type of stigma is also known as “courtesy stigma” and “associative stigma.”	**Structural Stigma** Institutional policies or other societal structures that result in decreased opportunities for people with mental illness are considered structural stigma.	**Health Practitioner Stigma** This takes place any time a health professional allows stereotypes and prejudices about mental illness to negatively affect a patient's care.

Note. Reprinted from National Alliance on Mental Illness Overcome Stigma by Grappone, 2017 Retrieved from https://www.namikenosha.org/uploads/4/9/0/6/49066629/overcoming_stigma.pdf

Figure 1. Conceptual Map



CHAPTER 5

MANUSCRIPT THREE

Perceptions of caregiving and healthcare uses among Korean American family caregivers of older adults: Qualitative descriptive study with thematic analysis

To be submitted to *The Journal of Cross-Cultural Gerontology*

Mihee Chung, PhD (c), RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
mc2by@virginia.edu, 1-508-963-3018
Jeanita Richardson, PhD
University of Virginia, School of Medicine
Po Box 800717, Charlottesville, VA 22903-0782
Jwr4f@virginia.edu, 1-434-924-8784
Jeongok Logan, PhD, RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
jl3zj@virginia.edu, 1-434-924-0082
Cathy Campbell, PhD, RN
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
clc5t@virginia.edu, 1-434-243-6789
Ishan C. Williams, PhD, FGSA
University of Virginia, School of Nursing
Po Box 800782, Charlottesville, VA 22903-0782
icw8t@virginia.edu, 1-434-924-0480

Abstract

Background: As the number of older adult increases, the number of Asian American older adults in the U.S will grow as well. Among older adults, more than 80 percent have an informal caregiver to help maintain their daily lives. In many cultures, family caregivers are the backbone of informal caregiving. This is especially important among Korean American immigrants who may culturally believe that older adults should be kept in their community due to the filial responsibility. These cultural beliefs may also influence their health care choices.

Aims: 1) To explore the perceptions of caregiving and responses to the challenges of the caregiving role, and 2) to describe the perceived factors that contribute to the use of health care services among Korean American caregivers of older adults.

Design Qualitative descriptive study

Methods: Semi-structured interviews were conducted. Thematic analysis was the method used to analyze the data.

Setting/Participants: Korean American family caregivers of older adults, including caregivers of people with dementia, who live in the metro New York and Virginia area were included. Semi-structured interviews were conducted.

Findings: Thirty-three Korean American caregivers were recruited. Most caregivers were female (87.9 %) and adult children (75.8 %). Five themes related to perceptions of caregiving were identified. Cultural influences such as filial piety among the caregivers were prominent. A variability between caregivers of PwD and general older adults were noticed

Conclusion: A better understanding of different ethnic minority groups may improve the development of educational tools and intervention materials to improve the health status of both caregivers and their care recipients.

Key words: caregivers, perceptions, challenges, health services use

Introduction

In the U.S., there were 46.2 million Americans aged 65 and over in 2014, and it will be more than double by 2060 (US Department of Health and Human Services, 2018). Among this fast growing population, more than eighty percent of older adults have at least one or more family or informal caregivers to maintain their activities of daily life (Kasper et al., 2015). As the number of older adults increase, the number of caregivers for them increases as well. Previous studies have shown that family caregivers have more physical and emotional stress from caregiving than non-caregivers, which could negatively affect the state of public health (Grunfeld et al., 2004; Musich et al., 2017; Paekh et al., 2017; Schulz & Beach, 1999). Specifically, according to Musich and colleagues (2017), they reported that approximately 30 % of caregivers experienced negative mental or physical health outcomes. Previous studies have also revealed that family caregivers of older adults underutilize healthcare services compared to non-caregivers, particularly among Asian Americans, including Korean Americans, who are under the influence of their own cultural beliefs (Casado & Lee, 2012; Han et al, 2008; Park et al., 2004). What is less known is why they make these choices.

Caregiving of older adults often involves assisting in the activities of daily living including dressing, feeding, bathing and helping in and out of bed. Family caregivers may have to put in a lot of time and effort to maintain older adults' daily living. They spend an average of

24 hours per week to provide care for their care recipients, and among those family caregivers who reside with their care recipients, they work an average of 40 hours per week (National Alliance for Caregiving and AARP, 2015). Family caregivers who reside with their care recipients may feel more overwhelmed emotionally than those who are living separately, because they are unable to be separate from their care recipients.

Researchers have found that caregivers have higher morbidity and mortality risks than non-caregivers (Musich et al., 2017; Paekh et al., 2017; Schulz & Beach, 1999). They also have a higher prevalence of depression, cardiovascular disease, and diabetes (Bruce et al., 2008; Burgener et al., 2013; Laditka et al., 2012; 1989; Mannion, 2008). Furthermore, Grunfeld and colleagues revealed that caregivers had equal to or greater psychological morbidity than care recipients who were suffering from breast cancer (Grunfeld et al., 2004). Parekh and colleagues showed that 30 percent of caregivers experienced health problems related to caregiving (Parekh et al., 2017). All of these previous studies showed one common feature that caregiving affects one's physical and psychological health. Thus, to maintain caregivers' well-being, more attention should be given to these populations.

One factor that may affect caregivers' well-being is health service utilization. Researches have shown that family caregivers underutilize the formal care resources compared to non-caregivers; they also have a low awareness of available healthcare services (Boots et al., 2015; Casado & Lee, 2012; Musich et al., 2016). Boots and colleagues (2015) found that family caregivers of persons with dementia (PwD) expressed fear of stigma and low levels of acceptance from their community, which hindered them from seeking help (Boots et al., 2015). Burgener and colleagues (2013) support this finding, such that fear of a negative response and social isolation could be a stressor, which may influence caregivers' healthcare utilization that results caregivers' quality of life (Bergener et al., 2015).

This phenomenon—underutilization of healthcare services—is pertinent to a better understanding of caregiving among Korean American older adults (Kwak et al., 2007). Korean Americans are 4th largest sub-group among Asian Americans. Their immigration rate started to grow after the passage of immigration Act in 1965. Among them, 90% of age 65 and over are foreign born, 64% speak little or no English , greater than 20 % have incomes below poverty level, 19% lived alone, and 30% have less than 9 years of education (McBride & Yeo, 2011). These demographic factors may affect Korean American caregivers' health service utilization. Furthermore, Korean American adults have the highest uninsured rate among the subgroups of Asian Americans (The Kaiser Family Foundation, 2008), which may be the reason for their underutilization of healthcare services as well. Additionally, mental health services for older adults with cognitive impairment has also been shown to be underutilized, due to the cultural beliefs around moral duty as adult children in terms of filial piety (Kwak et al., 2007; Lee et al., 2014). Including Kwak and colleagues' study, previous studies have identified the caregivers' attitudes toward healthcare services (represented as familism), filial piety, differences in food, and language barriers as factors important to understanding health care utilization (Han et al., 2008; Kwak et al., 2007; Lee et al., 2014; Park et al., 2004; Youn et al., 2004). Cultural influences described above may have a significant impact on how Korean American caregivers use health care services.

Based on what is known, healthcare providers should acknowledge the negative consequences of caregiving and underutilization of health services among Korean American caregivers and its consequences. Even more importantly, studies regarding healthcare service utilization among Korean American older adults and their family caregivers are scarce (Jang, Kim, & Chiriboga, 2010; Lee, Lee, & Diwan, 2009). Given these factors, Korean American caregivers need to be further examined to better understand how they perceive their roles as a caregiver and what affects their healthcare service utilization for caregivers and care recipients.

The primary purpose of this study is to explore the personal experiences and perceptions of caregiving among Korean Americans who are caring for older adults who are age 65 and older. Based on the literatures, caregiving for older adult is physically, mentally, and financially challenging, which may negatively influence the health status of Korean American caregivers. Exploring the individual's experience and perception of caregiving can expand our knowledge and understanding of what influences health services use and add to the existing evidence of cultural influences on one's caregiving role.

The second purpose of the study is to explore negative and positive responses to the challenges of the caregiving role. Acknowledging the responses to caregiving can help researchers build the foundation to develop an intervention to decrease the negative impact or challenges of caregiving of older adults from Korean American families.

The last purpose is to describe the factors that contribute to Korean American famiy caregivers' use of health services.

Methods

Research Design

The study was conducted using a qualitative descriptive design. The qualitative descriptive design allows for an understanding of the cultural nuances and personal impact of caregiving by adapting a person-centered and holistic perspective (Holloway & Wheeler, 2014).

The qualitative descriptive method is “the method of choice when straight descriptions of phenomena are desired” (Sandelowski, 2000, p. 334). According to Sandelowski (2000), the qualitative descriptive approach facilitates a comprehensive summary of an event in people’s daily lives, which is a good fit to understanding caregivers of older adults. Additionally, the qualitative descriptive approach can stay closer to the data than other qualitative methods. In other words, this approach requires low inference, which results in researchers not putting much of their interpretive opinion on the event they observed or experienced (Sandelowski, 2000).

University Institutional Review Board-Social and Behavioral Sciences (IRB-SBS) approved this study (IRB# 2016-0431-00).

Sampling and Recruitment. Participants were recruited by purposive, non-probability, convenience sampling methods and the snowball technique, from the metro New York area and Virginia where a majority of Korean immigrants reside (Yeo & Gallagher-Thompson, 2006, p 246; Yoon et al., 2016). According to the U.S. Census Bureau, 9% and 4.8% of Korean Americans are living in both metro New York and Virginia, respectively (U.S Census, 2010). They are second and fourth place in population following California, New Jersey, and Texas.

Based on the sample characteristics and suggestions from the literature (Lee & Smith, 2012; Lee & Yim, 2012; Moore & Cahill, 2013; Navab et al., 2013; O’Sullivan et al., 2014; Park et al., 2004; Prorok et al., 2013; Sun, Mutlu, & Coon, 2014), the sample range was set between twenty and forty. Thirty three interviews were conducted and stopped collecting data when the saturation (no more new concepts or repeatedly shown similar concepts) had been reached (Creswell, 2016, p110).

IRB-approved emails were sent to the leaders of organizations, churches, or clinics, such as Korean American Senior Centers or Korean American clinics in targeted areas. Flyers that also indicated the incentive for participating in the study (gift cards with a value of $10) were posted in multiple places.

The author utilized social network sites, such as Kakaotalk, by posting the flyer to promote recruiting. Kakaotalk is a worldwide social network that a majority of Koreans use as a means of communication. However, the recruitment from the social network sites was not productive. People who recognized the postings on social network sites mentioned that there were people who they could refer to participate, but they did not contact further. Therefore, the main recruiting strategy of this study was the snowballing technique (Creswell, 2016, p 109).

Inclusion criteria were 1) age 18 and older, 2) be a caregiver who is caring for family member/relative aged 65 years and over, 3) reside with care recipient or contact with at least twice a week, and 4) be self-identified as a Korean or Korean American. Once the participants were validated, the author set appointments for interviews.

Informed Consent and Participant Information Form. Once participants verbally agreed to participate in the study the author contacted each of them and arranged an appointment to elicit informed consent (Korean or English version). Study participants completed a consent form prior to the collection of any research data, which is needed to confirm confidentiality and participants’ voluntary participation.

At the beginning of the interview session, the Participant Information Form was completed by participants after they had completed the written consent form. The Participant Information Form includes basic demographic information and characteristics of participants such as language, religion, the type of health insurance, income, relationship to the care recipient, the length of caregiving, and the length of living in the U.S.

Interviews. Face-to-face interviews, with a semi-structured interview protocol, were conducted by the author in Korean. The semi-structured interview questions were focused on the experience of caregiving. Furthermore, the interviewer could manipulate the sequence of questions depending on each participant's reaction. Through this, participants could express their thoughts freely within semi-structured interviews, while the researcher could have the freedom to prompt for more information. Thus, this method of data collection satisfied both the researcher and the participants.

The interviews took on average 37 minutes (range15~90minutes), and were audio-recorded. Participants were asked open-ended questions about their experiences as caregivers of older adults. General questions, such as, "Please tell me about your experience taking care of your parents/spouse," and questions that ask for any challenges or experiences during the caregiving period were included. Interview questions were developed by the author and adapted from previous caregiving research studies. The author made notes during and after each interview (See Appendix A). After each interview was completed, the participants received a gift card ($10) as a token of appreciation for participating in the study.

Data Analysis

Thematic Analysis (TA) was used to address the two specific aims because it is a method for "identifying, analyzing, and reporting patterns (themes) within data. It minimally organizes and describes [the] data set in (rich) detail" (Braun & Clarke, 2006, p. 6). Braun and Clarke asserted that TA is the first qualitative method of analysis that researchers should learn. TA is the basis for conducting many other forms of qualitative analysis. One of the benefits to conducting TA is flexibility. With or without the theoretical framework, TA is a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data (Braun & Clarke, 2006). The author analyzed the data using the seven steps of thematic analysis as stated by Braun and Clarke (2006); 1) read and re-read the transcript to become familiar with the data, 2) generate initial codes (in this process, the author conducted open coding), (3), conduct focused coding during the second coding, (4) categorize and search for themes, (5) review themes, (6) define and name themes, and (7) produce the report.

Recorded interviews were transcribed verbatim and analyzed by the author. After analysis, codes and excerpts were translated, as needed, into English. The software Dedoose (Dedoose Version 8.0.35, 2018) was used for storing, coding, sorting, and retrieving data. Dedoose was primarily used for data management.

To add to the rigor of the study, conceptual and methodological verification was done by sharing the coding and categorizing processes with other researchers (IW, JL) or discussing them with a qualitative expert (JR). To ensure rigor and validity, the author confirmed the contents with the informants for member checking and, during the coding process, the author sent the English translated codes and excerpts of the first five interviews to a bilingual researcher to check whether the translations, including the nuance of the meaning of codes, were accurate.

Findings

Thirty-three caregivers were interviewed. Of these participants, 13 were caring for someone with self-reported dementia. Average age of participants was 58 years old and 69% had at least a college degree. Caregivers were mostly female and adult children (87.9, 75.8%

respectively) (See table 1). Five themes were identified from analyzing interview transcripts to answer research questions. The themes were 1) perceptions of caregiving, 2) challenges, 3) strategies to overcome, 4) benefits of caregiving, and 5) healthcare and resources. Each theme has subthemes to define their meanings. There were results, which were prominently different among caregivers of PwD than the caregivers of general older adults. Further explanation is below within each theme.

Perceptions of Caregiving

Perceptions of caregiving among Korean American family caregivers of older adults included four subthemes, which are 1) role in action, 2) self-assurance, 3) paying-back, and 4) reciprocity. The noticeable finding of this section was the different perceptions between caregivers of general older adults and caregivers of PwD. While caregivers of general older adults perceive caregiving as reciprocity, caregivers of PwD perceive caregiving as filial responsibility. This may be explained by the nature of the disease symptoms and progression, and PwDs' dependency on caregivers to maintain their daily living.

Role in action. Most of the family caregivers perceived supporting their care recipient's daily routine and healthcare uses as basic actions in caregiving. Assisting with care recipient's activities of daily living, maintaining a healthy diet and exercise, and assisting with transportation and language when visiting primary care physicians are included. One participant who is caring for a mother with dementia stated, "She cannot do anything…so I have to do everything she cannot even take a shower by herself." Caregivers of general older adults stated that mostly their job is helping parents' activities outside of their home.

> "Well…visiting doctor's office every month, and then…um…like mom's food…like…bad to her, because she's diabetic. Make her stop eating those and tell her to do this and that for the diet…and like that…try to maintain her diet…"

> "What I do is…um…make an appointment...um…call the [doctor's] office and take him [father] to the doctor and translate…such things…and...Um…come with him to the follow ups…well…that's all."

Self-assurance. This is a perception that assures or persuades caregivers themselves for taking on a caregiver role. For example, some caregivers regard serving their parents as being for their own good. One participant, who was caring for a mother with dementia, stated, "Caregiving is fulfilling God's will," and another participant said, "Being a good example to my children." Another participant, who was caring for a mother with dementia, gives meaning to the role, stating, "Not to regret later when I look back in the future." Another participant, who is caregiver of a general older adult, said, "I think…it [taking care of my parent] is like spreading seeds. I just take care of her because she's my mom, but my kids might think the same thing when they watch me doing [caring my mom]." Participants put more meaning towards their own lives rather than for their care recipients'. One participant said, "I think…I think it is like the last time spending together with my mom…so I can deal with all the hardships. [I] just focus on it [caring mom]." Self-assurance can help caregivers to endure difficult situations by encouraging themselves.

Paying-back. Most adult child caregivers think that they are repaying their parents' hard work for them in the past. In other words, they are trying to fulfill their filial responsibility. Many caregivers of PwD reflected on caregiving as an opportunity to repay their parents' hard work for them go give themselves a reason to endure the hardship from caregiving.

> "So...I was not a good son until then…I did not serve my parents as enough as a first son should do...and…to my parents…um…I couldn't make them happy…so I decide to serve them until they leave [die]…."

> "Just…as a daughter in law, I think it is such a natural thing to take care of parents in law. I just want to do really well because this job was given to me. And...Uh…um…I want to support them [parents in law] to live peacefully until they leave [die]."

> "It [caring mom] is nothing compared to what she's done to me."

> "Like I said, I had surgeries seven times when I was little and she took care of me during that time. It must have been tough. Anyway…she did that…ah…maybe it [caregiving] is sort of paying back to her dedication?"

Reciprocity. Different from repaying their parents, caregivers in this sub-theme think of their caregiving role as a part of a continuous reciprocal relationship with their parents. In this subtheme, adult child caregivers perceive caregiving as co-living, reciprocal relation, or blessings to each other. Many adult child caregivers, who are working fulltime, accept help from their parents to maintain their lives in places such as participating in house chores and child care.

> "When we get home after work, it is 7 O'clock. After we get home, I have to give them dinner, and help with the homework, then 10 pm already then again….it's already time to sleep and 7am tomorrow we have to go to work again. Both of us…then mom and dad do all the house chores and take care of children while we are at work."

> "I cannot say the word caregiving. It's rather living together to help each other. Maybe I get more help from them [parent].

> "Mom and I, both of us are blessed people…she should not be ill but being healthy and living with us that is a blessing to us and to her as well…we say this to each other every day."

Challenges

There were four sub-themes of challenges identified, which are 1) cultural gap, 2) emotional challenges, 3) negative attitudes, and 4) feeling cramped. On the one hand, a majority of the caregivers of older adults expressed conflicts with their care recipients. On the other hand, caregivers of PwD did not mention difficulties in their relationships, but were more likely to express their own emotional and physical stresses as challenges during caregiving.

Cultural gaps. Many participants mentioned a cultural gap between generations, and between family members with a different cultural background. Cultural differences between different generations were mentioned by several participants. These were conflicts between people who kept traditional Korean values and people who were acculturated. Language barriers between different generations or races were mentioned as well.

> "My mom and I are not getting along very well because her way of thinking and mine are so different…"

> "Father-in-law must have a culture shock. He must have thought why my daughter-in-law is doing like this… And he gets mad…and I think [his way of thinking is] not fair…those were conflicts we had encountered. I guess in Korean culture, when elderly person gets mad, people [children] cannot say a word and just obey…but I can't…"

One participant stated about her care recipient (mother-in-law)'s traditional Korean value, "my mother-in-law thinks women should be treated like a slave…well….there is old saying ‘woman and dried pollack should be beaten every three days’….seriously….and she thinks men’s anger is mostly because of women’s wrong-doing.” This participant continuously experienced conflict because of the different perspectives on gender roles.

Challenges of cultural gaps not only occur to different generations, but also to different races in a family. One Korean American participant, who is married to a spouse who is White, and takes care of her mother, said, “My husband doesn’t speak Korean, and my mom doesn’t speak English….when my husband complains about my mom and then my mom does about my husband….I cried a lot…”

Emotional challenges. Many participants, mostly caregivers of PwD, expressed emotional challenges due to the prolonged period of caregiving. Hopelessness due to the late stage of disease was one such challenge. One participant who cared for his wife with late stage dementia stated,

> “I think it is better she [wife] is going sooner. Well…people are saying it’s better to be alive even though you are in a bad condition, and I used to think so….I agreed…but…now I think that it is not true if you live like her [terminal stage of dementia]…it’d be better to leave [die] sooner than later.”

Another participant stated, “My mom’s [physical] condition now is all right. That is a problem. I don’t know how long she will live like that [with late stage dementia].” This caregiver was also taking care of someone (his mother) with late stage dementia. Her behavioral symptoms were getting worse but her physical condition was fair, so she could easily escape their apartment and wander around the neighborhood. He felt hopeless and tired, and at the same time, he was worried. He stated, “I am worried… To be honest, I was worried… whenever I see my mother, I felt heavyhearted and worried.” Another participant stated, “For how long do I have to do this [caring for mom]?” She had been taking care of her widowed mother for several years at the time of the interview.

One of the emotional challenge from caregiving was depression. By imagining themselves in their care recipient’s position or just remembering that their social relationship had been destroyed due to the caregiving makes participants depressed. One participant, who was caring for a mother with dementia, stated that she reflected on herself in her mom’s condition and got depressed. She stated, “elderly people stay in their apartment all day long…well…that makes me depressed…because…soon I will be in the same route. And so…problem is….you are not sure what your health will be like…” and stated, “There’s nothing I can do...nothing…”

One participants expressed that she often felt isolated and lonely. She stated, “Where can I go while my husband is ill. I have nowhere to go…and I do not want to spend money…so I just stay home.” Another participant who is caring for PwD stated, “Dementia is the worst disease…it had broken every relationship I had. Until she [my wife] dies…after she’s gone, it is too late because I am too old…too old to rebuild a new relationship with people…it will be useless…it is gonna be time for me to go as well….[die]” Another stated about one’s limited boundary of life due to the caregiving for PwD; “Not really…If there is any [social activities], it is the fact that I cannot leave my mother alone not even for a second…I cannot let her out of my sight…so I cannot go out as freely as before.”

Negative attitudes. This subtheme involves care recipients’ and caregivers’ attitudes toward caregiving roles or healthcare service use. Care recipients’ non-cooperation and stigma regarding disclosure are in this subtheme. One participant who is living with her mother-in-law with dementia/psychosis stated, “Well, now...she extremely has hated to go to see the doctor ever since we found out her symptoms. It has been very difficult to take her to the hospital so we barely made it there." One participant stated that her parents-in-laws do not want to discuss anything regarding dementia, stated,

> "Father [-in-law] also denied his dementia symptoms, but mother [-in-law] just agreed that he had a negligible level of it. Then she seemed to not want me to speak with him about it. Mother [-in-law] told me to just pretend not knowing it"

Another participant who is also a caregiver of PwD, expressed his concern about being criticized by the members of the community. He stated,

> "It is something that I was deeply concerned about. For example, I am a pastor and I have been considering what other caregivers would say about me elsewhere. I know the Korean community is small...And people could criticize me...for not coming to visit my father often as his son... So, these are some of the things that would always be a part of the customs in Korea."

Feeling cramped. Participants were struggling due to a lack of energy, time, and social activities for themselves. Physical, emotional, and social strain can make caregivers feel challenged. Participants, mainly daughters and daughter-in-law, were physically exhausted due to the continuous demands for care. One participant, the daughter of a PwD stated, "Now, regardless of my mother's illness, I feel it's little hard taking care of her when I am tired physically, or when I have a hard time being in control of my life." Other participants expressed the challenges from the overloaded responsibilities in caregiving and working double duties between their ill parents and their own family members.

> "So, I have to take care of both my parents-in-law and my husband (laugh)...I have to make him a lunch box. Besides, I have to go to his working place over lunch time to eat with him because he does not eat when he's alone. As you cas see, it is not easy because I have to look after both."

> "The other people...some people feel sorry not just for my mom, but for me as well. Going to work and doing the house chores during the day and going to her place to sleep at night... some people think that this is tough...But I only do what I can do.... (Laughing)."

Strategies to Overcome

Identified subthemes from strategies to overcome challenges were 1) avoidance, 2) keeping a positive attitude, 3) utilizing manpower, and 4) setting up the boundary.

Avoidance. Caregivers tried to focus on their work or to stay silent to avoid conflict situations. These conflicts can be the caregiver's own feelings of being overwhelmed, conflicts between family members, or accumulating stress from caregiving. Participants who responded in this subtheme expressed that they either avoid or distract themselves from the problem.

> "Stop asking me any more….please ask me no more. Stop making me cry…(laugh)….because I don't want to cry…please don't ask me anything more."

> "I tried to open up some conversation to talk over the difficulty, then it changed into a big argument. So I had to stop."

Keeping a positive attitude. Acceptance and practicing religion were the ways to keep caregivers moving in a positive direction. Accepting reality, (being thankful with or without religion), and having support from family members or friends can encourage caregivers who encounter challenges from caregiving. One participant stated that accepting a parent's diagnosis of dementia is the only way to accept her caregiving role. She said, "In the past, I used to think carelessly that my parents should be healthy, but now, I started to think that I am not different than anyone else. What happens to others can happen to me, too." One participant caring for PwD stated, "There is nothing we can do to heal this disease. It comes together with the memory loss and gets only worse and never ends. Then we have to live with it. What can you do?"

Practicing religion can be a good way of fighting challenges for some caregivers. By participating in religious events or prayers, caregivers try to direct or lead themselves toward a better life.

> "If not, listening to praises, and praying are what I should do. Shouldn't I pray when I am weak? So I pray and feel empowered and then, I sing again. This is how I do."
>
> "As I look back, if someone asks me how I did it [caring for demented mother-in-law], then I will say that it's not me but God. He also gave this hard time…"
>
> "Today I also prayed when I drove around that God removes the stress. …… So when I feel really difficult in focusing on [working], I try to feel comfortable by agreeing that I should surrender to God who has control over all things and it never belongs to me. I think it worked out for me gradually as I trained myself in thinking this way."

Utilizing manpower. Participants stated that asking for help from other family members or friends for caregiving activities and for the caregiver's own social life was very helpful. Caregivers of PwD, especially, stated the importance of support from others such as physical help or emotional support. They stated,

> ”I just get rid of stress by having conversations.”

> “We have shared works. My sister takes care of all the documents and medicines. She also works on keeping the records regarding doctor visits as there are many doctors we need to see. I take care of some doctor visits too, because we have so many doctor’s offices to visit.”

Setting up the boundary. This is a strategy to overcome challenges from a different cultural belief, an emotional despairing due to the prolonged progress of dementia, or a lack of knowledge about dementia symptoms. Participants set a parameter to distinguish worsening symptoms or to change the plan such as considering institutionalization.

> “Well, now I say yes for what I can do and no for what I can’t. My parents [in-laws] might have felt disappointed as I started clearly expressing my opinions. However, I believe they will gradually accept my honest responses and their disappointment gets smaller. So, I feel better.”

> “I recognized that my mother-in-law is sick when she does not organize her surroundings. If she is alright, she would have cared about cleaning and organizing the things around her and also the house stuff.”

Benefits of Caregiving

Identified subthemes of benefits of caregiving are 1) better relationships, 2) handing down of culture, 3) emotional benefits, and 4) self-reflection. This was observed in all participants regardless of the care recipients’ disease type.

Better relationships. Many participants stated that giving care was a good opportunity to learn more about their parents and family members. Although participants started caregiving out of filial responsibility, they became more appreciative of their parents' presence after they spent time with them and learned about them. In addition, throughout the caregiving phase, the bonds between family members increased.

> "Before we lived together, I did not know what's going on with them unless I called or contacted them. And also, likewise, I did not know what happened to them until they told me. Now we live together, so it is very good for me to have the information about them much faster."

> "In a way, I feel grateful that my mother-in-law is sick. We initially argued because of her sickness as we thought differently about it, then you know that arguing does not resolve the issue, so after we argued over and over, we started having conversation on this. Sometimes she even makes a joke of her illness, and things are better."

Handing down of culture. Many participants expressed that the educational aspect was a great benefit. It was related to the self-assurance among the perceptions of caregiving. They were assured that their children are learning from their act of filial piety. They stated that their children showed respect to their grandparents and other older adults, practicing Korean culture naturally.

> "They make sure to greet grandmother whether or not she understands it. Such things are experiential learning methods to my children that their parents have done these things with their grandparents. I take this as an advantage out of them."

> "So things are like this; if I don't do well to my mother even though we live together, my child doesn't do well to me either. He does well to me if I do well to my mother. He learns things from me. That's why it says "parents are the mirror of their child."

Emotional benefits. One of the benefits from caregiving to parents was positive emotional outcomes such as feeling comfortable, secure, and stable. One participant stated, "……it is good to have such opportunity to serve her, and I feel fullness at home as my mom lives together….." Another participant stated, "She is like a home of my heart, and I can come to her right away when I am in a difficult situation. So, I feel secure… and I rely on her unnoticeably." Both expressed the emotional fullness and security by living with their parents.

Self-reflection. Participants were grateful to have a chance to experience aging indirectly and preparing for their own end of life. They continuously reflected on their care recipients' situation and imagine their own futures.

> "So, I feel I am being prepared [for death] as I take care of my mom. Although I help her to be prepared, I also feel, on the other hand, that I am prepared religiously, because I think it is the last moment for my parents although it is difficult….."

> "I also think that I have more chance to think about my old age. It comes to me soon, too…so how should I prepare my old age?"

Health services use and resources

Health services use were influenced by three subthemes including 1) accessibility, 2) availability, and 3) attitudes. Both caregivers of general older adults and PwD expressed similar perceptions in terms of health services use.

Accessibility. Most participants actively use community resources in the metro New York area and in Northern Virginia where Korean providers or Korean adult daycare centers are available.

> "S(he) goes to the adult daycare center and stays there from 8 AM to 1 or 2 PM, then comes back home when we have a homecare attendant until s(he) goes to bed. Now they do all these services and connect me to where I get the answer to my inquiry, so it is very convenient."

However, some caregivers and care recipients could not use available services actively because they did not have insurance. Language barriers also hindered participants from accessing health services.

> "Well...You let me know what to do [without an insurance]… (Laugh)… if we have pain in our feet here, we should go to Korea before it gets worse. So we have a flight ticket valid for any time so that we can go whenever we need to."

> "What was initially inconvenient was that I did not know the language and could not communicate because I do not speak English. There was no interpreter."

> "…… sometimes there is no interpreter at the hospital. The other day… I and my wife had to talk and answer roughly when we had the X-ray exam."

Availability of health services. Health services use were influenced by the residing area, the healthcare provider availability, and the relationship with the primary care physicians (PCP). Participants who reside in metro New York area visit their PCPs regularly and would call PCPs whenever they encounter any health problems. Korean providers are available in this area so the participants can maintain good relationship with their PCPs without any problem. The participant from the metro New York area stated. “Ah…that…hospital…there was a social worker….she’s able to speak Korean…well…I am grateful to that social worker. She stands for my family and protects the patient.” However, participants from Central Virginia expressed that it is not easy to visit health care providers because Korean doctors or healthcare providers are not available near the area. One participant stated, “Things for Koreans [Korean providers or adult daycares]…none in this area…even my kids don’t want to visit often because it is far from the metro area.”

Attitudes. Some negative attitudes towards healthcare providers and services use such as distrust, skepticism or stigma hindered caregivers and care recipient from using health services. Older adults were skeptical of the PCP’s service when they trusted their experience more than their care provider’s expertise. Further, they became more skeptical and distrusting of care providers after they went through assessment and diagnosis with PCPs. These seem to happen more among caregivers of PwD since there are few or no choices offered by the PCPs. In addition, prejudice regarding existing facilities and services influenced caregivers’ healthcare uses as well.

> “She has had asthma for a long time, so she is so knowledgeable about it. She even says to the doctor that she tried this medicine but it didn’t work, then the doctor feels embarrassed, and writes a prescription for different one. It is hard because it seems like she’s not trusting the medical professionals……”
>
> “It’s not gonna work even though you visit the doctor [for dementia symptoms]. I know well that doctors will say same thing over again.”

> "And…I don't go to the dental office covered by the insurance [Medicare] because the quality of care is terrible. I go to the dentist where I pay."

Healthcare resources. Almost every participant mentioned the Internet as a resource to seek health related information. PCP, Korean newspapers, and the Korean radio channel were mentioned as other methods. One participant stated, "So…my father-in-law learns a lot from surfing the Internet on his smartphone. He finds what fits him from there. He is very systematic." Another participant stated, "Internet, Korean Internet site I check because I have searched American websites…but it wasn't helpful. Yah...it was not…well….I tried to give vitamin A and others what the site said, but nothing worked…nothing helped…" This participant decided to search Korean Internet websites to seek information because that's more convenient for her since her first language is Korean.

Discussions

The purpose of this study was to explore the perceptions of caregiving and healthcare uses among Korean American caregivers of older adults and to explore their challenges and strategies to overcome. Study findings reveal and support that cultural beliefs influence and are interrelated to many aspects of caregiving of caregivers of Korean Americans, including perceptions, challenges, strategies, and their healthcare uses (Casado & Lee, 2012). This may lead to nurse clinicians and researchers looking at this population in a more holistic view to build nursing care plans or interventions. They would not simply focus on one challenge that clients or patients bring up to the clinic, but look at the whole picture to see what affects the problem that appears on the surface.

The most prominent perception of caregiving was caregiving as a way of repaying their parents' hard work: filial responsibility. Filial responsibility is one of the principles in Confucianism, which emphasizes the importance of loving and respecting parents (Dai, 1988; Lai, 2010). Many Asian immigrants including Chinese, Korean, and Vietnamese practice this principle to keep their family harmony (Han, Choi, Kim, Lee, & Kim, 2008; Sun, Ong, & Burnette, 2012; Xiao. Habel, & De Bellis, 2015). Even though Americans have a similar concept of filial piety which shows emotional support, substantial aid, and a sense of gratitude towards parents (Dai & Diamond, 1998), Asians' filial piety is differentiated with attributes of the practice such as interdependence, obedience, self-sacrifice and devotion to parents or family values which require more time and energy to keep (Dai & Diamond, 1998). Thus, filial responsibility is involved in caregivers' lives and relationships between family members (Lai, 2010). On the one hand, it has a role in the strategies to overcome challenges of caregiving; caregivers persuade themselves that they are fulfilling their filial responsibilities to stay positive, and regard it as a benefit of caregiving. On the other hand, due to the filial responsibility, caregivers are suffering and enduring emotional and physical strain, because they regard the enduring hardship with sacrifice and devotion is a virtue.

The key finding of this study is the variability of perceptions and challenges among caregivers of general older adults and caregivers of PwD. The differences in perceptions and challenges of caregiving between two groups may be explained by the presence of interaction between caregivers and care recipients. Caregivers of PwD are less likely interactive with their care recipients than caregivers of general older adults. Thus, they perceive caregiving as paying back other than reciprocity. In terms of challenges, emotional and physical strains were more obvious among caregivers of PwD than other caregivers while conflicts due to the cultural gap was expressed by the counterpart. These results are consistent with previous studies. According to a report by Alzheimer's Association (2018), 59% of family caregivers with ADRD reported high emotional stress from caregiving. Further, the physical and emotional impact of dementia caregiving is estimated to have resulted in $11.4 billion in healthcare costs (Alzhimer's Association, 2018).

Korean American caregivers, especially those who are caring for PwD, are more vulnerable to these challenges (emotional and physical strains) because they have pressure from multiple sources, in addition to that of the caregiving of older adults, face saving, and stigma regarding dementia. Many of the participants from this study were living with a "double duty", which means they were taking care of their family members while they were also caring for their ill parents. According to Lee and colleagues (2010), 74 % of Korean American participants have a strong sense of stigma regarding dementia and they regard dementia as a form of insanity. Interestingly, all of the participants in this study used dementia (치매; chi-mae; dementia), the medical term, instead of using the negative connotation of dementia (노망; no-mang; senile craziness) while they were talking about the challenges associated with the caregiving of PwD. This may be due to the level of education of the current sample (70% were college graduates), or it could be that the knowledge of ADRD had increased since the study of Lee and colleagues. Since this study was conducted with caregivers of older adults, including caregivers of PwD, the findings may explain more in terms of the challenges compared to the previous study which was conducted with a general population. Furthermore, Korean Americans have a concept called '체면; face saving', which reinforces the stigmatization. Face saving, in addition to filial responsibility, hinders caregivers from disclosing their family member's illness, especially diseases that can ruin their family name such as mental illnesses and dementia (Lee, Lee, & Diwan, 2010). Previous studies showed that caregivers of early stage dementia patients are less likely to seek help due to a fear of stigma and low acceptance from society (Boots et al., 2015; Sun, Mutlu, & Coon, 2014; Xiao et al., 2015). The results of the current study were in line with those previous studies regarding stigma. Thus, healthcare providers should be aware of the impact of stigma as it deters caregivers from seeking help and results in caregivers' emotional and physical strain.

Current literatures also supports that language barriers are another challenge for caregiving and healthcare utilization. The literature shows that, a language barrier was the biggest issue among ethnic minorities in terms of healthcare utilization (Casado & Lee, 2012; Haralambous et al., 2014; Lee et al., 2014; Lee et al., 2017; Xiao et al., 2015). Casado and Lee (2012) revealed that limited English proficiency was associated with underutilization of healthcare services among older Korean Americans. Caregivers who were more proficient in English were more acculturated to American ways of life and had a greater awareness about formal care. Thus, they were more conscious about care needs than those who were less proficient in English (Casado & Lee, 2012; Lee et al., 2010).

In terms of the strategies used to overcome challenges, Korean American family caregivers of older adults showed various types such as avoidance, utilizing the human power, keeping positive attitudes, and setting up the frame. These are mostly passive ways to decrease physical and emotional distress with the exception of utilizing human power. However, utilizing manpower is mostly limited to inside the family circle due to filial responsibility or face saving. To help caregivers overcome the adverse effects of caregiving, there should be approaches that are more aggressive. For example, caregivers should understand that participating in the caregiving role or getting support from the community is not against their cultural beliefs. Abundant resources should be available to make caregivers feel that it is normal to utilize them when the need arises. Further, health providers should consider more assertive advertisement or education on what is available to decrease caregiver's emotional or physical strains because participants of this study did not mention utilizing formal treatment to ease their own problems. According to Gallagher-Thompson and Coon's study (2007), there are various evidence-based psychological treatments such as depression management, counseling, and support group attendance (Gallagher-Thomson & Coon, 2007). Nurses and other healthcare providers who are working with Korean Americans should be aware of culturally tailored resources, and put more effort in utilizing those resources for their clients. Furthermore, healthcare providers may consider collaborating with Korean community centers, senior centers, adult day cares, and churches to create support groups which are better suited to Korean American caregivers' needs.

Study Limitations and Strengths

The convenience sampling method could be a limitation in that there is a possibility of sampling bias and social desirability bias. Also, findings from a small sample size from the metropolitan New York area and Virginia have limited transferability to the Korean-American population as a whole. Since this study is a cross-sectional study, research results are limited to understand the perceptions of caregiving and health service uses of caregivers of older adults among Korean-American over time. In addition, this study did not analyze by gender, the level of acculturation, and position in a family; thus, a further study to explore differences between each item may produce a different result.

To strengthen the study, a larger sample size is needed and or researchers can include participants from other Asian countries, such as China, Vietnam, or India. Future research should also include different geographical areas within the U.S. to increase the transferability. Adapting a variety of recruitment strategies such as multiple sampling methods (flyers, mailing, media, and provider referral) or consumer-centered approaches (face-to-face solicitation, utilization of community newsletters) will yield better results (Kwon & Kim, 2011).

In spite of the limitations, the sample size of this study is comparably large for a qualitative descriptive design. It is also the first study that explored Korean American family caregivers' perceptions and experiences of caregiving and healthcare service utilization including caregivers of PwD. In addition, the key finding suggested the variability of perceptions of caregiving between caregivers of general older adults and PwD. Thus, this study may contribute to a deeper understanding of caregivers of older adults' experiences and their needs, especially within their cultural context. Further studies comparing both population—caregivers of general older adults and caregivers of PwD to expand this finding is suggested.

Conclusion

Korean American caregivers of older adults including caregivers of PwD perceive caregiving as a filial responsibility as well as a reciprocal reaction to their parents working hard for them. To assist Korean American caregivers in overcoming challenges of caregiving and healthcare services utilization, culturally tailored healthcare services with bilingual staff, language specific information, and collaborated works and programs between the ethnic community and healthcare system should be considered. Furthermore, healthcare providers should be culturally sensitive when they encounter ethnic minority clients for a thorough assessment and intervention once they aware of the differences between caregivers of PwD and others. Lay public education to decrease stigma related to dementia should be considered.

Appendix A.

Table 1. Characteristics of participants

Characteristics	Participants	
	N=33	%
Age (years)		
Range	38-82	
Average	58.2	
Gender		
Male	4	12.1
Female	29	87.9
Education		
< High school	4	12.1
High school graduate	6	18.2
College and up	23	69.7
Religions		
Protestant	31	93.9
Catholic	2	6.1
Relationship to recipient		
Spouse	6	18.2
Children	25	75.8
Other	2	6.0
Identity		
Korean	11	33.3
Korean-American	22	66.7
Period of Caregiving		
< 1 year	0	0.0
1~4 years	11	33.3
>4 years	22	66.7
Care Recipient with Dementia	13	39.3
Caregiver's Insurance		
Medicaid/Medicare	14	42.4
Work/Self-paid	10/5	30.3/15.2
No Insurance	4	12.1
Care Recipient's Insurance		
Medicare/Medicaid	27	81.8
Self-paid	1	3.0
No Insurance	5	15.2

Appendix B.

Semi-structured Interview

(1) How was your life like back in Korea? What are some differences between Korean and America? 한국에서의 생활은 어떠셨나요? 미국에서의 생활과 어떤것들이 달랐습니까?

(2) Please tell me who are you caring for now and what kind of health problem she/he has (if there is any). 당신은 누구를 돌보거나 함께 살고 계시며, 혹시 건강상의 문제가 있다면 어떤 문제들인지 나눠주십시요.

(2)-1 what do you do to manage your family member's health problem. For example, manage the Dr.'s appointment, health care proxy, checking drug administration, checking blood sugar/blood pressure, etc. 어떤 방법으로 건강관리를 돕고 계십니까? 예를 들면 병원방문 예약, 법적인 대리인, 약먹는것 관리, 혈당수치 혹은 혈압체크, 기타등등.

(3) Can you tell me of your typical day with your family member who you are taking care of? 당신이 돌보는 가족분과의 일상에 대해 설명 부탁드립니다. 하루 일과를 나열해주세요.

Perceptions of caregiving 돌봄에 관한 인식--

(4) What does that mean to you taking care of your parent/ spouse/ other members? 간병하는것, 돌보는것이 당신에게는 어떤 의미입니까? 혹은 의미를 부여하십니까?

(5) Please tell me about your experiences in providing care to your family member. 가족을 돌보는 (간병하는) 사람으로서의 경험을 나눠주실 수 있으세요?

Consequences/ Challenges 돌봄으로 인해 생긴 일들 (달라진것들 혹은 힘든것들)

(6) What are some of the challenges you face in taking care of your family member? (Can you tell me what your biggest concern is when you care for the older adults in your family?) 간병하면서 경험한 힘든것들을 나눠주실 수 있으세요? (노인을 돌보는것에서 가장 걱정되는것 혹은 두려운것은 무엇인가요?)

(7) What are some of the positives in this role? 간병함으로 경험한 긍정적인 부분에 대해 나눠주십시요.

(8) What your life was like before? What sorts of things do you do when you have free time? 돌봄 혹은 간병하기 전의 당신의 삶에 대해서 나눠주세요. 간병하지않는 시간에 당신은 무엇을 하십니까?

Dealing with Challenges

(9) How do you handle the challenges that you face when you care for your family member? Please tell me what do you do care for yourself.

(10) If you need help (in reference to caregiving) who do you ask?

(11) If you need help personally who do you ask?

Healthcare utilization 의료시설 이용

(12) Please tell me if you have any health problems. If you have, can you tell me how often you meet doctors or nurses? What influences your decision to seek and use healthcare services? (e.g., language, money, or distance). 건강에 문제가 있으신지요? 있다면, 얼마나 자주 전문의료인 혹은 시설을 이용하시는지 나눠주실 수 있으세요? 어떤 것들이 이 활동을 막거나 촉진한다고 생각하세요? 어떤 것들이 영향을 미치나요? (예를 들면 언어, 금전적인 것, 혹은 거리)

(12)-1 Please tell me if your loved one has health problems, and if yes, tell me how you manage their health problems. For example, make an appointment, transportation, communication with the provider, etc. Please tell me what takes you away from going to the provider? 돌보시는 가족의 건강에 문제가 있나요? 있다면 어떻게 관리를 하세요? 예를 들면 예약, 이동, 의사와의 대화 등등에 대한 이야기를 나눠주시기 바랍니다. 무엇이 가족건강문제를 관리하는것에서 당신을 멀어지게 하나요?

(13) How do you get the information related to your health problem? (prompt: media, other people, books) 당신은 어떤 경로로 질병 혹은 치료에 관한 정보를 찾나요? (예: 소셜 미디아, 다른 사람들, 책)

a. How do you get the information for your loved one's health situation? 당신은 어떤 경로로 돌보는 가족에 관한 정보를 찾나요?

What else you would like to share about your life? 이밖에 다른 당신의 생활에 대해서나 어떤것에 대해서라도 나누실것이 있으시면 나눠주세요.

References

Alzheimer's Association (2018). Alzheimer's disease Facts and Figures. Retrieved from https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf

Boots, L. M. M., Wolfs, C. A. G., Verhey, F. R. J., Kempen, G. I. J. M., & de Vugt, M.,E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: The paradox between needing and accepting help. *International Psychogeriatrics, 27*(6), 927-936. doi:10.1017/S1041610214002804

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. Doi: 10.1191/1478088706qp063oa

Bruce, J. M., Mcquiggan, M., Williams, V., Westervelt, H., & Tremont, G. (2013). Burden among spousal and child caregivers of patients with mild cognitive impairment. *Dementia and Geriatric Cognitive Disorders, 25*, 385-390. doi: 10.1159/000122587

Bull, M. J., Boaz, L., & Sjostedt, J. M. (2014). Public health model identifies recruitment barriers among older adults with delirium and dementia. *Public Health Nursing, 31*(1), 79-87. doi:10.1111/phn.12075

Casado, B. L., Hong, M., & Lee, S. E. (2018). Attitudes toward Alzheimer's care-seeking among Korean Americans: Effects of knowledge, stigma, and subjective norm. *The Gerontologist, 58* (2). E25-e34.

Casado, B. L., & Lee, S. E. (2012). Access barriers to and unmet needs for home- and community-based services among older Korean Americans. *Home Health Care Services Quarterly*, 31, 219-242. Doi: 10. 1080/01621424.2012.703540

Creswell, J. W. (2016). *30 Essential skills for the qualitative researcher.* Thousand Oaks, CA: SAGE Publication, INC.

Dai, Y. (1998). Filial piety. *Journal of Gerontological Nursing, 24* (3), 13-18.

Dai, Y., & Diamond, M. F. (1998). Filial piety: A cross-cultural comparison and its implications for the well-being of older parents. *Journal of Gerontological Nursing, 24* (3), 13-18.

Dedoose Version ***8.0.35*** (2018). Web application for managing, analyzing, and presenting qualitative and mixed method research data. Los Angeles, CA: SocioCultural Research Consultants, LLC www.dedoose.com.

Gallagher-Thomson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging, 22* (1), 37-51. Doi: 10. 1037/0882-7974.22.1.37

Han, H., Choi, Y. J., Kim, M. T., Lee, J. E., & Kim, K. B. (2008). Experiences and challenges of informal caregiving for Korean immigrants. *Journal of Advanced Nursing,63* (5), 517-526. Doi: 10.1111/j.1365-2648.2008.04746.x

Haralambous, B., Dow, B., Tinney, J., Lin, X., Blackberry, I., Rayner, V., Lee, S., Vrantsidis, F., Lautenschlager, N., & LoGiudice, D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers. *Journal of Cross Culture Gerontology,* 26, 69-86.

Holloway, I., & Wheeler, S. (2009). *Qualitative research in nursing and healthcare (3rd Ed).* Chichester, UK: Wiley-Blackwell.

Jang, Y., Kim, G., & Chiriboga, D. (2010). Knowledge of Alzheimer's disease, feeling of shame, and awareness of services among Korean American Elders. *Journal of Aging Health, 22* (4), 419-433. Doi: 10. 1177/0898264309360672

Kasper, J. D., Freedman, V. A., Spillman, B. C., & Wolff, J. L. (2015). The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs, 10* (2015), 1642-1649. Doi: 10. 1377/hlthaff.2015.0536

Kwak, J., & Salmon, J. R. (2007). Attitudes and preferences of orean-American older adults and caregivers on end-of-life care. *Journal of American Geriatrics Society, 55* (1), 1867-1872. Doi: 10. 1111/j. 1532-5415.2007.01394.x

Kwon, Y., & Kim, E. J. (2011). Korean Americans in dementia caregiving research: Inclusive strategies to barriers in recruitment. *Clinical Gerontologist,* 34, 335-352. Doi: 1-. 1080/07317115.2011.572535

Laditka, S.B., Tseng, W., Price, A.E., Ivey, S.L., Friedman, D.B., Liu, R., Wu, B., Logsdon, R. G., & Beard, R.L. (2012). Beliefs about promoting cognitive health among Filipino Americans who care for persons with dementia. *International Journal of Aging and Human Development, 75*, 3, 273-296 doi: http://dx.doi.org/10.2190/AG.75.3.d

Lai, D. W. L. (2010). Filial piety, caregiving appraisal, and caregiving burden. *Research on Aging, 32* (2), 200-223. Doi: 10.1177/0164027509351475

Lee, S. E., & Casado, B. L. (2011). Attitudes toward community services use in dementia care among Korean Americans. *Clinical Gerontologist,* 34, 271-286.

Lee, H. B., Han, H., Huh, B., Kim, K. B., & Kim, M. T. (2014). Mental health service utilization among Korean elders in Korean churches: Preliminary findings from the memory and aging study of Koreans in Maryland (MASK-MD). *Aging & Mental Health, 19* (1), 102-109

Lee, S. E., Lee, H. Y., & Diwan, S. (2009). What do Korean American immigrants know about Alzheimer's disease (AD)? The impact of acculturation and exposure to the disease on AD knowledge. *International Journal of Geriatric Psychiatry, 2010* (25), 66-73. Doi: 10.1002/gps.2299

Lee, J., Nguyen, H., Park, J., Tran, L., Nguyen, T., & Huynh, Y. (2017). Usage of computers and smartphones to develop dementia care education program for Asian American family caregivers. *Healthcare Informatics Research, 23,* (4), 338-342.

Lee, Y., & Smith, L. (2012). Qualitative research on Korean American dementia caregivers' perception of caregiving: Heterogeneity between spouse caregivers and child caregivers. *Journal of Human Behavior in the Social Environment*, 22, 115-129. Doi: 10.1080/10911359.2012.646840

Lee, Y., & Yim, N. (2012). Korean American dementia family caregivers' experience of a psychoeducational support group: Investigation of role of culture. *Social Work with Groups, 36,* 13-26. Doi: 10.1080/01609513.2012.724214

Mannion, E. (2008). Alzheimer's disease: the psychological and physical effects of the caregivers' role. Part1. *Nursing Older People, 20,* 4, 27-32

Moore, V., & Cahill, S. (2013). Diagnosis and disclosure of dementia-A comparative qualitative study of Irish and Swedish general practitioners. *Aging & Mental Health, 17*(1), 77-84. Doi:10.1080/13607863.2012.692763

Musich, S., Wang, S. S., Kraemer, S., Hawkins, K., & Wicker, E. (2017). Caregivers for older adults: Prevalence, characteristics, and health care utilization and expenditures. *Geriatric Nursing, 38* (2017), 9-16. Doi: http://dx.doi.org/10.1016/j.gerinurse.2016.06.017

Navab, E., Negarandeh, R., Peyrovi, H., & Navab, P. (2013). Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneutic study. *Nursing and Health Science, 15,* 201-206. Doi:10.1111/nhs.12017

O'Sullivan, G., Hocking, C., & Spence, D. (2014). Dementia: The need for attitudinal change, *Dementia, 13*(4), 483-497. Doi: 10.1177/1471301213478241

Park, M., Butcher, H. S., & Maas, M. L. (2004). A thematic analysis of Korean family caregivers' experiences in making the decision to place a family member with dementia in a long-term care facility. *Research in Nursing & Health, 27,* 345-356.

Prorok, J. C., Horgan, S., & Seitz, D. P. (2001). Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. *Canadian Medical Association Journal.* 1-12. Doi: 10. 1503 /cmaj.121795

Sandelowski, M. (2000).Whatever happened to qualitative description? *Research in Nursing & Health, 2000* (23), 334-340.

Sandelowski, M. (2004). Using qualitative research. *Qualitative Health Research, 14*(10), 1366-1386.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 2010* (33), 77-84

Schulz, R., Cook, T. B., Beach, S. R., Lingler, J. H., Marire, L. M., Monin, J. K., & Czaja, S. J. (2013). Magnitude and causes of bias among family caregivers rating Alzheimer Disease patients. *American Journal of Geriatric Psychology, 21*, 14-25

Sun, F., Mutlu, A. & Coon, D. (2014). Service barriers faced by Chinese American families with a dementia relative: Perspectives from family caregivers and service professionals. *Clinical Gerontologist,* 37, 120-138.

Sun, F., Ong, R. & Burnette, D. (2012). The influence of ethnicity and culture on dementia caregiving: A review of empirical studies on Chinese Americans. American Journal of *Alzheimer's Disease & Other Dementias, 27* (1), 13-22. Doi: 10.1177/1533317512438224

The Henry J. Kaiser Family Foundation. (2008). Race, ethnicity & health care: Fact sheet. *Asian & Pacific Islander American Health Forum*. Retrieved from https://kaiserfamilyfoundation.files.wordpress.com/2013/01/7745.pdf

The National Alliance for Caregiving (2015). Research report: Caregiving in the U.S. Retrieved from https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf.

U.S. Census Bureau population Division (2013) Annual estimate the resident population retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk

U.S. Census Bureau. (2012). The Asian American Population: 2010. Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf

U.S. Department of Health and Human Services (2018). National plan to address Alzheimer's disease: 2018 update. Retrieved from https://aspe.hhs.gov/system/files/pdf/259581/NatPlan2018.pdf on December 19, 2018.

U.S. Department of Health and Human Services. Informal Caregiving for Older Americans: An Analysis of the 2011 National Study of Caregiving. Washington, DC. Retrieved December 28, 2015 from: https://aspe.hhs.gov/sites/default/files/pdf/77146/NHATS-IC.pdf; 2014

Xiao, L. D., Habel, L., & De Bellis, A. (2015). Perceived challenges in dementia care by Vietnamese family caregivers and care workers in South Australia. *Journal of Cross Cultural Gerontology,* 30, 333-352.

Yeo, G., & Gallagher-Thompson, D. (2006). *Ethnicity and the dementias (2nd Ed.).* New Your, NY: Routledge.

Yoon, H., Chatters, L., Kao, T. A., Saint-Arnault, D., & Northouse, L. (2016). Factors affecting quality of life for Korean American cancer survivors: An integrative review. Oncology Nursing Forum, 43 (3), E132-E142. Doi: 10.1188/16.ONF.E132-E142

Youn, G., Knight, B. G., Jeong, H., & Benton, D. (1999). Differences in familism values and caregiving outcomes among Korean, Korean American, and White American dementia caregivers. *Psychology and Aging, 14* (3), 355-364.

CHAPTER 6

CONCLUSION

Summary of the Research

Even though Korean Americans are a small population in relation to the general population, a comparatively young history with rapidly growing numbers and unique cultural beliefs, may put this group at risk of underutilizing healthcare services, especially among low income adults or where there is a lack of language proficiency. The findings of this study will contribute to the expanding of knowledge on Korean American caregivers of older adults in regards to maintaining their health management and health services utilization.

In chapter one, an introduction of the dissertation was explained. In chapters two, three, and four, manuscript one, two, and three was described, respectively. In this chapter, findings from each manuscript were summarized and implications for clinical practice and research are suggested.

The purpose of manuscript one in chapter two, *factors affecting help-seeking behavior among family caregivers of people with dementia: An integrative literature review*, was to examine the evidence related to help-seeking for caregivers of PwD in order to better understand barriers and facilitators in regards to seeking support services that were found in previous studies conducted in the past 10 years.

This study revealed the importance of caregivers understanding symptoms, treatment, and the progress of ADRD. Normalization was a prominent result from lack of knowledge. Interestingly, normalization exist not only among family caregivers but also healthcare providers. Thus, education regarding ADRD symptoms, available diagnostic tools and treatment options also are important. In addition, cultural beliefs and stigma hinder family caregivers' help-seeking behavior. Especially studies conducted among ethnic minority groups showed the influence of the filial piety and stigma. Fear of rejection from the social circle results in the stigmatization process among family caregivers of PwD.

In chapter three, manuscript two, *perceived stigma in dementia: Concept analysis,* was analyzed in 50 empirical studies. This study was part of a continuum that explores hindering factors. One such factor found from the review of the literature was stigma, however, the definition of stigma, especially perceived stigma in dementia was not clearly defined. Thus, this concept analysis was a necessity.

In this analysis, attributes of perceived stigma were defined; negative emotional reaction, living on the margin, inequality, and losing what's normal. Empirical referents were also determined; humiliation, loss of autonomy, the anticipation of social rejection, and negative social attitude. By defining a clear concept of perceived stigma, clinicians such as nurses and physicians may understand the physical and psychological consequences of stigmatization. Furthermore, researchers can continue to develop instruments that measure perceived stigma, which may help to develop interventions to reduce the negative consequences.

In manuscript three, *perceptions of caregiving and healthcare services use among Korean American caregivers of older adults: Qualitative descriptive study with thematic analysis*, 33 face-to-face interview transcripts were analyzed using thematic analysis to explore perceptions and experiences of the caregiving of older adults among Korean American family caregivers. Six themes were identified; the perceptions of caregiving, challenges of caregiving, strategies to overcome, benefits, healthcare uses and resources of healthcare information. The study included thirteen participants that were family caregivers of PwD.

The remarkable finding from this study was the variability of perceptions and challenges of caregiving between family caregivers of PwD and family caregivers of general older adults. The presence of interaction between caregiver and care recipient may be the reason for this phenomenon. The nature of caregiving among family caregivers of PwD are likely a one-way direction without interaction with their care recipient. Therefore, filial responsibility or paying back was differentiated with reciprocity in which caregivers and care recipients serve each other to maintain their daily lives. In terms of challenges, caregivers of PwD are less likely to experience conflicts from cultural differences with care recipients. Thus, most of their challenges are coming from physical and emotional strains. Nurses and researchers should address different issues when they encounter these two different groups of caregivers.

Language barrier was the prominent challenging factor in utilizing health services among caregivers of Korean American older adults. Since the previous study revealed that about 64% of Korean American immigrants have limited English proficiency, bilingual care providers, language specific information and assessment tools for Korean immigrants should be considered.

Clinical Implications

Nurses and other healthcare providers should acknowledge the difference between caregivers of PwD and caregivers of general older adults with other health problems in order to provide proficient care. Nurses and other healthcare providers should also address how Korean Americans’ perception of caregiving differ from other ethnic groups, so they can provide proper assessment tools and interventions specific to each client. They also should consider stigma as a prominent factor in terms of challenges and should be sensitive in addressing clients’ attitudes towards existing services to reduce the rate of underutilization.

Research Implications

Researchers should be aware of the specific needs of different ethnic groups because different cultural beliefs have a different influence on those who are caring for older adults. Researchers can continue to develop instruments and interventions to assess and reduce perceived stigma as well. They can also develop and apply structured education in different languages as well as culturally tailored versions for each client with different cultural backgrounds. The culturally tailored tools and education may increase the rate of healthcare service utilization among family caregivers of older adults, especially those who are caring for PwD among ethnic minority groups.

Future Researches

The relationship between healthcare service utilization and the level of acculturation is suggested. The level of acculturation influences the decision making process when caregivers of older adults seek help or are in need of healthcare services (McCleary & Blain, 2013). This study was not focused on the differences between genders, so future studies analyzing perceptions, challenges, and strategies as well as health services use is suggested. The association between different levels of education and different perceptions of dementia caregiving was also not explored in this study. Thus, future research including the level of education is suggested.

References

Cornally, N. & McCarthy, G. (2011). Help-seeking behavior: A concept analysis. *International Journal of Nursing Practice*, 17, 280-288. Doi: 10.1111/j. 1440-172x.2011.01936.x

Gellman, M. D., & Turner, J. R. (2013). Health Care Utilization. In Encyclopedia of Behavioral Medicine (pp. 909-910). New York, NY: Springer New York.

McCleary, L., & Blain, J. (2013). Cultural values and family caregiving for persons with dementia. *Indian Journal of Gerontology, 27* (1), 178-201.