

Using Life Course Perspective in Making Health Care Decisions in Later Life Among
Older Korean Immigrants

by

Hyeyoung Park

Nursing
Duke University

Date: _____

Approved:

Cristina C. Hendrix, Supervisor

Sharron L. Docherty

Ruth A. Anderson

Kimberly S. Johnson

Dissertation submitted in partial fulfillment of
the requirements for the degree of Doctor
of Philosophy in Nursing in the Graduate School
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ABSTRACT

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Abstract

As life expectancy continues to increase in the coming years, the promotion of quality of life in older adults, especially at the end of their lives, grows in importance. Thus, many studies have begun to focus on end of life (EOL) care where health care goals are critical to fulfill an individual's wishes and goals. Thoughts and values of older adults are diverse and heterogeneous because of their varied life experiences that contribute to their life perspectives (Peace et al., 2011). Beside individual unique life experiences, older adults who immigrated to the US have gone through significant changes in their lives following the changes of culture, which build and shape a person's beliefs and values. As such, older Korean immigrants in the US hold unique cultural perspectives, including collectivism or filial piety that originated from the influences of Confucius on Korean culture (Kim et al., 2001). These values often dictate how older Korean immigrants perceive their health and lifecycle events, including death. Older adults with multiple chronic conditions (MCC) often experience functional impairment while needing to follow a complex medical treatment plan, thus affecting their capacity for self-care management (Kristensen et al., 2017). While many health care providers frequently encourage early and frequent EOL care discussions with their patients who are at the terminal stage of their illnesses (Lowey et al., 2013), most older adults with MCC feel ill-prepared to discuss their EOL care goals (Etkind et al., 2017). Thus, the

purpose of this dissertation study is to explore health care decision making in later life among older Korean immigrants using life course perspective.

In chapter 2, a scoping review was conducted to synthesize the previous studies on Korean Americans and their EOL care. Korean Americans tend to avoid EOL communication hoping that their families would know about their wishes without discussing with them directly. Korean Americans consider advance directives unnecessary, and only a few Korean Americans use advance directives on the purpose of lessening their family's decisional burden. Many Korean Americans are unaware of what EOL care provides.

In chapter 3, methodological issues in conducting an EOL care study among older Korean immigrants were reported from a descriptive qualitative research that employed a case vignette design. Three semi-structured interviews were conducted and 11 interviews from 4 participants were analyzed using content thematic analysis. Ten themes (research topic, research place, research method, recruitment strategies: age cutoff, document and signature, preferred language, emotional distress, translation, use of case vignettes, and selection bias: positive attitude towards advance directives) were reported and those themes were reported as recruitment phase, data collection phase and data analysis phases.

In chapter 4, a qualitative descriptive study was conducted to explore health care goals and priorities of older Korean immigrants with multiple chronic conditions. Using

Life Course Theory as a guiding framework, the study also described how older Korean immigrants with multiple chronic conditions make decisions about health care goals and priorities. Twenty six interviews from 13 participants were analyzed using content thematic analysis. Seven themes (readiness of goal setting, health care goals, health care priorities, time, location, linked lives, turning point) and 14 subthemes were found.

The findings of this dissertation study provides primary data on how older Korean immigrants establish their health care goals and priorities. Future studies to investigate EOL care goals and priorities of general older adult population using life course approach is recommended. Also, I suggest future study on family dynamics between old children and older immigrants and influence on EOL care. The findings of this dissertation also has clinical implication on EOL care communication using narrative method.

Dedication

This dissertation is dedicated to the memory of Heejung Koh, a strong woman and a loving mom.

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1. Introduction

1.1 End of life care

As advanced technologies and development of various therapeutic methods had emerged in medical environment, life expectancy has dramatically increased (World Health Organization [WHO], 2016). Life sustaining treatment aims to prolong life for those who have irreversible medical condition, and often includes ventilator support, chemotherapy, dialysis, aggressive antibiotics, and artificial nutrition (American Medical Association [AMA], 2016). Accordingly, advanced medicine have focused more on life prolongation rather than symptom management. However, life prolongation results in extending the dying process, thus causing many patients to suffer from pain, incur higher medical costs, and increased burden for both patient and caregiver (Langton et al., 2014; Lee et al., 2015).

Terminal illness is defined as an incurable or unrecoverable ill status that is expected to cause death or permanent unconscious status usually within one year of occurrence (American Cancer Society [ACS], 2016). Since terminal illness is incurable by its definition, shared decision making is significant during this time point to set a goal for medical care considering both patient's own values and possible therapeutic options. To make this shared decision, communication between patient and health care providers is critical. However, when a person has a terminal illness, in most cases, they are already too ill to communicate with health care providers or to make a decision

about their treatment and their end of life (EOL) care. Terminal illness is not a diagnosis of disease, so there is no discrete start point of the status. This makes it difficult for many physicians and other health care providers to initiate EOL discussions. In addition, many physicians have difficulties in initiating EOL care discussion due to lack of knowledge, their own negative attitude, and lack of resources in EOL care (Visser, Deliens, & Houttekier, 2014), thus impeding shared decision making for optimal EOL care.

1.2 Health care decision making

Health care decision making is a complex task that ideally should involve collaboration between patients and health care providers in sharing information and preferences before decisions are made (Charles, Gafni, & Whelan, 1997). Historically, physician-provider relationships embodied the paternalistic approach to decision making where physicians often decided on what and how health care services should be delivered (Falkum & Førde, 2001). While physicians diagnose disease of patients, they set the most ideal treatment plan for the patients based on their knowledge of the disease and patient's health condition. Accordingly, patients play a mostly passive role in health care decision making and defer to their physicians to make the right decisions for them (Elkin, Kim, Casper, Kissane, & Schrag, 2007). However, evidence shows that when physicians lead the care decision making, patients' care preferences are often

misunderstood or misinterpreted (Caocci et al. 2015), and patients are less likely to report that they have received “excellent” quality of care (Kehl et al. 2015).

The shared decision making model is ideal when medical issues are complex and value driven (Friesen-Storms, Bours, van der Weijden, & Beurskens, 2015). In shared decision making, health care providers provide clinical evidence on benefits and risks of expected outcomes and patients provide their preferences and values to make decisions on treatment and care plans (National Learning Consortium [NLC], 2017). When shared decision making is applied, patients show better adherence to their health care plan (Bauer et al. 2014), and physicians are more satisfied with the care that they deliver (Bozic et al. 2013). Shared decision making requires open communication between the patients and providers that is based on a trusting relationship (Shay & Lafata 2014). This trusting relationship is enhanced when health care providers understand and respect the perspectives of patients towards their health care.

Shared decision making is particularly crucial in health care decisions with advanced illness or with dying patients. To formulate goals of care in this stage, individual wishes, goals, plans, and hopes should be valued as much as addressing the patient’s symptoms and health status (Latimer, 1991). With recognition of importance of decision making in health care, health care decision making has been widely studied that mainly focused within the context of decision making. First, decision making in various contexts of care has been studied related to the role of physicians, patients’

autonomy, and the accuracy of surrogate decision making (Bern-klug, 2014; Braun, Naik, & McCullough, 2009; Mo et al, 2011; Thelen, 2005). Health care providers often lead care decision making with their medical knowledge, while patients are the recipients of decisional outcomes. When patients have limited decisional capability, family members take over the patients' responsibility in decision making. The level of involvement among family members in health care decision making has been studied in various health care settings (Feely, Albright, Thorsteinsdottir, Moss, & Swetz, 2014; Martin, Bagdasarov, & Connelly, 2014; Yennurajalingam et al, 2013)

Second, health care decision making has mainly been studied in regards to the preferences of treatment decisions and affecting factor, such as facilitators and barriers on decision making. Particularly, preferences or decisions of health care with advanced illness or end of life (EOL) such as CPR decisions (Delgado-Guay, Chisholm, Williams, & Bruera, 2015), use of hospice care (Ornstein et al, 2016), place of death (Ahearn, Nidh, Kallat, Adenwala, & Varman, 2014), and withdrawal of life sustaining treatments (Ducos et al, 2017) have been examined in EOL care.

Health care decision making was also investigated as a process to understand how physicians and patients make health care decisions (Kim, Kim, Hong, Kang, & An, 2017). However, decision making was described as a phase of decision making process rather than as a cognitive process of decision maker resulting the selection among possible alternatives. Antecedents of decision making such as awareness and acceptance

of declined health status, seeking care options and alternatives and information exchange, then negotiating options and making decisions were suggested as steps of decision making (Bern-Klug, 2014; Birchley et al, 2016; Edwards, Olson, Koop, & Northcott, 2012; Thelen, 2005).

Accordingly, theories and conceptual frameworks used in health care decision making studies explained the context of decision making, communication and negotiation of decision making, characteristics of decision makers, goals of decision making, options and alternatives, and outcomes of decisions (Kim et al, 2017). However, these contextual findings are not sufficient to understand individual decision making process on health care. In complex health care setting where a single best health care options do not exist, it is important to understand how individuals deliberate in making a decision within those contextual factors.

1.3 Framing effect in decision making

Assessing the conditions and problems based on people's own perspectives, such as their values, norms, and habits, is referred to as "framing effect" in behavior economics (Tversky & Kahneman 1981). Framing effect explains the interplay of many factors in decision making such as why a person's values and priorities behave differently in different context, and why people who have similar values make different priorities when faced with a similar situation. For example, quality of life is an important value embraced by older adults when they make health care decisions

(Vandrevala, Hampson, Daly, Arber, & Thomas, 2006). However, each person evaluates their current quality of life differently, and make different health care priorities depending on whether their current quality of life is acceptable or worth to trade with other values such as extension of life (Lim et al. 2017). People have their own values and their own principles of setting priorities. However, when they face certain event that requires a decision, “framing” plays an important role in setting priorities among several goals.

Previous research studies examined the various factors affecting patients’ care preferences and decision making. As the patient gets older, the less they wanted active treatment (Bükki, Unterpaul, Nübling, Jox, & Lorenzl. 2014; Schonberg et al. 2014). Among older hospitalized patients, male patients were more likely to prefer cardiopulmonary resuscitation (Sharma, Jayathissa, & Weatherall, 2016). Patients with higher education preferred more active role such as deciding care options by themselves rather than wanting their family or doctor to make decisions for them (Tricou, Yennu, Ruer, Bruera, & Filbet, 2017). Religious belief and spirituality also influence care decisions: religious values guide decisions regarding preferred care location such as home or religious facilities and highly spiritual individuals appear to have a higher degree of tolerance to discomforts associated with poor health (Kypriotakis, Francis, O’Toole, Towe, & Rose, 2014; McLaughlin, Elahi, Ciesielski, & Pomerantz, 2016). Previous involvement in end of life (EOL) decision making and family structure also

affect care decisions (Clarke et al. 2017). People who had previously witnessed EOL care of their loved ones were more likely to have a living will (Van Scoy, Howrylak, Nguyen, Chen, & Sherman, 2014), and those experiences had a strong influence on their attitude toward advance care planning (Fried, Bullock, Iannone, & O'leary, 2009).

In decision making process, multiple factors including age, gender, education level, religiosity, and personal experiences play different roles depending on the individual context that the patient is facing. Compared with younger population, older adults are more likely to have had experiences in caring for someone. Old age is related to a decline functional and cognitive health status. Family structure and dynamic is also changing as a person ages. Previous studies show that age, previous experiences related to health problems, health status, and family related factors affect health care preferences and decisions. Older adults with MCC frame medical information based on the context created by the interplay of several factors. Therefore, to understand their decision making process, health care providers should understand the interplay of factors (framing) in the patients' decision making.

In addition to age and health status, race and ethnicity are important variables that affect framing. In a study involving trauma patients, African American, Hispanic, and Asian patients preferred to receive less hospice care compared to Caucasian patients (Haines et al. 2018). African Americans have the lowest rate of advance directive completion, less likely to have do not resuscitate (DNR) order and pain management

(Burgio et al., 2016; Kwak & Haley 2005). Hispanics have a low rate of advance directive completion and thought that family should make EOL decisions (Kwak & Haley 2005). Asians also have a negative attitude toward advance directive, and complete advance directives at low rate (Gao, Sun, Ko, Kwak, & Shen, 2015; Kwak & Haley 2005)

1.4 End of life care decision making

1.4.1 Factors on end of life care decision making

To understand end of life (EOL) decision making, it is critical to understand how people make EOL decisions including the affecting factors on EOL care preferences. Previous researches examined the various factors including age, gender, health status, education level, financial status, religion, family structure, and previous experience of significant other's EOL care affecting EOL decisions or attitude toward EOL care.

Older age is related to positive attitude towards hospice care or advance care planning and negative attitude towards life sustaining treatment (Van Scoy et al., 2014; Bükki et al., 2014; Ruff, Jacobs, Fernandez, Bowen, & Gerber, 2011). However, older age can be related to health conditions such as more comorbidities or more EOL care experiences. Previous study showed that patients with completed living will had more comorbidities and are more often admitted to hospital with chronic disease (Van Scoy et al., 2014). In addition, patients with cancer were more likely to have advance directive (Park et al., 2014). While age was consistently identified as a factor associated with decision making in several studies, health condition did not have consistent result. Thus,

further study to investigate the dynamics of age and health condition and how they affect attitude toward EOL care is needed.

Older age is also related to a higher likelihood of experiencing significant other's EOL care. People who had previously experienced EOL decision were more likely to have living will (Van Scoy et al., 2014), and experience with EOL decision making for loved one had a strong influence on attitude toward advance care planning (Fried et al., 2009). In addition, while personal experience of illness was not related to readiness for advance care planning, experiences in EOL care were significantly related to readiness for advance care planning (Amjad, Towle, & Fried, 2014). Therefore, age and the EOL care experience should also be investigated further to explain a person's attitude toward EOL care.

Education level is also a factor that showed consistent findings in previous studies. More educated people tend to have advance directives and have more positive attitude toward hospice care (Cagle, LaMantia, Williams, Pek, & Edwards, 2016; Zheng et al, 2016). Also, higher education level, having prior knowledge of living will and hospice affect the positive attitude toward hospice care (Ruff et al., 2011). In addition, knowledge about EOL care is related to more favorable attitude toward EOL care (Cagle et al., 2016; Johnson, Kuchibhatla, & Tulsky, 2009). Education level could be related to health literacy, thus affecting a person's knowledge about EOL care. For example, one of the most common reason for full code was misunderstanding of do not resuscitate

(DNR) order (Downar et al., 2011). In addition, it has been frequently found that patients preferences for DNR and do not intubate (DNI) often change that what was documented on their medical records may not reflect their actual preferences at a given time. This means that patients probably made decisions without full understanding of DNR and DNI (Jesus et al., 2013) or that preferences can change depending on situational contexts.

Previous studies also showed that more religiously affiliated people are more likely to have health care proxies (Van Scoy et al., 2014). Less religious people preferred to extend life regardless of pain, while higher spiritual well-being people valued the extension of life rather than pain relief (Kypriotakis et al., 2014). Some research showed that religious people were more likely to have negative attitude toward DNR (Jaul, Zabari, & Brodsky, 2014), while other research showed that having religious affiliation was associated with more medical intervention in EOL care (Ruff et al., 2011). This is because each person interprets the situation differently based on their own religious belief (Downar et al., 2011). In some research, religiosity was not significantly related to advance directive completion or DNR order (Karches, Chung, Arora, Meltzer, & Curlin, 2012). So religiosity may not affect advance directive completion or DNR order. Rather, it could affect people in counteractive way, thus resulting in non-significant relationship between religiosity and advance directive completion or DNR order.

Different race/ethnicity group had different attitude toward EOL care. Whites were more likely to prefer advance care planning (ACP) and they regarded ACP as

beneficial and helpful compared to Blacks (Bullock, 2011). African American had the lowest rate of advance directive completion since they often are suspicious of the health care system (Kwak & Haley, 2005). Hispanics had low rate of advance directive completion and thought that family should make EOL decisions (Kwak & Haley, 2005). Asians had also negative attitude toward advance directive (Kwak & Haley, 2005). These differences should be interpreted based on historical and cultural differences. For example, African Americans have negative attitude toward advance directive because historically they have been often mistreated in medical settings, which made them distrust health care providers (Bullock, 2011). Hispanic groups value the family and make family centered decisions. East Asian groups also value the family based on the Confucius idea.

Family is one of the important factors when patients make an EOL decision. Patients who had completed living wills were more likely to be widowed, and patients with more children were more likely to have health care proxy (Van Scoy et al., 2014). In addition, patients were more likely to complete a living will when they were asked from family and friends compared to medical staff (Van Scoy et al., 2014). Chinese older adults did not prefer life sustaining treatment, because they cared about their family's burden (Kwak & Haley, 2005). Therefore, family structure should be interpreted differently among those various racial groups.

1.4.2 Gaps on end of life care decision making research

Even if varied factors have already been identified to influence EOL care decision making, how these factors interplay to guide decision making is different for each individual. When these factors interplay with each other and they could make synergic effects or counter effects. Also, different people have different priorities, which confounds the complexity of the decision making process.

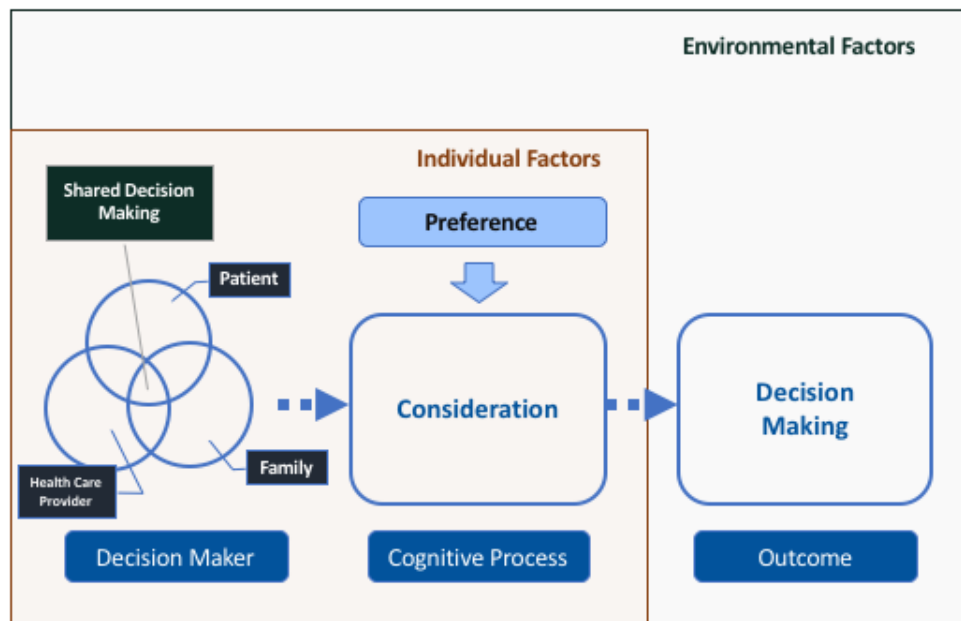


Figure 1: The Process of End of Life Care Decision Making

EOL decision making is a complex process (Figure 1). When a decision should be made for a person's EOL care, the decision maker should be identified first. Based on culture, or even a patient's preference, the physician can become the sole decision-maker. If the patient is too ill to make a decision, shared decision making occurs between only physician and family. After the decision maker is identified, the decision

maker deliberates on those options. During considering options, the interplay of individual factors such as age, gender, or education level and environmental factors such as culture or country occur. Previous preference for care decision plays an important role, but the preference does not necessarily match the decision that they make, because of the situation that they faced. After the deliberation, the decision maker finally makes decisions.

Although the Patient Self-Determination Act encourages to discuss the advance directive on patient's admission, the hospital is not the best place to discuss their wishes regarding EOL decision (La Puma, Orentlicher, & Moss, 1991). When patients are admitted to hospital with acute illness, discussions regarding preference of treatments for terminal illness could make them confused and bring misunderstandings. Therefore, the discussion on EOL care decisions should be done in community setting between older adults and their health care providers.

1.5 End of life care among older Korean immigrants

The population of older adults in the United States is growing, as is their ethnic diversity. The US Census Bureau estimates that, by 2060, older Americans will number about 98.2 million, accounting for nearly 25% of Americans at that time (US Census Bureau, 2015). Moreover, the number of minority group are expected to be more than half of the total population by 2044. To respond to this trend of increasing ethnic

minority group, institute of medicine emphasized on provision of cultural competent care in their 2014 report.

Korean Americans are the fifth largest ethnic group among Asian groups. More than 1.5 million Korean Americans live in the United States and about 14% of these Korean Americans are over 65 years old (US Census Bureau, 2015). More than half of these Korean Americans are immigrants, implying that they hold their original cultural perspectives. Korean immigration generally started in the 1950s and dramatically increased in the 1970s (Zong & Batalova, 2017). Seventeen percent of Korean immigrants are 65 or older, which is a higher percentage than those of the overall immigrant population in the United States (Zong & Batalova, 2017).

Korean people have a collectivistic culture based on Confucianism. This is distinguished from the individualism that most Western countries, including the United States, value. Korean patients' family members frequently "protect" them from the disclosure of distressing medical information, which often results in the hiding of distressing information (Eun, Hong, Bruera, & Kang, 2017). Korean patients, in return, are expected to value family decisions over individual decisions and preferences (Ko & Berkman, 2010). This tendency is more pronounced in older adults, because they accept filial piety, the main idea behind Confucius' teaching that dictates obedience and repayment from children. According to filial piety, children should unconditionally care for their parents with affection and respect for family continuity (Lum et al., 2016). Thus,

to protect older adults, Korean family members rarely discuss end of life (EOL) care with them and sometimes do not disclose when older adults have advanced illness (Berkman & Ko, 2009). In addition, Korean culture regards family members as the final decision makers (Kwak & Salmon, 2007). Therefore, older Korean immigrants who hold Korean cultural values could face challenges when they are treated by the American health care system or health care providers who do not sufficiently understand their cultural background.

Health care providers can provide the best care only if they understand how their cultural background influences older Korean immigrants' EOL care preferences and decision making. In the Korean culture, talking about death or serious illness is taboo based on the Korean proverb that "words uttered become seeds (of consequences)." Some older Korean adults adhere to the traditional collectivistic belief that the opinion of their family or older children is more important than their own wishes (Ko & Berkman, 2010). In addition, older Korean immigrants use EOL care at a low rate despite their positive attitudes toward EOL care (Jang, Chiriboga, Allen, Kwak, & Haley, 2010). Several factors affect older Korean immigrants' EOL care decisions, including their personal characteristics, social determinants, knowledge, and previous experiences (Dobbs, Park, Jang, & Meng, 2015; Jang et al., 2010; Ko & Berkman, 2012; E. Ko & Lee, 2010).

1.6 Research aims

The purpose of this dissertation study is to explore the process of health care decision making in later life. Research population of this dissertation study is older Korean immigrants. Older adults are more likely to have complex health issues related to the multiple chronic conditions and to start to consider their health care decisions with limited life expectancy. Older Korean immigrants has unique life experience, immigration, which is a transition from a country where they are born and raised to a country where they decided to live and spend their rest of lives. Understanding health care decision making of this particular groups will be helpful to understand individual health care decision making, since everyone has their own unique life experiences and their values and wishes guiding health care decisions are shaped by those individual life experiences.

1. The aim of chapter one is to introduce the research problem, significance and the purpose of this dissertation study.
2. The aim of chapter two is to provide a synthesis of literature on what attributes or behaviors do Korean Americans display regarding end of life (EOL) care, what methods have been used to study their behaviors, and what are some cultural aspects of Korean Americans that might be related to their attitude and behavior regarding EOL care.

3. The aim of chapter three is to describe the methodological and practical issues identified from a study that explored EOL care decision making among older Korean US immigrants, and provide suggestions for future study.
4. The aim of chapter four is to investigate the perspectives of older Korean immigrants on their health care goals and priorities using life course approach. Specific aims of this study were to:
 - i. Explore short-term health care goals and priorities among older Korean immigrants with MCC.
 - ii. Describe how older Korean immigrants with multiple chronic conditions set health care goals and priorities using concepts from the Life Course Theory.
5. The aim of chapter five is to provide a summary of the main findings, limitations, and future suggestion of this dissertation study.

2. A Literature Review on End-of-life Care Among Korean Americans

2.1 Introduction

The population of ethnic minority groups has been increasing in the United States to the extent that these groups are expected to make up more than 50% of the country's population by 2044 (Colby & Ortman, 2015). The goals of end-of-life (EOL) care are constructed within each person's values and beliefs, which are guided and shaped by their cultural backgrounds. Thus, EOL care should be understood and conducted particularly within a cultural context, and it is important for health care providers to be culturally competent when understanding those care goals. Cultural competency is the process of responding to people of all cultures and diversity factors by recognizing, affirming, valuing, and preserving their dignity rather than just having cultural awareness, knowledge, and skills (Danso, 2018). Ethnic minority groups have shown disparities in utilizing EOL care, primarily because of their different beliefs and attitudes toward EOL care preference, and EOL care decision making that involves their families (Fang, Sixsmith, Sinclair, & Horst, 2016; LoPresti, Dement, & Gold, 2016; Sanders, Robinson, & Block, 2016). Thus, the importance of providing culturally competent quality care to these 'majority-minority' diverse ethnic groups has increased (Institute of Medicine [IOM], 2015).

Korean Americans are people of Korean heritage or descent, mostly from South Korea, who reside in the United States. The number of Korean Americans has increased

by 40% over the past 10 years, and more than 1.7 million Korean Americans currently live in the US (Hoeffel, Rastogi, Kim, & Hasan, 2012). The population of Korean American in the US is composed of US-born Korean Americans and immigrants, of whom the latter makes up the majority (Noland, 2003). In general, studies have found that the immigration experience negatively influences an individual's health status, self-management, and health care utilization (Park & Bernstein, 2008; Park, Cho, Park, Bernstein, & Shin, 2013; Shin, Han, & Kim, 2007; Sok, 2008). For example, increased stress related to adjusting to a new environment, inadequate access to resources, changed diet, and less social support due to immigration have had a negative effect on Korean Americans' chronic illnesses, quality of life, and perceptions on their aging (Kim, Jang, & Chiriboga, 2012; Lee, Kim, & Han, 2015; Yang et al, 2007). The absence of health insurance, lower socio-economic status, and language barriers are frequent consequences of US migration that impede the use of health care services by Korean immigrants (Jang, 2016; Jang, Yoon, Park, & Chiriboga, 2016; Park et al, 2013).

The immigrant population has combined cultural identities; they preserve their original culture, while acculturating to the host culture (Bito et al., 2007; Jang, Kim, Chiriboga, & King-Kallimanis, 2007). Particularly, Korean Americans tend to keep their identity and intimate links with their home country, even after they have acculturated to their host culture (Lee, Herrera C, Lee, & Nakamura, 2012). This idiosyncratic tendency among Korean Americans could affect their preference and attitude toward EOL care. In

Korea, 87% of people die in hospital (Cohen et al., 2015), where they receive aggressive treatment until the very end of their lives (Baek et al., 2011). Only very recently has the health care system in Korea begun to recognize the value of hospice and palliative care for terminally ill patients. In 2016, Korea enacted the “Life-sustaining Treatment Decision Act”, which promotes the completion of advance directives and the use of hospice care services to guarantee patients’ best interests and respect for their self-determination. Despite this mandate, however, general awareness of EOL care by the Korean population remains low, and many Korean people continue to receive aggressive treatment, even in the presence of a terminal illness (Bae, Gong, Lee, Heo, & Koh, 2010). As such, Korean Americans who have permanently migrated to the US continue to embrace the curative approach to illness and have shown relatively little interest in completing advance directives and in receiving hospice services at the EOL compared to other ethnic groups (Pan, Abraham, Giron, LeMarie, & Pollack, 2015).

Although many research studies have provided detailed characteristics of ethnic groups and how they influence Korean Americans’ decision making with regard to EOL care, no literature review describes idiosyncratic values among Korean Americans toward EOL care. For example, Latino elders have unique cultural values such as family loyalty, belief in faith, and religiosity (Cruz-Oliver, Talamantes, & Sanchez-Reilly, 2014). They prefer family decision making and show low completion of advance directives and low hospice use (Cruz-Oliver et al, 2014). African Americans prefer aggressive treatment

at the EOL and show low hospice use (Wicher & Meeker, 2012). Lack of knowledge and historical mistrust of health care providers have been cited as reasons for this tendency of not using the services associated with EOL care (Wicher & Meeker, 2012). Similarly, Asian Americans prefer life-sustaining treatment in their EOL care (LoPresti et al., 2016) and family-centered EOL care decisions (Cheng et al., 2015). Some researchers have conducted studies on Asian Americans together as a group, since Asian countries, especially East Asian countries, including China, Japan, and Korea, have similar cultural backgrounds. However, when Chinese, Japanese, and Koreans were studied respectively and compared, they demonstrated different levels of need for information about hospice care and exhibited different attitudes toward death and dying (Ivo et al., 2012; Pan et al., 2015).

Thus, this review aims to provide information for comprehensive understandings towards EOL care among Korean Americans. Specific questions for this review are: 1) What attributes or behaviors do Korean Americans have regarding EOL care? 2) What methods have been used to study their behaviors? 3) What are some cultural aspects of Korean Americans that might be related to their attitude and behaviors regarding EOL care?

2.2 Method

A scoping review was conducted to provide a general idea of the cultural aspect of Korean Americans' end of life (EOL) care. EOL care refers to the care given to people

who are near the EOL to control pain and other symptoms so the patient can be as comfortable as possible (National Cancer Institute [NCI], n.d.). EOL care includes palliative care or hospice care, but more broadly, EOL care includes care plan for the EOL such as advance directives or advance care planning. With consultation from a librarian liaison from a nursing school in a large Southeastern University, four databases (CINAHL, PsycINFO, PubMed, and SocINDEX) were selected and searched using a systematic searching method. Medical Subject Headings (MeSH) terms were used in PubMed, MeSH Headings (MH) were used in CINAHL, and Subject Terms (DE) were used for searching in PsycINFO and SocINDEX. In addition, titles and abstracts were searched for key terms (Table 1). The search was limited to articles published within the past 10 years (2007–2017) and written in English. Peer-reviewed articles were selected, and only empirical studies were included for this review.

Overall, four databases yielded 433 articles, 333 of which were reviewed through title and abstract after excluding duplicates ($n = 100$). Three hundred twenty articles were excluded, since those studies targeted health care providers ($n = 5$), were not related to EOL care ($n = 191$), were not empirical study ($n = 12$), and were not related to Korean Americans ($n = 110$). Full-text was not available for 2 dissertation studies. After reviewing the full texts of the remaining articles ($n = 13$), one study was targeted Koreans living in South Korean, and another study was not about EOL care (Figure 2).

A matrix table for included articles was created to compare each study and extract themes across the studies. Data search and extraction were done by me, and another researcher has reviewed the search strategy and the search flow. Assessment of methodological quality of the included studies was not performed since this review is a scoping review to provide an overview of the existing evidence (Peters et al., 2015).

Table 1: Search terms

	Korean Americans	End-of-Life Care
CINAHL (N=689)	(Korea or Korean) AND (America or American or Immigrant or Immigrants or Immigration or Immigrated or United States)	"end of life" or hospice or death or dying or "serious illness" or "advance directive" or "advance directives" or "life-sustaining treatment" or "life support" or "advance care planning" or MH "palliative care"
PsycINFO (N=129)	(Korea or Korean) AND (America or American or Immigrant or Immigrants or Immigration or Immigrated or United States)	"end of life" or hospice or death or dying or "serious illness" or "advance directive" or "advance directives" or "life-sustaining treatment" or "life support" or "advance care planning" or DE "palliative care"
PubMed (N=162)	(Korea[mesh] or Korea[tiab] or Korean[tiab]) AND (America or American or Immigrant or Immigrants or Immigration or Immigrated or United States)	"end of life" or hospice or death or dying or "serious illness" or "advance directive" or "advance directives" or "life-sustaining treatment" or "life support" or advance care planning[mesh] or "advance care planning"[tiab] or palliative care[mesh]
SocINDEX (N=46)	(Korea or Korean) AND (America or American or Immigrant or Immigrants or Immigration or Immigrated or United States)	"end of life" or hospice or death or dying or "serious illness" or "advance directive" or "advance directives" or "life sustaining

treatment” or “life support” or
“advance care planning” or DE “
palliative treatment”

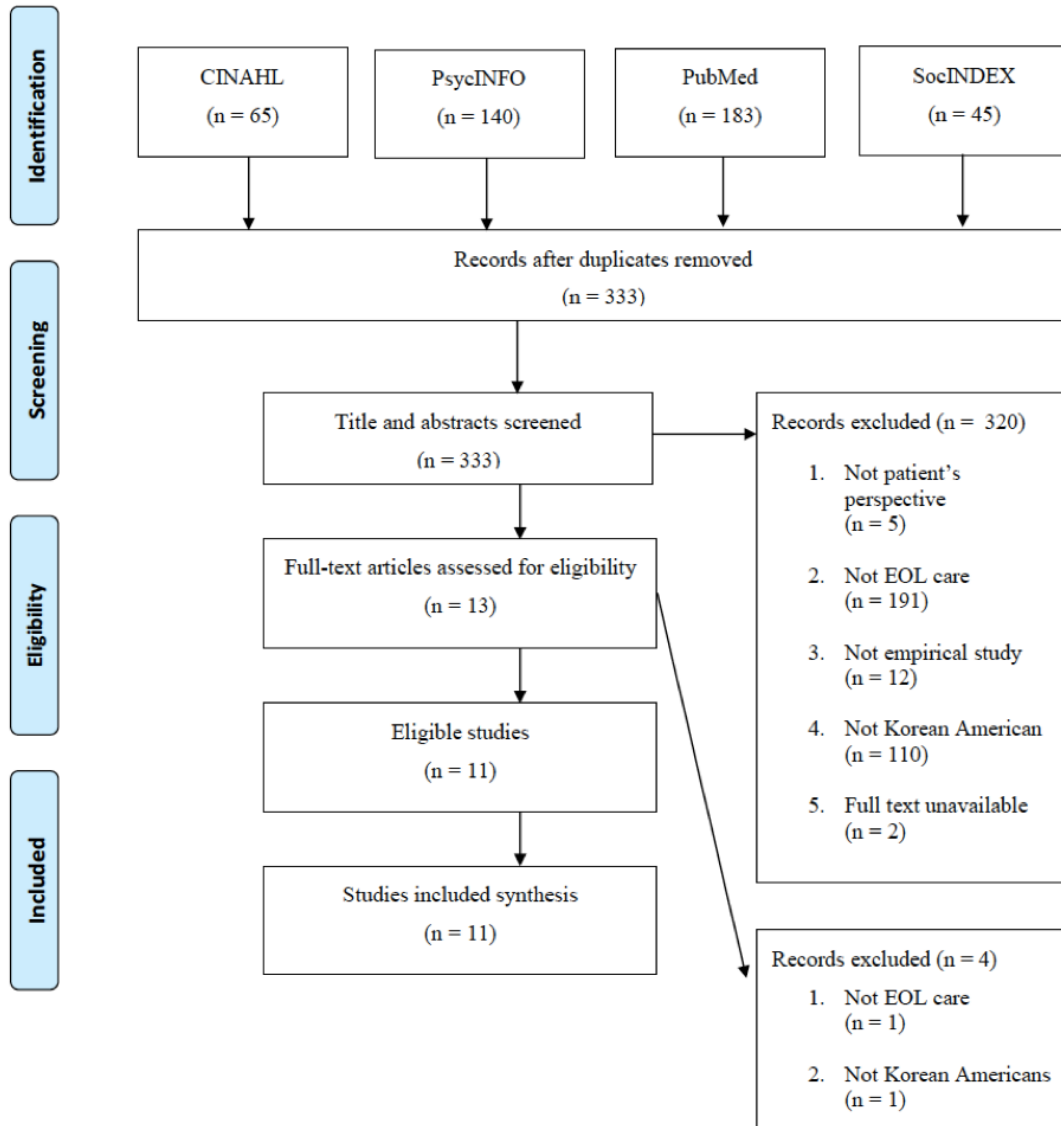


Figure 2: PRISMA Flow Chart

2.3 Results

The 11 studies selected for this review focused on various end of life (EOL) care topics, such as EOL communication, advance directive, the disclosure of serious illness,

treatment choices, and hospice care (Table 2). The authors of seven studies used a quantitative analytic approach such as linear regression model, while the authors of four studies used a qualitative approach such as grounded theory. All 11 studies were cross-sectional. In 10 out of 11 studies, “Korean American” was defined as people who lived in the US and self-identified as Korean for their ethnicity. In one study, “Korean immigrant” was defined as a person who identifies him/herself as a Korean immigrant. Most studies recruited participants from Korean churches or Korean senior centers using convenience sampling. After reviewing 11 studies, we identified five themes: Impact of ethnicity and acculturation; Lack of EOL communication; Preference for disclosure of illness; Role of family in EOL care; and Low level of awareness, knowledge, and utilization of EOL care.

Table 2: Summary of Review

Author	Topic	Design	Sample	Definition of Korean American	Cultural aspect
Kwak and Salmon (2007)	Preference for Advance Directive (AD) and Hospice	Qualitative Focus group	20 older adults 16 care givers	“Self-identified as Korean ethnicity”	Prefer indirect communication Family is ultimate decision maker Filial piety Place of death should be home
Ko and Lee (2009)	EOL care (life-sustaining treatment) and communication	Cross-sectional Descriptive	105 Non-Hispanic White 112 Korean Americans	“Born in Korea and primarily speak Korean”	Not described
Berkman and Ko (2009)	Disclosure preference of serious illness	Qualitative Interview	26 older adults	“Born in Korea or other East Asian country”	Had Korean doctor as their primary health care provider and communicate in Korean
27 Ko and Berkman (2010)	Adult children’s role in EOL care planning	Qualitative Focus group	23 older adults	“Born in Korea or other East Asian country”	Decision maker should be “rational and objective” Elder son (first son) is preferred decision maker Filial piety / compromise
Berkman and Ko (2010)	Disclosure of diagnosis and prognosis	Qualitative Focus group	23 older adults	“Not born in the US, primarily Korean speaking”	Conditional disclosure: agree to disclosure but physicians should give “hope” Belief that giving up will hasten death
Jang et al. (2010)	Willingness to use hospice	Cross-sectional Descriptive	678 Korean American adults (aged 60 and older)	Not specified	Acculturation was a predictor for willingness to use hospice

Author	Topic	Design	Sample	Definition of Korean American	Cultural aspect
Ko and Lee (2010)	Completion of Advance Directive (AD)	Cross-sectional Descriptive	105 Non-Hispanic White 112 Korean Americans	“Born in Korea and primary language is Korean”	Low advance directive completion rate. Among participants who had advance directive, most of them had health care proxy only. Health belief (perceived susceptibility, severity, benefits, and barriers) mediate the ethnicity effect on AD completion.
Kim and Foreman (2011)	Adult children’s beliefs about their parents’ EOL care	Cross-sectional Descriptive	115 Korean American adult children	Not specified	Believed that their parents would want a moderately high level of life-supporting treatment in a situation with no chance of improvement
Ko and Berkman (2012)	AD (Knowledge, attitudes, and behavior)	Mixed method Focus group	23 older adults	“Self-identified as Korean”	Low knowledge regarding AD Wide range of attitude toward AD None of them completed AD (contrary to focusing on living)
Ko et al. (2013b)	Preference for engagement in EOL communication	Cross-sectional Descriptive	195 older adults	“Self-identified Korean immigrants”	Few older adults engaged in EOL communication A greater number of children in the US were less likely to engage in EOL communication; family burden
Dobbs et al. (2015)	Awareness and completion of AD	Cross-sectional Descriptive	675 older adults	Not specified	Low awareness and low completion of AD Acculturation

2.3.1 Impact of ethnicity and acculturation

The studies found that ethnicity and acculturation levels were related to end of life (EOL) care preferences (Jang et al., 2010; Ko & Lee, 2009; Ko & Lee, 2010; Ko, Roh, & Higgins, 2013). Ethnicity was associated not only with the participants' level of knowledge about advance care planning (Ko & Lee, 2009) but also with the completion of their advance directives (Ko & Lee, 2010). The role of participants' ethnicity on the completion of advance directive was mediated by a positive perception of advance directive (Ko & Lee, 2010). Acculturation was defined as a process to adapt to a new cultural environment, which is the US culture (Kim & Foreman, 2011). Acculturation was measured by three domains; values, social relationships, and adhere to traditions; Higher score indicated a greater level of acculturation to the US culture (Kim & Foreman, 2011). When older Korean Americans were more acculturated to the US culture, they were more willing to use hospice care (Jang et al., 2010), more likely to know about advance directive, and more likely to complete advance directive (Ko et al., 2013b). For younger Korean American adults, the greater level of acculturation to the US was associated with a more positive attitude toward advance care planning. Additionally, when asked to speculate what their parents would prefer in EOL care, many young Korean Americans tended to believe that their parents would decline life-sustaining treatment when faced with a terminal condition (Kim & Foreman, 2011). This

preconceived notion of no treatment is particularly relevant in this culture since many older Koreans rely on their children to make EOL care decision on their behalf.

2.3.2 Lack of end of life communication

The lack of end of life (EOL) communication was one of the most common themes found in EOL care research among Korean Americans (Berkman & Ko, 2009; Ko & Berkman, 2010; Ko & Lee, 2009; Ko et al., 2013b; Kwak & Salmon, 2007). Factors that hindered EOL communication included the low frequency of discussing EOL care with family or health care providers (Ko & Lee, 2009; Ko et al., 2013b) and the discomfort of talking about EOL issues among Korean Americans (Ko & Berkman, 2010; Kwak & Salmon, 2007). Older Korean Americans rarely talked about their EOL treatment preferences, and even if they did, they usually talked to their family (Ko & Lee, 2009; Ko et al., 2013b). Korean American adult children, as well as older adults, were uncomfortable talking about EOL issues (Ko & Berkman, 2010; Kwak & Salmon, 2007). Older Korean Americans expected their children to know about their wishes without direct communication (Kwak & Salmon, 2007). Even if some older Korean Americans had a positive attitude towards talking and getting information about EOL care, they did not recognize the need for early discussion (Berkman & Ko, 2009). Adult children of older Korean Americans were also reluctant to discuss EOL treatment preferences with their parents (Ko & Berkman, 2010) because of the emotional difficulty imagining their parents' death (Ko & Berkman, 2010), the superstitious belief that what they speak will

happen (Kwak & Salmon, 2007), and their concern that discussing EOL treatment on their parents' behalf is a sign of disrespect (Kwak & Salmon, 2007).

2.3.3 Preference of disclosure of illness

While most Korean Americans preferred to have information about their illnesses, they had various opinions regarding when and how to disclose serious illnesses (Berkman & Ko, 2009; Berkman & Ko, 2010). In a focus group interview study, some preferred to know about their serious illness, while others wanted to die without knowing about their illness (Berkman & Ko, 2010). If information about their serious illness was offered to them, older Korean Americans preferred information delivered in a way that would not eliminate any hope of living or preferred that the information would be conveyed in such a way that it would "protect" their feelings and not distress them (Berkman & Ko, 2010).

2.3.4 Role of the family in end of life care

Only a few older Korean Americans believed that advance directive should be completed to alleviate the burden of decision making among family members in end of life (EOL) care (Kwak & Salmon, 2007). Rather, the majority of older Korean Americans would rely on their family to decide on their behalf in issues involving EOL care. For this reason, older Korean Americans believed that their diagnosis and medical status should be fully disclosed to their family members (Berkman & Ko, 2010). In many instances, family members were regarded as final decision makers in EOL care (Kwak &

Salmon, 2007). The perception that the family is the final decision maker attenuated the need to prepare for advance directive because older Korean Americans trust that their family would decide what is best for them (Ko & Berkman, 2010). Older Korean Americans believed family members would make the final decisions, regardless of the contents written in advance directive, because of the collectivistic nature of the Korean culture (Ko & Berkman, 2012). In addition, older Korean Americans stated that their children should not be required to follow their wishes as stated in their advance directive because their children were the ones who would carry the burden resulting from the consequences of those EOL decisions for their rest of their lives (Ko & Berkman, 2010).

2.3.5 Low levels of awareness, knowledge, and utilization

Overall, older Korean Americans showed low levels of awareness, knowledge, and the use of end of life (EOL) care (Jang et al., 2010; Ko & Lee, 2010; Ko et al., 2013b; Kwak & Salmon, 2007). Most older Korean Americans were not aware of EOL care, such as advance directive, advance care planning, or hospice. This lower level of awareness may explain why the completion rate of advance directive has been reported to be between 0% and 50% only (Dobbs et al., 2015; Ko & Berkman, 2010; Ko & Lee, 2010; Ko et al., 2013b). Completion of advance directive was related to their age, education, income, experiences of illness, social support, health status, insurance status, and acculturation level. Many Korean Americans misunderstood the EOL care. For example,

they thought that hospice care only provides basic care or EOL care decision is irreversible once it is made (Kwak & Salmon, 2007). For those who were aware of and understood the services offered by hospice care, the majority reported that they were willing to use hospice care (Jang et al., 2010).

2.4 Discussion

In most of the literature, Korean Americans were defined as people who live in the US but “were born in Korea.” However, according to that definition, Korean immigrants would be a more appropriate term to differentiate Korean Americans who were born and raised in the US from those who immigrated to the US. Older Korean Americans residing in the US are most likely to have been born in Korea. In the US, Korean immigration history is relatively short with the number of Korean immigrants significantly increasing only in the 1950s (Yoon, Pan, & Lubkemann, 2012). In describing older Korean Americans who immigrated to the US, many studies that used Korean Americans and Korean immigrants might have been referring to the same population. But, as Korean Americans who were born in the US become older adults, the terms Korean Americans and Korean immigrants should be differentiated to clarify the composition of the group.

The effects of ethnicity on Korean Americans’ attitude, knowledge, and preferences for end of life (EOL) care were consistent with previous research on other ethnic groups. For example, African Americans and Hispanics had a tendency to prefer

aggressive care while Whites did not (Abdollah et al., 2015; Choi et al., 2015). Asian Americans completed advance directive or enrolled in a hospice service at a low rate (Jang et al., 2016.; Ngo-Metzger, Phillips, & McCarthy, 2008). These different preferences for EOL care based on the ethnicity were derived from the different cultural backgrounds of different ethnic groups. Acculturated Korean Americans had a more positive attitude toward EOL care than less acculturated Korean Americans (Kim & Foreman, 2011). A previous study on Chinese Americans showed similar findings, that more acculturated Chinese Americans were more aware of advance directive (Gao et al., 2015). The effect of ethnicity on EOL care among Korean Americans supports the need to provide culturally competent care and to consider individual acculturation levels among Korean Americans.

The reluctance of discussing EOL care among Korean Americans was consistent with the research findings from the other ethnic groups (Egbert, Child, Lin, Savery, & Bosley, 2017). More than half of Korean Americans have not discussed EOL care with anyone, including family members (Ko & Berkman, 2010; Ko et al, 2013b; Kwak & Salmon, 2007). This finding seems to be related to the discomfort reported by older adults and their adult children when talking about death and dying (Ko & Berkman, 2010; Ko & Lee, 2009). The reluctance to discuss EOL was supported by the survey conducted in Korea, which results that 44.1% Koreans did not talk about death to anyone (Ministry of Health & Welfare, 2011). However, family members were expected

to know older Korean Americans' wishes and to serve as final decision makers, even if there had not been any EOL discussions (Kwak & Salmon, 2007). Previous studies of Koreans showed discrepancies regarding EOL care wishes between EOL care recipients and their family members (Shin et al., 2015). Therefore, family members could contradict older Korean Americans' wishes in the event they have not discussed their EOL care preferences. EOL care communication between patients and families is important because it allows patients to express their wishes.

Similar to other ethnic groups such as African American, Hispanics, and Chinese, most Korean Americans preferred to be informed about their health status (Ahalt et al., 2012), despite different views about the preferences of disclosing a poor prognosis or serious illness to the patients (Harding et al., 2013; Tang et al., 2017). Accordingly, studies on the disclosure of terminal illness have focused more on how to disclose, rather than whether to disclose this information (Magro et al., 2016). One finding indicated that older Korean adults preferred to be informed about their medical condition, even if their prognosis was poor (Ko, Nelson-Becker, Park, & Shin, 2013a). However, compared to the patients, fewer family members thought the patients needed to be informed (Yun et al., 2004). This attitude may reflect the desire to protect the patients, a finding that holds true for other ethnic minority groups such as Hispanic and Russian Americans as well (Larkin & Searight, 2014). Patients and family members

should discuss disclosure preference, and health care providers should know this preference in advance.

Previous studies of different ethnic groups and cultures have concluded that family plays an important role in delivering EOL care. Korean and Mexican family members tend to decide on EOL care for patients (Larkin & Searight, 2014). Research on EOL care conducted among East Asian ethnic groups, such as Chinese, Taiwanese, or Japanese, demonstrates filial piety, a Confucian value that emphasizes that children have a duty to care for their parents unconditionally with affection and respect for family continuity (Cheng et al., 2015; Lum et al., 2016). Korean Americans also stated that filial piety guided their EOL care decisions (Kwak & Salmon, 2007). Older Korean American adults, in particular, regarded family opinion as more important than their own wishes (Ko & Berkman, 2010). Because of this point of view, older Korean Americans doubted the usefulness of implementing advance directive (Ko & Berkman, 2010; Ko & Berkman, 2012). This could be one reason why Korean Americans completed advance directive at a low rate. However, older Korean Americans also found advance directive useful to guide their adult children who would make EOL care decisions for their parents (Ko & Berkman, 2012; Kwak & Salmon, 2007). Thus, if a family demonstrated understanding about the benefits of delivering adequate EOL care, older Korean Americans would be more accepting of EOL care, in view of their family centered culture.

Ethnic minority groups generally utilize EOL care less than the people in mainstream culture (Fang et al., 2016; LoPresti et al., 2016; Sanders et al., 2016), a tendency that is consistent among Korean Americans. Engagement in EOL care, such as enrolling in hospice or completing advance directive was related to the lower awareness and knowledge of EOL care (Jang et al., 2010; Ko & Berkman, 2012). In contrast, when EOL care was explained, Korean Americans had a positive attitude toward EOL care such as planning advance directive (Ko & Berkman, 2012). Korean Americans have generally formed Korean communities in the US and have supported each other. Since the majority of these Korean Americans are unfamiliar with EOL care, they may not seek or accept it. Therefore, Korean Americans need to be educated on the benefits of EOL care at the community level.

EOL care in the United States has evolved to emphasize individualism and autonomy, which are important philosophical tenets in the Western culture. Many health care regulations in the US are set up to protect patient confidentiality and privacy. However, in EOL care, individuals may be cognitively compromised to the point that individual decision-making is not possible. Therefore, the role that family and friends play in EOL care cannot be ignored in EOL care. This is especially true in individuals of non-Western descent such as Korean Americans who believe in the concepts of collectivism and harmony (i.e., Confucianism). Thus, a clear need for the US

health care system is to have mechanisms and processes in place that consider culturally relevant information essential for the delivery of patient-centric care.

Confucianism particularly influences and directs social norms among Korean Americans. Thus, understanding the Confucianism may assist in how to properly and sensitively interact with this ethnic group about difficult issues such as EOL care. However, Confucianism alone cannot predict how an individual may react and therefore cannot provide a “cookbook” formula on how to approach Korean Americans in distressing situations. Rather, cultural awareness is meant to provide health care providers a different way of perceiving things that would assist in understanding a person as a whole being. Thus, providing culturally competent care is not providing standardized care to all Korean Americans, but is providing a holistic care to them with the understanding of Korean culture, which is just one dimension of that person.

2.5 Implication

Some research gaps in previous studies need to be explored. First, communication gaps between health care providers and patients should be studied in greater depth. Physicians reported challenges in communicating with ethnic minorities (Periyakoil, Neri, & Kraemer, 2015). Because Korean Americans lack confidence in their English proficiency (Yoon et al., 2012), Juckett & Unger recommended choosing a translator outside of the family. However, in reality, adult children born or raised in the US generally translated for their parents (2014). End of life (EOL) care communication

with health care providers is critical to identify EOL care goals, so it is very important for patients and health care providers to understand and trust each other. Therefore, EOL care communication between Korean Americans and their health care providers should be explored further, focusing particularly on the quality of communication and challenges from both the patients' and health care providers' perspective.

Second, more research is needed on implementing EOL care. EOL care includes various types of care to help terminally ill patients physically, psychologically, and spiritually. However, previous research on Korean Americans has only discussed attitude, knowledge, and the use of advance care planning and hospice enrollment. Cultural background affects a patient's preference on specific treatments or procedures. For example, when Koreans choose EOL care, the likelihood of invasive procedures becomes an important consideration in deciding whether to get treatment or not. Because of the cultural belief based on the Confucian idea that the body comes from the parents, many Koreans believe the body should not be "harmed" as part of filial piety. Some Koreans have accepted the use of endotracheal tubes for ventilator care, but refused to have a tracheostomy. Furthermore, some Koreans prefer a nasogastric tube to a percutaneous gastric tube, despite a higher risk of infection. Without an understanding of this cultural context, these different preferences might be considered inconsistent.

Third, research comparing knowledge across minority groups is needed. Knowledge about EOL care or the behavior of Korean Americans has been compared to

that of non-Hispanic Whites in the US (Ko & Lee, 2009; Ko & Lee, 2010). Thus, research findings across ethnic minority groups have been similar: lower levels of knowledge, acceptance, and use of EOL care. These findings, however, only highlight the impact of being a member of an ethnic minority on EOL care, rather than highlighting different cultural backgrounds. Therefore, exploring difference among diverse ethnic groups would help us to understand aspects of each ethnic group's unique attitude toward EOL care and its use.

2.6 Conclusion and limitation

Most of the themes that emerged in this literature review of end of life (EOL) care of Korean Americans were consistent with previous studies targeting other ethnic minority groups in the US (Cruz-Oliver et al., 2014; Fang et al., 2016; LoPresti et al., 2016; Sanders et al., 2016). Korean Americans expect their family members to lead the discussion regarding EOL care on their behalf, want to know about their illness, but only a few Korean Americans use or plan to use EOL care.

The findings of this review should be cautiously interpreted because of the limitations. First, 7 out of 11 reviewed studies were conducted by one author (Ko). Because of this, this synthesis of research findings could have confirmation bias. Thus, more diverse perspectives on research about EOL care among Korean Americans are needed. Second, all of the qualitative studies were conducted using focus group interview method. Focus group interview can facilitate the discussion on a certain topic.

However, when the topic could be influenced by the subjective norm, focus group interview method have a risk of failing in obtaining individual perspectives. Lastly, the existing literature on EOL care among Korean Americans focused on older adults and immigrants, thus the knowledge of the second generation Korean Americans on EOL care is limited.

3. Methodological Issues in Conducting an End of Life Care Study Among Older Korean Immigrants

3.1 Introduction

With an increasing number of different ethnicities in the United States (US), research encompassing minority ethnic groups has steadily risen with the goal of developing culturally appropriate health care interventions for these populations (Smedley, Stith, & Nelson, 2002; Verhagen, Steunenbergh, de Wit, & Ros, 2014). In conducting studies, researchers should consider the influence of culture when designing study methods and interpreting the findings. The literature has shown that research methods and outcomes can be affected by cultural differences in participants. These cultural differences can impact not only a participant's attitude toward the research topic but also their attitude toward confidentiality, their preference in communication style and setting, and their desired reimbursement (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2006). Furthermore, some populations may require the implementation of multiple recruitment strategies because the target population may be difficult to approach. Several studies have required increased flexibility in recruitment strategies for ethnic minority populations due to the recruitment for these studies taking longer than expected (Im & Chee, 2005; Northridge et al., 2017). In addition, sensitive topics that are not openly discussed or are taboo in certain cultures require extra consideration when building rapport, recruiting participants, and collecting data (Yu, 2009). Thus, researchers should consider these cultural effects in each phase of their

research when designing a prospective study in order to conduct effective and successful investigations of sensitive topics.

In particular, extra care must be taken when conducting end-of-life research. Traditionally, end-of-life research has been treated with extra caution since the patients involved are typically physically and psychologically vulnerable. Even without a terminal illness status, talking about one's health care at the end of their lives or their potential death could cause distress to the subjects, depending on their cultural and personal beliefs. Different cultures have different perspectives on death and dying, which influence an individual's attitude toward end-of-life care. Though Chinese women living in England perceived death as a normal process of life (Fang, Malcoe, Sixsmith, Wong, & Callender, 2015), talking about death was considered as taboo among Chinese nursing home staff members (Ho et al., 2016). One study found that Maori-Pacific people were more open to talking about death and prognosis in comparison with Chinese people (Bellamy & Gott, 2013). Another study showed that older adults with Asian-Pacific heritage reported discomfort in talking about death (Ohr, Jeong, & Saul, 2017). In addition, Asian Indians reported that their culture is more accepting towards death than the American culture (Sharma, Khosla, Tulskey, & Carrese, 2012). In light of these prior studies, the degree of acceptance of talking about death in different ethnic populations should be taken into consideration when designing studies aimed at examining end of life care.

In the Korean culture, it is taboo to talk about death or serious illness because of the superstitious belief that talking about a thing will make it come about or happen (Kwak & Salmon, 2007). More than half of Koreans in a study by Kang et al. had never thought about their death, and almost half of the study's participants reported that they were not ready to accept death and had not thought about their plans regarding death (2010). Seventy-six percent of older Korean adults admitted an avoidance of death, reporting that knowing about death disturbed them (Cho, 2014). The older adults also agreed that they do not want to see people dying nor their friends becoming frail. Similarly, older Korean immigrants think that it is better to avoid talking about death and dying before it actually occurs (Berkman & Ko, 2009) and that, if necessary, they want the discussion regarding end of life (EOL) to be done by indirect communication (Kwak & Salmon, 2007). Accordingly, Korean Americans rarely discuss end-of-life care with anyone, including their family (Park & Hendrix, 2018).

Qualitative and cross-sectional research on end-of-life care for Korean-American populations typically uses focus groups methods to collect data (Park & Hendrix, 2018). Focus group interviews are effective in facilitating discussion, but can obstruct individuals from mentioning sensitive topics, particularly those that are counter to the opinions or beliefs of the group regarding those topics. However, there are few pieces of research to date that conducted individual interviews to study older Korean adults' end-of-life care.

Case vignettes are short stories about a hypothetical person and situations to learn participants' own set of beliefs by reflecting the local context that participants can relate to (Gourlay et al., 2014). Case vignettes may be a useful method for investigating Korean Americans' views on end-of-life care, as this investigation modality has been used in qualitative studies previously to elucidate the subject's opinions or expected behaviors regarding sensitive topics (Gourlay et al., 2014). For example, an older Korean woman in one study stated that she felt discomfort when talking about her death but that she would be willing to talk about death for research purposes (Frank et al., 1998). This may be this way because, despite her stated opinion, the research context depersonalized the topic of death. Research has shown that discussing a hypothetical case helps to establish a psychological distance between the participants and the phenomenon being discussed (Hughes & Hubby, 2002). In this way, case vignettes may help participants to converse on sensitive research topics more openly while experiencing less psychological distress during the discussion.

This study was conducted to address the methodological issues in conducting end of life care research among older Korean immigrants. I explored older Korean immigrants' views on advance directives by discussing a series of case vignettes in which patients were walked through the end-of-life care decision-making process. An advance directive is a legal document that specifies a person's wishes for health care. There are two types of advance directives: the living will that addresses the person's

preferences for treatments and the power of attorney that designates surrogates for decision making. Previous research findings have shown that a person's age, education level, religiosity, family structure, health condition, knowledge, previous experience, and acculturation level can affect the completion of an advance directive (Amjad et al., 2014; Bükki et al., 2014; Fried et al., 2009; Ruff et al., 2011). However, the results of these studies have been more inconclusive in terms of linking these factors to the completion of advance directives. Thus, the interplay of these factors must still be investigated to understand how a person comes up with their final decision regarding whether to complete an advance directive or not.

Advance directive is based on the premise of autonomy, which has been an important principle of Western bioethics (Fan, 2015). Koreans value relatedness and obligation as well as concern for others more than individual autonomy due to the influence of Confucian ideas (Kim, 2005; Tao, 2000). Because of these tendencies, advance health care directives have not been widely adopted among Korean Americans (Kwak & Salmon, 2007). The process of completing an advance directive is equally as important as the document itself, as it provides a way for patients and health care providers to have a comprehensive discussion regarding EOL care (Wilkinson, Wenger, & Shugarman, 2007). Because of the importance of this process and the actual document and the lack of existing research on this subject, an exploratory study is needed to examine how older Korean immigrants view possible conflicts and issues related to

advance directives. The purpose of this qualitative study, using a case vignette design, was to investigate the feasibility and acceptability of a study on end-of-life care decision-making among older Korean immigrants.

3.2 Methods

3.2.1 Study design

This study was a descriptive qualitative research that employed a case vignette design to examine the feasibility and acceptability of methods to collect data from older Korean immigrants on advance directives.

3.2.2 Participants and procedure

Four cognitively intact Korean immigrants aged 60 years or older who could read and write either in English or Korean were enrolled in this study. Korean immigrant status was defined as including people who (1) identify their subethnicity as Korean, (2) were born in Korea and thus had been exposed to Korean culture, and (3) who had been in the US for more than 10 years. Eligible participants also were required to have at least one diagnosed chronic disease such as heart disease, stroke, cancer, diabetes, or a chronic respiratory condition.

Recruitment began after obtaining Duke Health System (DUHS) Institute Review Board (IRB) approval. Convenience sampling was implemented in this study. One nonprofit organization for Korean Americans in North Carolina was contacted, and eligible participants were identified by the organization president. When eligible

participants were identified, a researcher contacted the potential participants and explained the purpose and procedure of the study. Informed consent was provided in either Korean or English depending on the participant's preference of written form.

The researcher conducted three semi-structured interviews with each participant over time. The interviews took place at a location of choice of each participant and were audio-recorded. During the first interview, participants' were asked questions to obtain data on their demographics (e.g., age, immigrant status, education level, religion, family, household income) and then open-ended questions were used to ask them about their experiences in participating in the EOL care of their significant others or friends. In the second interview, participants were asked about their own preferences and choices about advance directives and other EOL decisions using case vignettes. The last interview was conducted with focus placed on gathering general feedback about the study, including the participants' feelings about talking about EOL care and suggestions. After all three interviews were finished, reimbursements of up to \$30 per person were provided.

The interview guide was translated from English to Korean, and, to guarantee the reliability and validity of the translation, a translation panel was formed. The three members of the panel were fluent in English and Korean. The informed consent and interview guide were first translated from English to Korean by primary researcher. The aim of the translation was to achieve the conceptual equivalent of a word or phrase, not

a word-for-word translation. Afterward, the translated interview guide and original English interview guide were sent to the other two panel members, who checked the translated Korean interview guide by comparing it with the original English documents carefully, sentence-to-sentence. The goal of this check was to ensure accuracy of the translation and to check that the translation was culturally acceptable for the entire audience. Together, the three panel members then reviewed all documents to identify and resolve any unclear translations as well as any discrepancies between the original English version and the translated Korean version.

3.2.3 Case vignette

When patients begin to make EOL care decisions, they also often end up needing to make other decisions on how to handle their changing physical status. Slomka described this phenomenon as a "cascade of decisions" (1992). To reflect this complex situation in which people need to make end-of-life care decisions, a case vignette method was used based on existing literature and the researcher's empirical knowledge from clinical practice. This case vignette approach suggested that several factors and conflicts may affect patients' EOL decisions. Along with this, participants were asked their preferred decisions and the reasoning behind such (Table 3).

Table 3: Factors and Decision Types in Case Vignette

Factors	Decision type
Demographics	Completion of advance directives
Conflict with family member	Completion of advance directives
Religion (Advice from pastor)	Completion of advance directives
Health status change	Completion of advance directives
Conflict with family members	Designation of proxy
Conflict with family members	Disclosure of serious illness

3.2.4 Data analysis and rigor

The recorded interviews were transcribed verbatim by the researcher who had conducted all interviews. Eleven interview scripts from four participants and field notes from the researcher were included in the analysis. Data analysis was conducted simultaneously and continuously with data collection, and earlier findings were used to guide subsequent interviews. Qualitative content analysis was performed to identify dominant inductive themes and patterns of themes,. The researcher read the entire text of each transcript to grasp a “sense of the whole” in each interview and noted first impressions of each interview (Hsieh & Shannon, 2005). Then, the researcher began performing open coding in regard to acceptability of this study (Elo, & Kyngäs, 2008). These codes were categorized into similar clusters of themes and interpreted. To obtain credibility, the researcher had prolonged interaction with the participants through multiple interviews and wrote field notes reflecting her reflectivity on interviews. To ensure dependability and confirmability, the researcher wrote process notes to describe

each step of research, including recruitment, data collection, and data analysis, and her reflections about those steps (Krefting, 1991).

3.2.5 Translation

Translation is a complex but critical process in cross-language qualitative research because it involves subtle connotation and meaning (Marshall & Rossman, 2011). Translation is not only a technical work but also requires the researcher's judgment and interpretation (Marshall & Rossman, 2011). However, this interpretation can make it hard to convey the participant's words and intents as they are, which could harm the credibility of the research (Al-Amer, Ramjan, Glew, Darwish, & Salamonson, 2015). Thus, the process of translation should be carefully planned and implemented.

The timing of translation has been discussed among the qualitative transcultural researchers. Regardless of the timing of translation, the researcher's interpretations are not only inevitable but also needed in translation (Marshall & Rossman, 2011). Thus, the researcher should aim to have a reasonable approximation of the interview participant's words and intent after the translation (Marshall & Rossman, 2011).

Some researchers recommend translating data in early phases to acquire more narrative richness; early translation, however, requires considerable time and cost (Santos Jr, Black, & Sandelowski, 2015). In the early phase of translation, whole interview transcripts are translated word-for-word or sentence-for-sentence. This approach may inhibit from achieving both semantic equivalence, which is the similarity

of meaning of each item in each culture, and content equivalence, whether each word is relevant in both the original and target cultures, at the same time (Jones & Boyle, 2011). This is because the readability of the data could cause harm when there is no equivalent word in the target language (Al-Amer et al., 2015). In addition, when the semantics and syntactic structure are different between the source language and target language, there could be no singular translation for an expression (Al-Amer et al., 2015).

Suh and colleagues recommended to translate data later in the process of analysis after the first level of coding is preceded in the source language (Suh, Kagan, & Strumpf, 2009). This approach allows one to capture explicit and implicit meanings from the transcripts (Suh et al., 2009). Thus, in this study, the interview guide and informed consent were translated sentence-for-sentence while interview transcripts were translated during the data analysis.

In translation, the quality and the number of translators should be also carefully discussed and determined (Al-Amer et al., 2015). Using a person other than the researcher to translate the interview transcripts complicates the translation processes immeasurably because more issues of meaning and interpretation arise when someone other than the researcher translates written words (Marshall & Rossman, 2011). In addition, translators should be not only bilingual persons but should also be able to offer the researcher further insight and understanding of a studied phenomenon (Al-Amer et al., 2015). Thus, this study had one translator other than the researcher who was not only

fluent in both English and Korean but was also a graduate student with qualitative research experience.

3.3 Results

The average age of the participants was 74 years old (range: 64–88 years), and the average period of US residence was 47.5 years (range: 37–63 years). Out of the four participants, two identified as female and all identified as Christians. Two participants were married, and the other two participants were widowed. One participant had multiple chronic diseases, including advanced diseases (i.e., end-stage renal disease), while two participants had multiple chronic diseases without advanced disease and one participant had hypertension only. All of these individuals had completed their own advance directives.

3.3.1 Recruitment phase: barriers of recruitment

Nine older Korean immigrants initially agreed to participate, but only six (66%) signed the consent form. Reluctance to share their private stories with others and reluctance to provide signatures on multiple documents were reasons for three out of the nine participants declining to sign the consent form. Of the six people who were consented, three (50%) completed all three interviews, and one (17%) completed two interviews. Two participants withdrew from the study after the first interview, stating that they did not want to share personal information anymore.

All consenting participants agreed to take part in the research study primarily “to help a student from the same country as themselves.” One participant agreed to participate because of the benefit of talking about her end-of-life care in advance, which helped her to think about and express her opinions more clearly. Established trust with the referral person was also a major motivation for participating in the study.

3.3.1.1 Subjects reluctant to discuss research topic

The reluctance to talk about end-of-life care impeded the recruitment of older Korean immigrants to participate in this study. One of the recruitment strategies that the researcher planned to employ was snowball sampling, which is known as a helpful strategy for recruiting participants who may otherwise be hard to identify. However, a research participant shared her experience about this method of recruitment.

“People, because when you asked me if I know anyone, and when I asked people, most of [the] people, I talked to more than 20 people, about this interview, just talk and, all those people, they don’t wanna talk about it. They don’t wanna talk about dying, ‘Oh, I don’t just don’t want, it just give[s] me [a] creepy feeling’” (E, 64 years old).

Another research participant said that, although she is open to discussing about the end of her life because of her religious beliefs, most Koreans would not be open to talking about end-of-life care in advance.

“In America, people write their will in advance, but it does not work like this for Koreans (...) it is not our culture (...) Well, in Korea, we used to insult people with ‘you are

crazy' when someone suggested that you to write a living will while you are alive" (F, 71 years old).

3.3.1.2 Need for neutral interview setting

Most interviews were conducted in the participants' homes and having a guest (the researcher) in their home was one of barriers for participants to participate in this study. Older Korean immigrants believe that they should treat whoever visits their home well. This cultural norm could add another burden to them in addition to the potential time and emotional burden of study participation.

"I think I should treat my guest well. I don't want them to going back without feel them fully and without any gift. So, it's more my problem than yours" (F, 73 years old).

This cultural norm was strengthened, especially since the participants were older adults and they perceived the researcher as a young student needing their help. Two participants refused to receive study reimbursement, saying they did not need it, and they also did not want to provide their social security numbers. All participants treated the researcher with snacks, lunch, and packed Korean food. One participant tried to give money to the researcher, saying, "I do not need money that much since I am old, but it must be hard for you to study in a foreign country."

3.3.1.3 Unfamiliar with interview as a research method

Older Korean immigrants did not prefer the interview method because of unfamiliarity with an interview as a research method and the possibility of a privacy

breach. When the researcher mentioned study participation, older Korean immigrants largely expected to fill out a survey. After the researcher explained the research procedure and introduced the interview as a data collection method, some older Korean immigrants refused to participate, saying, "I am not good at talking about stuff," or "I do not have a special story to talk about." In Korean, "interview" is a loanword, which Koreans' define as "a person collects information from a specific person or group for a certain purpose." This certain purpose generally indicates a hiring process or news report, and the term "interview" is usually used in the context of a "job interview" or "news interview." Thus, "interview" implies a formal conversation, which made older Korean immigrants think that they required preparation and good communication skills.

In addition, as compared with a survey method, the interview method made them feel more exposed to the researcher, whom they perceived to be a stranger. Many participants were not convinced that the anonymity and privacy of the information they shared with the researcher would be maintained. Their fear of breach of privacy and confidentiality was compounded by the face-to-face interview and that the researcher would remember how they looked and how they responded.

"Well, if you need my help, I can help you as long as I can, because we are from the same country. However, I don't give this (personal) information or something"(F, 73 years old).

3.3.1.4 Recruitment strategies: age cutoff

The age cutoff, which was 65 years old or above, was changed to 60 years old or above during the study period to expand the scope of potential participants. However, this modification did not improve the recruitment success significantly. As compared with “old” older adults who were 75 years old or above, “younger” older adults who were between 60 and 74 years old were more socially active and most of them were also still working. Thus, it was easier to contact and initiate the conversation with those “younger” older adults than the “old” older adults since they were more socially active, but it was also more difficult to complete the interviews with “younger” older adult participants due to their busier schedules. Of the three participants who completed all three interviews, two participants who were “old” older adults stated that this study was not a time burden, whereas one participant who was a “younger” older adult stated that the requirement of three interviews was.

3.3.2 Data collection phase: barriers and considerations

3.3.2.1 Documents and signature

According to the policy of the IRB that approved this study, the researcher had several documents where participants needed to show approval via their signature. These included two copies each—one for the researcher and one for the participant—of a five-page-long informed consent, a notice of privacy practices acknowledgement booklet and receipt, and an IRB personal data disclosure form for reimbursement. After the

explanation of informed consent, the participants needed to write their initials on each page of both copies of the informed consent and put their signature on the last page of both copies of the consent form. Then, the researcher handed out the “Notice of Privacy Practices Acknowledgement” booklet and asked the participant to put their signature on the “Notice of Privacy Practices Acknowledgement of Receipt.” form. Participants also needed to provide their social security number in the “IRB Personal Data Disclosure Form” to receive reimbursement, and, if they rejected the reimbursement, they needed to put their signature in the form indicating they “do not want to take reimbursement.” All study participants were overwhelmed by the amount of documents, and one participant told me that she would sign it only after she asked her daughter about the document. One participant refused to provide her social security number, saying that there are a lot of scams related to such. She also showed reluctance in including her signature, saying,

“Well, I guess so. I don’t want to put any signature to anywhere if I can. Because you know, I cannot believe anyone these days...” (F, 73 years old).

3.3.2.2 Preferred language

Language played an important role in recruiting older Korean immigrants. One participant asked if the research was to be conducted in Korean, saying that she would not be able to participate if the research was conducted in English. Two participants did not reveal a dominant preference for either language: one participant was ultimately

interviewed in Korean and the other participant was interviewed in English. A participant stated that she uses English for work and daily life but feels more comfortable speaking in Korean when she expresses her own feelings or opinions:

“I think speaking Korean language would be easier [for] expressing (emotions/opinions) more clearly, maybe? Most of people that I talk to, they speak English, but [for an] interview, I don’t think they (Koreans) would speak in English” (F, 64 years old).

Another participant stated that speaking in Korean helped him to recall his old memories, since Korean is the language that he used in his early life.

“Well... I feel differently. I am reminded of old days when I speak in Korean. But, when I speak in English, that does not remind me of my past. So, even though I usually speak in English, I might express (myself) better in Korean” (M, 88 years old).

3.3.2.3 Emotional distress

No participants revealed any emotional distress during the interviews. One participant reported that, even though this is not a “delightful subject” for her, she thought that talking about end-of-life care was more beneficial than avoiding talking about that issue. One participant described that she did not have emotional distress or discomfort, unlike other Koreans, because of her religious beliefs. However, participants noted that many older Koreans would be reluctant to discuss end of life care because of the discomfort or uneasy feeling related to death and terminal disease and that they were “uncommon” people who were open to discussing end of life care.

3.3.3 Data analysis phase: interpretation of results

3.3.3.1 Translation issues

The researcher had challenges in translating the interview script from Korean into English. First, the use of translation and back-translation was not an effective means of ensuring accuracy of the translation. There exist variations in linguistic rules between Korean and English, and the translator needed to alter the sentence structure at times to successfully translate one language to the other. This change of the sentence structure required the researcher to interpret the original meaning of a sentence, which required potential changes or modifications to the original sentences (Flaherty et al., 1988). The translation of the informed consent and the interview guide was less problematic since the purpose of these documents was description and explanation and the meaning of each sentence was straightforward. Thus, translation and back-translation were conducted to ensure conceptual equivalence. However, the interview scripts contain participants' opinions or emotions, which require more contextual interpretation.

For example, one participant upon describing his health status said that "마음 편한 게 가장 필요한 거 같아." The primary term of this sentence, "마음 편하다," can be translated to mean "relaxed" or "care-free" in English. Thus, this sentence can be translated into "It is necessary to be care-free." However, this sentence in English was translated back into "걱정이 없는 것이 필요하다", which is a more direct translation of

the English sentence but different from the original Korean sentence. Since it is almost impossible to back-translate the sentence to match the original language, back-translation is not an effective way to check the accuracy of a translation between Korean and English.

Other issues related to translation were the time required for and the financial restrictions of the translation work. Although early translation during data preparation with verbatim transcriptions of interviews as the object of translation is beneficial to achieve narrative richness, it is also a time- and labor-intensive process. In this study, the transcribed scripts of interviews in Korean totaled 111 pages and 29,079 words.

3.3.3.2 Use of case vignettes

Providing case vignettes was not an effective method for investigating older Korean US immigrants' opinions or perspectives on decision-making related to advance directives. While some participants agreed that the case was likely to happen in later life among older Korean immigrants, others had difficulties in providing their opinions on this hypothetical situation.

“Well, we have not heard of that in the hospital” (M, 88 years old).

“Our children do not have that problem (conflicts); my youngest son takes care of financial things” (F, 71 years old).

In addition, some participants refused to provide an opinion on a case that was not their own situation, stating that, “Everyone is different. I don't know the other's

situation,” or “You should not make a comment on a family thing even if you are their best friend. Especially about the end-of-life things.”

3.3.3.3 Positive attitude towards advance directives

Convenience sampling was conducted to increase the recruitment rate of ethnic minority group on this sensitive topic. However, reluctance with discussing end-of-life care made it difficult to recruit older Korean immigrants who have negative attitude towards advance directives in the sampling of this study. All participants voluntarily participated in this study, stating their openness to talk about end-of-life care. All of the participants already knew and agreed with the benefits of having advance directives and having written their own. Accordingly, all participants had positive attitudes toward advance directives along with the case vignettes.

“I’d rather prepare and [be] safe than just laid [up]on, I wasn’t prepare[d], and something [could] happen [that] nobody [will] know what to do [about]. I don’t wanna have my children go through that burden (...) for 10 years, [five] years, whatever the time” (E, 64 years old).

3.4 Discussion

This study investigated the feasibility and acceptability of a qualitative descriptive study, exploring how older Korean immigrants view advance directives using an interview and case vignette study method. In the study recruitment phase, the sensitive research topic, the visitation of a participant’s home, and the data collection

method were barriers to recruitment and retention of participants. The completion of multiple documents requiring signatures was also specifically challenging, and the participant's language preference affected data collection. The researcher took into consideration translation issues and selection bias in sampling while analyzing and interpreting data. Emotional distress and the usefulness of a case vignette approach were also reported based on the researcher's observations and the participants' comments.

As we found, other researchers have addressed the difficulties in recruiting ethnic minority participants on sensitive topics. In a prior end-of-life study, recruiting older patients and caregivers in a primary care setting, achieved an overall recruitment rate of 15%. Authors found that the researcher's direct contact was more effective in recruiting participants as compared with contact from the research network staff (Hanratty et al., 2012). Timraz et al. reported slow recruitment to be one of challenges in conducting research on sensitive topics such as child sexual abuse, postpartum depression, or bullying among the Arab-American population (2017).

The cautious selection of words or phrases to describe end-of-life care may be helpful in recruiting participants from ethnic groups who are sensitive about direct communication. Older Korean immigrants prefer indirect communication when they discuss end-of-life care (Hong, M., Hong, S., Adamek, & Kim, 2018). Using indirect communication was emphasized as an important communication strategy to initiate

EOL discussion among ethnic minority groups with cultural taboos or superstitious beliefs regarding discussing death (Chi, Cataldo, Ho, & Rehm, 2018). During the recruitment phase, the explanation of advance directives caused the researcher to mention deteriorating physical status and impending death.

To improve the slow recruitment rate in the present study, the researcher expanded the age cutoff of this study from 65 years old and older to 60 years old and older. Perceptions of age are affected by one's sociocultural background. Although 65 years of age and older is widely considered as the age cutoff for older adults, 60 years of age and older is also considered to include older adults in developed countries, since 60 to 65 years of age is when people begin to retire from their jobs (Barry, 2016). We recruited 3 more participants after this change, but only one of them ultimately completed the interviews. The two participants who did not complete the interviews because of time strains were still socially active and had not yet retired from their work. While "younger" older adults who are 60 to 75 years of age reported this study as being demanding of their time, the "old" older adults who were older than 75 years of age stated that they did not experience a time burden during their study participation. As life expectancy is prolonged, some have suggested the need to redefine the age of older adults, since people who are younger than 75 years of age are still fairly robust and active (Ouchi et al., 2017). Thus, researchers should set an age cutoff for older adults in

accordance with the sociocultural background of the target population and the research purpose.

The research venue and requiring signatures on informed consent forms influenced older Korean immigrant's study participation. As the leakage of personal information and personal information-related crime has increased, concerns about breaches of privacy have also increased. These concerns, combined with a lack of proficiency of English, created a reluctance among older Korean immigrants to provide any personal information or signatures. Of note, the study procedures that the IRB required be implemented to protect researchers and research participants in fact became barriers to potential subjects participating in the study. In this study, the researcher conducted the interviews mostly in the participants' homes to secure their privacy. However, older Korean immigrants have a cultural norm of that they need to treat their guests well. Accordingly, conducting research at their house did not lessen their burden of time and effort. Church-based recruitment was also reported as an effective way to reach Korean immigrants (Park, Jang, Nam, Grey, & Whitemore, 2018). Conducting research in a private room at a church or other Korean institution would be an effective way to build trust and provide a private place while not overly burdening the participants.

In addition, unfamiliarity with the research method also affected data collection. Most older Korean immigrants are more familiar with a survey format than an interview

format. They perceived a research interview as a formal or/and serious conversation, which kept some from participating in the research. In our study, one older Korean immigrant identified a potential subject and was willing to refer the researcher to him. She suggested that the researcher initiate the conversation with him without mentioning research, so that he could share his thoughts more openly during the conversation. Her suggestion was not accepted due to research ethics, although it was deemed important to conduct interviews in more conversational manner to allow older Korean immigrants to share their stories more freely. One strategy for this could be the narrative approach. The narrative method has been used to obtain older adults' unique insights of their lives across the health disciplines (Clark, 2015). Thus, this method could be particularly useful to allow older Korean immigrants to discuss their perspectives on the research topic with the researcher.

Using a case vignette design was not particularly effective among older Korean immigrants who participated in this study. Participants had an open, positive attitude toward discussing end-of-life care because of the selection bias caused by the recruitment process. Thus, talking about a hypothetical case did not help to lessen the burden of discussing this sensitive topic. All participants had already completed advance directives; thus, the vignette describing the decisional conflicts that may arise regarding advance directives in this study caused disjuncture between the participants and the vignette character (Hughes & Huby, 2001). In addition, older Korean

immigrants reported their reluctance to provide opinions of others' situations according to their cultural norms, even though it was a hypothetical case. Thus, the use of case vignettes should be considered in the context of cultural norms that the research participants may participate in.

The findings of this study should be interpreted with caution because of some limitations, as follows. First, the sample size of this study was very small, but the data are rich in detail because the researcher conducted in-depth interviews with each participant. However, the perspectives of older Korean immigrants that were provided in this study could be limited. Second, the participants were recruited from a southeastern area of the US that traditionally has had only a small population size of Korean immigrants. Thus, their perspectives could be different from those who live in metropolitan areas where larger numbers of immigrants including Korean immigrants reside. Third, there were selection biases during the recruitment of participants. Convenience sampling led the researcher to identify potential subjects who were socially active in the Korean community. Korean churches are one of the most important social networking places in the US (Park et al., 2018) and, thus, all of the participants identified as Christian. Participants' religion could affect their attitude toward end-of-life care and end-of-life research participation and, given that all participants were of a single religion, such may further impact the study results. Moreover, most participants had a positive attitude toward advance directives, which let them to participate in this

research voluntarily. Thus, these selection biases should be considered when interpreting this study's findings.

3.5 Conclusion and implications

This study addressed methodological issues in researching older Korean immigrants' attitudes toward advance directives using interviews and case vignettes. This study provides foundational information for researchers who plan to implement sensitive research topics among ethnic minority groups. The description of recruitment barriers as well as methodological issues related to data collection and analysis in this study will help future researchers to design more rigorous research studies for older Korean immigrants on sensitive topics. Also, the cultural norms that were described in this research can be informative for health care providers in that they may be able to provide more culturally appropriate care by better understanding this population.

4. Health care goals and the influence of life course on older Korean immigrants

4.1 Introduction

4.1.1 Health care goals among older adults with multiple chronic conditions

Three out of four older adults in the United States have multiple chronic conditions (MCC), and this population is expected to increase in number as public health and medical science continue to advance (Anderson, 2010). MCC refers to a health status with two or more concurrent chronic diseases such as arthritis, chronic respiratory conditions, diabetes, and heart disease (U.S. Department of Health & Human Services, n.d.). Older adults with MCC often experience functional impairment while needing to follow complex medical treatment plan, thus affecting their capacity for self-care management (Kristensen et al., 2017). Older adults with MCC often face multiple care options and goals. Therefore, health care providers should encourage older adults with MCC to assume a more active role in shared decision making so that their preferences and priorities drive their health care treatment (Opmeer et al., 2007; Wouters et al., 2014).

Older adults are diverse and heterogeneous in thoughts and values because of their varied life experiences that contribute toward their life perspectives (Peace et al., 2011). At this later life, many have already accomplished significant life tasks such as raising their children or establishing their career, while they start to experience

functional decline and to have multiple chronic conditions. Declining health status and complex health problems require older adults to prioritize health care goals based on their own values and goals. Consequently, shared decision making increases in importance among older adults with multiple chronic conditions (MCC).

Older adults with MCC align their health care goals with their life goals and wishes when faced with limited life expectancy (Cho et al., 2018). According to the trajectories of health, end of life (EOL) phase starts from the decline of health status when the health problem is not recoverable anymore. While many health care providers frequently encourage early and frequent EOL care discussions with their patients who at the terminal stage of their illnesses (Lowey et al., 2013), most older adults with non-terminal MCC feel ill-prepared to discuss their EOL care goals (Etkind et al., 2017). Many, including providers, feel that their conditions do not warrant EOL care discussions. Health care providers, therefore, often miss the opportunity to discuss and make care decisions with patients due to this uncertainty of when EOL care discussions should begin (Brogan, Hasson, & McIlfatrick, 2018).

4.1.4 Older Korean immigrants and health care decision

As the population of older adults in the United States continues to grow, its ethnic diversity grows with it as well. The US Census Bureau estimates that by 2060, older Americans will number about 98.2 million, accounting for nearly 25% of Americans in the country (US Census Bureau, 2015). Korean Americans are the fifth

largest ethnic group among Asian groups. More than 1.5 million Korean Americans live in the United States and about 14% of these Korean Americans are over 65 years old (US Census Bureau, 2015). Korean immigration generally started in the 1950s and dramatically increased in the 1970s (Zong & Batalova, 2017). Seventeen percent of Korean immigrants are 65 or older, which is a higher percentage than those of the overall immigrant population in the United States (Zong & Batalova, 2017). Although there is no published report on the prevalence rate of MCC in the Korean immigrant population, the Center for Medicare and Medicaid Services (CMS) indicated that, in 2015, approximately 34% of Asian/Pacific Islanders in the US have 3 or more chronic conditions which was similar to that of non-Hispanic white (37%). Study also found that older Korean Americans have a higher rate of diabetes, hypertension, and chronic kidney disease than the White population (Lee, Yeo, & Gallagher-Thompson, 1993)

More than half of Korean Americans living in the US are immigrants, implying that they hold unique cultural perspectives, including collectivism or filial piety that originated from the influences of Confucius on Korean culture (Kim et al., 2001). These values often dictate how older Korean immigrants perceive their health and lifecycle events, including death. As this ethnic immigrant group seeks health care in the United States, health care providers need to understand the older Korean immigrant perspectives on health care goals so that the providers are able to deliver patient-centered care.

Health care providers can provide the best care only if they understand how older Korean immigrant's cultural background influences their health care goals and priorities. In the Korean culture, talking about death or serious illness is taboo based on the Korean proverb that "words uttered become seeds (of consequences)." The collectivistic culture based on Confucianism is distinguished from the individualism that most Western countries, including the United States, value. Korean patients' family members frequently "protect" the patients from the disclosure of distressing medical information, which often results in the hiding of distressing information (Eun et al., 2017). Korean patients, in return, are expected to value family decisions over individual decisions and preferences (Ko & Berkman 2010). This tendency is more pronounced in older adults, because they expect filial piety, the main idea behind Confucius' teaching that dictates obedience and repayment from children. According to filial piety, children should unconditionally care for their parents with affection and respect for family continuity (Lum et al., 2016). Korean culture regards family members as the final decision makers (Kwak & Salmon 2007). Thus, older Korean immigrants who hold Korean cultural values could face challenges when they are treated in the American health care system by health care providers who do not sufficiently understand their cultural background. The values such as personal standards or relationships that are important to other ethnicities are also important to older Korean immigrants. However,

older Korean immigrants may prioritize these values differently in challenging situation, such as in end of life (EOL) care.

Every older adult has life experiences and background that build and shape their own wishes and values for health care goals. Older Korean immigrants in the US experienced the fast change of technological development in medical field in the last decades. In addition, older Korean immigrants experienced the process of immigration, which is not only the change of location, but the change of language, food, culture, friends, and social system surrounding them. Therefore, appreciating the contribution of life experiences towards the interpretation of a particular situation will sensitize the health care providers that two older Korean immigrants may react differently even when facing similar situation.

4.2 Theoretical framework: Life course theory

The Life course theory provided the theoretical framework in exploring the perspectives of older Korean immigrants with MCC on their health status and health care goal priorities within the context of their individual lives. Older adults are more diverse than any other population groups in that every older adult has many unique life experiences that shape their perspectives and values on health care. Moreover, older Korean immigrants have gone through a major and unique life event (immigration) that exposes them to a new social context with dissimilar cultural values and traditions. Life course theory describes human lives and behavior based on individual lives and

socioeconomic context throughout a person's life events and reaction to those events (Giele & Elder 1998; Shanahan, Mortimer, & Johnson, 2016). Thus, understanding the life course of a person will provide appreciation of their current perspective and care decisions.

Life course theory suggests four principles and one major concept to understand and describe human lives and behaviors (Figure 3). "Location" includes times and place and refers to history, social structure, and culture (Giele & Elder 1998). To older Korean immigrants, immigration is not only a transition to a different physical location, but also to a change of social structure and culture where they live. In addition, since the US has had major technological advancements in health care within the last decade, older Korean immigrants have to adjust to the frequent use of technology in diagnostics and treatment, a practice that is rare in Eastern medicine. The interplay of changes related to time, places, and events and how older Korean immigrants' perceive these changes may provide an understanding of how current health care goals are decided by older Korean immigrants.

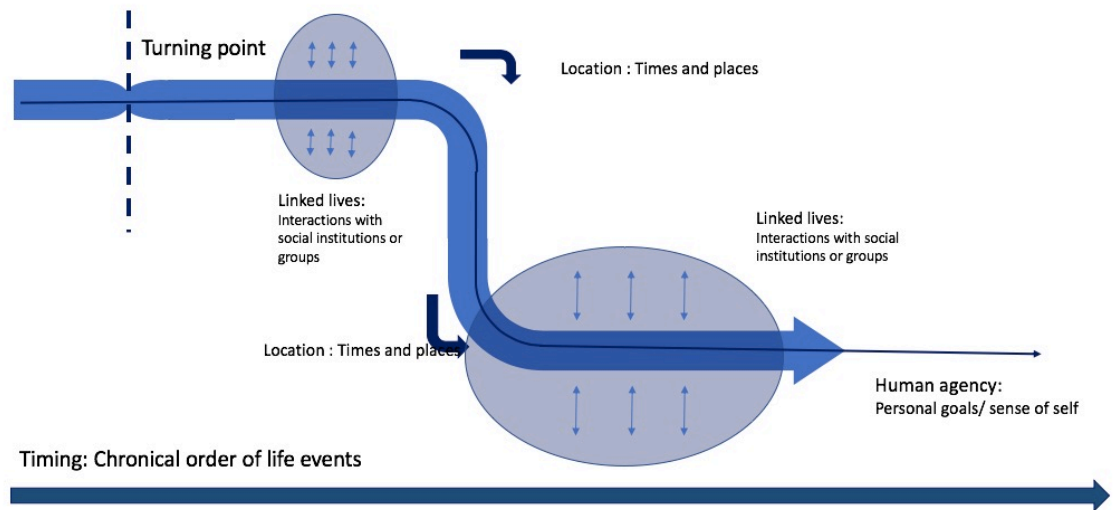


Figure 3: Theoretical Framework: Life course of older Korean immigrants

“Linked lives” means the interaction of individuals with societal institutions and social groups (Giele & Elder 1998). Older Korean immigrants, as an ethnic minority group, have different perceptions and expectations toward their health care providers and support system in the United States. Depending on their social network, they may not have access or they may not know about different health resources. In addition, it is important to understand the role and expectation towards family members and how these influence the health care goals of older Korean immigrants. “Human agency” is active pursuit of personal goals and sense of self (Giele & Elder 1998). This principle will explain individual values and wishes based on their life experiences. “Timing” refers to the chronological order of an individual life events. (Giele & Elder 1998).

Understanding their life in chronological order or their health trajectories can be

explored and will contribute toward the understanding of their current perception on health care decisions.

“Turning point” is a concept that describes a significant event that changes one status to another (Giele & Elder 1998). For older Korean immigrants with MCC, immigration could be a significant event for their lives that may affect other components in their life course including location, linked lives, timing and even human agency. Thus, these four principles (location, linked lives, human agency and timing) and one concept (turning point) will guide this research in exploring the older Korean immigrants life course perspective, and their health care goals and priorities.

4.3 Specific Aims

Aim 1: Explore health care goals and priorities of older Korean immigrants with multiple chronic conditions.

Aim 2: Using concepts from the Life Course Theory (location, timing, linked lives, human agency, and turning point), describe how older Korean immigrants with multiple chronic conditions set health care goals and priorities.

4.4 Method

4.4.1 Research Design

This study was a qualitative, descriptive study whose purpose was to investigate the perspectives of older Korean immigrants on their health care goals and priorities. Setting health care goals and prioritizing them to make care decisions are influenced by

individual values and wishes, particularly in later life. Those values and wishes are shaped throughout a person's lifetime with various experiences. Since a person's values and wishes are shaped by accumulation and interaction among various life experiences, setting health care goals and priorities is a complex phenomenon.

4.4.2 Study participants and sampling

Inclusion criteria for this study were older Korean immigrants who 1) identified as a Korean immigrant, 2) was at least 65 years of age, and 3) had multiple chronic conditions. The term "multiple chronic conditions" was defined as having two or more concurrent chronic conditions. Chronic conditions included hypertension, high cholesterol, arthritis, ischemic heart disease, diabetes, chronic kidney disease, heart failure, and chronic obstructive pulmonary disease, which are the ten most common chronic conditions in older adults outside of depression and Alzheimer's disease or dementia. (National Council on Aging [NCOA], n.d.).

Purposive sampling was used to maximize the diversity of the participants to achieve an in-depth description on the phenomenon of how older immigrants apply their life experience in deciding and prioritizing their health care goals. Purposive sampling was conducted based on age, gender, health status, and residence.

Age was categorized as young-old (65-74), old (75-84), and oldest-old (85 years old or above). As the number of the older adult population increases, the psychological, social, and functional status of this age group becomes more diverse (Margrett et al.,

2011; Cho et al., 2017; Chen & Jordan, 2018). This study recruited four young-old adults, six old adults, and three oldest-old adults.

When inspecting individual life course, gender should be considered as an important variable since expected social roles are different between men and women. This different social role also affects how men and women see their life differently. For example, when asked of their turning points, women answered parenthood, death of a family member, or departure of children, while men responded with an occupational event, educational experience, or divorce (Moen, Elder, & Luscher, 1995, p.373). Gender also yields different effects on aging, including susceptibility to diseases (Zhao, Mao, Woody, & Brinton, 2016), psychological symptoms (Tiedt, 2010), quality of life (Coley et al., 2017), and social support (Tiedt, 2010) in their later lives. In this study, six participants were male, and seven were female.

While older adults are more likely to have multiple chronic conditions, an advanced illness can significantly affect how one perceives his/her health status and functional abilities. According to the Coalition to Transform Advanced Care (CTAC), advanced illness is defined as the status of having “one or more conditions become serious enough that general health and functioning decline, and treatments begin to lose their impact”, such as in the case of end-stage renal disease, stage 4 heart failure, or metastatic cancer (American Hospital Association, n.d.). This study recruited five participants who were suffering from multiple chronic conditions with at least one

advanced illness and seven participants who were suffering from multiple chronic conditions without any advanced illness.

Social support is crucial for the older adults who have immigrated to the US and have language barriers (Liu, Cook, & Cattan, 2017). Korea immigrants have been reported to have a lack of proficiency in communicating, both written and oral, using the English language (Yoon et al., 2012). As a result, many started small businesses, which required a network of mutually supporting businesses in Korean communities (Noland, 2003). Although Korean immigrants are widely spread in all states throughout the US compared to other Asian American immigrants, they also tended to concentrate in large metropolitan areas in a few states (Noland, 2003). This study recruited participants from two areas: Ellicott city in Maryland and Raleigh/Fayetteville/Durham in North Carolina. As a part of the Baltimore–Washington metropolitan area, which has the third largest Korean American population in the United States, Ellicott City has the 66th largest Korean percentage (4.52%) out of the total population, while Fayetteville has the 728th largest percentage (0.73%), Raleigh has the 1,428th largest percentage (0.40%), and Durham has the 2,184th largest percentage (0.27%) (Zipatlas, 2017). In this study, five participants were recruited from Ellicott City, five participants were recruited from Raleigh, and two participants were recruited from Fayetteville and Durham.

4.4.3 Procedure

This study has been approved by the Duke Health Institutional Review Board (IRB). After obtaining IRB approval, the researcher contacted local communities, including Korean churches, Korean senior daycare centers, and non-profit organizations for Korean women. Flyers were distributed in those Korean communities, and older adults who were interested in participating in this study contacted the researcher or provided their contact information to the key person in the community. The researcher communicated regularly with this key person to obtain information of those who were interested in participating. Thereafter, the researcher met or called potential participants and checked if they met the inclusion criteria for participation, which were (a) older Korean immigrants, (b) without a medical diagnosis of cognitive impairment, (c) able to speak and write in either Korean or English, (d) able to understand the purpose and procedure of this study and voluntarily consent to participate in this study, and (e) with multiple chronic conditions. The researcher explained the purpose and procedure of this study to eligible participants, and written informed consent was obtained from participants who were willing to sign voluntarily. As a reimbursement, participants were given \$30 worth of gifts, regardless of the completion of the study.

4.4.4 Data collection

Semi-structured interviews were conducted in Korean at two time points at least 1 week apart.. In the first interview, the participants' perceived health status, short- and

long-term health care goals, and priorities were discussed. In the second interview, participants' own life courses were discussed in a narrative way.

Interviews took place in the participant's home or a private room in the church or daycare center to ensure the participant's privacy. All interviews (n=26) were conducted one-to-one and face-to-face. The length of interviews varied from 20 minutes to 90 minutes, and the average length of interview was 46 minutes (Figure 4). The recording was checked for audibility and completeness immediately following the interview. After conducting each interview, the transcripts were transcribed verbatim.

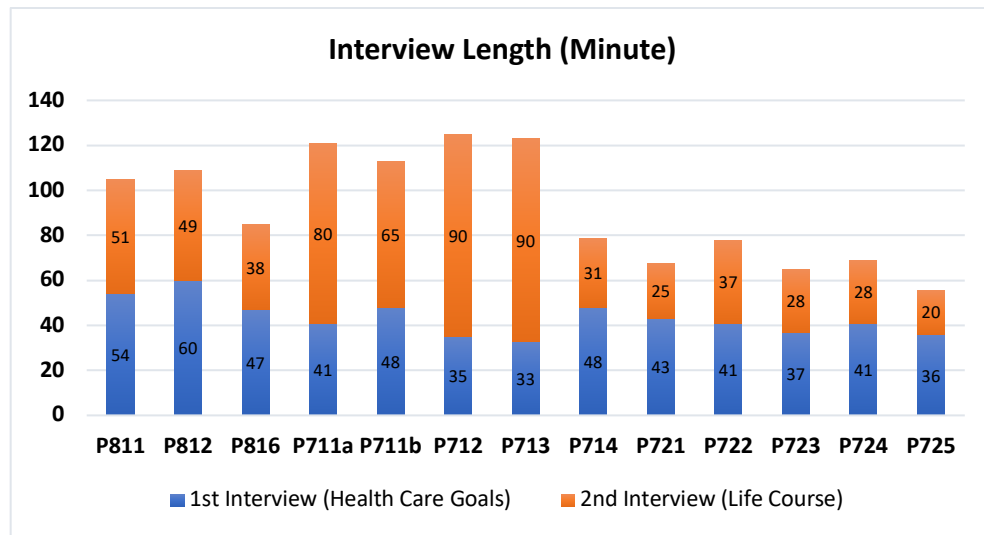


Figure 4: Interview Length

4.4.5 Translation

Translation is a complex but critical process in cross-language qualitative research because it involves subtle connotation and meaning (Marshall & Rossman, 2011). Translation is not only a technical skill but also requires the researcher's judgment

and interpretation (Marshall & Rossman, 2011) However, this interpretation can make it hard to convey the participant's words and intents as they are, which could harm the credibility of the research (Al-Amer et al., 2015). Thus, the process of translation should be carefully planned and implemented.

It will be helpful to describe here the translators (who were they) so that there is no confusion below on who did what. The interview guide and informed consent were developed in English then translated and back-translated by whom to verify the accuracy of the translation. When there were discrepancies between the original document and back-translated one, the researcher and translator discussed and revised the Korean translation iteratively until an agreement was reached. Interview transcripts were translated by whom during the data analysis (Chen & Boore, 2009). The researcher who conducted the interview and knew the direct and indirect communication that occurred during the interviews transcribed the interview verbatim and conducted the first cycle coding. Then, codes and excerpts were translated into English by the researcher, and, following this, a research assistant who is fluent in Korean and English back-translated codes and excerpts into Korean. These were compared to the original codes and excerpts, and extensive discussion was done iteratively to ensure semantic and content equivalence. Translated codes and excerpts were revised until the agreement was met between the two translators.

4.4.6 Data analysis

This descriptive qualitative study aimed to understand how older Korean immigrants with multiple chronic conditions set health care goals and priorities based on their life experiences. Since life course theory directed the research design and data collection, directed content analysis was conducted (Hsieh & Shannon, 2005). A set of priori codes was predetermined based on the theory deductively, while additional codes were generated from the data inductively when data did not fit priori codes (Table 4). Codes were grouped and organized into bigger clusters as emergent categories and those categories were organized into hierarchical structure (Hsieh & Shannon, 2005). QSR NVivo 11 software was used to manage data and facilitate the data analysis.

Table 4: Code List

Code type	Code name
A priori code	Time
	Linked lives
	Location
	Turning point
Emergent code	Getting aged
	Difficulties in symptom management
	Polypharmacy related side effect
	Lack of knowledge on multiple medication
	Lack of control
	Uncertainty of the future
	Keeping up self-management
	Family history related concern
	Advance care planning
	Life sustaining treatment
End of life care discussion	

4.4.7 Rigor of the study

Lincoln and Guba proposed four criteria to determine rigor in qualitative studies: credibility, transferability, dependability, and confirmability (1985). To ensure the credibility of this study, the researcher developed rapport and trust with participants throughout the prolonged engagement and cautiously conducted triangulation during the data analysis. . In addition, the researcher had peer debriefing sessions with whom during the data analysis. To ensure transferability, a thick description on the research context was reported. To ensure dependability and confirmability of this study, the researcher wrote an audit trail, which described the researcher's steps and decisions along with the data collection and analysis. The researcher's analytic memos and field notes were used to facilitate data analysis and to achieve confirmability (Saldaña, 2015).

4.5 Results

4.5.1 Participants characteristics

In total, 13 participants were interviewed. The average age of participants was 78.69 years old (67-88), and the average immigration period was 37.46 years (29-53). Six of the participants were male (46%), while seven of them were female (54%). Six of the participants were married (46%), five of them were widowed (39%), and two of them were separated (15%). Eight of the participants had multiple chronic conditions (examples are hyperlipidemia, hypertension, diabetes) without any advanced illness

while five had multiple chronic conditions with advanced illness, such as end-stage renal disease (ESRD) or cancer.

Seven themes (readiness of goal setting, health care goals, health care priorities, time, location, linked lives, turning point) and 14 subthemes were found. Older Korean immigrants' life and their perspectives were reported based on the 4 major themes (Time, Location, Linked lives, and Turing point) that life course theory directed. These 4 themes were divided into sub-themes or small categories (Figure 5,6).

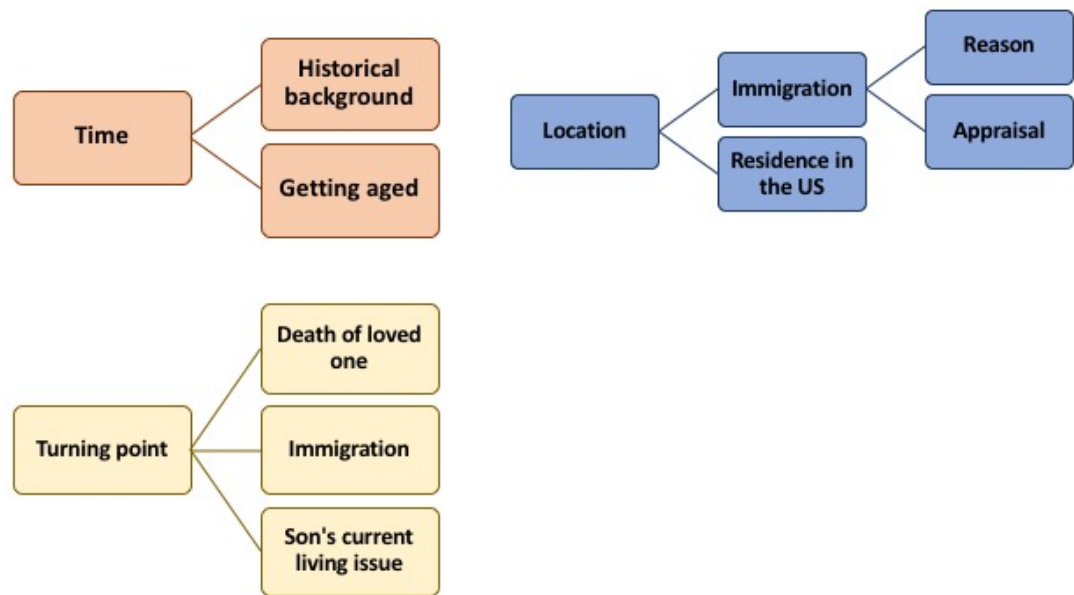


Figure 5: Data Structure 1-1

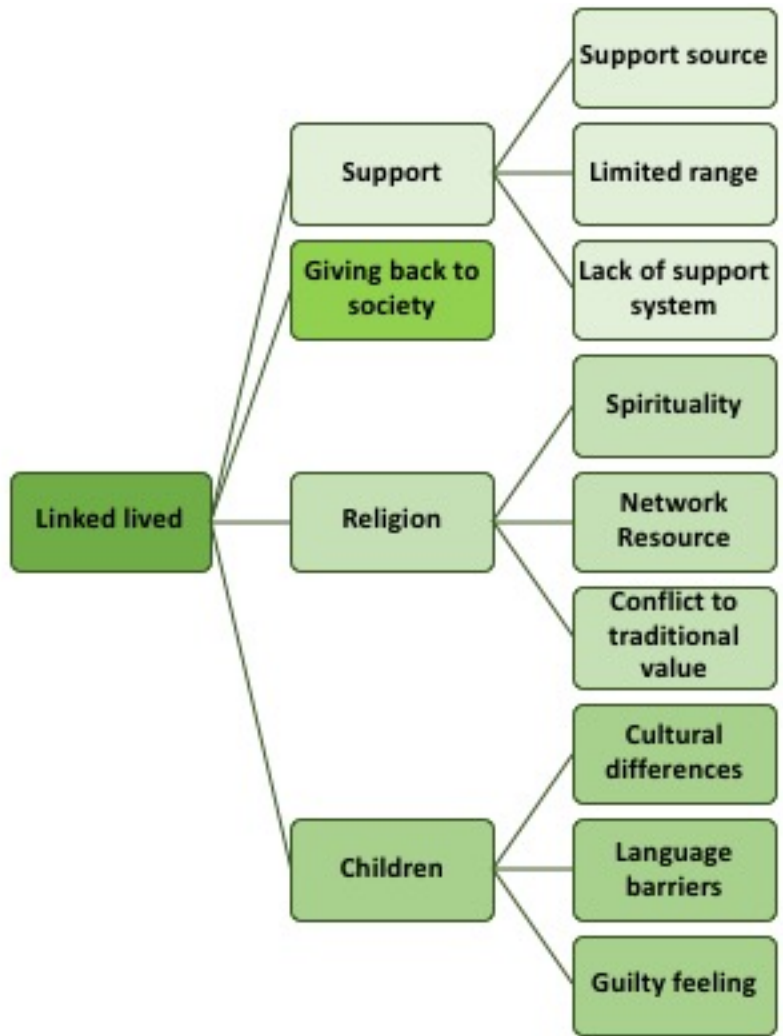


Figure 6: Data Structure 1-2

Emergent codes described older Korean immigrant’s health care goals and priorities were categorized into more abstract categories and themes. The readiness of goal setting was one of the major themes other than health care goals and priorities (Figure 7).

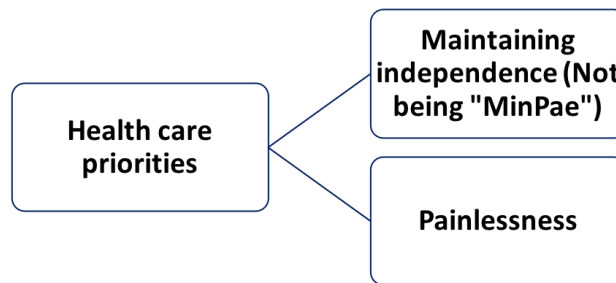
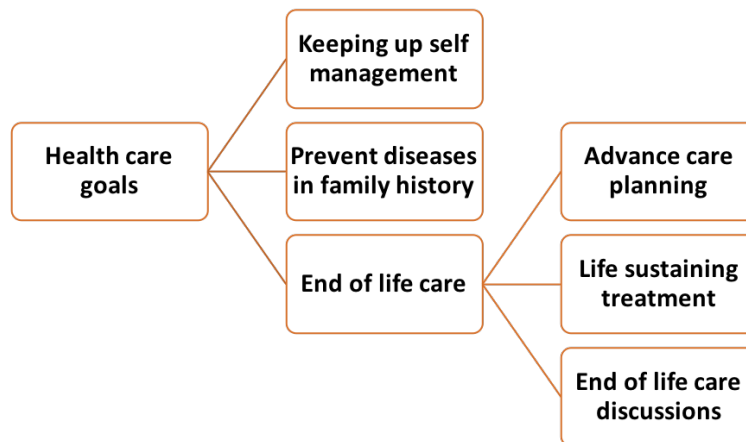
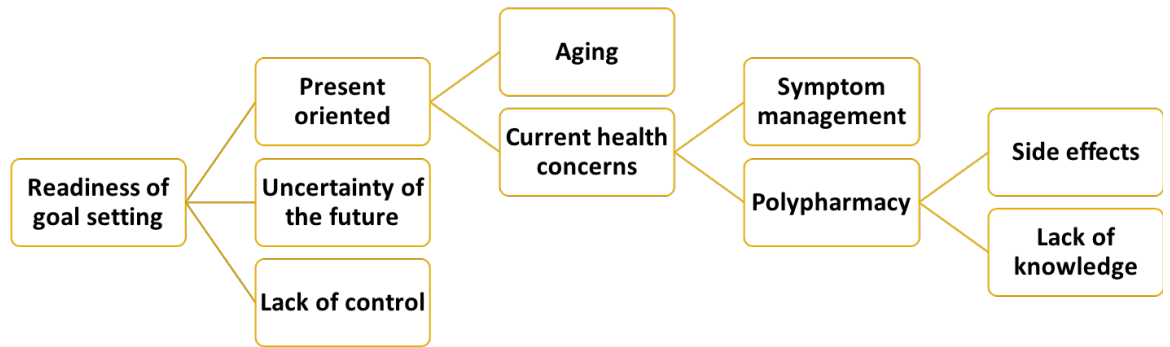


Figure 7: Data Structure 2

4.5.2 Time

4.5.2.1 Historical background

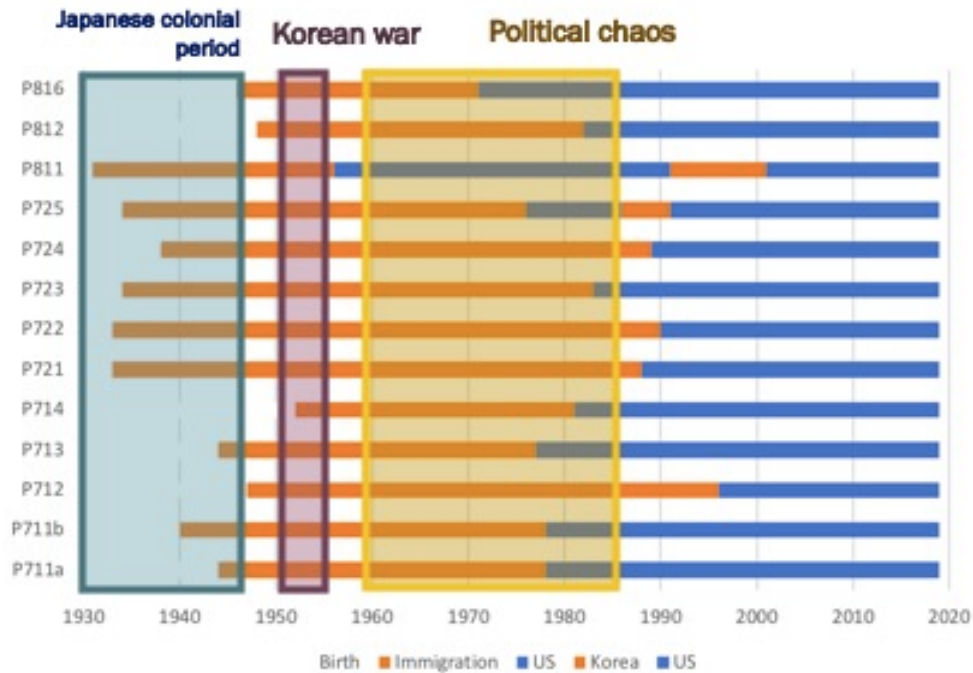


Figure 8: Historical Backgrounds of Participant's Lives

All of the study's participants were born between 1931 and 1952. The participants have all gone through dynamic historical periods in Korea, such as the Japanese colonial period (1910-1945) or the Korean War (1950-1953). After the Korean War, politically chaotic situations, such as fraudulent elections, military coups and/or political demonstrations lasted until the mid-1980s. They remembered those times in Korea as politically and economically hard times, which is a contrast to their situations in the United States (Figure 8).

One participant described those times, saying:

“Well, people like me, old and in the US. We were shortage of everything. That’s all you need to know about us. We have gone through everything. We have gone through Korean war. (...) In the Japanese colonial period, we could not buy rice even if we had money.”
(F, 86 years old)

4.5.2.2 Getting aged

Older Korean immigrants from this study had negative attitudes toward aging. Those negative attitudes were mostly related to their declining health status.

“Yeah, I think, you cannot cure old people’s illness. We just extend our lives gratefully, since we are taking medicines.” (F, 86 years old)

“People should not live too long. Anyway, all people should die in their sixties or seventies. Well, the life span has extended now so seventies or eighties. People should all die before then.” (M, 85 years old)

4.5.3 Location

All of the participants in this study had gone through similar life-altering change regarding their location as a result of immigration. The reasons for immigration included their dissatisfaction with Korean society, which made most of them appreciative of their lives after immigration. However, one immigrant stated his regret of immigration because of the disconnection that he felt from this traditional value.

“I came here because I failed my business in Korea. So I was forced to come here, not that I wanted to. (...) Everyone who immigrated here had their own stories, a lot of people

came here involuntarily (...) suppression.. like political suppression, well there are various reasons, some people just hated Korean society back then, but everyone had their own stories (that they cannot share)." (M, 67 years old)

"In my age, there's nothing more I can ask for. I am almost 90 years old, what regret I would have? I lived long enough. It is grateful enough to live this much. I think I could live like this because I immigrated to the US. The air is cleaner and the government offer helps to poor people like me. I think that's good." (F, 86 years old)

"My family line is totally broken since I came here. I am a third-generation only son. I was educated from my father about Confucianism and traditions (...) After they (children) get married, they are with their wives and started to go to the church. (...) So, every year, when the memorial day is coming back, I remember that day and bow to my father and grandfather, saying "forgive me." (M, 85 years old)

Another reason for moving to the United States , was their children. They perceived their children as a support source, but moving has resulted in a disconnection from the social support that they had already established.

"So before I came here, when I (decided to) move out, she suggested moving near where she lives. I thought about that. When I am about to die when I am more aged and about to die, I need to go near my kids." (M, 75 years old)

"If I was able to move by myself, I would not come here. But I did not think that I would be able to. That's why I came. That's why I moved here. I lived in California for 30 years

old, it is like my second hometown. After I came here I live with daughter's family and meet people at church though..." (F, 71 years old)

4.5.4 Linked lives

Older Korean immigrants receive support in their lives mainly from their children and the Korean church. In places where the Korean population is relatively large, they typically have a Korean community, including an adult daycare center; however, in a city that has a small Korean population, a Korean church becomes a hub for the Korean community.

4.5.4.1 Support

While they have various support sources, such as their children or church, participants said their support is limited to the Korean community. Furthermore, one participant compared his lack of support in the US to Korea and his hardships as an immigrant.

"Before I came to this daycare center, my children took care of me, otherwise, a person from church helped me. Mostly, people from church helped me. But since I have come to this adult daycare center, they took care of everything. So grateful" (F, 86 years old)

"There are many limitations such as visa problems. There are people who figure out getting the green card but there are more people who couldn't. So because of several things, you cannot resist the help from the person that you know." (M, 67 years old)

“Think about it. After you move here, some people come here by himself, or just his family only. Then if he tries to do something and it fails, what should he do? He does not have money anymore. (It is different (compare to living in Korea)) It is different. In Korea, you have friends or something. But you don’t have that kind of things here. So you know, immigration, living after immigration is really tough.” (M, 85 years old)

4.5.4.2 Giving back to society

While discussing their lives and interaction with society, older Korean immigrants in this study described their wishes to give back to society and what doing so means to them. One participant stated that she wanted to contribute to society by donating her organs since she received help from the welfare system. Some participants wanted to help others because of their religious beliefs, but others wanted to because they believed that what they gave would be what they would receive in return.

“Helping others is...for me, if I help others now, it helps me more than the person who receives my help, for my health. It makes me feel easy. So, um... it is very important to help others. Not only for those who need help but also for those who provide help.” (M, 88 years old)

“One reaps as one has sown, that’s for sure. I am currently doing volunteer works, we have helped people more than a hundred people voluntarily.” (F, 75 years old)

“I talked to my family doctor. I don’t know when I will die because of this (ESRD), but I have not done anything (for society) after I came to the US. I have not contributed

anything after I moved there. Since I have lived gratefully with insurance (Medicaid) I don't know what will be left after I die but I want to donate my organ. He said, 'okay.'
(F, 86 years old)

4.5.4.3 Religion

“Church” had various meanings to older Korean immigrants in this study. Not only was the church used for their spiritual needs, but it was also their network resource to connect them to the Korean community. On the other hand, one participant described his conflict with his son since his son started to go to church.

“So, just mentally, it's only God, who to ask for help. And I prayed to God like I will serve you well once I go to the US. I used to pray like that. A good thing about here is all family can come to church together, that's a really happy thing, and I am glad.” (F, 72 years old)

“We meet people in the church. Because we do not have many chances to meet Korean people here. There are not many, we do not have a big Korean community here. So, everyone gathers in their churches.” (F, 75 years old)

“Of course. We respect our ancestors, that's the way how I lived. (...) My eldest son, after he got married, my son and my daughter-in-law started to go to the church. They are almost crazy. They are willing to give money to the church. They never do that to me because they think it is a waste of money. They do not call me as well... [sigh]” (M, 85 years old)

4.5.4.4 Children

Most older Korean immigrants did not have extended family in the United States, and their children were the main support system for them. However, their children were born and raised in the United States, unlike older Korean immigrants who spent substantial portions of their lives in Korea; thus, they felt cultural differences with their children, and some had a language barrier with their children. Also, since most older Korean immigrants have worked such long hours, they had a feeling of guilt toward their children that they did not take care of them enough.

“Yes, there are a lot of cultural differences. We are still Koreans, but my kids are, totally, they were born and raised in the United States, so they are totally Americans.” (M, 75 years old)

“Yes, I told my kids, you should marry Koreans so that you can communicate with me. Otherwise, I cannot communicate with you because you cannot speak (Korean). So they said they would, and they did (marry Koreans).” (F, 71 years old)

“I feel sorry for my children because I have not fulfilled their needs when they need those.. I will regret and feel wrong until I die.” (F, 72 years old)

4.5.5 Turning point

Older Korean immigrants described their lives in a chronological order; in a way that was more close to a line than having points or events that affected their lives. When they were asked the turning points, one participant answered that he did not have any

turning points in his life, which is why he is not well-off right now. Only one participant (Figure 9) answered that his turning point was immigration since it changed the way he lived. However, others describe events other than immigration as turning points that affected their lives.

“Well, the only thing I feel sorry about is... when I was twenty...when I was twenty-nine, my mom passed away. After my mother passed away. When she passed away, I cried a lot. I had insomnia, and for about 6 month, I went through very hard times.” (M, 75 years old)

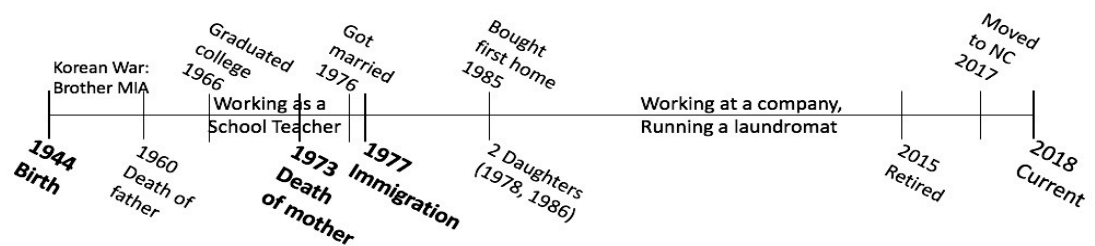


Figure 9: Life Trajectory and Turning Point of Participant C

“In my time... in my time, we respected our ancestors, that’s how we lived. My son is satisfied with living in the US, because he can do whatever he wants. However, the way we live is different from the way he lives.” (M, 85 years old)

“A big event is, to be honest, the death of my daughter has been the biggest event for me so far. However, for now, my son’s means of living is my biggest concern. I want to appeal that to someone. It is not because it has been a long time since my daughter died (...) I had such a hard time when I divorced with my husband. I cannot describe it. But my concern about my son’s living is more painful than that.” (F, 81 years old)

4.5.6 Readiness of goal setting

The study participants stated they did not have specific health care goals. Also, they focused more on stating their current health status or health concerns rather than talking about their future health care plans. In addition, participants discussed the uncertainty of the future and the lack of control of their lives, which also explain their unpreparedness toward setting health care goals.

4.5.6.1 Present oriented

Participants considered their old age as the time to focus on today rather than the future. They mentioned they do not have a long enough time to plan for the future:

“I am not of the age where I can sacrifice something for the future. That’s the case when you are young. That’s for when you are in your 30s, 40s, 50s, or 60s. I was in my 70s years ago, so I need to focus on the present. I don’t know whether tomorrow will come or not.” (M, 79 years old)

In addition, during the interview, participants discussed greatly their current health concerns, including difficulties of symptom management and taking multiple medications. They showed their frustration of ineffective symptom management, saying that even their health care providers were not able to explain the reason for the symptoms. One participant was afraid of discussing his new symptoms since he anticipated that his doctor would add another medication, which would result in another side effect:

“Every night, one (health problem) is added. I have itchiness, but when I see a dermatologist, he/she said there is nothing wrong with me. I don’t know why but if a doctor says it’s fine then I should just go back home...if they can treat the problem, I receive it...that’s just how I live.” (F, 81 years old)

“If it (medicine) works, that’s good. My urination might get better, but I am worried that other thing could be affected, like my liver. That’s why I hesitate to see a doctor.” (M, 75 years old)

“Coughing is the biggest problem now. I may need to see an ENT doctor. It is no use talking to other doctors. I talked to my current doctor, Dr.XX, but I guess he does not have any more medicine for me because I have coughed for long time.” (M, 85 years old)

4.5.6.2 Uncertainty of the future

Some participants said they do not have specific health care goals since they cannot predict the future:

“Well, you cannot predict that. You know once you get there.” (M, 67 years old)

“You, you cannot predict people’s lives. No one knows what will happen.” (M, 75 years old)

4.5.6.3 Lack of control

Some participants did not consider their lives to be something they can control. Some described it as a fate or destiny; others described it as “God’s will”. One participant described his attitude toward this ‘lack of control’ based on his life

experience of choosing a job as an immigrant. Some participants also perceived that their end-of-life care preference was not in their control. They said they did not want to go to the nursing home, but that's the only place they could go when they get older and become assistance-dependent.

“So, when you live, if you are doomed, you cannot help it. That is fate. You should say that is fate.” (M, 85 years old)

“In Korea, when you choose job, you consider what I have learned from school something like that, in general. But when you immigrate, for first generations, there are few people who do what they have learned. Everyone come here without choices and job of the person who pick you up from the airport, that become your job (laugh)” (M, 67 years old)

4.5.7 Health care goals

While some participants described that they did not have specific goals, others answered that their health care goal was to maintain their current health status or prevent diseases that are prevalent in their respective family history. Most of them did not differentiate their long-term goals from their short-term goals, but, while discussing their health care goals, participants initiated discussions about their end-of-life care.

4.5.7.1 Self-management

When they were asked about their health care goals, the study's participants answered that maintaining their current health by keeping up their self-management through healthy diet and exercise was one of their goals. They also believed that their

psychological well-being would affect their health and stated that their health goals also include maintaining psychological health.

“Well, rather than saying that I have certain goals, I keep studying, reading books, and writing notes. Also, I go to the gym and work out 5 or 6 days in a week, steadily. That’s my goal, keeping up that steadily. In other words, my goal is not being lazy.” (M, 79 years old)

“From now on, I think I should do more exercise. I have not gone to the gym so far. Just work and home.. (...) After that... what else... Like food. I try not to eat greasy food that much. I avoid it.” (F, 71 years old)

“As far as I know, dementia and stroke is the most scary (disease). So I pray to God saying: “I do not want that, Lord please save me.” I always pray, I always try to be happy listening the hymn or sermon, that is how I try.” (F, 80 years old)

4.5.7.2 Prevent disease via family history

Participants from this study were not able to obtain a family history from their parents since medical technology was not advanced in Korea when their parents received medical care. However, as their siblings have aged, participants started to become informed that they have similar diseases among siblings. Thus, they stated that their health care goals became more focused on preventing the disease that their family members were experiencing.

“Well...that is... I should say I have (family medical history). But in our generation... My parents passed away early. (...) They had an illness and then passed away but I do not know specifically. It was common at that time. Some people die of something have a specific diagnosis, but at that time health care service was not widely available. So it is hard to say what was the diagnosis or what caused them to die.” (M, 67 years old)

“But my biggest concern is that one. Since it was all of sudden, that my brother passed away because of the heart attack. (...) I did not think about that much, because I was young at that time. But since I am aged, and also my brother is only 3 years older than me so.” (M, 75 years old)

4.5.7.3 End of life care

While the study’s participants did not state receiving good end-of-life care as a health care goal, they revealed their end-of-life care wishes while discussing their health care goals and concerns. Some participants completed their advance directives; most of the participants were opposed to life-sustaining treatment and had funeral planning in mind, but only a few of them stated they have discussed end-of-life care preferences or funeral planning with their children.

“I don’t want to do oxygen respirators when we are incurable. We wrote those all. We have the document notarized. (So you wrote the advance directives?) Yes.” (F, 75 years old)

“Oh.. I said don’t do that. Don’t do that... Respirator, you don’t need to do that. When it is time, you should let people go. I do not want a respirator or those kinds of things.” (F, 86 years old)

“My brother-in-law is buried in the 00 cemetery, but their children don’t go there that much. It’s not like the old days. We should know that. Moreover, I do not have children here, so. Just totally. I told my daughter that “I wrote a memo for my body, so you should cremate my body.” (F, 86 years old)

“Of course, my son does not want to do that (cremation). Well, because he is a son, it [planning a funeral] is his duty. He just said, “Don’t say such a thing, just live a long, healthy life”. What else can he say now?” (F, 81 years old)

4.5.8 Health care priorities

4.5.8.1 Independence

Participants described their status using a Korean concept of “MinPae” (민폐). This Korean word meaning “bothering others ” or “being burden to others” reflect their unhappiness with being dependent on others. They described that being dependent becomes “MinPae” to not only their children but also to the health care providers and even the government since they are using tax money.

“People said that you beg for your life once you are ill and hospitalized. But to be honest, what is the meaning of living in that way? It causes troubles to children and country... it bothers everyone.” (F, 75 years old)

“(I prefer) The way not bothering others. I would rather bedridden with my illness. It is 10 times, 100 times better. It is better not bothering people around you.” (F, 75 years old)

“Maybe.. I think I should do that (live alone if I am widowed), I think it’s clearer (In what way?) Well.. So I don’t owe anything to anyone..” (F, 72 years old)

This value was highlighted from a woman (Figure 10) who lived her entire life independently. She was born in a rural area in Korea, but, when she was 20, she moved to Seoul to work. She described herself as “different from the ordinary girls” and she did not want to become a traditional woman. She ran her own business while she was in Seoul but decided to immigrate to the US after she realized that her business was in jeopardy as most of the business in Korea was becoming industrialized. After working in the US for years, she started her own business. She described herself as “always been independent”, which directs her value of being independent in her later life.

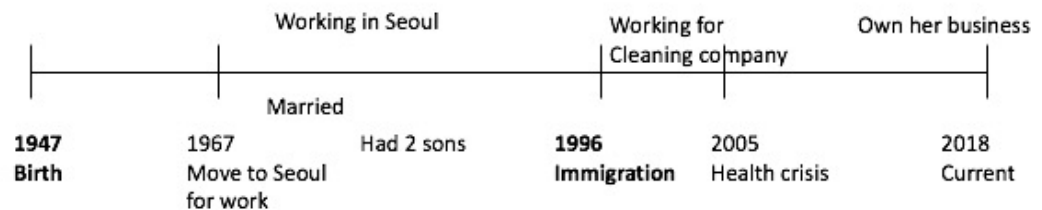


Figure 10: Life Trajectory of Participant A

4.5.8.2 Painlessness

Participants with advanced illnesses particularly emphasized painlessness as their goal of care. They were worried about the pain by prolonging life in the hospital.

One participant stated that staying at the hospital for a week was ideal since it was not long enough to endure too much suffering and also could give their children time to emotionally prepare for her death.

“First of all, I wish I do not have pain anymore. If I become bad in shape, usually people go to a nursing home in the US. My children try not to send me to there, but maybe (I think) that’s the place I would die...My wish is to die, before I go there, like my husband.” (F, 86 years old)

“Now I am just waiting for a day that I will die. I wish I could die without any suffering. (So you don’t have any pain) Without pain...hopefully.” (F, 81 years old)

For Participant B (Figure 11), painlessness is the most important factor in her later life because she has been ill for her entire lifetime. She said she had a bad bladder and kidney disease since she was 15 years old; thus, she was not able to do anything. She happened to hear that there was a charity clinic in another city, so she went there and got treated. She thought that it was a miracle, but her disease was not totally cured. She had had inflammatory symptoms and had surgery multiple times, including bladder and kidney transplantations. She described, “I could not enjoy this good era because I was always been sick and suffered,” and also stated, “There should be God’s will that he made me still alive but I have not figured out, why I am still alive with all those diseases.” From her lifelong illness and suffering, her priority in her later life health care became painlessness.

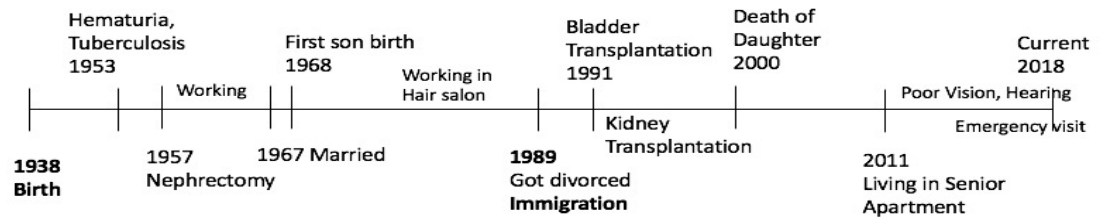


Figure 11: Life Trajectory of Participant B

4.6 Discussion

This qualitative descriptive study examined older Korean immigrants' health care goals and priorities in their later lives using the life-course approach. Participants in this study had gone through historical events in modern times, including Japanese colonial periods and Korean wars in their early lives. Most of them immigrated to the US around the 1980s with an expectation of being better off in their positions. They had a negative attitude toward aging. Many associated being old with their physical and functional declines, and some of them moved or were planning to move to places near their children in the US to get help from their children in their later lives. Older Korean immigrants had interdependent lives within Korean communities in the US. Those Korean communities were mainly formed based on Korean churches; thus, some of the older Korean immigrants considered the church as a place for not only their religious beliefs but also a social network. Their children were also an important support source, as their adult children take care them and act as a translator and advocate of them in US

society. Even though older Korean immigrants in this study shared their difficulties as immigrants, most of them perceived the US social system as fair and civil and were satisfied with the welfare that the government provides. Thus, they had wished to give back to society in various ways.

Unlike the researcher's assumption that older Korean immigrants would have health care goals that they want to achieve, some of them did not. This finding is consistent with a previous study that found older adults in US rural areas had not thought about their future health care needs or arrangements (Weaver, Roberto, & Blieszner, 2018). Similarly, in Chiu, Feuz, McMahan, Miao, & Sudore's study, which examined the advance-care planning of diverse, older adults—including whites, African Americans, Hispanics, and Asians—with multiple chronic conditions, 30% of them have not set their goals of health care because they were not ready to discuss the plan (2016).

Older Korean immigrants in this study were more present-oriented in their current health care issues, which prohibited them from setting health care goals for the future. Particularly, older Korean immigrants in this study were dealing with current health issues related to their multiple chronic conditions. One of the health concerns was an increase of symptoms related to their chronic disease and difficulties of symptom management. Older adults with multiple chronic conditions have multiple health care providers who has single treatment approach to specific chronic illness. Older adults in Canada also reported that their current health care approach is not wholistic and does

not address their complex health care needs (Ploeg et al., 2019). Another current health issue that older Korean immigrants reported was polypharmacy. Older Korean immigrants in this study lacked the knowledge of medications they were taking and stated their concerns with side effects of their medications. In Cervantes, Jones, Linas, & Fischer's study, Latinos who had advanced chronic illness also reported their concerns with medication because they were afraid of dependence or side effects of the medication (2017). Similarly, some of the older Korean immigrants believed that their symptoms, such as a tingling sense or itchiness, is a side effect of their medication; thus, they were reluctant to discuss their physical symptoms with health care providers because they thought that either they needed to endure it for treatment of their chronic illness or their doctor would add another medication for symptom treatment, which they did not prefer.

Older Korean immigrants stated their health care goals as keeping up with self-management, such as healthy diet or exercise. In addition, older Korean immigrants in this study emphasized the importance of psychological health since they believed that maintaining good mental health, such as being happy, could prevent future disease. Older adults dwelling in the US community reported that they are trying to stay as healthy as possible while recognizing their declining health conditions related to their multiple chronic conditions (Ploeg et al., 2019). Similarly, older Korean immigrants planned to stay as healthy as they could via self-management. In addition to these

general self-management measures, they planned to prevent the occurrence of their family diseases in which they learned about via information from their siblings.

While discussing their health care goals, older Korean immigrants also discussed their end-of-life wishes. Some of them stated they wrote documents of advance-care planning or discussed their wishes to doctors. Other older Korean immigrants in this study had their own wishes in their end-of-life care, but they were not confident that their wish would be incorporated to their care in the future. This is because older Korean adults believe that their family is the final decision-maker (Kwak & Salmon, 2007).

Maintaining independence and painlessness were important values for older Korean immigrants in their health care. Previous studies targeting the older adult population showed that older adults value independence, and it is significantly associated with their quality of life. Older adults who are dwelling in US rural areas valued maintaining independence and were concerned about burdening their families or friends when they became dependent on them (Weaver et al., 2018). This is especially true among oldest-old adults, as they valued functional independence more and less-valued morbidities and pain experience compared to younger-old adults (Hofman et al., 2015). Scottish older adults also expressed their wishes to be independent in their older age and wanted health care services to support their independence (King & Farmer, 2009).

4.7 Conclusion and limitation

One of the limitations of this study is that study participants mostly identified themselves as Christians. However, the level of religiosity of participants could be various since the Korean church was an important community resource for older Korean immigrants, thus some Koreans go to churches for networking. However, most women participants were very religious, and the way they delivered their lives and perspectives on life and health care reflected their religiosities. Most men in this study were also religious, while one participant was very critical toward religion. He was emotionally disconnected from Koreans who go to church, including his own son. Older Korean immigrants who are not church goers would be the people who need health care resources and information, particularly as the Korean church serves a role as a Korean community in the rural area. However, those Koreans who do not attend church were extremely difficult to reach. Thus, these research findings were not able to reflect the perspectives of people who are underrepresented, even among older Korean immigrants.

To the best of knowledge, this study is the first qualitative research that investigated health care goals and priorities of older Korean immigrants via individual interviews. Particularly, this study provided a thick description of older Korean immigrants' health care goals and priorities by investigating their life experiences using the life course approach. This study provides in-depth information on the perspectives

of older Korean immigrants' health care in their later lives and implications on using life course theory to investigate end-of-life research among ethnic minority group.

5. Conclusion

The ethnic diversity of older adults in the United States is growing. Older Americans are estimated to grow to 98.2 million in 2060, which will account for nearly 25% of the population at that time (US Census Bureau, 2015). The population of minority groups, including African Americans, American Indians, Alaskan Natives, and Asians, is also expected to increase significantly between 2014 and 2060, which will account for nearly 60% of the population at that time (US Census Bureau, 2015). Accordingly, the Institute of Medicine (IOM) recognized the importance of culturally competent care for these 'majority minority' people (Institute of Medicine [IOM], 2015). Korean Americans constitute the 5th largest ethnic group among Asian Americans. Over 1.5 million Korean Americans are living in the US, 14% of whom are 65 years or older (US Census Bureau, 2015). The preference and acceptance of end of life (EOL) care is highly influenced by a person's cultural background, which guides and shapes a person's values and wishes (Giger, Davidhizar, & Fordham, 2006). For this reason, this dissertation study explores older Korean Americans' EOL care decision making.

In Chapter 2, I explored what is currently known about EOL care among older Korean immigrants by conducting a literature review. As limited studies have examined older Korean immigrants' views on EOL care, I expanded the target population of this review to include older Korean Americans as well. In Chapter 3, I reported methodological issues I encountered while conducting a pilot study to investigate older

Korean immigrants' EOL care decisions. Decisions related to advance directives, such as completion, designation of proxy, or disclosure of terminal illness, were investigated among older Korean immigrants with chronic illness. In Chapter 4, reflecting on the methodological and practice issues from the pilot study, I examined older Korean immigrants' health care goals and priorities. This qualitative descriptive study was conducted to obtain a broad understanding of the health care goals that older Korean immigrants set later in life, with the aim of also indirectly discussing EOL care. In addition, life course theory was used as a theoretical framework to conduct an in-depth and meaningful exploration of older Korean immigrants' perspectives on setting personal health care goals. In this chapter, I summarize below the main findings of my dissertation, note any limitations, and offer future suggestions on research and care provision of older Korean immigrants.

5.1 Main findings

This dissertation study investigated older Korean immigrants' health care goals in their later life. In chapter 2, a literature review was conducted on end of life (EOL) care among Korean Americans: five themes were derived from the synthesis of 11 studies. These five themes were the influence of ethnicity and acculturation levels of Korean Americans on EOL care; lack of EOL discussion with health care providers and among family members; the preference for conditional disclosure of terminal illness;

dependence on family members regarding EOL decisions; and low levels of awareness, knowledge, and utilization of EOL care.

From the literature review, I discovered a research gap in regard to providing a holistic understanding of Korean Americans' attitudes towards EOL care. Second, all qualitative studies that investigated Korean Americans' EOL care were conducted using the focus group interview method. Focus group interviews can prevent individuals from sharing their true opinions, particularly when they have strong subjective norms constructed by their culture. Third, no research has yet been conducted on the decision making of older Korean immigrants. These research gaps prompted me to design a pilot study of older Korean immigrants' decision making on advance directives.

In chapter 3, I described the methodological issues I encountered while conducting the pilot study. The research topic (EOL care), research place (participant's home), and research method (qualitative interview) were all found to be barriers to recruitment. Moreover, changing the age cutoff from 65 to 60 did not increase recruitment rate. During the data collection phase, older Korean immigrants' reluctance to provide their signature, preferred language, and level of emotional distress also created challenges. In the data analysis phase, methodological issues of translation, use of case vignette, and biased sampling were found. Lessons learned from this pilot study were considered when designing the main study, which investigated older Korean immigrants' life course and health care goals.

In Chapter 4, older Korean immigrants' health care goals and priorities were examined using life course perspectives. Older Korean immigrants experienced a dynamic historical period in Korea before immigrating to the US. Once they reached the US, their economic life improved although they were now disconnected from their social support and traditional values. Children and Korean churches constitute older Korean immigrants' primary support system once in the US. Their tumultuous life experiences contributed to their current perspectives on health care goals and priorities (Figure 12).

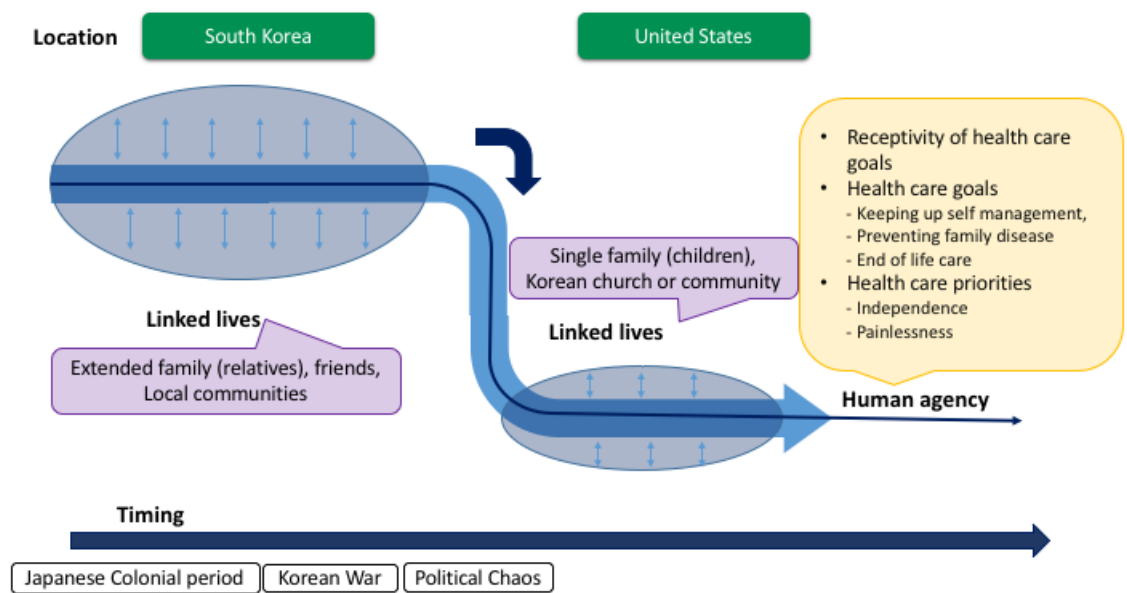


Figure 12: Life course of older Korean immigrants

5.2 Limitations

There are two limitations of this dissertation study that need to be addressed. First, this dissertation study was not able to comprehensively capture the phenomenon of EOL decision making. EOL decision making is a complex process. As such, even if an

individual has thought about their EOL care and set care goals in advance, their decisions could change depending on their situation. The best way to capture the phenomenon of EOL care decision making would be to study patients while they are in the midst of making EOL care decisions, or immediately after they have already made such decisions. However, studying patients who are currently in the middle of making EOL care decisions poses several challenges, including ethical considerations. For these reasons, I approached older adults with multiple chronic conditions for my dissertation study since their declining health status and health-related changes to their quality of life might reflect the situation they will face in an EOL context.

Second, the understanding of older Korean immigrants' perspectives might be limited due to issues with translation. The data were collected in Korean and subsequently translated into English during the data analysis process. More narrative richness could be achieved when translating the data during the data preparation period (Santos et al., 2015). However, in this study, the translation was undertaken during the data analysis due to time and financial constraints. As a result, the credibility of this study might be limited in this regard, as original meanings and nuances of the language may have been lost in translation.

5.3 Suggestions and implications

The dissertation study provides primary data on how older Korean immigrants establish their health care goals and priorities. Based on the main findings of this

dissertation study, I provide suggestions and implication on future research, health care provision in clinical setting, and health care education as follows: (i) Use of the life course theory in exploring older adults' health care goals, (ii) Receptivity of goal setting: palliative care, (iii) end of life care communication within narratives, (iv) End of life care discussion among family members, and (v) Culturally competent care for older Korean immigrants.

5.3.1 Use of the life course theory in exploring older adults' health care goals

Life course theory was adopted to direct the study design and interpret study findings and the use of this theory made it possible to describe older Korean immigrant's perspectives in a holistic manner by providing the context of their individual lives. This context was obtained by the dynamics of response to the timing of external events (Timing), cultural backgrounds (Location) and cultural, as well as institutional, social psychological, and sociobiological interactions (Linked lives). In addition to individual health care goals (human agency), I described the participants' individual life trajectories and provided a rich understanding of their health care goals. Using life course theory, this dissertation investigated older adult's health care goals for later in life, which are shaped by their unique life experiences. In researching end of life (EOL) care among ethnic minority groups, it is important to acknowledge individual differences while simultaneously understanding the general cultural background behind individuals' values and perspectives. Life course approach provides both a contextual

understanding of older adults' backgrounds and the trajectories of their individual life courses. Thus, I recommend future studies to explore EOL care goals and priorities using life course perspectives of other ethnic minority groups, such as African American or Hispanic populations. Moreover, cultural-specific beliefs and values can be identified more clearly when research findings are compared using a similar research method. Further research on the general population will be valuable to understand the influence of culture on individuals' decisions regarding health care goals and priorities later in life.

5.3.2 Receptivity of goal setting: palliative care

Setting the goal of health care is important for older adults with multiple chronic conditions. Older adults can incorporate their current health status to their lives by setting health care goals and working towards those goals in the context of their declining health status and chronic conditions. However, before acknowledging the benefits of setting health care goals and encouraging older adults to do so, health care providers should understand the receptivity of setting health care goals among older adults. In this study, some older Korean immigrants have not set any health care goals since they thought it is unnecessary. They thought they did not need to plan anymore because they were already old or because they could not predict the future. More importantly, older Korean immigrants in this study have gone through challenges in managing current symptoms related to their chronic conditions, which keep them from

prioritizing setting health care goals for the future. Thus, health care providers should address older adults' current health issues and seek better ways to improve health care provisions with older adults to set future health care goals.

Palliative care is an ideal approach for these older adults with multiple chronic conditions to address their current health concerns and set future health care goals. This study showed older Korean immigrants' frustrations with their difficulties in managing unexplained symptoms, and they are also concerned about side effects as a result of the multiple medications that they are taking. Palliative care would enable health care providers to approach these populations with holistic views focusing on symptom management rather than treating each chronic illness. Older adults with multiple chronic conditions would be able to care for themselves effectively and lessen their burden of treatment and health care management with this realistic approach. In addition, palliative care could help health care providers discuss health care goals in relation to older adult's end-of-life care. While cancer patients usually have a sudden event of becoming ill that causes an early openness toward discussing hospice and palliative care, patients with organ failure or frailty do not have a clear event of illness or decline; thus, they are not as open to discussing their end-of-life care (Kendall et al., 2015). To understand the patient's goals, health care providers and patients need substantial interactions and communications to clarify and understand the patient's values and preferences on care (Shah, Swinton, & You, 2017). Thus, discussions between

health care providers and older adults in regard to their health care values and goals can lead them to discuss end-of-life care without a specific event to initiate those conversations.

5.3.3 End of life care communication within narratives

It is not uncommon that people avoid talking about death across cultural backgrounds for various reasons. Those tendencies make it difficult for health care providers, patients, and their families to initiate and discuss end-of-life care. From the pilot study in Chapter 3, the researcher found that older Korean immigrants were reluctant to discuss end-of-life care; thus, in Chapter 4, the researcher tried to create understanding regarding older Korean immigrants' perspectives on end-of-life care decision-making by exploring the health care goals of older Korean immigrant's in their later lives. Surprisingly, many older Korean immigrants in this study initiated their end-of-life wishes while they were discussing health care goals. In the first interview, older Korean immigrants with multiple chronic conditions and advanced illnesses shared their concerns on their end-of-life care while discussing the current concerns of their declining health status. In the second interview, older Korean immigrants stated their end-of-life care while they shared their life histories in a chronological order. This approach implies that end-of-life care research could be conducted without necessarily mentioning the terms that some older adults deem taboo or feel uncomfortable talking.

Applying narrative research methods in end-of-life care research could be a good way for older adults to engage in the research and for a researcher to have in-depth insights on older adult's perspectives and behaviors. Fisher depicts a human's nature as a storyteller, referring to them as "Homo Narrans" (1984). Furthermore, older adults who are full of life experiences and developed their perspectives through those experiences have the quality to be a great storyteller. A narrative is not only the stories people talk about regarding themselves but is the process of making a story by reflecting their experiences, as they want others to see the way it is depicted (Becker, 1997, p.25; Polkinghorne, 1988, p.13). Thus, narrative research could help participants to provide their thoughts and values on end-of-life care while they construct their stories.

Narrative research is beneficial for researching end-of-life care on ethnic minority groups by providing a good tool to understand their underlying cultural backgrounds. This is because a narrative is a culturally congruent way to ascertain and understand the experience, and explaining narratives help to understand how people make sense of their world (de Medeiros, 2014; Lee, Fawcett, & DeMarco, 2016). There is no "cookbook" approach to provide culturally sensitive care to ethnic minority older adults. Searching for those resources or tools would only reinforce stereotypes or generalizations about different cultural beliefs, values, and practices. Storytelling can be helpful to understand different values in end-of-life care by illustrating culturally grounded messages and experiences of older adults with culturally diverse backgrounds (Lee et al., 2016). Thus,

further research on end-of-life care research is needed using narrative gerontology which comprehends, explains, and predicts older adult's health care through their narratives (de Medeiros, 2014).

Many health care providers have difficulty initiating and discussing EOL care with their patients, especially when their patients' cultural backgrounds are different from their own. This study found that older Korean immigrants were reluctant to discuss EOL care and participate in EOL care research when I initiated the discussion about advance directives. However, while they shared their health goals and life experiences in a narrative way, they shared their thoughts about EOL care naturally. Thus, the narrative method would be a good communication strategy to implement in clinical practice when patients are reluctant to discuss EOL care.

5.3.4 End of life care discussion among family members

The findings of this dissertation provide insight into the different family dynamics among immigrants and their influence on older adults' health care. Family members of older adults play an important role in end-of-life care and decision making. Preferences or opinions of family members influence care decisions that older adults make, and the family makes decisions on behalf of older adults when older adults become too ill to make decisions on their own (Keeley, 2016). Conflicts among family members on health care plans were one of the barriers that makes health care providers discuss health care goals with patients (You et al., 2015); thus, it is crucial for older

adults and their families to have end-of-life care discussions to understand each other and set health care goals based on those understandings.

Although the parents may be Korean immigrants, the children were often born and raised in the US. Older Korean immigrants may either be married to other Korean immigrants or individuals of other races. When both parents are immigrants, there may be a significant difference between the parents' and children's notions of culture. These difference in culture can cause conflict while also strengthening the role of children as "protector". In Korea, "filial piety", in which adult children are responsible for taking care of their parents, is a strong cultural norm. Even though the children of older Korean immigrants are not familiar with this norm, they often serve as advocates and translators for their parents since childhood. In addition, as the findings presented in Chapter 4 indicate, children of older Korean immigrants are an important support source for older Korean immigrants with an otherwise limited support system in the US. Thus, the role of older Korean immigrants' children is different from the role of other children in society, and this can affect the health care of older Korean immigrants.

Older Korean Americans and their adult children are reluctant to initiate end of life (EOL) communication, either because it is taboo or because of the concern that talking about death or dying would hurt each other's feelings (Ko & Berkman, 2010; Kwak & Salmon, 2007). In this study, older Korean immigrants shared their difficulties in discussing end-of-life care wishes with their adult children because their children

were not willing to discuss them. This is consistent with the previous study reported that children of older Korean Americans are resistant to discuss end-of-life care with their parents (Ko & Berkman, 2010). Similarly, Latino older adults reported that their children did not want to discuss end-of-life care even when older adults were willing to talk (Gutheil & Heyman, 2006). In addition, the reluctance of discussing advance-care planning among family was one of the barriers as to why Latinos who were on dialysis had no advance-care plans in place (Cervantes et al., 2017). On the other hand, from Lewis et al.'s study, caregivers thought that it was patients who did not want to discuss their death and dying (2019). The reluctance of discussing end-of-life care was mostly focused on older adult's perspectives, and not many studies investigated caregivers or adult children's perspectives. Adult children may not be ready to discuss end-of-life care of their parents because of fear of parental loss.

In EOL care, family dynamic plays an important role in decision making. Health care providers offer EOL care that satisfies both older adults and their families when there is open communication and discussion on EOL care for older adults among family members. However, older Korean immigrants in this study reported several barriers to communicating about EOL with their children. Thus, further research on the perspectives of adult children of older Korean immigrants, particularly their readiness and acceptability to discuss EOL care with their parents, is needed.

5.3.5 Culturally competent care for older Korean immigrants

Older Korean immigrants' health care goals and priorities in their later lives were not different from those of other ethnic groups. However, reasons underpinning those care goals and priorities were originated from Korean culture. For example, older Korean immigrants valued independence and thought they should not live too long because of "MinPae". The original meaning of "MinPae" is to cause harm, inconvenience, or a nuisance. In the context of health care, "MinPae" is close to "being a burden" or "bothering others". It is very important for Koreans not to be "MinPae" to others because of the subjective norm. Being "MinPae" does not only include their family who take care of them but also includes the society that older Korean immigrants belong. For them, living too long results in becoming "MinPae" to health care providers since health care providers take care of them for nothing and they will not be fully recovered. Living too long is also "MinPae" to society because they are spending the government's money for a long time. For older Korean immigrants, it is important to harmonize their needs to the needs of the family and the society that they belong to. Thus, they would make individual health care decisions in a way of negotiating their needs as long as it is not "MinPae" to others. It is important to understand the reasons underlying older Korean immigrants' values in addition to decisional outcomes or preferences of older Korean immigrants to provide culturally competent care.

Older Korean immigrants hold traditional Korean values since they spent substantial time in Korea before they immigrated to the US. However, they also acknowledged that the perspectives of their children who were born and raised in the US are different from their perspectives who are still under the influence of the Korean culture. In addition, older Korean immigrants in this study did not put importance on maintaining traditional values, stating they were acculturated to the US culture to some degree. Older Korean immigrants have lived in the US longer than they lived in Korea, and they might be influenced by their children who have a US cultural background. In addition, most older Korean immigrants were Christian, which made them follow more religious beliefs and values than traditional Confucius ideas. Thus, this mixture of cultural aspects should be considered in caring for older Korean immigrants.

As the population of older immigrants increases, health care providers encounter more patients from various cultural backgrounds. Open communication with patients is key to provide culturally sensitive care to these patients. In a clinical setting, the narrative approach discussed in this dissertation study would promote communication between health care providers and patients, and thus enhance health care providers' understanding of patients who are from different cultures.

Appendix A

Interview Guide (English)

Older Korean immigrants' decision making on advance directives: A Pilot Study

All interviews will be done conversational manner

[First Interview]

1. Demographics

- Age:
 - What year and where were you born?
- Immigrant status
 - When and what was the purpose did you moved to the US?
 - How long do you plan to stay here in the US?
- Education level
 - What is the highest level of education?
 - Where did you complete this degree?
- Religion
 - Do you consider yourself religious or spiritual?
 - Do you go to a place of worship, such as church? If yes, how often?
 - Do you engage in religious activities including group activity or individual praying? If yes, how often?
 - How many friends of yours are from your church?
 - How important is religion/religious belief in your life?
 - How much has religion played in making your important life decisions?
(For example: marriage, moving, finding a job, medical decisions)
- Family

- Have you ever been married? How long have you been (married, widowed, divorced)?
 - Who are you living with now?
 - Do you have children? How many? Are they married?
 - Where do your children live now?
 - How often do you meet with them?
 - How often do you talk with them on the phone?
 - How comfortable are you sharing your personal situation with your children?
 - Who do you plan to call for help if you become sick and in need of help?
 - Who usually makes decisions for the family?
- House Income
 - Are you currently working?
 - What is your main financial source?
 - Do you feel satisfied with your financial status? (sufficient for living, not sufficient for living)
 - What is your health insurance type?
 - Who pays for your health care fees?
 - Do you ask financial assistance from your children from time to time? If yes, how often?
 - Do your children or family ask financial help from you from time to time? If yes, how often?

2. Knowledge and attitude toward advance directive

- Have you heard of advance directives?
- If yes, in your own words and understanding, can you describe what advance directive is?
- If no, advance directives are a written statement of a person's wishes regarding medical treatment, often including a living will. These statements

are made to ensure a person's wishes are carried out should the person be unable to communicate them to a doctor.

- What do you think of the idea of advance directives?
3. Experience of significant other's EOL care and decision making
- Have you ever witness significant other's terminal illness and EOL care? If yes, can you share?
 - Have you ever made EOL decisions (such as advance directives, hospice care, preference of life sustaining treatment, place of death) for others? If yes, can you share?
 - How have those EOL care experiences affected you?
 - Would you change any of the choices you have made with respect to those EOL decisions

Good, this is all for now. Thank you.

In the next interview we will talk about more specific case about EOL situation and I would like to hear your opinion about that,

[Second interview]

1. Feedback of last interview
 - How did you feel after the last interview?
2. Priming questions for interview

- Have you ever discussed your EOL care with others? (i.e. advance directives, hospice care, preference of life sustaining treatment, place of death)

IF YES

- who did you talk with?
- when and how it happened?

IF NO

- why do you think the discussion did not happen?

3. Vignette case

Let us talk about cases and I want to hear how you feel about these cases. There are no wrong or right answers because each person reacts differently and that is okay.

Ms. Choi is a 75 years old women, protestant, and widowed. She has 2 sons and 1 daughter. They are all married and living in different states. They get together every holiday. She is financially independent from her children, but her children give her money on holidays and on her birthday. She has hypertension and hyperlipidemia but is able to control her blood pressure and lipid levels by taking medicine. She went to the clinic for check-up and heard about advance directives

- 1) Do you think Ms. Choi needs to write an advance directive? Why or why not?

She decided to write an advance directive and wanted to designate her daughter as her proxy. She called her daughter and asked her opinion. Her daughter agreed to be her proxy, but suggested not to write an advance directive at this point, because Ms. Choi is still healthy. Her daughter also said the fact that her mom is considering an advance directive hurts her feeling.

- 2) What do you think Ms. Choi should do? Why?

After her daughter's suggestion, Ms. Choi hesitated to write her advance directive, because she does not want to hurt her daughter's feeling. Therefore, Ms. Choi decided to get advice from pastor and discussed this with him. The pastor suggested that even if her daughter is opposed to completion of an advance directive, it would be helpful to both her and her family to do

so. He went on to say that she doesn't need to hurry, because she is still healthy and has enough time to consider her options.

3) What do you think about the pastor's advice?

4) What do you think Ms. Choi should do? Why?

After a while, on her birthday the family got together. Ms. Cho felt faint and dizzy. She and her family went to clinic and she was diagnosed with an early stroke. On admission, the physician asked her about advance directives, and she was reminded of the discussions regarding advance directives. She talked to her family about writing an advance directive and designated her daughter as her proxy. Her sons were surprised that she only discussed this with their sister and insisted that the first son should be her proxy. Ms. Choi thought that her daughter would understand her wishes better than her two sons, but could not tell this to her sons, because it could hurt their feelings. After hearing from her elder brothers, her daughter also said to Ms. Choi that it might be better to designate her brother as the proxy.

5) What do you think about two sons' opinion?

6) What do you think Ms. Choi should do? Why?

Finally, Ms. Choi made decision to write an advance directive and designated her first son as her proxy. After 10 years, she turned 85 years old and she was diagnosed pancreatic cancer. The physician said that she was stage 4, a terminal stage of cancer. Her family members didn't want to let her know, because they thought she would be shocked. Therefore, her sons and daughter told Ms. Choi that she has pancreatic ulcer, and she will be treated soon.

7) What do you think about the family's decision? Do you think the family should disclose the terminal stage to her? If so, how and who do you think should give her this news?

In her advance directives, she didn't want any life sustaining treatment including chemotherapy. However, her family, including her first son, wanted to try every treatment to cure their mother. Therefore, Ms. Choi's family member asked the physician to continue with aggressive treatment.

8) What do you think about the family's decision?

9) If Ms. Choi knew that her wishes are opposed to her children's wishes, what should she do?

[Third interview]

- How did you feel after the last interview?
- What do you think about the vignette? (Easy to understand? Is it realistic?)
- Can you suggest another case that I can use to discuss this EOL care?
- How do you generally feel about talking about EOL care?
- When you were listening the case, were you put yourself in Ms. Choi's position?
- What is your general opinion regarding this entire study? Do you have any suggestions?

Appendix B

Interview Guide (Korean)

미 거주 한국 이민 노인의 사전의료의향서에 대한 의사결정: 예비 연구

모든 인터뷰는 대화 형식으로 이루어 질 것입니다.

[첫번째 인터뷰]

1. 인구학적 특성

- 나이:
 - 몇년도에 태어나셨나요?
 - 태어나신 고향이 어디신가요?
- 이민 상태:
 - 언제 어떻게 미국으로 오시게 되셨나요? (어떻게 이민 오시게 되었나요?)
 - 미국에 계속 계실 예정이신가요, 아니면 한국으로 돌아갈 계획이 있으신가요?
- 교육상태:
 - 학교를 어디까지 마치셨나요?
 - 어디에서 마지막으로 학교를 나오셨어요?
- 종교:
 - 종교를 가지고 계신가요?
 - 교회(또는 성당, 절)에 가시나요? 얼마나 자주 가시나요?

- 교회 단체 활동 또는 집에서 기도와 같은 종교활동을 하시나요? 얼마나 자주 하시나요?
- 친구 분들 중에 몇 분 정도가 교회 친구분들이신가요? (대부분, 반 정도..?)
- 어르신의 삶에서 종교가 얼마나 중요한 비중을 차지하나요?
- 어르신께서 중요한 결정을 내릴때 예를 들어 결혼이나 이사, 직업, 또는 의료적인 결정을 내릴때 종교가 얼마나 영향을 미치나요..?
- 가족:
 - 결혼 하셨나요? (결혼, 사별, 이혼 하신지) 얼마나 되셨나요..?
 - 현재 누구와 함께 살고 계신가요?
 - 자녀가 있으신가요..? 몇명이 있으신가요..? 모두 결혼하였나요..?
 - (결혼하지 않으신 경우) 가장 가까운 가족분이 누구신가요..?
 - 자녀분들이(가까운 가족분이) 지금 어디에 살고 계신가요?
 - 얼마나 자주 자녀분들(가까운 가족분들)을 만나시나요?
 - 얼마나 자주 자녀분들(가까운 가족분들)과 통화 하시나요?
 - 개인적인 상황에 대해서 얼마만큼 자녀분들에게 터 놓고 얘기 할 수 있으신가요?
 - 몸이 아프거나 도움이 필요할때 누구에게 도움을 요청하실 수 있습니까?
 - 가족과 관련된 결정은 주로 누가 대표해서 내립니까?
- 경제적 상태:
 - 현재 일을 하고 계시나요?
 - 현재 주요 수입원(생활비)는 어떻게 되시나요?
 - 현재 경제적 상태에 만족하시나요? (생활하시기에 충분하신가요 혹은 부족하신가요?)
 - 의료보험 종류가 어떻게 되시나요?
 - 병원비는 주로 누가 부담을 하시나요?
 - 때때로 자녀분들께 경제적인 도움을 받으시나요? 만약 받으신다면 얼마나 자주 받으시나요?

- 자녀분들이 때때로 어르신께 경제적 도움을 받으시나요? 만약 받으신다면 얼마나 자주 받으시나요?

2. 사전의료의향서에 대한 지식 및 태도

- 사전 의료 의향서에 대해서 들어보셨나요?
- 만약에 들어 보셨다면 저에게 혹시 설명 해 주실 수 있으세요..?
- (들어본 적이 없는 경우) 사전의료의향서는 어르신의 치료 결정에 대해서 바라시는 바를 미리 적어 놓는 문서이며 보통 유언장이 포함됩니다. 이 문서는 만약 어르신이 많이 편찮으셔서 의사에게 직접 의사전달을 할 수 없으실 경우를 대비하여 어르신의 바람대로 치료가 이루어 질수 있도록 적어 놓는 것입니다.
- 이러한 목적을 가진 사전 의료 의향서에 대해 어떻게 생각하십니까?

3. 가족, 친지, 또는 친구분에 대한 생의 말 치료 및 결정에 대한 경험

- 가족분들이나 가까운 지인분들 중 생의 말 치료에 대한 상황을 경험하거나 지켜보신 적이 있으신가요..? 만약 있으시다면 말씀해 주실 수 있으신가요..?
- 가족분들이나 가까운 지인분을 대신하여 생의 말 치료 결정(사전의료의향, 호스피스, 연명치료 결정, 임종 장소 결정 등)을 내리신 적이 있으신지요? 만약 있으시다면 자세히 말씀해 주실 수 있으세요?

- 말씀해 주신 경험이 어르신께 많은 영향을 미쳤다고 생각하시는지요..? 만약 그렇다면 어떻게 영향을 미쳤는지요..?
- 만약 그때로 돌아가 다시 결정을 내릴 수 있다면 다르게 결정을 내리고 싶으신 부분이 있으신지요?

감사합니다. 오늘 인터뷰는 여기까지입니다

다음 인터뷰에서는 생의 말 상황에 대해서 조금 더 구체적인 사례에 대해 이야기 하고 어르신의 의견을 듣고자 합니다.

[두번째 인터뷰]

1. 지난 인터뷰에 대한 의견

- 지난 인터뷰 이후에 어떻게 지내셨어요? (혹시 지난 인터뷰에 대해서 말씀 주실 부분이 있으신지요?)

2. 인터뷰 전 사전 질문

- 생의 말 치료와 관련해서 다른 사람과 이야기 해본 적이 있으신가요? (예를 들어 사전의료의향서, 호스피스, 연명치료 선호, 임종 장소)

(있는 경우)

- 누구와 함께 이야기를 나누셨나요?
- 언제 어떻게 이야기가 이루어졌나요?

(없는 경우)

- 왜 한번도 이야기를 나눈 적이 없었다고 생각하시나요..?

3. 사례

이제 어르신과 한가지 사례에 대해서 이야기 하고 어르신께서 어떻게 생각하시는지 듣고자 합니다. 이 사례에 대해 모두 다르게 생각할 수 있기 때문에 옳고 그른 답이 없습니다. 그러므로 어르신께서 생각하시는 대로 말씀해 주시면 됩니다.

최 할머니(최 할아버지)는 75 세이시고 천주교 신자이시며 수년 전 사별하신 상태입니다. 할머니께서는 2 명의 아들과 1 명의 딸이 있는데요, 모두 출가한 상태이고 미국에는 살고 있지만 각기 다른 주에 살고 있습니다. 그리고 명절마다 가족끼리 모입니다. 최 할머니는 자녀들에게 경제적으로 도움을 특별히 받지 않고 있고 다만 자녀들이 명절 또는 할머니의 생신때마다 용돈을 드리고 있습니다. 최 할머니는 고혈압과 고지혈증이 있으시지만 약을 복용하며 혈압과 콜레스테롤을 잘 유지하고 있으신 상태입니다. 어느 날 최할머니는 정기 검진을 위해 병원에 갔다가 사전의료의향서에 대해서 듣게 되었습니다.

- 1) (어르신께서 생각하시기에) 최 할머니가 사전의료의향서를 쓸 필요가 있다고

생각하십니까? 왜 그렇게 생각하시는지요?

최 할머니는 사전의료의향서를 써 두기로 결정하였습니다. 그리고 막내딸이 대리인이 되어주길 원했습니다. 최 할머니는 딸에게 전화해서 의견을 물었습니다. 막내딸은 대리인이 되는 것에 동의했지만 아직 최할머니가 건강하시기 때문에 지금은

사전의료의향서를 쓰지 않으시는게 어떤지 물어보았습니다. 그리고 막내딸은 엄마가 사전의료의향서를 쓰는 걸 생각하고 있다는 게 마음이 아프다고 말을 했습니다.

2) (어르신께서 생각하시기에) 최 할머니가 어떻게 해야 한다고 생각하시나요?

왜 그렇게 생각하시나요?

막내 딸과의 통화 후 최 할머니는 사전의료의향서를 쓰기를 망설였습니다. 왜냐하면 딸의 마음을 상하게 하고 싶지 않았기 때문입니다. 최 할머니는 자주 가는 교회의 목사님께 조언을 구하기로 마음먹었습니다. 목사님은 따님이 사전의료의향서 작성을 반대한다 할 지라도 사전의료의향서를 작성하는 것이 최 할머니와 가족들에게 도움이 될 것이라고 말하였습니다. 하지만 최 할머니가 아직은 건강하시고 생각할 시간이 충분하기 때문에 서두를 필요는 없다고 덧붙였습니다.

3) 목사님의 조언에 대해서 어떻게 생각하십니까?

4) (어르신께서 생각하시기에) 최 할머니께서 어떻게 해야 한다고 생각하시나요?

왜 그렇게 생각하시나요?

그렇게 시간이 지난 후 최 할머니의 생일날 가족이 모두 모였습니다. 최 할머니는 현기증을 심하게 느껴 가족들과 함께 병원에 갔고, 초기 뇌졸중을 진단 받았습니다. 입원 시, 의사는 할머니께 사전의료의향서에 대해서 물었고 그때 최 할머니는 사전의료의향서에 대해서 고민했었던 것을 떠올렸습니다. 최 할머니는 가족들에게 사전의료의향서 작성과 딸을 대리인으로 지정하려 한 것을 이야기하였습니다. 할머니의 아들들은 할머니가 오직 막내 딸과 이러한 얘기를 나눈 것과 첫째 아들이 아닌 딸을 대리인으로 지정하고자 했던 것에 놀랐습니다. 최 할머니는 딸이 두 아들보다 할머니의 뜻을 더 잘 이해할 것이라고 생각했지만 아들들의 마음을 상하게 할까봐 딸을 대리인으로 지정하려고 생각했던 이유를 설명할 수 없었습니다. 오빠들의 이야기를 듣고, 최 할머니의 딸 역시 할머니께 오빠를 대리인으로 지정하는 것이 맞는 것 같다고 이야기 하였습니다.

5) 두 아들의 의견(아들들과 상의를 했었어야 했음, 첫째 아들을 대리인으로 지정해야 함)에 대해서 어떻게 생각하시나요?

6) (어르신께서 생각하시기에) 최 할머니께서 어떻게 해야 한다고 생각하시나요?
왜 그렇게 생각하시나요?

결국 최 할머니는 최종적으로 사전의료의향서를 쓰기로 결정하였습니다. 그리고 첫째 아들을 대리인으로 지정하였습니다. 10 년이 지난후 최 할머니는 85 세가 되었고 췌장암을 진단 받았습니다. 의사는 최 할머니가 현재 말기의 상태라고 하였습니다. 하지만 가족들은 할머니가 충격을 받을 것을 걱정하여 할머니께 알리지 않기로 하였습니다. 따라서 아들과 딸은 할머니께 췌장염이라고 말씀드리고 치료를 받으면 괜찮을 것이라고 말했습니다.

7) (할머니께 사실을 알리지 않은) 가족들의 결정에 대해서 어떻게 생각하시나요?

할머니께 말기 암의 상태를 알려야 한다고 생각하시나요? 만약 알려야 하다면 누가 어떻게 알려야 한다고 생각하시나요?

최 할머니의 사전의료의향서에는 항암요법을 포함해 어떠한 연명치료도 원하지 않는다고 작성되어 있었습니다. 하지만 할머니의 대리인인 첫째 아들을 포함한 가족들은 할머니를 치료하기 위해 가능한 모든 방법을 시도해 보기를 원하였습니다. 따라서 최 할머니의 가족은 의사에게 가능한 모든 치료를 계속하기를 부탁하였습니다.

8) 가족들의 결정에 대해서 어떻게 생각하시나요?

- 9) 만약 최할머니가 자신의 바램이 가족들의 것과 다른 것을 알았다면, 최할머니는 어떻게 해야 한다고 생각하시나요?

[세번째 인터뷰]

- 지난 인터뷰 이후 어떻게 지내셨나요?
- 지난 번 이야기한 사례에 대해서 어떻게 생각하세요? (이해하기 쉬웠나요? 실제로 일어날 법한 이야기라고 생각하시나요?)
- 이러한 생의 말 치료에 대해서 이야기할 때 또 다른 있을 법한 이야기를 제안해 주실 수 있으신가요..?
- 생의 말 치료에 대해서 이야기 하는 것에 대해서 어떻게 느끼셨나요?
- 사례를 듣고 저와 이야기할 때 최 할머니의 상황에 어르신들의 상황을 대입해 보셨나요?
- 이 연구에 대한 전반적인 느낌/의견은 어떻게 되시나요? 다른 제안사항이 있으신가요?

Appendix C

Letter of Support

Letter of Support

September 19, 2016

To whom it may concern:

We, (Organization of Korean-American Women of NC) are pleased to cooperate with Hyeyoung Park, a PhD student, on the study of “A Pilot Study of Older Korean Immigrants’ Decision Making on Advance Directives”, which aims at investigating the process of how older Korean immigrants view advance directives by describing the interplay of factors contributing to their decision making process. One of the works we do is to help people realize the importance of having completed Advance Directives set up for themselves. We feel this type of work is very important for our community and will help her identify participants and collect data in OKAW of NC.

Sincerely,


Hyeson Reed



Organization of Korean-American
Women of NC

President Hyeson Reed

PO Box 9625
Fayetteville NC 28311

Phone: 910-494-6956
Email: hyesonr@yahoo.com

OKAW of NC provides charitable services and assistance in areas of Social, Health and Welfare Information. OKAW of NC will focus on reaching the needs of all Korean-American Women in crisis situations.

Appendix D

Study Flyer

Older Korean immigrants' decision making on advance directives: A Pilot Study



Do you have an interest in talking about advance directives and end of life planning?

You may be eligible for participation if you are:

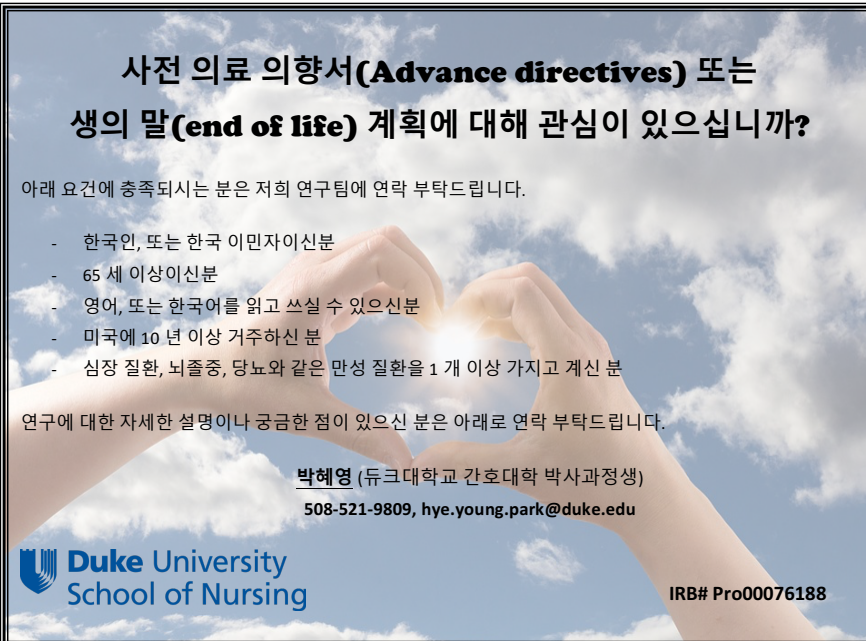
- Korean or Korean immigrant
- 65-year-old or above
- can read and write either in English or Korean.
- stayed in the US for more than 10 years.
- have at least more than 1 chronic disease such as heart disease, stroke, diabetes.

For more description of the study, please contact

Hyeyoung Park (PhD student at Duke University, School of Nursing)
508-521-9809, hye.young.park@duke.edu

 **Duke University**
School of Nursing

IRB# Pro00076188




사전 의료 의향서(Advance directives) 또는 생의 말(end of life) 계획에 대해 관심이 있으십니까?

아래 요건에 충족되시는 분은 저희 연구팀에 연락 부탁드립니다.

- 한국인, 또는 한국 이민자이신분
- 65 세 이상이신분
- 영어, 또는 한국어를 읽고 쓰실 수 있으신분
- 미국에 10 년 이상 거주하신 분
- 심장 질환, 뇌졸중, 당뇨와 같은 만성 질환을 1 개 이상 가지고 계신 분

연구에 대한 자세한 설명이나 궁금한 점이 있으신 분은 아래로 연락 부탁드립니다.

박혜영 (듀크대학교 간호대학 박사과정생)
508-521-9809, hye.young.park@duke.edu

 **Duke University**
School of Nursing

IRB# Pro00076188

Appendix D

Interview Guide (English)

Older Korean Immigrants' Life Course and Health Care Goals

[Interview 1]

Thank you for agreeing to participate in this study and allowing your time for this. Today, I would like to know about your health and health care goals.

Question 1. How do you **appraise your current health**?

You might have medical information about your current health status and might have discussed that with your doctor. However, different person 'perceive' differently regarding their own health. I would like to know what you 'know' about your health and how you 'think' about your health.

Probe :

- What is your most concern relate to your current health?
- When was your last visit to the hospital?
- Have you visited hospital recently, unexpectedly?
- What did your doctor tell you about your health?
- What do you think about his explanation?
- Are there any discrepancies between how you feel about your health and what your doctor told you?

Question 2. What are your **short-term health care goals**?

I understood that you have _____ health concerns/health issues. If you think about your current health, and then think about next 1 to 3 years, what will be the most important goal for you to achieve in health care?

Probe :

- Under current situation, what do you think is the best (ideal) status of health?
- Do you have any concerns relate to health when you think of next 1 to 3 years?
- What is the most important thing for you relate to your health status or health care?
- If you have any, what is your plan for next 1 to 3 year to reach your health care goals?

What is an important value for you relate to your health care goals? (or deciding your health care goals)

Question 3. What are your **long-term health care goals**?

We just talked about your health care goals for the near future. I would like to expand it to long term goals. If you think next 10 years, what would be your goal for health care?

Probe

- What do you think the best (ideal) status of health 10 years later?
- Do you have any concerns relate to health when you think of next 10 years?
- What is the most important thing for you relate to your health status or health care?
- If you have any, what is your plan for next 10 years to reach your health care goals?
- What is an important value for you relate to your health care goals?

[Interview 2]

Please share your **life stories**, when and how you came to the US and what was it looked like based on your thoughts on that.

We have talked about your health status and health care goals. I understood you think “ ” very important to you. I would like to understand better how that become so important to you. If you could share your life stories and experiences that you have gone through, it would be very helpful for me to understand you and your values.

- Where is your hometown?
- How was the societal situation like in Korea when you are born and raised in Korea?
- When and how you came to the US?

- How was your life looked like when you first came to the US?
- What was the big difference and transition you experienced after immigration?
- When you looking back your life, could you share a most important event for you to me?
- How do you think that event impacted to you?
- Do you have family and friends in Korea?
- Do you have family and friends in US?

Appendix E

Interview Guide (Korean)

미 거주 한인 노인의 인생 과정과 건강관리 목표

[인터뷰 1]

연구에 참여해주시고 또 시간 내 주셔서 감사합니다.

오늘은 어르신의 건강과 건강관리 목표에 대해서 말씀 나누고자 합니다.

질문 1. 현재 건강에 대해서 어떻게 생각하세요?

현재 어르신의 건강 상태에 대해서 의사나 다른 의료진에게 들으신 정보가 있으실 것 같습니다. 하지만 사람마다 자신이 어느정도 건강한 상태인가 생각하는 것은 각기 다를 수 있습니다. 어르신의 건강 상태에 대해서 설명해 주실 수 있으신가요? 또한 병원에서 들으신 객관적인 정보 이외에 어르신께서 생각하시는 건강 상태에 대해서 말씀해주세요.

Probe (후속 질문)

- 현재 건강상태와 관련하여 가장 염려되시는 부분이 있으시다면 어떤 것인가요?
- 가장 최근에 병원에 방문하신 게 언제 인가요?
- 최근에 예상치 못하게 병원에 방문하신 적이 있으신가요?
- 의사나 의료진이 현재 어르신의 건강상태에 대해서 어떻게 설명하였나요?

- 의사나 의료진의 설명에 대해 어떻게 생각하시나요?
- 의사나 의료진이 어르신의 건강 상태에 대해서 설명한 것이 어르신이 느끼시는 현재 건강 상태와 혹시 다른 점이 있으셨나요?

질문 2. 현재 혹은 가까운 미래의 어르신의 건강 관리 계획이나 목표는 어떻게

되시나요?

현재 어르신께서는 _____ 한 건강문제 (염려) 가 있으시군요.

그렇다면 현재 어르신의 건강 상태에서 올해, 또는 가까운 미래 (약 3 년정도) 에 어르신의 건강과 관련하여 가장 중요한 목표가 있으시다면 어떤 것이 있을까요?

Probe (후속 질문)

- 현재 어르신의 상황에서 가장 최적의 건강 상태는 어떤 상태라고 생각하시나요?
- 향후 1-3 년 정도의 가까운 미래를 생각하셨을 때 건강과 관련하여 걱정이나 염려가 있으신가요?
- 가까운 미래를 생각하셨을 때 어르신의 건강상태 또는 건강관리에서 가장 중요한 것은 무엇인가요?

- 건강 관리 목표가 있으시다면, 혹시 그 목표와 관련된 건강 관리 계획이

있으신가요?

- 건강 관리 목표를 세우실 때 어르신께서 가장 많이 고려하시는 것이 (가장 중요한

가치가) 어떠한 것인가요?

질문 3. 중장기 목표로서 어르신의 건강 관리 계획이나 목표는 어떻게 되시나요?

방금 어르신과 현재 또는 가까운 미래의 건강 목표에 대해서 이야기 했는데요, 이제

조금 더 먼 미래에 대해서 이야기 하려고 합니다. 만약 향후 10 년을 생각하였을 때,

어르신의 건강관리 목표가 어떻게 되시나요?

Probe (후속 질문)

- 10 년 후를 가정하였을 때 어르신의 가장 최적의 건강 상태는 어떤 상태라고

생각하시나요?

- 10 년 후 미래를 생각하셨을 때 건강과 관련하여 걱정이나 염려가 있으신가요?

- 10 년 후 미래를 생각하실 때 어르신의 건강상태 또는 건강관리에서 가장 중요한

것은 무엇인가요?

- 중장기 건강 관리 목표가 있으시다면, 혹시 그 목표와 관련된 건강 관리 계획이 있으신가요?
- 중장기 건강 관리 목표를 세우실 때 어르신께서 가장 많이 고려하시는 것이 (가장 중요한 가치가) 어떠한 것인가요?

[인터뷰 2]

오늘은 어르신과 어르신의 생애 과정에 대해서, 다시 말해서 어르신께서 살아오신 역사 이룰테면 언제 어떻게 미국에 오시게 되었고 어르신의 삶이 어떠셨는지 대해서 이야기 나누고자 합니다.

지난 번에 어르신과 함께 어르신의 건강 상태와 건강 관리 목표에 대해서 이야기를 하였습니다. 어르신께 “_____”가 매우 중요하다는 것을 알게 되었습니다. 그래서 오늘은 어떻게 “_____”가 어르신께 매우 중요한 것이 되었는지를 알고 싶습니다. 어르신께서 살아오신 인생 경험과 이야기를 저에게 해 주시면, 어르신이 현재 생각하시는 것과 건강 관리 목표와 관련하여 왜 “_____”가 어르신께 중요한지 더 잘 이해할 수 있을 것 같습니다.

- 어르신의 고향은 어디십니까?

- 어르신께서 태어나시고 자라실 때의 한국 상황에 대해서 말씀해 주세요.
- 언제 어떻게 미국에 오시게 되셨는지요?
- 처음 미국에 오셨을 때의 이야기를 조금 해 주세요.
- 미국에 오신 이후에 어르신께서 직접 겪으신 큰 차이나 전환점에 대해서 말씀해 주세요.
- 어르신의 삶을 되돌아보셨을 때 가장 중요한 순간이나 이벤트에 대해서 말씀해 주실 수 있으신가요?
- 그 이벤트가 어르신께 어떤 영향을 주었나요?
- 현재 한국에 가족이나 친구가 있으십니까?
- 현재 미국, 가까이에 가족이나 친구가 있으십니까?

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Biography

Hyeyoung (Kate) Park earned Bachelor's degree in Nursing at Seoul National University's prestigious College of Nursing. During her time at Seoul National University she was recognized two years in a row with a Superior Academic Performance award. Upon graduation she worked as a Registered Nurse at the nationally renowned Seoul National University Hospital. She spent 3 years at the hospital working in the cardio-pulmonary intensive care unit, performing post-operative care for open-heart surgery patients. After observing the curative approach of the surgery unit, even for patients at the end of life (EOL), she decided to return to Seoul National University to pursue a Master's in nursing studying EOL care. In the United States, Hyeyoung hopes to continue to pursue this topic as she explores how to build a more compassionate health care system for all populations in the US. She is a member of Sigma Theta Tau International, Duke's Beta Epsilon Chapter and She has published six papers of which two are first authored and relate to her focal research area:

Park, H., & Hendrix, C. C. (2018). A Literature Review on End-of-Life Care among Korean Americans. *International Journal of Palliative Nursing*, 24(9):452-461.

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